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Research paper

Navigating the landscape of child disability measurement: A review of available data collection instruments

Comprendre la mesure du handicap de l'enfant : examen des instruments de collecte de données

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ABSTRACT

The United Nations Convention on the Rights of Persons with Disabilities adopted in 2006 holds States responsible to "...collect appropriate information, including statistical and research data, to enable them to formulate and implement policies..." This recognition has led to an increasing number of countries gathering data on disability at the population level; however, there are currently no gold standards for its measurement and different data collection tools have been used throughout the years to fulfil data needs. Understanding how these differences have influenced the measurement of disability globally is crucial to developing reliable and comparable measures. The purpose of this paper is to describe the varying scope and content of data collection instruments on child disability and to provide a historical snapshot of the rates of reported disability among children. A total of 716 data sources were identified, corresponding to 198 countries covering more than 95% of the world's children. The findings reveal a lack of consistent definitions and measures of disability, which contribute to major challenges in producing reliable and comparable statistics.

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RÉSUMÉ

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La Convention des Nations Unies sur les droits des personnes handicapées adoptée en 2006 impose aux États de « recueillir des informations appropriées, y compris des données statistiques et résultats de recherches, qui leur permettent de formuler et d'appliquer des politiques ». Cette mesure a conduit un nombre croissant de pays à se lancer dans la collecte de données sur les personnes handicapées ; cependant, il n'y a actuellement pas de standards internationaux pour guider la collecte, si bien que différents outils ont été utilisés au fil des ans pour satisfaire ce besoin de données. Comprendre de manière générale comment ces différents outils ont influencé la mesure du handicap est essentiel afin d'aller vers l'élaboration de mesures fiables et comparables. L'objectif de cet article est de décrire la variabilité des différents instruments de collecte de données sur le handicap chez l'enfant, tant dans leur forme que dans leur contenu, et de fournir un point de vue historique sur les taux de prévalence estimés. Sept cent seize sources de données ont été identifiées, issues de 198 pays et concernant plus de 95 % des enfants à l'échelle mondiale. Il en ressort un manque de définitions et de mesures cohérentes du handicap, qui mettent en évidence les défis majeurs qui restent à relever dans la production de statistiques fiables et comparables.

1. Introduction

Reliable data are central to gaining the confidence of decision makers and the greater community when advocating for legislation, policies, funding, programming and the inclusion of disability on national and international political agendas (Albert, Dube & Riis-Hansen, 2005; Eide & Loeb, 2005; Fujiura, Park & Rutkowski-Kmitta, 2005). Furthermore, data allows policymakers, programme staff and researchers to monitor the level of disability within a population and to understand trends in disability prevalence; impacts of improvements in survival and exposures to nutritional deficiencies, environmental toxins, serious diseases and trauma; and interventions designed to improve child health and development (Durkin, 2001). Having statistics that are comparable can also highlight international and intra-national inequities between different populations of children with disabilities, for example by ethnicity, sex, age, region, or type of impairment (Robson & Evans, 2003).

With the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2006 during the sixty-first session of the United Nations General Assembly[1] (United Nations Enable, 2014), the international community acknowledged both the need and importance of reliable, valid and comparable data on persons with disabilities. Although efforts to collect disability statistics are not new, Article 31 of the Convention holds States Parties responsible, for the first time, to "...collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" (United Nations General Assembly, 2006). This recognition has led to increased attention, interest, commitment, and resources for collecting data on disability (Schneider, 2009; Trani & Bakhshi, 2008).

Despite this, there have been major challenges in producing reliable and comparable disability statistics due in large part to a lack of consistent definitions and indicators of disability, combined with differences in methodologies used to gather data and quality of study designs. In 2002, the UN General

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[1] There were 159 signatories to the Convention as of 1 December 2014. Signatories include countries or regional integration organizations that have either ratified, acceded or signed the Convention and its Optional Protocol.

Assembly Special Session on Children highlighted the difficulty in gathering accurate data on disability among children. The quality of statistical data was also identified as an issue of concern, alongside the shortage of relevant research activities on the lives of children with disabilities. As a result, there are currently no reliable and representative global estimates of the number and proportion of children with disabilities. The dearth of sound and comparable statistics has contributed to the misconception that disability is not an important global health and human rights concern (UNICEF-University of Wisconsin, 2008).

The field of disability measurement has long been populated with attempts to gather data using a range of different methods. One of the most common being national censuses (Bruyère & Houtenville, 2006), which typically ask a single generic question about all members of a population. Also common are general household surveys, which usually include a module or set of questions on the disability status of household members. Other sources of disability data include administrative records, school-based surveys, key informant reports, and targeted disability surveys (Maierhofer, Almazan-Isla, Alcade-Cabero & Pedro-Cuesta, 2011; Bruyère & Houtenville, 2006). Each of these measure disabilities differently and thus has their own merits and limitations. For example, national censuses that do not specifically ask about children have been found to be inadequate at identifying children with disabilities and thus often under-enumerate them (Durkin et al., 1991). This limitation is also recognized by the United Nations Statistics Division in its Principles ad Recommendations for Population and Housing Censuses, Revision 1, "The limited number of questions included in a census cannot provide a precise measure of the number of people with disability, especially among children. . ." (United Nations Statistical Commission, 1997: 94). In comparison, targeted disability surveys or general household surveys with a specific disability module tend to report higher disability prevalence rates because they include more numerous and detailed questions.

The method of data collection chosen is also dictated, to some extent, by the context of the country in which the research will be conducted. With regards to children specifically, wealthier nations are often capable of identifying children with disabilities through infrastructures such as educational and medical settings or national registries. However, in many low- and middle-income countries, children with disabilities might not be adequately identified when schooling or other formal services are lacking. In this instance, other methods of enumeration such as household surveys and censuses have commonly been used to estimate disability prevalence.

Disability has also been defined and conceptualized in several different, and often oppositional, ways. Until most recently, the field of disability measurement has been dominated by a medical model, wherein disability is seen as a consequence of disease and a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being (Baglieri & Shapiro, 2012). Measures developed from this perspective take into account only the presence or absence of specific impairments, thus assuming that disability is a dichotomous outcome (i.e., people either have or do not have a disability). The most widely adopted method for categorizing those with disabilities is by impairment type, which has perpetuated stereotypical views of persons with disabilities as wheelchair users or as being blind or deaf. Furthermore, utilizing a list of impairments alone will result in the identification of only a small sub-population with more severe restrictions and not those with varying degrees of limitations, thus the overall picture of disability is incomplete.

The biopsychosocial model seeks to address the identified limitations of the medical model by viewing disability as a result of the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others (World Health Organization, 2001). From this perspective, persons with disabilities are viewed as diverse and heterogeneous with differing gradients of experience. This shift in focus to an understanding of disability beyond an individual's impairment has not only expanded the conceptualization of disability but it has also provided new ways of measuring disability. These new approaches have generally yielded disability prevalence rates that are higher than ones obtained from methods that rely on a more narrow definition based on the medical model.

One example of the biopsychosocial approach to conceptualizing disability is the International Classification of Functioning, Disability and Health (ICF). The ICF allows for the classification of health-related human functioning taking into account the multidimensional and interactive nature of disability (Bickenbach, Chatterji, Badley & Ustun, 1999). The ICF conceptualizes disability on a continuum, from full participation in society to limitations in the performance of all activities. It supports the idea that dismantling attitudinal and environmental barriers can empower people with disabilities to participate as active members of society and enjoy the full range of their rights. This framework also recognizes that not all persons with disabilities are equally restricted in their participation. For example, girls with disabilities experience the combined disadvantages associated with gender as well as disability, and may be less likely to go to school than non-disabled girls (Groce, 2004).

Previous efforts to review and scope the landscape of disability research and data are numerous (Molden & Tøssebro, 2010; Altman & Gulley, 2009; Maulik & Darmstadt, 2007; Mont, 2007; Barbotte, Guillemin, Chau & the Lorhandicap Group, 2001; Gudex & Lafortune, 2000). However, such reviews often identified sources of data that were either not nationally representative (e.g., clinic-based), were restricted to a narrow range of countries, or focused on the entire population and not specific sub-sets of the population (i.e., children). For instance, an often cited discussion paper by Mont (2007) discusses various approaches to measuring disability and includes some reported disability prevalence rates for selected countries but these estimates are for the entire population and not children specifically. Another example is a review of 20 prevalence studies/surveys by Barbotte et al. (2001) that revealed disability prevalence rates in the general population ranging from 3.6% to 66%. The review however only included research undertaken between 1990 and 1998 and included both national and regional surveys and surveys that covered the population in only a specific area such as a city or district.

This paper is therefore, to the authors' knowledge, the first attempt to provide an overview of methods used to collect data on childhood disability and reported rates of disability prevalence among children in a wide cross-section of countries. In particular, the paper aims to describe the varying scope and content of data collection efforts and to illustrate how differences in concepts, terminology, methodologies and questionnaire design can affect disability statistics, with specific reference to children.

2. Methods

A review was conducted to identify large-scale population-based quantitative surveys or studies that collected nationally representative prevalence data on disability. Three search strategies were used to enhance the breadth and validity of the information found. It should be noted here that the searches were not limited to the child population, although the intention was to identify sources that have collected disability data on this population specifically. Casting a wider net was seen as necessary in order to capture as many publically available sources of child disability data as possible, given that many data collection efforts are undertaken on the general population, with children included among them.

The first strategy was a review of published literature identified by using Scholars Portal and OVID to search the electronic databases of: PubMed, Web of Science and CIRRIE (all until July Week 1 2014), using MeSH headings and free text key words that were applicable to the areas of interest of disability and statistics. Specifically, combinations of electronic search terms using the Boolean operators 'AND' and 'OR' were: disability, survey, census, quantitative study, prevalence, statistics, data and questionnaire. The search was conducted primarily in English, French and Spanish but sources in other languages were identified and reviewed when translation was feasible either through the authors' own knowledge of the language or through the use of an online translation programme such as Google Translate. No methodological limitations were applied; therefore, all types of sources were accepted including research papers, expert opinions, case studies and systematic reviews.

The second strategy was an electronic search of general (e.g., Integrated Public Use Microdata Series, International) and specialized (e.g., United Nations Statistic Division) statistical databases and websites of national statistical offices. Sources identified through these mechanisms published in languages other than English were still considered if they could be translated for review.

Finally, key informants were contacted through email to request sources they might be aware of related to the purpose of this review. Informants included individuals known to be active in the field of child disability measurement and representatives of organizations working in the field of disability.

Copies of the retrieved source materials were reviewed using the following inclusion and exclusion criteria. Inclusion criteria: sources for which supporting documentation (i.e., questionnaires, study/survey report) was found and was publicly accessible. Sources of data from any country, in any language with no limitation to the year of data collection were included in order to collect information on as many countries as possible. Exclusion criteria included: sources such as small-scale surveys, administrative records and qualitative studies. Initially the inclusion and exclusion criteria were applied to the executive summary or table of contents of the study/survey report. If the reports were unavailable, or did not provide sufficient detail to assess the methodology and tools used to gather the data, the implementing agencies were contacted to request access to the supporting documentation. Following the initial exclusion of sources, all of the remaining reports were reviewed in their entirety.

For all relevant sources, key information was entered into an electronic database including the definitions, questionnaire design, indicators, methodology and estimates of reported disability prevalence. Together, this information formed the basis of analysis, including simple numerical counts of some of the basic characteristics of the sources reviewed.

A total of 716 data sources were identified, corresponding to 198 countries, with a population coverage of more than 95% of the world's children. The data sources included censuses, generic household surveys that collected data on disability, such as the Multiple Indicator Cluster Surveys (MICS) and the Demographic and Health Surveys (DHS), and specialized disability surveys.

3. Findings

3.1. *Countries and year of implementation*

Practically all countries in the world have collected some information on disability. Specifically, data sources on disability were identified for 185 United Nations Member States. Therefore, the review was unable to trace data for only eight UN Member States. Of these, two are located in Sub-Saharan Africa (Equatorial Guinea and Somalia) and six are countries with a child population below 125,000 (Andorra, Brunei Darussalam, Liechtenstein, Monaco, San Marino and Tuvalu). The review also identified data for 13 countries that are not official UN Member States (Anguilla, Aruba, Bermuda, British Virgin Islands, Caymen Islands, Cook Islands, Montserrat, Norfolk Island, Northern Mariana Island, Sint Marteen, State of Palestine, Turks and Caicos, and the US Virgin Islands).

The majority of countries had more than one data source at the time the review was conducted (July 2014). Exceptions include, among others, Armenia, Cuba, Gabon, Guinea, Haiti, Kazakhstan, Latvia and Palau, where only one data source was identified. High-income countries tended to have the most number of data sources with the largest number (23) found for the United States of America, followed by Australia (16), Canada and the United Kingdom (each 13), Belgium and Ireland (each 10), New Zealand (10), Portugal (9), and Estonia and Hungary (each 8). Among low- and middle-income countries, India had the largest number of data sources with 12, followed by South Africa (11), Georgia and Jamaica (each 10), Zambia (9), Uganda and Uruguay (each 8).

One particularly striking finding of the review was the discovery that data on disabilities has been collected for a very long time, dating back to the early 1800s in some countries. Three countries (India, Portugal and the United States) included questions on disabilities in censuses conducted during the 19th century. In the United States alone, seven censuses during this time period collected such information. The oldest data source identified was the 1830 census in the United States, which collected data on the number of persons in the population who were classified at the time as "deaf and dumb" or "blind". Within the first half of the 20th century, only eight countries had included questions on disabilities in censuses including, for example, Israel and Slovenia. Over the past 60 years, however, the inclusion of disability questions on censuses and surveys has grown dramatically. Two countries were found to have collected data on disability in the fifties (Mozambique and Portugal). This number grows to eight in the sixties, 18 in the seventies, 58 in the eighties, and 98 in the nineties. Since the turn of the 21st century, some 180 countries have included disability in their national data collection efforts, including the country most recently admitted as a Member State to the United Nations, the Republic of South Sudan. The review identified some 545 data sources for years prior to 2006 while 149 were found to correspond to the period since 2006, with the latest being in 2014 from Myanmar.

Table 1
Classification of household surveys, by area of focus.

	General	Living or social standards/ conditions	Health/lifestyle	Labour force	Income and expenditures/ budget/ resources
Number of surveys	52	31	38	6	12

In 2006–2007 alone (year of the adoption of the UNCRPD), there were some 41 sources of data on disability.

3.2. *Type of data source*

The most common type of data source identified was, overwhelmingly, a census. Of the total 716 data sources, 375 were censuses (this included micro-censuses and pre-census/pilot census surveys). Censuses included reported disability prevalence rates for either both the child and adult populations (typically disaggregated by age) or for just the population legally entitled to work, usually ages 15 or 16 and above, depending on the country.

The second most common type of data sources were household surveys, many of which were general and covered a variety of topics while some had a more narrow focus ranging from living or social conditions to income and expenditures and health (see Table 1). There were a total of 139 household surveys that included questions on disability (surveys that were part of international survey programmes are not included in this count and are considered separately below); two of these surveys were exclusively about the child population (one in China and one in Namibia); 20 of these surveys did not collect data on persons under the age of 15.

The largest source of internationally comparable data was found to be the Multiple Indicator Cluster Surveys (MICS), a UNICEF-supported household survey program conducted in low- and middle-income countries (LMICs). The MICS are nationally representative surveys with data on more than 100 different indicators of women's, men's and children's health and well-being. Since the second round of MICS (MICS2; 2000–2001), countries have had the option of including a module on disability for children between the ages of 2 and 9 based on the ten questions (TQ) screen. Twenty-two countries participating in MICS2 chose to include questions on disability but a majority did not implement the complete TQ but rather an adapted set of questions, therefore limiting the comparability of child disability data collected across these countries. For MICS3 (2005–2007), all 26 countries that collected disability data used the standard disability module based on the TQ, thus creating a source of comparable data for a large cross-section of LMICs (UNICEF-University of Wisconsin, 2008). The exception was Algeria, which did not use the standard version of the module. A further six countries included the Disability Module for the fourth round of MICS (MICS4, 2009–2012)[2] but two used a non-standard version (Sudan and South Sudan).

Another large-scale international household survey program that has included disability as a topic of data collection are the Demographic and Health Surveys (DHS) funded by the United States Agency for International Development (USAID). The following surveys included a set of questions to assess disability status of household members: the Plurinational State of Bolivia 1998 and 2008, Cambodia 2000, Cameroon 2011, Chad 2004, Colombia 1995 and 2010, Ghana 1993 and 1998, Maldives 2009, South Africa 2003, Uganda 2006 and 2011 and Yemen 1991–1992. Questions on disability were also collected in a combined DHS/MICS conducted in Iran in 2010 but the survey was not a part of either DHS or MICS global survey programmes.

The review also considered surveys conducted as part of the larger World Health Survey (WHS) program developed and implemented by the World Health Organization (WHO). The surveys collected

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[2] This figure reflects those countries with published results as of October 2014. These include: Belize, Bhutan, the former Yugoslav Republic of Macedonia, Mongolia, Sudan and South Sudan.

Table 2
Child disability survey results, by country.

Country	Year	Age group	Child disability prevalence (%)
Armenia	2004	0–8	13.0
China	2007	0–19	0–9 years old: 1.6 10–14 years old: 1.5 15–19 years old: 1.8
Egypt	1999	2–18	8.1
The United Republic of Tanzania	2008	0–17	3.5
Viet Nam	1998	0–17	3.1

information on the health status of adult populations through a modular approach so countries had the flexibility to include or not include certain topics. These surveys were completed in 70 countries in all regions of the world from 2002–2004. The World Report on Disability (WHO, 2011) includes prevalence estimates of adults who experienced significant functioning difficulties in their everyday lives in 59 of the 70 countries participating in the WHS program.

Finally, this review captured 68-targeted surveys specifically designed to collect data on persons with disabilities. Of these, there were five surveys solely dedicated to childhood disability from Armenia, China, Egypt, the United Republic of Tanzania, and Viet Nam (see Table 2). These surveys were mostly commissioned and implemented by government ministries (e.g., National Bureau of Statistics in China; Ministry of Labour, Invalids and Social Affairs in Viet Nam; Ministry of Finance and Economic Affairs in the United Republic of Tanzania), often with financial and technical support from external agencies (e.g., UNICEF in Armenia, Egypt, the United Republic of Tanzania and Viet Nam; United Nations Statistics Division in China).

3.3. *Questionnaire design and content*

The majority of censuses and surveys used questions based on a medical model to determine disability status. From this perspective, disability is viewed as a health or medical condition or body impairment needing to be cured, treated or rehabilitated. For example, the 2006 Population and Housing Census for Lesotho asked if any persons were disabled, listing the following categories of disabilities: amputation of foot/leg/fingers/arms/toes, lame/paralysed limb, blind (total/partial), deaf (total/partial), mental retardation/illness and speech problems. Other surveys applied a broader, but still predominately medical, classification of disabilities by including chronic diseases and other health conditions. For example, the 1993 Census for Peru included polio among the list of possible impediments and the 1980 Census for South Africa classified those with addiction as among those who could be considered “mentally ill”. In contrast to surveys framed under the medical model, the World Health Surveys employed questions designed to assess functional difficulties experienced in the last 30 days with mobility, self-care (e.g., washing and dressing oneself), concentrating and remembering, as well as questions on personal relationships and participation in the community. It also inquired about conditions affecting functioning, such as bodily aches and pains, sleep and energy, sadness and depression.

Among both high- and low-income countries, questions used to assess disability status were found to evolve within the same country over time and across different data sources. For example, the United States has collected data on the presence of disabilities since the 1800s but the questions employed have changed dramatically over the years (see Table 3). In this example, questions used in earlier data collection were predominately based on the medical model and focused on listing possible impairments (often with language that would now be considered offensive or stigmatizing) while more recent efforts to collect such information has shifted towards assessing functional difficulties congruent with the biopsychosocial model of disability.

Most general household surveys and censuses were found to include a single generic question on whether there was anyone in the household who ‘is disabled’. For example, in the Sierra Leone

Table 3
Selected data sources and questions on disability from the United States.

Year	Type of data source	Question(s)
1830	Census	Something about the number of people who were "deaf and dumb" and "blind"
1850 and 1860	Census	Whether any members of the household were: deaf and dumb, blind, insane, idiotic, pauper or a convict
1880	Census	Is the person sick or temporarily disabled, so as to be unable to attend ordinary business or duties? If so, what is the sickness or disability? (blind; deaf and dumb; idiotic; insane; maimed, crippled, bedridden or otherwise disabled)
1910	Census	Whether the person was blind (both eyes) and whether the person was deaf and dumb
1970	Census	Does this person have a health or physical condition, which limits the kind or amount of work he can do at a job?
1990	Census	Does this person have a physical, mental, or other health condition that has lasted for 6 or more months and which: a: limits the kind or amount of work this person can do at a job? b: prevents this person from working at a job?
2000	Census	Do you have any of the following long-lasting conditions: blindness, deafness or a severe vision or hearing impairment? A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting or carrying?
2008, 2009, 2010 and 2011	American Community Survey	Is this person deaf or does he/she have a serious difficulty hearing? Is this person blind or does he/she have serious difficulty seeing even when wearing glasses? Because of a physical, mental or emotional condition does this person have serious difficulty with concentrating, remembering or making decisions? Does this person have serious difficulty walking or climbing stairs? Does this person have difficulty dressing or bathing? Because of a physical, mental or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

2004 Population and Housing Census, the household head was asked the following question of each member of the household, "Is (name) disabled?" The broad nature of this question means that the interpretation of what constitutes a disability is left entirely to respondents and some groups of people with disabilities may not be captured at all. For instance, children who have mild activity limitations might not be reported as having a disability if respondents perceive the question to only be asking about those with severe conditions. Not surprisingly, the reported disability prevalence rates from Sierra Leone were unusually low: below one percent for those under the age of 25 and about two percent for those aged 25 years and above.

In other cases, a generic question on whether there was anyone in the household with a disability was used as a filter before additional questions were asked. For example, in the Niger 1988 Census, respondents were asked of children in their household, "Is he (she) handicapped?" If a positive response was obtained, then additional questions were asked regarding the specific impairments of the child.

In the sources reviewed, response categories varied and included some that were dichotomous (e.g., Timor-Leste 2004 Census, "Is there anyone in your household who has a permanent disability?" Yes/No) and others that offered response options along a continuum (e.g., Serbia 2011 Census, "Does the person, and to which extent, have difficulties in accomplishing everyday activities at home/school/work due to some problem?" No difficulty/yes, some difficulty/yes, a lot of difficulty/yes, completely prevented). Having two-item answer categories might have led to more instances of non-reporting as the choice between a "yes" and a "no" is not always easy or clear for respondents. This can be the case particularly for reporting on mild impairments or disabilities that vary in frequency or intensity. On the other hand, surveys that used a multiple-item response scale on a continuum allowed the possibility of reporting impairments that are not constant but variable depending on a number of factors, including the environment.

Of the 716 data sources identified, 59 utilized the questionnaire developed by the Washington Group (WG) on Disability Statistics that was released in 2006. The WG was formed as a result of the United Nations International Seminar on Measurement of Disability that took place in New York in 2001 with the objective of developing general disability measures suitable for use in censuses, sample based national surveys, or other statistical formats to provide basic necessary information on disability throughout the world (Washington City Group on Disability Statistics, 2002). The WG questionnaire set was designed to identify those who are at greater risk than the general population for participation restrictions because of the presence of difficulties in six core domains: seeing, hearing, walking, cognition, self-care, and communication. The response categories introduce a scale to capture the level of difficulty experienced including no difficulty, some difficulty, a lot of difficulty, or cannot do at all. While the questions have been promoted for use primarily in censuses among the general population aged five years and above, the WG acknowledges that they are not ideally suited for application among the child population because some domains are not developmentally appropriate for very young children (e.g., independent washing, dressing)[3]. Some of the 59 sources utilized the exact WG questions while others employed a modified version of the questionnaire set. For instance, the Cabo Verde 2010 Census added a question on whether or not the respondent used any assistive device(s) such as a wheelchair or prosthetic limb. Other sources included only a subset of the six questions: for example, the 2009 Census in Viet Nam did not include the questions that measure the domains of self-care and communication.

Findings reveal that the majority of surveys and studies applied a single set of questions to both adults and children to assess disability status, or used questions developed for adults to survey children. Examples include the following question used to determine the prevalence of disability for the entire population (including children) in the 2011 Montenegro Census of Population, Households and Dwellings: “Does the person have any disability that prevents him/her from performing everyday activities due to long lasting illness, invalidity or old age?” Making explicit reference to the elderly/invalid population is clearly not relevant for assessing functioning difficulties among children and might introduce a bias in the respondent’s mind in terms of what should be considered as disability.

Even targeted household surveys that specifically addressed the issue of child disability were found to have utilized one set of questions or a general screening tool for children of all ages. By way of illustration, a 2008 household survey on children with disabilities in the United Republic of Tanzania applied the Washington Group’s six questions to all children aged 0–17. It is generally agreed among academics that capturing disability among children below two years of age may not be feasible through population surveys given the developmental processes that take place at such a young age. This highlights the importance of constructing different questions according to children’s age in order to reflect the developmental stages and evolving capacities of different age groups. It is important to mention that, in the case of about 40 identified sources, it was not evident if questions were asked specific to age cohorts due to the unavailability of the questionnaires in the survey reports.

Household-based surveys (whether general or targeted) and censuses are self-report with questions about child disability typically posed to parents or caregivers. Although caregivers often do very well at identifying whether their children are having difficulties performing specific tasks, their responses alone are not sufficient to diagnose disabilities or establish a prevalence of disability. For example, the Micronutrient Status Survey in Tajikistan conducted in 2008 asked respondents the following question: “Are there children under the age of 5 in this household with the following

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[3] In recognizing the need for a set of questions that would produce internationally comparable data on child disability, the Washington Group formed a subgroup in 2009 on child functioning and disability that is chaired by the National Statistical Office of Italy (ISTAT). UNICEF joined the subgroup in 2011 and since that time has been working with the WG to develop a module to reflect current thinking on child functioning and disability for inclusion in censuses and surveys. For more information, see: http://www.cdc.gov/nchs/data/washington_group/meeting13/wg13_unicef_child_disability_background.pdf.

disabilities: blindness, deafness, motor disability, mental disability?" In this example, caregivers are assumed to be in a position to adequately judge what disability is, and whether their child has a disability or not. In many developing countries, most children have not been previously screened for disability and parents may not be able to detect, by themselves, manifestations of certain conditions. Therefore, caregiver knowledge of norms and standards and expectations of children's performance will impact reporting of disability status and resulting prevalence rates.

Language that was stigmatizing or judgemental was commonly found in some of the questions used to determine disability status. For example, a 1982 Demographic Sample Survey conducted in Bangladesh asked whether any household member was "blind, crippled, deaf or dumb or mentally handicapped". Pakistan's 1998 Census asked, "God forbid, is there any disabled person in the household?" Finally, the 1960 Census in Cyprus listed persons of "unsound mind" among the categories of those with "infirmities."

3.4. Reported prevalence rates of childhood disability

Reported disability prevalence rates for the countries included in the review ranged from below one percent to close to 50 percent (e.g., 48 percent in the Central African Republic from the MICS3 among children ages 2 to 9 years). To provide a snapshot of this wide spectrum, countries were classified as having either low (i.e., below five percent) or high (i.e., above ten percent) reported prevalence rates. Countries with low reported child disability prevalence rates include, for example, Afghanistan, Angola, Argentina, Burkina Faso, Canada, Cambodia, Chad, China, Colombia, Egypt, El Salvador, Greece, Jordan, Lesotho, Oman, Rwanda, South Africa, State of Palestine, Uzbekistan and Viet Nam. At the other end of the scale, countries with high reported child disability prevalence rates include Armenia, Australia, Belize, Bhutan, Central African Republic, Ethiopia, the Former Yugolsav Republic of Macedonia, Madagascar, Maldives, New Zealand, Suriname and Yemen. The economic and social development of these countries represent a wide spectrum ranging from low to high income with pronounced differences also in cultures, disease patterns, mortality levels and experiences of conflict or natural disasters.

Large variations in disability prevalence rates were not only found between countries but also within the same country when multiple surveys had been conducted using different questionnaires and study designs. Questions used to assess disability status were found to influence the prevalence rates generated among both low- and high-income countries. In Zambia, for example, disability prevalence rates fluctuated between one and 15 percent over a 26-year period. The 1980 Census reported that about two percent of the population aged 15 to 59 years had some form of disability when respondents were asked whether they had any of the following conditions: blind, deaf and/or mute, crippled or loss of limb, mentally retarded and/or sick. The reported disability prevalence remained more or less the same during the next two Census rounds in 1990 and 2000, having included a similar question. However, the results from the 2003 World Health Survey indicated a higher disability prevalence among the adult population aged 18 and older at 15 percent when including a question in which respondents were asked to rate, on a scale, their level of difficulty within a number of domains.

A similar observation was also made with respect to the reported disability prevalence rates coming from various sources in Brazil (Fig. 1). A 1981 survey, for instance, reported that about two percent of the population aged 15 to 59 years had some form of disability when asked "What is the deficiency or disability you have?" while the 2000 Census found the disability rate to be at about 15 percent among all ages having utilized a set of questions based on activity limitations. The reported disability prevalence within the total population then jumped to 24 percent in the 2010 Census when respondents were asked whether they had any permanent difficulties with seeing, hearing or mobility or if they experienced any intellectual difficulties that interfered or limited their abilities to carry out daily activities.

4. Discussion

The purpose of this review was to describe the varying scope and content of efforts to collect data on disability and to provide a snapshot of rates of reported disability among children from

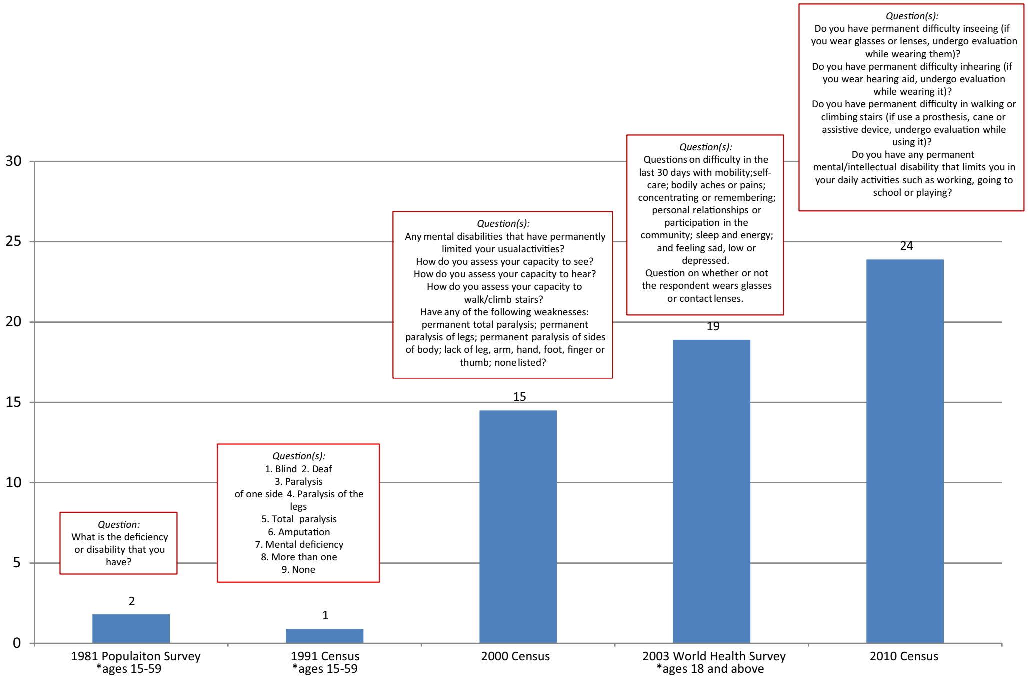

Fig. 1. Percentage of the population reporting some forms of disability in Brazil.

censuses and large-scale household surveys available globally. The findings add to the body of existing literature in illustrating how conceptual and methodological differences affect disability statistics, specifically when it comes to reporting about children. In the following discussion implications from the findings are discussed, including how the conceptualization of disability and operational definitions that guide data collection influence reported prevalence rates. The limitations of the review are also presented and considerations for harmonizing the measurement of childhood disability in order to produce estimates that are reliable, valid and internationally comparable are discussed throughout.

As seen in the range of sources reviewed, measuring disability is a complex process because there is no single definition that can be applied broadly across all cultural contexts (Gannotti & Handwerker, 2002; Schneider, 2009). Disability terminology, like many other terms within a culture, is not fixed but rather varies geographically and changes across time (Scully, 2004). Perceptions of disability are also dependent on the level of awareness of particular impairments within a country. In some contexts, chronic illnesses such as diabetes may be considered a disability while in others, disability may be thought of as referring only to severe functional limitations.

There has been a radical change in the last 30 years in the conceptualization of disability that has also altered the dialogue on how it is measured. This review found that, despite the fact that the conceptualization of disability has evolved from being seen as a consequence of disease (i.e., medical model) to being understood as a relationship between the individual and their environment in terms of limitations or barriers in performing daily activities and restrictions or supports to social participation (i.e., biopsychosocial model), the recognition and measurement of disability as something other than physical or mental impairments is still in its infancy. Up until relatively recently, few studies have designed questionnaires which reflect this new understanding despite the introduction of such concepts more than a decade ago (e.g., with the creation of the ICF in 2001). In the majority of countries, the medical model continues to dominate the field of child disability data collection and it also remains the most influential view of disability globally: "Despite the strides made in law, the medical paradigm of disability is still a persistent influence on the general public's perceptions of disability and disability-related political issues" (Baglieri & Shapiro, 2012: 96). A possible explanation for this can be that, as noted in the literature, the operationalization of disability in data collection and measurement tends to lag behind theoretical developments (Altman, 2001).

This notion was confirmed by the review since the majority of sources were found to conceptualize disability from a medical perspective, focusing on epidemiology and etiology of impairments (e.g., lists of health conditions). Disability was thus seen as separate diagnostic categories rather than broader restrictions to participation. Maulik and Darmstadt (2007) emphasized that relying on formal diagnostics is not the best way to ascertain the prevalence of disability among children because it does not take into account the level of functional limitations, degree of service utilization, or impairment of role performances. Evidence suggests that the availability of diagnostic services varies across countries and that, even within a country, children from low-income households tend to have less access to these services (Harris et al., 2011; Dahlgren & Whitehead, 2006). Thus, relying on such sources under identifies children with disabilities and is also very likely to correspond to only those with the most severe conditions. Furthermore, focusing on impairments does not account for what a child can accomplish by compensating for what is not functional as it is not necessarily the specific impairment itself that is the problem, but rather how it restricts a child's ability to fully engage in activities and participate within his or her environment.

Prevalence rates of disability are extremely sensitive to, and affected by, the types and ways in which questions are asked. Testing of questions in Canada has shown that when terms such as "long-term", "disability", and "handicaps" are used, respondents tend to think only about extremely severe conditions and thus underreport more mild or moderate difficulties or disabilities (Langlois, 2001). Considering the inherent limitations of conceptualizing disability from a purely medical standpoint, it was not altogether surprising that those surveys with this perspective generally yielded lower estimates of child disability than those that used more inclusive measures to account for environmental barriers to functioning and participation. Generally speaking, low- and middle-income countries were found to have lower prevalence rates than high-income countries, a finding that is consistent with previous research (Loeb, Eide & Mont, 2008; Trani & Bakhshi, 2008). This may be partly explained by the fact that new approaches to disability measurement based on the biopsychosocial model have largely been developed and implemented within such contexts and have not yet been taken up in low- and middle-income countries. The implication for data collection is that rather than asking solely about impairments, questions should be designed to assess activity limitations or difficulties in functioning and allow for gradations in responses. Viewing disability on a continuum that is influenced by impairments as well as environmental and personal factors will bring about a more complete picture of the nature of disability.

Attitudes towards individuals with disabilities and commonly-held stereotypes can also influence what questions are asked and the responses provided (Groce, 2006). This review found that many data collection instruments included language that was both outdated and offensive. How disability is operationalized in questionnaires can be especially important as respondents may be hesitant to report their own or a family member's disability if there is a lack of acceptance or stigma around disability in the country or community. In the majority of the world, the word "disability" still has negative connotations. As highlighted by Mont (2007), the simple question"Do you have a disability?", which has been utilized in many data collection efforts all over the world, has a different meaning depending on the cultural interpretation of what is considered as a disability that undoubtedly varies across and within countries. This question has been found to be especially inadequate at picking up mental or psychological disabilities in many countries as these types of conditions tend to be particularly stigmatizing (Patel, Flisher, Hetrick & McGorry, 2007). It is therefore necessary to be cognisant of language that is discriminatory, stereotypical or considered offensive to persons with disabilities, particularly during field testing, in order to ensure that people are being asked to respond to terms appropriate within their cultural context.

Despite the current fragmented landscape of disability data collection, the field is evolving and with continued advances in the development of theory and frameworks (including the development of the ICF and the adoption of the UNCRPD) and measurement tools (such as the WG modules), the international community is moving closer to realizing the full rights of children with disabilities.

4.1. Limitations

First, it is important to note that the review only included sources that were publicly available. Second, although efforts were made to identify and review sources published in languages other than English, it is likely that many sources of disability data were missed due to language restrictions. Third, due to the global and interdisciplinary nature of the topic, data sources may have been missed that were published outside of the electronic databases searched. Specifically in regards to the Internet search, there are limitations associated with the lack of permanence and number of sources posted on-line. This may be a reflection of the resources available within countries to post information on their sites. In regards to the prevalence rates of child disability, the reported figures reflect, to a large extent, the questionnaires and methods used to collect the information. Therefore, data across countries are not directly comparable given the differences in survey and questionnaire design and content, definitions of disability used and age groups reported. Finally, data quality was not part of the review as this would have required access to datasets that were for the most part unavailable. As a result, the review cannot be considered exhaustive or representative of all data collection efforts being undertaken in this field but is rather meant to illustrate the variety and range in the content and types of information on childhood disability available globally.

5. Conclusion

With an increasing number of countries signing on to the UN Convention on the Rights of Persons with Disabilities, the field of child disability measurement is confronted with an obligation to respond to two urgent needs. First, the need to produce statistics that can adequately reflect the new conceptualization of disability; and, secondly, the need to harmonize the measurement of childhood disability in order to produce estimates that are reliable, valid and internationally comparable. In the absence of solid and harmonized data collection instruments on disability, it is difficult to interpret varying prevalence figures across, and within, countries and to determine whether the rights of persons with disabilities have been fulfilled. Using a common framework and terminology in line with the UNCRPD and biopsychosocial approach to disability will allow for the production of comparable statistics that can be used as a powerful tool for advocacy and change. Such data can be used to inform governments and the international development community on appropriate policy and programmatic responses to meet the rights of children with disabilities.

Disclosure of interest

The authors declare that they have no conflicts of interest concerning this article.

References

Albert, B., Dube, A. K., & Riis-Hansen, T. C. (2005). *Has disability been mainstreamed into development cooperation*. UK: Disability KaR programme.

Altman, B. M. (2001). Disability definitions, models, classification schemes, and applications. *Handbook of disability studies*, 97–122.

Altman, B. M., & Gulley, S. P. (2009). Convergence and divergence: differences in disability prevalence estimates in the United States and Canada based on four health survey instruments. *Social science & medicine*, *69*(4), 543–552.

Baglieri, S., & Shapiro, A. (2012). *Disability studies and the inclusive classroom: critical practices for creating least restrictive attitudes*. Routledge: Barbotte et al., 2001.

Barbotte, E., Guillemin, F., Chau, N., & the Lorhandicap Group. (2001). Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature. *Bulletin of the World Health Organization*, *79*(11), 1047–1055.

Bickenbach, J. E., Chatterji, S., Badley, E. M., & Üstün, T. B. (1999). Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social science & medicine*, *48*(9), 1173–1187.

Bruyère, S. M., & Houtenville, A. J. (2006). Use of statistics from national data sources to inform rehabilitation program planning, evaluation, and advocacy. *Rehabilitation Counseling Bulletin*, *50*(1), 46–58.

Durkin, M. (2001). Measurement of childhood disabilities in population studies. In *United Nations Seminar on measurement of disability*.

Durkin, M., Zaman, S., Thorburn, M., Hasan, M., Shrout, P., Davidson, L., & Stein, Z. (1991). Screening for childhood disability in less developed countries: Rationale and study design. *International Journal of Mental Health*, *20*(2), 47–60.

Eide, A. H., & Loeb, M. E. (2005). *Data and statistics on disability in developing countries*. Disability Knowledge and Research Programme Executive Summary.

Fujiura, G. T., Park, H. J., & Rutkowski-Kmitta, V. (2005). Disability statistics in the developing world: a reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities*, *18*(4), 295–304.

Gannotti, M. E., & Handwerker, W. P. (2002). Puerto Rican understandings of child disability: methods for the cultural validation of standardized measures of child health. *Social science & medicine*, *55*(12), 2093–2105.

Groce, N. E. (2004). Adolescents and youth with disability: issues and challenges. *Asia Pacific Disability Rehabilitation Journal*, *15*(2), 13–32.

Groce, N. (2006). Cultural beliefs and practices that influence the type and nature of data collected on individuals with disability through National Census. *Research in Social Science and Disability*, *29*(4), 41–55.

Gudex, C., & Lafortune, G. (2000). An inventory of health and disability-related surveys in OECD countries. In *OECD Labour Market and Social Policy Occasional Papers, No. 44*. Paris: OECD Publishing.

Harris, B., Goudge, J., Ataguba, J. E., McIntyre, D., Nxumalo, N., Jikwana, S., & Chersich, M. (2011). Inequities in access to health care in South Africa. *Journal of public health policy*, *32*, S102–S123.

Langlois, R. (2001). *Global measures of disability. Submitted to the First Meeting of the Washington Group on Disability Measurement, February 18–20, 2002*. Retrieved from http://www.cdc.gov/nchs/data/washington_group/meeting1/langlois.pdf

Loeb, M. E., Eide, A. H., & Mont, D. (2008). Approaching the measurement of disability prevalence: the case of Zambia. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, *2*(1), 32–43.

Maierhofer, S., Almazán-Isla, J., Alcalde-Cabero, E., & de Pedro-Cuesta, J. (2011). Prevalence and features of ICF-disability in Spain as captured by the 2008 National Disability Survey. *BMC public health*, *11*(1), 897.

Maulik, P. K., & Darmstadt, G. L. (2007). Childhood disability in low-and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology. *Pediatrics*, *120*(Suppl. 1), S1–S55.

McIntyre, D., Thiede, M., Dahlgren, G., & Whitehead, M. (2006). What are the economic consequences for households of illness and of paying for health care in low-and middle-income country contexts? *Social science & medicine*, *62*(4), 858–865.

Molden, T. H., & Tøssebro, J. (2010). Measuring disability in survey research: comparing current measurements within one data set. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, *4*(3), 174–189.

Mont, D. (2007). Measuring disability prevalence. In *World Bank Social Protection Discussion Paper*.

Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: a global public-health challenge. *The Lancet*, *369*(9569), 1302–1313.

Robson, C., & Evans, P. (2003). *Educating children with disabilities in developing countries: the role of data sets*.

Schneider, M. (2009). The difference a word makes: responding to questions on 'disability' and 'difficulty' in South Africa. *Disability & Rehabilitation*, *31*(1), 42–50.

Scully, J. L. (2004). What is a disease? *EMBO reports*, *5*(7), 650–653.

Trani, J. F., & Bakhshi, P. (2008). Challenges for assessing disability prevalence: the case of Afghanistan. *ALTER-European Journal of Disability Research/Revue Européenne de Recherche sur le Handicap*, *2*(1), 44–64.

United Nations Enable. (2014). *Convention on the rights of persons with disabilities*. Retrieved from http://www.un.org/esa/socdev/enable/rights/convtexte.htm#convtext

United Nations General Assembly. (2006). *Convention on the rights of persons with disabilities*. Retrieved from http://www.un.org/disabilities/default.asp?id=150

UNICEF-University of Wisconsin. (2008). *Monitoring child disability in developing countries. Results from the multiple indicator cluster surveys*. Retrieved from http://www.childinfo.org/files/Monitoring_Child_Disability_in_Developing_Countries.pdf

United Nations Statistical Commission. (1997). *Principles and Recommendations for Population and Housing Censuses. Revision 1*. Retrieved from http://unstats.un.org/unsd/default.htm

Washington City Group on Disability Statistics. (2002). *Final Report of First Meeting. Washington City Group on Disability Statistics. February 18-20, 2002.* Retrieved from http://www.cdc.gov/nchs/data/washington_group/meeting1/WCGFinRep.pdf (n.d.)

World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. Geneva: WHO.