

# WHO COUNTS? MEASURING DISABILITY CROSS-NATIONALLY IN CENSUS DATA

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Despite established recommended standard definitions, measures, and methods by the UN Washington Group on Disability Statistics and the International Classification of Functioning, Disability and Health (ICF) to assess dimensions of disability, national censuses vary widely in the questions used to identify people with disabilities. Although many seek to conform ex-ante to ICF definitions, they also deviate from this basic framework in different ways. This complicates ex-post harmonization and standardization for cross-national comparisons of disability

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prevalence and outcomes influenced by disability status, such as labor market participation. Addressing these issues, this study uses IPUMS International Census microdata since 2,000 to examine disability measurement across 65 countries. We find that definitions, terminology, measurement, and instructions to both respondents and enumerators matter for understanding disability prevalence cross-nationally. For instance, questions that included potentially stigmatizing language were associated with lower rates of disability reporting, but questions that listed specific limitations were associated with higher rates. Beyond disability, our findings also speak more broadly to ongoing challenges in survey harmonization for cross-national comparison.

**KEYWORDS:** IPUMS; Census; Survey methods; Cross-national; Culture; Measurement; Disability; Microdata; Harmonization; 3MC.

## **1. INTRODUCTION**

Accurate counts of disability populations are integral for learning about this historically marginalized community, evaluating and improving policy mandates and programs, assessing benefits enrollment and, more broadly, understanding disability's relationship to aging and other characteristics that compound disadvantage like gender, class, and race (Erosheva, Fienberg, and Joutard 2007). Despite a great deal of progress in measurement, defining and operationalizing disability remains a persistent challenge. This is not surprising, given the multitude of definitional sources that include law, medicine, and the disability rights movement, as well as socio-culturally specific definitional

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differences, making counting and cross-nationally comparing disability an incredibly difficult task.

Governments sometime define disability narrowly to reduce the number of individuals receiving benefits. And, those deemed disabled for benefit purposes are not necessarily considered disabled in, for example, work-place antidiscrimination cases (Maroto and Pettinicchio 2014a). Political debates continue regarding which health conditions should be considered disabilities and whether a person's status should account for their disability when "mitigated" through aids, equipment, and medication that can effectively remove barriers (Pettinicchio 2019). Navigating this complex, structural, cultural, and multilayered definitional landscape no doubt shapes how and whether respondents identify as having functional limitations or disabilities in self-reported surveys.

More broadly, the shift away from impairment (or cause) toward the interaction between individual and society (or impact) (Me and Mbogoni 2006; Loeb 2013; Cappa, Petrowski and Njelesani 2015) has emphasized that what is "disabling" is not an individual's "condition" but rather, their relationship to the cultural and physical environment. Disablement is consequently a process defined by the experiences of individuals in their respective social, cultural, political, and economic contexts (Shakespeare 1996; Altman 2001). To capture disabling environments, activists and advocates in many countries championed reforms to disability questions on surveys and censuses as a matter of equality and policy monitoring (Groce 2006; Kostanjsek et al. 2013).

Who counts, then, reflects who is doing the counting, under what conditions they are counting people, and for what purpose. Survey researchers, especially those interested in cross-national comparisons, are left with the unenviable task of asking about disability in ways that are temporally and culturally meaningful on the one hand, and practically useful (i.e., comparable across surveys) for quantitative research on the other. Recent efforts to consider the relationship between disability and the environment reveal a tension between conciseness and comparability, while considering diverse sociocultural settings requiring some engagement with culturally specific meanings to obtain accurate estimates.

This study addresses these issues through a broad assessment of disability measurement in national censuses, answering three central questions as follows: (1) How does the measurement and understanding of disability differ across countries as reflected in census data? (2) Does the prevalence of disability correlate with differences in disability measurement questions across countries? (3) And, given that definitions and measures vary cross-nationally and influence estimates of the prevalence of disability, how do these differences vary by country income levels? We situate this research within a broader discussion regarding the growing prevalence of multinational, multiregional, and multicultural context (3MC) survey research and efforts to create harmonized data sources. Disability is a socio-culturally specific concept posing challenges for measurement and studying disability measures across countries offers

additional insight into the construction of surveys and challenges associated with their cross-national comparative usage.

Using harmonized IPUMS International Census microdata (IPUMS-I) since 2,000 for 105,306,364 working-age adults, we consider disability measurement across 65 countries. We examine both broad disability measures, for instance whether a country includes a general or work-limiting disability question, and specific details in disability questions that include whether the country asks about disability type and severity. We find that even though estimates of disability prevalence did not differ much in relation to whether surveys included work-limiting definitions, specific question wording did appear to affect disability estimates. Questions that included potentially stigmatizing wording, such as a reference to impairments or suffering, were associated with lower reported rates of disability. Including questions about disability severity or considering mitigated states was also associated with lower estimated disability rates, potentially because having these options led respondents to not consider certain limitations to be disabling. In contrast, including questions about specific types of limitations and describing disability as permanent in some way was associated with higher estimated rates, likely because this provided respondents with a broader range of options to consider as disabilities.

As one of the first papers to use IPUMS-I data to examine disability prevalence across countries, this study offers important insights about the use of combined census data for the analysis of outcomes among marginalized groups, such as people with disabilities. In addition to providing information about disability prevalence using official statistics based on census data from 65 countries, this study addresses the many challenges that arise in harmonizing census data and in designing questionnaires for disability measures that are socially and culturally appropriate but also consistent across countries.

## **2. “GLOBAL” MEASURES IN COMPARATIVE SURVEYS AND HARMONIZED CENSUS DATA**

Ideally, if the objective is to analyze a range of topics across diverse sociocultural contexts—from family and household structure to voting and political engagement to economic and social wellbeing—then surveys should be designed to do so from the get-go. Incorporating such goals, 3MC surveys have an added layer of consistency. With these, standardization and harmonization occur ex-ante, at the planning phase, when concepts and constructs are defined and deliberated, and survey items are carefully written, translated, pre-tested, and analyzed to ensure both measurement validity and cross-national comparability.

Most users of cross-national data agree that this is the only real way to reduce total survey error (TSE). In the case of cross-national measurement, TSE includes sampling variability, as well as validity and measurement error

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resulting from issues with standardization and harmonization across samples. Errors resulting from sampling variability and from standardization are not unrelated. Comparison depends on quality control at the national level that can affect not only how surveys are conducted, but also, for example, whether difficult to survey groups, including people with disabilities, indeed have a non-zero chance of being sampled (Gabler and Hder 2017).

Harmonization—which involves reducing complex and culturally specific concepts to the lowest common denominator of detail for comparison (Ruggles, King, Levison, McCaa, and Sobek 2003)—can be relatively straightforward when dealing with common demographic questions. However, with many variables, such as disability, important complexities can arise. As Scott, Mohler, and Cibelli Hibben (2019) note, even in 3MC surveys designed to be comparative from the start, it is impossible to have a one-size-fits-all approach. In the end, experts are performing a balancing act between standardizing measures across cultures while trying to retain specific meaning or “unique flavor” to those respective cultures to minimize error (Cibelli Hibben, Pennell, Hughes, Lin, and Kellye 2019). In cross-national comparative surveys, this typically means developing broad questions that still remain valid and reliable with respect to their specific contexts (Pennell and Cibelli Hibben 2017). Referring to 3MCs, Pennell, Cibelli Hibben, Lyberg, Mohler, and Worku (2017, p. 183) state, “The challenge is that design decisions that may be optimal in terms of minimizing TSE for one context may be suboptimal for another.”

3MC surveys have come a long way thanks in large part to cross-disciplinary coordinated efforts among experts. Although the objective is to minimize error, a perfect balance between comparability and meaning may never be achieved for many measures. Thus, not surprisingly, a key goal in harmonization early in the survey design process involves resolving how distinct cultural frameworks with their own language and lexicon around socio-cultural specific concepts (including disability) can effectively produce cross-national comparisons with as little error as possible (Johnson, Pennell, Stoop, and Dorer 2019).

### **3. “GLOBAL” MEASURES OF DISABILITY**

Hard-to-survey populations that include people with disabilities tend to share some commonalities—concealing stigmatized status characteristics, individuals believing they do not identify with a status characteristic and, relatedly, a reluctance to participate in surveys or identify with a status in a census. Meanings surrounding disability also vary widely cross-nationally and between different communities within the same country (Miller 2016; Weeks 2016). In addition, some members may be hard to survey because the status characteristic they share makes it difficult to do so. For instance, someone who

is deaf, blind, or neurodiverse, or who communicates and understands speech differently (see [Pescosolido 2013](#)) may not interact with a census taker or enumerator in a meaningful or productive way. Even within national surveys, quality control varies with the availability of sampling frames and populations registers, which affect how difficult to survey groups are reached (see [Pennell and Cibelli Hibben 2017](#)).

Fully assessing a range of disabilities and addressing issues of identification often requires long sets of involved questions, which is not always possible for surveys, especially national censuses. In many countries, a reliance on the census to capture disability is problematic because they are often limited to a single disability question with a dichotomous yes/no response ([Loeb and Eide 2006](#); [Loeb 2013](#)). Restrictive definitions almost always produce more conservative estimates than surveys with more detailed questions ([Cappa 2015](#)). This has important implications for estimating the number of people with disabilities. According to the World Health Survey, approximately 14–16 percent of people age fifteen and older live with a disability (WHO 2011; [Mitra and Sambamoorthi 2014](#)). Prevalence, however, varies considerably cross-nationally, in part because of the way disability is conceptualized and how people are in turn counted.

In 2001, the UN statistical division created the Washington Group on Disability Statistics (WG) whose expressed purpose was to refine, monitor, update, and analyze the use of disability measures around the world. Together, the WG and ICF promote a definition of disability based on basic functional limitations (e.g., in seeing, hearing, walking, cognition, self-care, and communication) that addresses the extent to which individuals experience these difficulties on a continuum. Operationalizing disability in terms of “building-block” activities that form the bases of broader participation is thought to more efficiently capture the limitations in life activities as a dimension of individuals’ interaction with their environment ([Altman and Bernstein 2008](#)). This has important implications for understanding the link between disability and participation because individuals with limitations in some basic activities may not identify as being limited in broader life activities like work.

Based on these goals, the ICF has sought to ensure that cross-national disability measurement promote the following international standard:

The questions cover six core domains of functioning or basic actions: seeing, hearing, walking, cognition, self-care, and communication. Furthermore, each question has four response options: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. This scale of degree of difficulty is used in the response categories in order to capture the full spectrum of functional difficulty ranging from mild to very severe.

Consensus is that surveys should use an array of questions to address multiple dimensions of disability, highlighting the impacts rather than causes of

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disability. Furthermore, they should ask about activity limitations rather than impairments and include questions about severity. In addition to providing better estimates of the prevalence of disability, including such questions also helps researchers to better assess the consequences of disability in terms of social participation whether in civil society, education, or the labor market.

### 3.1 Context Matters in Conceptualizing Disability as Functional Limitations

Functional disability refers to difficulties performing activities of daily living. Limitations represent a move away from a focus on impairment by considering environmental barriers vis-à-vis an individual's status. Measures based on these definitions are thought to be more neutral as they do not rely on terms like "disabled" or "impaired" to obtain information about disability from survey respondents. An important underlying assumption of this approach is that many more individuals, presumably even those who may not consider themselves as persons with disabilities experience some degree of limitation in daily activity ([Sabariego et al. 2015](#)).

Conceptualizing disability as a dynamic interaction between individual and environment inherently requires knowing about the context surrounding disability. Structural and cultural factors shape access to mitigating aids and medications that reduce barriers to participation. Variation in access to aids may make some basic activities more accessible than others and shape participation in social, political, and economic spheres of life ([Altman and Bernstein 2008](#)). Thus, access to mitigating factors may lead to underreporting if an individual does not experience limitations as a result ([Federici, Meloni, Catarinella, and Mazzeschi 2017](#)). In addition, the way individuals experience barriers because they cannot access aids and medication might capture broader forms of gender, race, and class-based inequality ([Groce 2006](#); [Kostanjsek et al. 2013](#)) and the intersection of these ([Maroto, Pettinicchio and Patterson 2019](#)). Two individuals with the same disability may have widely different experiences with accessing aids and medications and with environmental barriers and obstacles depending on status and location.

In addition, individuals who report limitations in basic activities are not necessarily limited in all life activities. This is especially relevant to studies interested in disability and labor market participation ([Haveman and Wolfe 1990](#); [Lewis and Allee 1992](#); [Altman, Rasch, and Madans 2006](#); [Robert and Harlan 2006](#); [Bambra and Pope 2007](#)). Work-limiting definitions assume that having a disability prevents an individual from working or limits the kind or amount of work ([Maroto and Pettinicchio 2014a](#)). If researchers are specifically interested in how disability affects employment, then using a work-limiting measure could be appropriate because it targets the specific population of interest ([Maroto and Pettinicchio 2014a, 2014b, 2015](#); [Pettinicchio and Maroto 2017](#)).



Issues do arise with work-limiting measures (Burkhauser, Houtenville, and Tennants 2014). For instance, self-reported disability often differs from employer-perceived disability (Beegle and Stock 2003). Some individuals might not count short-term limitations as work-limiting (Burkhauser and Houtenville 2006), and others with significant limitations may not report their disability as work-limiting if they do not believe it limits their work (Burkhauser, Daly, Houtenville, and Nargis 2002). The work-limiting measure presents an especially relevant example of the considerations involved when using functional limitations to capture disability, particularly when it comes to the political, cultural, and economic contexts within which disability is defined, and whether legislated workplace accommodations mitigate work limitations (Weil 2001; Jolls and Prescott 2004). This highlights how cross-national comparisons of disability measures based on functional limitations cannot be understood outside structurally and culturally specific contexts.

### 3.2 Contested Definitions and Deviations from the ICF

The ICF encourages the adoption of a functional limitations approach ex-ante by surveys and censuses to facilitate both measurement validity and cross-national comparability. Yet, deviations from the ICF definition are still widespread (Me and Mbogoni 2006) and measures and definitions are contested (Federici et al. 2017). Initial cross-national comparisons, finding that low- and middle-income countries reported a considerably lower prevalence of disability compared to high-income countries, raised concerns about data collection (Madans and Loeb 2013; Loeb 2013). This was not because populations with disabilities were smaller in these countries, but because the cultural and institutional contexts of these locations shaped how individuals from historically stigmatized groups were counted (Michaels and Lhomond 2006).

Census disability questions may broadly subscribe to ICF definitions, but are often tailored to fit with cultural definitions thought to resonate with citizens and programmatic objectives that may or may not intersect with ICF definitions (Sabariego et al. 2015). Despite efforts to implement a global or universal measure, as Cappa et al. (2015, p. 327) write, “measuring disability is a complex process because there is no single definition that can be applied broadly across all cultural contexts.” The result has been a broad range of survey questions and definitions for disability.

Analyses repeatedly reveal that asking about specific limitations in basic activities increases disability counts (Madans et al. 2004; Me and Mbogoni 2006). The word “disabled” might make less sense to some respondents than specific functional limitations they can more readily identify with. Yet, in many contexts, perhaps to help respondents better relate to questionnaire items, enumerators use outdated (and negative) language that others might find offensive, perhaps to better capture their experience and their culturally specific



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understanding (Groce 2006; Malam, Emerson, and Davies 2014). At the same time, this kind of question wording can lead to underreporting if these terms are stigmatizing (Loeb 2013). For example, disability-related terms are frequently tied to suffering and difficulty, and even to punishment for sinning and incest, comparing functional limitations to some state of normality.

Not only are these marked deviations from the ICF, but they are also pathological understandings that ignore the social construction of disability (Baglieri and Shapiro 2012; Cappa et al. 2015). Even listing specific conditions is rife with problems, especially when the conditions are stigmatized. This may lead households to underreport, fearful of being ostracized and marginalized by their communities. Relatedly, citizens might be suspicious about the very purpose of data gathering. Being identified as a person or household with a disability has historically led to segregation in school or work, exclusion from social welfare programs, and even forced institutionalization. Thus, with many more national censuses and surveys adopting variations of the ICF, it is important to note the persistent variation in how questions are asked and the challenges this poses for standardizing and harmonizing measures.

### 3.2 Ex-Post Harmonization of Disability Measures

How people understand terms put to them based on language (and translation) and cultural frameworks (see Smith 2004), and social desirability biases, especially the case with stigmatized identities like disability, contribute to measurement error. Following Wolf et al.'s (2017) recommendation, properly harmonizing disability measures would require establishing ex-ante the entire scope of what disability is—"the universe of manifestations"—in order to determine whether cross-cultural equivalents exist for comparable outputs (p. 5). Teams of experts require specific cultural knowledge in order to ensure harmonization including translation (Mohler, Dorer, De Jong, and Hu 2016).

The task is far more complicated when harmonizing outputs from national censuses, whose primary goal is collecting country-specific data for government use, not comparing outcomes between nations. Strongly coordinated efforts in standardizing measures for comparative purposes are less likely to take place. Even though international guidelines about how to include certain measures exist, interests and efforts to follow these guidelines vary considerably. Disability presents an important case in this regard. Although the ICF and Washington Group advocate for more stringent input or ex-ante harmonization around disability measures, these are in no way coordinated like those found in 3MC surveys with strict input harmonization ensuring standardized constructs, language, and wording (e.g., European Social Survey).

With far less coordination at input, IPUMS-I cross-national census data relies entirely on ex-post harmonization (Harkness et al. 2010; Granda and Blasczyk 2016). Error associated with input (ex-ante) harmonization

contributes to error in output (ex-post) harmonization (Pennell et al. 2017), especially with weaker standardization efforts at the input stage. Experts must determine ex-post whether measures across different surveys address the same construct. These efforts do not guarantee resolving meaning and interpretation differences across measures as a result of the way censuses were originally implemented especially when it comes to sensitive, sociocultural-specific topics. On ex-post harmonization and translation specifically, Wolf et al. (2017) note that “This approach by and large works if the question to be translated does not refer to any issue strongly shaped by specific institutions, culture or history of a country” (p. 5). Disability-related questions are not such examples.

Language and cultural frames shape how people understand and respond to disability in surveys. Using culturally specific terms, wording, and lexicon around disability is necessary for ensuring validity but it makes comparison more complicated. Harmonization involves leaving as few differences between surveys as possible to reduce measurement error; it is a key part of survey quality control (Mohler et al. 2016). But, as Harkness, Dorer and Mohler (2016) note, there will always be a tension between semantic and pragmatic meaning around sociocultural-specific terms and concepts, and as we note, this remains salient with disability despite efforts to standardize disability measures in cross-national censuses.

For these reasons, it is important for any user of ex-post harmonized data to more broadly consider the challenges associated with cross-national data collection and comparability when it comes to historically marginalized and stigmatized groups. In this study, we investigate how the prevalence of disability varies across countries and in relation to the specific questions asked within censuses. Using data from 65 censuses, we focus on how input, including instructions and definitions given to enumerators and census-takers, the connections made to types of functional limitations and disability severity, and the specific wording used to describe disability in terms of permanence, impairment, suffering, and its mitigated state, potentially influence output and in turn, analyses about the prevalence of disability across countries.

#### **4. DATA AND METHODS**

We examine measures of disability across countries using harmonized IPUMS International Census microdata, the world’s largest archive of publicly available census data made possible through the collaboration of numerous statistical agencies (Minnesota Population Center 2019).<sup>1</sup> The full database includes over 730 million people across 399 censuses and surveys in 98 countries since

1. For more information about harmonization please see: <https://international.ipums.org/international/harmonization.shtml>.

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1960. As the most comprehensive collection of census data available, this dataset provides an excellent resource for examining disability measurement across countries.

IPUMS-I uses sophisticated and careful means to harmonize ex-post national censuses, but as [Esteve and Sobek \(2003\)](#) note, “virtually all variable-level harmonization is imperfect because of variations in the wording of questions, the classifications employed by each census, and the cultural meanings of census concepts” (p. 68). Quality source documents from each census—meta data ranging from information provided to enumerators to information used by local topic-specific experts—is of the utmost importance for experts seeking to harmonize output ([Jeffers et al. 2017](#); [Ruggles et al. 2015](#)). This is why IPUMS also compiles questionnaire text and shares it with researchers, so they can evaluate question wording themselves ([Sobek 2016](#)). Researchers must make informed decisions about using measures in a comparative way and for that reason, documentation should be as detailed as possible. It should note any comparability issues experts encountered given how different censuses ask about certain topics, like for example, disability ([Ruggles et al. 2003, 2015](#)).

On disability, [Jeffers et al. \(2017, p. 392\)](#) warn that “Even when IPUMS-International variables are given consistent names and coding schemes, such integrated variables may incorporate subtle differences across samples for example, in the definition of disability. Researchers thus need to be attentive to underlying variations in question wording, instructions to enumerators and question universes. Fortunately, the IPUMS-International variable-specific online documentation is designed to highlight such differences.” However, online documentation becomes less helpful once users consider potential translation issues regarding socially charged terms. We therefore posit that for disability, these differences may not always be so subtle, and users should take caution in how they interpret outcomes. Much goes into ex-post harmonization and with publicly available detailed information about the process, the buck ultimately stops with the user interested in making cross-national comparisons.

In the case of disability on national censuses, Washington Group guidelines may have had some isomorphic impact at the input stage (i.e., questionnaire design) by bringing diverse disability survey items closer together. Nonetheless, users should be aware of the variation in how different censuses adopt those guidelines, which means that the output should be considered carefully for cross-national comparison. This has been a primary concern with the harmonization process used to create the IPUMS-I dataset.

We restrict our dataset to countries that included a disability-related question in their census. In order to ensure recent definitions for disability, we rely on harmonized data since 2000, taking the most recent census year available for each country. Of the 95 countries with data available after 2000, 65 included some form of a disability question on their census. We also restrict our sample

to working-age adults between 18–64 years of age. This resulted in a sample of 65 countries and 105,306,364 observations.<sup>2</sup>

We begin by examining the census questionnaires and instructions provided to enumerators. We code each country's disability questions across eight areas: (1) whether they provide detailed instructions to census-takers; (2) whether they provide a general definition of disability; (3) whether they record information about functional limitations among basic activities (e.g., vision, hearing, cognitive, and physical); (4) whether they record information regarding the severity of disability; (5) whether they note that disability should be considered to be a permanent (long standing and not temporary) condition; (6) whether they specifically describe disability as an impairment, limitation, or handicap; (7) whether they consider the mitigated state of disability; and (8) whether they describe disability as a state of "suffering." We also note whether the country includes an additional question gathering information about work-related disabilities, whether disability limits a respondent's ability to work, or whether disability is the specific reason that respondent might not be working. In total, 29 countries included both general disability questions and work-related disability questions, 24 included only general questions, and 12 included only work-related questions.

In addition to providing a descriptive overview of different disability questions across censuses, we examine variation in the prevalence of disability across high-income, upper-middle-income, lower-middle-income, and low-income countries. We are specifically interested in how different definitions of disability and question wording shape findings about disability prevalence. Although we analyze the individual-level microdata across countries, we present results as averages for each country. This allows for a broader comparison of the relationship between disability measurement and prevalence across countries.

## **5. FINDINGS**

Most countries asked about disability using either a general disability question with different components, an employment-related disability question, or both. As [table 1](#) shows, 82 percent of countries included a general disability question in their census. Among countries that included both a general and employment-related question ( $N = 29$ ), estimated age and gender adjusted rates

2. Appendix A lists the countries, years, and country-specific samples included in the analyses, as well as a comparison between the IPUMS countries with and without disability questions. Within our final sample, 14 percent of countries were located in East Asia and the Pacific, 11 percent were in Europe and Central Asia, 31 percent were in Latin America and the Caribbean, 5 percent were in the Middle East and North Africa, 2 percent were in North America, 3 percent were in South Asia, and 35 percent were in Sub-Saharan Africa. This is in part due to the countries represented in the harmonized data and differences in those that included disability-related questions.

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**Table 1. Disability Prevalence by Disability Question Type**

	Number of countries	Average disability prevalence rate	
		Estimate	SE
Both general and employment questions	29	4.16	0.03
General disability question	24	4.10	0.03
Employment-related disability question	12	4.35	0.05
Total	65	4.17	0.03

NOTE.—Disability prevalence rates are adjusted for age and sex differences across countries. Prevalence refers to the proportion of adults reporting a disability in that year.

SOURCE.—Author compiled country-level data based on IPUMS-I for 2000s;  $N = 65$  countries.

Rates provided for 10 countries with only employment-related questions (Cuba, Fiji, Honduras, Kyrgyz Republic, Mongolia, Papua New Guinea, Peru, Portugal, Spain, and the United Kingdom) refer to the percentage of people with disabilities in the population without employment because questions about disability were only asked of this population.

of disability were approximately 4.16 percent. Among countries with just a general question ( $N = 24$ ), the estimated prevalence of disability was 4.10 percent. These estimates were similar to those for countries that only asked respondents without employment if disability was their reason for a lack of employment ( $N = 12$ ), which reported a rate of 4.35 percent.<sup>3</sup>

Among countries that included a specific disability question in their censuses ( $N = 53$ ), question wording and instructions varied considerably. [Table 2](#) highlights how these variations are also reflected in the differing prevalence estimates across countries.

The amount of information provided to enumerators across countries varied considerably. In total, 40 countries provided detailed instructions to census-takers for how to measure disability, but these instructions also varied in terms of who should be interviewed and how information should be recorded. In many cases, survey administrators were not specifically instructed to interview a person who may have a disability but, rather, someone in their household instead (e.g., Malawi and Senegal). In other cases, survey administrators were instructed to record information about all household members (e.g., Costa Rica

3. Rates for 10 countries with only employment-related questions (Cuba, Fiji, Honduras, Kyrgyz Republic, Mongolia, Papua New Guinea, Peru, Portugal, Spain, and the United Kingdom) refer to the percentage of people with disabilities in the population without employment because questions about disability were only asked of this population. When the full population is included in the denominator, rates are, as expected, much lower.

**Table 2. Disability Prevalence by Disability Question Phrasing**

	Number of countries using specified phrasing	Average disability prevalence rate for countries that do not use specified phrasing		Average disability prevalence rate for countries that use specified phrasing	
		Estimate	SE	Estimate	SE
Provide detailed instructions	40	4.13	0.05	4.13	0.03
Include disability definition	30	4.85	0.04	3.58	0.02
Record type of disability	42	3.14	0.02	4.39	0.03
Record severity of disability	8	4.25	0.03	3.45	0.02
Define disability as permanent condition	20	3.79	0.03	4.69	0.03
Describe disability as impairment, limitation, or handicap	30	5.18	0.04	3.33	0.02
Consider mitigated state	18	4.43	0.04	3.54	0.02
Refer to suffering	4	4.28	0.03	2.28	0.02

NOTE.—Disability prevalence rates are adjusted for age and sex differences across countries. “Using Specified Phrasing” refers to countries that include the phrasing listed in the left-hand column.

SOURCE.—Author compiled country-level data based on IPUMS-I for 2000s;  $N = 53$  countries with general disability questions.

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and Ethiopia) although it is unclear whether this meant interviewing respondents directly or obtaining second-hand reports about other household members' experiences with disability. But in Mexico, survey administrators were specifically instructed to interview all household members. In Vietnam, a note to administrators that level of disability should be determined by the actual respondent also indicates that a person who "is clearly disabled" and cannot be interviewed cannot also be classified as having "no difficulties." We found that regardless of how instructions were provided, it had a limited effect on reported rates of disability which were 4.13 percent.

Whether survey instructions included some definition for disability appeared to be associated with disability estimates, which were lower among surveys that included such definitions. Among the 30 countries that provided a specific disability definition, 3.58 percent of working-age adults reported a disability. For countries that did not include a definition, average prevalence was estimated to be 4.85 percent. Many of the more detailed disability definitions were also situated within a broader programmatic and policy context. The Bangladeshi and Kenyan censuses provided definitions of disability tied directly to their respective national policies. In Poland, definitions of disability were explicitly framed in terms of "legal statements"—individuals "lawfully" deemed disabled by the state.

Requesting additional details about disability by referring to different types of disabilities in questions, discussing the severity of disability, and referring to disability as a "permanent" condition was also associated with reported rates of disability across countries. Disability rates were higher among countries that included multiple questions about different disabilities, but rates were lower when disability severity was recorded. Surprisingly, defining disability as a permanent condition was associated with higher reported rates of disability, perhaps due to how this term interacts with different question wordings of disability.

There was also considerable cross-national variation in how disability was understood when potentially mitigated by aids, devices, and other measures. In Brazil, questions specifically asked whether a person had a hearing difficulty even when using a hearing aid. In Cameroon, disability was defined in terms of needing an aid (i.e., "One is considered handicapped if they need the assistance of specific equipment"). Most common, individuals were considered as having a disability if they continued to have difficulties even while using aids (e.g., South Africa, Ghana, and Mexico). Other countries, however, defined disability only in an unmitigated state (e.g., Ecuador and Morocco) or in the Panamanian survey, "impairments that cannot be normalized." Indonesian survey administrators were expected to ensure that if respondents did not experience difficulties while using aids, not to count them as having a disability. Paraguay is somewhat unusual because they distinguished individuals who were blind and deaf from those who had difficulty seeing or hearing with aids.



Considering whether disability was defined in its mitigated form is important for prevalence rates. Estimated rates of disability were lower for countries that included specific questions related to disability's mitigated state. Within these countries, estimated disability prevalence was 3.54 percent, indicating that discussing disability in its mitigated form potentially leads persons to not consider certain limitations as disabilities. As Miller (2016) outlined in the National Center for Health Statistics field evaluation of the Washington Group questionnaire, individuals may identify with having a vision problem that glasses (i.e., the "glasses clause") cannot correct or they may not think they have a disability if wearing glasses removes the impairment. Miller (2016) found considerable variation in how disability was understood in its mitigated state within countries as this varied by factors like gender, as well as between countries because of terminology and translation issues.

Finally, even though censuses sought to move closer to the ICF ideal, many still deviated from the ICF. Furthest away were those countries that used terms emphasizing problems, inabilities, and abnormalities. In Bangladesh, for example, census instructions specifically refer to the Washington Group recommendations in terms of categorizing disability into six types, but it also uses the terms "mentally retarded" and "disabled," as well as "problem" and "cause." When translated into English, other countries use terms like "dumb" (e.g., Cambodia), "crippled" (e.g., Sierra Leone), "deficiency" (e.g., Dominican Republic), "impairment" and "malformation" (e.g., Rwanda), "damaged" (e.g., Ethiopia), and "anomaly" (e.g., Venezuela). At the outset, these terms are not congruent with the WG or ICF frameworks. However, it is unclear from the provided IPUMS-I documentation how the terms were translated. It may be useful here for researchers to have access to questionnaires in their original language to ascertain any translation-related issues.

In other countries, like Bangladesh, censuses also include problematic language that compares disability to some "normal" state. In the Ecuadorian census, disability is defined as a "permanent difficulty doing an activity considered normal." In Indonesia, the question is framed in terms of normal functioning and in Jamaica, disability is defined as an inability to perform "an activity in the manner or within the range considered normal for a human being." Similarly, in Jamaica and Senegal, people with disabilities are considered to be "suffering" from a condition.

Other examples more closely follow the ICF model but with some modifications. For example, the Costa Rican census asked individuals to select one or more permanent functional limitations (including intellectual and mental) but did not ask about severity. Other variations include Ghana where individuals were asked to note one of several limitations but words like suffer, disabled, impairment, and disorder were also used (all actively discouraged by ICF). The question recognized that disability can be partial or total, but did not ask about severity. Kenya, Uruguay, Nepal, and Mexico were similar. Indonesia

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and Brazil perhaps came closest to an ICF ideal by asking about functional limitations as well as their severity.

These differences have important impacts on prevalence. The largest disparities were present between countries that did and did not describe disability as an impairment, limitation, or handicap and those that did and did not refer specifically to “suffering” in the survey. When surveys described disability as an impairment, limitation, or handicap, the average reported rate of disability was 3.33 percent. When questions specifically referred to “suffering”, the rate was 2.28 percent. These findings imply that cultural differences in definitions for disability and the stigma of reporting a disability might have a larger effect on reported prevalence than simple question wording. For these reasons, we also explore differences in reported prevalence by country income-level and country region in [table 3](#) and [figure 1](#).

[Table 3](#) indicates large average differences across countries in reported rates of disability. As shown by [Kostanjsek et al. \(2013\)](#), estimates of disability tend to be greater in higher-income countries when based on individual country survey data. The average rate of disability in these countries was 8.27 percent, more than twice the rate for low-income countries. Notably, our sample included fewer higher-income countries, which means that outliers, like the United Kingdom, could be skewing average results here. North America, Europe, and Central Asia also reported higher rates of disability, with the highest being North America at 10.18 percent. The lowest average rates were reported in Sub-Saharan Africa and East Asian and Pacific countries.

A further investigation of the spread of estimates in [figure 1](#), however, shows a broader range of values across high-income and upper-middle-income countries than in low- or lower-middle-income countries. Highest reported age and gender adjusted rates of disability were present in the United Kingdom with 22.07 percent of working age adults reporting a disability, followed by Puerto Rico at 16.12 percent, both of which are high-income countries. The lowest rates were found in Peru, Malaysia, Indonesia, Thailand, Nicaragua, Egypt, and Mali with less than 1 percent of persons reporting a disability in these countries.

Census wording and instructions also varied in relation to county income level, as shown in [table 4](#). Low-income countries, in particular, stand out in several areas. Compared to higher-income countries, those in this category were less likely to record the severity of disability and less likely to consider its mitigated state, but much more likely to refer to suffering in disability-related questions. Low- and lower-middle-income countries were also more likely to include definitions of disability for the census enumerators.

Thus, this analysis shows that estimates of disability are connected to phrasing within census questions, which is also linked to income levels across countries. These different question wordings, which reflect broader cultural views of disability, partly explain other findings showing different rates of disability

**Table 3. Disability Prevalence by Country Income Level and Region**

	Number of countries in category	Average disability prevalence rate	
		Estimate	SE
Income			
High income	11	8.27	0.06
Upper middle income	18	3.91	0.03
Lower middle income	21	2.91	0.03
Low income	15	3.24	0.03
Region			
East Asia and Pacific	9	1.81	0.04
Europe and Central Asia	7	8.46	0.04
Latin America and Caribbean	20	4.72	0.04
Middle East and North Africa	3	2.52	0.02
North America	1	10.18	0.03
South Asia	2	1.89	0.01
Sub-Saharan Africa	23	3.46	0.03

NOTE.—Disability prevalence rates are adjusted for age and sex differences across countries.

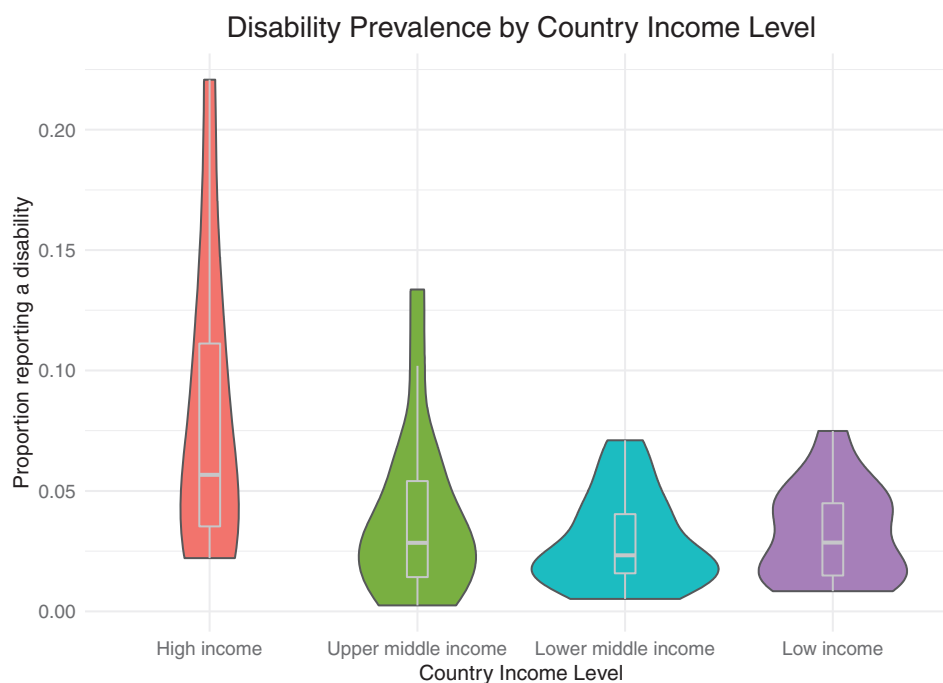
SOURCE.—Author compiled country-level data based on IPUMS-I for 2000s;  $N = 65$  countries.

across countries by income level ([Kostanjsek et al. 2013](#); [Mitra and Sambamoorthi 2014](#)). Further, it is also likely that these different ways of phrasing disability questions influence estimates of socioeconomic outcomes, including labor market participation.

## 6. CONCLUSIONS

Definitions and measures of disability are neither ahistorical nor independent of socio-cultural contexts. Survey research necessarily has had to contend with the context-specific nature surrounding the norms, values, and meanings attached to disability. Cultural and political changes, in part the result of social movements and advocacy, have shaped how and why governments seek to obtain information about their citizens with disabilities. With the United Nations Convention on the Rights of People with Disabilities, renewed efforts to capture social barriers experienced by people with disabilities have led to fundamental shifts in how disability is defined. Central to contemporary definitions of disability is that the kind of exclusion and inequality people with disabilities experience is not located in the individual, but rather, in the environments they inhabit. It is an inherently sociological understanding of disability.

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**Figure 1. Disability Prevalence by Country Income Level.**

SOURCE. Author compiled country-level data based on IPUMS-I for 2000s;  $N = 65$  countries

This has posed many conceptual and methodological challenges not least of which is settling (if at all possible) on a standard definition of disability, especially important in facilitating cross-national comparisons of disability prevalence and other associated outcomes. The WG recognizes that there are many reasons motivating the collection of data on disability and that there may not be one single measure that can accomplish these multiple goals. This raises some unique considerations for scholars interested in cross-national comparative work. Despite efforts to harmonize census questionnaires and the broader global push to construct definitions in line with a human rights and social model of disability, these shifts are mediated by cultural and institutional contexts manifesting themselves differently and at uneven paces.

This study presents a broad overview of cross-national disability measures and the implications for comparative quantitative work. It is by no means a comprehensive analysis of all nations or all factors influencing definitions and measures. Nevertheless, it continues the larger discussion of definitional challenges and questionnaire implementation and alludes to connections between measurement differences and outcomes. Our analysis of disability census questions across 65 countries shows that how disability is defined and measured shapes the prevalence of disability. We found that definitions, terminology, measurement, and instructions to respondents and enumerators matter for understanding disability prevalence. High-income and upper-middle-income

**Table 4. Disability Question Wording by Country Income Level**

	Percentage of countries using specified survey phrasing, income level			
	High income	Upper middle income	Lower middle income	Low income
Provide detailed instructions	75.00	64.29	87.50	73.33
Include disability definition	50.00	50.00	62.50	60.00
Record type of disability	87.50	78.57	81.25	73.33
Record severity of disability	37.50	14.29	12.50	6.67
Define disability as permanent condition	37.50	57.14	25.00	33.33
Describe disability as impairment, limitation, or handicap	62.50	57.14	62.50	46.67
Consider mitigated state	50.00	42.86	37.50	13.33
Refer to suffering	0.00	7.14	6.25	13.33

SOURCE.—Author compiled country-level data based on IPUMS-I for 2000s;  $N = 53$  countries with general disability questions.

countries tended to report the highest rates of disability, but this is partly due to how they ask questions about disability.

Efforts to encourage standardization in disability measurement, as well as ongoing work by disability experts worldwide to document how culturally specific uses impact comparability have shined a spotlight on the problem. However, using harmonized census data poses concerns given weak standardization at input leading to significant challenges in harmonizing output. Ideally, 3MC-like surveys focusing on disability would more directly address tensions between validity and cross-national comparability. For example, in 3MCs, extensive pre-testing of comparable translations is done to minimize post-survey treatments or back translating. Extensive documentation is also provided including translation annotations critical in ascertaining the “degrees of freedom” around terminology allowing comparability while maintaining intended meaning (Behr and Scholz 2011; de Jong, Cibelli Hibben, Kelley and Behr 2020).

One example of such surveys is the World Health Organization’s World Health Survey, which uses comparable self-reported measures of disability closely linked to WG and ICF guidelines on functional limitations (World Health Organization 2011).<sup>4</sup> Culturally specific constructs are identified ex-ante, developed in multiple languages and extensively pre-tested. While they do use back translating, cognitive interviews and cultural applicability tests are used to ensure equivalency. Nonetheless, as Mitra and Sambamoorthi (2014)

4. <https://www.ncbi.nlm.nih.gov/books/NBK304080/>

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note, missing data and the exclusion of hearing and communication limitations from the survey distort prevalence rates.

Harmonized IPUMS census data still provide a useful global picture of disability but like with all data, should be used with care. We suggest that differences, such as those shown in our findings, likely influence any cross-national work using IPUMS or other compiled census data to predict a range of outcomes, whether labor market participation, educational attainment, household characteristics, and more. When analyzing such data, it is imperative that researchers carefully address how disability is measured in each survey or census and consider how and in what way questionnaire items are presented.

**Appendix A****Table A.1. Country Information**

Country	Survey year	<i>N</i>
Bangladesh	2011	4,006,473
Benin	2002	444,096
Botswana	2011	113,269
Brazil	2010	12,747,667
Burkina Faso	2006	613,036
Cambodia	2013	73,503
Cameroon	2005	805,731
Chile	2002	924,003
Colombia	2005	2,200,489
Costa Rica	2011	267,704
Cuba	2002	722,724
Dominican Republic	2010	543,954
Ecuador	2010	814,428
Egypt	2006	4,215,815
El Salvador	2007	303,306
Ethiopia	2007	3,339,032
Fiji	2014	52,717
Ghana	2010	1,248,703
Haiti	2003	429,788
Honduras	2001	153,045
Indonesia	2010	14,295,008
Ireland	2011	286,977
Jamaica	2001	110,228
Jordan	2004	269,247
Kenya	2009	1,797,492
Kyrgyz Republic	2009	330,067
Lesotho	2006	95,308
Liberia	2008	168,437
Malawi	2008	577,251
Malaysia	2000	243,414
Mali	2009	606,172
Mexico	2010	12,819,356
Mongolia	2000	132,466
Morocco	2004	843,524
Mozambique	2007	894,084
Nepal	2011	1,700,491
Nicaragua	2005	264,171
Panama	2010	198,273
Papua New Guinea	2000	260,554
Paraguay	2002	264,829

*Continued*



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**Table A.1.** *Continued*

Country	Survey year	<i>N</i>
Peru	2007	1,567,635
Philippines	2010	5,256,563
Poland	2011	2,380,113
Portugal	2011	332,649
Puerto Rico	2010	21,511
Senegal	2002	462,039
Sierra Leone	2004	232,861
South Africa	2011	2,483,728
South Sudan	2008	238,262
Spain	2011	2,558,568
Sudan	2008	2,341,240
Tanzania	2012	2,043,922
Thailand	2000	389,822
Togo	2010	283,777
Trinidad and Tobago	2011	73,323
Turkey	2000	2,024,642
Uganda	2002	1,047,470
United Kingdom	2001	1,077,013
United States	2015	1,907,233
Uruguay	2011	187,838
Venezuela	2001	1,287,968
Vietnam	2009	8,609,278
Zambia	2010	553,622
Zimbabwe	2012	312,229

SOURCE. Author compiled country-level data based on iPUMS-I for 2000s; *N* = 65 countries.

**Table A.2. Distribution of Full Sample and Final Sample Countries**

	Full sample	Final sample
<b>Income</b>		
High income	24	11
Upper middle income	29	18
Lower middle income	26	21
Low income	16	15
<b>Region</b>		
East Asia & Pacific	12	9
Europe & Central Asia	22	7
Latin America & Caribbean	24	20
Middle East & North Africa	7	3
North America	2	1
South Asia	3	2
Sub-Saharan Africa	25	23

SOURCE. Author compiled country-level data based on iPUMS-I for 2000s;  $N = 95$  countries in full sample and 65 countries in final sample.

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