Disability Statistics: An Integral but Missing (and Misunderstood) Component of Development Work

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Abstract: Policy development and rights-based actions depend on the existence of good data and statistics. In the field of disability definition and measurement, the Washington Group on Disability Statistics (WG) has developed internationally comparable questions on disability that can be used worldwide to address both policy development and the rights of persons with disabilities. The WG, a United Nations Statistical Commission sponsored city group, was established to address the methodological and measurement challenges that have characterised disability statistics and to develop questions that will provide cross-nationally comparable, valid and reliable disability statistics. The WG carefully considered the theoretical and conceptual issues associated with disability, transformed disability concepts into measurement tools, and used mixed-method evaluations (both cognitive and field interviewing methodologies) to test the proposed questions. The resultant question sets will greatly improve the international comparability of disability statistics and will aid governments in developing and evaluating policies and programs with the objective of improving the lives of people with disabilities.

Keywords: Disability; Measurement; Washington Group; International; Development

I. Disability and Development

In order to develop and evaluate policies and programs with the objective of improving the lives of their constituents, governments rely on the availability of data in the form of statistics that are relevant, valid and reliable. Much of the information that is collected, typically through censuses and surveys, is intended for domestic purposes. There is however, within the international community, a long standing interest in drawing comparisons between countries, not only to monitor how one’s own country ranks against others but also to learn and benefit from the experiences of others.1 In order for these cross-national comparisons to

be meaningful, the information itself must be comparable across countries; the
indicators used must address the same constructs and the data collection process
must not introduce differences that would affect the relevance and validity of the
comparisons. Many countries collect information on disability – and have been
doing so for decades. Disability statistics however have long been plagued as
examples of indicators where international comparisons are the most difficult.²

With respect to disability statistics that have been reported internationally, the
fact that there are differences among countries does not mean that the data are
not comparable; however when these differences exhibit unexpected patterns,
questions are raised. Observed differences illustrating the highest disability rates
among the most developed countries and the lowest rates among the least devel-
oped countries are counterintuitive.³ A closer examination of how the data have
been collected illustrates that there are major differences in approach, definition
and methods.⁴ This lack of comparability has hampered not only international
uses of the data but also draws into question the usefulness of the information for
domestic purposes.

The United Nations Convention on the Rights of Persons with Disabilities
provides, for the first time within a human rights framework, specific articles that
call for the international collection (article 31) and reporting (article 36) of sta-
tistical data on disability.⁵ In the absence of valid and reliable population-based
data on disability, it is not possible to monitor, over time, the effects of policies
instigated that would promote the lives of persons with disabilities and ensure
their participation in all aspects of life on an basis equal to those without disabil-
ity. These data would provide the evidence that can be used to address whether
countries have been successful, or the degree of their success, in meeting the gen-

² Nora Groce, 'Cultural Beliefs and Practices the Influence the Type and Nature of Data Col-
lected on Individuals with Disability through National Census’ in Barbara Altman and Sharon Barnartt (eds), Research in Social Science and Disability (Elsevier 2006); Mitchell E Loeb and Arne H Eide 'Paradigms Lost: The Changing Face of Disability in Research' in Barbara Altman and Sharon Barnartt (eds), Research in Social Science and Disability (Elsevier 2006); Angela Me and Margaret Mbogoni, 'Review of Practices in Less Developed Countries on the Collection of Disability Data’ in Barbara Altman and Sharon Barnartt (eds), Research in Social Science and Disability (Elsevier 2006); Daniel Mont, 'Measuring Disability Prevalence, Social Protection’ Discussion Paper No. 0706, The World Bank (2007).
³ Madans and Loeb (n 1).
WHO, Geneva (2011); Loeb and Eide, 'Paradigms Lost’ (n 2).
⁵ Convention on the Rights of Persons with Disabilities (adopted 13 December 2006, entered
eral principles outlined in the Convention (article 3) including the achievement of equalisation of opportunity and accessibility, among others. Monitoring the UN Convention and other international initiatives such as the Millennium Development Goals, depend on the production of quality and internationally comparable data – and these have been sorely lacking.6

According to the bio-psycho-social model of disability, disability is understood as a complex concept involving the outcome of the interaction between a person (with a health condition) and that person’s contextual factors (environmental factors and personal factors).7 People are not identified as having a disability based solely upon a medical condition, but rather are classified according to their functional capacity, along various domains, including specific body functions and structure, limitations in basic activities (e.g., walking and seeing), and regarding the extent of their participation (or restrictions therein) in work, school, family life and other social activities. Disability is conceived as a complex process that defies an “all or nothing” categorisation. Disabilities can be classified not only by type (mental, physical, sensory or psycho-social), but also by degree of severity: ranging from mild to severe.

II. Disability Prevalence Rates Internationally

Several sources report disability prevalence rates globally and each of these sources point to a characteristic divergence.8 Lower prevalence rates are consistently reported from low-income countries compared to high-income countries.9 This observation begs several questions. Why are reported prevalence rates of disability so disparate? What are the underlying reasons for the differences seen in disability prevalence rates between low-income and high-income countries? What does it tell us about the “culture” of disability in a population? What can this tell us about disability vis-à-vis social inclusion/exclusion?

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8 See for example Loeb and Eide, ‘Paradigms Lost’ (n 2); Mont, ‘Measuring Disability Prevalence’ (n 2).
9 Ibid.
I have previously attested to several possible reasons for the prevalence discrepancy – it is worth re-visiting and expanding upon those here.\textsuperscript{10}

**Choice of Model: Medical versus Social**

Observed lower disability prevalence rates reported from some low-income countries tend to reflect the most severe cases of disability in the population, as is evidenced (in part) by the method of measurement. Several low-income countries have employed a medical model approach to the measurement of disability that focuses on the individual’s physical/mental impairment or “type of disability”. This operationalisation is captured with questions like those used in the Zambian census of 1990 and still used in several censuses and surveys today: Are you disabled in any way? (Yes/No); What is your disability? (Blind, Deaf/Dumb, Crippled or Mentally retarded).\textsuperscript{11}

Coincident with the impairment-based approach that likens disability to the outcome of functional difficulty on body function and structure (ie blind, deaf etc), disability has also (in some surveys) been linked to diagnosable conditions – associating disability with cause. Classifying disability in this way may also result in under-reporting and lower prevalence, since many people without access to basic health care, or those with some intellectual/mental and psycho-social conditions, may not know their medical diagnosis. As a contributing environmental contextual factor, access to health care services can vary widely, for example, untreated diabetes can lead to profound functional limitations such as blindness or mobility limitations due to the loss of limbs, while diabetes under proper management can have a relatively minor impact on someone’s life.\textsuperscript{12}

Questions that focus on basic actions, like those proposed by the Washington Group on Disability Statistics (WG, see Section III below),\textsuperscript{13} serve as a better basis for identifying disability and result in prevalence rates that are not only higher, but are more suited to capture some of the complexity of disability. The social model approach to measuring disability focuses on the limitation of activity and the restrictions of participation. Accordingly the medical or health condition

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\textsuperscript{10} Loeb and Eide, ‘Paradigms Lost’ (n 2).


\textsuperscript{12} Mont, ‘Measuring Disability Prevalence’ (n 2).

becomes the underlying cause, rather than the basis for definition. For example, a question that focuses on a basic action like lower body functioning such as “do you have difficulty walking or climbing steps?” is able to identify mobility limitations resulting, not only from paralysis or amputation, but also from serious heart problems or other medical conditions, for instance, that may be associated with vision or balance that adversely impact mobility. Similarly, the question “do you have difficulty communicating?” can identify limitations associated with stuttering, loss of speech due to stroke, autism, and also a number of other conditions. For purposes of determining social participation and the equalisation of opportunities, the functional status of an individual – and how that impacts their life – is in focus and of interest, and not necessarily the cause (medical or otherwise).

Furthermore, a social model approach to measuring disability that also incorporates multiple response options (ie, no difficulty, some difficulty, a lot of difficulty and cannot do at all) is not restricted to an imposed all or nothing disability dichotomy (ie, yes/no). This type of operationalisation allows for the derivation of a range of disability prevalence rates encompassing mild, moderate and severe levels of functional difficulty.

Lack of a Neutral Language

The historic lack of a neutral language to describe and define disability has also had an impact on how disability is perceived in some cultures. According to Daniel Mont (2007), in some cultures the word “disability” may suggest negative associations – some people in these cultures may be reluctant to self-identify as disabled due to stigma or shame. Moreover, to some respondents the term “disability” may be equated with severe or very significant conditions. Persons who can walk around their homes but are incapable of walking to the market may perceive their situation as not severe enough to be considered a disability, even though their daily activities are limited.

With the advent of the International Classification of Functioning, Disability and Health (ICF) by WHO in 2001, the disability research community has taken a large step in the direction of a common or neutral language for disability, and a small yet significant step in the direction of a common means/methodology to measure disability. There remains, however, no gold standard for disability measurement. Nor should we be looking for one. A gold standard or a litmus test (here, a particular question or set of questions) that would correctly and definit-
tively classify an individual into one or another disability “category” is necessarily absent. Disability is not something that can be simply morphed into a convenient yes/no dichotomy.

The questions developed by the WG do not mention disability, rather they employ a more neutral language that focuses on difficulties a person may have in carrying out some basic actions.\(^{15}\)

Similarly, in some surveys individuals are asked whether they suffer from difficulty or disability. Suffering may be associated with disease or illness and not necessarily with the life experiences of a person with disability. This language may also negatively influence the self-reporting of functional difficulties.\(^{16}\)

Socio-cultural Determinants

Another reason for under-reporting of disability may be that individuals do not acknowledge a limitation, should they be they are unaware of the possibility of improving the situation with relatively simple technical aids. In other words, you may not know that you’re having difficulty until you have experienced how easy it is to do the same task with some aid or assistance. This can be addressed in terms of coping mechanisms and the gap between what an individual is able to accomplish and what society demands of that individual – taking into account what may be provided and available in terms of assistance. Perhaps in a low-income, rural culture an individual with a physical or intellectual impairment can contribute to the welfare of their family through participation in agrarian activities within the scope of their own abilities and capabilities. In such circumstances, that individual may not be considered by family members as having a disability. In the extreme, if there is nothing to read, is the inability to do that activity (as a result of a visual or intellectual impairment) considered a disability? In 1995, Aud Talle claimed that, in many aboriginal African cultures, disabled individuals are both integrated and accepted.\(^{17}\) Being identified through family and community or through membership to an age cohort was more important to social identity than impairment or disability was.

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\(^{15}\) ICF and WHO (n 7).

\(^{16}\) Marguerite Schneider, “The Difference a Word Makes: Responding to Questions on “Disability” and “Difficulty” in South Africa” (2009) 31 Disability and Rehabilitation 42.

\(^{17}\) Aud Talle, ‘A Child is a Child: Disability and Equality Among the Kenya Maasi’ in Benedicte Ingstad and Susan Reynolds Whyte (eds), Disability and Culture (University of California Press 1995).
On the other hand, in what I refer to as techno-dependent cultures (mostly representing high-income countries)\(^\text{18}\) where time becomes an important factor in accomplishing a task, the demands of society on the individual are far greater. For example, the inception of the fax machine in the 1980s cut response times to correspondence markedly – and today much inter-personal communication is computer-based, electronic and occurs in real-time, with miniscule response-times. In addition, the complexity of performance and demands on the individual have grown exponentially with multi-tasking (the ability to handle more than one task at a time). With technological advancements, many individuals can rightly claim that they can do much more today in an hour than they could in a day a decade ago. However, the more society or your culture demands of you, the more you need to do in order to perform – to keep up, to meet goals – and, consequently, more can go wrong. Humans are finely tuned “machines” and when we become over-stimulated/over-worked then, like a machine, we can burn-out – and those of us who were previously non-disabled may in fact become disabled. Moreover, if people with existing functional difficulties are considered to be at a disadvantage, to be at risk of reduced social participation, then under such circumstances, their risk is further increased. This type of work disability is not uncommon in high-income countries like Norway, Japan and the USA.

To further contrast these two cultural paradigms, Bendicte Ingstad and Susan Reynolds Whyte (1995) put it this way:

…unlike Euro-American societies, where disability exists within a framework of state, legal, economic and bio-medical institutions, such institutional infrastructure exists only sparingly in developing countries. In these countries “disability as a concept and an identity is not an explicit cultural concept. The meaning of impairment must be understood in terms of the cosmology and values and purposes of social life.\(^\text{19}\)

Definition and (Self) Identity

Finally, there are two extremes of definition and outcome that may reflect how we define disability and how an individual may self-identify as disabled. Re-visiting the definition of disability that claims that disability arises from the interaction of an individual’s functional status with their physical, cultural and policy enviro-

\(^{18}\) Loeb et al (n 11).

\(^{19}\) Ingstad and Whyte (n 17) 10.
it may be claimed that if the environment is designed for the full range of
human functioning and incorporates appropriate accommodations and supports,
then people with a non-normative functional status would not be disabled, in the
sense that they would be able to fully participate in society. That is to say, in the
sense of the ability to “fit in” to society (not unlike the example above from rural,
agrarian cultures). In such circumstances, an individual may not self-identify as
disabled – or their family members may not consider them as such.

Similarly, disability may also be interpreted relative to what is considered nor-
mal functioning and this may vary across cultures or age groups. Elderly people,
for example, who experience significant functional limitations may not self-iden-
tify as having a disability because, from their perspective, they can function as
well as they may expect someone their age to function.

On the other hand, there are those with a disability who, even when given the
appropriate accommodations and able to fully participate in society, hold on to
their “disability identity” for purposes other than those described here. Disability
is in some instances linked to the receipt of financial support by the government
in the form of disability grants (to which any individual so “determined” would
be entitled); alternatively, disability may be associated with a means of cultural
adhesion or belonging, as in the deaf community. Under these circumstances,
even though barriers to participation are overcome affording the individual
equalised opportunities, an individual may more readily self-identify as disabled.

III. Disability and the Washington Group on Disability
Statistics

In recent years, a functional approach to measuring disability that draws upon
the social model of disability has become more standard; it has recently been
adopted by the World Health Organisation’s International Classification of Func-
tioning, Disability and Health and it has operationalised through the work of the
UN’s Washington Group (WG) on Disability Statistics.

21 Sharon Barnartt, ‘Disability Culture or Disability Consciousness’ (1996) 7 Journal of Disabil-
ity Policy Studies 1.
22 Mont, ‘Measuring Disability Prevalence’ (n 2); Mont, ‘Measuring Health and Disability’
(n 20).
Historically, disability data reported internationally have varied greatly. Across countries and across years within a country, reported prevalence rates have fluctuated depending on the source of the data; the methodology for collecting the data; and the questions used to operationalise disability in a census or survey. The lack of internationally comparable data on disability has been well documented previously and was the subject of a UN International Seminar on the Measurement of Disability in 2001. There was a broad consensus at the seminar on the need for statistical and methodological initiatives at an international level to facilitate the measurement of disability and the comparison of data on disability cross-nationally. The WG was constituted in 2002 as a UN City Group under the aegis of the UN Statistical Commission, with a mandate to meet those challenges.

In the area of disability question design, over the course of the past ten years, the WG has:

- Developed and adopted a short set of six questions on functioning that are suitable for censuses. The approach endorsed by the WG has been incorporated in the 2008 UN Principles and Recommendations for Population and Housing Censuses.

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24 Loeb and Eide, ‘Paradigms Lost’ (n 2).
25 See Barbara Altman, ‘Disability, Definitions, Models, Classification Schemes and Applications’ in Gary L Albrecht, Katherine D Seelman and Michael Bury (eds), Handbook of Disability Studies (Sage Publications 2001), among others.
28 See UNSD (n 23) 178-183, 292-294.
• Developed and adopted an extended set of questions on functioning that: expands on the six domains covered by the short set, adding questions about age at onset and impact of difficulty; expands the number of domains covered, including learning, affect, pain and fatigue; and begins to construct the links between functioning in core domains without accommodation, functioning with accommodation, environment and participation.29
• Embarked (in collaboration with UNICEF) on the development of a set of questions on child functioning and disability. A module of fourteen questions has been developed and is currently being cognitively tested in USA and India, with plans for further testing (in 2013) in Belize and beyond.

Most recently, the World Report on Disability addressed similar concerns regarding internationally comparable disability data and made specific recommendations to enhance the availability and quality of data on disability internationally, which, in fact, reflect the approaches taken by the WG.30 These include, among others, the adoption of the International Classification of Functioning, Disability and Health (ICF)31 as a framework for the development of questions on disability; improved comparability of data; the development of appropriate tools (both quantitative and qualitative methodologies) to improve and expand data collection on disability; and the collection of national population census data according to the recommendations from the UN Statistical Commission.32

Development of an Internationally Comparable Measure for Census

As stated above, the main objective of the WG has been the promotion and coordination of international cooperation in the area of health statistics by focusing on disability measures suitable for censuses and national surveys.

Herein lies a dilemma: for many low-income countries, the main source of population-based data is the decennial census. Furthermore, a census is normally constricted in the number of questions that can be included. The inherent complexity of the disablement process defies, by its very nature, encapsulation in a simple, single construct.

30 WHO and the World Bank (n 4).
31 ICF and WHO (n 7).
32 WHO and the World Bank (n 4).
Taking into consideration the restrictions placed on censuses, the WG set out to develop a short set of questions that would capture the majority of those with limitations in one or more functional domains. The measures identified were to be comparable cross-nationally and cross-culturally and developed according to the Fundamental Principles of Official Statistics and in a manner consistent with the ICF. Extensive cognitive and field-testing of the question set has shown that they produce internationally comparable data.

The questions cover six core domains of functioning or basic actions: seeing; hearing; walking; cognition; self-care; and communication. One question was constructed for each domain.

The following questions ask about difficulties one may have in carrying out certain activities because of a health problem.

Do you have difficulty seeing, even if wearing glasses?
Do you have difficulty hearing, even if using a hearing aid?
Do you have difficulty walking or climbing steps?
Do you have difficulty remembering or concentrating?
Do you have difficulty with self-care (such as washing all over or dressing)?
Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?

Each question has four response options:
   a) No, no difficulty;
   b) Yes, some difficulty;
   c) Yes, a lot of difficulty;
   d) 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.

This short set of six domains may appear incomplete: specific questions on difficulties that relate to intellectual or developmental disability and emotional or

34 ICF and WHO (n 7).
psychological difficulties are either absent or limited in scope. As the WG short set was designed to be used in national censuses, this objective limited the number and format of the questions. This apparent oversight will be addressed in more detail in the discussion section later.

Determination of Disability

The WG chose to first focus on core domains of functioning or basic actions. Since these are considered to be less likely to be influenced by either specific cultures or the environment, they are therefore more suited as international measures capable of providing comparable data cross-nationally. Moreover, basic actions form the building blocks for more complex activities. 36 For example, a complex activity like going to the doctor involves a combination of basic actions and can, in fact, encompass all six of the WG functional domains: mobility; cognition; communication; self-care; seeing; and hearing. While the ideal would be to collect information on all aspects of the disablement process and to identify every person with a functional difficulty within every community, this would not be possible given the limited number of questions that can be asked on a National Census. The basic actions represented in the question set are those that are most often found to limit an individual and result in participation restrictions. Domains were selected using the criteria of simplicity, brevity, universality and comparability. It is expected that the information that results from the use of these questions will:

a) represent the majority of (although not all) persons with limitation in basic actions;

b) represent the most commonly occurring limitations in basic actions;

c) be able to capture persons with similar problems across countries.

The WG has identified the assessment of equalisation of opportunity as the purpose for measuring disability that can best be achieved in a Census. 37 Over the course of time, the Census allows for assessment of equalisation of opportunity, by monitoring and evaluating outcomes of anti-discrimination laws and policies, and service and rehabilitation programmes designed to improve and equalise the participation of persons at all levels of functioning in all aspects of life.


37 Madans et al (n 13).
In accordance with the purpose selected for measuring disability, the WG determined that, in a census, persons with disabilities are defined as those who are at greater risk of experiencing limitations in performing specific tasks (activities) or restrictions of participation in society than the general population.38 This group would include persons who experience difficulties in one or more of the six core domains (such as walking or hearing for example) irrespective of whether the difficulties experienced are alleviated by the use of assistive devices; living in a supportive environment; or having plentiful resources. Some of the individuals may not experience restrictions in participation, such as in shopping, doing household chores, working or going to school, because the necessary adaptations have been made at the level of the person (technical aids, assistive devices or personal assistance) or their environment (physical, social or civic accommodations). They would still, however, be considered to be at greater risk than the general population for participation restrictions owing to the presence of difficulties in the six core domains and also because, in the absence of such accommodations, their level of participation would be jeopardised.

Analytic Approaches

At the sixth annual meeting of the Washington Group held in Kampala, Uganda in October 2006, test results from 15 countries were reported, and the short set of questions on disability was endorsed by the 23 countries and 5 international agencies in attendance. In 2008, the United Nations Statistical Division (UNSD) presented Principles and Recommendations for Population and Housing Censuses.39 Among the recommendations outlined in the document are several that pertain specifically to the measurement of disability and that incorporate the approach taken by WG.40

The six WG questions cover many, but not all, areas of functioning. Furthermore, the response categories capture a range of severity of the difficulty experienced. Multiple disability scenarios can be described depending on the domain(s) of interest and the choice of severity cut-off. There is more than one way to capture disability through the application of this set of core questions, resulting in not one but several possible population prevalence estimates that will vary in both size and composition.

38 Ibid.
39 UNSD (n 23).
The WG recommends that the following cut-off be used to define the populations with and without disabilities, for the purpose of computing disability prevalence rates and reporting to the UNSD to enable international comparisons:

The sub-population disabled includes everyone with at least one domain that is coded as a lot of difficulty or cannot do it at all. ④¹

This recommendation is not intended as a restriction, and (as will be illustrated below) using the WG approach to disability measurement facilitates the analysis of the continuity of disability and a full assessment of disability in a population by different levels of severity.

IV. International Comparability

At its inception, certain goals were identified for the WG. Among them, to foster international cooperation in the area of health and disability statistics; to develop a short set of general disability measures suitable for censuses; and to untangle the web of confusing and conflicting disability estimates; and to produce internationally tested measures for use to monitor status of disabled populations. By standardising these questions, it was believed that it would be possible to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

The WG routinely monitors the collection of disability data internationally, and annually requests detailed information from representatives from National Statistical Offices. This information covers survey periodicity; sample size and frame; mode of data collection; language(s) used; the actual questions operationalised with response options; and, finally, prevalence data.

Recently, about 30 countries indicated to the WG that they intended to use the short set of questions on this current (2010) round of censuses. We saw this as an opportunity to follow-up on the implementation of the questions in practice. We sought to collect information from all countries using the WG short set of questions (or not, as the case may be) and to catalogue the actual questions used and response options applied; the year of data collection and the purpose (census or survey); and the prevalence of disability derived. We were explicit in our

④¹ WG, ‘Measurement of Disability Recommendation’ (n 27).
request for the exact wording of the questions, in order to determine whether this may have any impact on the results.

Annually, approximately 120 countries receive requests to report national activities that relate to disability statistics. Responses are voluntary and, in the last round, responses (including both those that provided data and those that did not) were received from 48 countries. This represents a response rate of about 40%. These findings were combined with results from other national data collection initiatives of which we were apprised and that also made use of the Washington Group short set of questions.

Data supplied by the countries diverged in a few important ways: data were reported from both censuses and surveys; some countries reported data that predate the 2006 adoption of the WG short set of questions; and there was a clear distinction between countries that took a more medical-model approach to identifying disability on their census or survey (ie by listing impairments or types of disability) and those that operationalised a social-model approach (by addressing activity limitations). All data received were included in the assessment to provide a breadth of internationally collected disability data and prevalence rates.

Specifics of the data collected will be presented in a separate publication but some highlights of the results will be presented here. We were able to demonstrate, as was shown previously, that historically and geographically disability prevalence rates vary greatly. Data were submitted to the WG from across the globe and these spanned several years: from 2000 to 2011. Prevalence rates ranged from 0.4% in the Dominican Republic (2002, census) to 16.6% in New Zealand (2006, survey). As mentioned earlier, reasons for the disparity observed in disability prevalence rates may be attributed to both the methods used to identifying disability and data collection methodologies. Questions that focus on activity limitations generally produced higher rates that impairment-based questions did; and surveys generally produced higher rates than censuses.

The objective of the WG in proposing its approach to disability definition and measurement is not to achieve the highest disability prevalence rate possible, but rather to report the rate that best reflects the situation of persons with disability in the country. According to the WG, this means those at risk of being restricted in their ability to fully participate in society. Another objective was to propose a methodology that could be used internationally to produce disability prevalence rates that could be compared cross-nationally.

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42 Loeb and Eide, ‘Paradigms Lost’ (n 4); Mont, ‘Measuring Disability Prevalence’ (n 2).
We have found that, while countries have reported disparate disability prevalence rates; with few exceptions, those that use the WG as intended and without modifying either questions or response options have reported disability prevalence rates that are comparable: Israel (census, 2008); Aruba (census, 2010); Zambia (survey, 2006); and the Maldives (survey, 2009), with 6.4%; 6.9%; 8.5%; and 9.6% respectively. Again, it can be noted that prevalence results generated from surveys generally produce higher rates than those generated from a census do. This is partly due to the fact that surveys are more often targeted to specific populations and are unrestricted in terms of the number of questions that can be included.

Bangladesh used the WG questions as intended in their 2010 Household Income and Expenditure Survey (HIES) but, by lowering the threshold for disability to include those who had reported ‘some difficulty’ they increased the size of the target population and produced a prevalence estimate of 9.1%. Had they used the suggested cut point of ‘a lot of difficulty or unable to do’, the resultant prevalence rate would have been lower.

Additionally, a few countries claimed to use the WG questions but, upon closer examination, certain deviations were observed. For example, WG questions preceded by a qualifying or filter question (Oman); response categories that were dichotomised (yes/no), usually associated with a change in the wording of the question (permanent difficulty as in the case of Panama; or serious difficulty in the case of the USA). In some cases, domains have been modified, deleted or added. All of these deviations affect the resultant prevalence rate and subsequently diminish the overall comparability of the results. Furthermore, some uncertainty must be apportioned to the translation of the questions: from English to the local/national language(s) for the census or survey; and back again when reporting results internationally. It becomes incumbent upon the WG – and others interested in the international comparability of disability data – to not only ensure that translations are accurate but that they also correctly (for the language in question) capture the concepts that are being measured.

V. Implications for Disability Policy

Policy implications related to the flexibility in this approach to disability may be profound. If service provision is based on the disability prevalence then clearly this would impact policy, particularly in low-income, developing countries where
essential resources and capital are scarce. However, one can ask “What are the implications of developing a policy that provides services for, say, 3% of the population (those with more severe impairments) if 10% (based on difficulty performing in their current environment) require some service?” Also, would it not be more appropriate and efficient to provide services to the specific population that requires them. Using the WG approach to disability measurement it is possible to provide data for each functional domain separately and at different levels of severity (e.g., those with mild, moderate or severe difficulty seeing).

Targeting specific sub-populations would be more cost-effective, and would provide for the equitable and efficient delivery of services. With the knowledge that many children with disabilities in low-income countries do not attend school because of vision problems that are correctable by glasses, policy could be directed to target this specific sub-population, to provide necessary services and to rectify inequalities. A relatively minor and easily correctable functional problem that would otherwise have significant debilitating personal consequences could be avoided.43

The provision of relevant, valid and reliable disability statistics will potentially influence policy in a number of ways. By defining a population at risk of social exclusion through participation restrictions, early interventions can be initiated to prevent, for example, at-risk children from dropping out of school. A rather modest preventative investment in technical aides may allow these children to complete their education, achieve the twin goals of employment and independence, and, ultimately, become net contributors to society. Furthermore, such data will provide the evidence, over time, that targets that are set through, for example, Millennium Development Goals or the UN Convention on the Rights of Persons with Disability, are being addressed and met.

VI. Conclusions

With the data presented here, we have shown that the WG has been successful in fostering international cooperation in the area of health and disability statistics, through the development and implementation of a short set of general disability measures suitable for censuses and surveys. Working collaboratively with many countries from all regions of the world, the WG was able to develop and test
questions for use in censuses and surveys to produce internationally comparable data. The short set provides a comparable mechanism for identifying a population at risk when it comes to restrictions in the ability to fully participate in society due to functional limitations in key domains – an approach that has been incorporated into the UN Principles and Recommendations for Population and Housing Censuses.44.

In so doing, we have taken an important step in untangling the web of confusing and conflicting disability estimates and in producing internationally tested measures for use to monitor status of disabled populations. We have illustrated the importance of careful translation and operationalisation of the concepts put forward by the WG. When adopted as intended, this standardised set of questions was able to provide comparable data cross-nationally for populations living in a variety of cultures with varying economic resources.

A major challenge faced by the WG in developing the short set of questions was to attempt to capture the complexity of disability in a parsimonious manner. The WG has acknowledged that the six questions do not cover all functional domains equally well. Specific questions on upper body functioning; difficulties that relate to intellectual or developmental disability (other than those related to memory and concentration); and emotional or psychological difficulties; are either absent or limited in scope. The WG short set was designed to be used in national censuses and this objective limited the number and format of the questions. The functional domains represented in the short question set – selected using the criteria of simplicity, brevity, universality and comparability – are those that have most often been found to limit an individual and result in participation restrictions.45 The WG expects that the information that results from the use of these questions will:

a) represent the majority of, but not all, persons with limitation in basic activities;

b) represent the most commonly occurring limitations in basic actions;

c) be able to capture persons with similar problems across countries.46

Currently, approximately 30 countries have indicated that they intend to use the WG short set of questions on this current round of censuses. The WG short set of questions has also recently been added to the National Health Interview Survey (NHIS) in the United States. Data analyses pairing the WG short set with

44 UN Principles and Recommendations for Population and Housing Censuses (n 23).
45 Madans et al (n 13); Altman and Bernstein (n 36).
other, more detailed, measures of functioning and health on the NHIS are currently ongoing.

In 2011 the WHO and the World Bank jointly launched the World Report on Disability (WRD).\(^{47}\) The report acknowledges the historic lack of comparable disability data internationally and recommends that data collection efforts be improved through the adoption of the ICF as a framework for disability data collection; and the development of appropriate tools (both quantitative and qualitative methodologies) that would improve the quality and comparability of data collected on disability. The WG has been working to meet those goals for the past 11 years - with documented success. The WRD recognises the work of the WG in this area and suggests that the WG short set of questions provides a core set that can be operationalised to meet both the needs of countries and the recommendations itemised in the report.

Finally, the WG chose to focus on the equalisation of opportunity and improvement of the extent to which persons with disability fully participate in society as the specific purpose for developing a measure of disability for censuses. In so doing, the WG short set questions will contribute to monitoring whether, over time, the objectives of the UN Convention on the Rights of Persons with Disabilities have been achieved.\(^ {48}\)

\(^{47}\) WHO and the World Bank (n 4) 45-47.

\(^{48}\) WG, 'Monitoring the UN Convention on the Rights of Persons with Disability' (2009) available at <http://www.cdc.gov/nchs/data/washington_group/meeting8/UN_convention.pdf>; Disclaimer: The findings and conclusions in this paper are those of the author and do not necessarily represent the views of the National Center for Health Statistics (NCHS); Centers for Disease Control and Prevention (CDC).