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Measuring Disability Prevalence

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Table of Contents

| | | |
|-------|---|----|
| I. | Introduction..... | 1 |
| II. | Defining Disability..... | 2 |
| III. | Different Approaches to Measurement..... | 5 |
| IV. | Purpose of Measurement..... | 14 |
| V. | Census Questions for Disability Prevalence | 18 |
| | General Prevalence Measures | 20 |
| | Pre-Testing of Washington Group Questions | 21 |
| VI. | Case Studies: Disability in Brazil, Ecuador and Nicaragua..... | 30 |
| VII. | Conclusions..... | 35 |
| VIII. | References..... | 37 |
| | Annex 1: ACTIVITY AND PARTICIPATION MATRIX | 39 |
| | Annex 2: INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL) | 41 |

I Introduction

1.1 Disability and poverty are intricately interlinked. Poverty can cause disability with its associated malnutrition, poor health services and sanitation, and unsafe living and working conditions. Conversely, the presence of a disability can trap people in a life of poverty because of the barriers disabled people face to taking part in education, employment, social activities, and indeed all aspects of life.

1.2 Recognizing the crucial link between equity, disability, and poverty, in 2002, the World Bank embarked on mainstreaming disability into Bank operations and analysis. In 2006, the UN adopted the International Convention on Rights of Disabled People, and many governments and international development agencies are turning their attention to the goal of including disabled people in development.

1.3 Unfortunately, the availability of high quality, internationally comparable data on disability that is important for the planning, implementation, monitoring, and evaluation of inclusive policies is often not available. This paper is an attempt to clarify some good standards in collecting data on disability and make recommendations for prevalence measures of disability suitable for censuses.

1.4 Reported disability prevalence rates from around the world vary dramatically, for example from under 1% in Kenya and Bangladesh to 20% in New Zealand¹. This variation is caused by several factors: differing definitions of disability, different methodologies of data collection, and variation in the quality of study design. The result is that generating disability prevalence rates that are understandable and internationally comparable is a difficult enterprise. This situation is complicated further by the idea that there is no single correct definition of disability, that the nature and severity of disabilities vary greatly, and that how one measures disability differs depending on the purpose for measuring it.

¹ Bangladesh Bureau of Statistics, Disabled population of Bangladesh, Evidence from Demographic Sample Survey (1987), Central Bureau of Statistics, Kenya Population Census, 1989, Analytical Report, Vol. IX - Labour force (1996), and Statistics New Zealand, Disability Counts (1998).

1.5 This paper reviews what is meant by disability and puts forth a way of measuring disability suitable for internationally comparable prevalence rates.² The basic trend in this regard is to measure functional limitations, rather than disability, and then use different severity thresholds for defining disability based on the purpose of measurement. After explaining this approach, the paper then goes on to summarize recent studies that use this methodology.

1.6 Overall, as generally defined, disabled people represent a significant proportion of the world's population. Data from developed countries and some recent studies in developing countries over several regions (namely, Brazil, Ecuador, India, Nicaragua, Vietnam, and Zambia) suggest that an estimate of 10-12 percent is not unreasonable. This estimate is in line with the United Nations' often cited figure of 10 percent, which in fact was an informed guess based on data available from developed countries.

1.7 This paper will argue, however, that a single disability prevalence rate can be highly problematic. Better practice would be to report at least two prevalence rates, one representing a moderate threshold for functional limitations and one with a more severe threshold.

II Defining Disability

2.1 Disability has often been defined as a physical, mental, or psychological condition that limits a person's activities. In the past, this was interpreted according to a medical model. That is, disability was linked to various medical conditions, and was viewed as a problem residing solely in the affected individual. Disability was seen solely as the result of an individual's inability to function. Interventions usually included medical rehabilitation and the provision of social assistance.

2.2 This medical model has recently been replaced by the social model of disability, which conceptualizes disability as arising from the interaction of a person's functional status with the

² The general approach for defining such prevalence follows closely the UN Washington Group on Disability Statistics. Their website can be found at <http://www.cdc.gov/nchs/citygroup.htm>

physical, cultural, and policy environments.³ If the environment is designed for the full range of human functioning and incorporates appropriate accommodations and supports, then people with functional limitations would not be “disabled” in the sense that they would be able to fully participate in society. Interventions are thus not only at the individual level (e.g., medical rehabilitation) but also at the societal level, for example the introduction of universal design to make infrastructure more accessible, inclusive education systems, and community awareness programs to combat stigma.

2.3 According to the social model, disability is the outcome of the interaction of person and their environment and thus is neither person nor environment specific. The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization is the starting point for recent developments in measuring functional capacity.⁴

2.4 Based on a theoretical model that draws upon the social model of disability, disability in the ICF is not an “all or nothing” concept. People are not identified as having a disability based upon a medical condition, but rather are classified according to a detailed description of their functioning within various domains. The first of these domains – body structure and function – is the most closely related to the medical model as it refers to the physiological and psychological functions of body systems. Body structures are defined by the ICF as “anatomic parts of the body such as organs, limbs and their components.” This domain relates to very specific capabilities, for example being able to lift one’s arm over one’s head or produce articulate speech sounds. Thus, it is not a “whole” person classification, as are the other domains -- activities and participation.

2.5 Activities pertain to a wide range of deliberate actions performed by an individual, as opposed to particular body functions or structures. Activities are basic deliberate actions undertaken in order to accomplish a task, such as getting dressed or feeding oneself. Participation refers to activities that are integral to economic and social life and the social roles

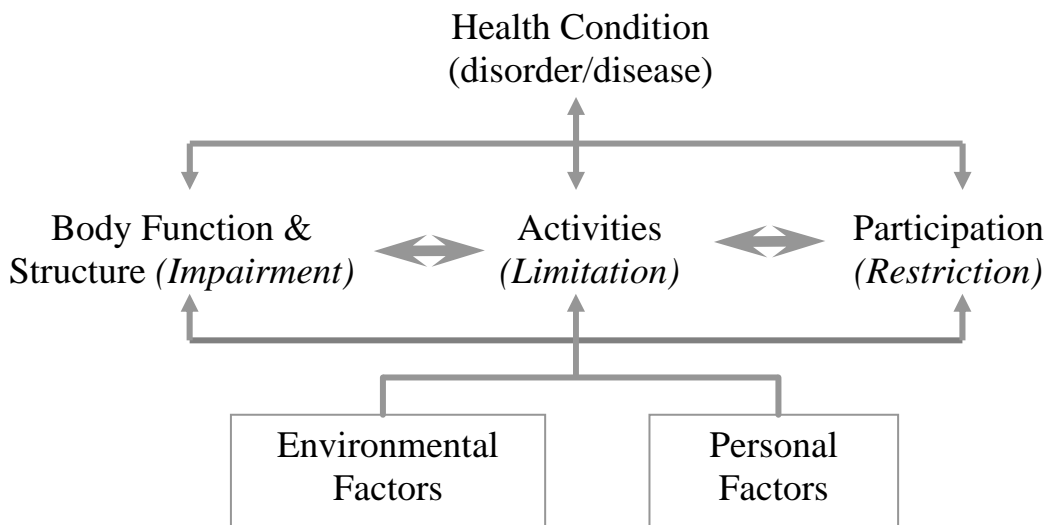
³ See, for example, Shakespeare, T. and N. Watson, “Defending the Social Model,” *Disability and Society*, 12(2):293-300, April (1997) and Hughes, B. and K. Paterson, “The Social Model of Disability and the Disappearing Body: towards a sociology of impairment,” *Disability and Society* 12(3):325-340, June (1997)

⁴ See the ICF homepage at www3.who.int/icf/icftemplate.cfm

that accomplish that life, such as being able to attend school or hold a job. Moreover, the ICF incorporates the social model by including information on how a person’s ability to function is affected by the environment they face. For example, a given level of impairment in the body function domain will not necessarily translate into an activity or participation limitation if the environment accommodates a person’s different functional status.

2.6 Disability in the ICF arises out of Activity limitations and restrictions placed upon Participation that grow out of the interaction between Body Structure and Function limitations and an unaccommodating environment. These interactions are summarized in Figure 1.

Figure 1: The ICF Model



2.7 If disability arises out of a complex model such as this, how can it be captured in a single measure? In fact, each domain represents a different area of measurement and each category or element of classification within each domain represents a different area of operationalization of the broader domain concept. To generate a meaningful general prevalence measure one must determine which component best reflects the information needed to address the purpose of the data collection. To determine that, one needs to settle on the question behind having such a statistic.

2.8 After reviewing various approaches to measuring disability, this paper will summarize various purposes for measurement, and then recommend which purpose is best suited for general prevalence, and how to go about estimating it.

III Different Approaches to Measurement

3.1 Censuses and surveys from around the world take very different approaches to measuring disability. In fact, different instruments within the same country often report very different rates of disability. For example, in Canada, the reported rate of disability in 2001 ranged from 13.7% to 31.3% (see Table 1). In the Participation and Activity Limitations Survey disability was defined as having limitations in undertaking various activities. The reported prevalence rate was about 14%. The Canadian Community Health Survey reports a much higher rate of disability because it considers any condition that affects one’s health, even those that do not necessarily have an impact on the range of activities a person could perform in daily life.

| Table 1: Adult Disability Rates for Major Canadian Surveys, 2001 | |
|---|----------------|
| Instrument | Percent |
| Participation and Activity Limitations Survey – Filters | 13.7 |
| Participation and Activity Limitations Survey – All | 14.8 |
| Census | 18.5 |
| Survey of Labor and Income Dynamics | 20.5 |
| Canadian Community Health Survey | 31.3 |
| Source: Rietschlin and MacKenzie, 2004 | |

3.2 Across countries the variation is even greater, as observed in Table 2. Generally speaking, developing countries tend to report the lowest rates of disability. While some factors would lead to higher rates of disability in richer countries – namely, more elderly people and higher survival rates for people with disabling conditions – the wide range of factors operating in the opposite direction – for example, poor health care, poor nutrition, and unsafe living conditions – makes the breadth of this gap highly questionable. In fact, when similar approaches are taken to measuring disability in developed and developing countries, prevalence rates fall within a narrower band, as shown later in this paper.

3.3 According to one recent review of the literature disability rates ranged from 3.6 to 66 percent and low quality of life resulting from disability ranged from 1.8 to 26 percent (Barbotte, et al., 2001). The authors note that “the heterogeneity of the conceptual framework and insufficient recognition of the importance of indicator accuracy, the age factor and the socioeconomic characteristics of the studied populations impede reliable international comparison.”

3.4 Table 2 also reveals that, in general, surveys tend to report higher rates of disability than censuses. This can be explained, in large part, by the types of questions usually asked on censuses compared to the more detailed and more numerous questions posed on surveys. Nevertheless, general prevalence measures for international comparison purposes need to have a census-based approach because in poorer countries, that is often the only alternative for data collection.

| <u>Censuses</u> | | | <u>Surveys</u> | | |
|-----------------|------|---|----------------|------|---|
| Country | Year | Percent of population with a disability | Country | Year | Percent of population with a disability |
| United States | 2000 | 19.4 | New Zealand | 1996 | 20.0 |
| Canada | 2001 | 18.5 | Australia | 2000 | 20.0 |
| Brazil | 2000 | 14.5 | Uruguay | 1992 | 16.0 |
| United Kingdom | 1991 | 12.2 | Spain | 1986 | 15.0 |
| Poland | 1988 | 10.0 | Austria | 1986 | 14.4 |
| Ethiopia | 1984 | 3.8 | Zambia | 2006 | 13.1 |
| Uganda | 2001 | 3.5 | Sweden | 1988 | 12.1 |
| Mali | 1987 | 2.7 | Ecuador | 2005 | 12.1 |
| Mexico | 2000 | 2.3 | Netherlands | 1986 | 11.6 |
| Botswana | 1991 | 2.2 | Nicaragua | 2003 | 10.3 |
| Chile | 1992 | 2.2 | Germany | 1992 | 8.4 |
| India | 2001 | 2.1 | China | 1987 | 5.0 |
| Colombia | 1993 | 1.8 | Italy | 1994 | 5.0 |
| Bangladesh | 1982 | 0.8 | Egypt | 1996 | 4.4 |
| Kenya | 1987 | 0.7 | | | |

Source: United Nations Statistics Division; IBGR (Brazil), INEC (Nicaragua), INEC (Ecuador), INEGI (Mexico), Statistics New Zealand, INE (Spain), Census of India 2001, SINTEF Health Research (Zambia) 2006

3.5 The different approaches taken in generating these prevalence estimates include:

- **Self-identification as disabled.** In this instance, the respondent is directly asked if they are disabled.
- **Diagnosable conditions.** The respondent is read a list of conditions, such as polio, epilepsy, paralysis, etc and is asked if they have any of them.
- **Activities of Daily Living (ADL).** The respondent is classified as disabled if they have difficulty performing any ADLs, which are task based and center on basic activities such as dressing, bathing, and feeding oneself.
- **Instrumental Activities of Daily Living (IADL).** This approach is similar to the ADLs except that IADLs are higher order tasks. Examples include whether a person has problems managing money, shopping for groceries, or maintaining their household. For an example of IADLs from a developed country, see Annex 2.
- **Participation.** This method asks if the person has some condition which affects a particular social role, such as attending school or being employed. For example, the question in the US Current Population Survey is (*Do you/Does anyone in this household have a health problem or disability which prevents (you/them) from working or which limits the kind or amount of work (you/they) can do?*)

3.6 The first method – that is, asking some variant of *Do you have a disability?* – generates the lowest rates of disability. The positive response rate to this question is typically in the one to three percent range (see Table 3), even when surveys of the same population using a more functional approach yield estimates in the 10 to 20 percent range.

3.7 The reasons that this question identifies few people as being disabled are several-fold. First, the word “disability” has very negative connotations. People may feel stigma or shame at identifying themselves as disabled. In fact, in some cultures disability is seen as punishment for transgressions committed in previous lives. According to one author, people can perceive that “At a profoundly serious and spiritual level, disability represents divine justice (Bacquer and Sharma, 1997).” For this reason, the question *Do you have a disability?* is especially inadequate at picking up mental or psychological disabilities which tend to be particularly stigmatizing and are sometimes more easily hidden.

| Table 3: Census-based Disability Rates by Type of Question | |
|---|------------------------|
| Country | Disability Rate |
| “Do you have a disability? Yes/No | |
| Nigeria | 0.5 |
| Jordan | 1.2 |
| Philippines | 1.3 |
| Turkey | 1.4 |
| Mauritania | 1.5 |
| Ethiopia | 3.8 |
| Jamaica | 6.3 |
| List of conditions | |
| Colombia | 1.8 |
| Mexico | 1.8 |
| Palestine | 1.8 |
| Chile | 2.2 |
| Uganda | 3.5 |
| Hungary | 5.7 |
| Activity Based | |
| Poland | 10.0 |
| United Kingdom | 12.2 |
| Brazil | 14.5 |
| Canada | 18.5 |
| United States | 19.4 |

3.8 Even if people do not feel stigma, the word “disability” often implies a very significant condition. 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.

3.9 Finally, disability is interpreted relative to some unspoken cultural standard of what is considered normal functioning. This may vary across various cultures, age groups, or even income groups. For example, elderly people who have significant limitations may not self-identify as having a disability because in their minds they can function about as well as they expect someone their age to function. However, at the same time they may have significant difficulties performing basic activities.

3.10 The approach of asking about diagnosable conditions is also problematic. First of all, many people may not know their diagnosis, particularly when it comes to mental and psychosocial conditions. Second, knowledge about one’s diagnosis is probably correlated with

variables such as education, socio-economic status, and access to health services, thus introducing a potential bias in the collected data. And finally, the functional effects of a particular condition can vary widely. For example, untreated diabetes can lead to profound functional limitations such as blindness or the loss of limbs. Diabetes that is properly managed can have a relatively minor impact on someone's life. The same thing is true for something like the amputation of a leg. With proper medical treatment and a prosthetic, a person may have few limitations when it comes to daily life. Poor treatment, on the other hand, can lead to a series of painful and dangerous infections. (For examples of countries that use a list of conditions in their census questions, see Table 3.)

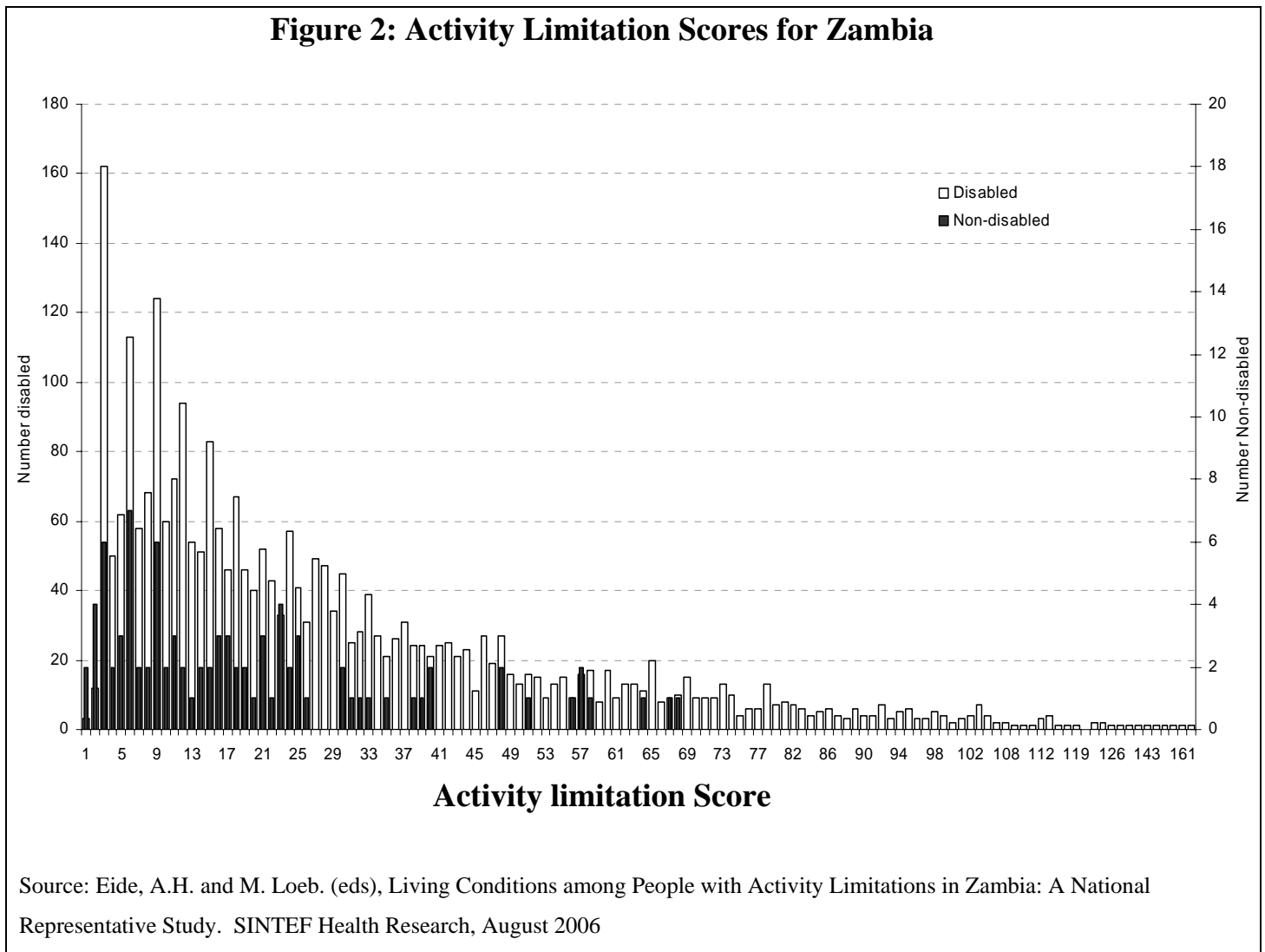
3.11 Questions that focus on basic activities or major body functions serve as better screens. In fact, a question such as *Do you have difficulty walking?* can pick up mobility limitations resulting not only from paralysis and amputation, but also serious heart problems or other medical conditions. (For examples of countries taking a more activity based approach, see Table 3). A question such as *Do you have difficulty holding a conversation with others?* can pick up stuttering, loss of speech due to stroke, autism, or a number of other conditions. And for most purposes, it is the functional status which is of interest – and how that impacts someone's life – and not necessarily the cause (medical or otherwise). Of course, for a study designed to uncover the best approaches towards preventing disabilities, the cause and age of onset could be important data to collect.

3.12 For purposes of promoting inclusive economic development, it is more appropriate to view disability as a reduced ability to undertake “activities” and “participation” resulting from functional limitations, rather than as a diagnosis of a medical condition.

3.13 The notion of a functionally based view of disability is captured well in Figure 2, which shows the distribution of activity limitations in a selected sample of the population of Zambia. In the Zambian census (1990) a simple “Do you have a disability?” type question yielded a disability prevalence rate of only about 1 percent. However, a functional based approach using the UN Washington Group Questions (to be described later) in conjunction with a much more detailed survey, yielded a disability prevalence rate of over 13 percent.

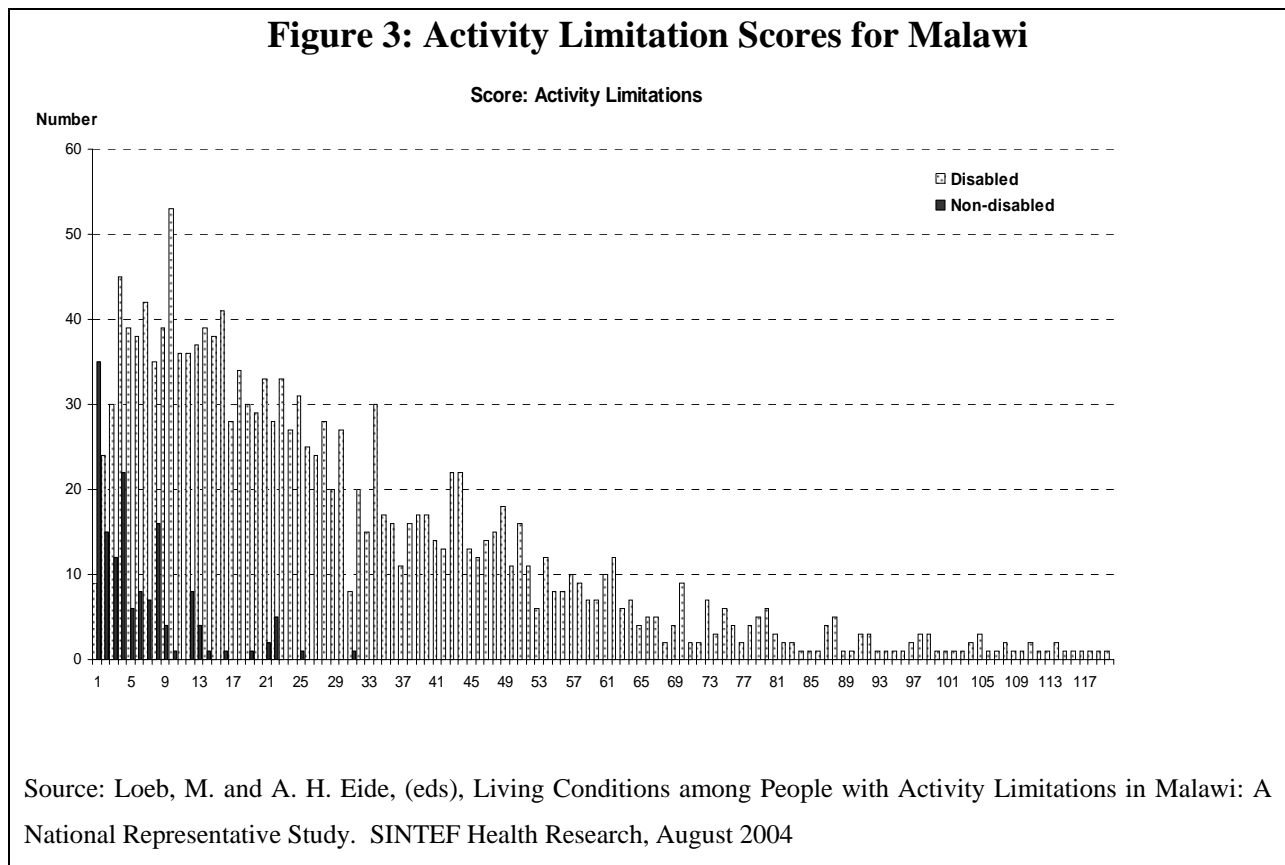
3.14 The activity limitation score represented in the diagram is based on the responses to questions on 44 activities across nine different functional domains (see Annex 1). Scores are a function of the degree of difficulty respondents had with these activities. Respondents received zero points for each of the 44 activities they reported having no difficulty with, one point for those with which they had a little difficulty, two points for some difficulty, 3 points for a lot of difficulty, and four points for activities they were unable to do. Activity limitation scores thus range from zero to 176.

3.15 Figure 2 shows a wide and skewed distribution of activity limitation scores. Most disabled people – identified by a set of screening questions – have low or moderate limitation



scores. A small sub-sample of people identified as not having disabilities by the screening questions were also asked the extended set of activity questions. Interestingly, a number of them report some activity limitations (as recorded by the black bars). The screening questions asked about general difficulties in doing day to day activities stemming from a physical, mental or emotional (or other health) condition. However, when asked more specific, functional questions these people identified as not having a disability did report some functional limitations.

3.16 The same basic results also held for a similar study done in Malawi. The results are shown in Figure 3. In this study, a different set of screening questions were used, but the same general results hold as to the distribution of activity limitation scores.



3.17 In the end, these functional approaches – coupled with scaled response categories– provide a description of the functional status of the population. Where one draws a line in Figures 2 and 3 to divide the world into disabled and non-disabled people will vary depending on

the reason the data is being collected. For example, setting the criteria for a disability pension system will most likely have a pretty severe cut-off for disability. On the other hand, when considering infrastructure design – such as a transportation system – the need for identifying people as “disabled” may not even be appropriate. What is important is that the transportation system suits the functional status of the population.

3.18 These diagrams also point out the limitations in defining people based upon medical diagnoses. The authors ask to consider two blind women, both aged 20 years old. One has been blind since birth. The other was recently blinded in an accident. Although both might have the same medical condition or impairment – that is, blindness – they will fall on very different parts of the functional continuums shown in the above figures. The woman who has never been able to see has spent her whole life accommodating herself to the world. She will be much further to the left of the functional scale than the recently blinded woman. And as time goes on, the woman who has only a short experience of living with blindness will surely migrate in that direction as she learns new skills that meet her new condition and hopefully begins to modify her environment to better suit her needs.

3.19 The choice of which activities to use for identifying people as having a disability is complicated if the desire is to have a measure that is internationally comparable. Even seemingly basic activities can create problems in making international comparisons. For example, “dressing oneself” can take on very different connotations in a society where one ordinarily slips into pants and a loose fitting shirt, compared to dressing in something as complicated as a sari. The ability to tie shoelaces or button shirts – often used as metrics for assessing hand functioning – are more or less relevant depending not only on culture but economic status. Even “bathing oneself” is very different for someone who can turn on a spigot as opposed to needing to travel to a community water source. This is not to say, of course, that such questions should not be asked. But care should be taken in making international comparisons and in writing questions to make responses from different countries as comparable as possible.

3.20 International comparability becomes even more difficult with participation questions, such as the one cited earlier from the US Current Population Survey relating to work disability. Clearly the conditions that affect the amount or type of work someone can do differ significantly across countries. In fact, they can even differ significantly within a country during different economic conditions. For example, evidence suggests that disability (as measured by such a question) and unemployment are correlated. As jobs are harder to find, the effect (real or perceived) of having a functional limitation on securing employment can be more intense (Stapleton and Burkhauser, 2003). Evidence from the US, UK, and the Netherlands suggests that the rates of self-reported work disability are affected by respondents justifying the receipt of disability benefits by overstating their work limiting disabilities (Banks, et. al 2004).

3.21 The World Health Organization has designed a set of Disability Assessment Schedules (known as the WHO-DAS) which have a long series of activity and participation based questions. Their 12-question set can be found in Box 1.

3.22 While some of these questions are internationally comparable (e.g., standing for long periods), some are less so (e.g., conducting household responsibilities). Furthermore, even the 12-question WHO-DAS set is too long to be of use for a census, which many countries must rely on due to limited resources for fielding household surveys.

3.23 Another source of questions comes from the UN Washington Group on Disability Statistics (WG) created by the United Nations Statistical Commission created with the charge of designing census questions that could be used to make meaningful comparisons of disability prevalence between nations.. Before turning to their approach, however, it is important to address the purpose behind estimating an internationally comparable measure of disability.

Box 1: WHO-Disability Assessment Schedule -- 12-Question Set

In the last 30 days how much difficulty did you have in:
(None Mild Moderate Severe Extreme Cannot Do)

Standing for long periods such as 30 minutes?

Taking care of your household responsibilities?

Learning a new task, for example, learning how to get to a new place?

How much of a problem did you have joining in community activities (for example, festivities, religious or other activities) in the same way as anyone else can?

How much have you been emotionally affected by your health problems?

Concentrating on doing something for ten minutes?

Walking a long distance such as a kilometre [or equivalent]?

Washing your whole body?

Getting dressed?

Dealing with people you do not know?

Maintaining a friendship?

Your day to day work?

Source: World Health Organization: <http://www.who.int/icidh/whodas/index.html>

VI Purpose of Measurement

4.1 The purpose of measurement determines the definition of disability to be used and thus the questions asked.⁵ Three major purposes for collecting data on disability include: monitoring the level of functioning in a population, designing service provision, and assessing the equalization of opportunity.

⁵ Much of this discussion follows from “Washington Group Position Paper: Proposed Purpose of an Internationally Comparable General Disability Measure” authored by Jennifer H. Madans, Barbara M. Altman, and Elizabeth K. Rasch for NCHS; Margaret Mbogoni, Malin Synneborn, and Jeremiah Banda for the UN; Angela Me for UNECE; and Elena DePalma for ISTAT, presented at the Third Meeting of the UN Washington Group on Disability Statistics in Brussels, 2004. See www.cdc.gov/nchs/citygroup.htm

4.2 *Monitoring the Level of Functioning in Population* – Monitoring functioning levels is important for two purposes: 1) Understanding the scope of potential concerns relating to disability, and 2) Evaluating interventions designed to prevent or minimize physical and cognitive limitations, activity limitation, and participation restrictions.

4.3 In regards to the first point, the question is how high a priority should disability issues receive? The more people who are living with particular functional limitations, the more important the issue will be. Collecting such data also allows us to measure how many children could benefit from a nutritional program aimed at preventing stunting, or a mental health intervention designed to limit depression, or the removal of landmines. Measuring the impact of preventive programs requires a description of the functional capacity of individuals.

4.4 Functional capacity, however, can be conceptualized according to all three functional domains: Body Functioning and Structure, Activities, and Participation.. Many indicators of functioning rely on Participation. For example, a question such as *Are you limited in the kind or amount of work you can do because of a physical, mental, or emotional problem?* As a higher order functional domain, Participation encompasses the other domains. However, the problem is that arises from the interaction between the limitations a person has at the Body Function (or even Activity) level with the effects of the environment. For example, maybe a mobility limitation only limits work ability because transportation and work places are not accessible. As environments become accessible, fewer people will answer positively to this question. So, for example, if the goal were to determine how well the health care system is impacting the long term effects of polio, this measured reduction in the employment of “disabled people” would be spurious.

4.5 Nevertheless, an affirmative response to: *Are you limited in the kind or amount of work you can do because of a physical, mental, or emotional problem?* does identify persons with limitations in Participation. Persons with impairments who have successfully adapted to their condition may be fully participating in the world of work, and would thus not be identified as having a disability, making them indistinguishable from people without functional limitations at the body functioning or activity levels.. If one is only interested in monitoring participatory

effects of disability this may not be a problem. However, this question can not address the objective of identifying how many people with functional limitations are benefiting from supports and accommodations.

4.6 Whether one wants to monitor functioning at the Participation level also depends on concerns about international comparability. Body Functioning is very comparable across cultures. Activities (like the example of bathing mentioned earlier) are less so. Participation is quite often not at all comparable. Take for example, mild to moderate vision problems correctable by glasses. In countries like the United States or Australia, this type of body function limitation would have no effect on a child's ability to attend school. In a developing country with large classes, limited reading material, and no access to glasses or vision screening, such a problem could very well lead to higher drop-out rates or an increased tendency to have to repeat a grade. In fact, 40 percent of disabled children not attending school in Brazil were found to be not attending because of vision problems correctable by glasses. A minor problem at the Body Function level was thus being translated into a significant problem at the Participation level.

4.7 *Provision of Services* – Another important purpose for collecting data on disability is to design and implement programs aimed at providing services to disabled people. Sometimes these might be general services that are being made more inclusive. Sometimes they may be specific services targeted at disabled people, or even targeted at a particular subset of disabled people (e.g., providing prosthetic devices and the associated rehabilitation services). This purpose requires more extensive information than simply monitoring the functioning of the population. For that reason census questions, which are generally limited in number and specificity, are inappropriate. Someone designing a service delivery program would need detailed information on peoples' functioning levels, the supports that people have available to them within their family and within their community, and environmental characteristics.

4.8 For example, suppose you were designing a program for people with vision problems. You would need to know how many people were blind as opposed to how many people had some limited vision they could utilize, and how many had problems that were correctable by glasses. If the plan was to design an on-site program, you would need to know their ability to

travel to the center to receive services. Their ability to travel, of course, would be a function of the extent of their vision problems, the presence of other functional limitations, the accessibility of transportation systems, and the resources (monetary and non-monetary) that they could employ.

4.9 For this reason, disability information gathered from censuses is not appropriate. For designing services, it is much better to have an extensive household survey or administrative database that is designed with an idea in mind of what services are going to be delivered.

4.10 *Equalization of Opportunities* – Another reason for collecting disability data is to assess the impact of having a limitation on individuals and their families. The goal of inclusive development is to enable all people to have equal opportunities when it comes to partaking in the economic and social lives of their communities. How can we measure this equalization of opportunity? Since the goal is for everyone to participate equally in society, it is tempting to use questions that address the domain of Participation directly. This approach, however, can be quite problematic for the reasons stated earlier.

4.11 For example, consider again the question, *Are you limited in the kind or amount of work you can do because of a physical, mental, or emotional problem?* Suppose a young deaf woman is having difficulty finding work and thus feels limited in her employment. She answers this question “yes” and is classified as disabled, and thus contributes to a negative correlation between employment and disability. Now, say that she finds an accommodating employer that values her services and she becomes fully employed. When asked this same question, she could quite easily answer “no” and thus be classified as non-disabled. Being “non-disabled”, she will not contribute to a positive correlation between employment and disability. In fact, as accommodations and supports expand and more disabled people get jobs, fewer of them will say they are limited in the amount or kind of work they can do. That will mean that the people remaining in the disabled category will, on average, be more limited in their functioning level. So you could get the perverse result that as a society becomes more inclusive, the wellbeing of its (measured) disabled population will decrease!

4.12 Therefore, the appropriate approach for looking at the equalization of opportunities and well-being is to focus on basic action/activity questions. Disability thus defined could be correlated with outcomes such as employment or education. If there is no correlation then disabled people have equal opportunities. If there is a negative correlation, then they are worse off. In essence, this would be a way of measuring the inclusiveness of the society. If people with various limitations are identified as not having equivalent outcomes, more detailed surveys could uncover the most damaging barriers that need to be addressed.

V Census Questions for Disability Prevalence

5.1 When considering what questions to put on a census, the WG had to consider the purpose for including disability questions. It is impossible in a census to capture the full richness of human functioning -- either by type of disability (physical, mental, sensory, psychological) or by functional domain (body structure/function, activities, and participation). Even more difficult would be to capture that all within the social model of disability where disability arises from the interaction between functional status and the environment. And as stated above, the goal was to produce general prevalence measures that were internationally comparable.

5.2 The WG membership agreed that a general prevalence rate that could be captured in a census should address the "Equalization of Opportunities" purpose. The questions thus focus on 4-6 basic core activities designed to capture the great bulk of disabled adults. People identified as disabled and non-disabled according to these questions can be compared to see if differences exist in employment levels, income, education, marital status, home ownership, etc since all those other data are already collected on most censuses. If people identified as having disabilities, when compared to those without disabilities, experience worse outcomes, that would be evidence of the extent to which disabled people do not have the same opportunities to be included in social and economic life as non-disabled people. This information can be used by policy officials and program managers to design mechanisms so that persons with disabilities will be included and participation levels will become equal for those with and without disability.

5.3 Box 2 contains a series of six questions recently endorsed by the WG for use as census questions. While they are not adequate to be used as screening questions - since they miss certain subpopulations, such as a fair number of those with mental health conditions – they do generate a recognizable group that encompasses a majority of people with disabilities⁶. The first three questions – on vision, hearing, and walking – tend to pick up a large majority of people with sensory or physical disabilities. The self-care question identifies many people who have upper-body mobility issues. And the cognition, communication and self-care questions were shown in pre-tests to capture at least some of those with psychological problems.

Box 2: Census Questions on Disability Designed by UN Washington Group on Disability Statistics

Because of a physical, mental, or emotional health condition...

1. Do you have difficulty seeing even if wearing glasses?
2. Do you have difficulty hearing even if using hearing aid/s or are you deaf?
3. Do you have difficulty walking or climbing stairs?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Do you have difficulty communicating (for example, understanding or being understood by others)?

Question response categories: No, Some, A lot, and Unable.

Source: <http://www.cdc.gov/nchs/citygroup.htm>

5.4 Screening questions for mental disabilities tend to focus on four components: learning, making decisions, remembering, and concentrating. The WG chose to focus on the latter two because the concepts of learning and decision making vary more across different cultures and economic situations. Moreover, listing all four components in a single question is problematic because respondents often get confused as to whether they must have problems with all four concepts in order to answer positively. A preferred way of identifying mental disabilities would be to ask each of these questions individually – learning, remembering, concentrating, making

⁶ Many people with mental health disabilities will be picked up, however. Those with conditions that are serious enough to limit the ability to care for oneself, for example. The questions on remembering, concentrating, and communicating will also pick up some people with mental health conditions.

decisions, and communicating. Unfortunately, space limitations often require combining or eliminating concepts.

5.5 Another possible screen for significant limitations in mental functioning is difficulty communicating, which also overlaps with other types of functional limitations such as deafness – The concept of “communication” refers to being able to understand and be understood by others.

5.6 Another approach to identifying people as having a disability, and that is incorporated in the fifth WG question, deals with self-care, and is thus related to ADLs. In truth, the self-care question is somewhat different in nature from the other questions, in that it focuses on a higher activity level. It was included in the WG questions because of the strong desire of countries to identify that subset of the population at risk for needing safety net services. However, as stated above, these questions must be interpreted carefully when making international comparisons

5.7 Even questions that focus on more basic activities, such as *do you have difficulty seeing?* can miss people with important functional limitations if not worded carefully. The National Center for Health Statistics in the United States found in their cognitive testing of proposed disability questions that blind people often answered “no” to such a question. Their reasoning was, “how can I have *difficulties* doing something when I cannot do it in the first place?” That is why the clause “or are you blind” is often incorporated into vision questions, although it is not in the WG question since “Unable” is included as a response category.

General Prevalence Measures

5.8 Drawing upon the previous discussion, a person should be categorized as having a disability for the purpose of a general disability prevalence measure based on:

- 1) Having some difficulty in a core, basic action/activity, such as seeing, hearing, walking, and some measure of mental functioning.** Self care can be included if there is a desire to identify the most significantly limited group.

- 2) **If international comparability is a priority, it would be best if the mental functioning question centered on remembering and concentrating** The activity of learning involves expectations and standards that are more culturally defined.
- 3) **Functioning should be recorded without the use of assistive devices, except for glasses or possibly hearing aids.** The appropriate purpose for a census based prevalence measure is “equalization of opportunities.” Asking for functioning with the presence of assistive devices undermines this purpose. Such devices can serve to equalize opportunities, so we want to capture their effect, not exclude people from the population of disabled people who are functioning well because they have them. Glasses, however, are so readily available that respondents will automatically factor them into their answers.
- 4) **Multiple prevalence measures should be used to capture different severity levels.** Due to the wide range in the degree of functional limitations, in addition to a general disability rate, a rate of severe or significant disability should also be reported. This will not only highlight the heterogeneity of this population, but serve as a useful breakdown for policymakers trying to identify populations that have different needs.

Pre-Testing of Washington Group Questions

5.9 Recently the WG cognitively tested its census questions in 16 countries, field tested them in Vietnam and South Africa. The WG questions were also field-tested by WHO and UNESCAP in The Philippines, Fiji, India, Indonesia, and Mongolia.

5.10 The cognitive testing undertaken by the WG involved interviewing a selected sample of diverse respondents to obtain a better understanding of what respondents thought the questions were asking and how respondents formulated their answers. These interviews included asking an extended set of more detailed questions about each functional domain, and then compared those responses to the response to the WG question to see if the population identified as having a disability with the WG question was actually the targeted population. For example, for the self-care question a series of questions were asked about dressing, feeding, fine motor skills, etc. The

results from these cognitive tests were very promising and lead to the WG endorsing their questions at their most recent annual meeting in Uganda in 2006.⁷

5.11 The results of the WHO/UNESCAP-tests show the wide variation in disability rates that can be generated depending on what is considered the cut-off for disability. They also highlight the difficulty of coming up with questions that are internationally comparable and still suited for a census.

5.12 In reviewing these data it is important to note that the samples drawn were not nationally representative. Therefore, these test results should not be interpreted as national prevalence rates. However, they are probably indicative of the variation that exists in these populations and they are similar to results reported later in the paper that are drawn from representative samples. The number of respondents for the six questions in each of the five study countries can be found in Table 4.

5.13 The WHO/UNESCAP testing was to get a sense of how the questions worked, rather than on reporting prevalence rates. The purpose of examining these data is to obtain a sense of the complexity of asking about disability, and the effect of employing different approaches – especially in regards to severity cut-offs.

5.14 Table 4 shows the responses to the question, *Do you have difficulty seeing even if wearing glasses or are you blind?* Mild refers to people who reported some difficulty, severe corresponds to a lot of difficulty, and complete corresponds to a respondent being unable to see.

⁷ The results from these tests are currently being written up into a report. Presentations of the cognitive tests can be found at the WG website: <http://www.cdc.gov/nchs/citygroup.htm>

Table 4: Number of Respondents for Pre-Test of Disability Questions, by country

| <u>Question Domain</u> | Philippines | Fiji | India | Indonesia | Mongolia |
|--|--------------------|-------------|--------------|------------------|-----------------|
| Seeing | 1045 | 992 | 584 | 799 | 1061 |
| Hearing | 1045 | 992 | 578 | 799 | 1060 |
| Walking & climbing | 1044 | 993 | 590 | 799 | 1061 |
| Remembering & concentrating | 1042 | 989 | 590 | 799 | 1061 |
| Self Care | 1044 | 992 | 590 | 799 | 1061 |
| Communicating | 1043 | 966 | 589 | 799 | 1061 |
| Source: WHO/UNESCAP | | | | | |

5.15 Again, because the samples are not nationally representative, it would be inappropriate to compare overall disability rates. But what is apparent is that in most instances – except India – the ratio between mild difficulty and severe difficulty is quite high. The same thing can be seen in Charts 2 through 6 corresponding to the questions for the other functional domains. In fact, a recent Bank study (referred to later) found a range of disability from 4 to 9 percent in two states of India, using a measure that identifies only people with more significant limitations.

5.16 If one only looks at the presence of any difficulties, then Philippines and Fiji have the highest rates of disability – except as measured by self-care. Those high overall rates are driven by the percentage of people with mild disabilities. As seen in Table 5, Philippines has the highest rate of mild disabilities across all domains except “concentrating and remembering” for which it is barely exceeded by Fiji. On the other hand, although India’s rate of mild disability is quite low in comparison to the other countries, its rate of more significant disabilities is higher. This may be the result of cultural differences in the valuation and reporting of functional limitations which are less extreme. Without cognitive testing to uncover how the questions are actually being interpreted by the respondents, it is not possible to tell. There is much less variance for disabilities reported as severe or complete. This may result from a clearer conception of what constitutes having great difficulty or being unable to do a particular activity.

Chart 1: Difficulties Seeing, by Country and Degree

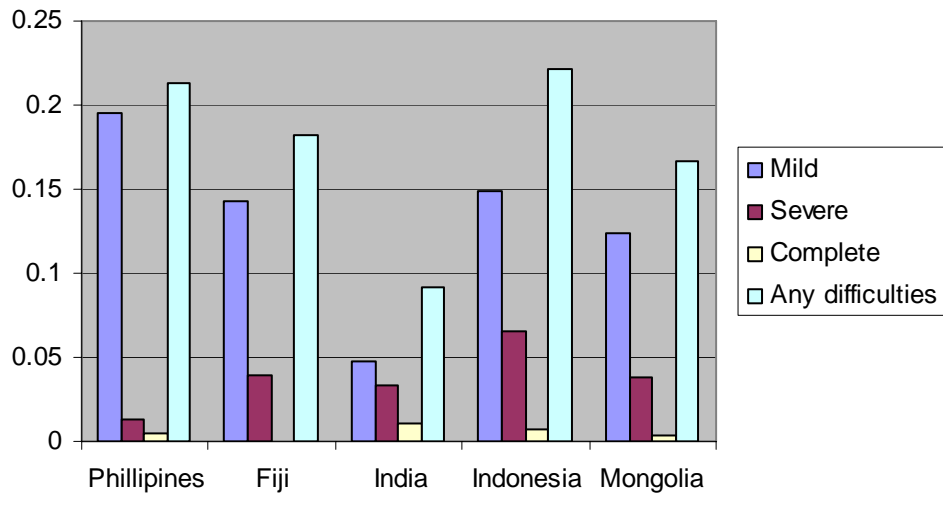


Chart 2: Difficulties Hearing, by Country and Degree

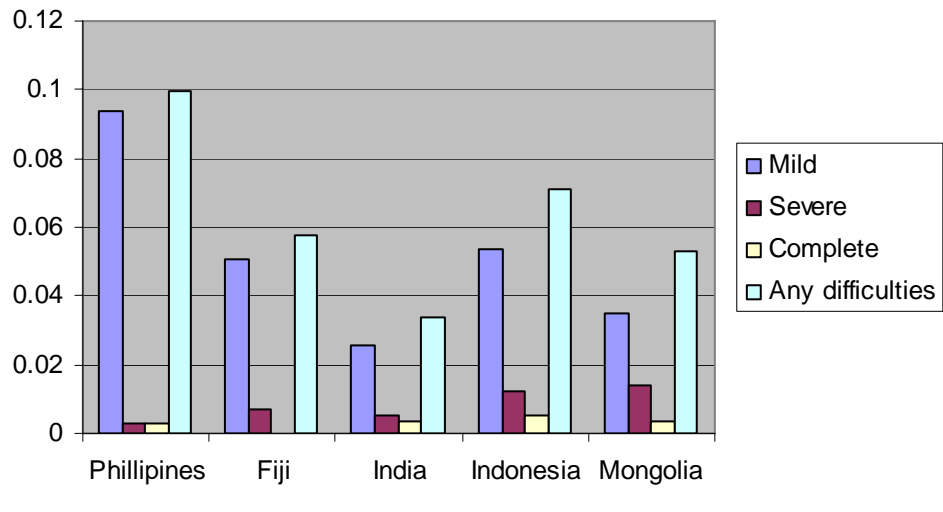


Chart 3: Difficulties Walking and Climbing Stairs, by Country and Degree

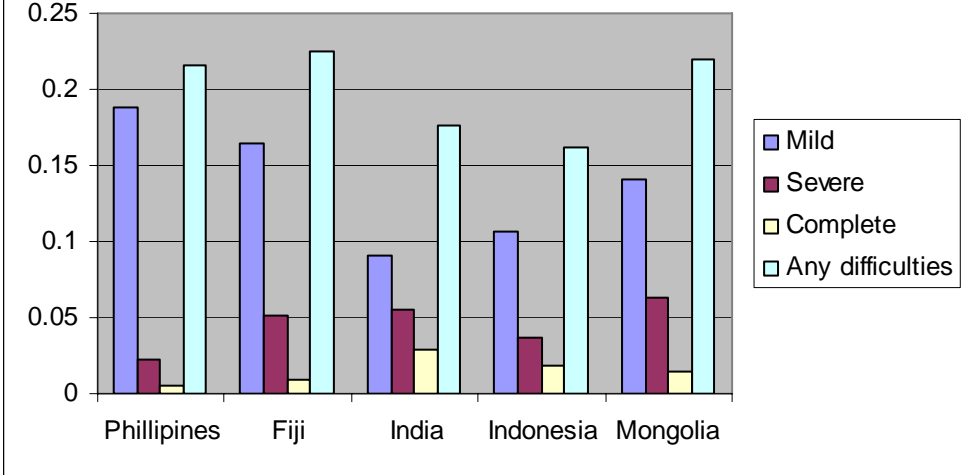


Chart 4: Difficulties Remembering and Concentrating, by Country and Degree

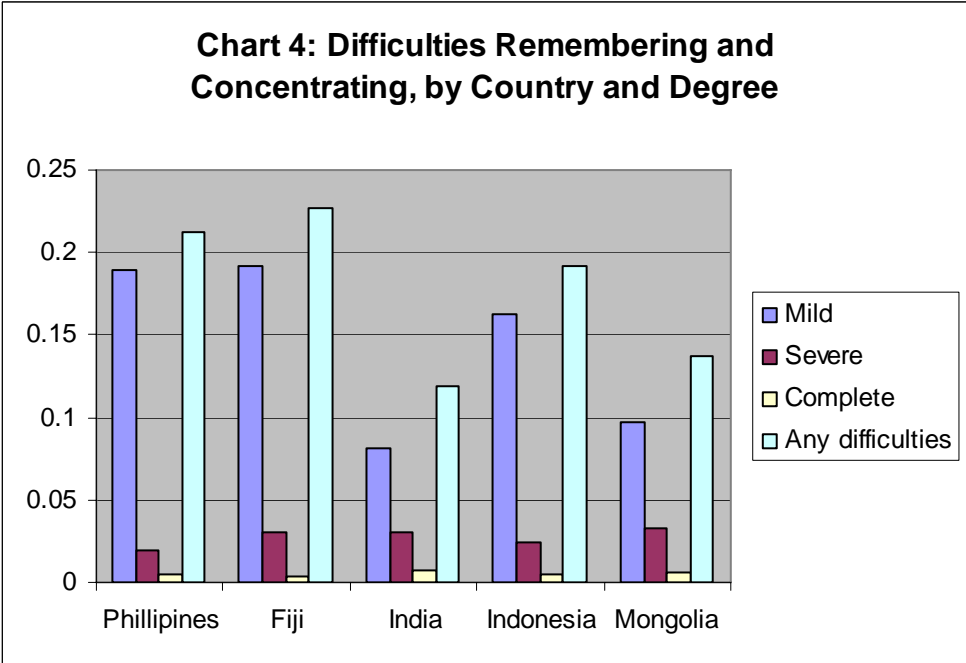


Chart 5: Difficulties with Self Care, by Country and Degree

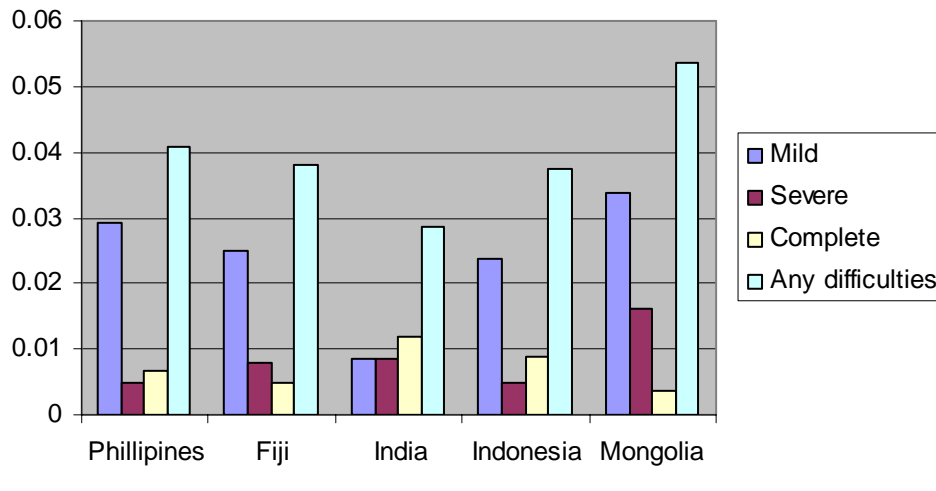
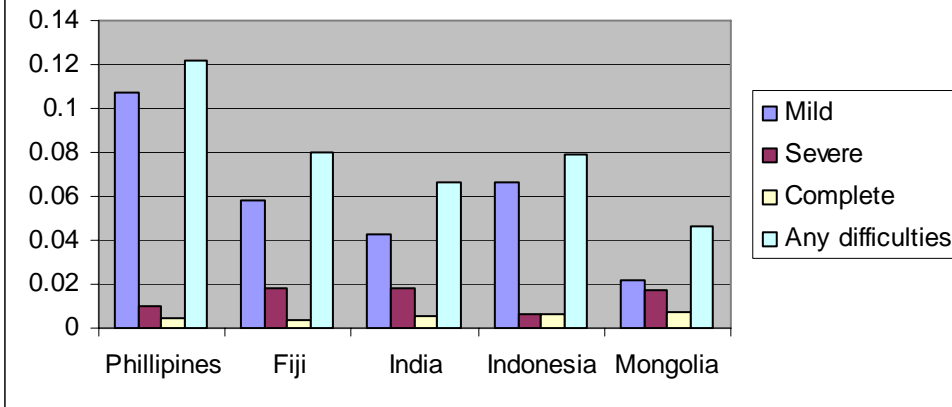


Chart 6: Difficulties Communicating, by Country and Degree



| Table 5: Disability Rates, by Domain and degree, by country | | | | | |
|--|--------------------|-------------|--------------|------------------|-----------------|
| <u>Question Domain</u> | Philippines | Fiji | India | Indonesia | Mongolia |
| Seeing | | | | | |
| Mild | 19.5 | 14.3 | 4.7 | 14.9 | 12.4 |
| Severe or unable | 1.8 | 3.9 | 4.4 | 7.3 | 4.2 |
| Any | 21.3 | 18.2 | 9.1 | 22.1 | 16.7 |
| Hearing | | | | | |
| Mild | 9.4 | 5.1 | 2.5 | 5.4 | 3.5 |
| Severe or unable | 0.6 | 0.7 | 0.9 | 1.8 | 1.8 |
| Any | 9.9 | 5.8 | 3.4 | 7.1 | 5.3 |
| Walking and Climbing | | | | | |
| Mild | 18.8 | 16.5 | 9.1 | 10.6 | 16.5 |
| Severe or unable | 2.7 | 6.0 | 8.5 | 5.6 | 6.0 |
| Any | 21.6 | 22.5 | 17.6 | 16.3 | 22.5 |
| Remember and Concentrate | | | | | |
| Mild | 18.9 | 19.2 | 8.1 | 16.3 | 9.7 |
| Severe or unable | 2.4 | 3.5 | 3.7 | 2.9 | 4.0 |
| Any | 21.3 | 22.7 | 11.9 | 19.1 | 13.7 |
| Self-care | | | | | |
| Mild | 2.9 | 2.5 | 0.9 | 2.4 | 3.4 |
| Severe or unable | 1.1 | 1.3 | 2.0 | 1.4 | 2.0 |
| Any | 4.1 | 3.8 | 2.9 | 3.8 | 5.4 |
| Communicating | | | | | |
| Mild | 10.7 | 5.8 | 4.2 | 6.6 | 2.2 |
| Severe or unable | 1.5 | 2.2 | 2.4 | 1.3 | 2.4 |
| Any | 12.2 | 8.0 | 6.6 | 7.9 | 4.6 |
| Source: WHO/UNESCAP | | | | | |

5.17 The variance across countries is also reduced when the questions become more specific. In addition to pre-testing the WG census questions, WHO/UNESCAP also tested a broader set of questions based on the WHO/DAS. For example, for the vision domain they asked separate questions for vision problems having to do with short- and long-sightedness. While the Philippines is still an outlier, Table 6 shows that the range of reported disability rates becomes somewhat more compressed. More specific questions are less open to interpretation.

| Table 6: Mild Visual Disability Rates, by Country | | | |
|--|----------------------|---------------------|---------------------------|
| | Short sighted | Long-sighted | Any vision problem |
| Philippines | 17.0 | 11.7 | 19.5 |
| Fiji | 8.4 | 6.9 | 14.3 |
| India | 4.9 | 4.2 | 4.7 |
| Indonesia | 8.4 | 12.1 | 14.9 |
| Mongolia | 7.1 | 8.0 | 12.4 |
| <i>Source: WHO/UNESCAP</i> | | | |

5.18 Still, there are interesting differences. For example, in Fiji there appears to be little overlap between different vision problems. And, the fact that fewer people in India reported any mild vision problems when responding to the general question as compared to the more specific question about short-sightedness could mean that people with a mild problem in one aspect of seeing did not consider their overall difficulties with vision to be a significant enough problem to warrant a positive response.

5.19 Vietnam is one country where similar type field tests were done on a population based sample. A representative sample of 1020 households was drawn from the Thai Binh province⁸. Overall, the disability prevalence rate was 31.6% if a cut off of any difficulty in any of the six

⁸ “Country Report: Results of the Field Test on Washington Group Disability Questions,” General Statistical Office of Viet Nam, Ha Noi-2006, presented at the 6th Annual Meeting of the Washington Group in Kampala, Uganda, October 2006

domains was used, 10.0% if the “a lot of difficulty” cut-off was used, and 2.6% if the “unable” cutoff was used.⁹

5.20 The results from these tests suggest that the very low rates of disability being picked up by censuses may correspond to only people with the most severe disabilities. Even in South Africa, where the census question is “*Does (the person) have a serious sight, hearing, physical or mental disability?*” disabled people are probably missed. Focus groups consisting of people with and without disabilities from different communities were asked the South African census question on disability and the Washington Group Questions. As seen in Table 7, the census question identified fewer of the disabled people.

| Group | Washington Group Questions | | Census 2001 | |
|-----------------------------------|----------------------------|--------------|-------------|--------------|
| | Disabled | Non-Disabled | Disabled | Non-Disabled |
| “Disabled” | | | | |
| English urban psychiatrically ill | 7 | 1 | 7 | 1 |
| English urban visually disabled | 9 | 0 | 2 | 7 |
| English urban physically disabled | 6 | 0 | 3 | 3 |
| Tsonga rural visually disabled | 9 | 1 | 5 | 5 |
| Tswana rural Physically disabled | 8 | 2 | 4 | 6 |
| “Non-Disabled” | | | | |
| English urban youth | 2 | 7 | 1 | 8 |
| Sesotho urban adults | 3 | 7 | 0 | 10 |
| Afrikaans rural adults | 4 | 5 | 1 | 9 |

Source: (Schneider, M. and D. Mont, “Presentation on Field Test Results,” 6th Annual Meeting of the Washington Group on Disability Statistics, October 2006, Kampala, Uganda

⁹ Researchers in Zambia also found the disability rate to be very high if a threshold of some difficulty in one domain was used to define disability. The 13.1% disability rate for Zambia referred to earlier is based on a person having some difficulty in at least two domains, or having a lot of difficulty or being unable to carry out an activity in at least one domain.

5.21 The next section summarizes the results from three nationally representative studies in Latin America that use a functional (body function, activity or participation) based approach in keeping with the spirit of the ICF and the WG.

VI Case Studies: Disability in Brazil, Ecuador and Nicaragua

6.1 Recently, Brazil, Ecuador, and Nicaragua collected data on disability based on a functional approach consistent with the ICF. Brazil incorporated questions on disability into their last national census, and experienced a dramatic rise in the measured prevalence of disability as compared to their last census -- 14.5% as opposed to 0.9%.¹⁰ Ecuador and Nicaragua implemented disability surveys which recorded prevalence rates of 12.1% and 10.3%, respectively (Flores, et. al. 2005, INEC, 2003)

6.2 The Brazilian census questions from 1991 and 2000 are shown in Box 3. The question generating the very low rate of disability prevalence asks the respondent to respond to whether or not they have a very specific set of conditions. The more recent questions expand to cover the difficulty to do particular activities, and to record various degrees of difficulty.¹¹

6.3 Questions from Ecuador and Nicaragua are much more detailed because they come from surveys dedicated to the disability issue, but they follow the same basic philosophy and draw heavily from the WHO-DAS. Questions attempt to gauge how much difficulty respondents have doing basic activities. If a person has difficulty in any of the functional domains examined (physical, sensory, cognitive, or psychosocial), then they are considered to have a disability. Box 4, for example, shows the Nicaraguan questions on comprehension and communication.

¹⁰ Bercovich (2004) and Fundacao Instituto Brasileiro de Geografia e Estatistica - IBGE, Censo Demografico, 1991, Caracteristicas Gerais da Populacao e Instrucao, No. 1 (1996).

¹¹ Note that mental disabilities relating to cognition and psycho-social disabilities relating to mental health are still excluded.

Box 3: Brazilian Census Questions on Disability

1991

Do you have any of the following physical or mental disabilities?

1. Blindness
2. Deafness
3. Paralysis of one side of the body
4. Paralysis of the legs
5. Total paralysis
6. Loss of a leg, hand, foot, or thumb
7. Mental disability
8. Other
9. None of the above

2000

1. Do you have any permanent mental disability that restricts your daily activities? (such as working, attending school, playing, etc.)

-Yes/ No

2. How do you evaluate your capacity to see? (With glasses or contact lenses, if used)

- Unable
- Severe permanent difficulty
- Some permanent difficulty
- No difficulty

3. How do you evaluate your capacity to hear? (With hearing aid, if used)

- Unable
- Severe permanent difficulty
- Some permanent difficulty
- No difficulty

4. How do you evaluate your capacity to walk / climb stairs? (With prosthesis, walking stick or an auxiliary devise, if used)

- Unable
- Severe permanent difficulty
- Some permanent difficulty
- No difficulty

5. Do you have any of the following impairments? (Choose only the first that applies based on the order of the list below)

- Permanent total paralysis
- Permanent paralysis of the legs
- Permanent paralysis of one side of the body
- Loss of a leg, arm, hand, foot or thumb
- None of the above

Source: UN Statistics Division website at <http://unstats.un.org/unsd/demographic/sconcerns/disability/disabmethods.aspx?id=United%20States%20of%20America>

Box 4: Questions on Comprehension and Communication from Nicaragua

Do you have difficulty learning a new skill, for example learning how to get to a new place or to play a new game?

Do you have difficulty concentrating on an activity for longer than 10 minutes?

Do you have difficulty remembering important things that you have to do on a daily basis?

Do you have difficulty finding solutions to problems of daily life?

Do you have difficulty understanding or being understood by others?

Do you have difficulty starting or maintaining a conversation?

For every positive response, the following questions are then asked:

How much difficulty do you have? *A little, Some, A lot, A great deal (or are unable to do it)?*

How much has this difficulty affected our life? *Not at all, a little, A lot, A great deal, Completely?*

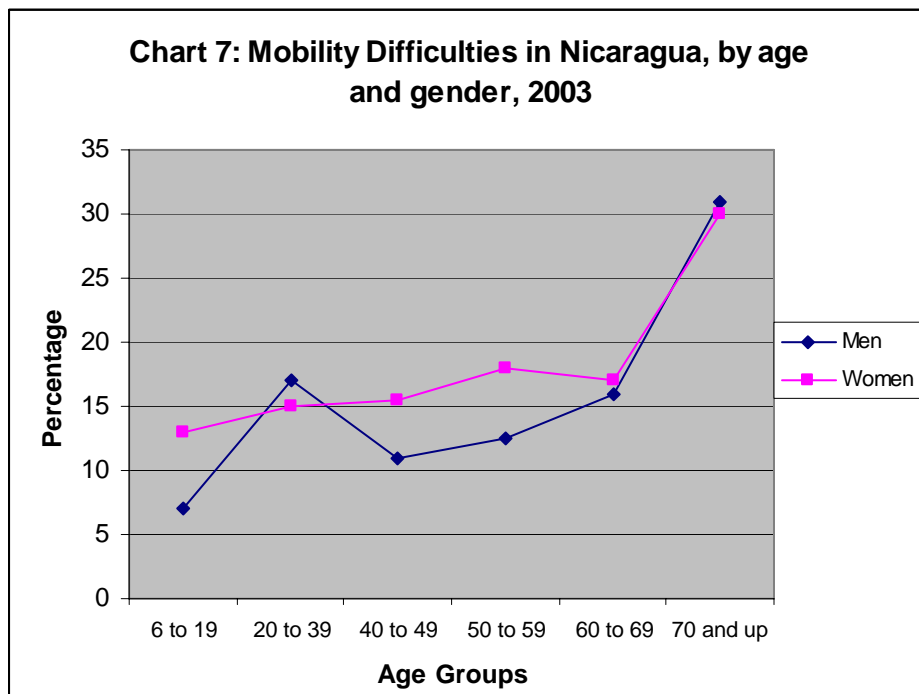
Source: INEC

6.4 The overall rates of disability in the three countries are similar. Also, males have a slightly lower rate of disability than females (Table 8). This gender difference is at least in part due to the fact that women live longer, since disability is strongly correlated with age. In Brazil,

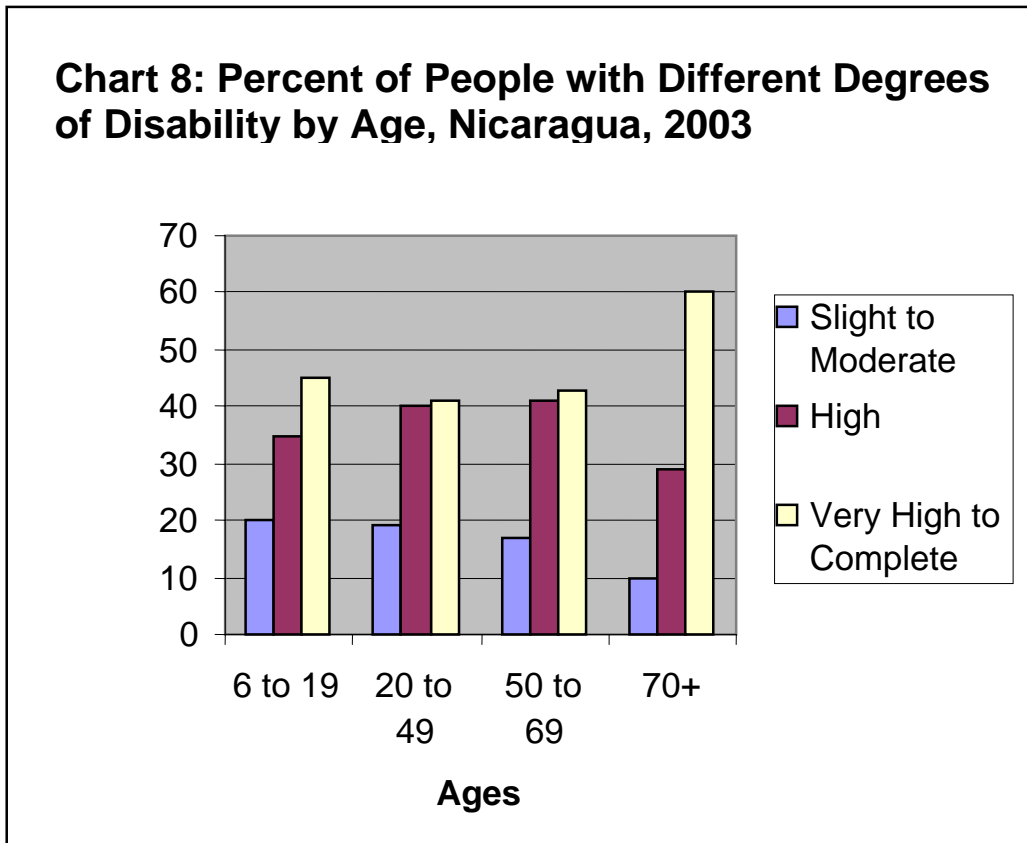
| | Total | Male | Female |
|------------------|--------------|-------------|---------------|
| Brazil | 14.5 | 13.7 | 15.3 |
| Ecuador | 12.1 | 11.8 | 12.4 |
| Nicaragua | 10.3 | 9.1 | 11.3 |

for example, the rate of disability for people over the age of 65 is 54%. However, it does not tell the whole story. In Nicaragua the rates of disability are very similar for men and women up until

the age of 39, when they begin to diverge to about a 10 percentage point differential. But it also may have something to do with differences in how and when men and women acquire disabilities. In every category of disability examined by the Nicaraguan study males have higher rates of disability as they enter adulthood, but during middle age women's prevalence rates exceed men's. Generally speaking, men's and women's disability rates became much closer as they age (although, of course, women are more represented in the older age groups). For example, Chart 7 shows the percentage of people with mobility difficulties by age and gender, which is indicative of the other functional domains.



6.5 For most of this section, all disabled people are referred to as a single group. But as pointed out earlier in the paper, the range of disability can be quite broad – from mild to moderate to highly significant. In fact, according to the Ecuador study, although the overall disability prevalence rate is 12.1 percent, only about 4 percent of the population is considered to have a serious disability. In Nicaragua, the breakdown by severity level is somewhat different, with nearly half of disabled people reported as having a very high level of disability. As seen in Chart 8, the degree of disability is highest for the elderly.



6.6 The needs and accommodations for people with more significant disabilities can be quite different than for those with moderate or mild disabilities. Therefore, it is very important when reporting prevalence rates to provide some idea of the range of functional limitations being addressed. Even the indications “mild, moderate, or severe” can vary from one study to another and might not be that comparable. Often, respondents themselves are asked to grade their disabilities along that scale.

6.7 A different way of approaching this is to categorize disability by the level of assistance needed. As can be seen in Table 9, a recent study in two states of India found that 13.6 percent of disabled people were in the most severe category. That is they could not take care of themselves even with assistive devices. Comparability issues still exist since the types of assistive devices vary by country as does what it means to “care for oneself. Still, this approach provides a sharper description of the range of disability.

Table 9: Reported extent of disability among Disabled People in Uttar Pradesh and Tamil Nadu, India, 2002

| Extent of disability | Share of all Disabled People |
|---|-------------------------------------|
| Can not take care of self even with aid-appliance | 13.6% |
| Can take care of self only with aid-appliance | 17.2% |
| Can take care of self without aid-appliance | 60.2% |
| Aid-appliance not tried/available | 9.0% |
| Source: World Bank, "People with Disabilities in India: From Commitments to Outcomes, 2006. | |

VII Conclusions

7.1 This paper reviewed the concept of disability and its measurement and set forth a standard for defining disability suitable for developing internationally comparable measurement procedures in order to provide comparable prevalence rates (a checklist of good measurement practices is provided in Box 4). That is, to report the percentage of people with a limitation in at least one of the core functional domains, as outlined by the ICF and as implemented by the UN's Washington Group on Disability Statistics. This coincides with the basic trend of measuring functional limitations, rather than disability.

7.2 However, it is important to note that the situation and the threshold at which a functional limitation is considered to be a disability will be different depending on the purpose of measurement. Therefore, when reporting general prevalence it is best to provide some notion of the range of disability. For example, in Ecuador the disability prevalence rate is 12.1 percent, but the rate of severe disability is about 4 percent.

Box 4: Measuring Disability for General Prevalence Estimates in Censuses

- 1) Questions should be based on functionality.
- 2) Questions should focus on basic core activities.
 - a. This is in line with “Equalization of Opportunity” purpose for measurement
 - b. This makes for more internationally comparable prevalence rates
- 3) The word “disability” should not be used. Avoid derogatory language.
- 4) Responses should be scaled rather than yes/no
- 5) A range of prevalence should be reported for various levels of severity, rather than a single prevalence rate.

7.3 Overall, as generally defined, disabled people represent a significant proportion of the world's population. Data from developed countries and some recent studies in developing countries (Brazil, Ecuador, India, Nicaragua, Vietnam, and Zambia) suggest that an estimate of 10-12 percent is not unreasonable.

7.4 Different countries will report different prevalence rates and that is expected. For a variety of reasons, a country might want to use a different set of functional domains or would prefer to use a different severity threshold for classifying people as being disabled. However, it is highly recommended that countries use similar types of limitations with a range of categories to allow for a representation of some of the continuum. Furthermore, they should try as much as possible to use actions and terminologies that allow for comparability across cultural contexts. By doing so, the prevalence estimates they report will be more understandable, more useful for benchmarking, and more in line with the social model of disability which is most conducive for building inclusive development policies to better the lives of the entire population.

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Annex 1: ACTIVITY AND PARTICIPATION MATRIX

1a. SENSORY EXPERIENCES

- a. watching/looking
- b. listening/hearing

1b. BASIC LEARNING & APPLYING KNOWLEDGE

- a. learning to read/write/count/calculate
- b. acquiring skills (manipulating tools, learning names)
- c. thinking
- d. reading/writing/counting/calculating
- e. solving problems

2. COMMUNICATION

- a. understanding others (spoken, written or sign language)
- b. producing messages (spoken, written or sign language)
- c. communicating with others
- d. communicating using devices (phone/typewriter/computer/Braille)

3. MOBILITY

- a. staying in one body position
- b. changing a body position (sitting/standing/bending/lying)
- c. transferring oneself (moving from one surface to another)
- d. lifting/carrying/moving/handling objects
- e. fine hand use (picking up/grasping/manipulating/releasing)
- f. hand & arm use pulling/pushing/reaching/throwing/catching
- g. walking
- h. moving around (crawling/climbing/running/jumping)
- i. moving around using equipment/assistive devices
- j. using transportation to move around as a passenger
- k. driving a vehicle (car/boat/bicycle/or riding an animal)

4. SELF CARE

- a. washing oneself
- b. care of body parts, teeth, nails and hair
- c. toileting
- d. dressing and undressing
- e. eating and drinking

5. DOMESTIC LIFE

- a. shopping (getting goods and services)
- b. preparing meals
- c. doing housework (washing/cleaning)
- d. taking care of personal objects (mending/repairing)
- e. taking care of others

6. INTERPERSONAL BEHAVIOURS

- a. making friends and maintaining friendships
- b. interacting with persons in authority
- c. interacting with strangers
- d. creating and maintaining family relationships
- e. creating and maintaining intimate relationships

7. MAJOR LIFE AREAS

- a. going to school and studying (education)
- b. getting and keeping a job (work & employment)
- c. handling income and payments (economic life)

8. COMMUNITY, SOCIAL AND CIVIC LIFE

- a. clubs/organisations (community life)
- b. recreation/leisure (sports/play/crafts/hobbies/arts/culture)
- c. religious/spiritual activities
- d. political life and citizenship

9. OTHER (specify)

Source: Loeb, M. and A. Eide, (eds), Living Conditions among People with Activity Limitations in Malawi: A National Representative Study. SINTEF Health Research, August 2004

Annex 2: INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.
2. Dials a few well-known numbers
3. Answers telephone but does not dial
4. Does not use telephone at all.

B. Shopping

1. Takes care of all shopping needs independently
2. Shops independently for small purchases
3. Needs to be accompanied on any shopping trip.
4. Completely unable to shop.

C. Food Preparation

1. Plans, prepares and serves adequate meals independently
2. Prepares adequate meals if supplied with ingredients
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.
4. Needs to have meals prepared and served.

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. “heavy work domestic help”)
2. Performs light daily tasks such as dishwashing, bed making
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.
4. Needs help with all home maintenance tasks.
5. Does not participate in any housekeeping tasks.

E. Laundry

1. Does personal laundry completely
2. Launders small items; rinses stockings, etc.
3. All laundry must be done by others.

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.
2. Arranges own travel via taxi, but does not otherwise use public transportation.
3. Travels on public transportation when accompanied by another.
4. Travel limited to taxi or automobile with assistance of another.
5. Does not travel at all.

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosages at correct time.
2. Takes responsibility if medication is prepared in advance in separate dosage.
3. Is not capable of dispensing own medication.

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.
3. Incapable if handling money.

Source: Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." *Gerontologist* 9:179-186, (1969).

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Summary Findings

Disability and poverty are intricately interlinked. Unfortunately, high quality, internationally comparable data on disability that is important for the planning, implementation, monitoring, and evaluation of inclusive policies is often not available. This paper reviews what is meant by disability and puts forth a way of measuring disability suitable for internationally comparable prevalence rates. It clarifies good standards in collecting data on disability and makes recommendations for prevalence measures of disability suitable for censuses. Since a single disability prevalence rate can be highly problematic, a better practice would be to report at least two prevalence rates — one representing a moderate threshold for functional limitations and one with a more severe threshold.

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