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# Understanding and Interpreting Disability as Measured using the WG Short Set of Questions

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## Washington Group on Disability Statistics (WG)

## 1. Background: Defining disability

Disability involves the interaction of a person's functional status with their physical, cultural, and policy environments. If the environment in which one lives is designed for the full range of human functioning and incorporates appropriate accommodations and support mechanisms, then people with functional limitations would not be "disabled" in the sense that they would be able to fully participate in society. Interventions designed to improve participation are not only targeted at the individual level, for example medical rehabilitation aimed at a specific impairment or basic action difficulty (defined below), 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.

The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO, 2001) provides a common language and a common point of reference in realizing this conceptualisation of disability. Embracing and operationalizing an ICF-based approach to disability has required the development of new measurement tools for use in censuses and surveys. The earlier impairment-based, medical model approach that focused on medical conditions and asked some variation of the question: *Do you have a disability?* is no longer satisfactory; and the focus of measurement has shifted to experienced *difficulties* in basic actions and *barriers* to participation.

## 2. Methods

### 2.1 Recommended Short Set of Questions on Disability for Censuses

The WG developed a short set of questions for use in censuses and surveys according to the Fundamental Principles of Official Statistics[1] and which is consistent with the ICF. Question testing has shown that they produce internationally comparable data.

It is intended that these questions will identify the majority of persons in the population who are at greater risk than the general population of experiencing limited or restricted participation in society. The questions cover six functional domains or basic actions: seeing, hearing, walking, cognition, self care, and communication.

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[1] See *Statistical Commission, Report on the Special Session (11-15 April 1994)*, Economic and Social Council, Official Records, 1994, Supplement No.9, Series No. E/CN.3/1994/18, United Nations, New York, 1994, para.59.

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?[2]
2. Do you have difficulty hearing, even if using a hearing aid?[2]
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual (customary) language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories: (1) No, no difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do it at all. The severity scale is used in the response categories in order to capture the full spectrum of functioning from mild to severe.

### 2.2 Analytic approaches

The six domains cover many but not all areas of functioning: vision, hearing, mobility, cognition, self-care and communication. Furthermore, the response categories capture the degree or 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 prevalence estimates.

## 3. Estimates of prevalence

Studies in countries that have used the WG approach show an improvement over the use of more traditional impairment-based census questions on disability. In Zambia for example, the questions used in the 2000 Census[3] to capture disability were: “Are you disabled in any way?” (Yes/No), and “What is your disability?” (Response categories included: blind, partially sighted, deaf/dumb, hard of hearing, mentally ill, ex-mental, mentally retarded, and physical handicapped.) This approach yielded a disability prevalence rate in Zambia of **2.7%** which , in fact, represented a trebling of the 1990 population prevalence rate of **0.9%** which used the same approach but included only 4 impairment categories: blind, deaf/dumb, mentally retarded, and crippled[3,4].

The short set of WG questions was included in a 2006 Living Conditions Survey in Zambia[5]. As mentioned above, several possible cut-off points for measuring disability were assessed. If the level of inclusion for disability prevalence is *at least some difficulty* in carrying out *at least one* of the six WG domains, a prevalence rate of **14.5%** is obtained. If a slightly more conservative cut-off was selected: *at least a lot of difficulty* on

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[2] The inclusion of assistive devices was considered for two domains only, seeing and hearing, as limitations in these domains can often be overcome with the use of glasses or hearing aids.

[3] CSO, 2000 Census of Population and Housing, Available online at: http://www.zamstats.gov.zm/census.php see Chapter 9: *Disability*; and http://www.hist.umn.edu/~rmccaa/IPUMSI/index.htm

[4] CSO, 1990 Census of Population, Housing and Agriculture, Available online at: http://www.hist.umn.edu/~rmccaa/IPUMSI/index.htm

[5] Eide AH, Loeb ME (eds.) (2006) Living Conditions among people with activity limitations in Zambia: A national representative study. Report No. A262, SINTEF Health Research, Oslo. Available online at: http://www.sintef.no/lc

*at least one* of the 6 domains, the resultant prevalence rate was **8.5%**. Both of these estimates represent a valid estimate of prevalence, and each has its own uses and limitations. These results speak to the flexibility of the instrument in allowing for a choice of definition based on the purpose of data collection.

### 3.1 To determine the prevalence of difficulty in single domains:

For each of the six core domains it was possible to calculate the proportion of those with disabilities based on the three possible cut-off values according to severity or degree of difficulty.

**Table 1**: Prevalence (%) by domain and degree of difficulty (Zambia data 2006; N=28010; 179 missing)

| | **Degree of Difficulty** | | |
|---|---|---|---|
| **Core Domains** | **at least some difficulty** | **at least a lot of difficulty** | **unable to do it at all** |
| Vision | 4.7 | 2.6 | 0.5 |
| Hearing | 3.7 | 2.3 | 0.5 |
| Mobility | 5.1 | 3.8 | 0.8 |
| Remembering | 2.0 | 1.5 | 0.3 |
| Self-Care | 2.0 | 1.3 | 0.4 |
| Communication | 2.1 | 1.4 | 0.5 |

Within each degree of difficulty, (columns in the table above) problems encountered with mobility have the highest prevalence (5.1%, 3.8% and 0.8% for some difficulty, a lot of difficulty and unable to do it at all respectively), followed by visual (4.7%, 2.6% and 0.5%) and hearing difficulties (3.7%, 2.3% and 0.5%); problems relating to remembering, self-care and communicating all have lower prevalence. Not unexpectedly for each of the core domains the prevalence decreases with increasing degree of difficulty; in the vision domain for example, more people have at least some difficulty with vision (4.7%), fewer have a lot of difficulty (2.6%), and fewest are unable to see (0.5%). The estimates presented in the table above are not mutually exclusive, and many individuals will have a disability that encompasses more than one domain.

### 3.2 To determine the prevalence of difficulty in all domains:

If the interest is in an overall estimate of disability prevalence that includes all domains, using the WG questions it is possible to construct several different measures, or levels, that reflect the multidimensionality of the disability experience. Four measures have been proposed by the WG:

1. a broad measure that includes everyone with at least one domain coded as *some difficulty*, *a lot of difficulty*, or *unable to do it*
2. a measure that excludes the mildest degrees of difficulty and includes everyone with at least one domain coded as *a lot of difficulty*, or *unable to do it*
3. a narrow measure that focuses on the most severe levels of difficulty and includes everyone with at least one domain coded as *unable to do it at all*
4. a measure that is slightly more restrictive than #1 and includes everyone with at least **one** domain that is coded as *a lot of difficulty* or *cannot do it at all* or at least *some difficulty* in **two** domains.

These data are presented in the table below.

**Table 2**: Prevalence measures (Zambia data 2006; N = 28010)

| **Determination of Disability** | **N** | **%** |
|---|---|---|
| Cut-off is: | | |
| at least one domain is scored *some difficulty* | 4053 | 14.5 |
| at least one domain is scored *a lot of difficulty* | 2368 | 8.5 |
| at least one domain is scored *unable to do it at all* | 673 | 2.4 |
| at least one domain is *a lot of difficulty* or *unable to do it* or at least *some difficulty* is scored in two domains | 1718 | 6.1 |

As in the previous table, higher prevalence rates in Table 2 above are associated with definitions of disability that include milder or lesser degrees of difficulty. Thus, by including as disabled those who reported even *some difficulty* on one of six domains, the sample prevalence is 14.5%; while including as disabled those who reported at least *a lot of difficulty* the sample prevalence is 8.5%. In the data from Zambia, the prevalence rate for those with the most severe levels of disability; that is, the individual is *unable to do* at least one of the 6 domains, was found to be 2.4%. This number is similar to the national prevalence rate from the 2000 census of 2.7% which was based on an impairment-based definition that included the more severe forms of disability. It has been postulated that the relatively low prevalence rates reported in many low-income countries, as in Zambia in 2000, may in fact correspond more closely to true rates of *severe* disability in these countries.

### 3.3 Evaluating Participation by Disability Status – a means to monitor the UN Convention:

Data on different levels of disability as defined above can be used, in combination with data on other variables, to measure compliance with the UN Convention on the Rights of Persons with Disability. Data derived from the short set of questions, coupled with information collected through the Census or a survey on employment, education, housing, transportation, social and health services, in addition to aspects of family, cultural and social life can be used to compare the levels of participation between those with disability (as defined above) and those without – and thereby assess equitable access to opportunities as mandated by the UN Convention. For example, disability data can be cross-classified with employment data to identify the proportion of persons with and without disability who are employed. This is an assessment of the equality of employment opportunities. If policy interventions are initiated to enhance workplace accommodations, their effect on the employment of persons with disability can be determined. From a theoretical perspective, if opportunities have been optimized then participation should be equal between persons with and without disability.

**Table 3**: Access to education and employment by Disability Status (Zambia data 2006)

| | **% never attended school (age 6 years or older)** | | **% not working (age 15 – 65 years)** | |
|---|---|---|---|---|
| **Determination of Disability** | **Not disabled** | **Disabled** | **Not disabled** | **Disabled** |
| Cut-off is: | | | | |
| at least one domain is *some difficulty* | 8.2 | 22.8 | 42.3 | 49.4 |
| at least one domain is *a lot of difficulty* | 8.8 | 23.3 | 41.9 | 55.3 |
| at least one domain is *unable to do it* | 9.8 | 37.2 | 42.7 | 71.7 |
| at least one domain is *a lot of difficulty* or *unable to do it* or at least *some difficulty* is scored in two domains | 9.5 | 24.7 | 42.6 | 58.0 |

The data from Zambia used in the table above illustrate that at each level of disability, from the broad measure including those with *some difficulty* to the more severe levels of disability including only those who are *unable* to carry out specific domain activities, people with disabilities are less likely to have attended school and, despite overall high levels of unemployment, are also less likely to be employed than their non-disabled counterparts. Furthermore, among those who are disabled, access to education and employment decreases (rates of non-attendance and unemployment increase) with increasing disability severity.

The collection and analysis of information on environmental barriers to inclusion, to supplement these data, would be beneficial in elucidating the situation for those excluded from participating in these activities and aid in realizing their equal opportunities as mandated by the UN Convention.

## 4. Discussion

Determining disability prevalence on the basis of the presence or absence of some major impairment can be both problematic and restrictive. A more sensitive and socially acceptable approach is suggested that focuses on functional limitations rather than impairment and allows the reporting of several prevalence rates based on thresholds of difficulty in performing different basic actions.

### 4.1 Disability in a cultural context: limitations on capturing prevalence[6]

The word “disability” often carries with it negative connotations and it is not uncommon that people may feel stigma or shame at self-identifying as disabled. For this reason, the question *Do you have a disability?* is considered inadequate at identifying, for example, mental or psychological impairments which tend to be particularly stigmatizing. Upon questioning, individuals may deny their disability or hide the fact that they have a disabled family member. Furthermore, “disability” often implies a very significant condition. Persons who can walk around their homes but are incapable of walking to the

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[6] Mont D. Measuring Disability Prevalence, SP Discussion Paper No. 0706, World Bank, 2007

market may perceive their situation as not severe enough to be considered a disability even though their daily activities are limited.

Disability may also be interpreted relative to an unspoken cultural standard of what is considered as normal functioning. This may vary across cultures or age 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 some basic actions.

Basing disability statistics on questions that ask about *diagnosable* conditions is also problematic. Many people may not know their diagnosis, particularly with respect to mental and psycho-social conditions; and knowledge about one's diagnosis is often correlated with education, socio-economic status, and access to health services, all of which may bias collected data.

Questions that focus on basic actions like those proposed by the WG, serve as a better basis for identifying disability. The question *Do you have difficulty walking or climbing steps?* is able to identify mobility limitations resulting not only from paralysis or amputation, but also serious heart problems or other medical conditions. Similarly, the question *Do you have difficulty communicating?* can identify limitations associated with stuttering, loss of speech due to stroke, autism, or a number of other conditions. For purposes of social participation and the equalization of opportunities, the functional status – and how that impacts someone's life – is of interest and not necessarily the cause (medical or otherwise).

Finally, other environmental determinants of disability, such as 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 that is properly managed can have a relatively minor impact on someone's life. Or in the case of the amputation of a leg, with proper medical treatment and a prosthetic a person may have few limitations in terms of daily life activities. Poor treatment, on the other hand, can lead to complications and a series of painful and severe infections.

### 4.2 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 on 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 2.7 % of the population if 13.4 % require some service?" And, would it not be more appropriate and efficient to provide services to the specific population that requires them. In Zambia, while 14.5 % of the sample population (Table 2) may have some difficulty in performing one or more basic actions, 0.5% was unable to see and 4.7% had some visual impairment. 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 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 have significant debilitating personal consequences could be avoided.