

Research Paper

Approaching the measurement of disability prevalence: The case of Zambia[☆]

Vers la quantification de la prévalence du handicap : études en Zambie

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Abstract

There exists no single definition of disability. The multidimensionality of disability demands that more complex, flexible measures that will capture disability in all its manifestations be developed and adapted. The measurement of disability prevalence must be seen in light of the purpose that these data are collected for example, provision of services, assessment of the level of functioning in the population or equalisation of opportunities and inclusion of people with disabilities in society. Any reported disability prevalence rate is dependent both on the definition or aspect of disability that is being targeted and on the intended purpose for collecting disability statistics.

Results from a national, representative survey of living conditions among people with disabilities in Zambia based, in part, on the work of the Washington Group on Disability Statistics (WG) that operationalises a functional approach to disability are presented and contrasted with historical census data to illustrate how a flexible approach to the measurement of disability is better suited to the multiple purposes of collecting disability statistics and to the diversity of disability in a population.

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Résumé

Il n'existe pas de définition unique du handicap. La nature multidimensionnelle du handicap requiert que des mesures plus complexes et souples, susceptibles d'appréhender le handicap dans toutes ses manifestations, soient développées et adaptées. La mesure de la prévalence du handicap doit être considérée en fonction de l'objectif qui préside à la collecte des données, c'est-à-dire, les services fournis, l'évaluation du niveau de fonctionnement de la population ou l'égalisation des chances et l'inclusion des personnes handicapées dans la société. Quel que soit le taux de prévalence du handicap enregistré, celui-ci dépend à la fois de la définition ou de la dimension du handicap prise pour cible et de l'objectif à l'origine de la collecte de données statistiques.

Les résultats d'une enquête nationale, représentative des conditions de vie des personnes handicapées en Zambie, fondée pour partie sur les travaux du Washington Group sur les statistiques du handicap destinés à opérationnaliser une approche fonctionnelle du handicap, sont présentés et mis en perspective avec les données précédentes de recensement. Ainsi, nous illustrons comment une approche adaptée de la mesure du handicap s'avère plus apte à prendre en compte la multiplicité des objectifs de constitution de données statistiques sur le handicap et la diversité du handicap dans une population.

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Mots clés : Définition du handicap ; Prévalence du handicap ; Approches fonctionnelles du handicap ; Enquête nationales sur le handicap ; Washington Group sur le handicap

Introduction

National disability prevalence rates reported from censuses or surveys from around the world vary dramatically. Many low-income¹ African countries, for example, report prevalence rates under 5%, while high-income countries report rates on average in excess of 10%, some as high as 20% (UN, 2003; Loeb & Eide, 2004; Eide & Loeb, 2006a). This variation is the result of several mitigating factors, among them: the use of different definitions of disability, different methodologies of data collection, and variation in the quality of the survey design.

That there exists no single definition of disability is an important issue; however, to complicate the situation further, the nature and severity of disabilities often vary greatly depending on cultural contexts (Altman, 2001; Loeb & Eide, 2006; Whyte & Ingstad, 1995). The chosen definition of disability will also frequently depend on the purpose for its measurement. Thus, achieving a standardised, international consensus with respect to disability prevalence rates is at the onset a challenging enterprise.

This paper revisits the “disability prevalence debate” and suggests that an approach to defining and measuring disability closely following that of the UN Washington Group (2004) better reflects the current disability paradigm based on functional limitations rather than impairments and is deemed suitable for the international comparison of prevalence rates. Both historical and recent statistical data from Zambia are presented to exemplify how changing concepts of disability are reflected in the disability prevalence rates reported.

¹ Low-income is used to include terms like developing, non-industrialised, etc; while high-income includes developed, industrialised, etc.

Background: defining disability

The medical model has recently been supplanted by the social model of disability, which conceptualizes disability as arising from the interaction of a person's functional status with their physical, cultural, and policy environments (Oliver, 1983; Shakespeare & Watson, 1997; Hughes & Paterson, 1997). 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.

The International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organization (WHO, 2001) "provides a consistent and complete conceptualisation of disability" (Leonardi et al., 2006) and accordingly, the ICF definition of disability focuses on the negative aspects of the interaction (measured as impairments affecting the body; activity limitations affecting an individual's actions or behaviour or participation restrictions affecting a person's experience of life) between an individual (with a health condition) and that individual's contextual (personal and environmental) factors.

While it becomes apparent that universal agreement in terms of disability definitions has yet to be achieved, it remains clear that regardless of the definition chosen, embracing an ICF-based approach to disability will require the development of new tools for its measurement in censuses and surveys. The impairment-based *Do you have a disability?* approach is no longer satisfactory; and the focus of measurement shifts to experienced *difficulties* and *barriers* to participation. The focus shifts from measuring deviations from the normative to assessments of difficulties encountered (both personal and environmental) and what an individual may need to become a fully active and integrated member of society.

Methods

Measuring disability in Zambia

The tools chosen to measure disability to a population mirror the conventional wisdom of the day. Thus, a census from 1980/1990 would reflect the disability paradigm of the time, namely the dependent relationship between an individual's impairment, and his disability and social handicap. This one-dimensional, cause and effect model focuses primarily on impairments and, based on a medical, normative approach, begs some variant of the question *Do you have a disability?* or *Are you disabled in any way?*. Accordingly, this approach was reflected in census questions used in Zambia in the 1990 census (CSO, 1990):

- *are you disabled in any way?* Yes or No, and;
- *what is your disability?*
 - Blind;
 - deaf–dumb;
 - crippled;
 - mentally retarded;
 - multiple disabilities.

Source: CSO (1990), CSO (2000)

Each of these impairment categories elicited dichotomous Yes/No responses and a positive response to any one of these would be indicative of a relatively severe form of impairment.

Further developments in the field of disability measurement are reflected in the *Zambian Census report for 2000*, that classifies disability as referring “. . . to a person who is limited in the kind or amount of activities that he or she can do because of on-going difficulties due to long-term physical, mental or health problems” (CSO, 2000). The *Zambian Central Statistical Office (CSO)*, furthermore, stated that this approach was in line with the *Persons with Disabilities Act of 1996 (Government of Zambia, 1996)* that defines disability as “any restriction or lack of ability to perform any action in the manner or within the range considered ‘normal’ for a human being and would or would not entail the use of supportive and auxiliary aids.” Despite this shift in focus from impairments to difficulties in performing activities or performance restrictions, the questions used to capture disability in the *2000 census* were similar to those of earlier censuses and focused on measuring disability by impairment rather than activity limitations:

- *are you disabled in any way?* Yes or No, and;
- *what is your disability?*
 - Blind (complete loss of sight);
 - partially sighted (loss of one eye or poor sight, but not complete blindness);
 - deaf/dumb (complete loss of sense of hearing/speech);
 - hard of hearing (partial loss of sense of hearing, but not complete loss);
 - mentally ill (a disorder related to the individuals mental state or state of mind);
 - ex-mental (a person that suffered from mental disorder before, but is now rehabilitated or undergoing rehabilitation);
 - mentally retarded (a person that is very slow to learn or has deficiency of mental intellect);
 - physically handicapped (physically disabled) – a person with a physical impairment relating to the loss of bodily stature.

Source: CSO (2000)

The concession made in the 2000 census was to expand upon the original categories (and coverage) of disability from the 1990 census and include the more moderate forms of visual and hearing impairments and persons who were previously classified as having a mental disorder or undergoing rehabilitation.

According to published results from the 1990 *Zambian census*, the disability prevalence rate in the country was 0.9% (CSO, 2000), while the derived prevalence rate based on the 2000 census was 2.7% (CSO, 2000). It has been postulated that the relatively low-prevalence rates reported in many low-income countries, as in *Zambia* in 1990 or 2000, may in fact correspond to true rates of *severe* disability in these countries (Mont, 2007).

The *Washington Group on Disability Statistics (WG)*² proposed a set of six core screening questions based on difficulties in six life domains. The purpose of the WG was to develop a general census measure of disability for international use that would serve at least three purposes:

- to identify the population of persons who may require specialized services or assistance;

² The UN Statistical Commission set up the WG on Disability Statistics, in part, to develop census questions to accurately measure disability prevalence in way that would improve international comparability. To-date over 50 countries have been involved to some extent.

- to monitor the level of functioning in a population and; to assess the inclusion and equalization of opportunities for people with disabilities.

The six WG questions (UN Washington Group, 2004) were adapted and operationalised in the 2006 Zambian survey of living conditions among people with disabilities as:

- because of a health problem (physical, mental or emotional 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?
 - do you have difficulty communicating; for example, understanding or being understood by others?
- four discrete response categories were offered as possible responses to each question:
 - no difficulty;
 - some difficulty;
 - a lot of difficulty or;
 - unable to do it.

Examination of the questions and response categories reveals that there are several approaches to the measurement of disability. The six domains cover the spectrum of impairment types: visual, aural, mobility, cognition, self-care and intellectual/developmental; it is further understood that through these domains (either alone or in combination), emotional and other impairments are also captured. Furthermore, the response categories allow for some measure of the degree or severity of the difficulty experienced. It becomes apparent that there is more than one way to capture disability through the application of this set of core questions; thereby, resulting in not one but several prevalence estimates.

Thus, in a theoretical model that draws upon a social, ICF-based model of disability, disability is not a dichotomous, “all or nothing” yes/no concept, but by allowing for a more flexible, holistic approach to disability measurement, people are classified according to a more detailed description of their functional ability within various domains that allows one to capture the complexity of the disability process or experience – and provides for the ability to present a range of “scores” that represent levels of functioning.

Survey of living conditions among people with disabilities in Zambia

Beginning in 2005, the Zambia Federation of the Disabled (ZAFOD) in collaboration with local partners: the Institute of Economic and Social Research (INESOR) at the University of Zambia, and the Zambian Central Statistical Office (CSO); and international partners: SINTEF Health Research and the Norwegian Federation of Organizations of Disabled People (FFO), undertook a national representative survey of living conditions among people with disabilities in the country.

With the assistance of the Zambian CSO, a national representative sample was chosen for this survey. The sampling frame used for the survey was developed from the 2000 census of population and housing. For the purposes of this survey, standard enumeration areas (SEAs) constituted the ultimate primary sampling units. All the selected SEAs and their corresponding households were further stratified according to either rural or urban location.

The survey was designed to cover 350 SEAs across the nine provinces and provide a cross-sectional sample of approximately 7000 noninstitutionalized, private households residing in the rural and urban areas of Zambia.

The survey employed a two-stage stratified cluster sample design whereby, during the first stage, 350 SEAs were selected with probability proportional to estimated size (PPES) from all nine provinces. All households in the selected SEAs were listed or screened for the presence of a family member with a disability. During the second stage, 10 households were systematically selected from among those households identified as having a disabled family member and a further 10 households were selected as being the nearest neighbor without a disabled family member. These were referred to as case and control households, respectively.

A total of 5751 households were included in the final sample, representing 28,010 individuals or approximately 0.24% of the Zambian population (ca. 11.5 million). Three thousands and ninety individuals (11%) of the sample population were identified as having a disability. (For further details of sampling and survey procedures, see: [Eide & Loeb, 2006b](#)).

Immediately following the disability screening procedure, households were selected for further interview (stage 2) and identified heads of households were interviewed regarding the living conditions of the households, including housing standards, composition of the households as well as the education and literacy, economic activity and disability status of individual family members. Subsequently, those individuals identified as having a disability (or a proxy) were interviewed (stage 3) using a separate detailed questionnaire to elicit further details of their experiences as a person with a disability, including details of their activity limitations and participation restrictions, experienced environmental barriers, their awareness, need and receipt of services, their experiences with assistive devices and technology, their accessibility in the home and surroundings, inclusion in family and social life and their health and general well-being.

Based on initial listing of all households in the selected enumeration areas, estimates of prevalence rates based on different severity cut-off points (to describe level of difficulty) in relation to the six domains described above could be calculated. In addition, the three-pronged survey methodology employed (screening, living-condition survey, detailed-disability survey) made it possible to address questions concerning the validity of the screening method. The disability status of all family members in selected households (case and control) listed during the disability screening procedure was assessed. Those who were screened as negative but were found to have at least some difficulty doing at least two of the six domains on the living conditions survey were classified as false negatives, and those identified as having a disability (among households with a disabled family member) were reassessed on the detailed disability portion of the survey to uncover false positives.

The entire survey was implemented by nine teams, each team composed of a supervisor, four enumerators and a driver. In addition, the survey was facilitated by a field coordinator assisted by five investigators from INESOR and CSO.

Results

The Zambian living-conditions survey of 2006 permitted several possible cut-off points for measuring disability. It was decided, in accordance with the theoretical approach as proposed by the WG, to take a more functional approach to the measurement of disability and two prevalence rates were calculated based on the results of the household listing in selected enumeration areas and the screening for disability. 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 17.8% is

Table 1
Functioning matrix: sample prevalence (in %) by domain and degree of difficulty (N = 28,010; 179 missing)

Core domains	Degree of difficulty ^a		
	D1	D2	D3
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
Communicating	2.1	1.4	0.5

^a D1, at least some difficulty; D2, at least a lot of difficulty; D3, unable to do it at all.

achieved and if a slightly more conservative cut-off was selected at the level of “at least some difficulty” on at least two of the six domains, the resultant national prevalence rate was 13.4%. 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 screening instrument in allowing for a choice of definition based on the purpose of data collection.

For each of the core domains it was possible to calculate the proportion of those with disabilities based on the three cut-off values as determined according to degree of difficulty (Table 1).

At each degree of difficulty (D), problems encountered with mobility have the highest prevalence, followed by visual and hearing difficulties; problems relating to remembering, self-care and communicating have lower prevalence. Not unexpectedly for each core domain, the prevalence decreases with increasing degree of difficulty. The data presented in the table above are not mutually exclusive, and many individuals will certainly have a disability that encompasses more than one domain. Based on these data, by combining information on core domains and degree of difficulty, it is possible to postulate several different measures, or levels, for disability prevalence (P) that reflect the multidimensionality of the disability experience. Four measures have been proposed by the WG:

- P1 = 1, if at least one domain has D1 = at least some difficulty;
- P2 = 1, if at least one domain has D2 = at least a lot of difficulty;
- P3 = 1, if at least one domain has D3 = unable to do it at all;
- PM = 1, if more than one domain has D1 = at least some difficulty (M stands for multiple domains).

In the presentation of the *Zambian data*, a fifth prevalence estimate level has been added; P1a = 1 if at least two domains have D1 = at least some difficulty

These data are presented in the Table 2.

The prevalence rate for those with the most severe levels of disability (the individual is unable to do at least one of the six domains) was found to be 2.4%. This is in agreement with the national prevalence rate from the 2000 census of 2.7% – that rate based on a slightly broader impairment-based definition also included the more severe forms of disability.

Validity of the screening instrument

Among the 5751 households selected for inclusion in the *Zambian survey* (Eide & Loeb, 2006b), 2885 (50.2%) were identified by household listing as households with one or more

Table 2
Survey sample prevalence measures ($N = 28,010$)

Disability prevalence	<i>N</i>	%
P1: at least 1 domain is scored some difficulty	4053	14.5
P1a: at least 2 domains are scored some difficulty	3090	11.0
P2: at least 1 domain is scored a lot of difficulty	2368	8.5
P3: at least 1 domain is scored unable to do it at all	673	2.4
PM: more than 1 domain is scored some difficulty	1718	6.1

disabled family members. Likewise, 2866 (49.8%) of the households were preidentified and selected as households without a disabled family member (control households).

On conducting the living conditions portion of the survey, 192 of the 12,979 individuals in the control households were found to have a disability (at least some difficulty doing at least two of the six domains). These can be classified as false negatives, and the specificity of the screening instrument can be calculated as 98.5%.

Similarly, the living conditions survey among households with a disabled family member identified 2898 disabled individuals. Upon carrying out the detailed disability portion of the survey (intended for those identified as having a disability), 65 of the 2865 respondents to this questionnaire were discovered not to have a disability. These can be classified as false positives, and the sensitivity of the screening instrument can be calculated as 97.7%.

Discussion³

Determining disability prevalence on the basis of a single disability prevalence from rate, that is, in turn to rate that is in turn based on the presence or absence of impairment can be both problematic and restrictive. A more sensitive and socially acceptable approach is suggested that focuses on functional ability rather than impairment and allows the reporting of several prevalence rates based on thresholds of difficulty in performing different activities of daily living.

Disability in a cultural context: limitations on capturing prevalence

The word “disability” often carries with it negative connotations. In fact, among the Shona-speaking Zimbabweans, the word disability translates as nonhuman; and in some cultures disability is seen as punishment for transgressions committed in previous lives. It is, therefore, not uncommon that people may feel stigma or shame at identifying themselves as disabled. According to one author, people can perceive that “at a profoundly serious and spiritual level, disability represents divine justice” (Bacquer & Sharma, 1997). For this reason, the question *Do you have a disability?* is particularly 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. Even if stigma is not associated with an individual’s situation, “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 The discussion draws upon Mont, D. “Measuring disability prevalence” SP Discussion Paper, No. 0706, 2007.

Disability is also often interpreted relative to an unspoken cultural standard of what is considered as normal functioning. This may vary across various 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 activities.

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

These environmental determinants of disability can vary widely; for example, untreated diabetes can lead to profound functional limitations, such as blindness or the loss of limbs while properly managed diabetes can have a relatively minor impact on someone's life. The same thing is true for the loss of a limb. 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 a series of painful and dangerous infections.

Questions that focus on basic activities or major body functions, like those proposed by the WG, serve as a better basis for disability screening. The question *Do you have difficulty walking?* 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 stuttering, loss of speech due to stroke, autism, or a number of other conditions. For most purposes, the functional status – and how that impacts someone's life – is of interest and not necessarily the cause (medical or otherwise). Though, for a study designed to uncover the best approaches to preventing disabilities, the cause and age of onset would be important data to collect.

Disability measurement: to what purpose?

The purpose of measurement plays a role in the determination of the definition of disability to be used and thus, the questions asked.⁴ 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.

Monitoring the level of functioning in a population

This purpose for collecting data on disability is important for both understanding the scope of potential concerns relating to disability and evaluating interventions designed to prevent or minimize disability. The more people living with particular functional limitations, the more important the issue will be and the higher priority it should receive. Collecting such data also allows for the measurement of, for example, how many children are benefiting from a nutritional program aimed at preventing stunting, or a mental health intervention designed to limit depression, or the

⁴ Much of this discussion follows from a white paper presented at the Third Meeting in Brussels of the UN Washington Group on Disability Statistics, 2004.

removal of landmines. Measuring the impact of preventive programs requires a description of the functional capacity of individuals.

Provision of services

Another important purpose for collecting data on disability is to design and implement programs aimed at providing services to disabled people. These might be general services that are being made more inclusive, or they may be specific services targeted at people with disabilities in general or even targeted at a particular subset of people with disabilities (e.g., providing prosthetic devices and 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, are inappropriate. The design of 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 characteristics that are specific to the environment in which they live (both barriers and facilitators to participation).

Equalization of opportunities

Another reason for collecting disability data is to assess the impact of having a disability on individuals and their families. The goal of inclusive development is to enable all people to have equal opportunities within the economic and social lives of their communities as stated in the *Convention on the rights of persons with disabilities* (UN, 2006). By focusing on body function and/or basic activity questions (as proposed by the WG), disability thus defined could be correlated with outcomes, such as employment or education. If no significant correlation was observed, then disability would be independent of employment or education and the equality of opportunities would be assumed. An observed significant correlation on the other hand would be indicative of an inequality. In essence, this would be a way of measuring the inclusiveness of the society. If people with various functional limitations are identified as not having equivalent outcomes, more detailed surveys could uncover the most damaging environmental barriers that need to be addressed.

The role of environmental factors

Cultural and social parameters have already been mentioned as important determinants to the definition and understanding of the complexity of disability. These are but two of several environment factors that impact on disability. In addition, however, implicit in an assessment of an individual's functional status is the coincident assessment of their environment (both barriers and facilitators) and their ability to negotiate in that environment. This article touches on certain of these aspects and additional analyses of the data from the *Zambian survey* will elicit further associations and dependencies between disability and environment – and these will be the subject of subsequent articles.

Implications for Zambian disability policy

Policy implications related to the flexibility in the approach to disability may be profound. If service provision is based on the disability prevalence, then clearly this would impact on policy, and particularly in a low-income country like Zambia, 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 activities of daily living, 0.5% was unable to see and 4.7% had some visual impairment. Targeting specific subpopulations 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 glasses⁵, policy could be directed to target this specific subpopulation 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.

Conclusions

For the multiple purposes of promoting inclusive economic and social development, measuring the level of functioning in a population or providing services to people with disabilities, it is more appropriate to measure disability through a multidimensional set of parameters than an “all or nothing” static state.

Data from Zambia have illustrated that different instruments used to measure disability based on different approaches to the disability phenomenon yield quite different estimates of disability prevalence. A screening instrument based on the work of the Washington Group on Disability Statistics was found to be both robust and amenable in describing the complexity of disability in Zambia.

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