Challenges to Measure and Compare Disability: A Methodological Concern

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Abstract

Disability is a complex multidimensional condition and poses a number of challenges for measurement. Operational measures of disability vary according to the purpose and application of the data and the aspects of disability examined. Various sources can be used to examine the prevalence of disability, but they are not directly comparable because they use different approaches to estimating and measuring disability. The definitional issues underlie some of the difficulties in statistical analysis, and to understand the conceptual questions shaping the efforts of those working in the various fields relating to disability. Disability data of Nepal is no exception, and researchers and organizations that have been working for people with disabilities have questioned the reliability of such data.

Keywords**:** Measuring disability, census data, survey data

1. Introduction

In the context of health, disability is an umbrella term which denotes impairments, activity limitations and participation restrictions. Disability is a major public health issue, denoting the negative aspects of the relationship between an individual's health condition and her/his environmental and personal factors.[1] Disability can be measured in different ways, affecting both the number of incidences and distribution on various variables.

This article focuses on the causes of data variation in disability rates in censuses and surveys. It also looks at thematic issues in disability data in Nepal obtained in censuses and objective based surveys. It is important to note that definitional issues underlie some of the difficulties in statistical analysis, and also to understand the conceptual questions shaping the efforts of those working in the various fields relating to disability. Disability is a relative term, relying on interpretation of 'normal activity' and summarizes a great number of different functional limitations occurring in any population. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature.

In 1976, World Health Organization (WHO) operationalized three different terms – impairment, disability and handicap. Impairment is any loss or abnormality of psychological, physiological or anatomical structure. Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range of what is considered to be normal for a human being. Handicap is a disadvantage for a given individual, resulting from impairment or a disability, which prevents the fulfillment of a role that is considered normal (depending on age, sex, social and cultural factors) for that individual. In 1980, the WHO reaffirmed this classification (WHO, 1980), and in 2001 issued the International Classification of Functioning, Disability and Health (ICF). The ICF distinguishes between body function and body structures (WHO, 2002)[2].

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[1] A common way of understanding is that having a disability makes an individual less competent to perform the variety of activities. However, many disabled people are capable to perform various activities ranging from simple to highly skilled. Now it is more customary to refer to such people as 'differently able' rather than disabled.

[2] Impairment in body structure or function is defined as involving an anomaly, defect, loss or other significant deviations from certain generally accepted population standards, which may fluctuate over time. Body function relates to the physiological or psychological (e.g. vision)

The activists, who are working for the disabled, argue that impairment refers to physical or cognitive limitations that an individual may have, such as the inability to walk or speak. In contrast, disability also may refer to socially imposed restrictions, that is, the system of social constraints that are imposed on those with impairments by the discriminatory practices of society[3].

In many cases, the language used in certain contexts becomes critical in shaping and reflecting thoughts, beliefs, feelings, and concepts. Some words by their very nature degrade and diminish people with a disability. The term ‘disabled young person’ tends to convey a message that the only thing worth mentioning about a person is her/his disability. It is better to say ‘young person with a disability’ as this emphasizes the person first without denying the reality of the disability. Sometimes people with a disability are compared to *normal people*. This implies that the person with a disability is abnormal and ignores the fact that everyone has her/his own unique identity and abilities.

Disability data collected do not reflect the full extent of disability prevalence. The limitation is due partly to the conceptual framework adopted, the scope and coverage of the survey undertaken, as well as the definition, classification, and the methodology used for disability data collection.

2. Defining disability and conceptual models

Disability has often been defined as a physical, mental, or psychological condition that limits a person’s activities. It has different meanings to different people, and in different contexts. The Global Burden of Disease (GBD) uses the term disability to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing, and vision (WHO, 2004).

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, resulting in an individual’s inability to function (Mont, 2007a). Interventions usually included medical rehabilitation and the provision of social assistance. The medical model of disability views the body as a machine to be fixed in order to come to a normal state. The line of analysis which derives from viewing disability as a medical model condition creates a deficit in an individual, rather than changing his or her functional status – a status that affects a person’s life depending on the environment they live in (Mont, 2007b). In the medical model of disability, there are some linked concepts (Hutchison, 1995):

Disease or disorder → Impairment → Disability → Handicap

Once a person starts to suffer from a disease or disorder, she/he loses the normality of a psychological, physiological or anatomical function. Due to her/his disability, a person’s ability to perform expected human activity is restricted or totally absent. She/he is categorized as a disadvantaged person (handicapped) that limits or prevents fulfillment of expected social roles due to impairment or disability. The concept *normalization* becomes popular as part of the medical model, and establishing curative services is regarded as the main way to make a person as normal as possible.

The medical model has been criticized by sociologists, anthropologists, human rights activists, and also by disabled people. Disabled people want acceptance in society and therefore reject being defined as abnormal. The social model conceptualizes disability as arising from the interaction of a person’s functional status with the physical, cultural, and policy environments. If the environment is designed for the full range of human functioning, incorporating appropriate accommodations and supports, people with functional limitations would not be ‘disabled’ in the sense that they would be able to fully participate in society.

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and body structure related to anatomical parts, e.g. the eye and related structure (WHO, 2002).

[3] Personal communication with activists and disabled persons in Kathmandu, December 2012.

The social model highlights disability as the outcome of the interaction between a person and her/his environment and, therefore, being neither person nor environment specific. The ICF, developed by the WHO (2002), is the starting point for recent developments in measuring functional capacity, and disability is increasingly seen as a multidimensional condition encompassing a wide range of physical and cognitive problems that are difficult to categorize and measure. The ICF listed 9 broad domains of functioning: learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interaction and relationships, major life areas, and community, social and civic life (WHO, 2002). The ICF was officially endorsed by all 91 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001.

The social model does not negate the worth of medical and rehabilitation services for persons with disabilities. It does, however, caution against the over-medicalization of their problems and issues. In the social model, persons with disabilities are rights holders, and are entitled to advocate for the removal of institutional, physical, informational, and attitudinal barriers in society (UN-ESCAP, 2010). The advocates of the social model argue that the interventions should be taken not only at the individual level (e.g., medical rehabilitation), but also at the societal level, for example by introducing designs to make infrastructure more accessible, provide inclusive education systems, and create community awareness programs to combat stigma. This is the heart of disabled people's current fight for civil and political rights. As the Convention on the Rights of Persons with Disabilities took effect on 3 May 2008, the social model of disability is gaining importance in awareness raising, policy actions, and the empowerment of persons with disabilities around the world.

3. The issue of comparable data

The problems related to defining disability make it difficult to collect data about this condition. Disability also depends on a person’s perception of her/his ability to perform activities associated with daily living. The United Nations (UN, 2001) noted that disability rates from diverse national data collection sources are not yet comparable across the world because of differences in definitions, concepts, and methods. Differing definitions made it difficult to document the extent of the disability problem. A major point in this article is that the two major designs for collecting data, census and survey, register disability differently, resulting in different numbers of people with disabilities.

In 1981, the first estimates by the WHO were that 10 percent of any population was disabled (WHO, 2011). Later, these figures were modified to 6 or 7 percent, giving a global figure of 245 million disabled people (Whyte and Ingstad, 1995). Estimates depend on what counts as disability, on how severe an impairment must be before it is considered disabling, and how categories are implemented in actually gathering data.

The proportion of disabled people per national population varies between less than 1% in Peru and 21% in Austria, given differences in data collection designs, definitions, concepts, and methods (Elwan, 1999). Regional comparisons can be very misleading if the methodological differences are not taken into account. The use of different measurement instruments, the older age structure, as well as the larger capacity to observe and diagnose various kinds of disabilities in developed countries, are likely factors in the higher rates of disability generally recorded in developed countries. In addition to the type of measurement instrument used, estimates of the proportion of disabled people in a population can also vary depending on whether disabled people are identified by using a ‘disability screen’ or an ‘impairment screen.’ African and Asian countries tend to use impairment screens in their censuses, surveys, and registration systems, and generally report lower rates than countries in Europe and North America, which tend (with some exceptions) to use disability screens. These sources can be used to examine the prevalence of disability, but they are not directly comparable because they use different approaches to estimating and measuring disability.

4. Prevalence of disability

There are relatively few censuses, surveys, and registration sources of information on disability in developing countries, and conceptual and definitional problems abound. However, several attempts have been made to find out roughly how many people in the world are disabled, what the main causes of disability are, and how the disabilities encountered in different countries and regions affect quality of life.

As mentioned before, in the early 1980s, WHO estimated that an average of 10% of all national population were disabled. However in 1992, this estimate was modified to 4% for developing countries and 7% for industrialized countries. There is no consensus as to which figures to use. Reported disability prevalence rates from around the world vary dramatically, for example, from under 1% in Kenya and Bangladesh to 20% in New Zealand (Mont, 2007a). *Does it mean that the number of disabled people in Bangladesh is twenty times higher than among people living in Kenya? Are these figures comparable?* This is a serious issue to be considered by the researchers, policy makers and planners, and international organizations that work for people living with disabilities. This variation is caused by several factors: deciding a definition of disability, different methodologies of data collection, and variation in the quality of the 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. A higher estimated figure is sometimes used when learning disabilities are included.

The quality of information collected depends in large part on the validity and reliability of the questions. Designing a questionnaire is both an art and a science, and in the early stage of developing a questionnaire a number of issues must be considered, preferably in consultation with persons with disabilities. Using these individuals and their families to test and refine questions is an excellent pre-test approach (United Nations, 2001). Thus, understanding the number of people with disabilities and their circumstances can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate. Collecting appropriate statistical and research data at national and international levels has been a challenging issue in order to implement internationally agreed development goals for disabled people.

5. Measuring disability with the census method

The census is a country’s most important data collection activity. The primary objective of a census is to count the population present or residing in the country and the absentee population living abroad. Generally, a national population census covers a range of information: age, sex, education, language, ethnicity, religion, occupation, income and assets, fertility, mortality, migration, and disability. A census format offers only limited space and time for questions on any one topic, including disability and human functioning. For countries that do not have regular special population based disability surveys or disability modules in ongoing surveys, the census can be the only source of information on the frequency and distribution of disability and functioning in the population at the national, regional and local levels.

Reported disability prevalence rates vary widely. In many developed countries, the rates are quite high. The prevalence rates in the United States and Canada are 19.4% and 18.5%, respectively

(Mont, 2007a). Conversely, developing countries often report very low rates. In countries such as Kenya and Bangladesh the reported rates of disability are under 1%. These rates vary for a number of reasons: different notions of disability, different measurement methodologies, and variation in the quality of measurement.

Table 1: Prevalence of disability in different countries, using the census method

Country	Year	Percentage of the population with a disability
United States	2000	19.4
Canada	2001	18.5
Brazil	2000	14.5
United Kingdom	1991	12.2
Poland	1988	10.0
Ethiopia	1984	3.8
Uganda	2001	3.5
Mali	1987	2.7
Mexico	2000	2.3
Chile	1992	2.2
India	2001	2.1
Colombia	1993	1.8
Bangladesh	1982	0.8
Kenya	1987	0.7

Source: Mont (2007a).

Different countries use different approaches to measure disability in their national census. Some countries include a specific question in the census questionnaire, for instance: *Do you or any member of the household have a disability?* This method generates the lowest

rates of disability. The positive response rate to this question is typically in the one to three percent range. By using this method, the disability rate of Nigeria, Jordan, Philippines, Turkey, and Mauritania was found to be 0.5%, 1.2%, 1.3%, 1.4% and 1.5%, respectively (Mont, 2007a; WHO, 2011).

People in many societies may feel socio-economic pressure to underreport disability. Respondents may be unenthusiastic to admit the presence of a person with disabilities in the household. One of the important issues to be taken into consideration is to design the census in such a way that the respondent will not perceive that they are asked about the stereotypes, often stigma, of disabilities. There are some limitations to use a census to collect data on disability. Disability is a condition that needs to be measured to consider several issues like intensity, duration and framework. It is not a phenomenon that can be easily described with a binary classification – YES or NO. Questions that can cover various contexts, clarify terminology, and define multiple domains are required.

Some countries report higher rates of disability because they consider any condition[4] 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. By using this method, the disability rate of Poland, United Kingdom, Brazil, Canada, and the United States was found to be 10.0%, 12.2%, 14.5%, 18.5% and 19.4%, respectively (Mont, 2007a: 8).

The census data of the developing countries focus on the severe level of physical, mental or emotional conditions of an individual. Such countries generally incorporate specific questions in their

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[4] This method asks if the person has some condition which a particular social role, such as attending school or being employed. For example, do you/ does anyone in this household have a health problem or disability which prevents you/them from working or which limits the kind and amount of work (you/they) can do.

population census. The most incorporated conditions creating difficulty in their daily lives are:

- Does any member of your household have a physical, mental, or emotional condition that have difficulty doing everyday jobs alone such as visiting a doctor’s office or shopping?
- Does any member of your household have a physical, mental, or emotional condition that have serious difficulty concentrating, remembering, or making decisions?
- Does anyone have difficulty dressing or bathing?
- Does anyone have serious difficulty walking or climbing stairs?
- Is anyone blind or does anyone has serious difficulty seeing even when wearing glasses?
- Is anyone deaf or does anyone have serious difficulty hearing?

Countries that have a registration system providing regular data on persons with the most severe types of impairments may use the census to complement these data with information related to selected aspects of the broader concept of disability and functioning based on the ICF. Census data can be utilized for general planning programs and services (prevention and rehabilitation), monitoring selected aspects of disability trends, and evaluation of national programs and services concerning the equalization of opportunities in the country. However, for international comparison of selected aspects of disability prevalence in countries one should be serious on its operational definition.

The questions usually asked in general censuses are about life expectancy at birth, fertility, mortality, migration, education, urbanization, and also about ethnicity, language, age, and disability. These questions are kind of door-to-door screening questions that are included in a national census. Generally, a

member of the household, for instance, a senior person, is asked directly if someone in the household is disabled[5].

Compared to the more detailed and more numerous questions posed in surveys, the general census shows lower figures of prevalence of disability. For example, a common question in a census is: *Is anyone in the household disabled?* This question generates lowest disability rates both in developed and developing countries. Another way of asking is: *Do any member of this household have any difficulty in moving, seeing, hearing, speaking or having learning problems?* Though the theme is the same, the way the question has been asked can provide higher rates of disability compared to the more simple way of asking the question.

The former way of formulating and asking questions to the household head or to the senior person in the household generates the lowest rates of disability, typically in the one to three percent range. Surveys among the same population using an approach that emphasizes functional ability yield estimates in the 10 to 20 percent range.

The reasons for not claiming oneself as a ‘disabled person’ are many. People may feel stigma or shame at identifying themselves as disabled. The question *Do you or any member of your family have a disability?* is inadequate to pick up mental and psychological disabilities, which tend to be particularly stigmatizing and are sometimes more easily hidden. Likewise, people who can walk slowly within their home and in the kitchen garden, but incapable of walking more than one hour, may perceive their situation as not severe enough to consider oneself disabled. A person with a condition that affects a particular social role, such as attending school or being employed can be identified by asking, for

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[5] In the 2011 Nepal Population Census, the instruction to each information collectors was that the questions should be asked to the Household head or to a Household member who was able to answer. Answers should be marked by circling the number corresponding to the appropriate answer.

example, *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?* If one calculates the prevalence rate of disability based on the response of this question, it certainly would be high.

It is also important to note that the concept of normal functioning varies across various cultures, age or even income groups. For example, elderly people with significant limitations and significant difficulties performing basic activities may not identify themselves as having a disability because, in their minds, the activity limitations are related to their age.

6. Measuring disability with the survey method

In general, surveys tend to report higher disability rates than censuses because they offer several dimensions in more extensive surveys. Short sets of disability questions that can be included in censuses and extended sets suitable for population-based surveys are being developed and tested. In some surveys, the respondent is read a list of conditions, such as polio, epilepsy, paralysis and others, and is asked if they have any of them. Mont (2007a) proposes several limitations to this approach. First, many people may not know their diagnosis, particularly when it comes to mental and psychological 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.

The disability status among the elderly is best assessed through questions of Activity of Daily Living (ADL), such as bathing, eating, moving, dressing, and toileting (UN, 2001). The term ADL refers to a set of common, daily activities, the performance of which is required for personal self-care and independent living. ADLs are, therefore, a measure of ability to perform and ultimately of the quality of life associated with functional status.

A person is classified as disabled if she/he has difficulty performing any ADLs, which are task based and centered on basic activities such as dressing, bathing, and feeding oneself. 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?*, may pick up mobility limitations resulting not only from paralysis and amputation, but also serious heart problems or other medical conditions. A question such as *Do you have difficulty holding a conversation with others?*, may 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 that is attention grabbing – 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. For example, there are two visually impaired persons, both 25 years old. One has been blind since birth and the other was recently blinded in an accident. Although both have the same medical condition or impairment – that is, blindness – they fall on very different parts of the functional continuum. The person who has never been able to see has spent her whole life accommodating herself to the world. This person will score lower on a functional scale than the recently blinded one. And as time goes on, the person who has only a short experience of living with blindness will surely cope with the new situation by learning new skills that meet new conditions and hopefully begin to modify the environment to better suit relevant needs.

Instrumental Activities of Daily Living (IADL) is another approach similar to the ADLs, but with more demanding tasks. Examples include whether a person has problems managing money, shopping for groceries, or maintaining her/his household. The questions to be asked are: *Do you have any difficulty in moving, seeing, hearing, speaking, or learning, that has lasted or is expected to last six months or more?* This approach is also complicated if the desire is to have a measure that is internationally comparable. For example, 'bathing oneself' or 'dressing oneself' can have very different connotations in rural and urban situations, for rich and poor. Dressing in pants and a loose fitting shirt is different than dressing in something as complicated as a *sari*.

Table 2: Prevalence of disability in different countries, using the survey method

Country	Year	Percent of the population with a disability
New Zealand	1996	20.0
Australia	2000	20.0
Uruguay	1992	16.0
Spain	1986	15.0
Austria	1986	14.4
Zambia	2006	13.1
Sweden	1988	12.1
Ecuador	2005	12.1
Netherlands	1986	11.6
Nicaragua	2003	10.3
Germany	1992	8.4
China	1987	5.0
Italy	1994	5.0
Egypt	1996	4.4

Source: Mont (2007a)

Thus, the prevalence of disability in surveys in different countries varies across countries based on disability framework of the state, legal, economic and biomedical institutions as well as the concept

of personhood, identity, and value. Notions of citizenship, compensation and value lost through impairment and added through rehabilitation, are institutionally reinforced constituents of disability as a cultural construct. In developing countries where such institutional infrastructure exits only to a limited degree, reported disability is low (Ingstad and Whyte, 1995). On the other hand, in many developed countries, people may also exaggerate disability at work in order to justify receiving disability benefits.

WHO (2008) has developed a 12-Question Set of Disability Assessment Schedule (WHODAS 2.0) with questions about difficulties with health related conditions. Health conditions include diseases or illnesses, other health problems that may be short or long lasting, injuries, mental or emotional problems, and problems with alcohol or drugs. Respondents are asked to think back over the last 30 days trying to remember how much difficulty she/he had doing the activities mentioned in table 3 below. For each question, only one response is allowed.

Table 3: The WHO set of disability assessment

Level of difficulty	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 kilometer (or equivalent)?						
Washing your whole body?						
Getting dressed?						
Dealing with people you do not know?						

WHODAS 2.0 was developed through an international collaboration, with the aim of developing a single generic instrument for assessing health status and disability across different cultures and settings.

7. The disability situation in Nepal

There have been varying estimates of disabled persons in the past studies in Nepal. Censuses and surveys have taken varying approaches to measure disability. They have covered only a few disability relevant questions, and provided limited information about participation and activity difficulties. Surveys provide richer information through more comprehensive questions. Some surveys also provide information on the origin of impairments, the degree of assistance provided, service accessibility, and unmet needs.

The 1971 Census referred to the population of persons in Nepal with disabilities as the ‘economically inactive’ population due to ‘physical disability’. This definition included four types of disability: blindness, deafness, deaf-mute, or other physical impairments. The study indicated a national disability rate of 1.5% of the total population over 10 years of age (JICA, 2002). The National Population Census of 1981, 1991 and 2001 stated rates of disability at 0.5%, 1.5% and 0.46%, respectively[6].

Table 4: Types of disability in the 2001 Population Census

Disability Type	Number of people with disability	Percentage of the total population
Physical	40,798	0.18
Blindness /Low Vision	16,526	0.07
Deaf /Hard to Hearing	25,540	0.11
Mentally Retarded	13,171	0.06
Multiple Disable	7,760	0.03
Total	103,795	0.46

Source: CBS (2003)

The 2011 Nepal Population Census formulated a specific question related to disability: *What is the physical and mental disability of (Name)?* The options were: 1. Not disable. 2. Physically disable. 3. Blind and low vision. 4. Deaf and hard-of-hearing. 5. Deaf-blind. 6. Speech problem. 7. Mental illness. 8. Intellectually disable. 9. Multiple disable. The response given by the head of the household or by another person in the household was circled by the enumerator. The 2011 Population Census reported 1.94% disability prevalence rate of the total population.

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[6] These various censuses, however, did not give the detailed data of disabled people. The Population Monographs of 1987 and 1995 were prepared based on the censuses of 1981 and 1991 respectively, but the attention was not given to present disability data publicly.

Is there data consistency among the various censuses? The answer is YES. In each census, the disable population is less than 2% in Nepal. However, it is also argued that the data through the census focused exclusively on a narrow choice of impairments.

Table 5: Types of disability in the 2011 Population Census

Disability Type	Number of people with disability	Percentage of the total population
Physical	186,457	0.70
Blindness /Low Vision	94,765	0.36
Deaf /Hard to Hearing	79,307	0.30
Deaf-Blind	9,436	0.04
Speech Problem	58,855	0.22
Mental Disable	30,997	0.12
Intellectual Disable	14,888	0.06
Multiple Disable	38,616	0.15
Total	513,321	1.94

Source: CBS (2012)

High disability prevalence tends to have been based on disability data collected through surveys that record activity limitations and participation restriction in addition to impairments. The underlying purpose of the survey – whether a disability specific program intervention or a general survey, also affects how people respond.

The disability sample survey of 1980 reported a prevalence of about 3% disability among the total population. This study defined 'persons with disabilities as those who by virtue of congenital disease, acquired disease, or injury, are incapable of living an independent personal or social life, or engaging in gainful employment, or acquiring normal education consistent with his/her age or sex' (JICA, 2002).

A study carried out in five districts in 1991 stated that 16.6 % of children aged over five were deaf. The Mother and Infant Research Activities (MIRA) conducted a study focusing on the 'Prevalence of Childhood and Adolescents Disabilities in the Makawanpur district' (Sauvey et al., 2005). The data were collected from September 1999 to June 2000. The study aimed to determine the number of children and young people reported by family members to have a disability, and to classify impairments leading to disability. All households in 24 VDCs in the Makawanpur district were covered in the study. Each head of the household (or, if not present, the next more senior person) was invited to respond to a questionnaire including two questions about disability: (a) *Is there anyone in your household under the age of 20 who has a disability?* (b) If yes, *What is the nature of the disability?* People under the age of 20 with a disability lived in 733 of 28,376 households, a household prevalence of 2.58%. A total of 829 people under the age of 20 were reported as having a disability, a population prevalence of 0.95% (Sauvey et al., 2005).

A Danish International Development Agency (DANIDA) funded study estimated the disability prevalence rate as 5.04% (DANIDA, 1995). Another study also funded by DANIDA covered 8 districts. This study classified disabilities into five categories (hearing, visual, physical, mental, and intellectual) and indicated a prevalence of 4.55% (CERID/SED/BPEP/DANIDA, 1995). In 2005, the BP Koirala Institute of Health Sciences (BPKIHS) conducted a disability survey in the Sunsari district. Among a total of 640,259 individuals, 31,160 individuals (4.87%) had a disability, with a household prevalence of 6.89% (Karkee et al., 2008).

A national level survey on 'Situation of Analysis of Disability in Nepal' was carried out under the aegis of the National Planning Commission and the Social Welfare Council funded by UNICEF in

1999-2000[7]. The study was conducted in 30 districts spread over the country's 15 eco-development regions. A sample of 13,005 households, covering a population of 75,944, was included in the study. Based on the definition adopted for the study, the prevalence of disability was estimated to be 1.63% in the total population, with estimates of 1.65% in rural areas and 1.43% in urban areas (National Planning Commission/UNICEF/New Era 2001). Similarly, in 2006, WATCH, a non-governmental organization based in Kathmandu, carried out a survey in three geographical areas of Nepal, covering a total of 19,210 persons in 3,397 households. A total of 355 persons with disabilities were identified, giving an overall disability prevalence of 1.84% (Shrestha et al., 2009). These survey findings are closer to the findings of the national censuses of Nepal.

The discrepancies between the estimates of disabilities in Nepal could be due to a lack of a standard definition of disability (National Federation of Disabled-Nepal, 2010). Therefore, there is a need to clearly spell out the definition of disability for Nepal and then investigate the prevalence of disability.

8. Conclusion

The heterogeneity of the conceptual framework and insufficient recognition of the importance of indicator accuracy, the age factor, and the socio-economic characteristics of the populations under study, all affect the prevalence disability rate in any country or place. Although census data are quite detailed, disability is not a phenomenon that can be easily categorized with a simple binary classification. Thus, census data can underestimate some forms of disability. People may not report certain socially stigmatized conditions, such as alcohol and drug related conditions, and mentally related problems.

On the other hand, in the focused surveys, disability data can be too inclusive and measure minor difficulties in functioning that do not require assistance from another person, group or the support from a state agency. This method also has the potential to count people with disabilities more than once. It is difficult to ascertain whether the increase in disability rates is real or a statistical anomaly resulting from methodological and conceptual problems. For example, a greater willingness by people to reply, when interviewed in surveys, that they have a disability, may be the result of economic incentives to report disability in order to benefit from disability support programs, or be the result of a greater acceptance of, and openness to, people with disabilities in the society. The prevalence may be affected also by the number and types of questions, the scale indicating levels of difficulty, the range of explicit disabilities, and the methodology used. The different disability rates obtained in census and survey methods are mainly due to the domain included and the threshold for defining a disability.

The variations across countries, as, for example, shown in table 1 and table 2, can be more reliable when the questions become more specific and are used in a similar way. In practice, disability should be appropriately measured according to the purpose for which it is used. A collaboration and coordination between various initiatives to measure disability prevalence at the global, regional and national levels is urgent. WHO, an umbrella organization, can be a key facilitator to solve methodological debates and issues.

Acknowledgements:

I am indebted to Professor Marit Bakke for her continuous feedback, suggestions, and encouragement for shaping the article into this form.

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[7] The main purpose of the study was to develop a comprehensive definition of all kinds of disabilities and to obtain nation-wide data and information about the situation and services for persons with disabilities in Nepal. The definition considered a person to be disabled if the person could not perform the daily activities of life considered normal for a human being within the specified age and where the person needed special care, support and some sort of rehabilitation services (National Planning Commission/UNICEF/New Era 2001).

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