

RESEARCH ON DISABILITY: CHALLENGES OF ASSESSMENTS AND MEASUREMENT

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Abstract

Disability is a major public health problem especially in developing countries like India. Rehabilitation is the process of removing, or reducing the impact of disability. Rehabilitation measures should be targeted according to the need of country. In India, disability is mostly confined to rural areas which lacks awareness, accessibility, availability and utilization of rehabilitation services. Research on disability burden, appropriate intervention strategies, and their implementation to the present context in India is a big challenge because proper measuring assessment is not available in our country, like Survey tends to report higher rates of disability than census due to less concerned and generalized measurement. Administrative collections and registers are also useful in proper analysis. It is often found that the quality of administrative register data is closely related to the quality of the administrative system. So, it is a major challenge for a researcher to assess and measure disability. This paper is an attempt to clarify some good standards in collecting data on disability.

Key Words: Disability, measurement, assessment, rehabilitation.

INTRODUCTION

Any restriction or lack of ability to perform an activity in a manner or within the range considered normal for the human beings, resulting from impairment is termed as disability. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impairment organ; handicap is a measure of the social and cultural consequences of an impairment or disability. Poverty can cause disability with its associated malnutrition, poor health services and sanitation, and unsafe living and working conditions. Conversely, the presence of a disability can trap people in a life of poverty because of the barriers, disabled people face to taking part in education, employment, social activities, and indeed all aspects of life.

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

disability and make recommendations for prevalence measures of disability suitable for censuses. 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.

This paper reviews what is meant by disability and puts forth a way of measuring disability suitable for internationally comparable prevalence rates. The basic trend in this regard is to measure functional limitations, rather than disability. This paper will argue, however, that a single disability prevalence rate can be highly problematic.

DISABILITY

There is no single definition or classification of disability so it is difficult to define, (Capper, 1996, P-75; Wellner, 1998, P-308). The term “Disability” has different meanings. It has different meaning in different situation.

According to WHO- “Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.”

On the basis of PWD Act 1995:S-2(t), “Person with disability means a person is suffering from not less than forty percent of any disability as certified by a medical authority” .

Aspects of Disability:

“The disabled population is wide in age range and in the severity and cause of disability. Form a social psychological perspective the precise medical category of disability is not particularly relevant- except if it carries a social stigma. If we want consider disable man and women in their social context be may divided this group five psycho-social category of disability-handicap.

1. It is highly visible and provides early information which acts as an anticipatory signal to others (the blind person’s white cane, the paraplegic’s wheelchair). These signals convey clues about the social identity of the disabled person.
2. In this category the dominant theme is difficulty in effective interpersonal communication. Deafness and speech impediments are typical examples.
3. Here the person appears normal both from a distance and during social encounters. His disability is episodic or phasic as with asthma, epilepsy, hemophilia and maladjustment.
4. The category relates to such carried by the label: a disability is associated with social stigma, as in severe retardation and educational sub normality.
5. A combination of the above with its physical aspects and social stigma.”

Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. When most people think of the word "disability" they immediately picture someone in a wheelchair. But there are many different types of disability.

People with a disability may include:

- People who are blind or partially sighted
- People with learning or intellectual disabilities
- People who are deaf or hearing impaired

- People with a physical disability
- People with long term illnesses
- People with mental health or psychological difficulties
- People with an acquired brain injury.

REHABILITATION

Disability and their rehabilitation is a great challenge and requirement of India. Rehabilitation is the process of removing, or reducing as far as possible, the factors that limit the activity and participation of a person with disability, so that he/she can attain and maintain the highest possible level of independence and quality of life: physically, mentally, socially and vocationally.

Disability is complex, dynamic, multidimensional, and contested, poses several challenges for measurement. Approaches to measuring disability vary across countries and influence the results. Operational measures of disability vary according to the purpose and application of the data, the conception of disability, the aspects of disability examined – impairments, activity limitations, participation restrictions, related health conditions, environmental factors – the definitions, question design, reporting sources, data collection methods, and expectations of functioning. Impairment data are not an adequate proxy for disability information. Broad “groupings” of different “types of disability” have become part of the language of disability, with some surveys seeking to determine the prevalence of different “types of disability” based directly or indirectly on assessments and classifications.

PURPOSE OF MEASUREMENT

The purpose of measurement determines the definition of disability to be used and thus the questions asked. 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 Population – Monitoring functioning levels are important for two purposes: 1) Understanding the scope of potential concerns relating to disability, and 2) Evaluating interventions designed to prevent or minimize physical and cognitive limitations, activity limitation, and participation restrictions.

MEASUREMENT OF DISABILITY

A primary goal of collecting population data on people with disabilities is to identify strategies to improve their well-being. Comprehensive and systematic documentation of all aspects of functioning of the population can support the design and monitoring of interventions. For instance, such data would enable policy-makers to assess the potential benefit of assistance programs to help people with mobility limitations get to work or to assess interventions to reduce depression. Data on prevalence and need should be population-based and relevant to policy, but at the same time not dependent on policy. If data are dependent on policy, estimated prevalence rates can suddenly change if, for example, the benefit system changed and people switched from an unemployment benefit to a disability benefit. With population data and administrative and service data based on the same basic concepts and frameworks, a strong integrated national information database can be developed.

Different steps taken during evaluating disability:

- ❖ Self-identification as disabled. In this instance, the respondent is directly asked if they are disabled.
- ❖ Diagnosable conditions. The respondent reads a list of conditions, such as polio, epilepsy, paralysis, etc. and is asked if they have any of them.
- ❖ Activities of Daily Living (ADL). The respondent is classified as disabled if they have difficulty in performing any ADLs.
- ❖ Instrumental Activities of Daily Living (IADL). This approach is similar to the ADLs except that IADLs are higher order tasks. Examples include whether a person has problems managing money, shopping for groceries, or maintaining their household.
- ❖ Participation. This method asks if the person has some condition which affects a particular social role, such as attending school or being employed

According to NSSO, 2002, persons with disabilities constitute only 1.8 percent of the population. Whereas, according to census 2001, persons with disabilities constitute 2.13 percent of total population. As per census 2011, the population of persons with disabilities in India is 2.68 crore which is 2.21 percent of the total population of the country. So, whether it is good news for our country as there is slight increment in the disability rate during the long gap of 10 years or it is a point of awareness about our census result.

CHALLENGE FOR RESEARCHER

There are lot of confusions for a researcher in considering a proper and particular data, as different aspect give different data because they have different evaluating steps.

1. PWD Act state that a “Person with disability means a person is suffering from not less than forty percent of any disability as certified by a medical authority”. Then the person who is not aware of this act or don’t content any certificate related to disability will not be considered as disability?
2. WHO state that a person having any malfunctioning of body part or having default in body structure will be considered as disabled. Then the person having less than 40 percent disability will be considered as disabled on the basis of WHO but PWD will not consider those people as disabled. So, there will be variance in report of PWD and WHO.
WHO also includes people who are unable to perform own daily activities as disabled. The person suffering from Diabetes is also unable to move or perform their activities due to their swollen body, but they are not disabled.
3. The physical disability is easily seen by the people but the mental disability can’t be analysis without using proper steps. The person on the wheel chair, is identify as disabled because his wheel chair act as messenger.
4. In some cases, it is seen that the disabled person appears normal both from a distance and during social encounters. His disability is episodic or phasic. So, it is a big confusion in classifying them as disabled or normal.

Conclusion

Therefore, it is a major challenge for researchers in adopting report or data. Researcher has a lot of reports or data in front of him at the time of research which creates confusion due to variable reports provided by different authorities on single topic which affect the research. Therefore,

collection of data should be done on single basis having some criteria which is easily understood by the people and variability in the reports and data can be removed. This will be helpful to researcher, government in implementing services, etc.

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