

Measuring Disability in India : Spatial and Socio-economic Variations

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India is a developing country with the second largest population in the world, so to a certain extent it is difficult to collect accurate figures of the total number of people with disabilities. More than 22 million in India are debarred from full participation in their families, communities and societies due to their disabilities. The lack of physical access to facilities, transportation, and information circumscribes them from enjoying equal opportunities in housing, employment and health care. With the shift in emphasis from providing welfare assistance to ensure the rights of persons with disabilities, the importance of convergence of policies and programmes in different sectors so as to provide synergy has emerged to the forefront. The Persons with Disabilities (Equal Opportunities, Full Participation and Protection of Rights) Act 1995 is landmark legislation and an appreciable attempt to alter the disabled scenario in India.

Defining disability is not an easy task, and it is becoming clear that no single definition can cover all disabilities. According to International Classification of Impairment, Disability and Handicap, disability is interference with activities of the whole person in relation to the immediate environment. Disability Discrimination Act 1999 (DDA) defines a disabled person as someone with "a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities."

People with disabilities must surmount workplace obstacles that those without disabilities never even notice, everything from inaccessible work spaces to indifferent or even intolerant colleagues. The picture is now beginning to improve, however, spurred by the recent passage of legislations all over the world to ensure the protection of human rights of disabled people. Disability rights are being incorporated in international, national, and states legislations.

This paper measures disability levels of across different Indian states: between literate and illiterate, urban and rural, and workers and non-workers. The study also outlines challenges ahead to achieve Equal Opportunities, Full Participation and Protection of Rights for disabled persons in India. Crude Disability Rate (CDR) per 100, 000 are calculated for above mentioned categories. Then CDR for different types of disability is calculated. The disability rates are computed for different literates and illiterates, urban and rural, male and female, and according to types of employment. The disability indices specific to five types of disability measurement

are computed first for different states of India. Then a weighed Index for disabled persons has been developed by considering severity of particular types of disability.

This study is primarily based on Indian Census 2001 data and disability data Collected by Indian National Sample Survey Organization(NSSO) Survey during 2002. The five types of disabilities are recorded in the Census 2001 as the disabilities in: (i) Seeing (ii) Speech (iii) Hearing (iv) Movement and (v) Mental disorder.

The definitions and instruction for recording five types of disabilities for Indian census 2001 are given below:

In Seeing: A person who cannot see at all (has no perception of light) or has blurred vision even with the help of spectacles will be treated as visually disabled. A person with proper vision only in one eye will also be treated as visually disabled. You may come across a situation where a person may have blurred vision and had no occasion to test whether her/his eyesight would improve by using spectacles. Such persons would be treated as visually disabled.

In Speech: A person will be recorded as having speech disability, if she/he is dumb. Similarly persons whose speech is not understood by a listener of normal comprehension and hearing, she/he will be considered to having speech disability. This question will not be canvassed for children up to three years of age. Persons who stammer but whose speech is comprehensible will not be classified as disabled by speech.

In Hearing: A person who cannot hear at all (deaf) or can hear only loud sounds will be considered as having hearing disability. A person who is able to hear, using hearing-aid will not consider as disabled under this category. If a person cannot hear through one ear but her/his other ear is functioning normally, should be considered having hearing disability.

In Movement: A person, who lacks limbs or is unable to use the limbs normally, will be considered having movement disability. Absence of a part of a limb like a finger or a toe will not be considered as disability. However, absence of all the fingers or toes or a thumb will make a person disabled by movement. If any part of the body is deformed, the person will also be treated as disabled and covered under this category. A person who cannot move herself/himself or without the aid of another person or without the aid of stick, etc., will be treated as disabled under this category. Similarly, a person would be treated as disabled in movement if she/he is unable to move or lift or pick up any small article placed near her/him. A person may not be able to move normally because of problems of joints like arthritis and has to invariable limp while moving, will also be considered to have movement disability.

Mental: A person who lacks comprehension appropriate to her/his age will be considered as mentally disabled. This would not mean that if a person is not able to comprehend her/his studies appropriate to her/his age and is failing to qualify her/his examination is mentally disabled. Mentally retarded and insane persons would be treated as mentally disabled. A mentally disabled person may generally depend on her/his family members for performing daily routine. It should be left to the respondent to report whether the member of the household is mentally disabled and no tests are required to be applied by you to judge the member's disability.

If a person suffered from two or more types of disabilities, only one of these was recorded. In such cases it was left to the respondent to decide as to the type of disability she/he wants the member of her/his household to be classified into. Persons with temporary disability on the date of enumeration were not considered as disabled.

This question on disability was universal – enquired for all the members of the household. It was enquired from the respondent, if any of them suffered from any physical or mental disability. If a person suffered from two or more types of disabilities, only one of these

was recorded. In such cases it was left to the respondent to decide as to the type of disability she/he wants the member of her/his household to be classified into. Persons with temporary disability on the date of enumeration were not considered as disabled. Multiple disabilities are recorded in NSSO Survey 2002.

Crude Disability Rate for i^{th} type of disability is given by:

$$\text{CDR}_i = \{ \text{Number of persons belonging to } i^{\text{th}} \text{ type of disability} / \text{Total number of person.} \} * 10^5$$

Index of i^{th} Type of Disability = $I_i =$

$$[\{ (\text{Max. (CDR}_i) - \text{Observed (CDR}_i) \} / \{ (\text{Max (CDR}_i) - \text{Min. (CDR}_i) \}) * 100$$

where CDR_i = Crude disability rate per 100, 000 person of disability of i^{th} type for a particular group of people, $i = 1, 2, 3, 4, 5$.

1 = Seeing, 2 = Speech, 3 = Hearing, 4 = Movement and 5 = Mental.

The index varies from 0 to 100 scales. These indices are so designed that the lower values of these indices reflect the better disability status. Zero indicates an ideal situation whereas 100 measures worst state of disability prevailing in a society.

Then a composite disability Index (DI) is computed as:

$$\text{DI} = [W_1 I_1 + W_2 I_2 + W_3 I_3 + W_4 I_4 + W_5 I_5] / [W_1 + W_2 + W_3 + W_4 + W_5],$$

where W_i is the weights of the i^{th} type of disability.

Disability weight represents ability level to carry out normal day-to-day activities corresponding to a type of disability. Disability weights for these five types of disability are elicited empirically in discussions with health care professionals or non-health care professionals with an academic background. Weights for disability in hearing and in speech are considered to same and equal to one. The weight for disabilities in movement is double of that of hearing or speech and the weight for disability in seeing or metal is same and is considered as triple of that of hearing. So, the sum of all weights is equal to 10.

Officially so far India has said that 1.9% of its population is affected by disability (National Survey Sample Organization, NSSO Survey, 1991). According to 2002 census report it is 2.1%. According to NSSO -2003 report, about 10.63 per cent of the disabled persons suffered from more than one type of disabilities.

The Disability Index (DI) is constructed to measure the disability health status of different states of India. Indices for the five parameters measuring their contribution in Disability Index are computed. Disability Indices over the census period 1991-2001 are calculated for all 26 Indian states. The DI for all India is 36. These indices are also compared among different Indian states. It is found that Disability Index is biggest (60) for Kerala and it is smallest (15) for a tiny tribal state Nagaland. There is a strong Urban –Rural in DI. For Nagaland Urban, it is small as 3. In most of the states rural people have higher DI in comparison to that of rural. Most of the North Eastern states of India reflect lower disability indices. As many as 12 Indian states have Disability index higher than 40 indicating a very grim pictures in these states. Disability indices for Literate and Illiterate, and workers and non-worker are computed for all Indian states

as well as for urban and rural areas of these states and for male and females. Significant variations in DIs are observed for these characteristics among different Indian states.

The disabled in different states of India continue to suffer discrimination at every level in spite of the existence of a number of Acts prohibiting prejudice and inequality on grounds of disability. Public places even medical and educational institutions, and public transport and other facilities remain inaccessible to the disabled, while the police and the administration are found to be abysmally lacking in awareness about the existing legal provisions for persons with disabilities. In many cities, there are a number of newly –constructed public buildings that have no facility to ensure barrier-free access for the disabled.

Interestingly, the scenario in the lower class and lower caste Indian families is quite different. Here the garb of pride and honour has not covered over the real facts of life. In these poor Indian homes, almost all members of the family are engaged in some remunerative activity. Their existence depends on their job, which gets them barely two square meals a day. Here, each member has to work for existence and 'survival of the fittest' is the governing principle. Under such circumstances, the disabled members are often left to their own fate or at best, institutional confinement is resorted to as a solution. At this extreme end of the economic spectrum, families do not hesitate to abandon their disabled children, or look for institutionalized arrangements. In fact, the existence of shelter homes and sanatoriums, asylums etc. has been sustained by the needs of this section.

It seems that PDA 1995 have hardly been adhered by the administration in its dealings with the disabled. In most of the Indian states, the office of the full-time commissioner for disability is yet to be made functional, and there is no awareness in the Government departments about the mandatory three percent reservation in all poverty alleviation schemes. Job reservations too are mainly confined to the grade C and D categories.

The Persons with Disabilities Act (PDA), 1995 has been landmark legislation for the disabled in India. A developing society has to be sensitive to the needs of the disabled. Cognitive adjustments can change the way disabled people function, the attitudes they encounter. "The Persons with Disabilities Act, 1995" (PDA) is the Indian attempt to bring about change but due to lack of implementation, it has not made much difference. "The Americans with Disabilities Act, 1990" (ADA) in the USA, within 10 years of legislation has made a substantial difference to the quality of life for the disabled. The salient features of the statutes of both countries are similar and seek to provide for education, employment, affirmative action, full participation, non-discrimination, research and manpower development. While USA has successfully implemented the legislation during the past decade, India has painfully dragged its feet.

PDA can be an effective statute if there is better implementation. Guidelines should be formulated and implemented. All efforts must be made to disseminate information on the rights of the disabled. Pressure groups and advocacy groups should actively work towards the implementation. The voice of the disabled is weak and society has to come out stronger. In India this segment of the country's population needs a specific endeavor not only for the identification of people with disability but also requires special attention for creating conditions allowing people with disabilities to live life in a dignified manner and with a sense of fulfillment. This study will be useful to the planners, policy makers and programme managers to develop basic infrastructure services supporting physical access to facilities, transportation for disabled person to have equal opportunities in housing, employment and health care.