

Commentary on the 'Proposed Purpose of an Internationally Comparable General Disability Measure'

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The proposed purpose of an internationally comparable general disability measure is one of the most potent strategy papers for the welfare of the disabled population across the globe. The disabled population that lives in various countries in different environment is faced with similar problems and is subjected to discrimination in day-to-day life. The proposed purpose is in tune with the growing need for a concerted effort to ensure that people with disabilities are treated as equal in every sphere of life, have access to services, health care and they live a dignified life, their role in nation building is recognized and they are provided with legal support through legislations. The implementation and monitoring of a common program for the equalization of opportunities, rehabilitation and prevention simultaneously across the countries would not only help the noble cause but will create environment where these measure would be comparable. The proposed purpose is the outcome of the hard work put in by the Washington Group. In their endeavor, the WG has looked into almost every aspect concerning disabled persons in the existing environments, which vary. The role of census and surveys, their significance as also shortcomings have been examined.

The WG has skillfully presented a module that would execute the objectives of the World Programme of Action for disabled persons adopted by the United Nation's General Assembly in the year 1983 where principles concerning prevention of disability, measures for their rehabilitation and equalization of opportunities were outlined. The initiative taken by the UN prompted governments to take appropriate welfare and legislative measures. In India, enactment of the 'Persons with Disabilities Act, 1995' was a major step forward in this direction. This has brought about a major change in the approach from welfare and charity to equalization of rights and opportunities.

The position paper on 'Proposed Purpose of an Internationally Comparable General Disability Measure' aims to achieve three major goals set out by the WAP namely, equalization of opportunities, rehabilitation and Prevention. The prevalence and extent of disability is proposed to be measured through population census, as population Census is more suited to collect information on certain individual characteristics. The disability matrix has been worked out after much deliberation keeping in view the prevailing social and other environment across the countries as also the methods of data collection and its use. The WG, has in fact, prepared a module for all round assessment of disability scenario and has formulated purpose that will ensure rehabilitation, prevention and equalization of opportunity for disabled population with international comparability. The WG has selected three classes of purpose for identification of persons with disabilities at aggregate level. These are:

- to provide services, including the development of program and policies for service provision and evaluation of these programs that includes addressing need for housing, transportation, assistive technology, vocational or educational needs and long term care;

- to monitor the level of functioning in the population meaning estimation of rates and analysis of trends; and
- to assess equalization of opportunities, these classes of purpose are most relevant and feasible for implementation. These will go a long way in achieving the most important objective, that is, overall welfare of the disabled population across the globe.

Although practical measures have been suggested for the scheme, it remains to be seen as to how these are executed under different environments. Monitoring would be the key factor for the long-term success / assessment of this well developed strategy and international comparability. It also remains to be seen that even after identification how the disability would be measured to further identify true disabled who need immediate attention.

Difficulties in census: An important aspect of Identification and measurement of disabled population is the definition of disability that is used. There are different definitions of disability in use internationally. The particular definition chosen has implications for the numbers of people with disabilities and the prevalence of disability in the country. The definition of disabilities requires measurement of disability which census enumerators find difficult to handle. Similarly, imparting special training to a huge contingent of Census Enumerators for collection of information on such a sensitive topic is not easy. They are usually not trained to go into the technical aspects. Despite the fact that the Population Census has the advantage of providing complete coverage of the population, it is difficult to collect accurate information on disability in the census. Because disability is a sensitive topic and the respondents are reluctant to divulge information on this aspect. Some of the disabilities are considered stigma and these are not reported honestly by all. The stigma does not always affect the disabled person alone but the entire family is subjected to social disability. It is probably for this reason that historically the information collected in Indian Census on disability has never been satisfactory. Lack of awareness on the part of respondent's results in low reporting of disabled population.

Census of India 2001: At the Census of India 2001, information on five types of disabilities has been collected. These are:

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| 1. Disability in Seeing | 2. Disability in Hearing |
| 3. Disability in Speech | 4. Disability in Movement, and |
| 5. Mental Disability. | |

The question on disability was canvassed with simple definitions without having to measure the extent of disability. To overcome the problems faced in earlier censuses, awareness – cum- publicity campaign and extensive training for the Census Enumerators was organized. The NGOs and other Government agencies also joined hands in this endeavor. It is believed that this strategy has worked to a large extent and the combined efforts have resulted in better enumeration of disabled population under various categories.

Utility of Census Data: The census data would provide basis for the three selected purposes identified by the WG. This helps in preparation of sound frame for formulating programs and policies and to provide essential services to the disabled. It is also easier to assess the need of housing, transportation, education, employment, etc. for this section of the society. The data also provide details of age-groups, sex, size of household, economic pursuits, education, marital status, religion, migration, type of households, etc. in the rural and urban settings by type of disability at the lowest administrative level. These data could

also be utilized to cull out information on certain other variables. In India, we propose to make such data available on CDs and on the Internet as well.

As envisaged, rehabilitation is significant to the welfare of people with disabilities. It is necessary to keep track of both the requirement and the availability of accessibility and appropriate aids and support services, which are coordinated across agencies. Rehabilitation would involve measures proposed to compensate for a loss of function or a functional limitation (for example by technical aids) and other measures intended to facilitate social adjustment or readjustment. The Census Data would help in identifying both the persons by type of disabilities and the locations. This will be of help to generate schemes for providing specific assistance and also to reckon the future needs. Monitoring the level of functioning require developing certain indicators. It is rightly mentioned that functioning encompasses the conceptual domains of body functions and structures as well as activities and participation. The Census Enumerators are not trained to canvass such questions. Such information could be gathered by other agencies using basic census data. Further, The role of utilization of technology for enhancement of body functions and skills cannot be ruled out. The development of appropriate technology is an aspect that needs to be looked into.

The data collected through census are also useful in meeting the purpose of 'Assessment of Equalization of Opportunity' to a great extent. It may not provide information on the outcome of the anti-discrimination laws and rehabilitation programs, but it would definitely provide information that would be used for planning and framing of policies. The level of participation of disabled population in economic activities by type of activity would form the basis for international comparability. We totally agree with the basic theme that if people with disabilities are to be given a life of dignity and reach their optimal potential they need to be able to participate with others on an equal footing. Adequate legal and financial support must come from the governments that will ensure that the disabled have the power to control their own lives and have access to information, equipment and the full range of services, including education, employment, health, housing, transportation, recreation, etc. Measurement of these elements would then become an integral part of the information system on disability. However, the first and foremost need is to make the disabled aware about their own rights. The mind-set of general population at large may also have to be changed through a sustained publicity / awareness campaign.

The WG has rightly proposed the assessment of equalization of opportunity as the purpose for the first general disability. This is probably the most suitable purpose to be implemented internationally. This is, where census data, would come handy. Based on the census data specific surveys with specific objectives can be conducted. The methodological challenges as well as the objectives of small sets of surveys would meet with certain amount of difficulties but it would be worthwhile to accept this challenge for the sheer joy of ameliorating the lot of disabled.

The Census of India on its part would cooperate in every endeavor as and when the need arises.