

Chapter 1

Introduction

“Science may have found a cure for most evils; but it has found no remedy for the worst of them all - the apathy of human beings.” - **Helen Keller**

1.1 What is Disability?

As defined by the World Health Organization **Disability** “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. Thus disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives.*”

The Convention on the Rights of Persons with Disabilities (2006), the first legally binding disability specific human rights convention, adopted by the United Nations gives two descriptions of disability. The Preamble to the Convention states that “*Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.*” Again it emphasizes that “*Persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*” Both the expressions reflect a shift from a medical model to social model of disability.

In the medical model, individuals with certain physical, intellectual, psychological and mental impairments are taken as disabled. According to this, the disability lies in the individual as it is equated with restrictions of activity with the burden of adjusting with environment through cures, treatment and rehabilitation. In contrast in the social model the focus is on the society, which imposes undue restrictions on the behaviour of persons with impairment. In this, disability does not lie in individuals, but in the interaction between individuals and society. It advocates that persons with disabilities are right holders and are entitled to strive for the removal of institutional, physical, informational and attitudinal barriers in society.

The WHO estimated that more than six hundred million people across the globe live with disabilities of various types due to chronic diseases, injuries, violence, infectious diseases, malnutrition, and other causes related to poverty. People with disabilities are subject to multiple deprivations with limited access to basic services, including education, employment, rehabilitation facilities etc. Widespread social stigma plays a major role in hindering their normal social and economic life. To work towards an inclusive, barrier free

society through raising awareness and policy actions, there is a need to have comprehensive reliable statistics on people with disability and their socio-economic conditions.

1.2 Disability in India

While estimates vary, at the turn of the new millennium about 21 million people in India were found to have disability as per the official statistics. These included persons with visual, hearing speech, locomotor or mental disabilities, who constituted about 2 percent of the population. However, some sources claim that the magnitude in actuality is more with at least 5 per cent of population suffering from one disability or other and the official statistics accounting for only the most severe ones. By and large, people with disability are further disabled through unequal treatment and denial of basic rights by the broader society. The voiceless disabled people are inseparable part of India's growing population of marginal, weaker and vulnerable sections of society.

The roles and responsibilities of the Government of India are clearly identified in laws but there is a need to study the gap between the law and the practice. This report aims at presenting a statistical profile of disability in India, especially in the new millennium.

1.3 Constitutional Provisions on Disability in India

Dignity of the individual is a fundamental notion behind all the fundamental rights guaranteed under part III of the Constitution of India. The Preamble to the Constitution of India & Part III of the Constitution imposes a negative obligation on the part of the state, not to restrain the liberties and rights guaranteed under the same part. Further the State has been directed under the various provisions of the constitution to extend similar treatment to all persons. Article 41 declares that, the State shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement. Article 46 lays down an obligation on the State to promote with special care the educational and economic interests of the weaker sections of the people, and protect them from social injustice and all forms of exploitation.

Indian Constitution while distributing legislative powers between the Centre and States kept the disability issue in the State list. The Parliament of India gained competence to legislate on disability issues with the signing of the Proclamation of Equality and Full Participation of People with Disabilities in Asian and Pacific Region. Article 249 of the Constitution empowers the Parliament to legislate on any subject falling in any list in order to fulfill its international obligations. Being a signatory to a number of conventions, with a view to implement the Proclamation, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 was enacted with effect from 1st January 1996.

The formal recognition of discrimination on grounds of disability is a recent phenomenon and laws enacted even twenty years ago generally did not include disability in the list of prohibited discriminations. For instance, the Constitution in Articles 15 and 16 prohibits discrimination in the matter of employment and access to public facilities on grounds of religion, race, caste, sex and place of birth, but is silent on disability.

In fact, the service rules until 1995 prevented entry of persons with disabilities in higher grades of service. These rules gave the employer the authority to force premature retirement in public interest and often employees who acquired disability during service were either forced out of job or got their rank reduced. In most cases their opportunity for career enhancement was suspended forever.

With increasing awareness of disability-based discrimination, explicit legal safeguards have now been put in place. The enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is a signal achievement of the Indian disability movement. Preamble to this Act clearly delineates its objective of promoting and ensuring equality and full participation of persons with disabilities. The Act aims to protect and promote economic and social rights of people with disabilities. Though the words disability has not been defined under the Act, but it covers seven disabilities under section 2(i) of the Act - blindness; low vision; leprosy-cured; hearing impairment; loco motor disability, mental retardation, mental illness etc.

1.4 Acts on Disability

In our Indian Constitution several Articles and Clauses provide ample opportunities for the development of legal instruments to protect the rights of the disabled people. The first major legal advancement for the protection of the rights of the disabled people after the constitutional guarantee took its shape as the Rehabilitation Council of India Act, 1992 and it came into force on 31st July 1993. The Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995, came into force after a decade old lobbying by the activists working for the rights of the disabled. This Act classifies the categories of the disabled and further identifies the duties of the Government of India, State Governments and local administration towards the welfare of the disabled people.

The Mental Health Act, 1987

This was an Act to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto.

The Rehabilitation Council of India Act, 1992:

The Act was created to provide for the constitution of the Rehabilitation Council of India for regulating training of the Rehabilitation Professional and maintaining of a Central Rehabilitation Register and for matters related to these issues.

Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 :

The enactment of the Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act 1995 (referred to as persons with Disability Act) is guided by the philosophy of

empowering persons with disabilities and their associates. The endeavour of the Act has been to introduce an instrument for promoting equality and participation of persons with disability on the one hand, and eliminating discriminations of all kinds, on the other. The Act aims to protect and promote economic and social rights of people with disabilities.

The Act covers seven disabilities. The criteria for classification of each disability are embodied in a biomedical model. Section 2(t) of the Act proclaims that a person with disability means 'a person suffering from not less than forty percent of any disability as certified by a medical authority.' The disabilities that have been listed in Section 2 include blindness, low vision, hearing impairment, locomotor disability or cerebral palsy, mental retardation, mental illness and persons cured of leprosy. In addition, autism and multiple disabilities have been covered under the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

The Act spells out responsibilities of the Government at all levels including establishments under its control. It lays down specific measures for the development of services and programmes for equalising opportunities for the enjoyment of right to education, work, housing, mobility and public assistance in case of severe disability and unemployment. To execute the mandated responsibilities, a Central Co-ordination Committee and State Co-ordination Committees representing major development ministries, Members of Parliament and disability NGOs and having a woman with disability as a member have been envisaged in a multi-sector model. Furthermore, the institution of Chief Commissioner in the Centre and Commissioner for Persons with Disabilities in States has been proposed. Their mandate is to redress individual grievances, provide safeguards to the rights of persons with disabilities, monitor implementation of disability related laws, rules and regulations, and oversee utilisation of budget allocated on disability. These quasi-judicial bodies are vested with the powers of a civil court.

The PWD Act has an exclusive chapter entitled Non-Discrimination. Sections 45, 46 and 47 of this chapter prohibit discrimination on the basis of disability in the matter of public employment and in access to public facilities. It is another thing that corresponding reforms in service rules, building codes and motor vehicle standards have been extremely slow. Consequently, disability litigation is on the rise but the redeeming feature of the current scenario is efficient disposal of disability discrimination cases both by courts and quasi-judicial bodies.

This historic legislation is a corner stone of evolution of jurisprudence on the rights of persons with disabilities in India. As a result, disability concerns have come into sharp focus. However, within a period of ten years of enforcement of this Act its weaknesses have also surfaced in the absence of a powerful implementing instrumentality. Unlike usual indifference the government soon realised these weaknesses and acceded to the demand of the disability movement for overall review of the Act. Towards this end a committee was constituted which harmonised views of the disability sector and relevant bodies in its comprehensive report.

The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999:

The Government has also introduced a National Trust for the Welfare of Persons with Mental Retardation and Cerebral Palsy Bill, 1995. The trust aims to provide total care to persons with mental retardation and cerebral palsy and also manage the properties bequeathed to the Trust.

As certain groups among the disabled are more vulnerable than others, a special enactment for the protection of such persons, their property and well-being was felt necessary. The enactment of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (referred to as the National Trust Act) aims to fulfill a common demand of families seeking reliable arrangement for their severely disabled wards. The specific objectives of the Act are:

- To enable and empower persons with disabilities to live as independently and as fully as possible within and as close to the community to which they belong;
- To promote measures for the care and protection of persons with disabilities in the event of death of their parent or guardian; and
- To extend support to registered organisations to provide need based services during the period of crisis in the family of disabled covered under this Act.

1.5 Framework for Disability Statistics

The Disability Division in the Ministry of Social Justice & Empowerment, Government of India, through its programmes and policy formulations facilitates empowerment of the persons with disabilities, including persons with visual, hearing, speech, locomotor and mental disabilities. They run a few schemes for disabled persons and released the National Policy for Persons with Disabilities in the year 2006. However, there are inherent challenges in the implementation for MSJE as the nodal agency since disability has a multi-sectoral implication. For example, for early detection of disability or for special education needs of the disabled children Ministry of Health & Family Welfare and the Ministry of Human Resources Development together with Ministry of Women and Child Development are the appropriate lead agencies. To address this issue, the PWD Act mandates central and state level Coordination and Executive Committees as key institutions in development of disability policy. Disability Statistics in India are captured through decennial Population Censuses and periodic dedicated National Sample Surveys conducted by Ministry of Home Affairs and Ministry of Statistics & Programme Implementation respectively.

International Classification of Functioning, Disability and Health (ICF) has a comprehensive classification of disability which is found to be extremely difficult to canvass in census or surveys, particularly in developing countries like those in the SAARC. It was therefore, felt necessary that an appropriate survey framework based on feasible concepts and definitions and classification of disability conditions is adopted in consultation

with stakeholders in various fields including medical, legal, social justice and statistics. Towards this end, a framework, considering inter-alia the ICF for collecting statistics on disability was developed by the Ministry of Social Justice and Empowerment. The framework had been field-tested while in the mean time India proposed to develop a framework for disability statistics in keeping with the same to be developed for the SAARC region countries through SAARC-STAT mechanism. Accordingly, in the SAARC-STAT meeting held in Dhaka, Bangladesh in April 2008 it was decided to constitute an Informal Virtual Group under the Chairmanship of Pakistan to collect information on existing practices and definitions followed by the Member States on collection of data on disability.

In India the collection of statistics on disability like collection of statistics on other socio-economic subjects by Ministry of Statistics & Programme Implementation is governed by the Collection of Statistics Act. The Act has been amended and the Act currently in force is Collection of Statistics Act, 2008

1.6 International Classification of Functioning, Disability and Health (ICF)

ICF is a classification of health and health related domains that describe body functions and structures, activities and participation. The domains are classified from body, individual and societal perspectives. Since an individual's functioning and disability occurs in a context, ICF also includes a list of environmental factors. ICF is useful to understand and measure health outcomes. It can be used in clinical settings, health services or surveys at the individual or population level. Thus ICF complements ICD-10, the International Statistical Classification of Diseases and Related Health Problems and therefore is looking beyond mortality and disease. After nine years of international revision efforts coordinated by the World Health Organization (WHO), the World Health Assembly on May 22, 2001, approved the International Classification of Functioning, Disability and Health and its abbreviation of "ICF." This classification was first created in 1980 (and then called the International Classification of Impairments, Disabilities, and Handicaps, or ICIDH) by WHO to provide a unifying framework for classifying the consequences of disease.

The ICF classification complements WHO's *International Classification of Diseases-10th Revision* (ICD), which contains information on diagnosis and health condition, but not on functional status. The ICD and ICF constitute the core classifications in the WHO Family of International Classifications (WHO-FIC). The ICF is structured around the following broad components:

- Body functions and structure
- Activities (related to tasks and actions by an individual) and participation (involvement in a life situation)
- Additional information on severity and environmental factors

Functioning and disability are viewed as a complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors. The picture produced by this combination of factors and dimensions is of "the person in his or her world." The classification treats these dimensions as interactive and dynamic rather than linear or static. It allows for an assessment of the

degree of disability, although it is not a measurement instrument. It is applicable to all people, whatever their health condition. The language of the ICF is neutral as to etiology, placing the emphasis on function rather than condition or disease. It also is carefully designed to be relevant across cultures as well as age groups and genders, making it highly appropriate for heterogeneous populations.

ICF has two parts, each with two components:

Part 1: Functioning and Disability

- (a) Body functions and Structures
- (b) Activities and Participation

Part 2: Contextual factors

- (a) Environmental factors
- (b) Personal factors

These components are denoted by prefixes in each code.

- b for body functions
- s for body structures
- d for activity and participation
- e for environmental factors

The letters *b,s,d,e* are followed by a numeric code that starts with the chapter number (one digit) followed by the second level (2 digits) and the third and the fourth level (one digit each).

<i>b2</i>	sensory functions and pain	first level item
<i>b210</i>	seeing function	second level item
<i>b2102</i>	quality of vision	third level item
<i>b21022</i>	contrast and sensitivity	fourth level item

Further qualifiers (1 digit) are added after decimal point to denote the extent or magnitude of impairment: xxxxxx.0 – No impairment, xxxxxx.1 – mild impairment etc., the qualifier going up to ‘9’. In some cases there are second qualifier also which are denoted by integers 0 to 9 in second place after decimal point. The number of qualifiers and what they represent are specific to the components *b*, *s*, *d* and *e*. Eg. *b21022.1* means mild impairment in contrast and sensitivity of visions.

1.7 Sources of Disability Statistics

In any society estimating reasonably accurately the population suffering from physical or mental infirmities is always a challenging task. In the absence of a complete and perfect administrative statistics, recourse is

taken through surveys and censuses in spite of their inherent limitations in netting rare personal characteristics. The Persons with Disabilities (Equal Opportunities, protection of Rights and Full Participation) Act which came into force in 1995, imposes specific obligation on the government to undertake surveys, investigation and research concerning causes of disability. As already discussed in India, the major sources of statistics on disability are the decadal Population Censuses and the regular large scale sample surveys on disability conducted by National Sample Survey Organisation (NSSO).

i) Population Census: The history of collection of data on disability/ infirmity dates back to the inception of modern Indian Census in 1872. The questionnaire of the 1872 Census included questions not only on physically and mentally infirm but also persons affected by leprosy. Collection of information on infirmities in each of the successive decadal censuses continued till 1931. However, in view of the serious doubts expressed by the then Census Commissioners about the authenticity and quality of data collected on infirm population, the enumeration of physically disabled persons was discontinued during the 1941 Census. It was felt that question on disabled population did not lend themselves to a census enquiry since these did not seem to provide accurate data due to variety of reasons particularly due to the social stigma attached with this characteristic.

After a gap of 50 years, a question on disabilities was again canvassed at the 1981 Census. Since 1981 had been proclaimed as the "International Year for the Disabled" it resulted in inclusion of a question on disability during censuses the world over and India was no exception to it. However, the question on only three broad categories of physical disabilities, viz. 'Totally Blind', 'Totally Dumb' and 'Totally Crippled', was canvassed during the House listing Operations of 1981 Census. When the results of 1981 Census were finally available, it was felt that there was considerable under enumeration of physically handicapped persons. The 1981 Census results also supported the views expressed by the earlier Census Commissioners that the enumeration and determination of the physically handicapped and their characteristics were beyond the scope and capacity of Census Operations due to the complexity of the definition of disability and inherent reservations of the population to share this information with the enumerator usually a local government official. The question on disability was not canvassed again at the 1991 Census of India.

The question on disability was again incorporated in census of India 2001 under the pressure from the various stakeholders and obligation under PWD Act, 1995, although it was generally felt that it was difficult to collect accurate information on disability during the census enumeration process. Further, the concepts and definitions spelt out in the act were found to be difficult to canvass in the absence of expert investigator specifically trained for the purpose. However, considering its advantage of comprehensive coverage of population characteristics and scope to provide estimates at sub-state level the decision to include the question on disability for all the members of the households was finally agreed upon.

ii) NSS Surveys on Disability: The National Sample Survey made its first attempt to collect information on the number of physically handicapped in its 15th round survey (July 1959-June 1960). The enquiry was exploratory in nature and was confined to rural areas only. In its 16th round (July 1960-June 1961) the geographical coverage was extended to urban areas. Thereafter the subject was again taken up for nationwide survey in its 24th round (July 1969-June 1970), 28th round (October 1973-June 1974). These surveys (undertaken during 15th, 16th, 24th, and 28th rounds) were intended mainly to get a count of persons in the country who suffered from certain specified physical handicaps. However, the types of physical handicap covered were not always same. For reasons of economy information on physically handicapped was collected in the early rounds in survey schedules meant for other subjects. Therefore, there was very little scope for collecting information on cause, specific nature and other details of physical handicap.

NSSO undertook a comprehensive survey on this subject for the first time in the NSS 36th round (July-December 1981) as 1981 was the International Year of the disabled persons. Detailed information relating to magnitude of disability, type of disability, cause, age at onset, type of aid/ appliance used and other socio-economic characteristics was collected in this survey. A decade later, at the request of MSJE, NSSO covered this subject again in its 47th round (July-December 1991), with the same basic framework including concepts, definitions and operational procedures as followed in the 36th round. While the earlier surveys were restricted to only the physically handicapped persons, in the survey conducted since NSS 36th round (1981) an extended definition was used to cover all persons with one or more of the three physical disabilities – visual, communication (i.e. hearing and/ or speech) and locomotor. Also, data on developmental milestones and behavioural pattern of all children of age 5-14 years were collected, regardless of whether they were physically handicapped or not.

Again, after a gap of eleven years, the survey on the persons with disabilities was carried out in the 58th round during July-December, 2002. This round also maintained the same definitions and procedures for physical disabilities as were adopted in earlier two rounds. This round, however, extended the coverage by including the mental disability. Along with the particulars of physical and mental disabilities, the socio-economic characteristics of the disabled persons such as their age, literacy, employment, vocational training etc. were collected. Governing Council (GC) of NSSO through the working groups with National Experts in different medical institutions, eminent professors, academicians and other important users including Ministry of Social Justice and Empowerment, finalised the questionnaire, sampling design, tabulation plan etc. for the survey.