

Access to Health: Problems of the Differently Abled in India



LAW

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ABSTRACT

The United Nations convention guarantees persons with disabilities right to highest standard of health without discrimination. But in reality, the impediments such as Inaccessible buildings and diagnostic equipments, negative/stereotypical attitude of health professionals or their ignorance, lack of training to communicate with people with hearing/ speech impairment or intellectual disability, inaccessible transport to reach the health centre or sheer expense of treatment etc hinders the right of the disabled persons to access healthcare facilities. The protection of persons with disabilities Act, 1955 and other laws on the protection of disabled persons are silent on the issue. The paper will analyze the issue in the light of legislative framework in domestic level and international level with the recent draft on the right of disabled person's Bill 2014.

Introduction

Health is a human right. It is equally accessible to all. But the studies in India show that there is wide disparity between the rights of the differently-abled with regard to health. As per the latest census report of the government, the total number of persons with disabled constitutes 26.8 million, of which 14.9 million consists of male and 11.8 million includes female. Issues such as inaccessible buildings and diagnostic equipments, negative/stereotypical attitude of health professionals or their ignorance, lack of training to communicate with people with hearing/speech impairment or intellectual disability, inaccessible transport to reach the health centre, or sheer expense of treatment/rehabilitation etc complicates the problems of persons with disabilities.

Disability –Different Models

The United Nations Declaration on the Rights of Disabled Persons defines disabled persons as any person who are unable to ensure by himself or herself, wholly or partially, the necessities of a normal individual and/ or social life as a result of deficiency, either congenital or not, in his or her physical or mental capabilities. The Persons with Disability Act 1995 identifies seven situations to define disability such as blindness, low vision, leprosy cured, hearing impairment, loco motor disability, mental retardation and mental illness. Persons with disabilities have been defined in different ways/models such as the Medical model (This model defines people with disability as those whose lives are defined by medical and rehabilitative need), the Charity model (This model defines people with disability as individuals who were considered to be appropriate recipients of social and economic support), the social model (This model defines the hindrances faced by persons with disabilities such as the social, cultural and economic barriers) and the right based model (This model emphasis the rights of the disabled especially right to access their rights such as education, health, employment, economic empowerment etc.

Legislative Measures in India

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

The Act has been enacted under Article 253 of the Constitution read with item No. 13 of the Union List. It gives effect to the proclamation on the full participation and equality of the persons with disabilities in the Asian & Pacific Region and provides for their education, employment, creation of barrier free environment, social security, etc. The implementation of the Act requires a multi-sect collaborative approach by the appropriate governments, including various Central Ministries/Departments, States/Union Territories, local bodies.

Rehabilitation Council of India Act, 1992

The Act provides for constitution of the Rehabilitation Council of India for regulating the training of rehabilitation profession-

als, maintenance of a Central Rehabilitation Register, recognized rehabilitation qualifications, minimum standards of educations etc.

National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999

The Act provides for constitution of the Board of the National Trust, Local Level Committees, Accountability and Monitoring of the Trust. It has provisions for legal guardianship of the four categories of the persons with disabilities and for creation of enabling environment for their as much independent living as possible.

The Rights of Persons with Disabilities Bill, 2014

The Rights of Persons with Disabilities Bill, 2014 repeals the Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act, 1995. Disability is defined to include 19 conditions such as: autism; low vision and blindness; cerebral palsy; deaf blindness; hemophilia; hearing impairment; leprosy; intellectual disability; mental illness; muscular dystrophy; multiple sclerosis; learning disability; speech and language disability; sickle cell disease; thalassemia; chronic neurological conditions; and multiple disability. Persons with benchmark disabilities are defined as those with at least 40 per cent of any of the above specified disabilities. The Bill also mentions about social security measures, health, rehabilitation and recreation facilities. The bill casts a duty on Government and the local authorities to take measures to promote health care facilities among persons with disabilities such as methods to prevent disabilities; facilities for training to the staff at the primary health centers; awareness campaigns and dissemination of information for general hygiene, health and essential medical facilities, sexual and reproductive health care especially for women with disability etc

The National Policy 2006

The National Policy recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides those equal opportunities, protection of their rights and full participation in society. The focus of the policy is on (a) Prevention of Disabilities and (b) Rehabilitation Measures. The policy specifically focuses on issues concerning women and children with disabilities.

Niramaya Health Insurance Scheme

The government of India has now introduced a health insurance scheme named the 'Niramaya' for the welfare of persons with Autism Cerebral Palsy, Mental Retardation and Multiple Disabilities. It covers an Insurance cover up to Rs.1.0 lakh.

Scheme of Assistance to Disabled Persons for Purchase / Fitting of Aids/Appliance

The main objective of the Scheme is to assist the needy disabled persons in procuring durable, sophisticated and scientifically

manufactured, modern, standard aids and appliances that can promote their physical, social and psychological rehabilitation.

Statutory Bodies

The main statutory bodies in India are the Rehabilitation Council of India, Office of the Chief Commissioner of Persons with Disabilities and The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. The main functions of the Rehabilitation Council of India are to regulate the training of rehabilitation professionals, maintenance of a Central Rehabilitation Register and to recognize rehabilitation qualifications etc. The Office of the Chief Commissioner for Persons with Disabilities is set up to take steps to safeguard the rights of persons with disabilities. The National Trust is mainly concerned with the realization of equal opportunities, protection of rights and full participation of persons with disability.

International Conventions to safeguard the rights of differently abled

Universal Declaration of Human Rights 1948

The Universal Declaration of Human Rights was adopted by the General Assembly of the United Nations in 1948. The declaration guarantees rights of the disabled including food, clothing, social services, medical care and right to security (Article 23).

International Year of Disabled Persons 1981

The General Assembly proclaimed 1981 as the International Year of Disabled Persons. The main purpose of the plan is equalization of opportunities, rehabilitation and prevention of disabilities. It highlights the right of persons with disabilities to take part fully in the life and development of their societies, enjoy living conditions equal to those of other citizens and have an equal share in improved conditions resulting from socio-economic development.

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities 1993

The General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on 20th December 1993. The standard rules provide a strong moral and political commitment of Governments to take action to attain equalization for persons with disabilities. Rule 2 provides provision of effective medical care to persons with disabilities.

Asian and Pacific Decade of Disabled Persons, 1993-2002 (Biwako Millennium)

The Draft Biwako Millennium Framework identifies seven priority areas for action, in each of which critical issues and targets with specific time frames and actions (1) Self-help organizations of persons with disabilities and related family and parent associations (2) Women with disabilities (3) Early detection, early intervention and education (4) Training and employment, including self-employment (5) Access to built environment and public transport (6) Access to information and communications including information, communication and assistive technologies (7) Poverty alleviation through social security and livelihood programmes

The Millennium Development Goals and Disability

The Millennium Development Goals established a unifying set of developmental objectives for the global community. It identifies the most pressing issue faced by persons with disabilities as their lack of equitable access to resources such as education, employment, health care and the social and legal support systems etc.

The Convention on the Rights of Persons with Disabilities 2008

Article 25 of the Convention on the Rights of Persons with Dis-

abilities 2008 obliges the states Parties to take measures to ensure access for persons with disabilities to health services such as providing quality and free health care, early identification to prevent further disabilities, to promote awareness about the human rights, dignity and needs of persons with disabilities, prohibition of discrimination against persons with disabilities in the provision of health insurance and to prevent discriminatory denial of health care on the basis of disability.

Asia-Pacific Decade of Persons with Disabilities

The UN Economic and Social Commission for Asia and the Pacific have declared the year '2013-2022' as the "Asian and Pacific Decade of Persons with Disabilities" The decade is designed to "promote, protect and ensure the rights of persons with disabilities".

Main Concerns

The majority of the legislation in India related to people with disabilities is based on the medical model of disability; it adopts a welfare attitude, looking at physical impairments of people. The UN Convention believes that, 'disability' results from the interaction of impairments with various barriers which hinder full and active participation in society on an equal basis with others. The main challenges faced by persons with disabilities with regard to health service are:-

1. Accessibility to Medical Care Institutions

Accessibility, is not confined to constructing buildings that have ramps, or building roads – it means ensuring that people with disabilities have access to transportation systems, signs that are both audio and Braille, sports auditoriums, public facilities, hospitals, malls, clinics, and other facilities. Despite being the PWD Act, 1995 in place, which mandates all public places to be accessible, none of the medical care institutions in India is completely barrier-free.

2) Exclusion of Social Model of Disability

Even if we take care of physical barriers, the main hurdle will remain attitudinal barrier. Our medical curriculum talks only about 'medical model of disability' rather than 'social model of disability'. Healthcare professionals can help improve healthcare for disabled through disability studies, a multi-disciplinary field of enquiry that draws on the experiences and perspectives of people with disabilities to address discrimination.

3) Rehabilitation

The need of the hour is to have a Physical Medicine and Rehabilitation (PMR) Department in every medical institution. Despite the orders of Medical Council of India, only a handful of hospitals have PMR department. Similarly, many hospitals do not have Developmental Disabilities Clinic because of which much treatable impairment become permanent disabilities.

4) Affordable Healthcare

Globally, 70 million people need a wheelchair but only 5-15 per cent has access to one. About 360 million people globally have moderate to profound hearing loss but the current production of hearing aids meets only 3 per cent of the developing countries needs. The cost of assistive devices is still high in India. Free devices available through various schemes also come with a tiresome process.

5) Reproductive Health issues and women with disabilities

Women with disability in India have low access to reproductive Health services. It is widely believed that women with disability are neither sexually active nor capable of bearing children. Attitudes of health professionals and negative beliefs prevent them from communicating the issues of reproductive health Physical, sexual and mental abuse inflicted on them is manifold. The issues of women with disabilities are ignored by the disability sec-

tor. There are no schemes by the government for women with disabilities.

6) HIV/AIDS

There is no mention about disability in the HIV Programmes of the Ministry of Health. Disabled people are generally excluded from HIV/AIDS programmes because it is assumed that they are not sexually active and therefore they have no risk for HIV infection. But recent studies show that adolescents and adults with disability are as likely as their non-disabled peers to be sexually active. Men and women with disabilities are even more likely to be victims of violence or rape.

7) Personal Assistance / Care Giver Service

Care giving services are extremely crucial for people with disabilities and elderly.

8) Health Insurance

People with disability are denied insurance on the grounds of disability. People with cerebral palsy and other several disabilities are denied insurance or being asked to pay high premium by private insurance companies.

Conclusion and Suggestions

The theme of International Day of Persons with Disabilities is to "Break barriers, open doors: for an inclusive society for all." But to reach this goal, efforts are needed. Some suggestions includes-

- 1) The schemes of the Health care should be based on provision in the Article 25 of UNCRPD
- 2) A National Disability Health Mission shall be launched
- 3) Reproductive needs of women with disabilities shall be given due importance by the government of India
- 4) National Mental Health Programme shall be implemented effectively
- 5) A comprehensive health insurance shall be provided for people with disability

- 6) Disabled people should be included in HIV/AIDS programmes
- 7) Enhance awareness and improve communication strategies about health and rehabilitation
- 8) Expand training programs to the care givers of disabled persons
- 9) Health needs of elderly people with disabilities shall be taken care of.
- 10) As Poverty and disability are inter-linked. More measures are needed to eradicate poverty by enhancing education and employment facilities
- 11) District disability rehabilitation centers and availability of devices like wheelchairs, surgical footwear, learning equipment like Braille writing machines, low-vision and hearing aids etc shall be expanded to cover uncovered and under-served areas.
- 12) Inclusive education shall be provided at the primary school level, and vocational training courses and Self employment schemes and employment opportunities shall be promoted
- 14) Barrier-free environment such as barrier free facilities in roads, highways, buildings/places/ transportation systems for public use shall be created

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