

PEOPLE WITH SPECIAL NEEDS: INDIA V/S DEVELOPED COUNTRIES

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Abstract

Social exclusion covers various kind of social and economic problems and one of the largest groups that faces social exclusion is that of 'People with Special Needs/People with Disability'. So much so, that many of us are not even aware of the term or its meaning. This paper is an attempt to give an idea about 'People with Disability', laws related to them in India and abroad and finally to discuss the kind of social inclusion policies and systems available for these people in developed countries and policies and systems that are available in India. This study is an effort to highlight the lack of good quality government infrastructure to train and educate children with special needs and lack of social awareness amongst Indians regarding the needs of these people. It is high time for the society as a whole to start thinking of ways to socially include and bring meaning to the lives of People with Special Needs.

Key Words: Autism, Children with Disability (CWD), Disability, Discrimination, People with Disability (PWD), Social Exclusion, Special Children.

Introduction: Social Exclusion is a hard fact of life. Social exclusion is discrimination that can take various forms. It can be on the basis of caste, creed, gender, financial status and can have many more dimensions. Social exclusion means lack of equal opportunities to social services such as health, education; lack of job opportunities; inability to participate in cultural, political, social or economic life. One of the most prominent yet less discussed dimension of social exclusion is on the basis of 'Disability'.

The term 'Disability' is very complex & heterogenous and the exact meaning is still evolving and being redefined continually. Disability covers a wide spectrum of impairments covering physical, mental, intellectual and sensory aspects and that also over a wide range of severity. Disability may be visible or invisible; congenital or geriatric; genetic or acquired. Disability is viewed not just as a medical condition but it is strongly felt that many-a-times people are disabled by society rather than by their bodies. Another issue is measurement of Disability. There are various conceptual and practical problems regarding data collection resulting in lack of uniformity in the data and it becomes difficult to compare them across time or regions.

According to the first official global report on disability conducted by World Health Organisation (WHO) and World Bank in 2011, 15% of the world's population - one billion people have some kind of disability and 3.8% of the world's population – 195 million people have significant disabilities. The number has increased since 1970s when this proportion was 10% of the population. The report also states that disability prevalence is more in developing countries.

In India, 2001 census collected data on **FIVE** kinds of disabilities – seeing, speech, hearing, movement and mental. As per this census 2.1% of the population i.e. 21 million people had some kind of disability. But the 2011 census used a broader definition of Disability and collected data on **EIGHT** kinds of disabilities.¹ As per 2011 census, 2.2% of the total population i.e. 26.8 million people have some kind of disability.² These data are gross under-estimation. As per other estimates such as by World Bank and some NGOs this number could be as high as 80-90 million.³

Various laws have been made across the world and in India for the rights of people with disabilities. But most of these laws were non-binding. First hard law that was binding to all those who signed and accepted it was the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Not much attention was paid to PWD/CWD till this Convention. We will have a cursory look on the major laws that have been framed in India regarding the rights of PWD and then a look on the international laws that are binding.

Laws for People with Special Needs in India

1. First of all, the Constitution of India provides six **fundamental rights** to all her citizens including PWD.
2. **Mental Health Act 1987** focuses on regulating standards in mental health institutions.

¹See Annexure 1.

²This percentage is a bit higher for rural India at 2.3% than urban India with 2.0% of people having disability. Disability was also found more prevalent in males (2.4%) than females (1.9%). Persons with Disabilities in India NSS 76th Round - Report 583 Final July - Dec 2018. Annual Report 2013-14, Department of Disability Affairs.

³ Dr. Nidhi Singal 2010.

3. **The Rehabilitation Council of India Act, 1992** under which The Rehabilitation Council of India was set up to regulate and monitor the training of rehabilitation professional and personnel and to promote research in rehabilitation and special education.
4. **The Persons with Disabilities(Equal Opportunities, Protection of Rights and Full Participation) Act, 1995**(PWD Act 1995) whose objective was to protect and promote the economic and social rights of PWD and to ensure and promote their equality and full participation. The Act was quite exhaustive and covered almost all aspects. The Act recognized the need for economic empowerment of the PWD and for this the Act contained various provisions such as – Identification of posts that can be reserved for PWD; Reservation of posts; Reservation in poverty alleviation schemes. There were other provisions for affirmative action, non-discrimination against PWD, relaxations etc. Yet, the Act had many loopholes e.g. ‘.....authorities are expected to do their best possible within their economic capacity and development’; reservation in jobs only for people with physical disability leaving out people with intellectual, psycho-social and other disabilities.
5. **The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999**was brought to make arrangements for severely disabled children. Under this Act a National Trust Board was established which would look into the appointment of legal guardians for the people suffering from the four named categories of disabilities. The Trust will ensure that PWD lead independent life with dignity.
6. Apart from these laws India has ratified **UNCRPD**,though we have yet not signed the Optional Protocol of the CRPD. Now India is expected to synchronise her laws regarding PWD to the terms of the Convention.
7. The Government of India also announced **National Policy on Disability in 2006**. The policy recognizes that PWD are valuable human resources and must be given an environment where they enjoy full freedom, have equal opportunities and are able to participate in the society. Such an environment will bring vast improvement in their quality of life.
8. **Sarv Shiksha Abhiyaan** that seeks to provide free and compulsory education to all the children, including CWD, till the age of 14. Under SSA a new scheme for inclusive education by the name ‘Home Based Education’ (HBE) has been started where severely intellectually/physically disabled children are provided both home based and alternate education so as to enable them to become independent. Under this programme, parents are taught to become effective teachers. But the problem is that this scheme cannot work for the illiterate parents from low income families.
9. **The Rights of Persons with Disabilities (RPD) Act 2016** replaced PWD Act 1995 and was in consonance with UNCRPD. RPD Act redefined Disability and included 21 types of disabilities as compared to the earlier 7. This Act now looked at Disability from ‘Human Rights’ perspective rather than a ‘Social Welfare’ concern. It increased reservation for PWD in jobs (from 3% to 4%) and higher education institutions (from 3% to 5%) and stated that children with Benchmark Disability (not less than 40% of a specified disability and certified by the certifying authority) shall have right to free education and shall have the choice of regular or special schooling. The Act for the first time talked about inclusive education – a ‘system of education wherein students with and without disabilities learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with disabilities’.
10. **National Education Policy (NEP) 2020** recognises the need for additional special educators who, apart from subject-teaching knowledge, have relevant skills to understand the special requirements of CWSN. For this, shorter post-B.Ed. certification courses will be made available. Also, the policy recognised ‘the importance of creating enabling mechanisms for providing Children with Special Needs (CWSN) or Divyang, the same opportunities of obtaining quality education as any other child’⁴. For this NEP 2020 adopted the provisions of RPD Act 2016.

International Standards on Disability

1. All the human rights listed in the Universal Declaration of Human Rights (UDHR), International Covenant on Economic, Social, and Cultural Rights (ICESCR), and International Covenant on Civil and Political Rights apply to persons with disabilities as well. Similarly, rights envisaged in the ‘Convention for Elimination of All forms of Discrimination against Women’ (CEDAW) and‘Convention of the Rights for the Child’ (CRC), also apply to women and children with disabilities respectively.
2. UN adopted **The Convention on the Rights of Persons with Disabilities** on 13 December, 2006. As noted earlier, UNCRPD is a legally binding instrument and it used the expertise of lived experience of PWD. All the

⁴National Education Policy 2020: 6.2.5 pp 25.

countries signing and ratifying the Convention will follow it in full spirit and will bring changes in their laws in consonance with the Convention and will repeal all such regulations that are inconsistent with it. The Convention uses Human Rights based approach. *It recognizes that PWD also have dignity and worth and their diversity, dignity, independence need to be respected.* They should be given equal opportunities to evolve their capacities and must have a right to preserve their identities. The Convention ensures full and effective enjoyment of fundamental freedoms and human rights. It has 50 Articles of which 26 Articles discuss about a wide range of rights of PWD – right to equality, non-discrimination, equal recognition before the law, education; right to marry, reproduce, retain fertility, privacy; right to participation in cultural life, recreation, leisure, sports, political and public life; right to adequate standard of living, social protection, work and employment and many more. **The Convention also made us understand that children are born with impairments and not disabilities. It is when our society creates barriers for their impairments that these children become disabled.** The UNCRPD recognizes that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others’.⁵

3. In September 2000, United Nations Millennium Summit agreed to achieve certain goals in order to decrease disability.

Indian Systems for People with Disabilities

In India PWD get some scholarships, income tax benefits and a few institutions providing insufficient educational facilities through untrained teachers. As per a report by Ministry of Human Resource Development, India inhabits over 2 million people with autism and there were only 20 autism specific schools in India and each school enrolls 15 to 70 students only. This shows the extent of deficiency of special schools in our country. As per the DISE data, total number of CWD getting education till Grade XII in 2014-15 were 25,99,133 (2.6 million) forming just 1% of the total number of students⁶. Even if we go by the data provided by Census 2011 of 2.2% of the population being afflicted with any kind of disability, then also we can see that less than 50% of the CWD are getting any kind of education. And if we consider the data provided by other institutions then less than 20% of our CWD are getting education. This despite the fact that first school for children with hearing disability came into being in 1884, for blind children in 1887 and for mentally challenged in 1934⁷. Despite various laws made by the government for the PWD and various other efforts undertaken, literacy rates of the disabled are very poor and hence, unemployment and poverty amongst them is alarming. As per a World Bank study (2007) CWD are five times more likely to be out of school than children belonging to SC/ST group. The report also notes that whatever the level of severity, CWD rarely go beyond primary level education. All this affects their job prospects and their future economic and social independence.

Across the world, especially in developed countries the concept of inclusive education is trending. It is felt that CWD should be taught in mainstream schools instead of special schools as it is widely believed that education in special schools segregates CWD from the mainstream and develops a culture of specific disability. Interestingly, since long, educationists in India have also recommended ‘dual approach’ to educate CWSN (India calls her CWD as CWSN i.e. Children with Special Needs). Preferably, such students should be included in the mainstream education system. Yet, if they feel uncomfortable/psychologically disturbed to study in mainstream schools, then they should be sent to special schools.⁸ This dual approach was adopted in the National Policy of Education (MHRD, 1986) stating that “where feasible children with motor handicaps and other mild handicaps will be educated with others, while severely handicapped children will be provided for in special residential schools” (MHRD, 1986: 6). NEP 2020 also reinforces inclusive education. Hence, in India inclusive education is not an issue. The problem here is that most of the children with disabilities are not getting education. The supply of special schools is much less than required and if CWD want education, they have no other option but to join mainstream schools despite the fact that mainstream schools lack teacherstrained to teach them; and curriculums, teaching methods and pedagogy used in mainstream schools may not be suitable for them.

Over the past few years, Indian government is making an effort towards increased access of schools to CWD but the quality of education is not receiving the required attention. Lots of money is being spent through SSA (Sarv Shiksha Abhiyan) and DPEP (District Primary Education Programme) to provide aids and appliances such as white cane, hearing aids, wheel chairs, crutches etc. and in the construction of ramps in the educational institutions. But even the quality of all the appliances and the ramps is under question. Besides, very few people are aware of the schemes of free aids and appliances. And in cases where people received such aid, they had to bribe the officials.

⁵ The Convention on the Rights of Persons with Disabilities, point (e) of the Preamble.

⁶ This data is based on the information culled from Table 3.1 (pp 32 - 33) and Table 3.10 (pp 43) of DISE Data. District Information System for Education (DISE) is the only institution that has been collecting comprehensive data on annual basis on CWD since 1995-96. It started with covering 42 districts but since 2005-06 DISE has been covering all the districts in India (680 districts in 2014-15).

⁷ NHRC, 2010.

⁸ Sargent Report 1944 and Kothari Commission Report 1966.

It is not just education but the other aspects affecting the lives of PWD also lag behind. Transport, buildings and information systems are designed on the same old standards though the law demands creation of barrier free facilities. Today the world has the technology that can help improve and change the lives of PWD. This technology can be in the form of appliances, computers, specially designed vehicles etc. but all these gadgets are available in a wide range of quality. The poverty in India hinders in acquiring good quality products and the cheaper versions instead of helping create inconvenience and many-a-times people stop using them.

There are four approaches to understand and deal with this problem - Medical approach, Welfare approach, Functionality approach and Human Rights approach. In India Disability is only a medical issue and for this Indian government has undertaken certain welfare measures. That PWD are human beings and they also have a right to to everything. All the rights and fundamental freedoms available to a common man should be available to the PWD as well. 'What They Think', 'What They Want' should matter. It should not just be the case of 'What they need'. They must be given a chance and environment that enables them to fulfill their needs and wants as per their own desires independently and with self-respect. We must enable them to participate in all walks of life. Instead, what we are doing is that we are keeping these people outside our routine life. They are mostly invisible, dependent, disempowered. Our government approaches their problems from Welfare perspective and not Human Rights perspective. PWD are considered objects in need of economic, social and medical charity from the govt. They are not considered at par with a normal human being, they are not expected to be productive, to contribute to the society. It was the UN Convention that brought these issues to the fore using Human Rights Approach to understand and help PWD.

Various developed countries have adopted early intervention practices. For this they have launched various schemes e.g. Sure Start Programme in UK, ECEC Programme in Finland, Early Intervention Centre in Hungary, Networking as a model for language learning in Norway Of these, I would like to discuss Early Intervention Centre in Hungary. In this centre situated in Budapest children aged 0-6 years with delayed or impaired development are helped to reach their full potential. For this, a team of specialists – paediatricians, special teachers, physiotherapists, psychologists, social workers and integration specialists pay attention to the development of the child and also on the needs and circumstances of the family. All the above said programmes are appreciated and are in great demand by the families of PWD. When UK govt. decided to scale down her Sure Start Programme, people protested.

It is not only the children with special needs who suffer social exclusion but their families as well. To give more time to the disabled child one of the parents may have to forego job prospects. The other parent may have to forego promotions. Their movement in social circle gets limited and sometimes if the child is severely disabled, such as autistic children prone to violence, get-to-gathers become impossible. Siblings are also affected not only because they have to take care of their special/disabled sibling but also because of the public attitude towards them. All this affects and restricts their routine activities. Families of CWD can experience high levels of stress and need support – emotional, financial and physical. In India our joint family system used to provide such kind of support but the breakup of the system ends all this support. Hence, whenever policies are made for the social inclusion of the disabled children, the policies must also cover their families.

Developed countries also support various schemes that train and assist the families of disabled children. One such scheme is 'Relief Families'. Under this scheme some families offer their services to take care of the CWSN ranging from a day to one week. This gives time to the parents for themselves, for each other and for their other kids. Though we Indians may not appreciate such schemes where one leaves a special child to the care of unknown people for one's own enjoyment. But one who has gone through the stress and suffering of bringing up a disabled child will understand that this respite is badly needed by the entire family.

Hence, if India wants to improve the quality of life of her PWD, then first of all she should make arrangements to provide education to them. And for this, apart from the aid and appliances, what is required is good quality and number of trained teachers. India has an array of laws covering almost all the aspects of issues related to PWD yet what is required is their proper enforcement.

We should also not expect that only govt. will/can bring all the changes. We, as a society also need to wake up and come forward to support the families of PWD as some kind of disabilities are on a rise, especially with increased life expectancy. As per UN Dept of Economic and Social Affairs, countries where life expectancies are over 70 years, people suffer Disability for about 8 years on an average i.e. 11.5% of their life span. It was thought that there are 45-67 cases of Autistic Spectrum disorder (ASD) per 10,000 children. But recent research in Europe has shown this number to be increasing alarmingly with 116.1 cases per 10,000 children. Dr Margaret Chan, director general of the WHO, said disability was part of the human condition. "Almost every one of us will be permanently or temporarily disabled at some point in life. We must do more to break the barriers which segregate people with disabilities, in many cases forcing them to the margins of society."

In the end, I would like to discuss the case of Stephen William Hawking, an eminent cosmologist and theoretical physicist, who suffered from a rare motor neuron disease that was diagnosed at the age of 21 and had gradually paralysed him over the years. He was given two years of life at most by the doctors. His wife Jane Hawking married him after knowing his disabilities and his two years of life expectancy. But with her love, medical help and the use of technology for his communication and movement, he survived and lived 76 extremely productive years. Though in his last years he was able to use only his cheek bone to communicate through appliances made especially for him. Stephen Hawking rightly said 'People with disabilities are vulnerable because of the many barriers we face:

Attitudinal, physical, and financial. Addressing these barriers is within our reach and we have a moral duty to do so..... But most important, addressing these barriers will unlock the potential of so many people with so much to contribute to the world. Governments everywhere can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education, and employment—and never get the chance to shine.

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Annexure 1 Definition of Disability in India

India is a signatory of UN Convention on The Rights of Persons with Disabilities (UNCRPD)(2006). There has been continuum evolution of the definition of 'Disability' in India but in 2016 she adopted the definition as given by UNCRPD. The Rights of Persons with Disabilities Act, 2016 (RPD Act, 2016) defines Disability as 'long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his (a person's) full and effective participation in society equally with others'. "Barrier" means any factor including communicational, cultural, economic, environmental, institutional, political, social, attitudinal or structural factors which hampers the full and effective participation of persons with disabilities in society.

RPD Act 2016 classified Disability as under:

1. Locomotor Disability	2. Visual Disability	3. Hearing Disability
i. Acid attack victims, ii. Leprosy cured person, iii. Polio, iv. Cerebral palsy v. Dwarfism, vi. Muscular dystrophy vii. Other locomotor disability	viii. Blindness ix. Low vision	x. Hearing disability
4. Speech and Language Disability	5. Mental Retardation/ Intellectual Disability	6. Mental Illness
xi. Speech and language disability	xii. Specific learning disabilities xiii. Autism Spectrum Disorder xiv. Other mental retardation/ intellectual disability	xv. Mental illness
7. Other Disabilities	8. Multiple Disabilities	
a) Chronic neurological conditions xvi. Parkinson's disease, xvii. Multiple sclerosis, xviii. Other chronic neurological conditions b) Blood disorder xix. Thalassemia, xx. Haemophilia, xxi. Sickle cell disease	xxii. More than one of the above specified disabilities including deaf	