EVOLUTION OF DISABILITY RIGHTS IN INDIA: LEGAL ISSUES AND CHALLENGES

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ABSTRACT

India has signed and ratified the United Nations Convention on the Rights of Persons with Disabilities, which shows their commitment to promoting equal participation and the rights of persons with disabilities. The Rights of Persons with Disabilities Act, 2016 plays a very significant role in addressing the challenges and providing opportunities for persons with disabilities. But even after the act has been passed, many people with disabilities still face unique challenges in society, including stigma and discrimination. Although it is very important to eliminate barriers, create an inclusive society for everyone, and create awareness to provide support for people with disabilities so that they may ensure and exercise their rights and participate fully in society, In this research paper, the researcher has focused on the hurdles faced by people with disabilities. The author has also focused on the time period of COVID-19, when people were facing a lot of issues and challenges with their disabilities.

Keywords: Covid-19, Diabilities, Inclusive Society, Rights and United Nations Convention.

1. INTRODUCTION

India is believed to have a large number of people with disabilities, second only to China. The 2001 Census estimates that 1.8 to 2.1% of India's population has some form of disability, corresponding to 18.49 to 21.92 million individuals. However, accurate clinical and demographic data on disability is not readily available. The total number of persons with disabilities can vary based on the definition of disability, the level of impairment considered disabling, and the survey methodology used.

The 2001 Census identified specific disabling conditions, but the World Health Organisation estimates that 6–10% of India's population has physical or mental disabilities, affecting over 90 million individuals. Factors like war, conflicts, diseases, accidents, and increased life expectancy contributed to the increasing number of individuals with disabilities worldwide.

In India, there is a unique coexistence of the medical and social models of disability. While disability rights activists have brought attention to the social model of disability, the government and non-governmental organisation sectors still focus on issues of prevalence, management, and prevention of disabilities. This can create a complex situation, especially considering India's obligation to the United Nations Convention on *the* "Rights of Persons with Disabilities," which aims to implement the principles of the social model. It's important to navigate this intersection and work towards a more inclusive and rights-based approach to disability¹.

2. DISABILITY RIGHTS: ORIGIN AND DEVELOPMENT

The background of disability rights in India is characterised by a complex interplay of cultural, societal, and legal factors. Traditionally, people with disabilities in India have faced discrimination, stigmatisation, and marginalization. Various myths and superstitions further perpetuate misconceptions about disability, reinforcing societal biases. Disability was often perceived as a result of past sins, and individuals with disabilities were isolated and excluded from mainstream society. During the colonial period, the British introduced some legislation

¹ RENU ADDLAKHA, DISABILITY STUDIES IN INDIA: GLOBAL DISCOURSES, LOCAL REMEDIES (Routledge India 2013)

that aimed to address disabilities, such as the Lunacy Act of 1912. However, these laws were primarily focused on custodial care and did not emphasise the rights and dignity of individuals with disabilities. After gaining independence in 1947, India faced the formidable task of addressing not only the issue of disability rights but also the broader challenges of poverty, illiteracy, and healthcare disparities.

The perception of disability in India has evolved over four decades, influenced by cultural, social, and legal factors. In the early 1970s, there was scattered advocacy for the rights of people with disabilities². However, in the 1980s, demands for the rights of the disabled began to consolidate under a cross-disability umbrella, leading to the emergence of many non-governmental organizations. In 1995, the government passed the Persons with Disabilities Act, which reserved three percent of government posts for individuals with disabilities³. This marked a turning point, bringing visibility to people with disabilities in educational institutions and government services. The United Nations adopted the Convention on the Rights of Persons with Disabilities in 2006, which India signed and ratified in 2007. The Union Government of India introduced a disability bill in 2012, which was later passed by both houses of parliament in 2016, marking the Rights of Persons with Disabilities Bill. Despite obstacles, the disability rights movement has gained recognition and is the subject of academic work.

3. LEGISLATIVE FRAMEWORK IN INDIA

The Rights of Persons with Disabilities Act, 2016 was a significant development in India's disability rights framework⁴, aligning with the UN Convention on the Rights of Persons with Disabilities. It highlighted accessibility, non-discrimination, and the rights of women and children with disabilities. The bill marked a crucial step in India's evolution of disability rights.

The act expands the types of disabilities recognised from 7 to 21, and the central government has the authority to include more disabilities in the future.

² Nikhil Mehrotra, *Disability Rights Movements in India: Politics and Practice*, 46(6) ECON. & POL. WEEKLY (2011)

³ The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, No.

^{1,} Acts of Parliament, 1996 (India)

⁴ Rights of Persons with Disabilities Act, 2016, No. 49, Acts of Parliament, 2016 (India)

- Blindness: It is a style of disability that refers to total blindness, which means a person can't see anything and can't distinguish between light and dark. It must be incredibly challenging.
- Low Vision: Low vision is a disability where a person's vision is not very clear, with acuity ranging from 6/18 to 10/200 in their better eye and a limited field of vision from 40 degrees to 10 degrees, even with the best possible corrections.
- Leprosy is a chronic infectious disease that can cause various disabilities due to its effects on the skin, nerves, and other body parts. These disabilities may include loss of sensation, muscle weakness, and other complications. It is crucial to provide support and resources to those cured of leprosy to address any disabilities they may have developed⁵.
- Hearing imprisonment is a type of disability that refers to a partial or total inability to hear. It is a disability that can be further categorised into two groups: "deaf" and "hard of hearing." When we say someone is "deaf," it means they have a hearing loss of 70 decibels in speech frequencies in both ears. On the other hand, "hard of hearing" individuals have a hearing loss ranging from 60 decibels to 70 decibels in speech frequencies in both ears⁶. These categories help us understand and address the specific needs of individuals with different levels of hearing impairment.
 - Locomotor disability: It is a type of disability that refers to difficulties in getting from one place to another, often related to disability in the legs. It can encompass issues with bones, joints, and muscles, which can impact a person's movements such as walking, picking up objects, or holding things in their hands.
 - Dwarfism is a growth disorder that causes individuals to have shorter heights than average. It's crucial to understand and support individuals with dwarfism, recognising their unique characteristics and abilities. Creating an inclusive environment ensures equal opportunities and access to resources. It's important to understand and support individuals with dwarfism, just like any other person with unique characteristics and abilities.

⁵ Renu Addlakha & Saptarshi Mandal, *Disability Law in India: Paradigm Shift or Evolving Discourse?*, 44 ECON. & POL. WEEKLY (2009)

- Intellectual Disability: Recognising and addressing the challenges faced by individuals with intellectual disabilities is crucial for fostering an inclusive environment that promotes their well-being and independence. Addressing communication, self-care, social skills, safety, and self-direction can help them lead fulfilling lives.
- Mental Illness: It's important to raise awareness, provide support, and promote understanding for individuals facing mental health challenges. Recognising the impact of mental illnesses such as "bipolar disorder, depression, schizophrenia, anxiety, and personality disorders" on a person's thoughts, emotions, and behaviours is crucial for creating a supportive and inclusive environment.
- Autism spectrum disorder is a type of disability that is indeed an umbrella term that encompasses various conditions, such as autism. Support and understanding are crucial for individuals with autism spectrum disorder, as they affect brain processing and storage. Recognising challenges in communication, social interactions, and other activities is vital for creating an inclusive and supportive environment⁷.

• Cerebral palsy is a type of disability in which a physical condition affects muscle coordination due to brain damage, typically occurring at or before birth. It's important to note that cerebral palsy is not a progressive condition, meaning it does not worsen over time.

- Muscular dystrophy is a genetic disease or disorder causing muscle weakness and mass loss, which worsens over time. It is crucial to provide support and resources to individuals affected by this progressive condition.
- Chronic Neurological Conditions: Chronic neurological conditions, including Alzheimer's, Parkinson's, dystonia, ALS, Huntington's, neuromuscular, multiple sclerosis, and epilepsy, are disabling illnesses affecting a significant portion of the population⁸. These individuals may experience various symptoms that require healthcare services.
- Specific Learning Disabilities: SLD includes conditions like dyspraxia, dysgraphia, dyscalculia, and ADHD, which can impact learning. Each condition

⁷ Nikhil Mehrotra, *supra* note 2

⁸ Vineet Chaturvedi, *International and Indian Legal Framework for Disabled*, 5(6) INT'L J. L. MGMT. & HUMAN. (2021)

presents unique challenges, necessitating the provision of appropriate support and accommodations to aid individuals in their learning and daily activities.

- Multiple Sclerosis is a disease that disrupts the central nervous system, causing symptoms like fatigue, weakness, pain, tingling, numbness, muscle spasms, difficulty walking, vertigo, dizziness, memory problems, vision and hearing changes, depression, anxiety, sexual problems, bladder and bowel issues, and speech and swallowing difficulties.
- Speech and Language Disability: It is a type of disability that refers to a permanent disability that arises from conditions such as laryngectomy or aphasia, which can affect one or more components of speech and language due to organic or neurological causes. It can impact a person's ability to communicate effectively.
- Thalassemia is a type of disability that is a genetically inherited blood disorder that affects the production of hemoglobin. People with thalassemia produce less or abnormal haemoglobin, leading to the destruction of a large number of red blood cells, causing anemia. Common symptoms of thalassemia include pale skin, fatigue, and a dark coloration of the urine⁹.
- Haemophilia is a type of disability in which a blood disorder is characterised by a lack of blood clotting proteins, which leads to prolonged bleeding. It is more common in males, while females are rarely affected by haemophilia¹⁰.
 - Sickle Cell Disease: It is a type of disability that is indeed a group of blood disorders that cause red blood cells to become sickle-shaped, misshapen, and break down. It is a genetically inherited disease.
 - Multiple Disabilities, including Deaf Blindness: Multiple Disabilities, including Deaf Blindness, is a disability characterised by the simultaneous occurrence of multiple physical and mental disabilities, such as intellectual disability and blindness, mental retardation and orthopaedic impairment, and locomotor disability and speech impairment.
 - Acid Attack Victim: It is style of disability in which individuals, mostly women, who have been victims of the heinous crime of acid throwing. These attacks often result in severe disfigurement of the face and other body parts. It's a devastating form of violence that has long-lasting physical and emotional effects.

⁹ Id.

¹⁰ Renu Addlakha & Saptarshi Mandal, *supra* note 5

• Parkinson's Disease: It is a central nervous system disorder that primarily affects movement. It is characterized by symptoms such as tremors, stiffness, and difficulty with coordination and balance. PD is a progressive disease, meaning it tends to worsen over time.

3.1 Schemes Under Which Disabled Persons Access Their Rights.

• Scheme of assistance to disabled persons for purchase/ fitting of aids/ appliances scheme (ADIP scheme)

The ADIP Scheme helps people with disabilities buy and fit aids and appliances that can improve their lives. The scheme aims to promote their physical, social, and psychological rehabilitation by reducing the impact of their disabilities¹¹. To be eligible, a person must be an Indian citizen, have a 40% disability certificate, and have a monthly income of not more than Rs 20,000. The scheme provides assistance to those who haven't received help for the same purpose in the last few years. The scheme covers aids and appliances that cost up to Rs 10,000 for a single disability and even more for students with disabilities,

• Scheme of scholarships for students with disability.

The National Scholarships for Persons with Disabilities programme provides 500 new scholarships annually for post-matric professional and technical courses for students with disabilities like cerebral palsy, mental retardation, multiple disabilities, and profound or severe hearing impairment¹². Eligibility requires a 40% or more disability and a monthly family income of Rs. 15,000. Scholarship amounts vary based on study level and student status. Students receive up to Rs. 10,000 per year for course fees, supporting their education.

• Schemes for voters with disabilities.

Voters with disabilities and reduced mobility or physical functions are provided with facilities to ensure their inclusion in the electoral process. Eligible individuals can enrol in the electoral roll by filling out Form 6 online at www.nvsp.in or at designated

¹¹ Vineet Chaturvedi, supra note 8

¹² Ayushi Pandey, *Rights of Person with Disability in India*, 4(3) INT'L J. L. MGMT. & HUMAN. (2021)

voter enrolment centers. These centres and the offices of Electoral Registration Officers and Assistant Electoral Registration Officers are accessible for persons with disabilities and reduced mobility or physical functions. The necessary forms and assistance in filling them out are available at these locations. Alternatively, individuals can also send the forms by post. It's important to ensure that everyone has equal access to the voting process¹³.

4. THE IMPACT OF COVID ON PEOPLE WITH DISABILITIES

The COVID-19 pandemic has disproportionately affected certain groups with disabilities, including children, women, and girls; those experiencing homelessness; and those in remote and rural areas. Governments worldwide have failed to address these unique challenges. Inclusive responses should consider the intersectionality of discrimination faced by individuals with disabilities, addressing the risks they face due to multiple forms of discrimination.

5.1 Issues Faced by Children

Children with disabilities have been disproportionately affected by the measures taken by governments during the pandemic. It is very disappointing to learn that many governments did not take adequate measures to protect the health and safety of these children, both in institutions and in the community. The lack of essential supplies and services, such as food, medicine, healthcare, respite care, rehabilitation, and education, is alarming. It's distressing to know that children with disabilities and their families were left without the necessary support during such a challenging time.

So it is very crucial for governments to recognise the unique needs of children with disabilities and take disability-specific and child-specific measures to support them and their families. By ensuring access to essential resources and services, we can help mitigate the

impact of the pandemic on these vulnerable children and promote their well-being¹⁴. Also, it is very disappointing that children with disabilities, especially those living in poverty or rural areas, faced challenges accessing essential supplies during the pandemic. NGOs and charities play a crucial role in delivering these supplies, but it's concerning to learn that they faced difficulties in reaching children with disabilities. The closure of schools and disability services further exacerbated the situation, as many children relied on these institutions for food and medication. The lack of access to these vital resources must have been incredibly difficult for them and their families.

Hence, governments and organisations need to work together to ensure that children with disabilities have equal access to essential supplies, regardless of their location or socioeconomic status.

5.2 Issues faced by women and girls

The COVID-19 pandemic has disproportionately affected women and girls with disabilities, leading to severe human rights abuses. Discrimination based on disability, gender identity, and age has resulted in sexual assault, domestic violence, and police brutality, causing distress. It is very disappointing to know that these vulnerable individuals have faced such horrific acts of violence. Governments must recognise the unique challenges faced by women and girls with disabilities, take active measures to protect their rights, and provide support¹⁵.

The lack of government interventions and support for sexual assault victims is unacceptable, and governments must prioritise the safety and well-being of women and girls with disabilities by providing necessary resources and assistance.

5.3 Issues faced by Persons with disabilities in remote and rural areas.

It's unfortunate that the government did not take measures to protect people with disabilities in remote and rural areas¹⁶. This lack of action has resulted in additional barriers for them,

¹⁴ Shanaz Hajira, Advancing Disability Rights in India: From Fragmented Movements to Inclusive Policies, SSRN ELEC. J. (2023)

¹⁵ Shailaja Tetali, Sureshkumar Kamalakannan, Shilpa Sadanand, Melissa Glenda Lewis, Sara Varughese, Annie Hans and G. V. S. Murthy, *Evaluation of the Impact of the First Wave of COVID-19 and Associated Lockdown Restrictions on Persons with Disabilities in 14 States of India*, 19(18) INT'L J. ENV'T RSCH. PUB. HEALTH (2022)

including difficulties accessing essential resources like food, medication, healthcare, and technology. It's important for governments to address these disparities and ensure that all individuals, regardless of their location, have equal access to necessary support and services.

6. CHALLENGES IN PSYCHIATRIC DISABILITY CERTIFICATION

Mental disorders can encompass a wide range of conditions, including those you mentioned like schizophrenia, anxiety disorders, mood disorders, and more. The certification for disability benefits can vary across different countries and there are ongoing debates about which mental disorders should be considered for these benefits. In India, policymakers have taken a progressive approach by including all mental illnesses for disability assessment and benefits¹⁷.

Hence, it is important to understand that the certification is based on the amount of disability which has been experienced by the individual rather than the specific diagnosis.

6.1 Challenges in validating temporary Vs. permanent disability.

When it comes to psychiatric illnesses, the validation process can be challenging. The fluctuating nature of these conditions makes it difficult to determine the extent of impairment and the potential for improvement. In some cases, a temporary disability certificate may be issued if there's uncertainty about the possibility of improvement with treatment.¹⁸ This temporary certificate is valid for 5 years and allows for reassessment as the individual's condition evolves. It's important for psychiatrists to carefully consider the potential for improvement and exercise caution before issuing a permanent disability certificate.

Thus, the nature and course of mental illness can introduce some margin of error in the certification process.

6.2 Challenges in the validation of autism.

The Rights of Persons with Disabilities Act, 2016 has yet to include the assessment of autism. The specific names of professionals certifying disabilities can create roadblocks for individuals seeking disability certificates. It would be more beneficial to have a flexible

¹⁷ Shanaz Hajira, *supra* note 14

¹⁸ Ayushi Pandey, *supra* note 12

approach where the medical authority can determine the appropriate specialist for certification. This would save people from the hassle of travelling to different cities and hospitals. Additionally, allowing private practicing doctors to certify disabilities with proper checks and balances could address the shortage of human resources and provide accessibility to disabled patients in rural areas.

6.3 Challenges in the validation of learning disability.

Learning disorders, or biologically based neuro-developmental conditions, impact a child's ability to process and communicate information. The 2018 notification defines "specific learning disabilities" as a diverse group affecting language processing, including comprehension, speaking, reading, writing, spelling, and mathematical calculations. This recognition in disability certification is a positive step towards providing support and accommodations for individuals with learning disorders.

Also, the gazette notification issued on January 4, 2018 regarding the assessment of specific learning disabilities did have some gaps. It's important to involve a multidisciplinary team in the diagnosis and certification process, and it seems that the involvement of psychiatrists or child psychiatrists was not explicitly mentioned. In reality, these professionals often play a crucial role in assessing and supporting individuals with learning disorders. Additionally, the requirement for repeat certification at the ages of 14 and 18 may pose challenges and an unnecessary burden for individuals with specific learning disabilities¹⁹.

So, it is important to address these gaps and work towards a more comprehensive and inclusive approach to assessing and supporting individuals with learning disorders.

7. CONCLUSION

At the end, the author concludes that the ratification of the United Nations Convention on the Rights of Persons with Disabilities was a significant step for India in recognising the rights of persons with disabilities. The Rights of Persons with Disabilities Act, 2016 is a significant improvement over the previous act, which was the Persons with Disabilities Act, 1995. The Rights of Persons with Disabilities Act focuses on ensuring rights, reducing discrimination,

¹⁹ Ayush Bhojwani, Disability Laws in India: Conceptual Study, 11 SUPREMO AMICUS (2019)

and promoting barrier-free access. The shift from a charity-based approach to a rights-based approach, as well as the adoption of a biopsychosocial model, are some of the positive steps forward. While there is some criticism about the act not focusing on mental disabilities, it is still a major improvement compared to the previous act over approximately two decades ago.

Thus, there are also some shortcomings in the act on which the government must work. So it becomes the duty or it is important for the state governments to take proactive measures in implementing and addressing the shortcomings of the act, as in the time period of COVID-19, the government failed to do so. So, by ensuring effective implementation, the community can provide a more inclusive and equitable environment for people with disabilities in society.

Hence, the researcher concludes the paper by suggesting some of the key points of the Rights of Persons with Disabilities Act, 2016, such as implementing prevailing laws in such a manner that disabled persons access their rights and creating awareness among the people who are facing such problems with their disabilities.

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