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RIGHTS OF PERSONS WITH DISABILITIES IN INDIA: PROVISIONS, PROMISES AND REALITY

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RIGHTS OF PERSONS WITH DISABILITIES IN INDIA: PROVISIONS, PROMISES AND REALITY

Abstract

The paper *Rights of Persons with Disabilities in India: Provisions, Promises and Reality* traces the historical evolution of the disability related legal provisions in India briefly, in the context of the United Nations mandated Declaration on the Rights of Disabled Persons (1975) and the Convention on the Rights of the Persons with Disabilities (CRPD,2007). In such a scenario, the paper attempts to arrive at an understanding of the extent to which the provisions have been implemented. To this extent, the researcher conducted a series of telephonic interviews with several parent-advocates who have been vocal about disability rights in India. An extensive interview was also conducted with a parent-activist, Mr. A.Joshi, who has been at the forefront of the disability rights movement in India with his personal as well as professional engagements at a national level and who was able to provide a critical understanding of the systemic roadblocks in the implementation of the legal provisions. The paper particularly tried to look at the implementation of the provisions of the Rights of Persons with Disabilities Act (RPwD Act), 2016 and the proposed dilution of the National Trust Act (NTA), 1999 that was hailed by many as a landmark Act for its provision of legal guardianship of individuals with special needs (after 18 years of age). A critical reading of the press coverage on these issues as well as the extensive interview with Mr. Joshi threw significant light on them. In conclusion, although several remarkable disability laws have been passed in India, till date, due to systemic inadequacies and loopholes, the fissures between *what could have been achieved* and *what has been achieved*, are quite wide. A more concerted effort needs to be taken towards strengthening the dialogue between various stakeholders in the disability sector as well as place pressure on the powers that be, to acknowledge the gaps inherent in the system.

Keywords

Human Rights, Disability, India, Convention on the Rights of the Persons with Disabilities, the Rights of Persons with Disabilities Act (RPwD Act), 2016, National Trust Act (NTA), 1999, Legal Provisions, Implementation, Dilution

1. INTRODUCTION

At its very core, the term Human Rights refers to the rights and freedoms that an individual is entitled to, without any discrimination. The United Nations founded in 1945, adopted the Universal Declaration of Human Rights in 1948. This was considered a milestone as it “was the first attempt to set out at a global level the fundamental rights and freedoms shared by all human beings”

“What are Human Rights?” (2020, Dec 28) Retrieved from <https://www.equalityhumanrights.com/en/human-rights/what-are-human-rights>.

The United Nations website states:

Drafted by representatives with different legal and cultural backgrounds from all regions of the world, the Declaration was proclaimed by the United Nations General Assembly in Paris on 10 December 1948 by General Assembly resolution 217 A (III) as a common standard of achievements for all peoples and all nations. It sets out, for the first time, fundamental human rights to be universally protected. Since its adoption in 1948, the UDHR has been translated into more than 500 languages - the most translated document in the world - and has inspired the constitutions of many newly independent States and many new democracies. The UDHR, together with the International Covenant on Civil and Political Rights and its two Optional Protocols (on the complaints procedure and on the death penalty) and the International Covenant on Economic, Social and Cultural Rights and its Optional Protocol, form the so-called International Bill of Human Rights. “Human Rights” (2021, Jan 5) Retrieved from <https://www.un.org/en/sections/issues-depth/human-rights/>

Human Rights include the Right to Life and Liberty, Freedom from Slavery and Torture, Freedom of Opinion and Expression, the Right to Work and Education, amongst others. Although, the Universal Declaration of Human Rights (UDHR) has a wide-ranging influence on the policies and legal frameworks of its member countries, it is not legally binding. But there are other international agreements that have arisen from within the framework of the UDHR, that are legally binding for those countries that ratify them. For example, the International Covenant on Civil and Political Rights (ICCPR) and International Covenant on Economic Social and Cultural Rights (ICESCR). “What is the Universal Declaration of Human Rights?” (2021, Jan 13) Retrieved from

<https://humanrights.gov.au/our-work/what-universal-declaration-human-rights#:~:text=The%20Universal%20Declaration%20begins%20by,are%20or%20where%20they%20live>

2. HOW DO WE DEFINE DISABILITY?

The Merriam-Webster dictionary defines Disability as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.”

“Disability” (2021, Jan 13) Accessed from the website <https://www.merriam-webster.com/dictionary/disability>.

According to the World Health Organization, Disability has three dimensions:

Impairment in a person's body structure or function, or mental functioning; examples of impairments include loss of a limb, loss of vision or memory loss.

Activity limitation, such as difficulty seeing, hearing, walking, or problem solving.

Participation restrictions in normal daily activities, such as working, engaging in social and recreational activities, and obtaining health care and preventive services.

“Disability and Health Overview” (2021, Jan 13) Retrieved from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html#:~:text=According%20to%20the%20World%20Health,%2C%20walking%2C%20or%20problem%20solving>

The meaning of the term disability as well as its nomenclature has evolved over the years. The term disability is all encompassing and may include a wide range of conditions, such as an individual’s mental health, vision, hearing, social relationships, movement, communication, speech, fine motor and gross motor skills, executive functioning (memory, processing, perception) etc. Not all individuals with the same impairment, will have the same experiences nor is a disability, a static condition—it can vary in its degree (mild, moderate, severe), intensity (high/low) as well as its effects on the functional adaptability of the individual to their environment.

3. DECLARATION ON THE RIGHTS OF DISABLED PERSONS

The General Assembly of the United Nations passed the Declaration of the Rights of Disabled Persons on December 9, 1975. It was the 3447th Resolution passed by the General Assembly.

According to the website of the Office of the High Commissioner of Human Rights (United Nations), the Declaration on the Rights of Disabled Persons included the following,

“Declaration on the Rights of the Disabled Person” (2021, Jan 5) Retrieved from <https://www.ohchr.org/en/professionalinterest/pages/rightsofdisabledpersons.aspx>

1. The term "disabled person" means any person unable to ensure by himself or herself, wholly or partly, 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.
2. Disabled persons shall enjoy all the rights set forth in this Declaration. These rights shall be granted to all disabled persons without any exception whatsoever and without distinction or discrimination on the basis of race, colour, sex, language, religion, political or other opinions, national or social origin, state of wealth, birth or any other situation applying either to the disabled person himself or herself or to his or her family.
3. Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.
4. Disabled persons have the same civil and political rights as other human beings; paragraph 7 of the Declaration on the Rights of Mentally Retarded Persons applies to any possible limitation or suppression of those rights for mentally disabled persons.
5. Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.
6. Disabled persons have the right to medical, psychological and functional treatment, including prosthetic and orthetic appliances, to medical and social rehabilitation, education, vocational training and rehabilitation, aid, counselling, placement services and other services which will enable them to develop their capabilities and skills to the maximum and will hasten the processes of their social integration or reintegration.
7. Disabled persons have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions.
8. Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning.
9. Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned, to differential treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom. If the stay of a disabled person in a specialized establishment is indispensable, the environment

and living conditions therein shall be as close as possible to those of the normal life of a person of his or her age.

10. Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.
11. Disabled persons shall be able to avail themselves of qualified legal aid when such aid proves indispensable for the protection of their persons and property. If judicial proceedings are instituted against them, the legal procedure applied shall take their physical and mental condition fully into account.
12. Organizations of disabled persons may be usefully consulted in all matters regarding the rights of disabled persons.
13. Disabled persons, their families and communities shall be fully informed, by all appropriate means, of the rights contained in this Declaration.

These provisions provide a framework for the purposes of international or domestic law and are not legally binding on member countries. In 2007, the **Convention on the Rights of the Persons with Disabilities** was adopted.

4. THE CONVENTION ON THE RIGHTS OF THE PERSONS WITH DISABILITIES

In 2007, the United Nations adopted an international human rights treaty—the Convention on the Rights of the Persons with Disabilities—to protect the rights and dignity of persons with disabilities. Signatories of the Convention are “required to promote, protect and ensure the full enjoyment of human rights by persons with disabilities and ensure that persons with disabilities enjoy full equality under the law.”

“Convention on the Rights of Persons with Disabilities” (2021, Jan 5) Retrieved from the website https://en.wikipedia.org/wiki/Convention_on_the_Rights_of_Persons_with_Disabilities

The Convention lays down eight Guiding Principles namely,

There are eight guiding principles that underlie the Convention and each one of its specific articles:

“Guiding Principles of the Convention” (2021, Feb 8) Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/guiding-principles-of-the-convention.html>

1. Respect for inherent dignity, individual autonomy including freedom to make one’s own choices, and independence of persons.
2. Non-discrimination
3. Full and effective participation and inclusion in society
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
5. Equality of opportunity
6. Accessibility
7. Equality between men and women
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

There are 163 signatories to the Convention on the Rights of Persons with Disabilities and 181 Ratifications/Accessions (as of February 20, 2020)

“CRPD List of Countries by Signature: Confirmation: Accession: Ratification” (2021, Feb 8) Retrieved from the website <https://www.disabled-world.com/disability/discrimination/crpd-milestone.php>

5. INDIA AND THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES (CRPD)

India ratified the CRPD in 2007. In 2015, the First Country Report on the CRPD was submitted. The National Disability Network (NDN) and the National Committee on the Rights of Persons with Disabilities (NCRPD) prepared a Parallel Report of India on the CRPD. The Parallel Report on the CRPD includes extensive data collated from field research, workshops, discussions etc., with partner organizations on the implementation of the Convention in the Indian context.

The report sheds light on the lacunae inherent in the Rights of Persons with Disabilities (RPWD) Act (2016), a landmark legislation, brought in by the Government of India, amending the previous RPWD Act of 1995. The report states,

“This Act has adopted the CRPD definition of disability for non-discrimination. It covers the private sector, mentions timelines for making buildings and services accessible and provides for the right to home and family, reproductive rights, right to live in a community, protection from abuse and violence, access to justice and other rights. However, there are concerns that the Act does not fully comply with the CRPD in certain aspects and that there is some dilution of some of the rights. These aspects include the provision of limited guardianship, not mentioning accessibility as a right, not stating the right to vote/stand for elections explicitly, allowing for the termination of the pregnancy of a woman with severe disability without her express consent and a few others.” (Parallel Report of India on the Convention on the Rights of Persons with Disabilities (CRPD), National Disability Network (NDN) and National Committee on the Rights of Persons with Disabilities (NCRPD) March 31, 2017”.

“Parallel Report of India on the Convention on the Rights of the Persons with Disabilities” (2021, Feb 8, pp.4-5) Accessed from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/DRAFT%20CRPD%20India%20Parallel%20Report%20\(31st%20March%202017\).pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/DRAFT%20CRPD%20India%20Parallel%20Report%20(31st%20March%202017).pdf)

6. DISABILITY RELATED ACTS AND POLICIES IN INDIA: A BRIEF HISTORY

The 2011 Census of India pegs the number of disabled individuals in India at 26.8 million. But various other reports have provided estimates that are higher than the number arrived at by the Census. A 2009 World Bank report estimated that 5-8% of India’s population had a disability. “Disability in India” (2021, Feb 9) Retrieved from https://en.wikipedia.org/wiki/Disability_in_India#:~:text=1%20October%202007.-,National,the%20disabled%20in%20the%20country

A brief timeline of significant legislations in the field of Disability in India are:

INDIAN LUNACY ACT (1912)

“Indian Lunacy Act (1912)” (2021, Feb 10) Retrieved from <http://www.bareactslive.com/ACA/act3595.htm>

The Indian Lunacy Act of 1912, of Pre-Independence era, defined a “lunatic” as “an idiot or a person of unsound mind” and a “Criminal lunatic” was defined as “any person for whose detention in, or removal to an asylum, jail or other place of safe custody, an order has been made in accordance with the provisions of section 330 or sections 335 and 336 of the Code of Criminal Procedure, 1973 or of section 30 of the Prisoners Act, 1900, or of section 103A of the Indian Army Act, 1911.” On the provision of Asylums, the Act stated the following;

“(1) No person other than a criminal lunatic or a lunatic so found by inquisition shall be received or detained in an asylum without a reception order save as provided by sections 8, 16 and 98 (2) A boarder received in an asylum under the proviso to sub-section (1) shall not be detained in the asylum for more than twenty-four hours after he has given the person in charge of the asylum notice in writing of his desire to leave such asylum.”

THE MENTAL HEALTH ACT (1987):

The Mental Health Act was passed on May 22, 1987. The Act was passed 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.” “Mental Health Act, 1987” (2021, Feb 9) Retrieved from https://en.wikipedia.org/wiki/Mental_Health_Act,_1987

It is interesting to note the change in nomenclature from “lunacy” to “mentally ill”, perhaps signalling the need to look deeper into the mental states of the affected individuals.

THE REHABILITATION COUNCIL OF INDIA ACT, 1992

The Rehabilitation Council of India was set up as a registered society in 1986. In 1992, the Rehabilitation Council of India Act was enacted in the Parliament and it became a statutory body in 1993. The RCI Act was amended by the Parliament in 2000 to make its reach more broad-based. Some of its functions include:

- a) To standardize norms to regulate and monitor services provided to individuals with disability.
- b) To standardize syllabi and to maintain a Central Rehabilitation Register of all qualified professionals and personnel working in the field of Rehabilitation and Special Education.
- c) The Act also provides the Rehabilitation Council the power to prescribe punitive action against unqualified persons delivering services to persons with disability. “Rehabilitation Council of India Act, 1992” (2021, Feb 9) Retrieved from the website <http://www.rehabcouncil.nic.in/>

THE PERSONS WITH DISABILITIES (PwD), ACT 1995

“The Persons with Disabilities Act, 1995” (2021, Feb 9) Retrieved from <http://niepid.nic.in/acts-and-policies.php>

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation Act, 1995) came into force on February 7, 1996.

Under this Act, 7 types of Disabilities were recognized, namely,

- 1) Blindness
- 2) Low Vision
- 3) Leprosy cured
- 4) Hearing Impairment
- 5) Locomotor Disability
- 6) Mental Retardation
- 7) Mental Illness

The Act provided for both “preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of person with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc.”

NATIONAL TRUST ACT, 1999

According to the National Institute for the Empowerment of Persons with Intellectual Disabilities (NIEPID) website, in 1999, the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, was passed. “The Act provides for the constitution of a body at the national level for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and for matters connected therewith or incidental there to.” “National Trust Act, 1999 (2021, Feb 9) Retrieved from <http://niepid.nic.in/acts-and-policies.php>

The National Trust is a statutory body of the Ministry of Social Justice and Empowerment, Government of India.

The Objectives of the National Trust are:

“Objectives” (2021, Feb 9) Accessed from <https://www.thenationaltrust.gov.in/content/innerpage/introduction.php>

- 1) To enable and empower persons with disability to live as independently and as fully as possible within and as close to their community as possible.
- 2) To facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability
- 3) To extend support to its registered organizations to provide need based services and
- 4) To evolve procedures for appointments of guardians and trustees for persons with disabilities.

RIGHTS OF PERSONS WITH DISABILITIES (RPwD Act), 2016

According to the Department of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, Government of India, the RPwD Act, 2016 was enacted on December 12, 2016, and came into effect from April 19, 2017. The RPwD Act of 2016 superseded the Persons with Disabilities Act of 1995. Considered a landmark judgement, it expanded the number of recognized disabilities from the previous 7 (Low vision, Blindness, Locomotor Disability, Hearing Impairment, Leprosy Cured, Mental Retardation and Mental Illness) to now include 21.

The salient features of the Act “The Rights of Persons with Disability (RPwD) Act, 2016” (2021, Feb 9) Accessed from <http://disabilityaffairs.gov.in/content/page/acts.php> , are:

- i. Responsibility has been cast upon the appropriate governments to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others.
- ii. Disability has been defined, based on an evolving and dynamic concept.
- iii. The Act covers the following specified disabilities:-
 1. Physical Disability
 - a. Locomotor Disability
 - i. Leprosy Cured Person
 - ii. Cerebral Palsy
 - iii. Dwarfism
 - iv. Muscular Dystrophy
 - v. Acid Attack Victims
 - b. Visual Impairment
 - i. Blindness
 - ii. Low Vision
 - c. Hearing Impairment
 - i. Deaf
 - ii. Hard of Hearing
 - d. Speech and Language Disability
 2. Intellectual Disability
 - a. Specific Learning Disabilities
 - b. Autism Spectrum Disorder
 3. Mental Behaviour (Mental Illness)
 4. Disability caused due to-
 - a. Chronic Neurological Conditions such as-
 - i. Multiple Sclerosis
 - ii. Parkinson’s Disease
 - b. Blood Disorder-
 - i. Haemophilia

ii. Thalassemia

iii. Sickle Cell Disease

5. Multiple Disabilities

- iv. Additional benefits have been provided for persons with benchmark disabilities and those with high support needs.
- v. Every child with benchmark disability between the age group of 6 and 18 years shall have the right to free education.
- vi. 5% reservation in seats in Government and Government aided higher educational institutions for persons with benchmark disabilities.
- vii. Stress has been given to ensure accessibility in public buildings (both Government and private) in a prescribed time-frame.
- viii. 4% reservation in Government jobs for certain persons or class of persons with benchmark disability.
- ix. The Act provides for grant of guardianship by District Court or any authority designated by the State Government under which there will be joint decision – making between the guardian and the persons with disabilities.
- x. Broad based Central & State Advisory Boards on Disability to be set up as policy making bodies.
- xi. The Act provides for strengthening of the Office of Chief Commissioner of Persons with Disabilities and State Commissioners of Disabilities which will act as regulatory bodies and Grievance Redressal agencies and also monitor implementation of the Act. These Offices will be assisted by an Advisory Committee comprising of experts in various disabilities.
- xii. Creation of National and State Fund to provide financial support to the persons with disabilities.
- xiii. The Act provides for penalties for offences committed against persons with disabilities.
- xiv. Designated special Courts to handle cases concerning violation of rights of PwDs.

THE MENTAL HEALTH CARE ACT (2017)

On April 7, 2017, the Mental Health Care Act was passed. It superseded the already existing Mental Health Act of 1987. The Act in its opening paragraph stated its purpose as “to provide for mental healthcare and services for persons with mental illness and to protect, promote and fulfil the rights of such persons during delivery of mental healthcare and services and for matters connected therewith or incidental thereto.” One significant change this Act brought in, was that it decriminalized attempted suicide which was a punishable offence under Section 309 of the Indian Penal Code. “Mental Healthcare Act, 2017” (2021, Feb 9) Accessed from https://en.wikipedia.org/wiki/Mental_Healthcare_Act,_2017

7. IMPLEMENTATION OF PROVISIONS AND EXISTING REALITIES: A DISCUSSION

Although the brief history of the legal provisions in the field of disability in India reflects the changing mind set towards mental health and disability, the reality on the ground is far from perfect. Over the years, questions have been raised by activists in the field regarding the non-implementation or half-hearted implementation of the legal provisions, attempts to dilute the autonomous nature of institutions working for disability as well as not enough being done towards accessibility and inclusion.

A recent controversy that has created a furore amongst parent-activists is the proposal to repeal the National Trust Act, 1999. According to a report in a leading newspaper, the parents raised three main objections—First, they cited how the move could be disastrous as it may do away with the provision of legal guardianship of individuals (on attaining the age of 18); Secondly, the Niramaya Health Insurance Scheme offering free coverage up to 1 lakh may also be scrapped.

Thirdly, parents are apprehensive of the future status and the potential loss of educational scholarship of Rs.28,500/- allocated through local bodies under *Ashwasam Kiranam* received by mothers taking care of those under the National Trust Act “Parents of special children up in arms over move to repeal National Trust Act” (2021, Jan 7) Accessed from <https://www.thehindu.com/news/cities/Kochi/parents-of-special-children-up-in-arms-over-move-to-repeal-national-trust-act/article32993804.ece>

Another report states how the proposed repeal is short sighted in nature— “The plan, apparently, is to include all disabilities under the Rights of Persons with Disabilities Act, 2016; this signifies a fatal form of myopia. Disability is a diverse spectrum of challenging conditions. Bringing every piece of legislation together—a typical bureaucratic urge to centralize—could lead to the exclusion of specialized protections” “Short-sighted: National Trust Act repeal” (2021, Jan 7) Accessed from <https://www.telegraphindia.com/opinion/short-sighted-national-trust-act-repeal/cid/1795628>

The Parallel Report of India on the Convention on the Rights of Persons with Disabilities (CRPD), 2017 has shed light on several significant shortcomings in the implementation of the the RPwD Act (2016), due to loopholes existing in the systems of governance, nomenclature used in Constitutional provisions etc. For the purpose of the paper, a few of them will be highlighted here—

“Article 326 of the Constitution allows for the disqualification of persons with ‘unsound mind’ from being registered as voters for elections. The disability sector has objected to the vague phrase ‘unsoundness of mind’ which is commonly used to deprive mentally and intellectually impaired citizens from exercising their voting rights or contesting elections.

The RPwD Act, 2016 only mentions the access to voting but does not provide for the right to vote and the right to stand for elections.

There are elaborate quasi-judicial systems of Child Welfare Committees, Child-lines (a countrywide help-line for children in distress), the State and District child protection societies, adoption agencies and homes. Unfortunately, experience and study show that none of these agencies know how to respond to children with disabilities. The Integrated Child Protection Scheme (ICPS) makes specific references to children with disabilities only in the context of institutionalisation.

Way back in 2001, the Supreme Court had directed the Government to —universalise Integrated Child Development Services (ICDS) and make eight food related schemes into legal entitlements, which included the mid-day meal scheme. However, even till date, it is seen that children with disabilities continue to remain excluded from these programmes.

As per the Parallel Report to the CRC (Child Rights Convention) Committee by the NDN (National Disability Network), a) The only specific direction in the guidelines of the ICDS Scheme is for the anganwadi worker to conduct a survey of children with disabilities in the community and to refer the child with disability to the nearest Primary Health Centre (PHC). b) The mid-day meal scheme has not been expanded to reach out to children with disabilities enrolled in special schools, those in home based education and the very large numbers who are out of school.”

“Parallel Report of India on the Convention on the Rights of Persons with Disabilities (CRPD), National Disability Network (NDN) and National Committee on the Rights of Persons with Disabilities (NCRPD), 31 March 2017” (2021, Feb 8) Retrieved from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/DRAFT%20CRPD%20India%20Parallel%20Report%20\(31st%20March%202017\).pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/DRAFT%20CRPD%20India%20Parallel%20Report%20(31st%20March%202017).pdf)

The report highlights how systemic loopholes can create genuine roadblocks in the accessibility and inclusion of the disabled, in the numerous schemes created by the Government.

The researcher carried out an extensive interview with a parent-activist, Mr. Anil Joshi, who has been involved in the field of disability in India for over two decades now. His involvement has spanned across both his personal as well as professional lives. He was one of the founder members of Parivaar (a national level umbrella organization for parent led organizations across India). He has a 27 year old daughter with Down Syndrome and has been one of her biggest

cheerleaders since her birth. Today, she is employed in a regular full-time job in the corporate sector.

Mr. Joshi headed the ICT Accessibility Centre of Excellence that worked on inbuilt environment, transport and information communication. The concept of Universal Design was brought in. He was the Program Director, Accessibility Centre of Excellence of IBM Research in New Delhi. This Innovation Centre developed ICT technologies to facilitate inclusion. IBM was recognised by the President of India 7 times not only for, innovation of cost effective technologies to improve the Quality of Living of Persons with Disabilities but also for creating Diversity & Inclusion Practices. Mr. Joshi was a Board Member of the National Trust for 4 terms since 2003. By 2019, he was disappointed & disillusioned. In his own words, “The very purpose of making it an autonomous statutory body was violated reducing it to a Government department with no touch with reality on the ground.” (Joshi, A. Telephonic Interviews and Personal Communication over Emails, February 18-March 10, 2021).

With his vast experience accumulated from his in depth involvement with issues in the disability sector, over two decades, Mr. Joshi could provide a bird’s eye view of the systemic deficiencies that weaken the implementation of the various disability laws governing the country.

Providing an overview of the evolution of the laws in the disability sector in India, he stated the following,

“The Lunacy Act of 1912 was a ‘disqualifying’ Act in that, if you came within its ambit, you would no longer be considered a citizen. Human Rights were suspended. The Government machinery was authorized to take full responsibility. In 1963, for the first time, Intellectual Disability, as a category was even considered worthy of survey/ study. But it was first recognized in India only in the Persons with Disability (PwD) Act 1995, albeit with very little understanding of the specific needs of Persons with Intellectual and Developmental disabilities (PwIDD). In 1992, the Rehabilitation Council of India (RCI) Act was passed without defining a clear roadmap, no official manpower structure, as well as lacking structured planning in both manpower as well as deployment. One of the drawbacks of the PwD Act 1995 (amongst many others), was that the provisions could be implemented on a condition that it was subject to fund availability. The State could not implement it meaningfully. Many States did not even appoint State Commissioners to oversee the implementation of the Act. In 1999, parents and disability activists wrote to Justice Venkatachiah, the Chairperson of the National Human Rights Commission (NHRC) and after that, the first Chief Commissioner was appointed under the PWD Act. Due to concerted efforts in ‘96-’97, the National Trust Act was drafted and with a lot of persuasion from Parivaar, on 30th Dec 1999, the National Trust Act was passed.” (Ibid)

The National Trust Act was considered a landmark Act as it seemed to work on the main concern of innumerable parents/guardians of individuals with special needs—what happens to our children after we are gone? So, the recent controversy regarding its proposed dilution has been heavily criticised by all sections within the disability sector.

Elaborating on the functioning of the National Trust, Mr. Joshi stated, “A corpus of 100 crores was allocated and the National Trust was supposed to function autonomously (on the interest generated from the corpus. Approximately 3 crore population with disability need to be addressed through the Act, for which the amount incurred from the interest, is a pittance). The first Chairperson of NTA was appointed in 2000-01.

The PwD Act also provided for 3 % of the annual budget of Central and State Ministries (in a non-lapsing manner) for persons with disability. This too was never implemented. Ideally, every Ministry should have provided to the citizens information about what policies /provisions, they have worked on.

In the National Trust, the First Board of members was appointed but in the subsequent years, it was elected. Over the years, the National Trust has been run like a fiefdom, instead of an autonomous body. The functioning of the National Trust Act has been derailed.

A Public Interest Litigation (PIL), was filed for not seriously implementing the National Trust Act (NTA). By 2013, fifty different areas were identified that had objectionable irregularities, but no action was taken on them. The central Government wants the Chairperson of the National Trust to be an ornamental position. The powers of the Chairperson National Trust have been withdrawn. There hasn’t been a regular Chairperson since 2014 till date” (Ibid).

Mr. Joshi's narrative sheds light on how systemic failures within the National Trust have paved the way for more challenges in the implementation of its provisions. On the question of the recent proposition to merge the National Trust within the Rights of Persons with Disability (RPwD) Act, 2016, Mr. Joshi explained how this would further dilute its very essence as an autonomous entity.

Elaborating on it further, he said, "There are two ways of looking at the proposal—First, the status quo. If one considers the seriousness with which the Government has taken the responsibility to implement the provisions, one sees that a lot more could have been done. Twenty five years of the existence of the Disability Act yet there is a gaping hole between *what could have happened* and *what has happened*.

Secondly, the National Trust Act was created as a unique and exceptional Act but it never really took off. A lot of wisdom had gone in to making its provisions. The structure was made two tiers. The State Government's involvement was deliberately kept away. The District Administration was supposed to safeguard the interests. It was hoped that they would be sensible enough to rope in the personnel /stakeholders to take responsibility and provide proper care.

In all these years, there has been no follow up on the whereabouts of the ward/guardian. No records have been maintained. No one cares as the parents in most cases may have already been deceased, leaving their children in a lurch or ready targets for exploitation and abuse of all sorts. Quarterly meetings at the local level do not get organized and there are no statistics on them, yet.

During the Covid-19 pandemic, there had been a proposal to do away with the penalty clause from the NT Act, 1999 and RPwD Act 2016 (that would have included the accountability of all public services/administration etc). But that proposal was done away with due to strong reactions from stakeholders and activists" (Ibid).

Shedding light on the specific proposal of the merger of National Trust Act (NTA, 1999) under the Rights of Persons with Disability (RPwD Act, 2016), he stated, "The proposal will entail bringing the NTA under the Ministry, which would in turn increase the siphoning off of money due to rampant corruption, misreporting/ glossing over of, already prevalent and routinely 'accepted practice' in various Government departments. And the very purpose of setting up the National Trust as an autonomous body would be lost.

There is also a proposal to merge nine national institutes in 4 clusters. As it is most national institutes are headed by individuals who do not have the mandated experience & working background. If one creates clusters (across various disabilities), how they would be operational with individual agendas of their own, is questionable too" (Ibid).

Mr. Joshi believes that the Disability sector is highly fragmented. There are innumerable people working in this sector, but very few are truly working for the rights of the disabled /individuals with special needs.

Another specific challenge that has emerged in the implementation of the RPwD Act, 2016 has been in the issuance of the disability certificates. The process of procurement of a certificate is extremely cumbersome, stretching across several days, multiple visits to the registered centres for assessments (with extended wait times) and then further visits to get it certified from designated hospitals etc. Efforts need to be taken to bring it all under one umbrella type organization or a better organization of a de-centralized coordination, cutting down on wait times and unnecessary bureaucratic barriers.

The other issue brought up by several parents is that despite Autism Spectrum Disorder (ASD) being recognized as one of the 21 disabilities in India, according to the RPwD Act, 2016, till date the disability certificate that is issued is for Intellectual Disability with ASD, rather than ASD with Intellectual Disability. One can argue that this is an issue of mere semantics, but it actually reflects a much larger state of systemic inadequacy that isn't willing to keep up with the changes and thereby, not accord the recognition that ASD as a standalone disability, deserves (Discussions carried out with various parents Srinivas, M; Rathore, K and Sharma, K, between February 10-15, 2021).

8. CONCLUSION

The brief history of the evolution of the laws and policies for the disabled in India, throws up interesting insights on how the perception of the differently abled has transformed in the popular perception. Although, constitutionally several rights have been accorded to the individuals with special needs, a critical reading of the press coverage on issues of disability as well as discussions with several activists and parents, have revealed that a lot more needs to be done.

Fissures between the countless governing systems and the legal provisions for the disabled create contested spaces for their non-implementation or half-hearted implementation, leaving large swathes of population with special needs, short changed.

The need of the hour is to work towards strengthening the dialogue between various stakeholders in the disability sector as well as place pressure on the powers that be, to acknowledge the gaps inherent in the system, recognize the challenges faced by the parents on the ground and as well as work towards the creation of spaces that accord the differently abled, a life of dignity, their basic rights and respect.

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PERSONAL INTERVIEWS (Over the phone and emails)

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