

The Rights of Persons with Disabilities Act 2016: Mental Health Implications

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ABSTRACT

India's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) necessitated the need for a rights-based, biopsychosocial model of disability, which was endorsed in the Rights of Persons with Disabilities (RPwD) Act, 2016. This article examines the Act, its rules, and guidelines provided by the Government of India, from a mental health perspective, and compares it to its predecessor, the Persons with Disabilities (PwD) Act, 1995. The RPwD Act provides clearer definitions of various constructs, a greater focus on rights of PwD, and guidelines for assessment and certification of disabilities. There is, however, an underemphasis on mental illnesses in the reservation and legal decision making, and a move toward centralizing the process of disability certification. Also, there is a lack of clarity about screening instruments to be used, resource allocation to implement the provisions, and the guidelines for inclusive education. This article suggests recommendations that could strengthen some of these provisions.

Key words: Disability, India, mental illness, rights, RPwD

INTRODUCTION

For the World Report on Disability (2011), the International Classification of Functioning, Disability and Health (ICF) conceptualized disability as a dynamic interaction between health conditions and contextual factors that include attitudinal and environmental barriers. This view of disability implies and emphasizes that it is not an attribute of the person. Disability encompasses both the medical model, wherein disability lies in the individual's body or mind, and the social model, which holds that societal barriers


cause disability. The resultant model is biopsychosocial in approach.^[1]

This paradigm shift from the stigmatizing medical approach to the medical-social one needs to be reflected in the Indian legislation as well. The Rights of Persons with Disabilities (RPwD) Act (2016), which replaced the Persons with Disabilities (PwD) Act (1995), was a move in this direction. India ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in October 2007, which

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called for a change in the legislature, and the RPwD Act was passed in December 2016. The rules that serve as a guide to implement the Act came almost 6 months later on June 15, 2017, after many months of inviting public opinion before finalization. Finally, on January 4, 2018, the Ministry of Social Justice and Empowerment provided guidelines and procedures for the certification of the various disabilities specified by the Act.

The understanding of disability as biological, psychological, and social is quite fitting for mental disorders that are caused by a complex interaction of biological, social, environmental, cultural, and economic factors. In developing countries like India, the rampant poverty, illiteracy, unemployment, and lack of access to resources contribute to the causation of and recovery from mental disorders. Some mental illnesses are associated with substance abuse, homelessness, violence, crime, and trauma.^[2] The National Mental Health Survey (2015–2016), conducted in 12 states from six regions in India, found that 10.6% of the population suffers from mental illness. Three out of four persons with a severe mental disorder were found to experience significant disability in work and social and family life.^[2]

The RPwD Act has important implications for the rights of persons with mental illness, who are vulnerable to exploitation and violation of their rights.^[3] These persons need the legal system of the country to ensure a mechanism to protect their rights. This article attempts to examine the implications of the Act, particularly from the mental health standpoint.

CHANGES INTRODUCED IN THE RPWD AND THEIR MENTAL HEALTH IMPLICATIONS

Greater number of disabilities recognized

The Act has expanded the number of conditions included under it from 7 to 21. Table 1 provides a list of differences between the two Acts. The PwD Act, 1995, accorded for blindness, low vision, hearing impairment, leprosy cured, locomotor disability, mental retardation, and mental illness.^[4] The RPwD Act includes cerebral palsy, dwarfism, muscular dystrophy, chronic neurological disorders (including Parkinson's disease and multiple sclerosis), blood disorders (including hemophilia, thalassemia, and sickle cell disease), acid attack victims, speech and language disability, and intellectual disability (ID; which includes specific learning disability [SLD] and autism spectrum disorder).^[5] This has broadened the range of disorders and affected individuals who would be eligible to avail reservations and benefits under the Act.

Clearer definitions

The 2016 Act has been able to provide greater clarity into hitherto undefined constructs. For example, the definitions of discrimination, barrier, mental illness, and benchmark disability have been elucidated. In the 1995 Act, a person with disability meant “a person suffering from not less than forty per cent of any disability as certified by a medical authority.”^[4] In the 2016 Act, this definition has been replaced by the following: A person with disability “means a person with long-term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others.”^[5]

The former definition typifies a person based purely on the degree of disability. The latter, in contrast, provides a holistic view of what the person's disability could comprise, emphasizing not only on biological determinants but also on social, environmental, and relational ones.

The concept of disability itself has been altered in the new Act that views the concept on a continuum. Figure 1 illustrates the continuum of disability as conceptualized by the RPwD Act. This is a broader and more inclusive understanding of disability, in comparison with the 1995 Act which recognized PwD as only those with a disability equal to or higher than 40%.

Similarly, in the PwD Act, mental illness was defined as “any mental disorder other than mental retardation.” The new Act provides a broader definition of mental illness:

“Mental illness means a substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgment, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, mental conditions associated with the abuse of alcohol and drugs, but does not include mental retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by subnormality of intelligence.”^[5]

This definition is the same as that provided by the Mental Health Care Act 2017 (MHCA)^[6] and reflects a progressive move. It may be argued that the use of the term “substantial” may lend itself to varying interpretations again, due to the lack of



Figure 1: Continuum of disability as discussed in the RPwD 2016

Table 1: Comparison of the RPwD Act 2016 with the PwD Act 1995

Item	PwD Act 1995	RPwD 2016
Model adhered to	Medical model	Medical plus social model
Approach	Charity based	Rights based
Applies to the whole of India	Except to Jammu and Kashmir	Yes
Definitions	Poorly defined	Definitions of discrimination, barrier, caregiver, person with benchmark disability, rehabilitation
Definition of mental illness	“Any mental disorder other than mental retardation” Narrow definition without any elucidation	“A substantial disorder of thinking, mood, perception, orientation or memory that grossly impairs judgement, behaviour, capacity to recognise reality or ability to meet the ordinary demands of life, but does not include retardation which is a condition of arrested or incomplete development of mind of a person, specially characterised by subnormality of intelligence”
Number of disabilities	7	21
Rights and entitlements	Mentioned but fewer	Rights are more with special mention of women and children, legal capacity being explained better with rules on ensuring accessibility to vote
Limited Guardian	No mention of the term	Mention of the term with clear rules defining the same and defining when a conflict of interest arises
Provision for barrier free access	Broadly mentions the need to ensure removal of architectural barriers in schools, public, and work places	Has clear rules and specification about accessibility of buildings and transportation, including a 2-year deadline to ensure barrier free access and no approval without ensuring standards
Right to free education	Right to free education until 18 years of age Provision of free books and equipment	Right to free education and free assistive devices, 5% reservation in high school
Inclusive education	Integration into normal schools Part-time classes for those who discontinued school after 5 th standard or for functional literacy	Move toward inclusive education including training teachers in Braille, other assistive devices
Rights in higher education	Age relaxation mentioned (number of years not mentioned)	5 years age relaxation in institutions of higher education
Surveys to identify and treat disability	No mention	1st survey after 2 years, then a survey yearly for early detection, management
Reservation at the workplace	3% in every establishment	4% in government institutions
Chapter on offences and penalties	Not mentioned	Mentioned with specific redressal mechanisms and quantum of punishment

RPwD: Rights of persons with disabilities; PwD: Persons with disabilities

operationalization. Nevertheless, the new act defines constructs much more clearly than its predecessor. The term mental retardation has been replaced by ID, which was intended to reduce the associated stigma, and this is also in line with the MHCA 2017.

Rights

Taking a leaf out of the UNCRPD, the RPwD Act has introduced the right to legal capacity, that is, the right to equal recognition of PwDs before the law. In this, PwDs have a right to own or inherit property, control their financial affairs, and have access to financial credit. In addition, the Act has attempted to improve the accessibility to voting services by providing instructions to the Election Commission of India and the State Election Commissions to ensure that all polling stations are accessible to PwDs and all materials related to the electoral process are easily understandable by and accessible to them. PwDs also have a choice of a limited guardian who can help the person in taking legally binding decisions. If there is a conflict of interest or when deemed otherwise, the PwD has the right to change the guardian.^[5]

However, in case of mental illness, several problems may arise in the implementation of these provisions

for equal legal capacity and choice of a limited guardian. In case of a person with a psychiatric disability, where there might be impaired judgement and poor insight, or psychopathology interfering with decision making, the validity of the affected individual's report of discrimination/abuse/exploitation (against the limited guardian) or their judgment of an appropriate guardian can come to question. A provision in the act to better handle such a scenario would have been ideal as it is in the MHCA which allows for an advanced directive and a nominated representative (both of which are decided when the person is of sound mind).^[6]

Rights of women and children, including the right of a child to not be separated from her or his parents on the grounds of disability, have been mentioned in the RPwD as it was in its predecessor. The Act provides protection from abuse, violence, and exploitation, and means to report any such act to the Executive Magistrate.

The difference in the two acts in this regard is the removal of the following clause from the new Act: “the appropriate Governments and the local authorities shall, within the limits of their economic capacity and

development, provide...,” which appears in several locations of the PwD Act. Math and Nirmala (2011) call this clause the “disabling clause” of the act, stating that this empowers the authorities to never realize the provisions of the Act.^[3]

The new Act, in contrast, reflects a shift from this charity-based model, wherein only what is feasible for the authorities is done for the PwD, to a rights-based model, where the provisions in the Act are mandated.^[5]

Role of the family

If a court or any other designated authority finds that a PwD who has been provided support is still unable to take legally binding decisions, he or she may be provided with the support of a legal guardian who may take decisions on the PwD’s behalf. Limited guardianship is limited to a specific decision and to a specific time period.

The family, both in limited guardianship and in applying for support on behalf of the patient, may be of utmost value in case of mental illness as most often, they are responsible for the burden of care and may understand the person’s illness best. The Act provides that any person with a benchmark disability can apply to a competent medical authority if he or she considers himself or herself to require high support needs. This can also be done by a non-governmental organization (NGO) or any other person on his or her behalf. The Act also includes a clause which states that in case of a conflict of interest between the person providing support and the PwD, the person providing support must withdraw the support for the duration of the conflictual situation. Despite this clause being in the best interest of both the parties, it may prevent an otherwise willing family member from helping out the person with disability, due to the consideration of possible legal consequences.

The Act also specifies that the family member can apply for a disability certificate on behalf of the PwD. This is in keeping with the PwD Amendment Rules, 2009.^[7]

Narayan and John (2017) have critiqued the RPwD, stating that the Act criminalizes service providers and family members for perceived abuse or exploitation toward the PwD when the PwD may, in fact, be mentally ill and a threat to himself or herself.^[8] Section 7^[2] of the Act, which the authors identify in this regard, mentions that if anyone has a reason to believe that a PwD has been, is being, or may be abused or exploited, they may give information to the Executive Magistrate. The provision has been made to protect PwDs against violence and exploitation and not to keep the family away. In fact, the Act stipulates that if on an investigation the Executive Magistrate finds that the

complaints ring true, he or she may forward the complaint to the Judicial or Metropolitan Magistrate. This action seems to be reasonable and do not warrant the critique it received in the review.

Reservations

Another positive change in the new Act has been with respect to reservations for PwD. The 1995 Act allowed for 3% employment reservations for PwDs in government and government-aided institutions, with 1% reservation each for (1) hearing impairment, (2) blindness/low vision, and (3) locomotor disability/cerebral palsy.^[5]

The 2016 Act allows for 4% reservations for PwDs, and this includes reservations for persons with mental illness, autism, SLD, and ID for the purpose of employment in all government establishments [Table 2]. There is also a provision for at least 5% reservation in higher education; 5% reservation in allotment of agricultural land and housing, with priority accorded to women; 5% reservation in poverty alleviation schemes (3% in the 1995 Act), with priority accorded to women; and 5% reservation in the allotment of land at concessional rates.^[5] These provisions are important steps in the empowerment of PwDs.

On the downside, the Act allocates only 1% reservation for the following disorders combined—SLD, ID, mental illness, autism spectrum disorder, and multiple disabilities. In a country where depressive disorders are 7th on the list of problems causing most disability (Institute for Health Metrics and Evaluation, 2017), this figure of 1% for all the above categories seems inadequate.^[9]

The Act is also silent on how the support system would be built in a country that has millions of people with mental illness. Also, as the number of people with disability increases, with an increase in the number of included disabilities, the state would find it difficult to tackle the load.

Education

While both the Acts provide free education for children between 6 to 18 years, the PwD Act allocated 3%

Table 2: Reservation for specific disabilities

	Nature of disability	Percentage of reservation	
a	Blindness and low vision	1	
b	Deaf and hard of hearing	1	
c	Locomotor disability	1	
d	Autism, intellectual disability, SLD, and mental illness	1	} (for both d and e combined)
e	Multiple disabilities		

SLD: Specific learning disability

reservation in high schools, which the RPwD Act has increased to 5%.^[4,5] These provisions are greater than those proposed in the Right of Children to Free and Compulsory Education Act, 2009, in which all children would receive free education from the age of 6 years until the age of 14 years.^[10] RPwD Act also specifies 5 years upper age relaxation of PwDs in institutions of higher education.

The PwD Act included provisions for setting up special schools and promoting the integration of students with disabilities in normal schools. In its successor, more specific goals aimed at inclusive education have been included. These are early detection and intervention of SLD and conducting school surveys every 5 years for identifying children with disabilities to ascertain their needs and the extent to which these needs are being addressed.

Inclusive education, while ideal to ensure nondiscrimination and equality, may be difficult to implement in a country where there is a shortage of teachers (18% shortage in primary schools and 15% shortage in the secondary schools).^[11] Inclusive education would require specially trained teachers for dealing with children with disabilities in assistive and augmentative communication, behavior analysis techniques, and parent management.

Also, the Act does not specify which categories of PwD can be included in inclusive education. People with moderate to severe ID or children requiring high support needs would not be expected to do well with the inclusive approach as they might be unable to cope with the demands of normal schooling and would need a much more targeted approach.

Assessment of disability and certification

In a notification released on January 4, 2018, the Ministry of Social Justice and Empowerment provided guidelines for the certification of the various disabilities specified by the RPwD Act. This document outlines screening, assessment, and certification procedures. The screening of ID (in addition to hearing, vision, etc.) is to be done by pediatricians. However, the screening tool to be used has not been specified. Subsequently, the children/persons will be referred to child or clinical psychologists, who will conduct the assessment of adaptive functioning and intelligence quotient (IQ) testing. The standardized tools to conduct the assessments have been specified and include the Vineland Social Maturity Scale (VSMS) for the assessment of adaptive functions and the Binet Kamat Test of Intelligence (BKT) or the Malin's Intelligence Scale for Indian Children (MISIC) for the assessment of intellectual functioning. With regard to ID, a

progressive move has been that 25% disability has been afforded to the borderline IQ group (range = 70–84), allowing children to attain some benefit for suboptimal intellectual functioning.

The screening for SLD must be conducted by 8 years of age or class third (whichever is earlier) by school teachers, and each school must establish a screening committee. However, here too, the screening tool for SLD to be used by teachers has not been specified. After the initial screening, the parents must be involved, and a referral must be sent to a pediatrician. After a detailed neurological examination and ensuring normal vision and hearing, an IQ assessment by a child or clinical psychologist must be conducted. The SLD assessment is done only if the IQ is more than 85, and the National Institute of Mental Health and Neurosciences (NIMHANS) Specific Learning Disability Battery has been specified for this purpose. The age for certification, validity of the certificate, and the renewal process have also been specified.

However, the recommended tool does not provide severity scores in its assessment of SLD, and thus, the weighted benefits of different levels of severity would not apply for SLD. In fact, the quantification of SLD has not been possible till date. Another significant concern is that, in a populous country like India, where the prevalence of SLD varies from 3% to 10%,^[12] the number of people who have SLD and reservations for them would be in millions. As the professionals who assess SLD, that is, clinical psychologists with adequate training, are limited in our country, the implementation of this section of the Act requires policy-level changes.

In the assessment of mental illness, a clinical assessment by a psychiatrist, rating with the Indian Disability Evaluation and Assessment Scale (IDEAS), and/or IQ assessment by a qualified psychologist must be carried out.^[13]

As per the PwD Act 1995, the assessment and certification of disabilities have to be done by the respective specialists, which meant that only about 35% of PwDs had been issued disability certificates as in October 2010.^[14] The RPwD Act and the subsequent guidelines have clearly mentioned the procedures regarding certification, but this again implies that patients would need to seek multiple appointments with specialists or super-specialists in order to get a certificate.

It was to avoid this that the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Amendment Rules, 2009^[15] and the subsequent guidelines^[14] were issued to state

governments such that the disability certificate can be issued at the level of primary health centers (PHCs), community health centers (CHCs), and hospitals at the subdivisional level. Also, in the case of non-obvious single disabilities, certificates can be issued by a single specialist, and only in case of multiple disabilities, a multi-member board would be required to issue the certificate.^[14]

The RPwD Act appears to have taken a step back by not decentralizing the assessment and certification processes, as was the case in the PwD Amendment Rules, 2009. This would lead to people needing more time and resources to avail certification, which could work against the intention of empowerment which the Act sought to do.

Employment

The PwD Act encouraged private institutions in which 5% of the workforce comprised of PwDs, with incentives. The Government of India, in 2008, promulgated an incentive scheme to the employers for providing employment for PwDs in the private sector. Under this scheme, the employees with disabilities (covered under the PwD Act of 1995 and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999) would be covered.^[16]

In addition to this, the RPwD Act mandates 4% reservations in government and government-aided organizations. Both the PwD and the RPwD Acts clearly mention provisions for situations wherein an employee acquires a disability while in service. In such a scenario, he or she cannot be dismissed. If the affected individual is unable to carry out the job adequately, then he or she may be shifted to another post, without a decrease in pay scale or service benefits. If that is not possible, then he or she can be kept on a supernumerary post until a suitable post is available or until retirement.^[4,5] This provision is of immense relevance in mental illnesses, which often develop during the early productive years of working life and can lead to significant social and occupational dysfunction. This provision would allow for continued livelihood despite an inability or reduced ability to perform at work. Also, mental illnesses may be episodic in nature, allowing for several months or years of productive work. This provision could ensure that even if there are periods of unproductivity, affected persons would be able to retain their jobs.

RECOMMENDATIONS

1. There needs to be a greater recognition of the changing mental functioning of the persons with

mental illness, and allowances for legal capacity and guardianship should be ascertained according to the soundness of mind

2. Although there are more types of disabilities recognized, the percentage of reservation may be inadequate for mental health conditions and disproportionate to the morbidity caused. There is an urgent need to extend these allowances so as to represent the numbers of persons with mental illness or ID in the country
3. Specifying which categories of PwDs would be suitable for inclusive education or specifying institutions that can ascertain such suitability would go a long way to streamline the process of inclusion and allow for clearer guidelines in inclusive schools
4. The view of SLD as a condition that requires accommodation (such as additional support during examinations in the form of scribes, extra time, etc.), rather than entitlement in the form of reservation, would serve to reduce the paucity of reserved seats for other disabilities. By removing reservations for SLD, the issue of a lack of severity scale for SLD would also be redundant
5. Decentralization of the process of assessment and certification of disabilities needs to be reconsidered (as in the 2009 amendment rules) to ensure a less cumbersome process for the PwDs. For example, from a mental health perspective, people with severe or profound ID can be given a certificate at the PHC level itself, and for cases wherein the deficits are not striking, appropriate referrals to specialists may be made.

CONCLUSION

The RPwD Act 2016 replaces the PwD Act 1995, and the RPwD Rules, 2017, indicate how the provisions need to be implemented. The major changes include improved definitions and operationalized terms, increased focus on the rights of PwDs, measures to reduce discrimination, a movement toward an inclusive approach in education and work, the process of appointing a limited guardian, and the section on offences and penalties for contravening the rules. The Act appears to follow the initial covenants of the World Health Organization (WHO) and focuses to a great extent in ensuring that there are lesser discrimination, more barrier-free access, and more usable rights. The moves from charity-based to rights-based laws and from a purely medical model to a biopsychosocial model are certainly steps in the right direction. Although there is criticism that the Act could have focused more on mental disabilities, it definitely seems to be much ahead of the previous Act of more than two decades ago. For the same reason, it needs to be linked to the MHCA 2017 which in and of itself has

an equally rights-based and progressive approach. The links which have already occurred at the conceptual level in terms of similar definitions of mental illness, and in terms of a move from a charity-based to a rights-based method in both the RPwD Act and the MHCA, along with the advanced directives and nominated representative concept (which runs parallel to the concept of guardianship) need to be taken further to ensure overall better care for the person with mental disabilities. On examination of the Act, there emerges a need for greater reservation for mental disabilities and greater clarity with regard to the screening tools, decentralization of certification, and guidelines for inclusive education. SLD remains a challenging area with large numbers requiring remediation and perhaps not reservation and, thus, may need to be reconsidered.

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