JUSTICE DEFERRED: A CRITICAL ANALYSIS OF SYSTEMIC VIOLATIONS OF THE RPwD ACT FOR PERSONS WITH MUSCULAR DYSTROPHY

Siddharth, Research Scholar, University of Lucknow

ABSTRACT

This paper critically explores the structural and judicial issues that arise in India with respect to Muscular Dystrophy (MD) especially in the context of Duchenne Muscular Dystrophy (DMD) and Limb Girdle Muscular Dystrophy (LGMD). The Rights of Persons with Disabilities (RPwD) Act, 2016, a super-statute that was to replace the medical model with a human right- based approach to disability, has not led to improvement of the situation of MD patients, instead, they continue to be excluded from medical admissions, healthcare funding. This paper contends that the justice of a person living with MD cannot simply be treated as charity; it is a constitutional right and one that is currently being denied by the practice of repeating the same processes and discriminating indirectly against the person with MD. The study points to the fact that facially neutral criteria unfairly excluded MD patients, and notes that tests of functional competency are more important than a fixed, quantified criterion.

It calls for the change of the Disability Assessment Boards to Ability Assessment Boards and emphasizes evaluation of abilities instead of deficits, including the use of assistive devices to evaluate cognitive, psychomotor and affective skills. The study highlights positive obligations of the Act in relation to access to healthcare without barriers and 5% quotas for higher education. These violations are continuing due to administrative inertia. The study highlights positive obligations of the Act regarding barrier-free healthcare access. Landmark judicial precedents such as Omkar Ramchandra Gond v. Union of India, Om Rathod v. Director General of Health Services, and Master Arnesh Shaw v. Union of India underscore the need for purposive interpretations that prioritize functional competence, reasonable accommodations, and state obligations for treatment access in rare disease cases.

Keywords: Muscular Dystrophy, RPwD Act 2016, Reasonable Accommodation, Indirect Discrimination, Functional Assessment, Ability Assessment Boards.

1. The Opposite Banks of Legal Principle and Application

Often situations arise in India where legal principles and the way they are applied are in stark contrast. This is the furthest distance experienced in the lives of those who are afflicted with MD. In DMD, a progressive genetic disorder, muscles waste away and a person's need to walk diminishes and, in some cases, results in death.[1] The RPwD Act, 2016 has made MD as a "specified disability" but the society in general and medical institutions in particular treat these people as 'biological anomalies' to be 'measured', instead of empowering them as citizens. In spite of the clear improvement in the Act towards a rights-based approach which defines 21 disabilities and stipulates equal rights, reservations in education and accessibility measures for persons with MD, this medicalised lens persists[2].

The current system is inadequate in solving issues in courts and hospitals, and it frequently overlooks the substantive issues and focuses more on the technicalities. This enforcement gap is manifested in the lack of funding, which is a result of coordination problems with other departments and lack of awareness and inadequate opportunities, so that many patients with MD do not receive timely rehabilitation and inclusive opportunities. This paper examines how recent jurisprudence has started to overcome these barriers. Courts are increasingly prescribing medical institutions to adopt strong accessibility protocols and participation strategies, based on harmonisation of national legal norms with international human rights standards.[3] Similarly, the CRPD emphasizes the importance of adopting the rights-based approach to mental health care and ensuring that domestic health policies and practices do not further stigma and discrimination against persons with complex neuromuscular conditions, as discussed in the aforementioned shift in judicial thinking in the context of India's Mental Health Act 2017.

Moreover, the shift from a charity-based approach to a rights-based approach in the RPwD Act has identified indirect discrimination based on facially neutral criteria that does not take into consideration individual barriers faced by persons with progressive conditions such as MD.[4] A

[1] Frédéric Relaix, "The rise of rat models for Duchenne muscular dystrophy and therapeutic evaluations" Skeletal Muscle (BioMed Central, 2025).
[2] Siddharth and Dr. Niharika, "NON-GOVERNMENTAL ORGANIZATIONS AND THE LEGAL SYSTEM FOR MUSCULAR DYSTROPHY IN INDIA: AN INTERDISCIPLINARY ANALYSIS," 2026.
[3] Abduvalieva Mumtozkhan Asilbekovna, "Comparative Analysis of International Standards for the Protection of Persons with Disabilities and National Legal Norms," 1 International Journal of Law and Policy (2023).
[4] B.R. Gavai, K.V. Viswanathan and Aravind Kumar, "Omkar Ramchandra Gond v. Union of India SUPREME COURT OF INDIA CIVIL APPELLATE JURISDICTION CIVIL APPEAL NO. 10611 OF 2024," 2024, at p. 18.

focus is placed on assessments of functional competency with assistive devices as opposed to applying percentages, rather than any "one size fits all" approach to medical admissions, Landmark rulings stress[5]. However, the failure to implement statutory guarantees for MD patients has been undermined by systemic inertia, as NGOs have filled the gaps in implementation through provision of physiotherapy, genetic testing, advocacy and psychosocial support[2]. All of these changes signal the need for continued judicial supervision and policy changes to put the laws into practice and make them a reality.

2. The RPwD Act 2016 – An 'Inclusive Super-Statute'

The RPwD Act, 2016 is a radical shift in disability laws in India and from the medical model of disability to a rights-based model that acknowledges 21 categories of disabilities including muscular dystrophy and puts a responsibility on the government to ensure there is no discrimination and reasonable accommodation of people with disabilities in the real world[6]. Even though such sweeping normative mandates have been legislated, the execution of such aspirations to action, such as in the field of healthcare, is often disjointed, and at times impeded by a lack of harmonisation between the universal standards set at the international level (like the UNCRPD) and the lived reality at local level[7]. Section 2(y) of the Act defines 'reasonable accommodation' as necessary and appropriate modification and adjustment without imposing disproportionate or undue burden to ensure that persons with disabilities enjoy or exercise the rights equally with others, including measures needed for full and effective participation in society.[8] Section 3 affords the right to equality and non-discrimination for persons with disabilities, whereas Section 32 mandates that all government institutions of higher education reserve not less than five per cent seats for persons with benchmark disabilities, whereupon the upper age relaxation of five years has been provided for admission in the said institutions.[9]

[5] Dhananjaya Y Chandrachud, J.B. Pardiwala and Manoj Misra, "Om Rathod v. The Director General of Health Services & Ors.," 2024.
[6] Siddharth and Dr. Niharika, "NON-GOVERNMENTAL ORGANIZATIONS AND THE LEGAL SYSTEM FOR MUSCULAR DYSTROPHY IN INDIA: AN INTERDISCIPLINARY ANALYSIS," 2026; Utkarsh Kumar, "ENFORCEMENT GAP IN DISABILITY RIGHTS: FROM LAW TO LIVED REALITY" Zenodo (CERN European Organization for Nuclear Research) (2026).
[7] Utkarsh Kumar, "ENFORCEMENT GAP IN DISABILITY RIGHTS: FROM LAW TO LIVED REALITY" Zenodo (CERN European Organization for Nuclear Research) (2026).
[8] Dhananjaya Y Chandrachud, J.B. Pardiwala and Manoj Misra, "Om Rathod v. The Director General of Health Services & Ors.," 2024; B.R. Gavai and K.V. Viswanathan, Anmol v. Union of India SUPREME COURT OF INDIA CIVIL APPELLATE JURISDICTION CIVIL APPEAL NO. 14333 OF 2024, 2025.
[9] B.R. Gavai, K.V. Viswanathan and Aravind Kumar, "Omkar Ramchandra Gond v. Union of India SUPREME COURT OF INDIA CIVIL APPELLATE JURISDICTION CIVIL APPEAL NO. 10611 OF 2024," 2024; Dhananjaya Y Chandrachud, J.B. Pardiwala and Manoj Misra, "Om Rathod v. The Director General of Health Services & Ors.," 2024.

Section 25 also places a positive duty on the appropriate Government and local authorities to provide free medical treatment in the surrounding area. It ensures that there is no hindrance in the availability of medical facilities in all parts of Government hospitals and private hospitals and medical institutions. They are given priority in attendance and treatment.[10] Even with all these positive statutory safeguards, MD patients still experience a 'systemic indirect discrimination' where seemingly facially neutral criteria exclude them from society.

3. Judicial Precedents: Interpreting Due Process in Disability Rights

3.1. Omkar Ramchandra Gond v. Union of India

The first activist in the existing disability jurisprudence is the case of *Omkar Ramchandra Gond v. Union of India, 2024*[4]. The principles laid down by the Court were the basis for MD cases, although Gond had speech and language disability. The National Medical Commission guidance made an exception that any candidate having more than 40 percent speech handicap would be declared "ineligible" for the course of medicine.[4] The quantified disability per se will not disentitle a candidate was the verdict of the Judicial Intervention.**Error! Bookmark not defined.** The Court stated that Disability Assessment Boards should not be "monotonous automations" based on a percentage and dismiss a candidate.**Error! Bookmark not defined.** The Court placed emphasis on the inclusive education where the education system is suitably adapted to the learning needs of students.[11] It stipulated the board would have to consider whether a candidate was "functional" even if they were quantified.

3.2. Om Rathod v. The Director General of Health Services & Ors

The case of Om Rathod provides the special context of Gond to the issue of Limb Girdle Muscular Dystrophy.[5] Rathod attended AIIMS Nagpur where he was declared "88% disabled" and "ineligible" after scoring a Pwd rank of 84 in National Eligibility cum Entrance Test (NEET). As an academic success, Rathod secured an 84% rank in NEET as a PwD and was declared "88% disabled" and "ineligible" by AIIMS Nagpur.

The Court highlighted that Rathod came in AIIMS Delhi on a short notice and flew for the first time, and then was asked to do things like "climbing stairs" without the use of assistive

[10] "Om Rathod v. The Director General of Health Services & Ors.," 2024.
[11] Shruti Kirti Rastogi and Geetika Nidhi, "Inclusive Education and avenues of learning for learners with Muscular Dystrophy: A Case Study," 24 International Journal of Psychosocial Rehabilitation 4783–91 (2025).

devices.**Error! Bookmark not defined.** The medical board's report also admitted that there were “no clear guidelines” to evaluate candidates who were using assistive devices to essentially adopt the “medical model of disability” under which MD is a disease or disability to be prevented or cured.**Error! Bookmark not defined.**

The Supreme Court had appointed Dr Satendra Singh for conducting Functional Competency Test (FCT) on a simulation basis. The report found that Rathod lacked certain limitations, but had the "cognitive, psychomotor, and affective skills" to become a doctor. Rathod showed that he could carry out clinical activities with “innovative coping mechanisms” on a compact scooter and an adjustable table.[12]

a. Ability Assessment Boards: The Court changed the name of Disability Assessment Boards to Ability Assessment Boards to help reorient the focus from what a person can't do to what they can do.

b. Right to Reasonable Accommodation: Article 21 and Article 14 are violated by the denial of these reasonable accommodations.

c. Inapplicability of the 2019 Vidhi Himmat Katariya standard: The Court rejected the 2019 standard laid down by Vidhi Himmat Katariya that allowed the boards to disqualify candidates on the ground of “not having both hands intact”**Error! Bookmark not defined.**.

Building upon these precedents, the Supreme Court in *Anmol v. Union of India* further strengthened the functional competency model for a candidate with multiple disabilities including phocomelia and speech impairment. The Court appointed Dr. Satendra Singh to perform a simulation-based assessment, concluding that Anmol could successfully navigate MBBS with clinical accommodations and assistive technologies without presuming incompetence at the threshold stage. It mandated detailed individual analysis focusing on cognitive, psychomotor and affective skills in favor of reasonable accommodations and adaptive equipment to ensure equal participation[13].

3.3. Judicial Landmark: Master Arnesh Shaw and the Healthcare Impasse

[12] “Om Rathod v. The Director General of Health Services & Ors.,” 2024.
[13] B.R. Gavai and K.V. Viswanathan, “Anmol v. Union of India SUPREME COURT OF INDIA CIVIL APPELLATE JURISDICTION CIVIL APPEAL NO. 14333 OF 2024,” 2025.

While MD aspirants struggle for education, MD patients—particularly children with DMD—struggle for survival. The case of Master Arnesh Shaw v. Union of India highlights a "clear violation" of the state's positive obligations under the RPwD Act and Article 21[14].

a. The Funding Crisis: DMD treatment is "exorbitantly expensive," costing upwards of INR 30 lakhs per month. The National Policy for Rare Diseases 2021 provides a cap of INR 50 lakhs per patient. For a progressive disease like DMD, this amount is "completely insufficient"[15].

b. Bureaucratic Apathy and Underutilization: The Delhi High Court expressed "deep concern" that while children were dying, the government had failed to utilize the Rare Diseases Fund. In 2021-22, only INR 3.15 crores were spent out of a budgeted INR 25 crores; overall, budgets of over INR 200 crores remained unutilized. This "gross under-utilization" reflects a lack of a "concerted and coordinated approach"[16].

c. The Patent Impasse: Companies like M/s Sarepta Therapeutics hold patents for DMD medicines but have failed to ensure their availability at "reasonably affordable prices" in India. The Court noted a "sufficient delay" between orders and supplies, violating the Patents Act, 1970.

4. Critical Analysis: Systemic Violations of the RPwD Act

The "trio" of landmark judicial interventions—encompassing the National Medical Commission guidelines challenge on speech disability with its emphasis on functional competency over quantified benchmarks, the Om Rathod case addressing Limb Girdle Muscular Dystrophy through ability-based assessments and reasonable accommodations, and the Master Arnesh Shaw case exposing rare disease funding shortfalls and bureaucratic apathy—collectively reveals three interconnected levels of RPwD Act violations:

[14] JUDGE PRATHIBA M. SINGH, "Master Arnesh Shaw vs Union of India Anr on 4 October 2024," 2024.
[15] Jaspal Singh, "Strengthening Rare Disease Management in India: A Critical Evaluation of NPRD 2021 and Ayushman Bharat in Addressing Financial Barriers, Healthcare Infrastructure Gaps and Policy Implementation Challenges," 36 Journal Academy of Hospital Administration 73–4 (2024).
[16] Balamurugan Shanmugaraj, Ajith Nagaraj and Ashwini Malla, "National strategies and government initiatives for rare diseases management in India," 5 Journal of Rare Diseases (2026).

4.1. Denial of Reasonable Accommodation

The failure of medical boards to assess candidates with their assistive devices is a direct denial of a "gateway right". Without these accommodations, the "six freedoms" and the "right to life" under Article 21 "ring hollow". As the Court noted, the disability of a person is often a "reflection on the inaccessibility of the society" rather than a comment on the individual**Error! Bookmark not defined.**.

4.2. Indirect Discrimination and "Facial Neutrality"

The system often uses "facially neutral" criteria that target specific identities. For example, requiring a surgeon to stand for six hours without offering a hydraulic stool is an "ableist" standard. True equality requires "reasonable differentiation"—recognizing that unequals cannot be treated equally.**Error! Bookmark not defined.**

4.3. The Failure of the Social Model

The United Nations has identified the "prevalence of the medical model" in India as a major concern. Assessment boards continue to "pathologize and problematize" disabled bodies. The Court has demanded a transition to the "human rights model," where MD is treated as an "attribute to be acknowledged and accommodated," not a "thing to be overcome"[17].

5. Shining Examples: "It Can Be Done"

Building on the judicial emphasis on the human rights model of disability[17], the analysis is reinforced by individuals who have succeeded despite progressive disabilities. These professionals demonstrate that, with appropriate accommodations, doctors with disabilities effectively leverage their unique lived experiences to enhance diagnostic empathy and patient communication[18]. This shift towards valuing disability as a form of human variation underscores the necessity of moving beyond mere legal compliance toward a fundamental transformation of medical training and institutional culture[19]. Such a transformation requires dismantling the pervasive "ableist culture" within healthcare spaces that currently forces

[17] Moumita Barman, “Towards Inclusivity: Assessing the Rights of Persons with Disabilities Act, 2016,” 2023.
[18] Anwar A. Sayed, “Exclusion and inequity: a national analysis of disability-inclusive admission criteria in Saudi medical schools,” 12 Frontiers in Medicine (2025).
[19] Neera R. Jain, “Legibility: knowing disability in medical education inclusion,” 29 Advances in Health Sciences Education 507–30 (2023).

trainees to expend excessive energy on self-advocacy just to navigate inaccessible infrastructure[20]. Implementing formal accessibility clauses within residency contracts could systematically codify the right to an inclusive workspace, thereby mitigating the burden of constant individual negotiation[21].

A. Dr. Satendra Singh: Founder of "Infinite Ability" and a leader in disability justice, exemplifying advocacy for functional assessments.

B. Dr. Sharad Philip: Successfully completed an MD in Psychiatry despite progressive vision loss, embodying the social model's focus on accommodations.

C. Judge Ronald M. Gould: A U.S. judge with progressive multiple sclerosis who advocates for "systemic reforms" rather than "charity", aligning with the rejection of charity-based approaches.

These examples compellingly prove that MD is no bar to professional excellence if the "principle of legitimate expectation" and non-arbitrariness are upheld under the RPwD Act.

6. The Path Forward: Policy Recommendations

To address the "clear violations" of the RPwD Act, the following steps are mandated by the Court:

(a) Reform Guidelines: The NMC must issue fresh guidelines for medical admissions that prioritize functional competency over quantified benchmarks**Error! Bookmark not defined.**.

(b) Inclusive Assessment Boards: Every board must include at least one doctor or health professional with a disability to ensure empathy and lived experience in the evaluation.

(c) National Fund for MD: The state must establish a permanent fund to ensure MD patients are not left to the "elusive promise of crowdfunding"[22]

[20] Meaghan Roy-O'Reilly and Arghavan Salles, "Stigma Associated with Requesting Accommodations—the High Cost of Ableism in Medicine" JAMA Network Open (American Medical Association, 2023).
[21] Quinten K Clarke, "The utility of accessibility clauses in resident contracts" BMC Medical Education (BioMed Central, 2023).
[22] Sumrah Danish and Ishrat Rasool, "Evaluation of the National Policy for Rare Diseases (NPRD) 2021 and Ayushman Bharat in Addressing Financial Barriers, Infrastructure Gaps, and Healthcare Accessibility Challenges," 36 Journal Academy of Hospital Administration 50–61 (2024).

(d) Accessibility Databases: NEET and other application portals must provide a database of college accessibility and available accommodations foe applicants with disabilities[18].

7. Conclusion: Justice as an Inalienable Right

Justice for persons with MD is currently "delayed and denied". The "costs of judicial and administrative delays" are paid in "organ damage, disability, and death". However, the shift from a "suspicion-ridden medical expertise-driven model" to a "rights-based approach" offers a blueprint for reform**Error! Bookmark not defined.**.

The Supreme Court has made it clear: "Injustice anywhere is a threat to justice everywhere". To exclude MD patients from medical education or life-saving medicine is not only a violation of the RPwD Act but a breach of the "pact between the people of India" enshrined in the Constitution. The goal is to create the "RPwD generation"—a generation of disabled Indians who regard full constitutional entitlement as their "birthright". Justice for those with MD is not a favor; it is a long-overdue fulfilment of the promise of equality, dignity, and fraternity. Ultimately, fostering an inclusive medical culture requires moving beyond performative compliance to institutionalize disability as a vital form of diversity that enhances the empathy and efficacy of the entire healthcare workforce.