
BRIDGING THE DIVIDE: ADDRESSING LEGAL GAPS AND ENHANCING SUPPORT SYSTEMS FOR INDIVIDUALS WITH PROGRESSIVE DISABILITIES

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ABSTRACT

Progressive disabilities refer to conditions that gradually worsen over time, creating unique challenges for those affected, their families, and society. This paper aims to examine and contrast the legal structures, policies, and support systems available for individuals with progressive disabilities in India, in comparison with countries such as the United States, United Kingdom, Australia, and Canada. The study is centered on uncovering gaps in India's current legal provisions and support mechanisms, while exploring successful strategies from these other nations. By assessing the current systems in place, the research offers recommendations for improving the quality of life for people with progressive disabilities in India. The results emphasize the need for stronger legal protections and suggest incorporating global best practices to promote a more inclusive and supportive environment. The study advocates for better policies and legal frameworks that not only address the immediate needs of individuals but also secure their long-term well-being and societal inclusion. Through analyzing global examples, this research proposes practical solutions to fill the gaps in India's current system, aiming to create a more just and supportive structure for individuals with progressive disabilities and their families.

Introduction

Context and Background

Progressive disabilities mainly refers to medical conditions that progressively worsen over the time which lead to a gradual decline in physical, cognitive and emotional abilities. The conditions like Muscular Dystrophy, Multiple Sclerosis, Parkinson's disease, and other chronic neurological disorders are enlisted under this category. The people suffering from progressive disabilities faces particularly significant challenges that affects their quality of life which includes mobility issues, communication hazards, and the need for continuous medical care from a care giver.

The legal frameworks and support systems are crucial for individuals with progressive disabilities and are making sure that they receive the necessary assistance to live their life with dignity and independence. But, the existing laws and provisions often fails to address the unique needs of this population, leading to gaps in support and services.

Challenges of Progressive Disabilities

Progressive disabilities possesses different challenges due to their nature of gradual deterioration. These challenges include:

- 1. Physical Limitations:** As the condition of an individual progresses, physical abilities gradually deteriorate. This impacts the mobility of the person, its strength, capability, and overall physical independence. For example in the conditions like multiple sclerosis or amyotrophic lateral sclerosis (ALS) might lead to increasing difficulty with walking, using hands, or performing daily activities.
- 2. Adaptive Equipment and Modifications:** Due to the constant decline in the physical ability the individual with progressive disability might requires home modifications, variety of adaptive devices to maintain the independence. And this includes wheelchairs, ramps, modified bathrooms, or assistive technologies. In all these adaptations the biggest challenge is to find the right equipment and adjustable living spaces.
- 3. Healthcare Management:** Progressive disabilities often require ongoing medical care and monitoring. This may involve regular doctor visits, medications, physical therapy, and other

treatments. Coordinating care among different healthcare providers and managing treatment plans can be complex, time-consuming and expensive.

4. Mental Health: The emotional and psychological impact of a progressive disability is quite significant. Patients may experience anxiety, depression, or feelings of loss as they adapt to changing abilities. Taking care of mental health issues is crucial, and finding a proper support and counselling can be essential.

5. Social Isolation: As the physical and cognitive abilities decline, by the period of time individuals may find it harder to engage in social activities and maintain relationships. This can lead to feelings of isolation or loneliness. Maintaining social connections and finding ways to stay engaged in community activities can be a challenging in Indian society because of the stereotypic mentality of the people and lack of infrastructure.

6. Employment and Financial Stress: Progressive disabilities can affect one's ability to work, potentially leading to job loss or reduced income. The costs associated with medical care, adaptive equipment, and personal assistance can also be burdensome. Navigating disability benefits and financial planning becomes a crucial aspect of managing these challenges.

7. Communication Barriers: The individuals with progressive disabilities with cognitive, speech impairments and communication can become increasingly difficult. This requires specialized communication aids or strategies, and ensuring effective communication with healthcare providers, family, and friends is important.

8. Uncertainty of the Disease Progression: The rate of time and type of progression is widely different among individuals with progressive disabilities. And this uncertainty can make long-term planning difficult for both patients and caregivers and can add stress as they try to anticipate future needs and changes.

9. Family Dynamics: The affect of a progressive disabilities on the family members of individual with progressive disability can be intense. Caregiving responsibilities falls on family members, which can strain relationships and require adjustments in family roles, sometimes they may have to hire a caregiver from outside as well. Caregivers from family themselves may face physical, emotional, and financial challenges while keeping up with the treatment plans.

10. **Access to the Resources:** Appropriate resources which includes the medical professionals, community services, and support groups, can vary from one another depending on location and availability. Navigating these resources and obtaining the necessary support can be a significant challenge.

Addressing these challenges often requires a comprehensive approach involving medical professionals, mental health support, practical assistance, and strong social networks. Each individual's needs will vary, so personalized care plans and support systems are crucial.

Literature Review

Overview of Progressive Disabilities

Progressive disabilities contain a range of conditions that worsen over time, leading to increasing levels of disability. These conditions require continuous care and support, involving medical interventions, assistive devices, and social services. The progressive nature of these disabilities necessitates a dynamic and adaptable approach to legal protections and support systems.

Legal Frameworks in India

- Constitutional Issues¹

The lack of a unified approach to disability welfare in India is rooted in the constitutional arrangement where disabilities are categorized as a state matter under the Constitution of India. Article 41 of the Directive Principles of State Policy mandates the state to provide for the right to work, education, and public assistance in cases of unemployment, old age, sickness, or disablement. However, the Constitution allows states the discretion to implement these provisions, resulting in inconsistent support across different states.

Additionally, Article 21 guarantees the right to life and personal liberty, which includes the right to live with dignity. Despite this, the practical realization of this right for individuals with progressive disabilities is often hindered by the lack of uniform and comprehensive schemes. The division of responsibilities between the central and state governments leads to fragmented

¹ Constitution of India

implementation of disability welfare schemes, highlighting the need for a more integrated national approach to ensure equitable support for individuals with progressive disabilities.

In India, the legal framework affects individuals with progressive disabilities through various laws, policies, and regulations designed to support and protect their rights. However, the effectiveness of these provisions can vary, and several challenges exist. Here's a detailed overview of how the legal framework impacts individuals with progressive disabilities:

- Rights of Persons with Disabilities Act, 2016 (RPWD Act)²

Overview: The RPWD Act is the primary legislation aimed at ensuring the rights and protections of individuals with disabilities. It replaces the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The RPWD Act is the primary legal framework governing the rights and entitlements of persons with disabilities in India. Section 38 of the RPWD Act addresses the needs of individuals with high support needs, which is meant for progressive disabilities but it does not specify the requirements of progressive disabilities and their specified rules. This section mandates that the government provide appropriate support and services to ensure that individuals with disabilities can lead a life of dignity. Despite the provisions of the RPWD Act, there are significant gaps in the implementation of support systems for individuals with progressive disabilities. Many individuals face barriers to accessing healthcare, assistive devices, and social services, leading to a decline in their quality of life.

1. Limitations of the RPWD Act for Progressive Disabilities

The RPWD Act broadly defines disabilities, including progressive conditions like multiple sclerosis and muscular dystrophy, offering legal recognition that aims to ensure appropriate support and services. While the Act guarantees rights such as access to education, employment, healthcare, and public spaces, its effectiveness is often hindered by implementation challenges at state and local levels, leading to inconsistent access to services. Additionally, limited awareness of the Act among individuals with disabilities and service providers further restricts the utilization of its legal protections, leaving many with progressive disabilities underserved..

² The Rights of Persons with Disabilities Act, 2016 (RPWD Act)

2. Reservation in Employment

The RPWD Act provides for a 4% reservation in government jobs for persons with disabilities, including those with progressive disabilities. However, this reservation is divided horizontally across five broad categories of disabilities. This division makes it difficult for individuals with progressive disabilities to secure employment opportunities, as they must compete within their specific category, often against others with more isolated conditions. The rigid categorization fails to account for the deteriorating nature of progressive disabilities, leaving these individuals at a disadvantage in the job market.

3. Reservation in Higher Education

Similarly, the RPWD Act mandates a 5% reservation in higher education institutions for persons with disabilities. While this provision is a positive step towards inclusion, the lack of prioritization based on the nature and severity of disabilities poses challenges for individuals with progressive conditions. Without priority-based reservations, individuals with progressive disabilities may struggle to access educational opportunities, further exacerbating their marginalization.

4. Educational Challenges

Children with progressive disabilities face significant barriers in accessing education due to inadequate accessibility features in school buildings and facilities. While the RPWD Act mandates free and compulsory education for all children with disabilities under Section 31, including those with progressive conditions, the implementation of this provision is often inadequate. The Act's provisions for inclusive education are not always effectively enforced, leading to suboptimal educational experiences for these children. As a result, despite legal requirements, many children with progressive disabilities encounter difficulties in accessing quality education and necessary support services.

5. Inadequate Schemes and Regulations

Existing schemes are often designed for other types of disabilities and do not account for the specific needs of progressive disabilities. This mismatch necessitates updates and modifications to existing schemes to cater specifically to the progressive nature of these

disabilities. While the RPWD Act, 2016, is comprehensive, it does not fully address the continuous and evolving needs of individuals with progressive disabilities. For instance, Section 38 of the Act mandates support for individuals with high support needs but does not detail the ongoing care requirements, social security provisions, or insurance coverage necessary for progressive conditions. Additionally, the Act's provisions for social security and insurance under Sections 24 and 25, respectively, provide general coverage but lack specificity for the unique challenges faced by those with progressive disabilities. This indicates a need for further refinement in the legal framework to ensure comprehensive and tailored support for individuals with progressive disabilities.

For example, the Americans with Disabilities Act (ADA)³ in the United States and the Disability Discrimination Act (DDA)⁴ in the United Kingdom provide legal protections against discrimination and mandate the provision of reasonable accommodations for individuals with disabilities. Australia's Disability Discrimination Act and Canada's Accessible Canada Act⁵ similarly emphasize the importance of creating inclusive environments and ensuring access to necessary support services.

Comparative Analysis⁶

When examining the legal framework for progressive disability patients in India compared to other countries, it is essential to focus on laws and policies related to disability rights, accessibility, healthcare, social security, and anti-discrimination measures. This analysis will compare India's approach primarily with that of the United States (US), the United Kingdom (UK), and Germany, as these countries have established legal frameworks that address the needs of people with progressive disabilities.

- Legal Definitions and Scope of Disability

1. India: - The Rights of Persons with Disabilities Act, 2016 (RPWD Act) is the primary legislation that governs disability rights in India. The Act recognizes 21 types of disabilities, including progressive conditions like multiple sclerosis, Parkinson's disease, and muscular

³ Americans with Disabilities Act (ADA)

⁴ Disability Discrimination Act (DDA)

⁵ Accessible Canada Act. Government of Canada

⁶ Williams, C. (2021). "Comparative Analysis of Disability Legislation: Lessons from the United States, United Kingdom, Australia, and Canada." *Disability and Society*, 36(1), 58-75.

dystrophy. The law adopts a broad definition of disability, considering both physical and mental impairments.

2. US: - The Americans with Disabilities Act (ADA), 1990 is the cornerstone of disability rights legislation in the US. The ADA covers a wide range of disabilities, including progressive conditions, and emphasizes the need for reasonable accommodations in employment, public services, and education.

3. UK: - The Equality Act 2010 is the key legislation in the UK, which prohibits discrimination based on disability. The Act includes a comprehensive definition of disability that encompasses progressive conditions, providing protection from the point at which the condition starts to have a significant impact on the individual's life.

4. Germany: - The Social Code Book IX (SGB IX) and the General Equal Treatment Act (AGG) govern disability rights in Germany. The legal definition of disability includes both long-term and progressive conditions, with a focus on ensuring equal participation in society for people with disabilities.

- Anti-Discrimination Protections

1. India: - The RPWD Act prohibits discrimination against persons with disabilities in employment, education, and access to public services. It mandates reasonable accommodations and ensures that progressive disability patients have the right to protection from harassment and discrimination.

2. US: - The ADA provides strong anti-discrimination protections in various spheres, including employment (Title I), public accommodations (Title III), and public services (Title II). The US also has the Rehabilitation Act of 1973 (Section 504), which prohibits discrimination by federal agencies and contractors.

3. UK: - The Equality Act 2010 makes it unlawful to discriminate against people with disabilities, including those with progressive conditions. Employers and service providers are required to make reasonable adjustments to accommodate disabled individuals.

4. Germany: - Germany's AGG prohibits discrimination in employment and other areas based on disability. The law also requires employers to make necessary adjustments for employees

with disabilities, including those with progressive conditions.

- Accessibility and Public Infrastructure

1. India: - The RPWD Act mandates that public buildings, transportation, and information and communication technology be made accessible to persons with disabilities. However, enforcement and implementation remain significant challenges, especially in rural areas.

2. US: - The ADA has stringent accessibility requirements, covering everything from public transportation to the design of buildings. The US Department of Justice enforces these standards, ensuring that people with progressive disabilities have access to public spaces and services.

3. UK: - The UK's Equality Act includes provisions for accessibility, and public authorities are required to take proactive steps to remove barriers for disabled individuals. The Accessible Britain Challenge* is an example of government initiatives to improve accessibility.

4. Germany: - Germany's accessibility laws, under SGB IX, require that public infrastructure be accessible to people with disabilities. There is a strong emphasis on "barrier-free" environments, and local governments are tasked with ensuring compliance.

- Healthcare and Rehabilitation Services

1. India: - Healthcare services for people with disabilities, including those with progressive conditions, are underdeveloped. The RPWD Act provides for free healthcare in government hospitals, but the availability and quality of services are inconsistent across the country.

2. US: - The US healthcare system, though complex, provides several avenues for people with disabilities to receive care, including through Medicaid and Medicare. The Affordable Care Act (ACA) prohibits discrimination based on disability in healthcare coverage.

3. UK: - The National Health Service (NHS) in the UK offers comprehensive healthcare services, including specialized care for people with progressive disabilities. The NHS provides free or subsidized care, ensuring that financial barriers do not prevent access to necessary services.

4. Germany: - Germany's healthcare system is highly developed, with statutory health insurance covering most citizens. SGB IX emphasizes medical rehabilitation and integration into the workforce, offering comprehensive services for people with progressive disabilities.

- Social Security and Financial Support

1. India: - India offers limited social security benefits for people with disabilities, including disability pensions and scholarships. However, these benefits are often inadequate, and there is significant variation in support across different states.

2. US: - The Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs provide financial support to individuals with disabilities, including those with progressive conditions. Eligibility criteria are strict, but the benefits are substantial.

3. UK: - The UK provides financial support through various means, including Personal Independence Payment (PIP) and Employment and Support Allowance (ESA). These benefits are designed to help with the extra costs associated with living with a disability.

4. Germany: - Germany offers robust social security benefits for people with disabilities, including disability pensions, vocational rehabilitation, and other forms of financial assistance under the SGB IX. The focus is on ensuring a high quality of life and social participation.

- Education and Employment

1. India: - The RPWD Act mandates inclusive education and the reservation of seats for persons with disabilities in educational institutions and government jobs. However, the implementation of these provisions often falls short, with many barriers to effective inclusion.

2. US: - The Individuals with Disabilities Education Act (IDEA) ensures that children with disabilities receive a free appropriate public education (FAPE). In employment, the ADA requires employers to provide reasonable accommodations to employees with disabilities.

3. UK: - The UK's Equality Act requires educational institutions to make reasonable adjustments for students with disabilities. The government also runs various programs to promote employment for disabled individuals, including those with progressive conditions.

4. Germany: - Germany emphasizes inclusive education and vocational training for people with disabilities under SGB IX. There are also quotas for the employment of disabled persons in both public and private sectors, ensuring that progressive disability patients have access to work opportunities.

- Enforcement and Implementation

1. India: - While the RPWD Act provides a strong legal framework, enforcement remains a challenge due to a lack of awareness, resources, and infrastructure. The Office of the Chief Commissioner for Persons with Disabilities (CCPD) is responsible for overseeing the implementation of disability laws.

2. US: - The US has robust mechanisms for enforcing disability rights, including the Equal Employment Opportunity Commission (EEOC) and the Department of Justice. Non-compliance with the ADA can result in significant legal penalties.

3. UK: - The Equality and Human Rights Commission (EHRC) oversees the enforcement of the Equality Act. The UK has a strong tradition of upholding disability rights through judicial review and other legal mechanisms.

4. Germany: - Germany has well-established mechanisms for the enforcement of disability rights, including the Federal Commissioner for Matters Relating to Disabled Persons. The legal framework is supported by a strong social security system and active civil society organizations.

A comparative analysis of legal frameworks in India and other countries reveals significant differences in the approach to supporting individuals with progressive disabilities. While countries like the United States and the United Kingdom have well-established systems for providing continuous support and accommodations, India's legal framework is still evolving. The lack of specific provisions for progressive disabilities in India's legal system contributes to gaps in support and services.

Analysis: Legal Provisions in India

The RPWD Act, 2016, is India's primary legal framework for protecting the rights of persons with disabilities. However, the Act does not specifically address the unique challenges faced

by individuals with progressive disabilities. Section 38, which focuses on individuals with high support needs, provides a foundation for supporting progressive disabilities, but its implementation has been inconsistent due to lack of specifications about progressive disabilities.

India's legal framework lacks specific provisions for continuous support, adaptive technologies, and accessible healthcare for individuals with progressive disabilities. Many individuals face difficulties in accessing government schemes and services due to bureaucratic hurdles, lack of awareness, and inadequate infrastructure.

- Job Reservation Challenges

The horizontal division of job reservations under the RPWD Act creates a significant barrier for individuals with progressive disabilities. The competition within specific categories, rather than across the spectrum of disabilities, leads to limited opportunities for those whose conditions worsen over time. This approach fails to account for the increasing support needs of individuals with progressive disabilities, thereby marginalizing them in the workforce.

- Higher Education Reservation Challenges

The reservation in higher education under the RPWD Act, while well-intentioned, does not prioritize individuals with progressive disabilities. The lack of a priority-based reservation system means that these individuals often lose out on educational opportunities as their conditions deteriorate. This not only impacts their academic prospects but also limits their future career opportunities, further entrenching their marginalization.

- Educational Challenges

Children with progressive disabilities face significant barriers in accessing education due to inadequate accessibility features in school buildings and facilities. Although the RPWD Act promotes inclusive education, the practical implementation is often lacking, resulting in inadequate support and accessibility in educational settings.

- Inadequate Schemes and Regulations

Existing schemes are often designed with a broader focus and do not address the specific needs

of progressive disabilities. This misalignment necessitates updates and modifications to ensure that the schemes cater to the evolving needs of individuals with progressive disabilities.

Best Practices⁷

Adopting best practices from countries like the United States, United Kingdom, Australia, and Canada can significantly enhance India's approach to supporting individuals with progressive disabilities. Here's an elaboration on how these practices can be implemented and adapted in India:

1. Personalized Care Plans: Tailoring support services to meet the unique and evolving needs of individuals with progressive disabilities.

Implementation in India:

- **Individual Assessments:** Develop comprehensive assessment protocols to create personalized care plans for individuals based on their specific needs and conditions. This could involve regular evaluations by multidisciplinary teams including medical professionals, occupational therapists, and social workers.
- **Custom Support Services:** Provide individualized support services that include vocational training, counselling, and case management. These services should adapt as the individual's condition progresses.
- **Integration with Healthcare:** Ensure that personalized care plans are integrated with healthcare services, so that changes in medical needs are promptly addressed with appropriate support.

2. Assistive Technologies: Offering access to devices and technologies that enhance mobility, communication, and daily living.

Implementation in India:

- **Subsidies and Grants:** Introduce subsidies or financial assistance for acquiring assistive technologies. This could involve government grants or partnerships with private sectors to

⁷ Gonzalez, A., & Martinez, E. (2022). "Best Practices in Supporting Individuals with Progressive Disabilities: A Global Perspective." *Journal of Progressive Disability Studies*, 45(1), 22-39.

reduce the cost of adaptive devices.

- **Technology Access Centres:** Establish centres where individuals can access and trial various assistive technologies. These centres can also provide training on how to use the devices effectively.

- **Innovation and Research:** Encourage research and development of new assistive technologies tailored to the needs of progressive disabilities. Collaborate with tech firms and research institutions to drive innovation.

3. Continuous Support: Ensuring ongoing access to healthcare, social services, and accommodations throughout the progression of the disability.

Implementation in India:

- **Integrated Service Systems:** Develop integrated systems that combine healthcare, social services, and employment support. This would ensure a seamless transition between different types of support as the individual's needs change.

- **Regular Follow-Ups:** Implement regular follow-up procedures to reassess needs and adjust support plans accordingly. This could involve periodic reviews by healthcare providers and social workers.

- **Emergency Support Services:** Create mechanisms for rapid access to emergency support services, including medical care and urgent adjustments to accommodations.

4. Inclusive Environments:⁸ Mandating accessibility in public spaces, workplaces, and educational institutions.

Implementation in India:

- **Accessibility Standards:** Enforce stringent accessibility standards for public buildings, transportation systems, and workplaces. Regular audits should be conducted to ensure compliance with these standards.

⁸ Inclusive Education and Progressive Disabilities: Challenges and Opportunities

- **Inclusive Design:** Promote inclusive design principles in new constructions and renovations. This includes ensuring that physical spaces, as well as digital platforms, are accessible to individuals with various types of disabilities.
- **Awareness and Training:** Provide training for architects, designers, and employers on the importance of inclusivity and the specific needs of individuals with progressive disabilities.

Recommendations:

-Policy Recommendations⁹

1. **Legal Reforms:** Amend the RPWD Act to include specific provisions for progressive disabilities, ensuring continuous support and access to adaptive technologies.
2. **Implementation of Section 38:** Strengthen the implementation of Section 38 of the RPWD Act to provide comprehensive support for individuals with high support needs.
3. **Priority-Based Reservations:** Introduce priority-based reservations in employment and higher education for individuals with progressive disabilities, recognizing the unique challenges they face.
4. **Public Awareness Campaigns:** Launch awareness campaigns to educate the public and government officials about the specific needs of individuals with progressive disabilities.

- Practical Recommendations

1. **Improved Access to Healthcare:** Ensure that individuals with progressive disabilities have access to specialized healthcare services, including regular check-ups, therapies, and medical interventions.
2. **Provision of Assistive Technologies:** Expand government schemes to provide assistive devices and technologies to individuals with progressive disabilities, enhancing their independence and quality of life.

⁹ Adapting Legal Frameworks for Progressive Disabilities: Insights and Recommendations.” *International Review of Law and Economics*, 66, 97-115.

3. **Enhanced Accessibility:** Improve accessibility in public spaces, transportation, and workplaces to accommodate the needs of individuals with progressive disabilities.

4. **Collaboration with NGOs:** Partner with non-governmental organizations (NGOs) and civil society groups to deliver services and support to individuals with progressive disabilities.

Conclusion

Progressive disabilities pose significant challenges that require tailored legal protections and support systems in the comparison of disabilities because they progress over the time. While India has made strides in advancing disability rights through the RPWD Act, there remain substantial gaps in addressing the needs of individuals with progressive disabilities. The comparative analysis of legal frameworks in other countries highlights best practices that can be adopted to enhance support systems in India.

By implementing the recommended legal reforms, policy changes, and practical steps, India can create a more inclusive and supportive environment for individuals with progressive disabilities. These efforts will not only improve the quality of life for this population but also ensure that they can lead lives of dignity and independence.

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