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NON-GOVERNMENTAL ORGANIZATIONS AND THE LEGAL SYSTEM FOR MUSCULAR DYSTROPHY IN INDIA: AN INTERDISCIPLINARY ANALYSIS

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ABSTRACT

The paper conducts a critical analysis on the determinant management of the non-governmental agencies in closing the implementation gap between legislative processes and actual experiences of people with muscular dystrophy in India. The severe disability, the inability to walk since ages 10-12, respiratory failure, heart-related problems, and premature deaths are caused by muscular dystrophy, a cluster of genetic inherited muscle diseases, which causes progressive muscle weakness, defects of muscle proteins, and cell death. There are higher rates of incidence in India as compared to those in the whole world. Rights of Persons with Disabilities Act, 2016, introduced 21 recognized disabilities with MD, taking the rights-based approach where equal rights, dignity, reservations, accessibility, and safeguards are guaranteed. The supportive programs such as Deen Dayal Divyangjan Rehabilitation Scheme are implemented successfully despite insufficiency of funds, low enforcement, lack of coordination, and low awareness.

It is necessary to fill these gaps with the help of NGOs whose activities include advocacy, service delivery, research, and comprehensive care. The case studies provide the Indian Association of Muscular Dystrophy which provides one-stop genetic testing, physiotherapy, hydrotherapy, and counseling; Dystrophy Annihilation Research Trust which concentrates on the research and rehabilitation of Duchenne MD; the Indian Muscular Dystrophy Society to prevent and raise awareness; and others such as Molecular Diagnostics Center, Mobility in Dystrophy Trust, BharathMD Foundation and Organization of Rare Diseases India. This interdisciplinary approach highlights the symbiotic relationship between civil society and the state and the impact of NGOs on policy, access to care, rehabilitation, and enhancement of physiotherapy to handle contractures, reduce pain, and use adaptive equipment and social inclusion of rare diseases since these areas are resource-limited.

Keywords: Muscular dystrophy, NGOs, Rights of Persons with Disabilities Act 2016, India, rare diseases, advocacy, rehabilitation, policy implementation

INTRODUCTION

Muscular dystrophy (MD) is a family of genetic and inherited muscle diseases, which weaken muscles used in movement. It is characterized by gradual skeletal muscle weakness, muscle protein abnormalities and muscle cell death. This contributes to serious disability, loss of ambulance since early 10-12 years of age, respiratory failure, heart issues, and passing away, which usually happens in late teens or early twenties[1]. In 2016, the Rights of Persons with Disabilities Act included 21 conditions, such as MD, in the list of recognized ones. It changed to a rights-based model, which ensures persons with MD equal rights, dignity, reservation in education and employment, accessibility, and person protections[2]. Legal and fund assistance is given through government schemes such as Deen Dayal Divyangjan Rehabilitation Scheme and Accessible India Campaign. However, the potential success of RPwD Act provisions with people having MD has been hindered by ineffective implementation caused by low funding, laxity, interdepartmental coordination issues and low awareness[3]. Therefore, these gaps have been filled by non-governmental bodies through community support, promotion of clinical research, provision of rehabilitation services, advocacy, and comprehensive care[4]. These groups are especially essential due to the fact that muscular dystrophies are clinically and genetically varied, often in the form of mutation of genes in the molecules of muscle proteins, and currently they have no specific treatment, which requires a multidisciplinary approach[5]. Physical therapy is an important part of this multidisciplinary solution to the increase in life expectancy and the quality of life of people with muscular dystrophy[6]. Such measures include

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[1] Atcharayam Nalini, “Duchenne muscular dystrophy: the NIMHANS experience” (maastricht university, 2020)

[2] The Rights of Persons with Disabilities Act, 2016, No. 49, Acts of Parliament, 2016 (India)

[3] Syeda Tahseen Kulsum, K Madan Gopal and Arpita Aggarwal, “Assessment of the Rights of Persons with Disabilities Act, 2016 in India: A Comprehensive Study on Implementation and Impact,” 6 International Journal For Multidisciplinary Research (2024)

[4] Moumita barman, “Towards Inclusivity: Assessing the Rights of Persons with Disabilities Act, 2016, CDPP,” 2023available at: https://www.cdpp.co.in/articles/towards-inclusivity-assessing-the-rights-of-persons-with-disabilities-act-2016.

[5] Potential Therapeutic Strategies for Muscular Dystrophy, 2022

[6] Saina Swathi, Kandhili Chandrasekaran Gayathri and Purushothaman Senthil, “Advanced Physiotherapy Intervention for Muscular Dystrophy,” in G. Gaina (ed.), Potential Therapeutic Strategies for Muscular Dystrophy (IntechOpen, 2023).

meeting the contracture, reducing the pain and fatigue, as well as ensuring the functional independence of adaptive equipment[5]. It is imperative to include the next-level physiotherapy activities, such as specific exercises and the application of assisting devices, to promote self-efficacy and mental well-being of muscular dystrophy people, allowing them to perform any daily activity independently[6].

The majority of the victims are found in the Indian Association of Muscular Dystrophy (IAMD), established in 1992 at Solan in Himachal Pradesh, the biggest of all such facilities in India. It boasts this one-stop shop treatment that comprises of genetic testing, physiotherapy, hydrotherapy, and psychological counseling. Even the Prime Minister in Mann Ki Baat recognized IAMD on a nationwide level and demonstrated an example of integrated rehabilitation[4].

Dystrophy Annihilation Research Trust (DART) is the research-oriented organization that operates in India and is a year old with the research interests based on Duchenne Muscular Dystrophy (DMD) in a genetic background with an aim to find some plausible curing up. It is also marked by free identification and prevention services to rural communities that solve the differences in access to care[7].

Muscular Dystrophy in India: Incidence and Legal Framework

It is critical in assessing the current legal tools and how well they have worked in the facilitation of the challenges that the individuals with MD in the country encounter. This discussion will be further broken down to an analysis of how the law provisions such as the RPwD Act can be converted into concrete support and protection to the MD community given the high prevalence rate of the disease in India. Moreover, the contribution of such national programs as the Deen Dayal Divyangjan Rehabilitation Scheme and the Accessible India Campaign to the legislative framework will also be discussed and evaluated in terms of its contribution to accessibility and rehabilitation services of persons with muscular dystrophy. The role of patient advocacy groups, like Organization for Rare Diseases India, in the implementation process and effectiveness of these legal and programmatic frameworks in addressing systemic gaps and encouraging clinical research and inclusiveness will also be discussed[8]. Nevertheless, this does

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[7] Manju Dubey and Mohan Kumar, "National Policy for Rare Diseases, 2021 – A critical perspective," 34 Indian Journal of Community Health 324–6 (2022).

[8] Yashodhara Bhattacharya et al., "Rare Disease Advocacy Groups and Their Significance in Diagnosis, Management, Treatment, and Prevention of Rare Diseases," in Z. He Wu (ed.), Rare Diseases (IntechOpen, 2020).

not exclude the fact that a serious gap exists in the detailed epidemiological research and the knowledge of genetic mutation patterns characteristic of the Indian population, which is fundamental to the creation of specific interventions and treatment[8]. As an example, the X-linked recessive condition Duchenne Muscular Dystrophy occurs in about 1 per 3600 male births, and up to 400,000 to 500,000 children in India have the disease, which has pronounced the necessity to develop improved diagnostic and treatment interventions[9]. Although the natural history and genotypic trends of DMD in India are rather similar to those found in Western countries, there is still a big problem with the presence of special medical staff and molecular diagnostic facilities[1]. More so, the widespread occurrence of limb-girdle muscular dystrophies also implies that more comprehensive multicentric research is required in order to record the occurrence and genetic causes of the disease in the heterogeneous Indian population[10]. This illustrates the urgency of a powerful, pan-Indian genetic epidemiology investigation to provide accurate definitions of the burden and molecular profile of MD in India to enable the use of precision medicine and focused therapeutic development. This is also complicated by that high rate of consanguinity marriages in some areas may lead to the uprising of autosomal recessive genetic forms of muscular dystrophy, which may require specific genetic counseling and screening programs.

Role of Non-Governmental Organizations

It is against this backdrop that NGOs in India become central to fill the gap between policy directives and real care and support being given to muscular dystrophy sufferers. They tend to address significant gaps in diagnostic care, treatment, and patient advocacy since there are no disease-specific registry and a full-scale epidemiological dataset of rare diseases in India[11] . This fragmented environment means that NGOs must frequently implement projects to consolidate the patient information and provide access to the novel therapeutic modalities such as next-generation sequencing, essential to the accurate molecular diagnosis and to inform the therapeutic plan[12]. Such initiatives are especially essential in a nation where many of the affected people are still undiagnosed in terms of molecular diagnosis because genetic

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[9] Aradhana Rohil, Gautam Kamila and Sheffali Gulati, "Status of Clinical Care of Duchenne Muscular Dystrophy: Global Perspective and Situation in India" Indian Journal of Pediatrics (2026).

[10] Satish V. Khadilkar et al., "Limb-girdle muscular dystrophies in India: A review," 20 Annals of Indian Academy of Neurology 87 (2017).

[11] RK Agrawal et al., "Baseline Knowledge of Rare Diseases in India - A Survey," 2 International Journal of Rare Diseases & Disorders (2019).

[12] Samya Chakravorty et al., "Clinical and Genomic Evaluation of 207 Genetic Myopathies in the Indian Subcontinent," 11 Frontiers in Neurology 559327 (2020).

myopathies are highly heterogeneous and new gene correlations are observed[12]. In addition, the lack of a national epidemiological surveillance system of Duchenne muscular dystrophy and other diseases of MD discourages the development of full genetic screening programs because it is challenging to estimate the actual occurrence of the disease and assess the treatment of the condition[13]. This gap is also made worse by the fact that a primary care physician frequently faces a lack of awareness of the issue and fears de-stigmatization of the patient, which further supports the argument that the NGOs can play an invaluable role in ensuring timely and correct diagnosis[14]. Moreover, NGOs usually promote the increased awareness of the medical community, which is essential in preventing the diagnosis odyssey that many patients with rare diseases go through, sometimes more than seven years[15].

Key Non-Governmental Organizations and Their Contributions

In this section, the particular works of the major NGOs will be discussed, as well as their different strategies to tackle the complex issues of muscular dystrophy, including patient support and rehabilitation, advocacy, and research. These organizations sometimes fulfill the role of playing a key intermediary, taking the world-level developments in muscular dystrophy care and translating them into localized, accessible interventions, and also play a role in the creation of localized data that is critical in policy-making. They often provide the solution to broken healthcare services by organizing multidisciplinary care and creating networks to support patients, and often they fulfil similar roles to what developed rare disease ecosystems do. As an example, a group of NGOs is actively involved in the access to genetic testing and counseling with the help of such methods as next-generation sequencing to detect specific genetic mutations, which is the key to effective diagnosis and individual treatment plans. Such undertakings are essential considering the high cost and low access of molecular diagnostics in most areas which can significantly contribute to delays in the correct diagnosis[16]. In addition, these non-governmental organizations often become especially important in enlightening patient organizations on various screening methods and the adaptive mechanisms in terms of managing inherited neuromuscular diseases, which contributes to earlier access to treatment

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[13] Marcela Orozco et al., "Genetic and clinical landscape of Duchenne muscular dystrophy in Guatemala: insights from a national study," 16 Frontiers in Genetics (2025), at p. 8.

[14] Adyya Gupta et al., "Multiple Stakeholder Perspectives on Cancer Stigma in North India," 16 Asian Pacific Journal of Cancer Prevention 6141 (2015).

[15] Mohua Chakraborty Choudhury and Gayatri Saberwal, "The role of patient organizations in the rare disease ecosystem in India: an interview-based study," 14 Orphanet Journal of Rare Diseases (2019), at p. 5.

[16] Nalaka Wijekoon et al., "Title-molecular diagnostics of dystrophinopathies in Sri Lanka towards phenotype predictions: an insight from a South Asian resource limited setting," 29 European journal of medical research 37 (2024).

and genetic counseling[17].

Indian Association of Muscular Dystrophy (IAMD)

Being a pioneering organization, the IAMD has played a central role in developing a holistic support system of the muscular dystrophy patients, including all levels of services, such as genetic counseling and rehabilitative therapies that are often limited or unavailable in the Indian public health system. Their combined method, which is recognized on the national levels, provides an example of comprehensive patient care, which involves not only a medical, but also a psychosocial component, which is especially important in the environment where there is a low number of specialized muscular dystrophy clinics[18]. The example of Manav Mandir is a residential care home agency under IAMD that offers rehabilitation and long-term care, which demonstrates the original concept of full-scale care of patients with muscular dystrophy of the progressive stages. The model of extensive care also incorporates research activities and collaborates with academic institutions to help in the knowledge base of genetic and phenotypic heterogeneity of muscular dystrophy among the Indian populace. In addition to direct patient care, IAMD also practices advocacy, which seeks to shape policy and increase awareness, which is essential in enhancing the entire system of rare diseases in India[15].

Dystrophy Annihilation Research Trust (DART)

DART is an organization that has a genetic specialization on DMD. It describes how the organization seeks to spread knowledge and create interventions targeting this particular and in many cases serious variant of MD[15]. This area encompasses much research on gene-editing therapeutics and exon-skips, which is essential to treat the genetic basis of DMD but has been demonstrated to be effective in preclinical and early-phase clinical trials. An example of these aims is the work by DART to fix components of the dystrophin gene, including exon 51 skipping via antisense oligonucleotides, and intends to add more exons in the same way[8]. In addition to gene therapy, DART is also looking at cell-based therapies and small molecule-based approaches, which could form a diverse range of research interests in the quest to come up with overall therapeutic solutions to DMD.

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[17] Françoise Lamy, Alessandra Ferlini and Teresinha Evangelista, “Survey on patients’ organisations’ knowledge and position paper on screening for inherited neuromuscular diseases in Europe,” 16 Orphanet Journal of Rare Diseases (2021)

[18] Gisela Găină, “Introductory Chapter: Muscular Dystrophy and Potential Therapeutic Alternatives” IntechOpen eBooks (IntechOpen, 2023)

The Indian Muscular Dystrophy Society (IMDS)

The IMDS works with other stakeholders in India to advance diagnostic services and early intervention measures of muscular dystrophy[19]. This is an organization established by an Advocate and known as Bharat Shantilal Shah that is especially active in terms of spreading information and networking various NGOs in order to establish a more coherent front in combating the challenges of MD patients.

Molecular Diagnostics, Counseling, Care and Research Centre (MDCCRC)

This centre symbolizes a synergistic concept whereby advanced molecular diagnostic means is coupled with general genetic counseling, the continued management of patients, and current state of art research activities are involved in solving the complex problems of muscular dystrophy. It seeks to speed up the process of research to clinical practice to create a direct pipeline of laboratory discoveries to practical patient outcomes. As an illustration, clinical services offered by the centre are informed by their research on the development of new gene-targeted therapies, including micro dystrophin gene transfer and exon-skipping therapies, which offer patients access to new, experimental and advanced therapies[20].

Regional Organizations and Umbrella Organizations

Such bodies are critical in mediating between the activities of uncoordinated, small-scale groups of operations and in lobbying at greater regional and national policies. However, in India, there is no single umbrella agency that can efficiently unite the impact of all the stakeholders concerned with a rare disease and express the voice of advocacy in one voice[21]. The potential effect of such a centralized organization is to make individual NGOs much more effective, as resources are more easily allocated and knowledge is more readily shared and communication is easier in case of an entire overall force of lobbying the government to pay more attention to rare diseases[7]. This lack of a unifying, cross-cutting organization contributes to ineffective advocacy and resource allocation, reducing the overall effectiveness of single NGOs in overcoming the significant issues that rare diseases entail, such as the high price and

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[19] C. Angelini, “Duchenne muscular dystrophy: diagnosis and perspective of treatment,” 8 Journal of Translational Genetics and Genomics 244 (2024).

[20] Dennis Keselman and John F. Brandsema, “Update on Treatment of Dystrophinopathy,” 27 Current Treatment Options in Neurology (2025).

[21] Harsha Rajasimha et al., “Organization for rare diseases India (ORDI) – addressing the challenges and opportunities for the Indian rare diseases’ community” Genetics Research (Cambridge University Press, 2014), at p. 4.

low accessibility of specialized treatment to rare diseases such as Duchenne Muscular Dystrophy[9].

Comparative Analysis of NGO Models

NGOs	Year Established	Headquarters	Significant Area of Interest
1. IAMD	1992	Solan, Himachal Pradesh	Integrated rehabilitation (genetic testing, physiotherapy, hydrotherapy, counseling) Largest facility in India; known in Mann Ki Baat
2. DART	2012	Bengaluru	Genetic-level studies of Duchenne Muscular Dystrophy Research on treatment; medical advisory service
3. IMDS	Early 2000s	Maharashtra	Prevention, diagnosis, awareness, doctor training Advocacy and medical awareness, networks with NGOs
4. Aveksha Foundation	Recent	Pan-India	holistic empowerment (financial aid, education, advocacy) Community integration and rights advocacy
5. Molecular Diagnostics Center	2000s	Coimbatore, Tamil Nadu	Holistic services of DMD and SMA; rural outreach Free identification and prevention programs.
6. Mobility in Dystrophy Trust	2010s	Kerala	Patient-led welfare and inclusion Enhances inclusive society in neuromuscular disorders.
7. BharathMD Foundation	Recent	Pan-India	Prevention, management, care; parent advocacy Partnerships with genetic screening, assistive devices.
8. ORDI	2014	National	Umbrella support of the rare diseases Unites 25+ patient groups; policy impact and multi-centered research.

NGO Models and the Lawful System

It is essential that it will start by integrating the efforts of NGOs into the legal frameworks that are already in place, including the Rights of Persons with Disabilities Act, 2016, which should transform the intent of the law into specific patient outcomes. In particular, NGOs are instrumental in facilitating the disconnect between good ideas in legislation and real life as they can offer invaluable assistive technology and advance inaccessibility advocacy that government efforts tend to ignore[22]. This is extended to helping access specialized medical services, which is not the easiest task in a country where public financing and out-of-pocket payments systems majorly finance the rehabilitation services of individuals with disabilities[23]. Besides, NGOs also play a vital role in vocational training, development of skills, and employment, which are critically important to the social economic inclusion of individuals with muscular dystrophy, thus removing systemic barriers to them fully involving themselves in society[24]. The organisations use their knowledge to further their objectives, operationalize, and develop institutional and social abilities, which are frequently aided by cross-sectoral cooperation with the government. This model of collaboration is specifically crucial in India, as there are still numerous gaps in awareness, diagnosis, funding, and access to care with rare diseases that still exist, despite the National Policy of Rare Diseases 2021[25].

Rights-Based Foundation and Implementation Gaps

Although these policy frameworks exist, there is still a large gap between the rights as a statutory provision and how they are practically being implemented especially in such aspects as equitable access to special medical treatment and rehabilitation services. Such a disconnect between the policy possibilities and the individual requirements of neuromuscular disorders complicates the successful interaction of disconnected healthcare systems in most cases[26]. Moreover, the lack of a strong national registry of rare diseases as discussed in the National Policy on Rare Diseases, 2021, makes it difficult to monitor the epidemiology and informed

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[22] Suraj Singh Senjam et al., “Assistive technology usage, unmet needs and barriers to access: a sub-population-based study in India,” 15 The Lancet Regional Health - Southeast Asia 100213 (2023).

[23] Mohsen Iravani et al., “A Comparative Study of the Rehabilitation Services Systems for People With Disabilities,” 21 Journal of Rehabilitation 544 (2021).

[24] Syed Ashfaq Hussain and Shaik Nazim Ahmed Shafi, “Implementation of Article 12 of the UN Convention on the Rights of Persons with Disabilities in India” Routledge eBooks 267 (Informa, 2023).

[25] Ashima Aggarwal et al., “Equity for the rare: a review on India’s rare disease challenges and policy responses,” 12 International Journal of Community Medicine and Public Health 5871 (2025).

[26] Charlotte Handberg and Ulla Werlauff, “Cross-sectorial collaboration on policy-driven rehabilitation care models for persons with neuromuscular diseases: reflections and behavior of community-based health professionals,” 22 BMC Health Services Research (2022), at p. 2.

distribution of resources[27]. This chronic implementation read does not end with the lack of such programs being fragmented in India, and that rates of poverty, among people with disabilities are higher in India, which only helps in emphasizing the importance of NGOs in complementing government initiatives[28]. Additionally, NGOs can also be granted an important service delivery in areas where the governmental infrastructure is insufficient and deliver a wide range of services, encompassing residential care, medical interventions, and strong advocacy[29].

NGOs as Intermediaries of the Systemic Vacuity

In this role, the NGOs sometimes turn out to be the main source of required services. The NGOs, particularly in the districts where the government lacks or has inadequate health and social support systems[30]. This is due to the fact that, their strong community integration and their specialized knowledge enable them to customize the interventions. They also meet the local needs, thus making sure legislative requirements including those spelt in RPwD Act are achieved. To introduce changes into the lives of people with muscular dystrophy into practice. These organizations often become the key contacts, making funding available, overcoming bureaucratic obstacles, and promoting the idea of the person with disabilities as one of the primary stakeholders in the decision-making patterns. They also persist in lobbying the formulation of national policies on rare diseases, a move that seeks to correct the current evidentiary gap and resource inertia that is usually a hindrance to the effective policymaking and implementation[31]. It can be the use of the cooperation between the government and multiple organizations to mobilize the resources and skills to create a more integrative and reactive healthcare environment, where muscular dystrophy victims are concerned[32]. Such a collaboration not only increases the coverage of healthcare services but also strengthens communities through self-advocacy and collective action and thus solving the systemic

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[27] Dhruvil Jakasaniya and Rutu Tekwani, "review on national policy of rare diseases, 2021," 6 Jindal Journal of Public Policy 99 (2022).

[28] S.F. Ugendar.U and Chandra Sekher, "DISABILITY AND POVERTY IN INDIA: POLICY FRAMEWORK, SOCIOECONOMIC CHALLENGES, AND IMPLICATIONS FOR INCLUSION" EPRA International Journal of Research & Development (IJRD) 163 (2025).

[29] Kaaren Mathias et al., "Inverting the deficit model in global mental health: An examination of strengths and assets of community mental health care in Ghana, India, Occupied Palestinian territories, and South Africa," 4 PLOS Global Public Health (2024).

[30] R. Thara and Vikram Patel, "Role of non-governmental organizations in mental health in India," 52 Indian Journal of Psychiatry 389 (2010).

[31] Shyamjeet Maniram Yadav and Saradindu Bhaduri, "Evidentiary vacuum, epistemic communities and rare disease policymaking in India: an evolutionary policy perspective," 24 Journal of Bioeconomics 133 (2021).

[32] Riddhi Kanubhai Parekh and Mayuri Pandya, "BEYOND THE INDIANS WITH DISABILITIES ACT: A NATIONAL EMPLOYMENT POLICY FOR THE PEOPLE WITH DISABILITY," 2024, at p. 4.

inequities that are current in the existing healthcare system. NGOs also act as crucial intermediaries by addressing the "last-mile connectivity" challenges in healthcare delivery, especially in resource-limited settings, by referring individuals to appropriate health facilities and minimizing out-of-pocket expenditures[33].

State-Non-Governmental Organisation Synergy

Considering the inherent shortcomings of those services offered by the state, especially in rural and low-income areas. In one point, NGOs often play essential functions where the government does not or effectively regulate it[34]. Such a complementary role is essential to bring the persons with muscular dystrophy the necessary healthcare and social support services[35]. They are agile and grassroots, which removes bureaucratic inefficiencies because they make direct deliveries of aid and support to the most in need[36]. Moreover, NGOs play the key role of promoting political representation and active civic participation of Pwds communities, to strengthen democracy on the ground. Such synergistic association between state and non-state officials is especially relevant in the context of rural environments, where the number of people with any form of disability who can access proper healthcare facilities is limited to a small percentage[3]. This may encompass their capability to be modified to the demands of the community swiftly and provide essential testing, triage and telehealth services, therefore, becoming invaluable in scenarios where the traditional healthcare establishment become overburdened or unavailable. This is enhanced by the fact that they can innovate and change strategies in line with the changing health issues and sometimes they are more competitive than governmental organizations[37].

Conclusion and Suggestion

In India, Persons with MD have given legal safeguards under the Constitution of India and RPwD Act, 2016. Though, the provisions RPwD Act is not implemented in true sense because of insufficient fund to establish the specific programs for expensive Health care services.

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[33] Anuja Jayaraman and Armida Fernandez, “Role of civil society in health care: Mechanisms for realizing universal health coverage in vulnerable communities of India,” 11 Frontiers in Public Health (2023), at p. 1.

[34] Elizabeth Donger and Jacqueline Bhabha, “Dilemmas in Rescue and Reintegration: A critical assessment of India’s policies for children trafficked for labour exploitation” Anti-Trafficking Review (2018).

[35] Tamara Rape Ziberna, Liljana Rihter and Tatjana Rakar, “Complementing the State: NGOs and the Challenge of Providing Inclusive Public Services in Slovenia,” 13 Social Inclusion (2025).

[36] Mohammad Ismail Bhuiyan and Md. Aminul Haque, “NGOs’ initiatives and grassroots approach for accessing to health care services for the slum people in Dhaka,” 4 Frontiers in Health Services 1386698 (2024).

[37] Leila Doshmangir et al., “The involvement of non-governmental organisations in achieving health system goals based on the WHO six building blocks: A scoping review on global evidence,” 20 PLoS ONE (2025).

Health care services for individuals with MD are very costly due to the necessity for specialized genetic testing, special physiotherapy, latest rehabilitative therapies, and mutation-specific pharmacological interventions. however, through NGOs efforts this high-cost medical systems can be easily provided to persons with muscular dystrophy. Government authorities must support the NGOs in their endeavors to bridge the gaps in healthcare delivery for this vulnerable population and also make a scheme regarding the development of a national fund trust to support the persons with MD. This financial mechanism would not only alleviate the economic burden on affected families but also ensure equitable access to advanced therapeutic modalities and supportive care, many of which are currently limited by prohibitive costs and infrastructural deficiencies in India. Indian NGOs can be linked with the international NGOs for formulate more efficient mechanism to protect rights of persons with MD.