

National Human Rights Commission

Proceedings of the Core Group Meeting

on

Rights of Persons with Disabilities

Recognizing Progressive Disabilities – Adopting a Holistic Approach to Disability Rights

The National Human Rights Commission (NHRC) convened a Core Group Meeting on Rights of Persons with Disabilities, on the theme - ***Recognizing Progressive Disabilities- Adopting a Holistic Approach to Disability Rights*** at the Manav Adhikar Bhawan on 17th February 2025. The meeting was chaired by Hon'ble Chairperson Justice Shri V. Ramasubramanian where Hon'ble Member, Dr. Justice Bidyut Ranjan Sarangi, Hon'ble Secretary General, Shri Bharat Lal, Director General (Investigation), Shri R. Prasad Meena, Registrar (Law), Shri Joginder Singh, Director, Shri Virender Singh, Deputy Secretary, Shri Sanjay Kumar were present. Attendees comprised representatives from various governmental ministries, NGOs, academicians, medical professionals and disability rights advocates, who discussed on pertinent issues surrounding rights of persons with disabilities.

2. Lt. Col. Shri Virender Singh, Director, NHRC, inaugurated the meeting, extending a warm welcome to the dignitaries present. He emphasized the pressing need for a more inclusive and holistic strategy to address the rights of PwDs. Recognizing the significant proportion of PwDs in India - approximately 2.2% in urban areas and 2.8% in rural areas - he stressed the critical need to bridge the existing data gap and establish a universally accepted and comprehensive definition of disability. He urged active participation from all attendees, expressing his expectation for a productive and insightful dialogue.

3. Shri Bharat Lal, Secretary General, NHRC, elaborated on the NHRC's ongoing engagement with a diverse array of stakeholders. These stakeholders encompassed domain experts, academics, government representatives, and non-governmental organizations (NGOs). Reaffirming the Commission's unwavering commitment to advocating for the rights of marginalized communities, he acknowledged the invaluable contributions of the Core Group in enriching the Commission's work. He underscored the government's dedication to addressing the challenges encountered by PwDs, citing the enactment of the Rights of Persons with Disabilities (RPwD) Act in 2016 as a testament to this commitment. Talking about progressive disabilities, he emphasized that timely diagnosis, affordable and quality healthcare, and meaningful employment are key to ensuring dignity and quality of life for them. He then proceeded to outline the three principal agenda items that would form the core of the meeting's discussions: i.) defining and classifying progressive disabilities, ii.) examining the existing legal and policy frameworks designed to address progressive disabilities, and iii.) promoting the development and implementation of inclusive and equitable support services. He concluded his address by inviting participants to submit any additional inputs or perspectives via email.



4. Shri Justice V. Ramasubramanian, Hon'ble Chairperson, NHRC, set the stage for the discussions by providing a historical overview of the evolution of the rights of PwDs. He characterized this journey as arduous and progressive, marked by significant milestones. These milestones included the 1971 Declaration of the Rights of the Mentally Retarded, the 1976 UN General Assembly proclamation of 1981 as the International Year of Disabled Persons, and the UN Decade of Disabled Persons (1983–1993). He pointed out that these early endeavours were often rooted in a charity-based approach, which was subsequently criticized for its inherent patronizing attitude towards PwDs. To illustrate this perspective, he cited the example of musician Ian Dury, who composed the song "Spasticus Autisticus" as a form of protest against the condescending attitudes that were prevalent during the UN Decade of Disabled Persons. Shri Justice Ramasubramanian stressed that the transition from a charity-based approach to a rights-based framework represented a profound transformation in societal perceptions. This transformation culminated in landmark legal developments such as the Convention on the Rights of Persons with Disabilities (2006) and the Rights of Persons with Disabilities Act, 2016, in India. He observed that it took nearly three decades to bring in effect this shift from a charity-based perspective to a rights-based framework for PwDs.



5. Shri Rajesh Aggarwal, Secretary, Dept. of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment initiated the substantive discussions by focusing on the percentage of individuals recognized as having disabilities. He noted that only 2.2% of individuals are officially recognized as having disabilities, which likely reflects a broader societal trend where disabilities among the elderly are frequently overlooked and not declared. He juxtaposed this figure with the World Health Organization's (WHO) global disability statistics, which indicate that 10% to 15% of the total population experiences some form of disability. Within this percentage, disability is evenly distributed across children, adults, and older persons. While acknowledging the remarkable progress made in the eradication of polio, which is now almost eliminated, he raised concerns about the observed rise in autism cases, especially in metropolitan cities. This trend, he suggested, pointed to a growing need for specialized interventions and support mechanisms for neuro-developmental disorders.

5.1 He also addressed the 4% reservation policy under the sub-quota for PwDs. He explained that despite this provision, representation in higher education, particularly in premier institutions, remains limited. He provided the example of IIT Delhi, where the majority of students availing reserved seats belong to the category of locomotive disabilities, while individuals with other forms of disabilities encounter significant challenges in securing admissions due to accessibility challenges and the absence of necessary accommodations. A major concern that he raised was accessibility, which he identified as a problem in three key dimensions: physical infrastructure (buildings), transportation, and digital platforms. He highlighted that numerous public and private buildings remain inaccessible to PwDs, characterized by inadequate ramps, elevators, and navigation assistance. Public transport systems do not fully accommodate the diverse mobility needs of PwDs, making daily commuting a challenging endeavour. Furthermore, digital platforms, which include

educational portals, government services, and workplace technologies, frequently lack adaptive features such as screen readers, voice commands, and easy navigation for PwDs.



5.2 To address these multifaceted concerns, he stressed the critical need for increased digital accessibility. He emphasized that online education, employment platforms, and government services must become more flexible and inclusive to cater to the specific needs of PwDs. He also spoke about the importance of education reforms, ensuring that learning environments are not only physically accessible but also provide equal opportunities to students with disabilities. Another crucial issue discussed was the concept of "reasonable accommodation," which refers to modifications and adjustments that enable PwDs to participate fully in education and employment without encountering systemic barriers. He highlighted that employment opportunities for PwDs should be increased not out of charity but as a fundamental right, ensuring sustainable livelihood options for this segment of the population. Additionally, he emphasized the significance of healthcare interventions, particularly in prenatal and postnatal diagnosis, which are essential in identifying and managing disabilities early in life. Early intervention services, including speech therapy, assistive technologies, and rehabilitation support, should be widely available to children with disabilities. Lastly, he called for extending benefits even to individuals with mild disabilities (2% disability) to ensure that no one is excluded from essential services and support.

6. Dr. Sunita Mandal, Additional Director General, Directorate General of Health Services, Ministry of Health and Family Welfare provided a detailed account of the Rights of Persons with Disabilities (RPwD) Act and its implementation at the national level. She explained that the Ministry of Social Justice and Empowerment has undertaken several steps toward preventive measures and awareness programs. Key initiatives include preventive healthcare measures, where the government has introduced awareness programs targeting conditions such as leprosy prevention, cancer detection, cardiovascular health, and speech disorders. These programs aim to educate the public and promote early diagnosis and treatment. She emphasized that health services for PwDs should not be treated in isolation but rather integrated into the mainstream healthcare system to ensure better access and inclusivity. Individual assessments are being conducted to identify needs and provide necessary support to individuals, and various training initiatives have been launched to

equip healthcare professionals, social workers, and educators with the necessary skills to support persons with disabilities effectively. She also highlighted the need to tackle inequality in healthcare access and ensure equal opportunities in education and employment through targeted policies and implementation frameworks. Additionally, she stressed the urgent need to increase the number of doctors involved in the certification process for PwDs, making it easier for individuals to obtain official recognition of their disabilities and access government benefits.

7. Dr. Rupali Roy, Assistant Director General, Ministry of Health and Family Welfare contributed to the discussion by reinforcing the importance of institutional contributions in disability inclusion. She emphasized the need for medical rehabilitation, stating that rehabilitation services should be a mandatory component of disability support rather than an afterthought. She further stressed the role of Information and Communication strategies in raising awareness about disabilities. The government has notified accessibility standards, but their implementation remains inconsistent across sectors. A structured training manual has been introduced to educate healthcare professionals on how to handle PwDs with care and efficiency. Awareness and sensitization campaigns are being conducted for government officials, educators, and healthcare workers to promote inclusivity in their respective fields. She also highlighted the growing availability of AI-powered assistive technologies, which can enhance the lives of PwDs through speech recognition, mobility assistance, and learning tools.

8. Shri Rajive Raturi, Private Consultant focused on the importance of financial security and rehabilitation for PwDs. He highlighted the need for disability insurance, as many persons with disabilities struggle financially, especially those with progressive conditions that worsen over time. Introducing comprehensive disability insurance schemes would provide financial security. He also advocated for caregiver allowances to support families who take care of PwDs, as they often face financial burdens. Additionally, he emphasized the urgent need for long-term rehabilitation programs for people with progressive disabilities, ensuring continuous medical intervention and support.



9. Ms. Shivani Jhadhav, Representative, National Centre for Promotion of Employment for Disabled People (NCPEDP) focused on critical policy gaps and legal rights issues faced by

persons with disabilities, particularly in the domains of health, education, and employment. A primary concern discussed was the challenges in medical insurance, where individuals are often denied coverage due to pre-existing conditions, resulting in financial dependency and limited independence. The implementation of the Rights of Persons with Disabilities (RPWD) Act was highlighted, with a need for more measurable outcomes and clearer definitions to ensure its effective execution. In education, the need for early intervention, better infrastructure, specialized educator training, and stronger advocacy was emphasized. Concerns over budget allocation were raised, with a particular focus on securing increased financial support for education and disability services. The importance of reasonable accommodations was underscored, alongside the necessity of educating professionals, including lawyers and medical practitioners, on disability-inclusive practices. The discussion also addressed the need for standardization in accessibility and the review of salary structures and benefit eligibility for persons with disabilities, noting the limitations of grant-based pay systems. The discussion concluded with a call for stronger policy implementation, enhanced financial investment, and structural reforms aimed at improving accessibility, protecting rights, and fostering greater inclusion.

10. Dr. Satendra Singh, Director-Professor of Physiology, University College of Medical Sciences & GTB Hospital centred on the challenges faced by the deaf and hard-of-hearing community, particularly in the areas of employment and policy gaps. A key issue raised was the ineligibility for benefits of individuals with less than 40% disability, which disproportionately affects those with hearing and speech disabilities due to the lack of specific job reservations. The absence of comprehensive disability policies further restricts access to essential benefits. The discussion highlighted the need for the effective implementation of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and emphasized legal remedies, including the 2019 gazette notification and Section 38, which offer distinct legal provisions. However, it was noted that states like Maharashtra, West Bengal, and Telangana are yet to establish disability boards, delaying policy execution. A major concern was the flaws in the disability assessment system, which often excludes individuals from receiving benefits. Complex disabilities, particularly those without intellectual impairments, often require additional testing, creating further barriers. The meeting also referenced Supreme Court judgments reinforcing the legal obligation to ensure equal rights for persons with disabilities. The discussion concluded with a call for immediate action to enforce existing policies, establish disability boards, and reform the assessment system to ensure better inclusivity and support.



11. Ms. Purva G. Mittal, Asst. Prof, University of Delhi highlighted several critical issues regarding the challenges faced by individuals with progressive disabilities, emphasizing the lack of visibility and recognition in policies and society. She shared her personal experience of initially being undiagnosed and later struggling with mobility loss and accessibility barriers. A key concern raised was the inadequacy of policies that fail to support individuals diagnosed later in life, leaving them without proper employment or healthcare provisions. She stressed the economic burden of treatment, which is often unaffordable due to outdated insurance and healthcare policies. Additionally, she pointed out the lifelong care giving responsibilities shouldered by families, with no structured state support. The discussion also touched upon inaccessibility in transportation and education, making it difficult for persons with disabilities to participate fully in society. The speaker urged for immediate action instead of prolonged deliberations, calling for inclusive policies, systemic reforms, and better support structures to ensure that individuals with progressive disabilities and their care givers are not left behind. The overarching message was a demand for recognition, rights, and urgent reforms to address the unique challenges faced by this community.

12. Shri Akhil S. Paul, Director, Sense International (India) conducted an analysis of the existing system supporting Persons with Disabilities, identifying several critical gaps hindering their full participation and inclusion in society. His analysis revealed weaknesses in the fundamental process of disability identification, noting that many cases remain undiagnosed or misdiagnosed, consequently denying individuals' access to crucial support services. He also highlighted the lack of adequate early childhood care programs, a deficiency that significantly impedes early intervention and optimal development for disabled children. Furthermore, he emphasized the persistent challenges PwDs face in accessing affordable healthcare and insurance, particularly those with progressive conditions requiring continuous medical attention. These systemic shortcomings create significant barriers to healthcare, economic stability, and overall well-being.

12.1 He pointed to the discrimination in employment, which limits economic opportunities and reinforces social exclusion for individuals with progressive disabilities. He also identified a lack of awareness regarding the legal rights and entitlements of PwDs, hindering their ability to seek justice and access available support. Compounding these

issues are the complex, time-consuming, and often insensitive processes for obtaining disability certificates, further obstructing access to essential benefits.

12.2 To address these multifaceted challenges, Shri Paul proposed a range of concrete solutions. He advocated for the development and implementation of community-based rehabilitation programs, particularly in rural areas where access to specialized services is often limited. Recognizing the need for trained personnel, he suggested government-led training programs for staff interacting with PwDs, ensuring sensitive and informed service delivery. He also emphasized the importance of improving accessibility in technology and the financial sector, allowing PwDs to participate more fully in these crucial aspects of modern life. Furthermore, he stressed the need for tailored care that addresses the specific needs of individuals with progressive disabilities, moving away from generic solutions towards personalized support.

13. Dr. Vaibhav Bhandari, Founder, Swavlamban Foundation focused on the educational challenges faced by individuals with disabilities, alongside other critical areas impacting their lives. He emphasized the persistent struggles in ensuring the right to education for disabled children, citing inadequate infrastructure, a shortage of trained teachers, and discriminatory practices as major obstacles. Beyond the classroom, he highlighted a unique and often overlooked need: the creation of adaptive clothing. He suggested collaborating with fashion designers to develop clothing specifically suited for individuals with rare or progressive diseases like muscular dystrophy, addressing a practical yet frequently neglected aspect of daily living. This focus on both educational access and practical daily needs underscored the multifaceted challenges faced by PwDs.

13.1 He also addressed systemic issues that undermine the support system for PwDs. He raised the concern of fraudulent or inaccurate disability certificates, which can divert resources away from those genuinely in need and erode the integrity of the entire system. He also pointed out the lack of implementation of provisions for caretakers under the RPwD Act, leaving families struggling to provide the necessary support for their loved ones. Furthermore, he advocated for universal laws and provisions to ensure consistency and equity in access to services and support across different regions and disabilities, aiming to eliminate disparities based on location or specific disability.

13.2 To address these diverse challenges, he offered a range of specific suggestions. He proposed including muscular dystrophy under the “Multiple Disability” category and providing genetic counselling services. He also suggested training Anganwadi workers to support children with disabilities and ensuring reasonable accommodations in educational settings. He emphasized the importance of promoting early intervention through prenatal and postnatal accessibility and respecting the dignity of disabled individuals in all interactions, including during examinations. He also called for streamlining legal processes, increasing state-level support, addressing the lack of state-level schemes for equipment purchases, and including rare diseases in existing laws while expanding financial assistance.



14. **Shri Vikas Trivedi, Member Secretary Rehabilitation Council of India** discussed the launch of specialized courses for teachers working with children with disabilities. However, he pointed out a significant limitation: the courses, and by extension the teacher training, are primarily focused on the six disability types explicitly mentioned in the RPwD Act. This leaves teachers ill-equipped to address the needs of children with other disabilities, highlighting the need for broader coverage in teacher training programs.

15. The meeting then proceeded with an open floor inviting a collaborative dialogue among all stakeholders, focusing on potential improvements to existing legislation and addressing any identified gaps.

16. This was followed by remarks from **Dr. Justice Bidyut Ranjan Sarangi, Hon'ble Member, NHRC**, who emphasized the crucial role of the National Human Rights Commission in advocating for increased governmental support and resources dedicated to empowering persons with disabilities to live with dignity. The NHRC's active involvement in this area underscores the importance of recognizing and upholding the fundamental human rights of PwDs, ensuring their full inclusion and participation in society. This advocacy extends to influencing policy decisions, raising public awareness, and holding relevant authorities accountable for fulfilling their obligations to PwDs.

17. Furthermore, Shri Justice Sarangi, stressed the essential nature of accessible medicine and medical support within the context of a welfare state like India. In such a system, the government bears a responsibility to ensure that all citizens, including PwDs, have access to necessary healthcare services. This includes not only the availability of affordable and appropriate medications but also the provision of comprehensive medical support, such as assistive devices, rehabilitation services, and specialized care. Accessible healthcare is not merely a matter of charity but a fundamental right, essential for PwDs to maintain their health, well-being, and overall quality of life.



18. Following this, **Shri Justice V. Ramasubramanian, Hon'ble Chairperson, NHRC** in his concluding remarks stated that the Rights of Persons with Disabilities (RPwD) Act, 2016 requires revisions to align fully with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This alignment, he suggested, can be achieved through parliamentary amendments to the existing legislation. He emphasized the need to meticulously examine current legal frameworks to identify specific clauses that can be modified to enhance their effectiveness and ensure more representative outcomes for PwDs. This process of legal refinement is crucial for guaranteeing the full realization of the rights enshrined in the UNCRPD.

19. Highlighting the potential for intervention by the National Human Rights Commission, he advised stakeholders to formulate and submit their suggestions, carefully considering both the necessary amendments to the existing law and the established mandate of the Commission. This targeted approach will enable the NHRC to leverage its authority and capacity to take appropriate action, thereby safeguarding and promoting the rights of PwDs. He concluded his address with an inspiring call to action, stating, "Things can be done, provided we have the will to do so," underscoring the importance of commitment and determination of the NHRC in advancing the rights and well-being of PwDs.



20. The meeting concluded with a vote of thanks by **Shri Bharat Lal, Secretary General, NHRC** who called for action at part of all stakeholders and stated that our end goal as well as theirs is towards the same direction, for which we must collaborate with joint determined steps.

Annex– I

National Human Rights Commission

1. Justice Shri V. Ramasubramanian, Hon'ble Chairperson
2. Dr. Justice Bidyut Ranjan Sarangi, Hon'ble Member
3. Shri Bharat Lal, Secretary General
4. Shri R. P. Meena, Director General (Inv.)
5. Shri Joginder Singh, Registrar (Law)
6. Lt Col Virender Singh, Director
7. Shri Sanjay Kumar, Deputy Secretary
8. Dr. Kanaklata Yadav, Consultant (Research)
9. Ms. Ahana Ray, JRC
10. Ms. Avani Verma, JRC
11. Ms. Madhura Naniwadekar, JRC
12. Ms. Swarna Singh, JRC
13. Ms. Niharika Sharma, JRC

Members of Core Group in attendance (In-person)

1. Shri Rajesh Aggarwal, Secretary, Dept. of Empowerment of Persons with Disabilities, Ministry of Social Justice and Empowerment, New Delhi
2. Shri RajiveRaturi, Private Consultant
3. Dr. Satendra Singh, Director-Professor of Physiology, University College of Medical Sciences & GTB Hospital

Members of Core Group in attendance (Virtually)

1. Shri. Akhil S. Paul, Director, Sense International (India)
2. Mr. Vikas Trivedi, Member Secretary, Rehabilitation Council of India
3. Ms. Shivani Jadhav, Representative, National Centre for Promotion of Employment for Disabled People (NCPEDP)

Special Invitees in attendance (In-person)

1. Dr. Sunita Mondal, Additional Director General, Directorate General of Health Services, Ministry of Health and Family Welfare
2. Dr. Vaibhav Bhandari, Founder, Swavlamban Foundation

3. Ms. Purva G. Mittal, Asst. Prof, University of Delhi

Special Invitees in attendance (Virtually)

1. Dr. Rupali Roy, Assistant Director General, Ministry of Health and Family Welfare