





# The State of Disability in India









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#### Introduction: The State of Disability in India



Disability does not have a singular meaning. It depends on how one defines ability or able-bodied persons. Most people experience some form of visible or invisible 'disability', either temporarily or permanently, at some point in their lives. As per the World Health Organization, an estimated **16% of the world's population** live with a disability! Despite how widespread the experience of living with a disability is, disability has long been seen as a taboo, often subject to misconceptions and ridicule.

Disability discourse globally has evolved from the **charity model** that was prevalent till the 1950s which viewed Persons with Disabilities ("PwDs") as persons who could not do anything on their own, needed help, and needed to be saved? Thinking worldwide shifted to the **medical model** in the 1950s that pathologised disability and looked at PwDs as persons who needed to be 'cured'? These traditional models portrayed PwDs as charitable objects deserving pity, and not as individuals who are entitled to equal rights and opportunities. Consequently, this resulted in their exclusion from public spaces. Relentless advocacy efforts by disability rights activists led to a paradigm shift in approach towards a **social model** of disability. The social model of disability looks at the disadvantages faced by PwDs not as an individual problem attributable to their impairments, but instead as a result of socially constructed barriers. The **human rights model** builds on the social model and places responsibility on the State to ensure that PwDs can exercise their rights meaningfully by providing an inclusive social, economic, political, and environmental framework. These sustained efforts led to the adoption of the **UN Convention on the Rights of Persons with Disabilities** ("Convention") on December 13, 2006, embracing a human rights-based approach and entitling PwDs to a bouquet of social and economic rights.

In India, the disability rights movement took shape in the 1970s? At this point, the movement was scattered and viewed disability through the charity / medical model. This transformed in the 1990s when activists started demanding equal rights for PwDs, which culminated in a wave of legislations for the empowerment of PwDs. The first kind of disability legislation to be passed in India was the Mental Health Act in 1987, which regulated standards in mental health institutions.10 This was followed by the Persons with Disabilities (Equal Opportunity Protection of Rights and Full Participation) Act, 1995 ("1995 Act"), which sought to protect the rights of PwDs to educational and employment opportunities, among others. These legislations were further supplemented by the Rehabilitation Council of India Act, 1992, and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, to enhance the integration of PwDs into society.1 Notably, India's ratification of the Convention on October 1, 2007, coupled with the calls from civil society to adopt human rights-based legislation, led to the 1995 Act being replaced with the comprehensive Rights of Persons with Disabilities Act, 2016 ("RPwD Act"). The RPwD Act recognises 21 categories of disabilities (as opposed to 7 categories recognised under the 1995 Act). The RPwD Act puts into practice a rights-based approach to disability in as much as it guarantees social and economic rights to PwDs, including reservation for PwDs in government jobs and mandating private companies to adopt PwD-friendly policies.13

While the RPwD Act is a progressive legislation, its implementation has met several roadblocks. These include serious gaps in enforcing accessibility standards, ineffective implementation of social security schemes, lack of political prioritisation of PwDs, discrimination in employment opportunities, and challenges in raising public awareness.









However, the larger issue that PwDs face is **invisibilisation**. They are excluded from educational institutions, public spaces, healthcare, political fraternity, and workplaces, thereby denying them fundamental human rights and freedoms. This problem is exacerbated by the lack of accurate and verifiable quantitative and qualitative data on PwDs, which reduces their visibility, and hinders data-backed policymaking.<sup>14</sup>

Hyundai's purpose-driven initiative "Samarth by Hyundai" with NDTV as an awareness partner seeks to address some of these pressing issues by altering mindsets surrounding disability while promoting inclusivity and affecting larger systemic changes. Samarth's goal is to create an equitable society with a level playing field for all, by leveraging the transformative capacity of technology, product innovations, partnerships, and storytelling. The Samarth initiative has employed a variety of tools to advance its objective.

'Samarth' means capable. The Samarth initiative is built on the belief that disabilities that some of us have to live with should not define how we live, or what we can – or cannot – achieve.

The Samarth initiative has ensured that disability has become a part of the mainstream news. Various panel discussions have been organised on critical issues such as assistive technology, mental health for PwDs, inclusive education, and accessibility in design, among others. The Samarth website also features success stories of PwDs who excelled in their respective fields when provided with requisite support, dispelling the misconceptions regarding their abilities and lack of independence. Notably, as a part of the initiative, sensitisation drives have been carried out in 120 schools across Delhi, Mumbai, Chennai, Pune, Bengaluru, and Hyderabad, to build more consciousness and awareness around disability, along with promoting inclusive and accessible infrastructure:

The Samarth initiative supports 20 para-athletes under the Hyundai Motor India Foundation (HMIF) & GoSports Foundation Partnership and another 6 para-athletes through the Hyundai, NDTV & Wheeling Happiness Partnership, whose remarkable journeys have been showcased in various documentaries to create more public awareness. Notably, two of them, Yogesh Kathuniya and Sheetal Devi, have won medals at the 2024 Paralympics in discuss throw and archery, respectively.

HMIF, under the Samarth initiative, is also supporting Blind Cricket in India. The first Samarth Championship for Blind Cricket was organised between the Indian and Sri Lankan teams, which India won 5-0.

To initiate conversations about technology-based solutions for PwDs, Samarth Assistive Devices Conclave was organised. Along with this, custom-made assistive devices were also provided to PwDs in partnership with Samarthanam Trust for the Disabled.

Remarkably, in addition to fostering greater public awareness, creating sensitivity about disability-related issues, and empowering PwDs, the Samarth initiative also conducted a first-of-its-kind survey across 20 cities in India assessing the state of accessibility and inclusivity for PwDs ("Samarth Survey"). The objective of the conducted on PwDs and persons without disabilities, was to understand the daily challenges faced by PwDs









in carrying out everyday tasks. The survey provided invaluable insights for improving urban accessibility by bringing to light the obstacles faced by PwDs in accessing education, workplace, healthcare, and recreational activities.

This White Paper is informed by the learnings and experience of the Samarth program over the last year, and the findings of the Samarth Survey. It is duly supplemented by existing literature on disability rights in India where necessary. The White Paper is divided into five chapters, each addressing a key area that calls for immediate attention: Infrastructure Accessibility, Social Security Framework, Political Prioritisation, Employment Opportunities, and Public Awareness. The White Paper concludes by providing the 'Samarth by Hyundai in partnership with NDTV' Charter of Recommendations that could aid disability-conscious policymaking while promoting inclusivity and challenging existing perceptions.







### 1. Infrastructure Accessibility



#### Introduction

In October 2023, Virali Modi, India's first wheelchair model and renowned disability rights activist, underwent a humiliating ordeal while registering her marriage. As the registrar's office did not have a lift, she had to be carried two flights of stairs to complete the necessary paperwork. Speaking at a Samarth episode telecast on November 28, 2023, she shared her ordeal, "For most people, 'accessibility' is just a side thought, but that is my everyday life. I have to adjust to the world that is made for people without disabilities rather than the world adjusting for me.<sup>20</sup>

Unfortunately, this is not an isolated instance and is symbolic of the larger systemic issue of inaccessibility that pervades both public and private spaces, significantly hampering the quality of life for PwDs.

Lack of accessible infrastructure prevents PwDs from availing essential services like education, healthcare, banking, and transportation, and as a result, also prevents their access to livelihood opportunities. Furthermore, the inability to participate fully in society hampers PwDs' social inclusion and affects their psychological wellbeing by fostering feelings of dependence.<sup>21</sup> Providing accessible infrastructure can play a significant role in helping break down social and environmental barriers, allowing PwDs to participate fully in society. The Samarth initiative, by taking cognisance of the role of sports in building a sense of community, especially among the youth, and the barriers that PwDs face due to facilities, lack of appropriate inaccessible equipment and societal attitudes, included sports as an integral pillar in its design. To this end, the initiative has supported several para-athletes and undertaken various initiatives to promote the importance of accessible sports facilities.

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I am a great believer that you can't have great quality of life in our cities without our cities being inclusive.

- Amitabh Kant (G20 Sherpa) speaking to Samarth

#### **Physical Infrastructure**

The RPwD Act is a progressive legislation that enshrines the principle of 'universal design', a method of designing environments, products, and services in a way that can be used by all people without the need for adaptation, within its mandate.33 It obligates the Union Government to establish accessibility standards for physical environments, transportation systems, information and communication systems<sup>24</sup> Accordingly, Government notified the the Harmonised Guidelines and Space Standards for Barrier-Free Built Environment for Persons with Disabilities and Elderly Persons ("Harmonised Guidelines") that apply to public buildings (government and private buildings used or accessed by the public at large), including sports and recreational facilities.25

However, gaps persist. For instance, while the Guidelines provide extensive measures to address the needs of persons with visible disabilities, it does very little to address the needs of persons with intellectual and psychosocial disabilities, aside from the section on universal signage.<sup>26</sup> There also gaps in implementation. implementation of these Guidelines lies within the domain of state governments (specifically the municipal bodies constituted under State laws) and most States have not yet updated their bylaws in conformity with the Guidelines?7 It is therefore essential that the state / municipal laws are aligned with the Harmonised Guidelines.

According to the report on 'Assessment of Scheme for Implementation of the Rights of the Persons with Disabilities Act, 2016' dated August







2021 ("Report"), only 494 out of 1662 identified buildings (29.7%) had been made accessible in nine States / Union territories. The Report also observed that railway stations, airports, and other road transport systems were either lagging behind schedule or only partially accessible. Hence, even though the timeline provided under the RPwD Act for making existing infrastructure accessible has elapsed, the goals of the RPwD Act continue to remain illusory.

The able bodied world needs to realise the simple able bodied privilege in going to a park, going to a studio.

- Abhishek Anicca (Author, Poet) speaking to Samarth

#### **Digital Infrastructure**

During the COVID-19 pandemic, the Supreme Court reiterated the importance of digital accessibility, while listing out problems with the CoWIN platform that prevented visually disabled persons from getting access to vital life-saving services like vaccination30 This underscores the importance of digital accessibility for PwDs in the present times. Recognising this, the Indian Government adopted Indian Standard 17802 in May 2023, which aligns with global best practices on Information and Communication Technology accessibility (such as Web Content Accessibility Guidelines, Section 508 of US Rehabilitation Act, 1973, and European Standard 301549) while also catering to the regional needs of Indian users.<sup>32</sup>The adoption of IS 17802 is laudable as it is legally enforceable and mandates both public and private services to make their content accessible for PwDs. Moreover, there are also separate accessibility standards applicable to websites and applications (both government-run or privatelyowned), namely the Guidelines for Indian Government Websites (GIGW), which conform to international standards on accessibility.33

Regrettably, there are still several shortcomings with the digital infrastructure accessibility. The delay of seven years in notifying IS 17802 has caused significant harm to PwDs. The Report noted that only 558 out of 917 websites (64.61%)

had been made accessible as of August 2021 and that no funds had been released by the Government in this regard in the preceding three years.<sup>34</sup> A study conducted in January 2023 further revealed that the accessibility rating of the top 10 most commonly used mobile applications varied from low to medium.<sup>35</sup> Significantly, despite the adoption of IS 17802, the Chief Commissioner for Persons with Disabilities issued notices to all Government ministries and several private establishments in July 2024 noting their failure to make websites and mobile applications accessible for PwDs.<sup>36</sup>

#### **Way Forward**

There is an old adage that says justice delayed is justice denied. I would say that access delayed is life denied.

- Mr. Gaurav Raheja (Professor & Head (Architecture & Planning) Founder, Laboratory of Inclusive Design, IIT Roorkee) speaking to Samarth

A world built for able-bodied persons creates social barriers for PwDs, making their daily lives challenging. While laws and regulations have an important role to play, a fundamental shift in mindset is also crucial to usher in accessibility, in letter and spirit. It is in this light that experts have been calling for the adoption of 'universal design'. However, there still is some distance to be covered as there is a lack of understanding about the needs of PwDs amongst architects, software designers, and policymakers.<sup>37</sup>

Universal design must be built into the curriculum of architecture and software design courses in every university. Further, a collaborative effort is needed from all stakeholders - with designers integrating accessibility from the outset and the Government actively overseeing and ensuring compliance.<sup>38</sup> The Union Government needs to play a more proactive role, in ensuring public and private entities abide by the physical and digital accessibility guidelines in place.







## From the 'Samarth by Hyundai in Partnership with NDTV' Charter of Recommendations

Ensure universal accessibility in all physical, digital, and transport infrastructure to promote independence and equal participation.

#### **Specific Recommendations**

- 1.Make all government-run physical infrastructure (offices, hospitals, schools, etc.) fully accessible.
- 2.Incorporate mandatory accessibility parameters in building codes for occupancy certifications and No-Objection Certificates (NoCs).
- 3.Ensure full accessibility of public transport systems and infrastructure.
- 4. Provide appropriate access to ramps and wheelchairs at bus stops, in buses, and in government buildings.
- 5.Install handrails at all bus stops and government buildings.
- 6.Implement tactile guidance and audio information at all public transport stops and government buildings.
- 7.Create barrier-free and clear pavements for better access.
- 8.Enforce regulations to prevent two-wheeler riders and motorists from parking and riding on pavements.
- 9. Provide accessible playgrounds and sports facilities.

## 2. Social Security Framework



#### Introduction

"Today there is a 5% GST on disability aids. I pay a 5% tax on my wheelchair. This is equivalent to a 5% tax on walking, seeing, and hearing. It's a shame that after 75+ years of India's independence, we still have to pay these kind of taxes. I do hope this tax is removed and GST becomes zero-rated for these particular goods and services. The irony is, that today my wheelchair is insured but I am not. I hope the Finance Minister comes up with strong regulations to mandate insurance companies to give insurance to persons with disabilities as well". These poignant and powerful words of Nipun Malhotra, a leading disability rights advocate and founder of the Nipman Foundation, were shared during a Samarth episode in the lead-up to the Union Budget 2024.

The cost of living with a disability might include hiring an attendant/caregiver for some. For others, it may be the need for a special educator or sign language interpreter. Imagine the cost of walking that is a wheelchair, the cost of hearing that is a hearing aid or the cost of using a computer that might have a variety of accessibility software. All these come at a staggering cost. The strain is compounded by the lack of employment and educational opportunities for PwDs (See Chapter 4).

Given this, social security becomes a lifeline, rather than a safety net, for PwDs to navigate an exclusive world built for able-bodied persons. In recognising this, the RPwD Act mandates that the appropriate governments come up with Social Security Schemes ("SSS") and programs, with PwDs entitled to a 25% higher allowance than others.<sup>39</sup> This includes comprehensive schemes







covering insurance, assistive devices, disability linkage, pension, and healthcare for PwDs to improve their socio-economic conditions, enhance their independence, and promote equal access.

The Samarth Survey found that financial challenges significantly impact the ability of 68% of respondents to manage their disabilities, highlighting the substantial burden of financial factors.

#### **Assistive Devices (ADs)**

Assistive Devices ("ADs") are essential for PwDs to carry out their daily activities independently and for their productive participation in family and community. The RPwD Act requires the government to provide free ADs to students with benchmark disabilities to the age of 18 and promote the development of assistive technology in recreational activities. The Government's flagship program, the Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances (ADIP), aims to help those in need with accessing ADs.

However, despite various commendable initiatives by the Government, issues persist on account of accessibility, affordability, and quality of ADs, with the needs of 70% of PwDs remaining unfulfilled.<sup>45</sup>The handing out of ADs in camps is infrequent and the devices are of poor quality leading to detrimental health outcomes.<sup>46</sup> To worsen this, a 5% GST is levied on ADs that increase the prices of these products.<sup>47</sup>

#### **Disability Linkage**

The Government has mandated the Unique Disability Identification (UDID) number issued to PwDs for availing government schemes to enhance efficiency and transparency.<sup>48</sup>

While the Government's objective is well-founded, the implementation has not been without problems. Pertinently, only 1,09,55,968 UDID cards have been generated as of July 2024,<sup>49</sup> 49 covering less than 50% of India's PwD community, even as per the estimates of the 2011

Census. While it is universally agreed that the 2011 figures are grossly underestimated, the RPwD Actalso increased the number of recognised disabilities from 7 to 21. Considering all this, the number of PwDs with a UDID card is still very low.

Moreover, the Government has recently proposed draft amendments to Rules 17 and 18 of the Rights of Persons with Disabilities Rules, 2017 to tighten the conditions for availing disability certificates.50 Transparency is a must, especially in the wake of recent reports that fake disability certificates have been utilised to misuse quotas. However, instead of extending the certification period from one month to three months and increasing paperwork by requiring further documents 51 what we need is a faster and more objective certification process. Stricter provisions are needed for those who misuse disability certificates for benefits along with the certificate providers. There is also a case for utilising technology like the Digital Public Infrastructure and having multiple levels of attestation based on the benefit claimed. At the same time, genuine PwDs must not suffer in the process.

#### Insurance

The RPwD Act obligates the government to formulate a comprehensive insurance scheme for PwDs. In furtherance of this, the Government has made remarkable efforts in introducing various schemes such as the Niramaya Health Insurance Scheme and the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana.

Despite such efforts, PwDs face discrimination while availing insurance, not based on any objective risk assessment, but simply on account of their disability. In one such instance, the Delhi High Court struck down Postal Life Insurance's policy of charging extra premium from PwDs as being discriminatory while reinforcing that living with a disability is not the same as living with a disease or bad health. The Saurabh Shukla case was a watershed moment for PwDs as the Delhi High Court directed the sectoral regulator, the Insurance Regulatory and Development Authority







of India (IRDAI), to develop a model policy which led to 29 insurance companies launching products for PwDs. However, issues high insurance premiums and loading charges are arbitrarily charged from PwDs. The Delhi High Court is currently considering a petition seeking the removal of 'congenital anomalies' from the list of general exclusions in insurance policies as it is discriminatory to PwDs. The policy which is the service of the product of the prod

#### **Healthcare and Caregiver Support**

The Government has launched various programs to provide quality and affordable healthcare to PwDs, including the Ayushman Bharat Yojana, ADIP, and Nirmaya Health Insurance. Moreover, the RPwD Act mandates the appropriate to provide PwDs with government healthcare, barrier-free access to hospitals and other healthcare institutions, and priority in treatment. In addition, the RPwD Act provides for formulating caregiver allowance schemes for PwDs with high-support needs.59 In furtherance of this, the Sahyogi Care Associate Training Scheme introduced by the Government sets up caregiver cells to provide training for caregivers and creates a skilled workforce of caregivers for PwDs and their families.60

Nevertheless, gaps in access to healthcare services persist due to physical barriers, lack of trained medical professionals who understand the specific needs of PwDs, and negative attitudes towards disability. As a result, PwDs' life expectancy is reduced by 10-17 years, often due to preventable causes and children with disabilities face a higher risk of mortality caused by diarrhoea, fever, and respiratory infection.

Disabled persons are the largest minority in the world. That being the case, what happens to a person with a disability in their family? Usually, they're a minority. So, there could be loneliness and alienation within the family itself. Moving on of course, the next stage of life, which is education and school. Procedures, policies and infrastructure again is not designed keeping in mind the needs of persons with disabilities. So there's another level of exclusion there.

- Raj Mariwala (Director, Mariwala Health Initiative) speaks at a Samarth event

#### Pension

The RPwD Act mandates that disability pensions be provided to PwDs falling within a specified income bracket. The Government's Indira Gandhi National Disability Pension Scheme provides a monthly pension of ₹300 to PwDs aged 18-79 years and ₹500 to those above 80 years, belonging to Below Poverty Line households. On top of this, it is recommended that state governments contribute a proportionate share, which ranges from ₹3,000 in Andhra Pradesh to ₹300 in Bihar.

Regrettably, however, only 5% of India's PwD population qualify for the eligibility requirements and children with disabilities remain excluded.<sup>67</sup> In any case, the pension amount is insufficient to cover the living costs of PwDs.<sup>68</sup>

#### **Way Forward**

The Indian Government has made great strides in introducing various SSS catering to the diverse needs of PwDs. However, there are some gaps in the implementation.

One of the key steps to improve the implementation is to increase awareness. To this end, healthcare facilities that issue disability certificates must integrate other disability-related SSS, including AD services, to improve access and awareness amongst PwDs.69 To improve the accessibility and affordability of ADs, introducing tax benefits (including exemption from GST), grants, funding, and other incentives to encourage research and domestic manufacture of ADs, can go a long way in making them affordable by decreasing reliance on imports?0 Further, as the sectoral regulator, the IRDAI must play a more proactive role in fulfilling its statutory obligations towards PwDs by ensuring that the premium amount, insured amount, and other policy terms are not discriminatory. Additionally, it is crucial to make healthcare services accessible to PwDs as it directly affects the quality and expectancy of their lives, as highlighted above.







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#### From the 'Samarth by Hyundai in Partnership with NDTV' Charter of Recommendations

Develop a robust framework for social security, encompassing access to resources, insurance, healthcare, and caregiver support.

#### **Specific Recommendations**

- 1. Provide access to resources, including assistive devices.
- 2. Prioritise disability linkage in social security schemes.
- 3.Offer affordable and accessible insurance, especially health insurance.
- 4.Incentivise healthcare companies providing services and insurance to PwDs

### 3. Political **Prioritisation**



#### Introduction

Speaking about the 'Vote from Home' scheme, Shabnam Begum (a wheelchair user in Aligarh) echoed her concern: "Voting is a deeply personal choice and I value the experience of physically casting my ballot. There is also a fear of undue influence (through such schemes)." 71

The 2024 Lok Sabha elections were in many ways a watershed moment for PwDs in India. Eightyeight lakh PwDs registered to vote in the elections.<sup>72</sup> The figure is higher than Singapore's population.

However, the more things changed, the more they remained the same. Across political parties, only one candidate with a known disability was given a ticket - Devendra Jhajharia, who contested on a BJP ticket from Churu, Rajasthan.73 While there is no provision for a PwD to declare their disability in nomination affidavit while contesting elections, 4 the fact that no other candidate came out as a PwD highlights the challenge PwDs face in political representation. Unfortunately, India has only seen four MPs and six MLAs who were known to be PwDs.75 In fact, this glaring invisibilisation of PwDs from the political landscape has left their voices unheard and struggles unnoticed, and left a lacunae in disability-conscious policymaking. disadvantaged communities are part of the mainstream political discourse, they stand to increase visibility of their members and issues, and reduce the societal stigma against them. Further, when the community participates in the political process as candidates and voters, they become part of the decision-making processes that affect their lives.







#### Insights from the Samarth Survey:

- Reserving Seats in Elections: a significant majority of 66% supported the idea;
- Electoral Engagement: an overwhelming majority of 92% of PwDs are committed to participating in elections;
- Travel Assistance to Voting Booths: 50% of the respondents reported receiving no travel assistance to voting booths; and
- Satisfaction with government policies on political participation of PwDs: mixed response with 40% expressing contentment and 45% remaining neutral.

## Political Participation - as a Candidate and as a Voter

Over the last decade or so, the Election Commission has taken proactive steps to make the voting process accessible to PwDs. The Election Commission attempted to resolve the problem of inaccessibility by providing the 'Vote From Home' scheme for individuals with more than 40% disabilities in the elections<sup>76</sup> Arrangements were also made to provide free transport passes to voters with visual/locomotor disabilities or with impaired movement to access polling booth on election day.77 The Commission also came out with guidelines for political parties asking them to refrain from making derogatory or insensitive references to PwDs in public speeches, campaigns writings, and prescribing accessibility standards for political party websites and spaces for holding events.78

However, challenges still remain. The Election Commission's Model Code of Conduct ("MCC") makes no mention of accessibility.<sup>79</sup> Moreover, the guidelines mentioned above have not been made part of the MCC and only remain advisory.<sup>80</sup> The lack of accessible public spaces makes it challenging for PwDs to participate in public rallies and reach out to voters.<sup>81</sup> Many voters still find polling stations to not be accessible - either ramps

are missing or improperly installed, or there are no wheelchairs, or there are no personnel to assist PwDs. Ironically, the Saksham App created by the election commission to ease the voting process for PwDs had some sections inaccessible to the blind.<sup>82</sup>

Moreover, political parties do not consider PwDs as a valuable voter base - there is barely any mention of PwDs in election manifestos and there are no accessibility features installed on party websites.3 A political party that addresses the concerns of PwDs is also likely to gain the support of their families as well. Importantly, political parties can also consider establishing PwDs Cells that can recruit and mentor candidates from the PwD community within their parties.84 This can be similar to dedicated cells that political parties gender and other marginalised communities to aid their political empowerment. Creating PwDs Cells within political parties could help to bring their issues to the forefront and also pave the way to include PwDs in election campaigns, party manifestos. and public outreach.85

#### **Budgetary Allocations**

The Government has come up with laudable initiatives like the Accessible India Campaign to ensure universal accessibility and to give effect to the RPwD Act. However, the budgetary allocation for such schemes and other initiatives for the empowerment of PwDs, either remains limited or has depleted over time.

## Budgetary allocation made to the various disability-related schemes has steadily declined:<sup>87</sup>

- Allocation for the Scheme for Implementation of RPwD Act (SIPDA) reduced from ₹315 crores (FY 19-20) to ₹135 crores (FY 24-25);
- Allocation for the Scholarship for Students with Disabilities reduced from ₹155 crores (FY 23-24) to ₹142.68 crores (FY 24-25).







Further, there is a lack of disability-disaggregated data for schemes that, while not specifically designed for PwDs, include them, making it difficult to ascertain the allocations and expenditures directed towards PwDs.<sup>89</sup> This is particularly problematic since disability is an intersectional issue and so it is necessary to have data segregated by disability on the budget allocated to other ministries. Having said that, the Department of Empowerment of Persons with Disabilities (DEPwDs), which bears the primary responsibility for the upliftment of the PwD community, only got 0.025% out of the total budget in 2024.<sup>90</sup>

Furthermore, there is significant underutilisation of funds in the department. The DEPwD only spent around ₹900 crores out of the allocated budget of ₹1,212 crores. An insufficient number of proposals from states / union territories for subschemes was cited as the reason for the underutilisation of funds, signifying the lack of government capacity at State and Central levels to effectively utilise the budget.

#### **Way Forward**

The status quo fails the PwD community - in terms of policies, infrastructure, and attitudes of political parties. It prevents the mainstreaming of disability issues and inhibits their participation in political decision-making.

To encourage and actively promote the participation of PwDs in State assemblies and Parliament, existing approaches of ensuring representation, including reservation and financial assisting, may be explored. It could also include infrastructural support by adopting inclusive campaign models that enable PwDs to participate in election campaigns. Apart from the obvious need to increase the budget allocated to the DEPwD, the SIPDA, and other disability-specific education, healthcare, and insurance schemes, a comprehensive and inclusive approach must be adopted to address the issue of disability. An earmarked disability budget must be allocated to every ministry, not limited to the Ministry of Social

Justice and Empowerment, for every scheme that can be of benefit to PwDs.<sup>94</sup> Moreover, disability-disaggregated data ought to be collected. It is also important to focus on building capacity within states / union territories to effectively utilise the budget allocated for PwDs.

## From the 'Samarth by Hyundai in Partnership with NDTV' Charter of Recommendations

Elevate disability issues in the budget-making process and increase political representation for PwDs.

#### **Specific Recommendations**

- 1.Include disability considerations in all budgets across all levels of government.
- 2.Allocate a specific percentage of the budget for PwDs.
- 3.Encourage political parties to include candidates with disabilities.







## 4. Employment Opportunities



#### Introduction

"If you need 100 rupees for your daily survival, if people with one or two disabilities have them- they would need 111 rupees, and people with severe disabilities, like me, will need 124 rupees for survival", says Sayomdeb Mukherjee, who is an author, radio show host, and Lead, International Projects, EnAble India, while speaking at a Samarth event about the severe financial burden that falls on PwDs."

This harsh economic reality is further exacerbated by the low employment opportunities available to PwDs. As per the 2011 Census, only 36% of the total PwD population in India were employed,96 highlighting an alarming level of unemployment amongst PwDs. This increases their dependence on family support and also hinders their social integration. Therefore, it is crucial to focus on improving the employability of PwDs to secure their employment in both public and private sectors. Achieving this requires not only interventions improve employment to opportunities for PwDs but also adopting a comprehensive approach that focuses on creating educational, skill development, and inclusion PwDs. Recognising opportunities for importance of inclusive schooling system for PwDs, the Samarth initiative also works on sensitising school children across 120 schools in Delhi, Mumbai, Chennai, Pune, Bengaluru, and Hyderabad<sub>97</sub>

#### **Employment Opportunities**

The RPwD Act mandates that at least 4% of all public sector jobs must be reserved for PwDs.<sup>98</sup> Further, the Supreme Court has clarified that such reservation must not only be limited to the stage of appointment but must also be considered at

promotion stage.99 As far as establishments are concerned, while there is no legal mandate on reservation, the Act places an obligation on government authorities to provide incentives to private sector employers to ensure that at least 5% of their workforce is comprised of persons with benchmark disability.100 Further, according to the Act, every establishment (both public and private) is required to publish an Equal Opportunity Policy ("EOP") on their website or at conspicuous places in their premises, which should, inter alia, provide details of the posts identified for PwDs, the manner of selection of PwDs, facilities and amenities provided to PwDs, infrastructural accessibility provisions, appointment of liaison officer.101

Some private players have set examples by actively employing PwDs. Lemon Tree Hotel, which led the way by hiring from the PwD community, 102 has reported increased retention rates and improved efficiency.103 Amazon India partnered with Mirakle Couriers, an organisation that works with persons with hearing disability, and set up 'Silent Delivery Station' entirely managed by deaf associates. 104 Similarly, JP Morgan launched its 'Autism at Work Program' that focused on hiring persons with autism and benefitted from the skills that PwDs bring to the workforce. In the IT Sector, companies such as Capgemini, Wipro and IBM have recruited PwDs, employees diagnosed including schizophrenia, and some have even reported that PwDs work harder than other employees. Thus, these companies have demonstrated that hiring PwDs can lead to positive outcomes for both the employees and the employer.

However, PwDs still continue to face difficulties at workplace. As mentioned above, the 2011 Census revealed that only one-third of the PwD population are employed. Further, the Census data also highlighted that there is a greater risk of unemployment amongst women with disability (as only 23% are working) than men with disability (47% are working). Moreover, a recent analysis by the Economic Times revealed that only one private company and four public sector compan-







ies in the Nifty Top 50 list have more than 1% of their workforce comprising of PwDs. 108 This is alarming not only because it shows lower participation of PwDs in the private sector, but also reveals that even public sector companies are falling short of the 4% target set by the RPwD Act. Further, a perusal of the websites of the BSE Top 30 companies has revealed that most of them have either failed to publish an EOP on their websites or have published incomplete ones with important statutory information missing. These challenges faced by PwDs are attributable to many factors, including, lack of accessible infrastructure, lack of appropriate skill training and education, and negative societal attitude towards PwDs.110 Moreover, making disability certificates mandatory to avail employment benefits under the Mahatma Gandhi National Rural Employment Guarantee Act, 2005, created an additional hurdle for PwDs as there was a shortage of specialists in rural areas who could issue these certificates.<sup>111</sup> Unfortunately, the RPwD Act has failed to address these problems on the ground as it lacks an effective and robust grievance redressal mechanism.<sup>112</sup>

Apart from the disadvantages faced by PwDs in accessing employment opportunities in the private and public sectors, lack of education also poses a significant barrier to their employability, as discussed hereinafter.

So I think that one of the factors that can help enhance employability is the access to education and skill. So when I talk about the Anganwaadi intervention, one needs to recognise that if you have this kind of intervention early in life, you are psychologically preparing the individual child and the family unit to succeed. This cannot be looked upon as an impediment to success, but this is a challenge that can be overcome with additional support academically, infrastructurally. I think there has to be a psychological conversation around the issue of disability at the grassroots.

- Smriti Irani (Union Minister) shares her insights at a Samarth program

#### **Educational Opportunities**

Access to educational opportunities has a direct impact on the employability of PwDs.<sup>113</sup> In terms of the RPwD Act, every child with a benchmark disability between the age of 6-18 years shall have the right to free education.<sup>114</sup> Further, persons with benchmark disabilities are also entitled to avail reservations in government-funded higher educational institutions.<sup>115</sup> Moreover, all institutions funded or recognised by the Government are required to provide inclusive education.<sup>116</sup>

However, the literacy rate among PwDs is far from satisfactory. According to the 2011 Census, 45% of India's PwD population is illiterate (as compared to 26% of all Indians). Further, the education level amongst PwDs is lower in rural areas (44%) as compared to urban areas (64%). Moreover, only 34.6% of the PwD population in higher education are female students with disabilities. Thus, women with disabilities face double disadvantage on account of their gender and disability, both in education and employment.

**Insights from the Samarth Survey** on the challenges faced by PwDs in accessing school education:

- Persons with physical disability face major issues with transportation (91%), stairs/lift (67%), toilets/restrooms (66%), caregiver support (60%), mobility aids (47%), and doorways (23%);
- Persons with hearing disability struggle with accessing hearing aids (85%), audiobased aids (81%), interpreters/sign language (48%), and captioning/subtitles (43%);
- Persons with visual disability encounter significant barriers including transportation (73%), braille material (69%), navigation (68%), toilets/restrooms (66%), doorways (47%), and tactile markers (43%).







#### **Skilling Opportunities**

Availing upskilling and training opportunities increases the employability of PwDs!<sup>21</sup> Lack of accessible vocational training coupled with the lack of vocational courses catered to the needs of the PwDs constitute significant barriers to employment for PwDs.<sup>122</sup> This is despite the fact that the RPwD Act places an obligation on the Government to formulate appropriate vocational training and skill development schemes/programs, including by providing loans at concessional rates.<sup>123</sup>

There is a serious lacuna in implementing such skilling and vocational training schemes. A recent survey revealed that only 5% of the respondents (1,647 persons across 9 States) had taken vocational training.<sup>124</sup> The main reasons for such poor participation rates were the lack of awareness amongst the PwDs coupled with the limited availability and accessibility of training centres, especially in rural areas.<sup>125</sup>

#### **Way Forward**

Respondents of the Samarth Survey suggested that the Government should provide increased scholarships, education aids, reservations, and skill development programs, with free education being the top requested facility.

The private sector must be encouraged to offer employment opportunities to PwDs, not as a matter of charity, but because it serves their business interests as well. Companies that employ PwDs have a competitive advantage over others, in as much as PwDs have unique talents that make them better suited for certain jobs, it elevates the company's collaborative culture and productivity, and improves the firm's reputation leading to enhanced customer satisfaction.<sup>126</sup>Some industries, like the hospitality and IT sectors, have been more successful in adopting PwD-friendly hiring policies and practices, leading to lower attrition rates, better workforce morale, and a happier customer base.<sup>127</sup> It is therefore in the business interests of private organisations to hire PwDs. To incentivise them, the Government may

adopt a carrot-and-stick approach: by providing tax breaks/subsidies to private companies to promote inclusive hiring as well as allowing corporates to deploy their CSR funds in creating accessible infrastructure.<sup>128</sup> Separately, Government could also forge partnerships with district-level cooperatives to create employment opportunities for PwDs that can improve their livelihood and social inclusion. Finally, there must be a renewed focus on education and skill development by making them available. accessible, and affordable for PwDs, as it can positively contribute towards improving their employability.

#### From the 'Samarth by Hyundai in Partnership with NDTV' Charter of Recommendations

Forge partnerships with the private sector and establish district-level cooperatives to create educational, skilling, employment, and inclusion opportunities.

#### **Specific Recommendations**

- 1. Partner with the private sector to create livelihood opportunities.
- 2.Establish cooperatives at the district level for decentralised job creation.
- 3. Prioritise skilling opportunities for PwDs.
- 4.Offer tax incentives and subsidies to businesses creating inclusive workplaces and hiring PwDs.







#### 5. Public Awareness



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#### Introduction

The problem in India is that people with disabilities are viewed as objects of pity, and it is thought all that they need is food, shelter and clothing. They have no other requirements or hopes besides these three. (Translated from Hindi)

-Nipun Malhotra (Disability Rights Advocate, Founder of Nipman Foundation) speaking at a Samarth event

When I began in sports, my relatives would say, what can she do? She can't do anything. She can't even ride a cycle, she can't walk. When my father first went to get me admitted to school, they refused to accept me saying, how will your daughter handle being here? Who will support her? I have endured a lot. (Translated from Hindi)

 Prachi Yadav (First Indian Para-Canoe player to win a gold in the Asian Para Games 2023) speaking at a Samarth event

Recently, a motivational speaker, Mahavishnu, while delivering a speech to school students made controversial and perverse claims, alleging that people are born with disorders because of "what they did in their past lives" and that "you have been given things in this life based on what you did in your past lives". During the event, he also verbally abused a teacher who challenged his statements, leading to his subsequent arrest. This incident is emblematic of the prevailing mindset and social stigma against PwDs within the Indian society.

The disability discourse in India suffers from a widespread lack of awareness and sensitivity regarding the challenges faced by PwDs and the rights available to them. Pertinently, the problem of under-utilisation of funds allocated to disability-related schemes (as mentioned above) stems from the absence of adequate awareness

initiatives aimed at equipping PwDs with the necessary knowledge and access to reliable information about government schemes.<sup>130</sup> Moreover, the lack of comprehensive data segregated by disability has also led to the formulation of schemes that do not cater to the specific needs of the community. Significantly, there is also a need to create realistic imagery of PwDs in popular media, as misconception and stigma attached to disability continue to persist leading to further marginalisation of the community.

It is necessary to strive for an inclusive society, where PwDs are not invisiblised, their challenges are acknowledged, and they are treated with respect and dignity, bringing their issues to the forefront of national discourse. A holistic approach, which includes stronger law enforcement, the use of reliable disability-disaggregated data for targeted and effective policies, widespread awareness campaigns, and sensitisation targeting policymakers and decision-makers at all levels, is necessary.

## Effective Enforcement of the RPwD Act and Increasing Public Awareness

As discussed earlier, the Report on the SIPDA revealed significant gaps in the implementation of the various schemes under the RPwD Act. The Report noted that only 11 States and Union Territories had applied for and received grants for building accessible infrastructures since 2017 and that only 30% of the buildings and 65% of the websites have been made accessible despite the extension of the deadline from July 2016 to June 2022. Further, it observed that while the subschemes under the SIPDA have doubled from 2016 to 2022, the budget allotted has only increased by 9%. The Indian Supreme Court also observed that "the implementation of the Act needs to be set right now" while noting that several States are yet to notify relevant rules under the RPwD Act, including rules prescribing the formation of the committee for research on disability and the composition of district-level committees, despite the law prescribing a 6







month time frame from the date of enactment of the Act. This ineffective enforcement of the RPwD Act has left its goals unfulfilled, thereby denying fundamental rights and freedom to PwDs.

The slow progress in the implementation of the RPwD Act can also be attributed to the lack of information or awareness regarding the RPwD Act and the schemes thereunder. Many government departments responsible for implementing the Act have limited idea about the schemes or the Act.<sup>133</sup> Similarly, lack of awareness accountability also persists amongst other experts and decision-makers who are in charge of implementing accessibility guidelines, example, the engineers at the public works department.<sup>134</sup>Thus, to ensure that the RPwD Act is effectively implemented, there is a need for mass sensitisation at all levels - from the PwD community to the policymakers - and a fundamental attitudinal shift towards the PwD community!35 This is where initiatives like Samarth play a crucial role, as it seeks to empower PwDs by providing them with a national platform to voice their issues, to dispel incorrect notions surrounding their disability, and to sensitise the masses.

We have to build capacity awareness at every level. We have to include persons with disabilities. Because we have to understand there's not a lot of visibility of the disabled in the public right now. And the more awareness there is, the more visibility there is, the more sensitisation will happen.

- Nidhi Madan (Access Auditor and Landscape Architect Director, Samarthyam) speaking at a Samarth initiative episode

#### Need for Comprehensive Disability-Disaggregated Data Collection

Both the Convention and the 2030 Agenda for Sustainable Development call for data to be disaggregated by disability whenever applicable.<sup>136</sup> The need for this data collection is threefold: to monitor the population and evaluate disability-specific interventions; to design targeted services

to meet the more specific needs of PwDs; and, to assess whether PwDs are participating on equal footing with others in the social and economic life.<sup>137</sup>

The 2011 Census, which was the latest exercise to collect nationwide data on disability, was both incomprehensive and also significantly underestimated, thereby preventing effective policy formulation. This underreporting was due to multiple reasons. The questions did not cover the different types of disabilities that are covered under the RPwD Act presently (the 1995 Act only disabilities). seven recognised questions were poorly framed, like 'Is the person mentally or physically disabled (yes or no)', in a way that did not elicit an accurate response from the respondents on account of the social stigma associated with disability 1.0 Further, it is likely that the usage of the word 'disability' or other words with negative connotations caused reluctance to reveal disability-related data.141 To make things worse, the Government also recently decided to drop disability questions from the National Family Health Survey that could have helped to gather critical information about PwDs and thereby aid in formulating effective policies targeting PwDs.142

This calls for a shift to a more comprehensive assessment of disability. The questionnaire developed by the Washington Group on Disability Statistics (WG), a United Nations Statistical Commission City Group, can serve as a useful reference as it focuses on functional limitations, asking questions such as 'Do you have difficulty seeing, even if wearing glasses?' or 'Do you have difficulty hearing, even if using a hearing aid?'.143 Instead of having binary responses like 'Yes' or 'No', it provides a range of responses like, 'No, no difficulty', 'Yes, a lot of difficulty', 'Yes, some difficulty', and 'Cannot do it at all'.144 However, the WG questionnaire has its limitations, as it does not address psychosocial or intellectual disabilities and was not framed for children below 5 years with developmental issues.<sup>145</sup> Despite this, the WG questionnaire provides a useful framework for developing a more nuanced questionnaire for India's next census.



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#### Societal Stigma and Media Portrayal

PwDs have long suffered discrimination on account of the societal stigma associated with their disability. There are misconceived and problematic notions about the causes and effects of disability, which are often cited as purported reasons for excluding them from public spaces, denying them employment and educational opportunities, and generally ostracising them within a community. Further, PwDs are also glorified for overcoming odds or challenges, in a way that reinforces the perception of their inferiority to others. This further hinders their social integration and creates feelings of exclusion within the PwD community.

Speaking at a Samarth event, Dr. Satendra Singh, Professor of Physiology at the University College of Medical Sciences, Delhi, and Co-chair of the International Council for Disability Inclusion in MedEd, said that even though there are thousands of doctors, "when a disabled person becomes a doctor, why is it considered a major achievement?". He said that on December 3 (International Day of PwDs), you will hear stories of people who have overcome their disability. Dr. Singh challenges this narrative by saying that, "We have not overcome our disability. We live each and every moment with our disability. We are disabled and we are proud."

These misconceptions are further reinforced through the negative portrayal of disability in popular media and movies-which, in turn, detrimentally influences society's treatment of PwDs.<sup>147</sup> The Supreme Court recently issued guidelines on the representation of PwDs in visual media, while considering a petition, Nipun Malhotra v. Sony Pictures Films India (P) Ltd., filed against the insensitive portrayal of PwDs in a Hindi film.<sup>148</sup> The Supreme Court, in holding that stereotyping PwDs in media can perpetuate discrimination, distinguished 'disabling humour' that demeans and disparages PwDs from 'disability humour' that challenges conventional wisdom about disability.149 The judgment also discourages the use of words like 'cripple', 'spastic', 'afflicted', 'the suffering' and 'victim' that stigmatise and devalue PwDs.150

#### **Way Forward**

Almost every single problem cited in this White Paper highlights the need for more public awareness campaigns to tackle the prejudices and misconceptions surrounding PwDs. These programs need to re-assess the policies and practices in both the public and private sectors and systemically eradicate the ableist value system that shapes them.<sup>151</sup> Such sensitisation programs should start early and be integrated into the school curriculum. The Samarth initiative has already made inroads into 120 schools across various Indian cities to promote awareness about the need for inclusive and accessible schooling.<sup>152</sup> All educational courses in the professional sphere should have a disability-related elective, like universal design course for architects, disability law course for law students, and special education courses for all teachers. Even persons in charge of running public systems, such as drivers of public transport, architects of public buildings like libraries, and officials in government departments handling schemes/benefits, should attend sensitisation workshops as their day-today interactions with PwDs significantly influence the lived experiences of the community. Overall, there is a need to foster a shift in behaviour and mindset towards PwDs, enabling them to live and contribute like equals in this society.

Every disability related law should be studied by our students, so then only are the disabled seen in an empathetic way. Otherwise, what happens is (although) we are capable of doing everything, we will be seen in a sympathetic way.

- Ashwini Angadi (Founder and Trustee of the Ashwini Angadi Trust) speaking at a Samarth event

#### From the 'Samarth by Hyundai in Partnership with NDTV' Charter of Recommendations

Launch a mass awareness campaign to educate the public about disability issues and increase awareness of the RPwD Act, fostering behavioural change.







#### **Specific Recommendations**

- 1.Ensure strict implementation of the RPwD Act.
- 2.Include all 21 disabilities in 'Persons with Disabilities' data collection for the next census.
- 3.Conduct public campaigns to increase awareness about disabilities and disability rights.
- 4. Make sensitisation programs mandatory in school curricula.
- 5.Conduct sensitisation workshops for all public transport drivers.
- 6.Ensure public libraries have reading material in braille.







# CHARTER OF RECOMMENDATIONS FOR ENHANCING ACCESSIBILITY AND INCLUSIVITY

By:

NDTV and Hyundai, on behalf of the 'Samarth by Hyundai in partnership with the NDTV' initiative

#### **Key Recommendations**

#### 1. Infrastructure Accessibility

Objective: Ensure universal accessibility in all physical, digital, and transport infrastructure to promote independence and equal participation.

#### **Specific Recommendations:**

- a. Make all government-run physical infrastructure (offices, hospitals, schools, etc.) fully accessible.
- b. Incorporate mandatory accessibility parameters in building codes for occupancy certifications and NoCs.
- c. Ensure full accessibility of public transport systems and infrastructure.
- d. Provide appropriate access to ramps and wheelchairs at bus stops, in buses, and in government buildings.
- e. Install handrails at all bus stops and government buildings.
- f. Implement tactile guidance and audio information at all public transport stops and government buildings.
- g. Create barrier-free and clear pavements for better access.
- h. Enforce regulations to prevent two-wheeler riders and motorists from parking and riding on pavements.
- i. Provide accessible playgrounds and sports facilities.

#### 2. Social Security Framework

Objective: Develop a robust framework for social security, encompassing access to resources, insurance, healthcare, and caregiver support.

#### **Specific Recommendations:**

- a. Provide access to resources, including assistive devices.
- b. Prioritise disability linkage in social security schemes.
- c. Offer affordable and accessible insurance, especially health insurance.
- d. Incentivise healthcare companies providing services and insurance to PwDs.

#### 3. Political Prioritisation

Objective: Elevate disability issues in the budget-making process and increase political representation for PwDs.

#### Specific recommendations:

a. Include disability considerations in all budgets across all levels of government.







- b. Allocate a specific percentage of the budget for PwDs.
- c. Encourage political parties to include candidates with disabilities.

#### 4. Employment Opportunities

Objective: Forge partnerships with the private sector and establish district-level cooperatives to create educational, skilling, employment, and inclusion opportunities.

#### **Specific Recommendations:**

- a. Partner with the private sector to create livelihood opportunities.
- b. Establish cooperatives at the district level for decentralised job creation.
- c. Prioritise skilling opportunities for PwDs.
- d. Offer tax incentives and subsidies to businesses creating inclusive workplaces and hiring PwDs.

#### 5. Public Awareness

Objective: Launch a mass awareness campaign to educate the public about disability issues and increase awareness of the RPwD Act, fostering behavioural change.

#### **Specific Recommendations:**

- a. Ensure strict implementation of the RPwD Act.
- b. Include all 21 disabilities in 'Persons with Disabilities' data collection for the next census.
- c. Conduct public campaigns to increase awareness about disabilities and disability rights.
- d. Make sensitisation programs mandatory in school curricula.
- e. Conduct sensitisation workshops for all public transport drivers.
- f. Ensure public libraries have reading material in braille.







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