



# **LEADING** **A LIFE OF DIGNITY** **IN THE POST-COVID WORLD**

**LEARNING FROM THE LIVED EXPERIENCES  
OF INTELLECTUAL & DEVELOPMENTAL DISABILITIES**



THE  
**SARVODYA**  
COLLECTIVE

**LEADING A LIFE OF DIGNITY IN THE  
POST COVID WORLD:**

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EXPERIENCES  
OF INTELLECTUAL & DEVELOPMENTAL  
DISABILITIES**

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The Sarvodya Collective is a non-profit organization serving persons with intellectual and developmental disabilities (PwIDD) in India by building greater awareness around the needs and lived experience of the community including PwIDD, their caregivers and organizations working with both. We do this with the dual goal of building an inclusive and enabling larger community around each PwIDD and translating our PwIDD centric understanding of the sector to inform the building and bolstering of the ecosystem.

## **Project Team**

Research Authors: Bhawna Parmar, Rubina Singh  
Report Design: Bhawna Parmar  
Research Interns: Devina Michelle Thomas, Srishti Uppal  
Editor: Lovleen Banga

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# A Note from our Advisor



Capturing the voices of people with intellectual and developmental disabilities and their families (parents and siblings) is an important task that needs to be taken up to create consciousness in society. It seems ironic that those who need the most support are the ones who get neglected and marginalized in a society simply because they are not like the majority. It leads to all kinds of mis-notions, doing grave injustice to a section of the human population whose lives should matter too. Their strengths and potential are overlooked while gross violation of their as well as their families' human rights is widely prevalent. We tend to forget that each life is a precious creation of nature and in that sense persons with disabilities are no different from the others. Who are we to judge who is worthy or not? A sensitive person can see how these judgemental attitudes have caused so much impoverishment of this population. Such misplaced notions have resulted in lack of growth opportunities, needed support services to persons with IDD and their families, and unhelpful non-inclusive attitudes in the society.

Each of us is born with a given body and mind. It serves well to remember that none of us has any role in choosing that. Depriving someone, who appears to be different, of growth opportunities and dignified life is irrational and inhuman. Working with and supporting persons with disability could also give rise to pertinent inquiry leading to improved understanding of their lives and minds. Unfortunately, this sentiment, which could potentially lead to breakthrough insights about the functioning of the minds of people with IDD, has not engaged many experts in the field. Attempts like this are needed more and more to create a consciousness that can transform how we look at fellow human beings, question so many discriminatory attitudes, and build a humane society.

A handwritten signature in black ink, appearing to read 'Shanti Auluck'.

**Dr. Shanti Auluck  
(Chairperson and Founder,  
Muskaan PAEPID)**

# Foreword



## List of Abbreviations

ANM – Auxiliary Nurse Midwives  
ASD – Autism Spectrum Disorder  
ASHA – Accredited Social Health Activist  
AWW – Anganwadi Workers  
CBR – Community-based rehabilitation  
CBSE – Central Board for Secondary Education  
CDC – Centre for Disease Control  
COVID-19 – Coronavirus Disease 2019  
CRPD – Convention on the Rights of Persons with Disabilities  
CSO – Civil Society Organization  
GDD – Global Developmental Delay  
HRD – Human Resource and Development  
ID – Intellectual Disability  
IDD – Intellectual and Developmental Disability  
IDPD 2021 – International Day of People with Disabilities 2021  
MCA – Ministry of Corporate Affairs  
MoHFW – Ministry of Health and Family Welfare  
MoE – Ministry of Education  
MSDE – Ministry of Skill Development and Entrepreneurship  
MSJE – Ministry of Social Justice and Empowerment  
MSME – Ministry of Micro, Small and Medium Enterprises  
MWCD – Ministry of Women and Child Development  
NCPO – National Confederation of Parents Organizations  
NGO – Non-governmental Organization  
NIOS – National Institute of Open Schooling  
NPPD – National Policy for Persons with Disabilities  
NREGA – National Rural Employment Guarantee Act  
NSS – National Sample Survey  
NSSO – National Sample Survey Office  
PwD – Person with Disability  
PwIDD – Person with Intellectual and Developmental Disability  
RCI – Rehabilitation Council of India  
RPwD Act – Rights of Persons with Disabilities Act 2016  
RTE – Right to Education  
SGD – Sustainable Development Goal  
SSA – Sarva Shiksha Abhiyan  
UNCPRD – United Nations Convention on the Rights of Persons with Disabilities

The COVID-19 pandemic has been a time of hard-hitting realizations for us all. Not only has it widened existing gaps and pushed people further into the margins, the pandemic has also made it increasingly obvious how wide those gaps already were. Of the many inequalities which have come to the forefront, the lived realities of people with disabilities, in particular people with intellectual and developmental disabilities, need to be acknowledged and addressed.

Like most of us, PwIDD struggled during this time of crisis, which not only presented new challenges but also intensified the existing challenges towards achieving a life of dignity and equality. The relatively small ecosystem of organizations, schools, support networks, doctors, and caregivers, has struggled to address the needs of PwIDD and their first line of support.

There is a need for building a shared understanding of intellectual disabilities at all levels, from families to communities to policymakers and heads of government. This is the time to identify and build capacity within and beyond the realms of this sector to ensure that people with intellectual and developmental disabilities are no longer neglected, but rather acknowledged, encouraged and accepted citizens whose lives matter too.

We have a commitment to the The UN Convention on the Rights of Persons with Disabilities (UNCPRD), to the Sustainable Development Goals (SDG), the Rights of Persons with Disabilities Act 2016 (RPwD Act) and most importantly to the Constitution of our country to provide a life of equality and dignity for PwIDD. The report, Leading a Life of Dignity in the Post-COVID World: Learning from the lived experience of Intellectual & Developmental Disabilities is an effort by The Sarvodya Collective to challenge this invisibility in an endeavour to understand the needs and challenges of the IDD community. It is a small step towards making our society more understanding, inclusive, and accepting towards this oft-neglected set of persons.

**Lt Gen (Retd) SM Mehta  
(CEO, The Banyan and BALM)**

# Executive Summary

Persons with Intellectual and Developmental Disabilities (PwIDD) form one of the most marginalized sections of the Indian Society. The disability rights movement which started in the 1970s in India brought forth many structural and mindset changes but as a society we have only been able to address a small percentage of the issues which plague the lives of PwIDDs.

The 2011 census reports that persons with disabilities (PwD) make up 2.21% of the population of the country – it is widely accepted this number is inaccurate. PwDs make up a larger part of society but their invisibility can be attributed to exclusion by default – the continued lack of data and understanding of the needs of PwDs perpetuates this exclusion, leaving them on the margins. They face multiple challenges from the beginning of their lives, be it dehumanization, exclusion, being misunderstood, stigmatized, and as a result, they end up being shunned from society. This makes it imperative that focused studies and research be undertaken to understand and then implement policy framework to alleviate issues faced by them.

With the services and resources concentrated in the urban metropolitan areas, many caregivers and PwIDDs get excluded due to their socio-economic or geographical realities. Starting from infancy and the subsequent diagnosis, the study finds a lack of information and structure that can aid caregivers in an early diagnosis and formal recognition of disability. Layered with the realities of caste, class, gender, geography, and economic status, the process of diagnosis and early intervention is a herculean task for some sections of the affected community. There is a strong need for onboarding parents to this expanded role with sound knowledge, compassion and care, requiring a structured capacity-building effort.

Ensuring a life of dignity for PwIDDs is a big task for primary caregivers in the absence of a conducive supporting environment, especially as the family members, including parents and siblings, of PwIDDs face a disproportionate burden of providing all the care. Another hurdle is the access to decent education,

with a clear gap in not just the availability of suitable infrastructure and adequately trained human resources, but also the intent and attitude of school administrations. Where schools do accept PwIDDs, they are unable to provide any meaningful learning. Between this and the social stigma and exclusion that follows, when such children enter into the school environment, they are often forced to drop out. The challenges continue further along as there are limited options for suitable vocational training, widely considered the more achievable goal, and sustainable independent or assisted living. Between the relative resource-intensive nature of the solutions, the sector being populated by parent-led civil society organizations and a deficit of trained professionals and adequate funding, the needs of PwIDDs, their caregivers and by extension the organizations that work with both remain grossly underserved.

The COVID-19 pandemic has brought along new challenges for PwIDDs and their caregivers while intensifying the existing ones. Many earlier studies in this sector have focused on the issue through a quantitative or technical lens. Whilst it has its merits, the quantitative studies lack a human perspective of the life of PwIDDs and their caregivers. The present qualitative study, looking at the various life stages of PwIDDs, brings forth the voices and concerns of caregivers, organization workers, and self-advocates, and puts forth contextualized recommendations. This is done with the dual intent of helping build a more inclusive society for the PwIDD community in the post-pandemic world as well as in forming potential solutions to challenges and need-gaps that exist. Each section in the report has specific recommendations related to different aspects of the lived experiences of PwIDDs. Some macro-recommendations include convergence between government departments and policymakers, employment of strategic advocacy, acknowledgment and exploration of the intersections in the community to provide more nuanced solutions. In addition, there are recommendations for building formal forums and spaces for individual and ecosystem support as well as using the potential of tech and tech-enabled solutions for capacity building at scale.

# IDD Landscape

## An Introduction

**‘The appropriate Government shall ensure that the persons with disabilities enjoy the right to equality, life with dignity and respect for his or her integrity equally with others.’**

**–The Rights of Persons with Disabilities Act 2016 (RPwD Act 2016)**

*For too long, and more so through the global COVID-19 pandemic, persons with intellectual and developmental disabilities (PwIDD) have been deprived of their right to full and equal life of dignity. There has been a disproportionate impact on persons with disabilities (PwD), and the challenges faced by the Intellectual and Developmental Disabilities (IDD) community in India have increased manifold post the pandemic. This makes it imperative to reexamine our existing systems, with these glaring gaps, and take this moment to reimagine new systems where the rights of PwIDD are respected and protected.*

Disability is not a medical condition attributable only to an individual; rather it is a complex matter that involves the community on the whole. The obstacles that individuals with IDD face are multi-dimensional, and include not only the disability, but also the class, caste, and gender of the individual making it a wicked problem. There needs to be systemic change which is structural, relational, and transformative to bring about integration of PwD in society. The process to make for a more inclusive society entails persistent efforts to inculcate a sense of dignity and belonging for all such individuals. In our highly competitive and hyper-productive world, especially in a country like India, which prides itself in being one of the fastest growing developing nations, PwD continue to be shunned. They are perceived to not offer any economic or social value to society, hence the public spaces and institutions are not designed for them, voices are not heard...concerted effort to understand their needs with the result that these misconceptions are greater when it comes to IDD in our country.

The contributing factors to inclusion, or lack thereof, are rather hard to deconstruct. Instead of competence, the perception of capability is based on stereotypes of class, gender, religion, ethnicity, and language for instance. Individuals with intellectual disability (ID) are seen by the majority of people in India as fundamentally 'flawed' with diminished capabilities, thereby placing them at the bottom of the social structure in our society. At present, although the legislation is beginning to take a rights-based approach, on the ground efforts are largely through a charity-based lens.

While globally, in higher income countries, inclusion of PwIDD is addressed with structural changes made to various institutions, in India, IDD remains one of the most untouched topics of research, policy making, and cultural conversation. Myths, misconceptions, and inadequate awareness continue to persist about IDD. However, over the years, there are some favourable developments for PwIDD and their families in the organization of health and other services, though they continue to be inadequate, relatively inaccessible and unaffordable, and unevenly distributed across geographies.

### COVID-19 and IDD

In the last few years, the COVID-19 pandemic has further marginalized an already marginalized community. It has not only added an additional layer of challenges, but also intensified many of these persistent barriers to creating an inclusive world. While the COVID-19 pandemic threatens all members of society, PwD are disproportionately impacted due to attitudinal, environmental, and institutional barriers that are reproduced in the COVID-19 response (United Nations, 2020). The pandemic has impacted people with IDD at different levels with changes in cognition, emotions, and behaviour patterns due to changes in routines and the larger uncertainty of life (Kumaaya, 2021). With limited access to the healthcare system, restricting movement to indoors and subsequently to digital platforms, limited human to human interactions and innumerable restrictions, people with IDD and their families have had a hard time coping with the pandemic. In addition to new challenges, the pandemic has also intensified existing challenges faced by the IDD community. For the last three years before the pandemic, a paltry 0.04% of the annual budget was allocated for PwD, which was further reduced to INR 1,171.76 crore from INR 1,325.39 crore in 2021 (Ali, 2021). Despite the pandemic's disproportionate impact on the community, this percentage has remained the same even in the latest budget.

The pandemic poses a lot of challenges, and makes it imperative to make information available as also education and healthcare potentially accessible through digital and other means. Organizations across the country have found

innovative ways to address the changing needs of PwIDD and their families. It is also time we redesign and reopen our world, to think about the systemic changes needed to build a more inclusive world.

### Leadership and Inclusion in the Post-COVID Era

Every year on December 3rd, the world celebrates the International Day of People with Disabilities (IDPD). This year, the theme of the IDPD 2021 is 'Leadership and participation of persons with disabilities toward an inclusive, accessible and sustainable post-COVID-19 world.' In line with the theme of the International Day of People with Disabilities 2021, we join the movement for enhancing leadership and participation of PwIDD towards building a more inclusive world. Leading a life of dignity in the post-covid world: Learning from the lived experience of Intellectual & Developmental Disabilities is an effort by The Sarvodya Collective to make visible the lived realities of an invisibilized sector, particularly addressing the multitude of challenges exacerbated by the global pandemic. We take this opportunity to share our thoughts on what it would take to build a more inclusive world wherein the fundamental human rights of PwIDD are respected and protected, in a post-COVID era.

### Understanding IDD in India

Historically, the understanding of IDD in India has been rooted in faith, often linking it to theories of Karma and past-life (Wilson, 2019). This has fuelled stigma around disability, which may be seen as penance for sins in other lives, reducing the dignity of the individual with IDD. Caregiving for PwIDD is similarly interlinked with religious duties, viewing it through a charity-based lens. Most recently, an attempt to shift perceptions around disability has been made by changing terminology from 'viklang' to 'divyang', meaning 'divine body'. However, invoking religious meaning to justify the existence of PwD may again serve to take away from the PwIDD community its humanity, acceptance in society at large, and subsequent human rights.

Internationally, the historical understanding of IDD varies across nations and communities ranging from religious layers to more recent scientific understandings. The understanding has shifted through pre-industrialization and industrialization phases, eventually reaching a space where it is most recognized through a scientific lens. This is evident from the recent global shift in terminology from 'mental retardation' to 'intellectual disability' (Chavan & Rozatkar, 2014). In India, before the RPwD Act 2016, Intellectual Disability was termed as 'mental retardation'. Even though the term 'Intellectual Disability' is preferred now, mental retardation is still used in some medical and other professional settings (Nash C, 2018). Socially,

derogatory and dehumanizing terms like 'mental', 'pagal' (mad), etc. are still commonly used.

### Taking a Rights-based Approach

To move away from the social stigma, it is imperative for society to recognize the inherent humanity and dignity of PwIDD. The UN Convention on Rights of Persons with Disabilities was a step in this direction, which found its voice in India through the enactment of the Rights of Persons with Disabilities Act 2016. This Act is cognizant of the right of all people, especially people with disabilities to live a life of dignity and have access to many of the spaces and opportunities afforded to others. The report is written with this approach in mind, centering the voices and agency of PwIDD and their caregivers.

### Recognizing the Intersections

Intellectual and developmental disabilities do not exist in isolation. A number of factors such as class, caste, gender, geography, and residence play a significant role in its prevalence and manifestation. Studies across the world note that IDD is more prevalent in lower income communities, particularly those caused by malnutrition or lack of prenatal care. The National Sample Survey of 2002 shows that disability in the general Indian population was 1.85 % whereas it was 2.4 % among the Dalit community (Pal, 2011). Further, a 2007 World Bank Report noted that Scheduled Caste and Scheduled Tribe men with disabilities have a 0.13 % chance of employment as compared to other men with disability who have a 1.8 % chance (Kothari et al., 2020).

Further, gender can impact the experience of IDD. While the prevalence of IDD is noted to be higher in males, females with IDD have their own challenges. They are less likely to have access to services, and also have their agency curtailed due to menstruation, sexual expression, and increased vulnerability to abuse. Three persons interviewed for this report shared instances of females with IDD being locked up, particularly in families from marginalized socio-economic backgrounds where there was no caregiving support. According to specific studies quoted by UNESCO in 2004, 90 % of girls and women with intellectual impairment have faced sexual abuse at some point in their life (UNESCO, 2004). The UN Factsheet on People with Disability quotes an Odisha-based survey from 2004, where they found that 25 % of women with intellectual disabilities have been raped and 6 % of women with disabilities have been forcibly sterilized (UNDESA, n.d.). Adding to this, women from Scheduled Caste and Scheduled Tribe communities are more vulnerable to sexual abuse than upper caste women (Mehrotra, 2013).

It is critical to acknowledge these intersections and the added layers they bring to the lives of PwIDD. There is a

need for much more research into understanding these layers, especially in the context of IDD.

### Data and Lack Thereof

According to the Census 2011, PwDs make up 2.21 % of the population in India. In the 76th National Sample Survey, conducted in 2018 by the National Sample Survey Office (NSSO), it was found that 0.2 % of people all over India have IDD, of which approximately 75 % can be estimated to live in rural areas (Chavan & Rozatkar, 2014). The data, however, can be deemed inaccurate as IDD is not always detected due to lack of awareness or lack of access to medical assessment or social stigma, among other causes. The prevalence of intellectual disability has been estimated at 1–4 %, i.e., about 30 people per 1000 in the population with excess prevalence in males, rural areas, and in low-income groups (Lakhan et al., 2015). Globally, according to the WHO, intellectual disability affects about 2–3 % of the general population.

The data collected from various resources shows the spread and pervasiveness of intellectual disability amongst the general masses, more so in the child population placing about 33 % of children in the disability category. About 75–90 % of the affected people have mild intellectual disability. Non-syndromic or idiopathic ID accounts for 30–50 % of cases. About a quarter of cases are caused by a genetic disorder (Daily DK, 2000).

There is, however, a huge disparity in data in India. While NSSO pegs it at 0.02 % according to studies cited by the Department of Education, New Delhi, the prevalence of ID is 1–3 % in India. Another paper cites that 31 million people in India have ID (Bhagat Singh, 2014) and independent studies quoted by the Department of People with Disability state that 1 in 8 children have a neurodevelopmental disorder. Triangulating these estimates, the report uses an average number of 35 million people with IDD in India. This clear disparity in data can be attributed to multiple factors including lack of a singular definition, lack of clear data collection norms, non-declaration due to unclear understanding of IDD or fear of social stigma, and lack of social understanding of IDD.

Article 31 of the Convention on the Rights of Persons with Disabilities (CRPD), to which India is a signatory states that, 'Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.' However, this finds no mention in the RPwD Act 2016, and is evident in the lack of consistent national level data available for disability. In the USA, the Center for Disease Control (CDC) has been undertaking multiple year-long studies with specific focus on IDD (Zablotsky et al., 2019). Mencap, a UK-based advocacy organization, also notes the significance of having

reliable data and statistics for policy shifts. We can take this opportunity to learn from countries like South Africa as well, who are closer to us socially and economically and have recognized the need for data and statistics. Colleen M. Adnams writes, 'Despite the existence of policies and services for the population with intellectual disabilities in South Africa, recognition of and provision for their needs carry low priority. It is imperative that the information gap in epidemiology and the burden of disability be recognized in order to plan for and meet the needs of those with intellectual disability across the lifespan' (Adnams, 2010). Similar initiatives and studies need to be carried out in India, if we wish to frame meaningful policies for an inclusive and just society in India as well.

### Defining IDD

Having a clear, co-owned definition of IDD is a first step towards a shared understanding of the lives of PwIDD and their families. Such a definition and conceptualization may be made in consultation with various stakeholders including the medical fraternity, PwIDD and their families, caregivers, educators, and policy makers in line with international medical standards.

At present, there are varying definitions across the world, which do not always translate similarly in all contexts. In India, the RPwD Act only defines Intellectual Disability to include specific learning disabilities and Autism Spectrum Disorder (ASD), and separately recognizes other forms of multiple disabilities. However, there is neither a clear definition of intellectual and developmental disabilities in India, nor is there a clear acknowledgement of the overlapping nature of many of these disabilities.

The National Institute of Health (NIH), UK and the American Association on Intellectual and Developmental Disabilities use the following definition:

### Intellectual Disability

**'Intellectual disability' starts any time before a child turns 18 and is characterized by differences with both:**

**Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and**

**Adaptive behaviour, which includes everyday social and life skills.**

### Developmental Disabilities

**'Developmental disabilities' is a broader category of often lifelong challenges that can be intellectual, physical, or both.**

### Intellectual and Developmental Disabilities

**'Intellectual and Developmental Disabilities' is the term often used to describe situations in which intellectual disability and other disabilities are present.**

For the purpose of this report, the above definition of IDD will be used and is inclusive of Intellectual Disability, Down Syndrome and Autism Spectrum Disorder but excludes specific learning disabilities.

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# Our Research

## What, Why, How?

### **Scope of the Research**

This report is intended to offer a qualitative look into the experiences, challenges, and needs of the IDD sector in India. Given that IDD itself has many overlapping definitions, the scope of the research is overarching and includes aspects encompassing all disabilities including intellectual disability. It may also be noted that this report is based on preliminary research in the sector and is designed to be wide rather than deep in its approach. The intent is to present the challenges and needs of the IDD sector in India through the lifespan of a PwIDD.

For the scope of this research, we have specifically worked with people with Intellectual Disability, Down Syndrome, and ASD as well as their caregivers, and the organizations in India working to cater to their needs.

### **Limitations**

The research is based on conversations with a small but diverse group of people with IDD, their caregivers, organization heads, special educators, and others. Further, given time, location, and pandemic-related constraints, the research has representation from PwIDD, caregivers, and organizations in urban and non-urban, upper- and middle-class contexts. The names of the interviewees have been changed on request.

### **Methodology of the Research**

Designed as a mix of primary and secondary qualitative research, as much as possible, the intent of the research has been to present voices and narratives of PwIDD and their

families. We have conducted qualitative interviews with 30 individuals including PwIDD, their parents and siblings, special educators, and sector organization representatives.

As part of the study, we have also designed surveys to understand the various needs and gaps faced by caregivers and organization workers associated with PwIDD.

### **Co-design Methodology**

Apart from traditional primary and secondary research methods, we have used participatory and co-design research tools for a deeper engagement with our stakeholders. In our endeavour to break silos in the sector and bring different stakeholders on the same platform, two co-design workshops were organized as a part of this. The participants belonged to various sections of the society with representation from PwIDD, their caregivers including parents and siblings, medical practitioners, special educators, NGO representatives from urban and rural spheres, as well as Accessible Tech developers. These participants came together to discuss challenges facing the community and brainstormed ideas to address them.

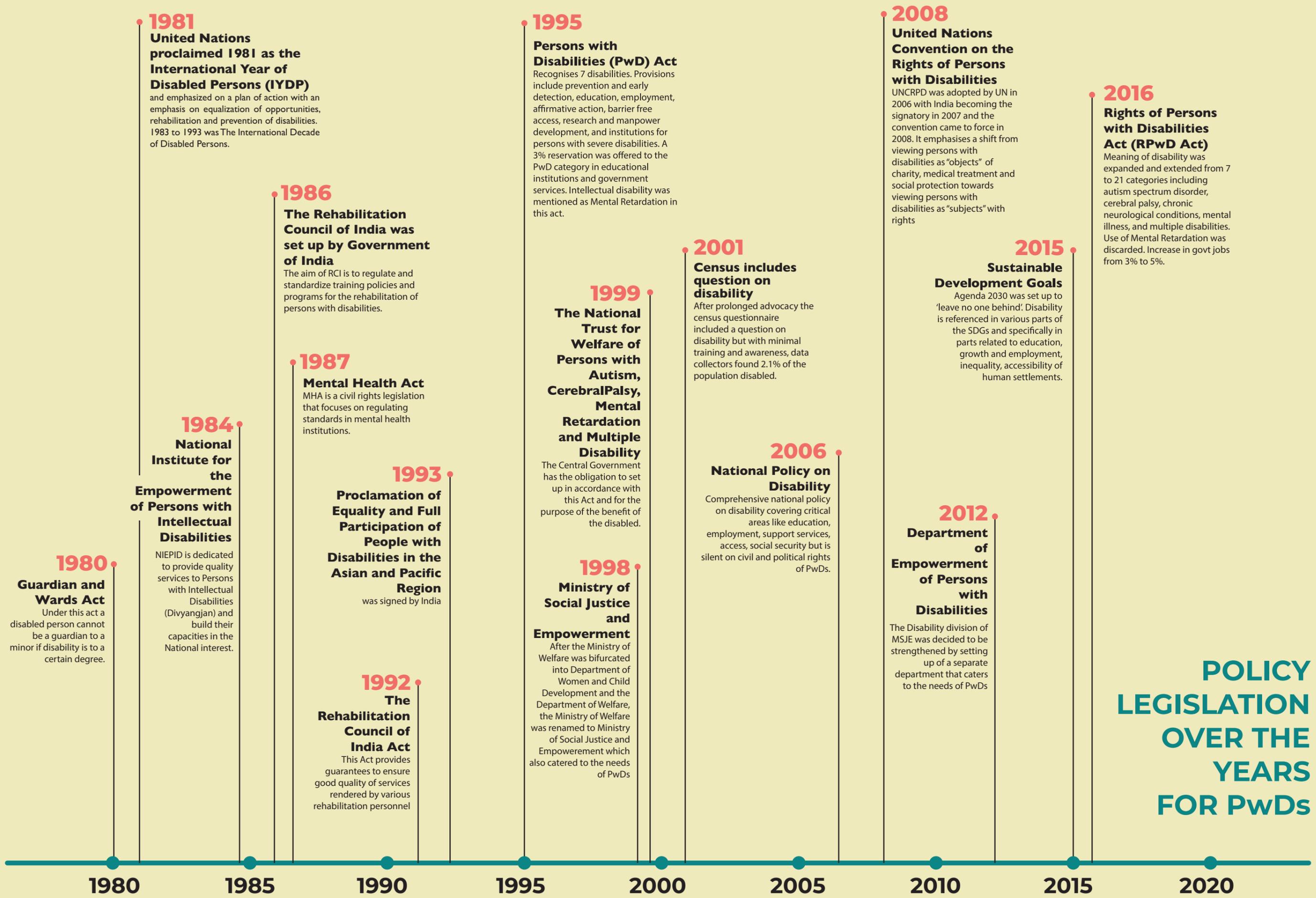
Note: Given the paucity of data about IDD in India and the scope of this research, all insights are indicative and do not represent an all-encompassing view of the sector.

# Taking a Systemic Approach to IDD

## **Policies and Legislations for PwIDD**

*Over the years, the Indian government, particularly the Ministry of Social Justice and Empowerment, has designed policies, legislations, and infrastructure to support the lives of PwIDD. These include the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999, Rehabilitation Council of India Act 1992, the National Policy for Persons with Disabilities 2006, and the Rights of Persons with Disabilities Act 2016. Along with the policies and legislations, the national and state governments continually enact various social security schemes for empowering PwD.*

*Policies and institutions have seen a gradual shift towards a rights-based approach, particularly after India signed the UNCRPD and enacted the Rights of Persons with Disabilities Act (RPwD Act) in 2016. The RPwD Act primarily mandates that all persons with disabilities have a right to equality and a life of dignity and respect. The other salient features of the Act are explained in the associated graphics.*



**1980.**  
**Guardian and Wards Act**  
 Under this act a disabled person cannot be a guardian to a minor if disability is to a certain degree.

**1984.**  
**National Institute for the Empowerment of Persons with Intellectual Disabilities**  
 NIEPID is dedicated to provide quality services to Persons with Intellectual Disabilities (Divyangjan) and build their capacities in the National interest.

**1981**  
**United Nations proclaimed 1981 as the International Year of Disabled Persons (IYDP)**  
 and emphasized on a plan of action with an emphasis on equalization of opportunities, rehabilitation and prevention of disabilities. 1983 to 1993 was The International Decade of Disabled Persons.

**1986**  
**The Rehabilitation Council of India was set up by Government of India**  
 The aim of RCI is to regulate and standardize training policies and programs for the rehabilitation of persons with disabilities.

**1987**  
**Mental Health Act**  
 MHA is a civil rights legislation that focuses on regulating standards in mental health institutions.

**1992.**  
**The Rehabilitation Council of India Act**  
 This Act provides guarantees to ensure good quality of services rendered by various rehabilitation personnel

**1993.**  
**Proclamation of Equality and Full Participation of People with Disabilities in the Asian and Pacific Region**  
 was signed by India

**1995**  
**Persons with Disabilities (PwD) Act**  
 Recognises 7 disabilities. Provisions include prevention and early detection, education, employment, affirmative action, barrier free access, research and manpower development, and institutions for persons with severe disabilities. A 3% reservation was offered to the PwD category in educational institutions and government services. Intellectual disability was mentioned as Mental Retardation in this act.

**1999.**  
**The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability**  
 The Central Government has the obligation to set up in accordance with this Act and for the purpose of the benefit of the disabled.

**1998.**  
**Ministry of Social Justice and Empowerment**  
 After the Ministry of Welfare was bifurcated into Department of Women and Child Development and the Department of Welfare, the Ministry of Welfare was renamed to Ministry of Social Justice and Empowerment which also catered to the needs of PwDs

**2001**  
**Census includes question on disability**  
 After prolonged advocacy the census questionnaire included a question on disability but with minimal training and awareness, data collectors found 2.1% of the population disabled.

**2006.**  
**National Policy on Disability**  
 Comprehensive national policy on disability covering critical areas like education, employment, support services, access, social security but is silent on civil and political rights of PwDs.

**2008**  
**United Nations Convention on the Rights of Persons with Disabilities**  
 UNCPRD was adopted by UN in 2006 with India becoming the signatory in 2007 and the convention came to force in 2008. It emphasises a shift from viewing persons with disabilities as "objects" of charity, medical treatment and social protection towards viewing persons with disabilities as "subjects" with rights

**2012.**  
**Department of Empowerment of Persons with Disabilities**  
 The Disability division of MSJE was decided to be strengthened by setting up of a separate department that caters to the needs of PwDs

**2015.**  
**Sustainable Development Goals**  
 Agenda 2030 was set up to 'leave no one behind'. Disability is referenced in various parts of the SDGs and specifically in parts related to education, growth and employment, inequality, accessibility of human settlements.

**2016**  
**Rights of Persons with Disabilities Act (RPwD Act)**  
 Meaning of disability was expanded and extended from 7 to 21 categories including autism spectrum disorder, cerebral palsy, chronic neurological conditions, mental illness, and multiple disabilities. Use of Mental Retardation was discarded. Increase in govt jobs from 3% to 5%.

**POLICY LEGISLATION OVER THE YEARS FOR PwDs**

1980 1985 1990 1995 2000 2005 2010 2015 2020

# SALIENT FEATURES OF THE RPwD ACT, 2016

The RPWD Act came into effect on 30th December 2016

 Disability has been defined based on an evolving and dynamic concept

 The types of disabilities have been increased from existing 7 to 21 and the Central Government will have the power to add more types of disabilities.

 Responsibility has been cast upon the appropriate governments to take effective measures to ensure that the persons with disabilities enjoy their rights equally with others.

 Grant of guardianship by District Court under which there will be joint decision-making between the guardian and the persons with disabilities.

 Strengthening of advisory boards, Office of Chief Commissioners of PwD

 Reservations for People with Disability in Government jobs has gone up from 3% to 4% and in higher education to 5%

 Free Education for every child with benchmark disability from the age of 6 to 18 years.

 *Special Courts* will be designated in each district to handle cases concerning violation of rights of PwDs

 Provides for penalties for offences committed against persons with disabilities and also violation of the provisions of the new law.

## Gaps in Policy and Implementation

While many of the government policies are in line with international norms and seek to empower PwD to live a life of dignity, there is a gap between policy and implementation. Availability of limited funds can also be a possible barrier between intentions and reality given that there is a large beneficiary group with varied needs. Most of the persons interviewed for this project shared that they were unaware of many government policies. This is also corroborated by secondary research which finds that there is poor awareness of laws and policies about disability benefits in families with IDD (Girimaji & Kommu, 2016). This lack of awareness is greater among people from marginalized socio-economic backgrounds.

Further, many interviewees have struggled with navigating existing government services. Acquiring disability certification, for example, was seen as a long process for almost everyone interviewed for this report. A parent advocate with many years of experience in the sector shared that the design of these policies sometimes excludes PwIDD and their families. There is a disconnect between the policy intent and the ground reality. There is a need to bring more diverse voices into the policy-making processes, especially self-advocates and people with on-ground experience in the sector.

*In the context of IDD, there is a lot more that needs to be done as PwIDD find themselves further marginalized and made invisible even with the larger disability community. Interviewees attribute this to three factors:*

- IDD is not always physically identifiable, and neither is it easily diagnosed, making it more likely to be ignored;*
- the perception of IDD as something shameful makes it harder for caregivers and advocates to reach policy makers; and*
- lack of relevant data to frame appropriate policies and inform resourcing to support policy implementation*

It may be useful to note an emerging practice from South Africa that seeks to address this gap between policy and implementation through refined data collection. A critical approach that the country is now adapting is to expand the scope of their education research and data collection. For instance, the School Monitoring Survey includes indicators like 'schools with at least one educator who has received specialized training in the identification and support of special needs' which enhances the depth and quality of data available, making it easier to address the gaps in making inclusive education a reality (Department of Basic Education, RSA 2018).

## Beyond the State

Despite rights-based policies that address the needs of PwIDD and their families, there is a clear gap between policy and implementation. This gap has presented an opportunity for the individual advocates and non-governmental organizations to offer much-needed services to PwIDD and their families. Many parents, struggling to find support for their children, have taken matters into their own hands, as is evident from the fact that a large number of organizations that cater to the needs of this community have significant involvement from parents and family members of PwIDD. Further, the existence of a network like PARIVAAR-NCPO, a National Confederation of Parents Organizations also points to the fact that parent associations and organizations are a primary source of services and information for PwIDD and their families. This begets the question: why don't other organizations or non-profits enter the IDD space? What can generate more awareness and understanding about PwIDD with varying abilities and needs? Where and how might other professionals and entrepreneurs, with no personal connection to the issue, be interested to step forward and build solutions to address the need-gaps in the sector, recognizing that this is a pressing issue that deserves to be addressed?

Last, the systemic approach requires centering the voices and experiences of PwIDD themselves. There is a strong case for facilitating self-advocacy and building capabilities of PwIDD to identify and address their own needs. At present, the few non-profit and for-profit services available are able to bring these voices to the forefront given their proximity to the IDD community, but government agencies and services, medical, educational and vocational systems, as well as policies are yet to reflect this approach. The UNCRPD and RPwD Act envisage a world where the choices and agency of PwIDD are respected. It is important for PwIDD and caregiver voices and experiences to be centered in all systems that impact their lives and form the basis of the sector's work. This would help create systemic change through a rights-based approach with a clear intent and focus to move towards an aware inclusive society which makes room for people with disability to live life with dignity!

## References

- Department of Basic Education, Republic of South Africa, 2018. School Monitoring Survey: Quantitative and Qualitative Summary Report.
- Girimaji, S.C. and Kommu, J.V.S., 2016. Intellectual disability in India: Recent trends in care and services. Health Care for People with Intellectual and Developmental Disabilities across the Lifespan, p. 461–70.

## The Act covers the following specified disabilities:

Expanding from the list of 7 disabilities defined in the PwD Act, this act recognises 21 disabilities, giving the government power to notify more if needed

### 1. Physical Disability

- Locomotor Disability
  - Leprosy Cured Person
  - Cerebral Palsy
  - Dwarfism
  - Muscular Dystrophy
  - Acid Attack Victims
- Visual Impairment
  - Blindness
  - Low Vision

- Hearing Impairment
  - Deaf
  - Hard of Hearing
- Speech and Language Disability

### 2. Intellectual Disability

### 3. Specific Learning Disabilities

### 4. Autism Spectrum Disorder

### 5. Mental Illness

### 6. Multiple Disabilities

### 7. Disability caused due to:

- Chronic Neurological conditions:
  - Multiple Sclerosis
  - Parkinson's Disease
- Blood Disorder:
  - Haemophilia
  - Thalassemia
  - Sickle Cell Disease

## Stakeholder Mapping

There are multiple facets to identifying and addressing challenges faced by the IDD sector in India. The first step towards a systemic approach is to understand the various stakeholders that play a role in the lives of PwIDD. The following graphic identifies the various stakeholders to address different needs across the lifespan of PwIDD.

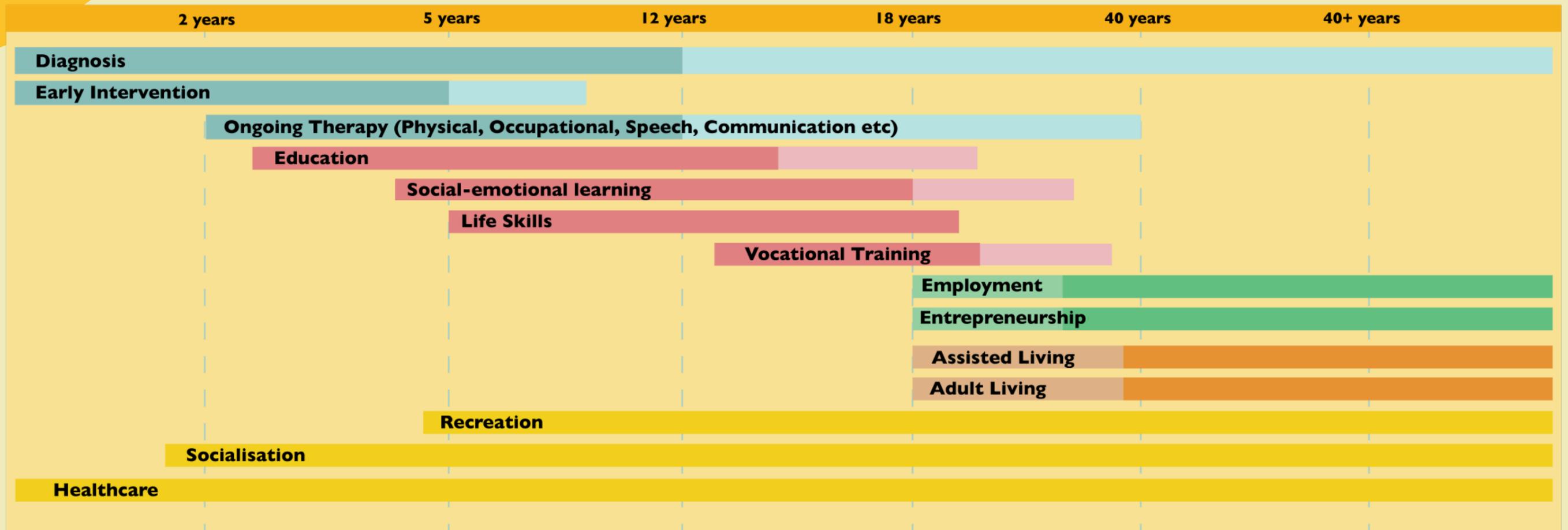
### Key of the terms

CSO - Civil Society Orgs  
 DEI - Disability, Equity, Inclusion  
 MOE - Ministry of Education  
 MSJE - Ministry of Social Justice and Empowerment  
 NIEPID - National Institute for the Empowerment of Persons with Disabilities  
 NIMHANS  
 RCI - Rehab Council of India  
 SCPwD - Skill Council for Persons with Disabilities  
 VIMHANS - Vidyasagar Institute of Mental Health and Neuro Allied Sciences

	ante-natal/post-natal	0-2	2-5	6-12	13-18	18-40	Over 40s	Overall
<b>HEALTHCARE</b>	ASHA workers	Aanganwadi workers	Early intervention centres	Child guidance clinics	Therapists (Physical, Occupational, Speech, Communication etc)		VIMHANS	Parents
	Ministry of Health and Family Welfare	Private hospitals	Hospital support staff	Government hospitals	Nurses	National Rural Health Mission	Doctors NIEPID	Siblings Siblings' friends
<b>EDUCATION</b>			School Administration	Teachers	Principal	CBSE	NIOS	Extended family & friends
			International Boards	NCERT/SCERT	State board	Therapists (Physical, Occupational, Speech, Communication etc)	Schools (government and private)	PARIVAAR
<b>VOCATIONAL TRAINING</b>			Aanganwadi Workers	Special Educators	School support staff	Schools (special, integrated and inclusive)	Higher education	Family Support Groups
			Civil society	NIEPID	Ministry of Education	Rehabilitation Council of India		National Institute for the Empowerment of Persons with Intellectual Disabilities
<b>OCCUPATION</b>					Technical and vocational training centres	SCPwD (Skill Council for PWD)	NIEPID	National Trust
					Training centre staff		Vocational Rehabilitation Centres for Handicapped	Media
<b>ADULT LIVING</b>					Trainers	Civil Society Organizations	Centre Administration	Department of Empowerment of Persons with Disabilities
						Disability and Inclusion experts	HR/recruiters	Colleagues and Peers
<b>RECREATION</b>						Employers (Govt / Pvt open market / Sheltered work centres)	National Handicapped Finance and Development Corporation (NHFDC)	Ministry of Social Justice and Empowerment
						Ministry of Labour and Employment	National Urban Livelihood Mission of Ministry of Urban Development	Training Centre Placement Cells
						NIEPID	National Rural Livelihood Mission of Ministry of Rural Development	Customers / Clients
						Facilities associated with Samarth, Gharaunda, other National Trust schemes	Volunteers	Authorities
						Civil society organisations like CLAPS and other assisted / independent living facilities	Support staff	Private organisations
							NIEPID	Rehabilitation Council of India
					Friendship / Buddy circles	Special Olympics Bharat	Social clubs for PwIDD, such as Club Youngistaan	

# Journey of a PwIDD

Persons with intellectual and developmental disabilities have varying needs across different life stages. These needs bring forth the challenges in day-to-day experiences for PwIDD, and they differ depending on socio-economic factors, context, and individual personalities. Given below is a representational map of the various needs of PwIDD across various life stages:



Keeping these needs in mind, the present study explores the challenges that emerge across the different phases in the life of a PwIDD.

# Meet Roshni and Sameer

*As one of our interviewees put it, 'if you've met one person with IDD, you've met one person with IDD.' We want to bring some diverse experiences of PwIDD throughout various life stages and aspects of their lives through this qualitative study. We have Roshni and Sameer, two fictitious characters to help us along the way.*

*Throughout the report, Roshni and Sameer will pop up and offer some perspectives from their point of view as PwIDD.*

*Note: Roshni's and Sameer's thoughts are based on the interviews conducted for this research and are not indicative or exhaustive as views of PwIDD.*



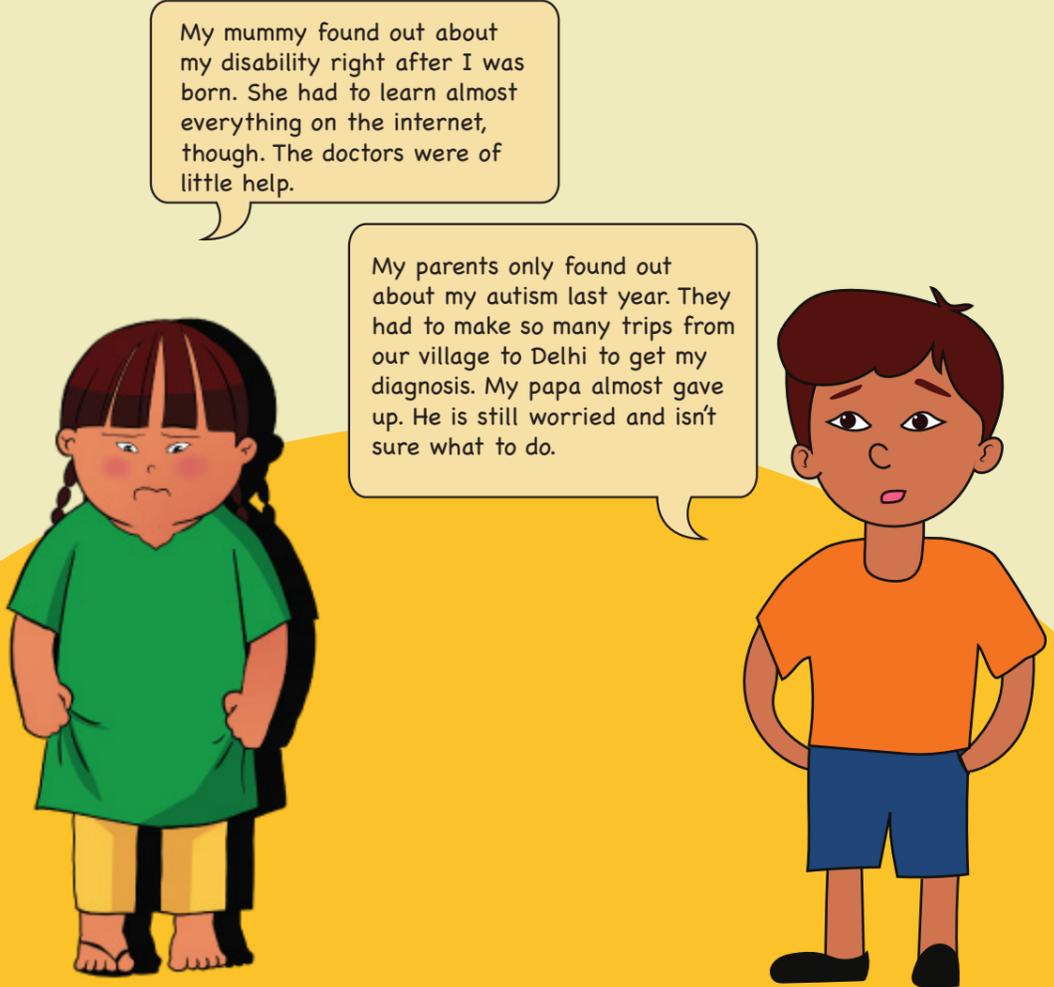
*Roshni is a young girl with the Down Syndrome living in New Delhi. Both her parents work in MNCs in Delhi/NCR.*



*Sameer is a young boy with ASD living in Nuh, Haryana, where his father works as a mechanic and mother is a domestic worker.*

# The Lived Experiences of PwIDD in India: Issues, Challenges, and Recommendations

*The following sections will explore what we see as eight key issues of the IDD sector in India. We present an understanding of the existing challenges heightened by COVID-19 as well as potential recommendations which can alleviate some of them in a post-COVID era.*



My mummy found out about my disability right after I was born. She had to learn almost everything on the internet, though. The doctors were of little help.

My parents only found out about my autism last year. They had to make so many trips from our village to Delhi to get my diagnosis. My papa almost gave up. He is still worried and isn't sure what to do.

# 1. Coming to Terms

One of the foremost, and also the most difficult things for PwIDD and their families is appropriately diagnosing the disability. Once diagnosed, caregivers may face many hurdles in finding reliable knowledge sources or caregiving support. Most importantly, coming to terms with the diagnosis that their child or family member will live with IDD for the rest of their lives, is at times an arduous process which necessitates building the much-needed support systems. The journey of acceptance is complex and is undertaken multiple times through one's lifetime, with every life stage transition. This section explores the various challenges that caregivers face during this process.

## 1.1 The Many Layers of a Diagnosis

Appropriate and timely diagnosis is the first step to ensuring a life of dignity for PwIDD. In India, diagnosis can be difficult because of many factors such as lack of awareness about IDD as well as the associated diagnostic process among caregivers, lack of information about growth milestones of a child, stigma related to disability, and lack of accessible and timely healthcare services along with other intersectional factors such as income, caste and gender.

Most parents have little knowledge about IDD before the child is born or shows any signs of disability as compared to physical disabilities or illnesses. Since institutions, especially in the healthcare sector in India are overburdened, many PwIDD and caregivers have to go through numerous hurdles to get a proper diagnosis. Parents from privileged socio-economic backgrounds are at an advantage here, with more potential of awareness of developmental milestones, thus helping them catch delays early which can lead to timely diagnosis and intervention. It is pertinent to note that cities and urban areas have greater access to medical and other resources to facilitate an early diagnosis.

Diagnosis becomes more difficult in the case of people from marginalized socio-economic backgrounds because of lack of awareness about IDD as well as reduced time

and resources that caregivers can dedicate towards their child's diagnosis. As many services are concentrated in metropolitan areas, caregivers living in Tier 2 or Tier 3 cities, or small towns and villages have to travel multiple times to these cities to get a diagnosis. Many-a-times, since the process becomes cumbersome, many are forced to give up on timely medical support, intervention, or diagnosis for their child.

In Indian culture, disability is often associated with karma, and coupled with lack of awareness and associated stigma, people are more prone to hide the disability to save themselves from being shunned from the society. Gender adds another layer to the challenge in our patriarchal society, wherein girls are less likely to receive medical care than boys. Girls with ASD may remain undiagnosed not only because autism presents differently in girls, but they are also more likely to mask than boys are. (Dean et al., 2017).

*'Log jaise polio samajhte hai, waise autism nahi samajh paatey' ('People don't understand autism like they understand polio') was the plight of one of the parents interviewed during this project. Hailing from a small town in Haryana, Karan\* couldn't understand why his child was different from others. For seven years of the child's life, he received different interpretations for his child's atypical behaviour. Some called his child pagal (mad), while others blamed*

*Karan saying that he must have done something wrong in his previous life. In his darkest hours, even Karan blamed God and wondered why it had to happen to him. After many years of trying to understand what his son is going through, Karan finally approached a hospital in New Delhi thanks to a suggestion from another parent of a PwIDD in his town. After multiple visits, the doctor gave a diagnosis of ASD and let the family be. Not having heard of ASD before, this confused Karan further, leaving him with more questions than answers.*

\*Name changed

As noted in Karan's case, it is not uncommon for families to try and rationalize the existence of a PwIDD in their family. They may attribute it to karma which may lead to a state of helplessness and can impact how children with IDD are treated at home. Parents may be looking for 'cures' to try which can lead them to misinformed practitioners or quacks. Our research also shows that mothers are disproportionately blamed for the disability of a child because of lack of awareness about the causes of IDD as well as patriarchal social norms. Mothers may have to bear the brunt of the stigma which can dramatically impact their mental and physical health. Such misattribution and misinformation can impact the treatment for PwIDD as well as the health of their caregivers.

## **1.2 Diagnosis after Early Childhood**

In some cases of IDD, due to various reasons diagnosis does not occur between birth and early childhood. Cases have been noted where children are diagnosed after school enrollment by teachers or staff. They may notice learning lags or different behaviour which can lead to teachers reporting it to authorities and parents, leading to a diagnosis for the child. This is an important avenue in diagnosis, especially in cases when the parents may not be aware of developmental milestones or other signs pointing towards an IDD. It is, however, pertinent to note that many educators may not be equipped to notice and address these signs. Sensitizing educators can provide a vital intervention point in diagnosing children with IDD earlier rather than

later.

More recently, we have also noted more instances of self-diagnosis in the case of ASD, pointing to a lack of access to information and assessment during early childhood. For example, two PwIDD interviewed for this report, had self-diagnosed and then sought a formal diagnosis in adulthood.

## **1.3 'Your Child has an IDD' – What now?**

The way a diagnosis is shared with the caregivers can have a lasting impact on parents in how they perceive their child. Diagnosis is offered with a tinge of sadness and remorse where the doctors express and expect disappointment for the child with an IDD. This can be compared to how the birth of a girl child is shared in a similar tone in many places in India, wherein the worth of the child is perceived to be less. Coupled with societal stigma, this has a non-trivial effect on how parents demand the rights of PwIDD and how they perceive the capabilities and potential of their child.

Some of the most common questions that doctors hear post diagnosis are 'ye theek ho jayega?' ('will he recover?'), 'ye normal life ji payegi?' ('will she be able to live a normal life?'), 'ye naukri kar payega?' ('will he be able to work?'). Diagnosis sets a precedent for future management of disability and approach to early intervention. There is a need for realistic optimism to be employed by medical practitioners to impart the right knowledge in the right way so parents do not lose hope and can do what is the best for their children.

## **1.4 Internet, the Saviour**

Diagnosis often leaves parents in a lurch with many questions unanswered. Almost all parents interviewed were unsatisfied with the information they got from the medical health practitioners about the diagnosis of the disability and how they could help their child cope better. In our current digital age, parents often turn to the internet to find answers to many of their questions and to feel that they are not alone. This happens across the socio-economic spectrum with parents who have access to digital devices with an internet connection.

Many parents mentioned how going through videos on Youtube about children with IDD made them feel like they are not the only ones. This inculcated a feeling of community support and gave them hope. Some parents found helpful blog posts written by various caregivers across the world which guided them through their caregiving process. Parents who lacked awareness about IDD have found

solace in the fact that there are other children and people in the world who live with a similar disability diagnosis, yet are able to thrive in their lives. As one parent mentioned, 'I relied on a blog post I found at the time of my child's diagnosis. I followed it for the next four years of my child's life. It was a saving grace for me.' In recent times, the power of social media has led parents to meaningful peer-mentoring communities through groups like The Special Mom, Forum for Assisted Living Solutions, and other parent support groups. Self-advocates have also reported the role of social media in finding a community. Parent and PwIDD influencers who share their journey online can offer moral support and bridge feelings of isolation.

Often in the early process of diagnosis, parents need and look for support. Parents have shared feelings of isolation, especially when they are unable to find support within their extended family due to stigma and misinformation around IDD. In such situations, a digital community and knowledge bank becomes the pillar of support.

The Internet, however, can also provide misinformation and warped views on disabilities. Post diagnosis, through medical practitioners or online research, parents come across worst-case scenarios rather than best-case scenarios, or at times best-case scenarios which increased the pressure on them and their children with disabilities to live up to 'best-case' standards. This can increase stigma and acceptance of disability among families as well as impact their health and well-being. Further, the veracity of information available online can be doubtful, and it is especially important that one is aware of and has access to credible sources. Across socio-economic backgrounds, parents lacked information about IDD and relied on online sources which may or may not be accurate.

## **1.5 Prevention of IDD**

According to studies, 25 % of IDD is preventable as IDD has been found to have direct correlations to poor nutrition of mothers, poverty, lack of adequate antenatal and postnatal care, and complications during birth (Girimaji, 2011). It has been reported by organizations that in some states, since families can only access free healthcare services for up to two child births, they more often than not choose to go through home births for their third child to save on cost and avoid facing ridicule about family planning. This can lead to higher instances of preventable IDD in the third child.

## **1.6 The Impact of COVID-19**

Not only has COVID-19 added new challenges for parents of PwIDD, it has also heightened the existing challenges in reaching a diagnosis. The pandemic has led to delay in diagnosis for many parents. With the healthcare system being more overburdened than before, many parents have

to wait to get a formal diagnosis. Many early intervention centres moving work to online medium have made it difficult for PwIDD and their caregivers in achieving the desirable outcomes, and in many cases regressing in the absence of adequate therapy support. Access to healthcare during childbirth has become cumbersome leading to many more risky births which might lead to more instances of IDD.

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## 1.7 Core Challenges and Need-gaps

**1. A need for increased awareness and sensitization about IDD, its various signs and symptoms, its causes, as well as reliable resources for newly diagnosed PwIDD across various stakeholders such as families, communities, medical professionals, and educators.**

**2. There is a need for onboarding parents on this journey with understanding and care in a structured format providing access to appropriate information and services about prevention of IDD, including support systems, particularly for those from marginalized socio-economic groups.**

**3. There is a dire need for capacity building and training of professionals involved in diagnosis to sensitively and carefully diagnose IDD and offer initial support to caregivers and PwIDD**

## 1.8 Recommendations

1. Through the research for this project, four key stakeholders have been identified for whom there is a need for focused effort on increasing awareness and sensitization for timely and appropriate diagnosis.

a. Parent awareness plays a key role in early diagnosis and intervention for PwIDD. Their education, access to information, access to support networks, access to resources and services, class background, caste background, their open mindedness, and physical location influence diagnosis and the subsequent intervention.

b. Government hospitals, medical practitioners, and authorities responsible for issuing formal certification also play a major role in diagnosis and early intervention. If they are not sensitized towards the needs of PwIDD and their caregivers, they can unknowingly contribute in impeding the lifelong growth of PwIDD. Medical practitioners need to give enough time and relevant information as well as guide parents to trusted sources to aid PwIDD early intervention. Medical practitioners in smaller cities and rural areas are often themselves unaware of IDD contributing to more misinformation. It is suggested to create trusted sources of information as public goods freely accessible for all.

c. School teachers also play a definitive role in diagnosis of IDD for children. Learning lags or other behaviours can be noticed by teachers and if reported to the right authority through proper channels, can aid parents in getting a diagnosis and proper treatment for their children.

d. Accredited Social Health Activists (ASHA) and Anganwadi workers (AWWs) are grassroots-level health workers who can play a major role in early diagnosis and intervention of PwIDD, especially for people from marginalized socio-economic backgrounds. Civil Society Organizations like Jai Vakeel have identified the potential of Anganwadis and have chosen to work with them as critical intervention partners for their early intervention program.

2. Given that IDD can be prevented with the right antenatal and postnatal care, it is critical that all pregnant women receive that care, and government medical centers, ASHA and Auxillary Nurse Midwives (ANMs) are equipped to provide the necessary awareness and training for this.

3. There is a need for convergence between various government ministries and departments to come together and ensure prevention and diagnosis, and make early intervention services accessible for all. Particularly for interventions through grassroots health workers like ASHA, Anganwadi workers, or ANMs, the Ministry of Social Justice and Empowerment (MSJE) as well as the Ministry of Women and Child Development and the Ministry of Health and Family Welfare come together to pool resources and address the needs of PwIDD and their families.

## 2. Formal Recognition

My papa doesn't know about these certificates and IDs. The shopkeeper from our village told us to get them because it will help my parents take care of me but we don't know how.



My mummy and I had to go to the hospital five times to get my disability certificate but I don't know about this UDID. Will it help me?



While a diagnosis is the first step for most when it comes to acknowledging IDD, the next is often to seek government recognition in order to protect and assert PwIDD's rights. Currently, there are two recognition options available for PwIDD — a Disability Certificate and a Unique Disability Identity Card (UDID). These two certifications are essential for PwIDD to access various government schemes and benefits. This section will highlight the various challenges PwIDD and their caregivers face in procuring these certifications and ideas for creating more accessible ways for formal recognition.

### 2.1 Disability Certificate Procurement

A disability certificate is required to ascertain the type and extent of a person's disability. It is needed for PwIDD to claim benefits, services, and resources mandated by the government. Benefits such as the disability pension and aid in accessing education and other provisions are covered in it making it more critical for PwIDD from marginalized socio-economic backgrounds to procure so as to be able to support themselves. The certificate is issued by a medical board constituted by the state government in each state to PwD with disabilities recognized under the RPwD Act 2016. Designated government hospitals in each state make assessments which qualify PwD for a disability certificate.

Procuring a disability certificate is not easy for many caregivers. Many caregivers noted having to make multiple rounds to the hospital to get the disability certificate. The IQ tests designed to procure it require the children to sit in one place for hours which is difficult for many PwIDD. This leads to the authorities taking the test multiple times to reach a conclusion. Many-a-times, the authorities don't recognize the disability which leads to denial of a certificate, like results indicating higher IQ on a test as noted by one interviewee, etc. It was also seen that there is no uniformity in terminology as well as understanding of certain disabilities across the country. A child with ASD

might have a certificate that mentions Intellectual Disability, Autism, or Mental Retardation. It is critical to note that despite 'Mental Retardation' being removed from the list of disabilities under RPwD Act 2016, one parent reported that they still received a certificate with the term, even after informing the authorities that their child is on the autism spectrum.

Parents have also reported that the procurement process can take months or years. It was also reported that caregivers who could afford private services gave up trying to procure the disability certificate halfway due to the process being complicated and inconvenient. Unfortunately, the truth remains that many do not have that privilege. This process is especially arduous for PwIDD from marginalized socio-economic backgrounds because of lack of information, or lower perceived influence and confidence in front of government authorities. They may find it challenging to take multiple days off from work, especially when it involves loss in income, while at the same time this certification is critical for them to be able to access support services. For example, the Disha Early Intervention and School Readiness Scheme under the National Trust Act requires a disability certificate as proof of disability before a PwIDD is allowed to access its benefits.

Although IDD is recognizable in infancy or early childhood, it is often difficult to accurately diagnose it before 5 years of age. Medical health practitioners too are not able to give a proper medical diagnosis and certificate to caregivers before that. Global Developmental Delay (GDD), which often predicts future development of ID, is used as a surrogate marker in children between the age group of 3 months and 5 years (Shevell, 2008). Since many caregivers are not aware of it, it can lead to them giving up on procuring a certificate till the PwIDD reach the age of 5 or above. This can have a significant delay in intervention for PwIDD from marginalized socio-economic backgrounds who may rely

on access to government schemes and services for early intervention and care. Getting a disability certificate and formal recognition is a fundamental right for PwIDD. The process should be designed keeping their needs in mind for easier accessibility.

## **2.2 UDID Procurement**

In addition to a disability certificate, PwIDD are also eligible to apply for a Unique ID (UDID), a Persons with Disabilities card which offers them formal recognition. The UDID is an identity card issued to PwD with the intent to create a national database of all the people with disabilities in the country to ensure uniformity as also for easier and more transparent access to services and resources. It is designed to give recognition for PwIDD nationally and collate all relevant data in one place.

The UDID is an initiative of the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice and Empowerment, brought on after the RpwD Act 2016. All persons with disability are eligible to apply, with or without an existing disability certificate. While meant to enhance access and inclusivity, the process still leaves a lot to be desired for many parents and PwIDD. Since this is a relatively new provision, many caregivers interviewed were not aware of its existence. The application process is entirely online, making it beyond the reach of a huge section of the population. Some parents also reported that they have applied for it but haven't received the ID card for months and in some cases years. Coupled with occasional technical glitches and challenging follow-up procedures, the process becomes exacting for applicants.

## **2.3 The Impact of COVID-19**

The COVID-19 pandemic has created a backlog when it comes to formal recognition certification. Medical services in India were adversely impacted due to the pandemic, making it almost impossible for people to approach hospitals for certification. After the second wave, although medical services were more accessible, but due to the increased risk to PwIDD, the caregivers avoid visiting a hospital for certification.

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## **2.4 Core Challenges and Need-gaps**

*1. Certification is difficult for people across socio-economic backgrounds, but there are more hurdles for those from marginalized communities including information about certification, awareness of processes, etc. The process needs to be made simpler for easy access.*

*2. UDID is also inaccessible for many parents / caregivers as it is an online and time-consuming process. Given that this ID was introduced to streamline access to services and benefits, it should have been designed keeping in mind accessibility for the most marginalized and vulnerable PwIDD.*

*3. There is a need for capacity building and training of professionals involved in the certification process.*

## **2.5 Recommendations**

*1. Awareness campaigns about the need, benefits, and procedures for getting formal recognition are the first and foremost suggestion. Knowing how certification can help and understanding the steps in the process can make it simpler for people to access these critical services. Knowing and understanding the benefits also make people more open to go through the process of seeking help, as needed.*

*2. Disability certification and UDID have overlapping benefits and it may serve to combine both certifications into one rather than two separate processes. While the UDID portal offers space to apply for a disability certificate as well, the process is still inaccessible for those who are on the wrong side of the digital divide.*

*3. The physical process for the disability certificate procurement requires multiple visits to hospitals that may not be accessible for PwIDD. Similarly, UDID applications being online only, limit access for many. It is critical that these processes are simplified, and a one-stop center where all that can be procured in a single visit should be facilitated.*

My mummy loves me a lot and left her job to take care of me. She even did a special education course so she could teach me at home. I spend most of my time with mummy and Kavita didi also helps. But I wish my grandparents would spend time with me like they do with my brother.

My papa and mummy both have to go to work otherwise they can't take care of me. I am left with my older siblings most of the time who are busy with their own school work and friends. I mostly spend my time alone and that worries my mummy-papa.



## 3. Caregiving A Lifelong Project

All humans need suitable care to survive and thrive. However, offering 'suitable care' to PwIDD may not always be easy to deliver. Learning to care for PwIDD, designing formal and informal care services, and lifelong caregiving are some of the crucial discussions amongst parents, sector organizations, and self-advocates in this space. This section of the report looks at various kinds of caregivers and their role in the lives of PwIDD through the initial diagnosis in the short run and across the various life stages in the long run. It also explores the challenges faced by caregivers as well as implications of long-term caregiving. Caregivers include family of PwIDD (parent, siblings and others), informal caregivers like 'didis, formal caregivers, and organizations that offer caregiving support, whether governmental or non-governmental.

### 3.1 The Early Stages

Taking care of PwIDD during their infancy and early childhood can be challenging for parents for a multitude of reasons, more so if the diagnosis has not yet happened. There is a lack of awareness about IDD and the perceptions around IDD are often laced with stigma and misinformation, making it hard for parents to access diagnostic services. However, once this barrier is bridged, during the initial stages of diagnosis, parents may wonder about aspects like:

*'How do I take care of my child when I don't understand them?'*

*'Will my caregiving help my child to become an independent adult?'*

*'What if my child needs care throughout*

*their life?'*

*And the most critical question all parents face, 'What happens after I am no longer able to care for my child?'*

This feeling of being overwhelmed and helpless resonated with many parents interviewed for this report, especially after the diagnosis is confirmed. As one parent puts it, 'Poore jeevan mein hulchul ho jaati hai' ('life becomes a flurry of activity'). In many cases, the diagnosis itself is shared with a tone of disappointment and shame, setting the tone for the rest of the child's and parents' lives. This shame makes it harder for parents to share the diagnosis with other family members and friends and many have reported feeling alone and alienated after diagnosis. A recent study conducted in Bangladesh corroborates this finding (Islam, 2020). The impact includes criticism and lack of support from family members, losing touch with friends and family members, alienation, social isolation, etc.

### 3.2 Life after Diagnosis

Parents across the socio-economic spectrum shared that they found the diagnostic process lacking in adequate support for them. They were not informed about what the life of their child would look like, or given only extreme examples. Many also shared that the practical information needed to care for their child was rarely shared, and parents helped themselves to internet searches and online forums to find information. Youtube, in rural as well as urban areas, has come out to be a great learning resource, where a lot

of parents find knowledge and similar stories that make them feel less alone.

There is a dire need for capacity building and structured onboarding of parents in order to equip them with the skills necessary for suitable caregiving and access to helpful resources. There are a few formal training programs available for parents which offer practical guides for taking care of a child with IDD like those offered by The National Trust. However, beyond that, parents are left to online forums or NGOs to help them learn how to best care for their child.

Further, parents reported that either medical practitioners or internet searches would lead them to rare stories of people living with the same IDD experience as their child. The stories would involve either extreme cases requiring intense medical attention or heroic stories of persons who have overcome all challenges associated with the disability. This creates a challenge for new parents who are looking for 'realistic optimism' and authentic role models which allow them to prepare suitably for their child.

### 3.3 Finding Support

Caregiving for a child with IDD can be challenging for many parents. There is an impact on the parents' and family's mental health associated with long-term care. Given that many parents and families consider caregiving a 'duty', taking time to address the mental health impact can be seen as dereliction of that duty (Girimaji 2011). Parents have reported instances of increased anxiety, depression, and negative impact on the family life.

Support groups offer significant relief for parents. Whether it is larger parent organizations like PARIVAAR or online forums like The Special Mom, these groups create a forum for asking and answering a range of questions. Similarly, organizations like Nayi Disha and Amrit Foundation of India have created resource and service provider databases for parents and families to access information and find institutions, services, or professionals who can support them. Parents use these groups to improve the quality of care for PwD as well as to find support for themselves when they need to address their mental health.

The emergence of 'respite' care services seeks to address this challenge. Some organizations offer care services for short durations of a few hours or days when parents need some time to address other responsibilities in their lives, to find time for leisure, or take care of their mental health. Informal caregivers also address this need as they may work full-time with families or organizations to support in caregiving. However, access and affordability of support workers is limited to those with privileged socio-economic backgrounds.

### 3.4 Gender and Caregiving

In the Indian context, the caregiving largely rests with the family of PwIDD, and as with most patriarchal societies, it lies most often with the mother (Girimaji 2011). Beginning with the diagnosis of the child, mothers have reported being blamed for the PwIDD's disability across all socio-economic groups. Further, mothers, more often than not, become primary caregivers of PwIDD and are more likely to quit their full-time occupation when a child is diagnosed with IDD. A majority of the mothers interviewed for this report had undertaken special education and other caregiving courses to enable them to address the needs of their child and address the sector's need for capacity building. This gendered approach to caregiving can also be reflected in the high number of mothers who set up organizations or work in the IDD sector.

### 3.5 Siblings and Caregiving

As part of the PwIDD's immediate family, siblings are also involved in various ways when it comes to caregiving. Not only are the parents not always able to devote adequate time and attention to siblings of PwIDD, the siblings often assume responsibility for the long-term care of PwIDD. Sibling support groups such as Saarthi: Sibling Support Network India are creating space for siblings to speak about and seek support for themselves. Some of the parents interviewed shared that they are conscious of this unsaid expectation on their other children and make it a point to find alternative long-term care options for PwIDD.

### 3.6 Socio-economic Factors and Caregiving

For those living in poverty or coming from marginalized socio-economic groups, caregiving is additionally challenging. Whether it is finding initial information about IDD, confirming a diagnosis, or caring for a child with IDD, income and geographical location determine access to services. Organizations and medical practitioners who specialize in IDD are concentrated in metropolitan cities. Further, accessing day-care or long-term care is intrinsically tied with income and affordability. There are various schemes under The National Trust, but research shows that they are largely inaccessible for those from marginalized socio-economic backgrounds due to lack of awareness (Girimaji 2016). It is due to these factors that there have been instances reported of PwIDD being locked up in their homes during working hours as there is no other affordable option to care for them.

### 3.7 Changing Perceptions

Caregiving comes with an additional difficult task – parents and caregivers are also responsible for sensitizing their communities and work towards changing perception to make the world more accessible for their children. This starts with the immediate and extended family, to schools,

neighbourhoods, and even strangers in public spaces. At least two of the interviewed parents shared that they carry brochures on flights to inform passengers that their child might have verbal or physical ways of communicating that may seem new. Parents believe that this additional burden of creating awareness should not be their responsibility, but rather the responsibility of the State or of others around them. It is here that the media can play a positive role in changing perceptions.

For example, Nigeria, a culture which like India can view disability as a burden or a curse, has experienced positive impact by creating awareness programs in mainstream media. In their paper *Coping strategies of families of persons with learning disability in Imo state of Nigeria*, it is noted that, 'information from television programmes helped them gain knowledge on the different aspects of learning disability, what to expect and how to teach them basic skills like hygiene, feeding, safety, and communication. This knowledge helped them realise that there is nothing wrong with them as a family. They also stated that it was through the information from such programmes that they came to know what causes learning disability, thereby debunking the superstitious myth that it is a curse. They expressed that knowledge from such programmes also helped them overcome unnecessary shame when in public with their family member with a learning disability.' (Chukwu et al. 2019)

### 3.8 Caregiving as a Burden

Caregiving for PwIDD is often seen as a burden for the family, given that it is largely unsupported and without a respite to the caregivers, getting difficult as they age and the needs of the PwIDDs change with the passage of time. Challenging as it may be, the perception that caring for a child or adult with IDD is a burden negates the rights of the latter. As a person entitled to life of dignity, PwIDD has a right to receive adequate and suitable care. There is a need for systemic support structures which allow for caring for PwIDD, whether short term or long term, to become more accessible to change this perception. This can also be addressed by directing caregiving towards fostering independence and autonomous living for PwIDD.

### 3.9 The Impact of COVID-19

The pandemic has impacted caregivers as well as PwIDD, much like the rest of the world. The unpredictability of these times has impacted the mental and physical health of all families. Those who contracted COVID-19 struggled to find caregivers for PwIDD in their families. If PwIDD contracted COVID-19, it added another layer to their existing health and care challenges.

Further, the lockdowns and changing social norms like masking and distancing have been difficult for some PwIDD and their families, especially when the tactile needs of

PwIDDs are such that wearing a mask is not possible. PwIDD were not able to step out and receive their education, therapies, healthcare, or trainings. The change in routine and lack of access to needed services have put an additional responsibility on family members to take on the role of these service providers. Most significantly, the pandemic has brought forth the need for long-term care services for PwIDD, especially as there can be situations wherein parents and family members are themselves sick and unable to care for the PwIDD.

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## 3.10 Core Challenges and Need-gaps

*1. Parents have enumerated a need for clear information, resources, and training for caregiving for PwIDD when they start their journey and as they transition through various stages of life.*

*2. Parents have also shared the need to have support systems through which they can interact with others who understand what it means to care for PwIDD. Also, so that there exists a second line of support.*

*3. With evolving needs of PwIDD, the caregivers (parents and siblings) are concerned with capacity building across the various life stages. As parents age, the siblings in most cases step in to shoulder the responsibilities more and more.*

*4. Given the intense demands of caregiving and the likelihood of long-term care, there is a need for different kinds of professional care services for PwIDD as it takes its toll on the mental health of the caregivers.*

*5. Caregiving is impacted by the gender and socio-economic background of the parents. The caregiving burden is higher for mothers, and for those from marginalized socio-economic backgrounds.*

## 3.11 Recommendations

*Based on research and inputs from various stakeholders consulted during this process, the following recommendations can potentially address the aforementioned challenges in this section:*

*1. Training and capacity building of parents is a clear need, especially in the early days after coming to terms with a diagnosis. It is critical to provide easily accessible and affordable training services for parents and family members so they can learn how to support PwIDD in living healthy and as far as possible independent and fulfilling lives. This is also an opportunity to explore new technology to assist and support caregivers find others in a situation similar to theirs and discuss solutions to common issues.*

*2. To address the feeling of alienation and isolation as also support in capacity building, various support systems including hyper-local support groups or those connected on specific needs for caregivers would work well across socio-economic groups.*

*3. Creation of affordable short-term and long-term care services including day care, short-term homes, long-term homes, respite care services, etc. for all socio-economic groups across India through government as well as private channels to ensure access and affordability, is key to bridging the socio-economic divide in caregiving.*

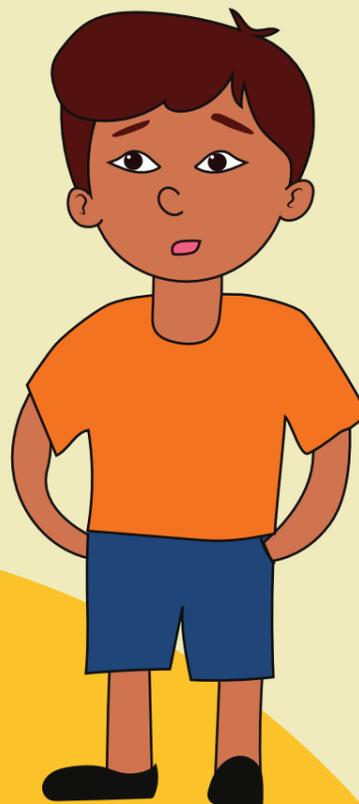
*4. Caregiving can have an adverse impact on the mental health of caregivers, especially mothers. It is recommended to offer affordable counselling and mentoring for parents after diagnosis, both in the short and long terms. There is certainly a latent and felt need for organizations that serve this need.*

# 4. Accommodation versus Inclusion

## Notes on Education

I finally got admission in a nice private school after some 10 schools rejected me. This school takes a lot of money and is one hour away from my house but they have nice teachers. I only wish the other students would not make fun of me and become my friends.

I don't go to school. They put my name in the school my sister goes to but Principal sir asked me not to come because they don't know how to teach me. I just hang out at home now and learn whatever my father can teach me.



Inclusive education is understood to mean equal access to quality education for every child who is excluded by design, either due to their special needs or because of belonging to a historically marginalized community. Sustainable Development Goal (SDG) 4 emphasizes the need for education for all, giving importance to quality education by ensuring inclusive and equitable and lifelong learning opportunities for all. There have been many initiatives taken in this direction by India such as Right to Education (RTE) and Sarva Shiksha Abhiyan, but inclusive education still remains a distant dream for many. This section explores how India is approaching making inclusive education a reality, and challenges caregivers and PwIDD continue to face in accessing education in an inclusive and equitable manner.

### 4.1 Inclusive Education in India

At the time of formulation of the Constitution of India it was mentioned that the state will endeavour to provide free education to all children till the age of 14. Right to Education (RTE) was declared a fundamental right in 1997 and, in 2002, the Constitution was amended to insert Article 21A which states that the state is bound to provide free and compulsory education to all children from the age of 6 to 14. Following this, the Right of Children to Free and Compulsory Education Act 2009 was enacted which built on the 'zero rejection' policy wherein no school can deny admission to any student, including children with disability.

The RPwD Act of 2016 defined inclusive education as 'a system of education wherein students with and without disability learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students with disabilities'. It further makes sure that 'the appropriate Government and the

local authorities ensure that every child with benchmark disability has access to free education in an appropriate environment till they attain the age of eighteen years in a special school or inclusive neighbourhood schools as per their choice in terms of Section 31 of the RPwD Act, this includes children with cerebral palsy, children with autism, children with mental retardation, and multiple disabilities defined by the National Trust Act, 1999.'

These policy decisions have been welcomed but being a diverse country, India keeps falling behind in including all its people when forming policies, especially those who are at the margins.

According to a joint report by UNESCO and Tata Institute of Social Sciences, 27% of children with disabilities have never been to school (UNESCO, 2019). Children with disabilities are still excluded from the education system with only 48.8% of persons with disabilities being literate as per the National Sample Survey 2018 and only 62.9% of people between the age of 3 and 35 being ever enrolled in a regular school (UNESCO, 2019). This exclusion gets exacerbated when we consider children with intellectual and developmental disabilities. This data gets further skewed when we look at different intersections of gender, caste, and class, with children with IDD structurally kept away from quality education. Because of the dearth of reliable data in the case of PwIDD, it is difficult to ascertain the gravity of the situation.

To make the education system inclusive for PwIDD, schools have to make sure the teachers are trained, the infrastructure is accessible, there are provisions for shadow teachers, support staff, special educators, and occupational therapists. In addition, there should be willingness from the

school administration to promote attitude shifts towards inclusion in all stakeholders. Currently, PwIDD can access education through mainstream inclusive and integrated private and government schools, special schools, home schooling and open schooling but the access to these is difficult as the availability is sporadic and oftentimes expensive.

#### 4.2 Education and Self-actualization

Quality education is a stepping stone towards being independent and becoming employable. There are direct correlations of quality education making people self-reliant and independent by empowering them with life skills and tools to navigate various life challenges. With PwIDD being pushed to the margins and not being provided quality education, they are robbed of the chance to realize their full potential and reach self-actualization. The barriers to inclusive education for PwIDD are multidimensional because of the layers of gender, caste, class, and economic status.

Furthermore, many education resources are concentrated in urban areas and hence their accessibility is limited. Since our systems are designed essentially for fully-abled, privileged class people, inclusion of PwIDD is often done with keeping the bare minimum in mind and is achieved through a charity lens. Since the general discourse around PwIDD is that they are constrained and are not able to become contributing members of the society in a more conventional sense, the efforts to include them in mainstream institutions is seen to potentially hamper its functioning. The measures to create inclusion in educational institutes is seen as cumbersome with no tangible returns, which in turn has resulted in decision makers not adequately addressing PwIDD-centered inclusion – this looks poised to change with the introduction of the National Education Policy (NEP).

A study done in 2009 by Special Olympics Bharat reiterated this fact that 80 % of people think kids with ID should be taught in special schools and not a regular school. More than 60 % of respondents believed that inclusion in educational institutes will impede the learning of other students and create discipline problems and unsafe environments. Coupled with the religious overtones of IDD being god given with links to karma, there is a stigma and fear attached to the existence of PwIDD (Siperstein et al., 2009).

#### 4.3 Status of Mainstream Schools

Even with the RTE and RPwD in place, many schools fall short of providing education to PwIDD with innumerable barriers and hurdles laid in the road to inclusive accessible education. Conversations on accessibility, be it physical infrastructure, trained professionals, learning materials, and

classroom structure, have started but there is a long way to go before all schools become accessible in a meaningful way. One major reason identified for this is the lack of motivation for inclusivity from school administrations. Parents across socio-economic backgrounds struggle with admissions for PwIDD in mainstream schools due to discriminatory practices as well as lack of infrastructure in schools. It is noted in Tier I cities like Delhi and Mumbai that many schools are not equipped to offer quality education and integrated learning for PwIDD. The RTE mandate to include PwD in all schools creates pressure for schools to offer accessible learning. However, many schools including government schools find ways to bypass these mandates. Inclusive education in mainstream schools needs investment and willingness of all stakeholders in the school, especially the management. It also requires sensitization of all including students and teachers towards the lives of PwIDD.

Government schools, being resource and infrastructure poor with already overburdened teachers, tend to enrol PwIDD but urge the parents to not send their children to school. The mandate for them essentially becomes equivalent to just giving a seat to PwIDD and not catering to their individualized needs. Many PwIDD spend 8 hours in classrooms without learning which, as a special educator pointed out, 'is a disservice to any child'. There is a cost associated with offering quality education including dedicated special educators, 1-on-1 attention, shadow teachers, dedicated 'didis' or 'caretakers' etc.. Government schools run low on funds, with makeshift infrastructure and high student to teacher ratio, making accessible inclusive education a distant dream.

Private schools charge higher fees, on top of their regular fees, for students with IDD which can make it prohibitive for those from marginalized backgrounds, or even for that matter single-income middle class families, to access quality education. Private schools are known to obstruct the admission of PwIDD citing incapacity of the school infrastructure and unwillingness towards meeting the special needs of PwIDD. Few special educators have mentioned that the first barrier for PwIDD in getting admission in a school is the application form. If the form mentions that the child has special needs, the application itself is obstructed from going forward. Many schools because of the provisions of RTE are mandated to admit students with IDD but do not make adjustments to the services, curriculum for the child. As one parent mentioned, 'inclusion does not happen just by giving a seat to a child with disabilities but making sure that the child learns and is able to grow in the institute.' Special educators interviewed also shared that it is often an uphill battle within the school to ensure that students with special needs get the requisite support.

Furthermore, private schools are known to discourage parents from letting their child be promoted to secondary schooling. Since compulsory education ends at grade 8, school administration starts pressurizing parents to de-enrol their children post that stage. The reason cited is: The child will not be able to keep up with the curriculum and other students. School administrations, being conscious of their school's ranking, are more worried about their performance coming down if PwIDD are included in secondary and senior schools. Hence, PwIDD are seen as an obstruction who they only enrol because of the RTE mandate.

#### 4.4 What After the Age of 14?

After crossing various hurdles to finish school till grade 8, PwIDD have to change schools and enrol in a special school if they want to further their education. As many PwIDD thrive with structure and routine, this uprooting shift can cause learning lags, adjustment issues, and mental-health issues. Given the inaccessibility of mainstream schools, other options for learning are exercised like the National Open School or Special schools. There is a lack of higher education spaces for PwIDD which offer specialized education like many schools in western countries. Even if a PwIDD wants to pursue higher studies in India, they either have to find ways of adapting in mainstream colleges or universities or find other avenues.

As noted by a special educator, many students require extra time to reach the same level of understanding and growth as others at the age of 14. Their learning outcomes which are set for the age of 13-14 are delayed, and are sometimes met by the age of 17-18. This again becomes exclusionary by design as the policies are not designed keeping in mind the actual needs of PwIDD. While the RPwD Act allows free education until the age of 18 for a person with benchmark disability, most kids are pressurized out of school post 14 years of age or in the years leading up to it as pressure to de-enrol starts in grade 6 itself.

#### 4.5 Asymmetrical Burden on Parents

The burden of admission, retention, and finding different schools lies asymmetrically on the shoulders of parents. Parents of PwIDD often have to face multiple rejections after finding a school suited to their needs. This is further exaggerated in the case of people who belong to marginalized income groups. Since many integrated mainstream private schools charge hefty fees, their only option is to enrol their child in a government school. More often than not, this is a bargain where parents enrol their child but the child doesn't receive the care or education that they deserve. In this case, parents have to teach their children on their own. Many mothers after witnessing the process, especially from privileged socio-economic groups, take it upon themselves to become a special educator to better cater to the needs of their child.

#### 4.6 Role of Special Educators

Special educators in many schools are seen as a boon for PwIDD since they are trained to properly cater to their needs. Onboarding a special educator is considered to be burdensome and not many schools do it. In 2019, Central Board for Secondary Education (CBSE) mandated for its schools to appoint a special educator but not all boards have such a mandate. Special education as a career option is not lucrative and in most cases people who take it on are related to PwIDD in some way. It is not seen as a viable career option due to the perception that the associated work is more of 'charity' and involves more work for less pay. Further, there are fewer growth opportunities as compared to mainstream teaching. There is a dearth of special educators in the country and parents are the first ones to step in to take charge of this aspect as well.

#### 4.7 Role of School Administration and Teachers

Many people in our primary research mentioned that one of the most difficult barriers in catering to PwIDD needs in schools is school administration. From parents to special educators, everyone has to make a case to the school administration to build a more inclusive system of schooling. School administration is bound to understand the depth of the issue only if they have a personal relation to PwIDD or else they put together less than optimal solutions to the problem of inclusivity, and find ways to bypass the government mandates, as pointed out by a special educator.

The willingness of the school administration to build a nurturing, compassionate, and inclusive school can have a tremendous impact on the lives of PwIDD. This culture flows down into all the stakeholders of the system – the teachers, parents, all students, and the support staff.

Many teachers of private and government schools alike are not equipped to cater to the needs of PwIDD. Not only do schools have a large student to teacher ratio, teachers also feel overburdened and are unable to focus on PwIDD, rather they put in efforts on achieving their target of finishing the syllabus. Many-a-times PwIDD are seen as a hurdle in the eyes of teachers as the ones who distract other students and create chaos in the classrooms. Lack of sensitization towards PwIDD in teachers and school administration has an immense impact on the lives of PwIDD where they have to face bullying, exclusion and in many cases, expulsion. There are many teachers who do seek to tweak their teaching methods to cater to the needs of PwIDD but without the support of the school administration, they often feel helpless.

### **The Shri Ram School: A Good Practice**

*The Shri Ram School (TSRS) presents a good practice showcasing an integrated and inclusive learning environment. A reputed private school located with branches in Gurugram and New Delhi, TSRS is working to make inclusive education a reality. Starting from the top management, there is a keen interest in ensuring that each student feels included and welcome in the school. Along with trained special educators, the school also makes it a point to sensitize other teachers, students, and parents about disability. Students with disabilities enter the early intervention programme or the learning centres where special educators work with the student. Students can transition in and out of the learning centres to the mainstream teaching environments as per their learning abilities and comfort, with the constant support of shadow teachers. The school also has a vocational training centre where students are taught life skills and other day-to-day skills apart from academic learning. The school offers a live example of how it is possible to have meaningful, integrated learning, provided one has the intention and the resources to make it happen.*

#### **4.8 Socialization and Exclusion**

Students get used to being around PwIDD if they are made to socialize from an early stage, reducing the stigma. Many parents and special educators mentioned that young students are more inclusive and do not discriminate against PwD. One parent even mentioned that her daughter with Down Syndrome has made many friends, and many of

them are protective towards her, keeping her away from harm. But this inclusion drastically reduces as children reach teenage, when there are more instances of exclusion and stigmatization. If a school system imbibes the value of inclusion from an early stage in all its stakeholders, this can be avoided. Many parents from privileged socio-economic backgrounds mentioned that the reason why they want to enrol their children in schools is because they want their children to be able to socialize in the real world, as they are expected to when they grow up.

Special schools have their benefits but inclusive, integrated schools help all students to adapt to each other and build the value of inclusivity which they will take forward for the rest of their lives. If PwIDD spend the formative years of their lives in a special school, it becomes difficult for them to adjust to the outside world once they finish school. Similarly, if kids aren't made aware of the needs of PwIDD, they may tend to hold discriminatory views towards PwIDD or simply be unable to relate meaningfully to PwD later in their lives.

#### **4.9 What After School?**

Many parents, often from privileged socio-economic backgrounds, who have found a good school for their PwIDD naturally feel uncertain about the future of their children after they graduate from school. Similarly, parents, from different socio-economic backgrounds who have found special schools and organizations catering to their PwIDD education needs, also, wonder the same. The schools provide a safety net for PwIDD and is arguably the best addressed need out of all the needs for PwIDD. Graduating from school often leaves PwIDD and caregivers at a loss, as there are not many provisions for pursuing higher education for them. They have to enrol in vocational training centres or try to find a job. But the reality is that oftentimes, PwIDD withdraw to their respective homes with their families. This leaves the parents in a lurch as they have to constantly keep charting out the journey of their PwIDD. Each time planning the next life stage is often a cause of anxiety for the caregivers as there are no structured guidelines or systems in place.

#### **4.10 The Impact of COVID-19 and the Digital Divide**

The education system was inaccessible before the pandemic for PwIDD but the pandemic and the subsequent lockdown brought many new obstacles while exaggerating the old. Moving to online education, even though celebrated as a welcome move by many, has further pushed PwIDDs to the margin. People with intellectual and developmental disabilities who are further marginalized due to their class, caste, gender, or location fall on the disadvantaged side of the digital divide. Many PwIDDs are neither able to retain attention in online education, nor are the teachers able to work with them without parental support. The

socialization that PwIDD got in a physical classroom setting is also missing in online learning. Since many PwIDD are not able to keep up with online learning, many parents have taken the tough decision to de-enrol the child. This shift has caused learning lags, behaviour changes, and attention issues for PwIDD. A parent mentioned how her child was not able to cope with online learning, even though she was enrolled in one of the best schools, and will now have to rejoin school after things ease up, losing at least two years of education. She will have to join in the same grade as her younger sister.

Since parents have become the intermediary between teachers and students, many teachers have to rely on parents to make sure the learning materials are reaching the students. Due to this, many concepts are lost in translation since parents are not equipped to become a substitute teacher. Parents in the pandemic have had to struggle with many new issues of their own, be it a different way of working, loss of livelihood, sickness, among many other things and this has added to their caregiving burden. The burden becomes multidimensional when we add the layers of intersectionality of caste, class, and gender. Many parents from marginalized socio-economic backgrounds are not able to aid their children's education because they have to make sure to put food on the table. In India, 26.1 % of students do not have access to the internet at all to attend online classes (ASER 2021). In this dire situation, PwIDD education often takes a backseat causing them to drop out.

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## 4.11 Core Challenges and Need-gaps

*1. There is a clear gap when it comes to trained staff and supportive infrastructure when it comes to accessible learning for PwIDD. Existing schools may enrol PwIDD to meet government regulations, but without the necessary staff and infrastructure, these just become numbers on paper. Private schools who have the resources remain accessible only for those at the peak of socio-economic privilege, while smaller private schools charge higher fees for PwIDD. There is a clear need to revamp the schooling system to become more inclusive and integrated.*

*2. Attitudinal changes are also required for a supportive learning environment. Firstly, schools may not admit students with IDD due to associated social stigma and negative perceptions. Once admitted (which may be after paying a higher fee than other students), educators, peers, or other parents may perceive children with IDD negatively. The social stigma attached to IDD also follows children to the school and makes learning challenging. Hence, there is a need for sensitization of the entire school ecosystem starting with the management. Further, parents may carry academic and professional aspirations for their children with IDD which may not match with the child's interests or abilities.*

*3. Some PwIDD may thrive in vocational skill-based courses while others may enjoy only one or two academic subjects. Their interests, skills, and capacities need to be respected while creating learning plans for them. Parallel curricula like that of the National Institute of Open Schooling (NIOS) can also be built in.*

*4. Most schools do not offer the option of customizing a school leaving certificate based on subject options close to a person's ability and interest. This bars students with IDD from pursuing subject-based academic courses in the future, effectively forcing them to drop out.*

*5. The COVID-19 pandemic has further exacerbated these challenges with the digital divide of the haves and the have-nots that has pushed students out of education systems.*

## 4.12 Recommendations

*Based on research and inputs from various stakeholders consulted during this process, the following recommendations can potentially address the aforementioned challenges in this section:*

*1. Building school infrastructure and adequately training staff is easier said than done. However, there are some solutions which can help:*

*a. Accessibility audits should be made mandatory for all schools to ensure compliance with requirements for inclusive education including admission and service provision as well as access to all accommodations school boards offer to enable right to education for PwIDD.*

*b. Peer mentoring for special educators from established schools offering good practices in this space can help build a stronger and more useful network of special educators.*

*c. The government should incentivize IDD-friendly learning for schools. A ranking system on the basis of how inclusive the environment in the school is may just as well force all schools to perform well.*

*d. Lack of infrastructure and money is a reality that will not change anytime soon. We must find creative solutions to work within our constraints. For example, if children with ASD need structure to function better in schools, it doesn't mean they need a fixed chair to*

*sit on. Some suggestions that came forth from some of our interviewees included even something as basic as a mat or a gunny bag which remains in the same location can help. We need to be creative and have the intent to attend to the needs of PwIDD, with simple gestures such as creating space in corridors for a child with CP for easy movement.*

*2. Changing perceptions is also critical for a holistic learning environment. Special educators can play an intermediary role in shifting parental aspirations to better suit the needs of PwIDD. Further, interaction between PwIDD and other children or young people through groups like Rotaract can benefit all students.*

*3. Peer mentoring and idea exchanges among schools, educators, and caregivers can offer tried and tested solutions for meaningful learning. During the COVID restrictions on in-the-classroom teaching, some sector organizations successfully managed phone-based learning, or hybrid learning models which can be shared with other organizations to facilitate learning.*

*4. PwIDD enrolled in schools should be offered flexibility to pick subjects that suit their ability and interest and the same should reflect in their school leaving certificates, if need be.*

I want to be an artist! I love drawing and painting and my mummy has already started sharing my work online. I wish I could learn more and more things so people pay me money for being good at something and not out of pity.

I don't know what I will do. Everyone around me feels I am good for nothing and will never get a job. My parents keep asking God if I ever will be able to live on my own, be kaabil. I want to earn my own money so they stop seeing me as a burden.



## 5. Finding Meaningful Vocation

The world we live in identifies occupation and vocation as intrinsically linked with financial and social productivity. A person's existence is often justified based on their contribution to society. One of the reasons PwIDD are sidelined from mainstream conversations as they do not fit in these conventional, traditional notions of productivity. The few employment avenues available for PwIDD are largely designed from a charity-based perspective, with the aim to keep them engaged earning small amounts through non-profits. This section presents the challenges faced by PwIDD in finding and sustaining meaningful vocation, as well as some potential suggestions for increasing access to decent work.

### 5.1 Vocation in a Productivity-driven Society

Financial independence and meaningful occupation are critical for an individual's self-esteem and living an independent, sustainable life – not just a dream that many PwIDD and their families carry but also their right. It is also pertinent to note that there are higher instances of IDD from marginalized socio-economic backgrounds (Pal, 2011). It is important for PwIDD to earn a living not just to financially support themselves but also in some cases to support their families. In such a scenario, finding appropriate skilling opportunities and decent work with fair compensation can become an uphill task for a community that is already ignored and often exploited.

It isn't just about keeping PwIDD 'busy', it is about creating opportunities for them to build their skills and engage meaningfully with the world around them. Globally, there is a shift from a charity-based to a rights-based approach for work. The USA has been steadily adopting a rights-based capabilities approach to understanding IDD and

creating opportunities for meaningful engagement for PwIDD (Conrad, 2018). In the UK, PwIDD are working across traditionally mainstream professions successfully and setting new standards of excellence; take, for instance, Councillor Gavin Harding, UK's first mayor with learning disabilities.

Gender and caste play a critical role in access to vocational and employment opportunities. Center for Law and Policy Research in its paper 'The Intersection of Disability and Caste' notes that women, dalits, and marginalized caste groups are less likely to know about and avail the few opportunities provided for PwD due to caste-based social stigma (CLPR, 2020). It can be reasonably extrapolated that even within marginalized PwD, dalits, and women with IDD will face further stigma and exploitation.

### 5.2 The Current Scenario

The PwIDD face many challenges when it comes to finding a meaningful occupation, and many of those challenges are external rather than internal. First, finding access to relevant and suitable vocational training is difficult for many PwIDD, especially those living outside metropolitan cities or coming from marginalized backgrounds. Interviewees have shared that as PwIDD or as caregivers of PwIDD, they are unable to find vocational training options that go beyond making candles and bags. Training options are still designed from a charitable lens rather than something which recognizes and builds on the capacities of PwIDD as individuals. For example, two parents from two dissimilar socio-economic backgrounds shared that their autistic children excel at 'runner' games on the phone. Is there a way to acknowledge and build on the aptitude and skills to offer relevant employment options for PwIDD?

Organizations as employers are rarely open to making minor changes to accommodate people with disabilities because they feel including PwIDD in their workforce will lead to a decrease in output and quality. Changing the mindset of society and decision makers is imperative for enhancing quality of life for PwIDD by helping them procure and sustain a job that utilizes their full potential. Whether it is pick and drop services by IT companies or digital, remote working post-pandemic, if value was attached to having PwIDD on board, it would not be impossible to make inclusive spaces. As stated by one of the interviewees, 'Attitudes go a long way, a longer way than a mandate.'

Another challenge that PwIDD have faced is in the context of sustaining employment. Vocational training alone is not enough to create sustainable employment for PwIDD. It has to be coupled with life skills training which encourages PwIDD to learn tools which can help them manage employment expectations better. Organizations like Jai Vakeel, Muskaan PAEPID, and others are leading the way in creating holistic vocational training programs which imbibe critical life skills as well. More importantly, employers have to create accessible spaces and policies to support PwIDD in fulfilling their work obligations. Sensitization of other employees, adaptive work and leave policies, clear task directions and feedback, mentoring or buddy systems – are just some of the steps that employers can take to ensure an inclusive work environment.

Persons with intellectual and developmental disabilities face stigma within and outside of the workspace and it is incumbent upon employers to prevent and address these issues. Companies like Ernst & Young and Lemon Tree Hotels are leading the way in showing that it is possible for PwIDD to survive and thrive given the right work environment provided organizations have a clear intent to be inclusive. However, it is pertinent to note that these companies are few and far between that recognize the importance and need for diversity in hiring people with varied IDD beyond the neurodiversity spectrum.

Non-profits in the sector have an opportunity to lead the way in this regard. The MBA Foundation in Maharashtra, for example, employs about 40 % PwD, many of whom are alumni of the foundation's various programmes. Employment within organizations can move beyond product making and find new avenues for PwIDD like Cafe Arpan in Mumbai, an initiative of the Yash Charitable Trust. However, it is also imperative that non-profits in the IDD sector themselves believe that PwIDD can and will excel in their chosen work. A self-advocate, currently working as a special educator, shared that they have faced stigma and discrimination even in the special education space where their skills and abilities were doubted due to their diagnosis.

Much of these insights are based on experiences of PwIDD

and organizations in metropolitan cities. In smaller cities, or amongst PwIDD from marginalized gender and socio-economic backgrounds, employment is rarely a choice. If they are able, many PwIDD will engage in some form of work or another but are more likely to be exploited, either by way of getting low wages or menial jobs. There are a few government schemes which offer training as well as employment for PwIDD, as well as reservation in various government jobs but there is a lack of awareness and intent to make these spaces accessible. Limited accessibility has been there but largely for people with physical disabilities and not those with intellectual or multiple disabilities. There is little convergence between the various ministries that deal with training, employment, and entrepreneurship to offer a holistic and systemic approach to vocation for PwIDD. In conversation with a social worker from Nuh, Haryana, a good practice in their area has been to engage with local leaders and build advocacy groups of PwIDD. They are able to assert their right to jobs under NREGA through this strategy.

### 5.3 The Impact of COVID-19

Many people who were trained and placed before pandemic through civil societies, often in the Hospitality industry lost their jobs during COVID-19 with so many of them downsizing or closing down as a result of the pandemic. Many organizations are still trying to get them re-employed. The Covid-19 pandemic brought about many new challenges in terms of employment. As the protocols were stricter, there were numerous changes in the everyday functioning. It is important to note that many people also lost employment for good as jobs went digital, thereby changing the skill set and the ecosystem for performing the job in question.

It is also pertinent to note that even within the disability sector, IDD often finds itself pushed to a corner. For example, the Diversity and Equal Opportunity Center's report on building inclusive work spaces post-pandemic does not mention the specific needs of PwIDD. However, the pandemic has demonstrated different ways of working exist and, therefore, PwD can meaningfully contribute to the hiring organization's mandate in certain cases. For example, working online and working from home have become more like the norm now, but weren't considered strategies for inclusion of PwIDD before COVID-19. This opens up avenues to explore more opportunities to rethink how best to gainfully employ PwD.

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## 5.4 Core Challenges

*1. Currently, there are limited options for PwIDD when it comes to vocation. Few trainings are offered in activities like candle-making or bag making, etc. whether run by NGOs or government agencies. These approach PwIDD employment through a charity-based lens. There is a need to recognize the various capabilities and choices of PwIDD and integrate them into vocational options.*

*2. Inclusive workplaces are possible, as shown by some companies like Lemon Tree Hotels and Ernst & Young. They require effort and intention, but the shift in perception of PwIDD as contributing members of the economy can positively influence policies as well as make aware and sensitize peers and colleagues on the basis of real lived experience of interactions and not a training module they sat through.*

*3. There is a need to build a support ecosystem and market linkages for PwIDD who wish to set up micro-enterprises. Some PwIDD choose to start their own ventures given the dearth of opportunities in mainstream vocations. There is a need for incubation and business mentoring support in order to increase their chances of viability.*

## 5.5 Recommendations

*1. Design vocational courses after exploring the different skill sets and choices of PwIDD keeping in mind the changing world of work. These can be supported by NGOs, private entities, or government bodies.*

*2. More awareness and outreach campaigns for government schemes for employment and training of PwIDD are needed. These reservations and benefits must reach those who need them the most. It is also recommended to explore modes of convergence with various ministries like Human Resource Development (HRD), Micro Small and Medium Enterprises (MSME), and Ministry of Social Justice and Empowerment to create employment and entrepreneurship opportunities for PwIDD.*

*3. Disability inclusive workspaces are possible if the intent is there. Much like policies for physically accessible buildings, policies for PwIDD accessible workplaces need to be designed and disseminated. These good practices should be widely shared.*

*4. Further, there should be awareness programmes and incentives to encourage organizations to create inclusive workspaces. An important aspect towards ensuring inclusivity is to take into account the needs and constraints of caregivers and support them at their places of work.*

My friend's mother started an NGO for children with Down Syndrome and I go there for my therapies. They really care about us like we are their own children but I wish the world outside that NGO was as accepting.

I haven't heard of any NGO in my village. Some social workers come once in a while and play with me but I have never seen their office.



## 6. On the Frontline

Over the last few years, the disability rights movement in India has been instrumental in the legislation of many policies, including the RPwD Act. Many organizations working to address issues faced by PwIDD have been on the frontline of this movement. The sector covers various issues such as Diagnosis, Early Intervention, Education, Vocational Training, Parent Awareness and Empowerment, and other support services needed by PwIDD and their caregivers. Many such organizations are founded and headed by parents or caregivers of PwIDD. The caregivers or the people who have an exposure and connection with PwD set up organizations in response to the gaps they experience with their own ward and others, taking it upon themselves to build a better society for all who face similar issues. This section explores some of the challenges faced by these organizations in addressing the needs of the IDD sector.

### 6.1 Caregivers on the Frontline

The sector has a mix of organizations led by parents or caregivers of PwIDD and people with little or no connection to IDD. The prominence of parent-led or caregiver-led organizations can be potentially attributed to the following reasons:

- a. *Given that there is little awareness about IDD in India, people who are not directly connected with a PwIDD are less likely to be aware of opportunities in this sector to build a career, venture, or social enterprise.*
- b. *There is a need for greater ecosystem support for early-stage*

- c. *organizations, to help models of good practice scale.*

*People connected to IDD are more likely to have the acquired skills and understanding needed to work in this sector and feel these needs more acutely. They have the motivation and, at times, the resources to up-skill to address some of these issues and challenges that impact them and those closely connected to them dearly.*

The research has shown a trend wherein caregiver-led organizations tend to grow to address varying needs of PwIDD, as the needs of the PwIDD in their care grow and change. This motivation and real-time need are often coupled with professional skills and resources which, in turn, can result in a much-needed service to the IDD community.

This approach has its pros and cons. Having a lived experience and understanding of the issues that PwIDD face makes these organizations empathetic towards them and they take extra care in designing and delivering their programmes. They may treat the PwIDD who seek support from their organization as their own children rather than humans with human rights. However, parents who have the energy and resources to set up organizations are more likely to come from privileged socio-economic backgrounds and may devise intervention programmes from their own personal learnings, not always catering to

marginalized socio-economic communities.

Parents, even though trying to provide the best services to their children and also to all other PwIDD who engage and associate with their organization, oftentimes, cannot distinguish between caring for PwIDD and building their capacity to care for themselves. There is a continuous trend noticed among organization heads who call middle-aged and adult PwIDD as 'children'. This perception hampers the rights-based disability movement as it questions the capabilities and potential of PwIDD. This is also one of the reasons why it has been seemingly difficult for this sector to move from a charity-based lens to a rights based lens. Many heads of organizations are of the belief that since PwIDD cannot vouch and advocate for themselves, they have to do it for them and their children. Even though in severe and profound cases of disability, this might stand true, IDD is not a homogenous category of disability. This belief undermines the agency of PwIDD in voicing their own needs and desires. Looking from a parental lens, it is bound to have certain gaps between the perceived needs and the actual needs. As a special educator and PwIDD self-advocate, mentioned, 'people who start services after realizing their child's or sibling's needs and cater to them, aren't specialists. They don't have the expertise required, they learn on the fly and hence miss the mark in some ways.'

That said there is also a need to change the perception of this sector as a professional space. People who work here, especially those who come with personal connections, are sympathized with or put on a pedestal rather than being treated as professionals. It is pertinent to note that many parents and siblings interviewed for this report have spent time in building their professional skills and running organizations that cater to the needs of hundreds or thousands of PwIDD. These are not just family-run organizations, but sector leaders who have successfully advocated for the needs of PwIDD.

## 6.2 Profession or Social Work?

There is a dearth of professionals who are dedicated to this sector. Many people don't see this as a meaningful career if they do not have a personal experience with IDD. Work in this sector is considered to be charity and not professional work by many in the outside world. As a head of the organization said, 'Other issues you can still empathize with, be it gender or poverty. They're omnipresent, and hence easier to understand. Issues like IDD are so isolated from the rest of the world that people get uncomfortable with even volunteering.' A few organizations, in their quest to try to change the perception of people, have started volunteering programmes after partnering with schools and colleges. They acknowledge that this might not create a lasting impact but is the first step to destigmatize the perception of PwIDD, so that people start seeing them as

humans just like any other person, and understanding that they're no different from the others and that their lives matter too!

There are people who work in the sector without any personal experience with disability. If they are at a management position, they boast of bringing a systemic, rational, or devil's advocate view to the issue, adding that they are more prone to looking at it objectively and thinking about scaling up. Other people who join the sector without a personal connection to disability look at it as a regular job like any other. They find a sense of purpose in working in the sector and derive moral goodness through this work, especially if they get recognition from others around them – be it family, friends, or neighbours. Many organization heads mentioned that it might not be a necessity for people to join this sector only for personal reasons, but those with a personal connection might be more likely to stick around in the long run. For professionals who seek to work in this sector, there are a few hurdles to cross because of the vetting system of the organizations. Many heads of sector organizations tend to not hire people who don't have a personal connection with disability as they feel a compassionate understanding can only come through lived experience. Lack of adequate funding and, therefore, fair compensation, coupled with many hours of hard work are among the other reasons this sector does not attract a lot of people. It is, however, pertinent to note that, howsoever few in number, people who are not directly related to PwIDD but work in the sector as professionals are more likely to consider PwD as adults and acknowledge their agency. This brings an objectivity in problem-solving and a rights-based approach to addressing the needs of PwIDD.

## 6.3 Concentration in Metropolitan Areas

Almost all organizations catering to the needs of PwIDD are concentrated in metropolitan cities. Even though some of them cater to the needs of all classes of people, especially the needs of PwIDD from marginalized socio-economic backgrounds, the physical location of these organizations restricts access for many. Lack of awareness and stigma are already existing barriers for many people, not having a supporting ecosystem with services and resources even betrays parents who want to make sure their child lives with dignity. The reach of these organizations often is limited to urban areas. This is in contrast to data which suggests many people with disabilities live in rural areas and towns. This asymmetrical distribution of resources and services excludes many people from asserting their right to live with dignity as accessing education, healthcare, and information becomes difficult for them. It puts added pressure on caregivers, especially those from marginalized socio-economic backgrounds to cater to the needs of PwIDD. In a quest to provide appropriate care to their child, many caregivers consider relocating and uprooting themselves from their existing lives.

Since many organizations are founded and run by parents who come from privileged backgrounds and urban areas, the organizations led by these parents are concentrated in metros as well. Those from marginalized socio-economic backgrounds may not initiate such efforts, or join existing organizations in leadership roles in order to bring their unique perspectives and needs to the forefront. However, some organizations are branching out to reach more people from marginalized backgrounds like Caritas India, Vidya Sagar, Samarathanam, AADDIT Charitable Trust, MBA Foundation of India and others.

## 6.4 Core Challenges

**1. Funding constraints:** Many organizations shared that they struggle for funds for a clearly underserved sector. They do not always meet the criteria of funding organizations who may not be familiar with the needs of PwIDD or wish to see quick impact. There may be less defined markers of an input–output–outcome benchmarks, unlike in healthcare and education, which may impact funds flowing into this sector. Further, the perception that PwIDD cannot give back to the society may have also influenced the funding of this sector. The scale of unmet needs requires more support to scale existing models that work and seed new models to protect the rights of PwIDD.

**2. Trained human resources:** There is a huge dearth of trained professionals in the sector as working in this sector is not seen as a profession, but rather a charity. The stigma attached to disabilities also stops people from working in this sector. Nature of work, as described by an organization head, is time consuming with relatively low pay which further discourages people from seeking jobs here. Trained professionals are also only possible if training programmes are available. Mainstream educational institutes rarely have courses focused around IDD or related issues and needs.

**3. Scaling and reaching rural areas:** Because the work is extensive and professionals are limited, the sector is constantly fighting fires. Scaling and expanding to rural areas require funding, expertise, and dedicated professionals for capacity building much beyond the bandwidth of these organizations. Further, providing incentives and resources to people from rural areas or marginalized communities is needed to bring their concerns forward.

**4. Disconnect between organizations:** Some heads of organizations reported that organizations in this sector mostly work in silos, being largely disconnected from each other. There currently exist no formal associations, forums, or platforms where these can come together and work collaboratively instead of individually and learn from each other's successes and failures.

**5. Need for introspection:** There is a need for self-reflection within the IDD community. The organization heads along with self-advocates and caregivers reported that the civil society needs to think about:

- a. how to work together;
- b. how to build an intersectional approach; and
- c. how to move to a rights-based framework, question their own assumptions and biases.

## 6.5 Recommendations

**1. The foremost need for this sector is increasing awareness about IDD. Understanding PwIDD, their needs, and lived experiences will facilitate education of the wider ecosystem and generate social interest in the sector.**

**2. Many of the core challenges faced by organizations, as well as PwIDD, can be addressed with the formation of a collective of organizations. This collective can offer space for larger and smaller organizations to work together, highlight the need for funding and resources in underserved spaces, exchange ideas and learnings to improve services, as well as advocate for policy-level changes for PwIDD. This is also a way for bringing more professional and skilled personnel to bring new ideas and approaches to address the needs of PwIDD.**

**3. Increased funding and capacity building for sector organizations is the need of the hour. This can be achieved through multiple avenues like offering incentives to private companies for directing CSR funds towards the IDD sector, using media to generate awareness about organizations in the sector, etc. Funding is directly linked to increasing the reach of these organizations and capacity building.**

I'm not sure where I will stay when I grow up. My parents don't want my brother to be burdened so they have set up a trust fund for me. But I don't know if I will have any friends to stay with me.

My parents are not thinking about this too much. My siblings and other relatives are around and hopefully, will be happy to take care of me. I wish I could take care of myself.



## 7. 'What After Us?'

One of the most commonly asked questions by parents and caregivers of PwIDD is, 'what after us?'. The looming question takes a central space in the lives of the caregivers of PwIDD who require lifelong care and support. Many parents from urban areas that were interviewed for this research shared that they worry about how their child will be taken care of once they and the PwIDD are older. Various needs emerge as adults for PwIDD, be it the need for companionship, finding meaningful occupation, or health-care concerns, etc. This need may look different in rural areas or tier-2 and tier-3 cities where the nuclear family set-up is not as prevalent as in metropolitan areas. This section elaborates the challenges keeping these needs in mind while exploring opportunities to live like adults for PwIDD, particularly in the urban metropolitan context.

### 7.1 The Living Arrangements: Possible Options

In India, there are limited options when it comes to long-term care for PwIDD. These are new and emerging needs that are relevant, given the societal evolution for this demographic, a key shift being the emergence of the nuclear family. The most common options include either depending on other family members like siblings or finding residential-care facilities. Some interviewees shared that they have either left this responsibility on siblings or other family members while certain others shared that they are exploring avenues which do not create a burden on their other children.

Both options come with their respective challenges. Siblings or other family members may not be able to care for PwIDD given the constraints of their own lives. A barrier to independent living can also be in the perception of seeing PwIDD as 'children' even after they reach adulthood. Infantilizing PwIDD and not recognizing their inherent capabilities to choose for themselves hinders their growth as adults.

Residential-care facilities are rare and concentrated in or around metropolitan cities. A large number of these are initiated by parents of PwIDD or parent-led organizations to

address an evident gap in the landscape. These facilities also work best if PwIDD shift there earlier in life to ease adaptation. Parents often wait till they and PwIDD are much older to shift and this can create preventable challenges for PwIDD to settle into new routines. These facilities may also be prohibitively priced making them inaccessible for people from non-upper-class backgrounds. Very few organizations, such as the GODS MBA Foundation in Maharashtra, offer long-term care to those from marginalized backgrounds but these organizations are few and far between. The government also offers some limited options through the National Trust's Gharaunda Scheme and state shelter homes.

A new option of assisted-living facilities has come up in the last few decades. These facilities offer more independence than residential-care facilities and are designed to encourage independent living with community support structures in-built keeping in mind the requirements of PwIDD. As intentionally designed accessible spaces, these can offer avenues for companionship and friendship with other PwIDD as well.

## 7.2 Core Challenges

*1. A big challenge to create inclusive living spaces for adults in the PwIDD sector is the lack of affordable facilities. Currently, the few governmental and non-governmental organizations running care homes are limited in their capacity while others are largely unaffordable for a majority of PwIDD. This is an emerging need and is expected to grow in the coming years with a shift in family structures and parental perceptions.*

*2. It is also critical to look beyond just having food and shelter as 'adult living'. These homes are only homes if they offer space for holistic development and support for adult PwIDD. Along with homes, there is also a need for more service providers catering to the needs of adult PwIDD. While many organizations cater to the early needs up until vocational training, PwIDD needs do not end with finding a vocation. As adults, and also as seniors, PwIDD needs change and evolve and, therefore, need greater attention.*

*3. There is a need to develop avenues of self-advocacy, caregiver advocacy, and government perceptions around PwIDD and their care. This can be achieved through capacity building and learning exchanges between other countries who have established such models. For example, the UK has a National Care Association to advocate for the right to assisted and supported living, especially in policymaking. The Australian government also funds support services like care attendants and living facilities for PwD. Similar initiatives can be taken up in India to address the need for better facilities for adult PwIDD.*

## 7.3 Recommendations

*1. Residential and long-term care facilities for adult PwIDD require land and resources. Funding for these facilities, especially given that not all PwIDD will be financially self-sufficient, is critical. Increase in government funding or private funding would be able to make this a reality for PwIDD.*

*2. Building sector capacity by training professionals as also establishing a variety of training models at various price points. Building capacities of PwIDD so as to help them live independently as adults will go a long way in addressing this challenge. Parents can be encouraged to work towards helping their wards learn critical life-skills early on.*

The pandemic was really hard. I hated staying at home and Kavita didi had to leave because her husband got COVID. At first I couldn't understand it but I guess I am used to it now. Papa is home more often so at least I can play with him sometimes.

My papa lost his job and my eldest brother had to stop studying to help with money. It's very hard to stay like this and my family also does not know what to do. They are so stressed all the time and that makes them more annoyed towards me.



## 8. The COVID-19 Pandemic and IDD

The COVID-19 pandemic has been challenging for our society as a whole. The unpredictability of the virus drove the countries into harsh lockdowns with digital life becoming a norm. People who were already at the margins were pushed further out, and relief policies continuously overlooked them. People with disabilities, especially people with IDD, were disproportionately affected due to the pandemic and the added layers of caste, class, gender, economic status, and geographical location further impact the lives of PwIDD.

The pandemic has also shone a light on the gaps that already existed when it came to the IDD community. This section brings together these needs that were exacerbated due to the pandemic by looking at some opportunities for the civil society, self-advocates, caregivers, and the government to build a better ecosystem for PwD.

### 8.1 Increased Risk for PwIDD

Studies reveal that intellectual disability is the second biggest risk factor for dying from COVID-19. Those with intellectual and developmental disabilities are 2.5 times more likely to contract COVID-19, 2.7 times more likely to be admitted to a hospital, and 5.9 times more likely to die from the infection than the general population. Despite this information, there were no provisions made for PwIDD to get vaccines on an urgent basis, there were no guidelines for the caregivers to follow. Even as the second wave soared, the vaccine was not prioritized for PwIDD. This put the families through a lot of helplessness and anxiety, and restricted their movements multifold. PwD from marginalized backgrounds who were disproportionately impacted by COVID-19 also experienced further marginalization.

### 8.2 Lack of Access to Traditionally Available Services

The lockdown pushed everyone inside homes and restricted the availability of services. Many centres were shut in the first lockdown, putting constraints on early intervention, therapies and other services for the PwIDD. Many caregivers reported that their wards' behaviour became erratic and their progress suffered a steep fall.

Further, healthcare became inaccessible for many as going to a hospital itself put PwIDD at risk of contracting COVID-19. PwIDD's socialization was already relatively restricted pre-pandemic, but the limited spaces they had for socialization were made unavailable post the onset of the pandemic.

### 8.3 Impact on Education and Employment of PwIDD

Education for PwIDD is already a challenging process. PwIDD need well-designed learning plans and strategies that cater to their specific needs, ideally with a small student to teacher ratio to facilitate learning outcomes. This was as it is tough to deliver in the absence of adequately designed digital tools needing greater support from parents or family members. Some PwIDD found it difficult to learn in digital environments as teachers were also not able to engage them as needed. The pandemic has caused attention deficit, learning lag, and drop outs across the socio-economic spectrum for PwIDD. PwIDD who belonged to marginalized socio-economic backgrounds did not have access to digital devices further excluding them from the evolution of the world.

In vocations, many PwIDD who were placed after receiving

training from various organizations lost their jobs with the onset of the pandemic. Those who received training from organizations had to stop abruptly and may have lost their hard-learned skill sets. Further, those involved in jobs that required physical attendance have had a more difficult time in returning to work with the COVID norms in place. The impact of this loss of independence, occupation, and income is yet to be calculated.

#### **8.4 Lack of Inclusive Policy Making**

Knowing that PwIDD were at risk of contracting COVID-19 and are heavily dependent on many services and resources available outside of their immediate surroundings, the policymakers responding to COVID should have taken into account the needs of people with IDD. The lockdown disrupted the routine of PwIDD with no provisions for them to access services of therapy and other forms of caregiving in the lockdown.

The vaccine dissemination also ignored taking into account PwIDD who were at high risk. The systems of vaccination were also not designed for people who were disabled and they had to follow the process the same as their non-disabled counterparts. Furthermore, some PwIDD found it difficult to understand COVID-19 and the related restrictions. While PwIDD have largely been an afterthought in most policies, if at all they find mention, it is critical that during times of crisis the most vulnerable are taken care of first rather than last.

#### **8.5 Impact on Sector Organizations due to COVID**

Many organizations had to shut their centres and move to online modes for reaching their beneficiaries. Organizations struggled to reach their beneficiaries but many developed innovative online programmes to cater to the needs of PwIDD during the pandemic. Given the unpredictability of the pandemic, there is uncertainty about what kind of programmes to develop in this context. Some organizations have found innovative models like phone-based learning or digital hybrid models, while others shut down completely. Those interviewed shared varied responses about reopening their doors, with some organizations believing that the old models would be revived after COVID, and others choosing to retain hybrid models for the future.

Funding was also impacted for organizations. There are some reports that funders diverted money to organizations actively working on COVID-related problems. Attendance in organizations was impacted, with many PwIDD dropping out due to pandemic restrictions or loss of family income. Some families of PwIDD left cities to return to their hometowns which abruptly ended PwIDD access to intervention and services. Because of these reasons, learning and socialization came to a halt in many cases and there were reports of PwIDD feeling increasingly isolated and vulnerable.

## **8.6 The Impact of COVID-19 Exacerbating Existing Gaps**

*The COVID-19 pandemic has laid bare the gaps in the systems while exaggerating many others and introducing new ones. Existing challenges in diagnosis, certification, education, employment, and caregiving were intensified. There was a disproportionate burden on parents and caregivers that increased anxiety around the most critical question, 'What after Us?'. Further, the pandemic has also shown that PwIDD need to find prominence on the national agenda. Access to critical services was stopped, with no clear alternative arrangement for PwIDD, leaving parents and caregivers scrambling again. Sector organizations, which cater to various needs of PwIDD to support the government's mandate are in need for greater support. While these gaps are only representative of the countless challenges faced by PwIDD, it is hoped that these can be turned into opportunities when civil society and government build the world back.*

# Key Recommendations

This report is an attempt to highlight the various facets, gaps, and challenges that exist through the various life stages of PwIDD and their caregivers. The COVID-19 pandemic has not just brought on daunting new challenges, it has also magnified those that existed, bringing to the fore the already glaring gaps in the IDD ecosystem. In this section, we offer some overarching recommendations for the government, sector organizations, and the rest of us who comprise the Indian society to consider.

## 1. Convergence between government departments and agencies:

Starting from the definition of IDD, to the various terms used for different disabilities, to overlapping schemes and benefits, there is a need for government agencies to speak the same language. Further, bringing various government representatives together to holistically address the needs of PwIDD will have a more powerful impact on the lives of PwIDD. For example, education for PwIDD is not just for the Ministry of Social Justice and Empowerment (MSJE) to consider, but together with the Ministry of Women and Child Development (MWCD), Ministry of Health and Family Affairs (MHFA), and the Ministry of Education (MoE) to address the needs of PwIDDs for accessible education. For employment and skilling, convergence between MSJE, MoE, Ministry of Skill Development and Entrepreneurship, Ministry of Corporate Affairs, and Ministry of Micro, Small and Medium Enterprises, etc., is needed.

## 2. Strategic Advocacy:

To ensure that PwIDDs are not left behind, and their rights translate meaningfully in real life, it is critical that the sector advocates strategically. Coming together and advocating as a group is far more effective than working in small pockets. A network or collective of organizations, parents, PwIDDs, and other stakeholders should be formed which have better potential of providing solutions that can be scaled collectively to address the most pressing needs of the community, in addition to making their voice heard in various forums and larger platforms.

## 3. Role of Tech:

### a. Capacity Building through Tech:

There is a need for capacity building and training for various stakeholders in the IDD sector. Using emerging technology, it is possible to explore low-cost and accessible training opportunities for PwIDD, their caregivers, educators, medical fraternity, and others.

### b. Resource Building through Tech:

It is also suggested to create trusted sources of information as public goods freely accessible by all.

## 4. Exploring Market Opportunities:

An estimated 35 million households make up the sector where the needs of individuals in various roles and capacities remain underserved. This presents a significant market opportunity for social enterprises and for-profit ventures, yet this sector remains populated by civil society and individual service providers (therapists, educators, and caregivers). It is worth exploring how one could cultivate a market-based ecosystem.

## 5. Acknowledging the Intersections:

IDD is not homogenous. It is impacted by various intersections like class, caste, gender, geographical location, and economic status. Those from marginalized socio-economic backgrounds, living in non-metro cities, are more likely to have greater challenges when it comes to addressing their needs. There is a need to consciously recognize and work towards bridging these gaps.

## 6. Further Research:

There is a dearth of data and research on IDD in India, and whatever little exists is marred with contradictions. Further research backed by facts, evidence, and data is required for fully understanding where we are, and finding ways to move forward and build an inclusive, sustainable ecosystem for PwIDDs. Suggested areas for further research include but are not limited to:

- Needs of PwIDD in various contexts in India, particularly as adults
- The gender-centric nature of caregiving and its consequences
- Mental health of caregivers and PwIDDs
- The potential and efficacy of assistive technology and tech-enabled solutions for PwIDD
- Intersections of gender, caste, and class with respect to IDD

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