COUNT ME IN

Building an inclusive ecosystem for persons with intellectual and developmental disabilities

Bank of America

dasra

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Dasra meaning 'enlightened giving' in Sanskrit, is a pioneering strategic philanthropic organization that aims to transform India where a billion thrive with dignity and equity. Since its inception in 1999, Dasra has accelerated social change by driving collaborative action through powerful partnerships among a trust-based network of stakeholders (corporates, foundations, families, non-profits, social businesses, government and media). Over the years, Dasra has deepened social impact in focused fields that include adolescents, urban sanitation and governance and has built social capital by leading a strategic philanthropy movement in the country. For more information, visit www.dasra.org

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GLOSSARY

AW - *Anganwadi* worker (community-based worker)

ASD – Autism Spectrum Disorder

CBOs – Community-based organizations

CBR – Community-based rehabilitation

CP – Cerebral Palsy

ID - Intellectual Disability

IDD – Intellectual and Developmental Disability

PwD – Person with Disability

PwD Act – Persons with Disabilities Act

PwIDD – Person with Intellectual and Developmental Disability

RCI – Rehabilitation Council of India

RPwD Act – Rights of Persons with Disabilities Act

SSA - *Sarva Shiksha Abhiyan* (Education for All)

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities

Foreword

People with intellectual and developmental disabilities (IDDs) routinely face discrimination and are denied basic dignity in India. This report, Count Me In: Building an inclusive ecosystem for persons with intellectual and developmental disabilities, delves deeply in to the issue and shows how we might address it.

The numbers are alarming. Up to 3% of India's 1.3 billion population lives with some form of IDD. Over 12% of Indian children aged 2 to 9 years have neuro-developmental disorders. As they grow older, they are stigmatized and are considered less deserving of education and employment. This impacts their ability to achieve their full potential.

It is clear that changing public attitudes towards disability will require effort by the government, the private sector and non-profit organizations. To address the problem, the report recommends a multipronged approach:
· Bring to the public's attention the issues faced by people with IDDs
· Enable self-advocacy by people with IDDs
· Promote a family-centered approach
· Provide enhanced adult support services

The findings of this report reflect Bank of America's global commitment to diversity and inclusion. As a company, we look to advocate for employees with visible or hidden disabilities and invest in their success.

As part of this effort, we support U.S.-based non-profit Skookum to hire people with disabilities to perform logistics and facilities management. Skookum today employs more than 1,200 workers with some form of disability who jointly manage inventory worth US$750 million. We have also been a long-term partner of the Special Olympics, helping give athletes the power to achieve their goals. Complementing these initiatives is our global 7,000+ employee disability advocacy network, which acts as a valuable source of support and information for our employees and their children, friends and colleagues with disabilities.

Our experience in disability advocacy and understanding of the extent of the problem in India encouraged us to work with Dasra to create this thought leadership piece. Our hope is that readers like you will join in the effort to address the issue.

Working together, let's strive to build an ecosystem for people with IDDs in which everyone has access to education, employment and opportunity, and where the social stigma attached to disability is overcome.

Kaku Nakhate,
President and India Country Head,
Bank of America

EXECUTIVE SUMMARY

Inclusive development holds the key to India achieving its commitments under the Sustainable Development Goals (SDGs) by 2030. The term 'inclusive' refers to a rights-based expansion of India's development paradigm – one that will create opportunities and conditions for each individual to live with dignity, to achieve his/her potential and to thrive, irrespective of any perceived disadvantages at birth.

One group that continues to be excluded from India's mainstream development narrative is the community of persons with intellectual and developmental disabilities (PwIDDs). In India, despite laws that recognize and protect their rights, PwIDDs are regularly mistreated and denied basic human dignity. They are stigmatized and widely considered less deserving of opportunities for education and employment. This in turn impacts their ability to access the prospects, privileges and resources they need to achieve their full potential. The report "Count Me In: *Building an inclusive ecosystem for persons with intellectual and developmental disabilities*" aims to break this cycle by changing the way India perceives intellectual and developmental disabilities altogether.

The report approaches this issue using the social model of disability. As per this model, disability is less a medical condition and more a social one, wherein social barriers such as prejudice and inaccessible infrastructure affect the ability of PwIDDs to participate in society. Using this framework, the report places PwIDDs at the center of its approach to understand the challenges they face across various life stages. It identifies key gaps in services and highlights the following strategic areas for investment and action to enable effective inclusion of PwIDDs:

Birth and Early Intervention:
Strengthen timely identification and family centered early intervention services

Education:
Equip educators with teaching strategies to cater to PwIDDs' needs

Employment:
Create employment opportunities and conducive work environments for PwIDDs

Sector Support:
Drive awareness and advocacy using evidence-based research

On the ground, non-profit organizations are trying to address these gaps through eight distinct interventions, ranging from the provision of diagnostic services to advocacy for legislative change. The report profiles ten outstanding non-profit organizations – Action for Autism, Bethany Society, Indian Institute of Cerebral Palsy, Jai Vakeel Foundation, Latika Roy Memorial Foundation, Muskaan, Rajasthan Mahila Kalyan Mandal Sanstha, Satya Special School, Ummeed Child Development Center and Vidya Sagar.

One key takeaway of the report is the apparent dependency on non-profit organizations to access even basic rights such as education and healthcare. It brings forth both the intense need and the absence of comprehensive systems and institutions across the country to address the needs of PwIDDs in a cohesive and structured manner.

This report, situated in the wider context of the growing momentum around disability rights, thus shines a spotlight on a traditionally underserved sector. It also gives us an opportunity to challenge societal attitudes towards disability and work towards inclusive development using targeted investments and collaborative approaches.

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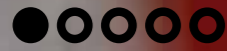
UNDERSTANDING INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

"Some children just take longer than others", the physician assured three-year old Aruna's parents. She had not said a word since her birth, and her parents had brought her for an initial examination to the primary healthcare center in their village in Uttarakhand. Without the money or access to a second medical opinion, the family returned home, hoping that Aruna's condition would improve as she grew older. But the situation only worsened with time: at age four, she was still having trouble speaking, was not toilet trained and was prone to regular, violent outbursts. Driven to desperation, her parents sought the advice of a neighbor who suggested that they send her to a traditional healer. The healer proclaimed that Aruna had been possessed by evil spirits and used a hot iron to drive the spirits away from her limbs and brain. When her parents returned to take her home, they found the four-year old child lying motionless outside the hut, with second degree burns all over her body.

While Aruna's story is a particularly extreme case of mistreatment, persons with intellectual and developmental disabilities (PwIDDs) have historically been denied the dignity and value attached to the status of being human.[1] Across the world, PwIDDs are stigmatized and widely considered less deserving of opportunities for education and employment. The negative social perception of persons with disability (PwDs), including those with intellectual and developmental disabilities (IDD), is pernicious and detrimentally affects their life outcomes. While limited data exists around PwIDDs, experts claim that they experience greater marginalization and higher rates of poverty than persons with other disabilities.

"

"Society has warped expectations from PwIDDs; they must be exceptional in some way, as if to make up for their disability, in order to be considered worthy. Awareness and sensitization is key to changing this narrative." [3]

– Merry Barua, Founder, Action for Autism

The World Bank Group estimates that India has anywhere between 40 and 80 million PwDs, yet 45% of them are illiterate and over 70% are not part of the labor force. [2]

A History of Neglect

With the dawn of the industrial revolution in Europe in the 19th century, a person's ability to participate in the labor force decided his/her value in society. As PwIDDs were perceived to be less capable of contributing to the economy, they were neglected by their families and not viewed as productive members of the community.[4] Scientific approaches such as Darwinism that emphasized the 'survival of the fittest' also reinforced this attitude. This justified state efforts to segregate 'feeble minded' persons from mainstream society.[5]

This shift in attitude also influenced practices in India. We moved away from 'community-inclusive' support for PwIDDs, which existed before colonization, to institution-based support through 'asylums' in the early 1900s.[6]

> It seems as if the life of an individual with an intellectual disability has been viewed as less valuable than the life of a non-disabled person, lacking in fundamental equality and moral status significance.[7]

Where We Stand Today

Due to the concerted efforts of academics and disability activists alike, the dialogue around disability has moved far away from theories of ableism and segregation. Decades of work to change attitudes and approaches towards PwDs has brought the concepts of diversity, equity and inclusion to the forefront of the disability discourse. Close on the heels of the international decade of disabled persons (1993-2003), in a watershed moment in the history of global disability rights, the United Nations ratified the Convention on the Rights of Persons with Disabilities, 2007 (UNCRPD). This treaty finally recognized the inherent rights of PwDs and the need for an inclusive world that protects these rights.

Deciphering Disability

Disability is an umbrella term that covers a range of experiences

Impairments:

problems in body function and structure

Activity limitations:

difficulties in executing tasks or actions

Participation restrictions:

problems experienced in involvement in life situations

-**World Health Organization**

In the last decade, India has made significant headway in protecting disability rights. It passed a law on the Rights of Persons with Disabilities (RPwD) in 2016 to uphold its commitments under the UNCRPD. The Government of India launched the 'Accessible India Campaign' in 2015 and even directed the Indian Railways (India's largest public-sector employer) to conduct a recruitment drive for PwDs, through which it hired 4,000 PwDs.[8] And yet, since PwDs are not a homogenous group – persons with certain kinds of disabilities continue to experience greater marginalization than others. For instance, while individuals

with sensory impairments can advocate for their rights, the stigma associated with, and ignorance regarding, persons with multiple disabilities make it far more challenging for them, leading to extreme marginalization and isolation. Growing momentum around disability rights gives us an opportunity to improve outcomes for PwIDDs and to empower them.

What is Intellectual and Developmental Disability (IDD)?

There is no conclusive definition of 'intellectual disability' within the sector. For instance, while the Diagnostic and Statistical Manual of Mental Disorders distinguishes between intellectual disability (ID) and autism spectrum disorder (ASD), the RPwD Act, 2016 includes autism within the purview of ID.[9] Furthermore, while service providers often club cerebral palsy (CP) with intellectual disability because there may be an overlap in the support they require, persons with CP do not experience any intellectual disabilities per se. For the purpose of this report, therefore, we are considering Intellectual and Developmental Disabilities collectively.

Developmental Disability:

A delay in sensory, cognitive, social, emotional or communication development is known as a developmental disability.[10] Such disabilities appear before the age of 22 and could involve physical disabilities such as blindness from birth and/or intellectual disabilities like Down's Syndrome.[11]

Intellectual Disability:

It is a condition characterized by significant limitation both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (which covers a range of every day social and practical skills).[12]

This grouping by no means discounts the differences between each of these disabilities or the varying levels of support that are needed by individuals with mild, moderate and severe disabilities. However, experts differ on which conditions fall under the umbrella of intellectual disability – it is both difficult and outside the scope of this report to advocate one interpretation over another, or to attempt to unify the different categorizations of disabilities. Considering intellectual and developmental disabilities together also helps to highlight the expanse of an issue that is widely prevalent and yet strikingly underserved.

This report specifically addresses four intellectual and developmental disabilities that echo the focus areas of the National Trust, set up by the Ministry of Social Justice and Empowerment, Government of India: **Autism Spectrum Disorders**[A], **Cerebral Palsy**[B], **Intellectual Disability and Multiple Disabilities**[C].

A: Autism spectrum disorder refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication.

B: Cerebral palsy refers to a group of disorders that affect movement. It is a permanent, but not unchanging, physical disability caused by an injury to the developing brain, usually before birth.

C: Individuals with several different disabilities, such as difficulties in learning alongside hearing or vision impairments, are said to have multiple disabilities.

The proportion of persons diagnosed with intellectual disabilities in urban areas as compared to rural areas is 243:100, indicating that many PwIDDs go undiagnosed and lack access to adequate support or services in villages.[13]

Differentiating between IDD and mental illness

WHO defines 'mental health' as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, work productively and is able to make a contribution to his or her community.[14] Therefore, mental illness refers to disorders that affect an individual's feelings, behaviors and perceptions, whereas IDD refers to conditions that affect cognitive, sensory and/or motor functioning.

Research indicates that mental health issues are more prevalent in PwIDDs than those without IDD. In fact, adults suffering from intellectual disability are twice as likely to be prone to co-morbid[A] psychiatric conditions such as depression and psychotic episodes.[15]

> "Diagnosing mental health issues in children with intellectual disability is still very much a grey zone. There are certain recurrent dual diagnoses, such as intellectual disability with psychosis or behavioral issues and autism spectrum disorder with obsessive-compulsive disorder. But for children with moderate to severe intellectual disabilities, accurately identifying depression or anxiety is extremely challenging. For persons with developmental disabilities like cerebral palsy, where the IQ remains unaffected, diagnoses of mental health issues are more common, and they need the right kind of support and therapy. Unfortunately, therapy culture, through counselling or group therapy, is lacking in our country and initiatives such as the Aditya Birla Integrated School and Mpower are trying to bridge this gap."
>
> - Mrs. Neerja Birla, Chairperson, Aditya Birla Education Trust

What causes IDD?

Causes for IDD range from genetic conditions to environmental factors such as pre and post-natal exposure to alcohol, toxins and infections that affect brain development. It is difficult to definitively diagnose an individual with intellectual disability before he/she reaches the age of four. However, it is possible to identify developmental delays that indicate that the child is likely to have such a disability. For instance, if a child fails to recognize and smile at his/her mother within the first four months of his/her birth, parents should be alerted that the child could be diagnosed with intellectual disability in the future.[16]

A: In medicine, comorbidity is the presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder.

> " "The most cherished component of the UNCRPD is that it makes living in the community a right, a human right for everyone including those with disabilities. You will rarely find provisions in a national constitution or international convention that treat living in the community as a human right and fundamental freedom."[17]
>
> - Bhargavi Davar, Founder, Bapu Trust

Who is affected?

While India lacks up-to-date prevalence and incidence data[18], currently available estimates indicate that about 1%–3% of the Indian population has intellectual disabilities.[19]

Some independent studies go so far as to suggest that one in eight children between the ages of two and nine years has a neuro-developmental disorder.[A, 20] What most research has conclusively shown, however, is that low-income communities and children living in poverty are disproportionately affected by neuro-developmental disorders.[21] One study calculated that in developing nations, 200 million children under the age of five do not reach their developmental potential because of poverty, malnutrition and high rates of infection.[22]

Why focus on IDD now?

While a significant proportion of these 200 million children reside in India, unless we act now, they will spend their lives without access to basic human rights. Here is why it is the right time to take a stand for PwIDDs:

○ **The Rights of Persons with Disabilities (RPwD) Act, 2016:** This critical legislation replaces the Persons with Disabilities (PwD) Act, 1995 and represents a paradigm shift in the nation's attitude towards disability. It recognizes 21 categories of disabilities, as compared to the seven categories previously identified under law. It also takes a holistic approach to disability rights and recognizes social, economic and political rights and freedoms of PwDs, in line with the UNCRPD. Legally, the Act provides 1% reservation for the intellectually disabled in government jobs in addition to the 1995 Act's provisions, which were largely for the physically disabled. The Act provides interested parties with an opportunity to mainstream issues of IDD to reach key decision-makers and to ensure sensitization of the wider audience.

○ **Inclusion of disability in the Sustainable Development Goals (SDGs):** Disability is an integral part of the Global Sustainable Development Agenda, which refers to PwDs in the goals on education, employment, reducing inequalities and inclusive cities. It is important to capitalize on this international momentum towards inclusion and advocate for disability rights.

> " "As a society, we need to redefine normalcy. We are focused only on educability and ambulation – so people who have needs that fall outside that frame are considered abnormal. We need to arrive at a place where everyone is regarded as normal. Everyone should have the opportunity to use their unique abilities productively and be well integrated in society." [23]
>
> - Dr. Suneeta Singh Sethi, Director, Amrit Foundation

Both the RPwD Act and the SDGs place PwDs squarely at the center of their approach and recognize the social model of disability. This model proposes that disability results from the interaction between persons with impairments and external barriers that hinder their participation in society.[24] Instead of looking at disability as a medical problem alone, this approach places the onus on the supporting environment and community to ensure that PwDs' rights are upheld.

A: Neurodevelopmental disorders are disabilities associated primarily with the functioning of the neurological system and brain. Examples of such disorders in children include attention-deficit disorder, autism, learning disabilities, intellectual disability, etc.

Understanding challenges for PwIDDs across critical life stages

1. Birth and Early Childhood:

The human brain experiences almost 75% of its growth in early childhood and children typically develop motor, social and cognitive skills before they turn five.[25] Delays in achieving developmental milestones (ability to roll over, sit, walk, or talk), may be early signs of IDD. If these delays are diagnosed and treated, it could significantly improve the child's developmental trajectory. Yet, several challenges stand in the way.

CHALLENGES

O Poverty and malnutrition are linked to poor cognitive development in children.[26]

As per the WHO, more than 200 million children below five years of age fail to reach their potential in cognitive development because of poverty, poor health and nutrition, and deficient care.[27]

O Lack of medical health specialists and medical tools (especially in rural areas) lead to late diagnosis.

Around 82% of posts for pediatricians in community health centers across India lie vacant[28] and only 112,808 trained professionals are qualified to provide rehabilitative support to PwDs.[29]

O Lack of understanding of IDD often means that families fail to accept the diagnosis or obtain treatment.

"Parents of children with IDD have to deal with huge challenges such as high medical costs, poor transportation services, and tedious paperwork to avail entitlements. Hence, even when the child is diagnosed and referred to an early intervention center, almost 90% of parents drop off mid-process."[30]

– Dr. Kishore Kumar, Director, The Banyan

2. Education:

All children between the ages of 6-14 (including those with IDD) are entitled to free and compulsory education under India's Right to Education Act and the *Sarva Shiksha Abhiyan* (SSA) scheme. Yet, limited efforts have been made on the ground to ensure that children with IDD have access to suitable, quality education for their comprehensive development.

CHALLENGES

O Children with IDD remain out of school.

A study of 2.1 million children between the ages of 6-13 years with disability in India indicated that 36% of children with intellectual disability are out of school.[31]

O Lack of human resources to ensure educational outcomes for PwIDDs.

The student to teacher ratios in inclusive government schools range from 59:1 to 115:1, as opposed to the average student to teacher ratio for children with disabilities of 30:1.[32]

O Limited training to teachers/special educators in schools.

Teachers of 'inclusive' government schools are only provided five days of training on educating children with disabilities.[33]

3. Employment:

The government aimed to skill half a million persons with disabilities by 2018 under the National Action Plan for Skill Training of Persons with Disabilities.[34] However, 'persons with disability' are not a homogenous group and due to negative perceptions around their capabilities, PwIDDs are least likely to obtain employment without targeted assistance and support.

CHALLENGES

O Widespread social stigma and lack of belief in the capacity or capability of PwIDDs.[35]

Studies show that disability decreases the likelihood of obtaining employment by over 30% in states such as Tamil Nadu and Uttar Pradesh. Even amongst the broader group of PwDs, PwIDDs are less likely to be employed (irrespective of the severity of the condition).[36]

O Most IDD vocational training programs provide skills that fail to translate to jobs in the market.

"There is a huge gap in employment opportunities for persons with IDD. Private sector companies should be more active in creating these opportunities for people with disabilities. The job market should be open to everyone."[37]

- Jeeja Ghosh, Founder, Inclusion Infinite Foundation

O Disability focused government schemes do not mandate IDD-friendly workspaces leading to limited economic opportunities for PwIDDs.

Census data indicates that 1.2 million of the 1.5 million individuals identified with intellectual disability are involved in 'non-economic' activities.[38]

4. Adult Support Services:

As adults, PwIDDs may require rehabilitative support, guidance to access government entitlements as well as assistance for independent living. Yet, without finances and the legal right to inherit property, PwIDDs lack access to these services and are often left helpless after their parents' demise.

CHALLENGES

O Lack of safe state-supported housing for PwIDDs

Residents of government-run residential institutions for PwIDDs in India sometimes experience a range of abuses including prolonged detention, neglect, physical, sexual and verbal abuse from caretakers.[39]

O Private assisted living facilities are unaffordable

Private care homes are extremely expensive and on average cost Rs. 35,000 per individual per month.[40]

Sector Support:

It is critical to foster an inclusive and supportive environment to ensure positive life outcomes for PwIDDs across all stages. Currently, there are key gaps that need to be addressed by stakeholders (including the government, academia, communities and social workers) to empower PwIDDs and ensure their social, economic and political inclusion.

O Dearth of reliable data on the prevalence of IDD and efficacy of interventions for PwIDDs

According to current prevalence estimates, 1% to 3% of the Indian population is considered to have intellectual disability;[41] a 2% variance in prevalence rates means a huge difference in the total number of PwIDDS, which affects the efficacy of government policies and budget allocation.[42]

O Lack of awareness and sensitivity in the community.

"People are only interested in intellectual disability when they have an experience of disability. It is always the parents who have to advocate. For disability to become a mainstream discussion there needs to be a shared understanding. I would like to see all disabilities come together, create a resource pool, and share best practices."[43]

- Poonam Natarajan, Ex-Chairperson, National Trust and Founder, Vidya Sagar

Who are the key stakeholders?

PwIDDs

Family Members

Medical Professionals / Educators

Communities and Private Sector

Government, Media and Academics
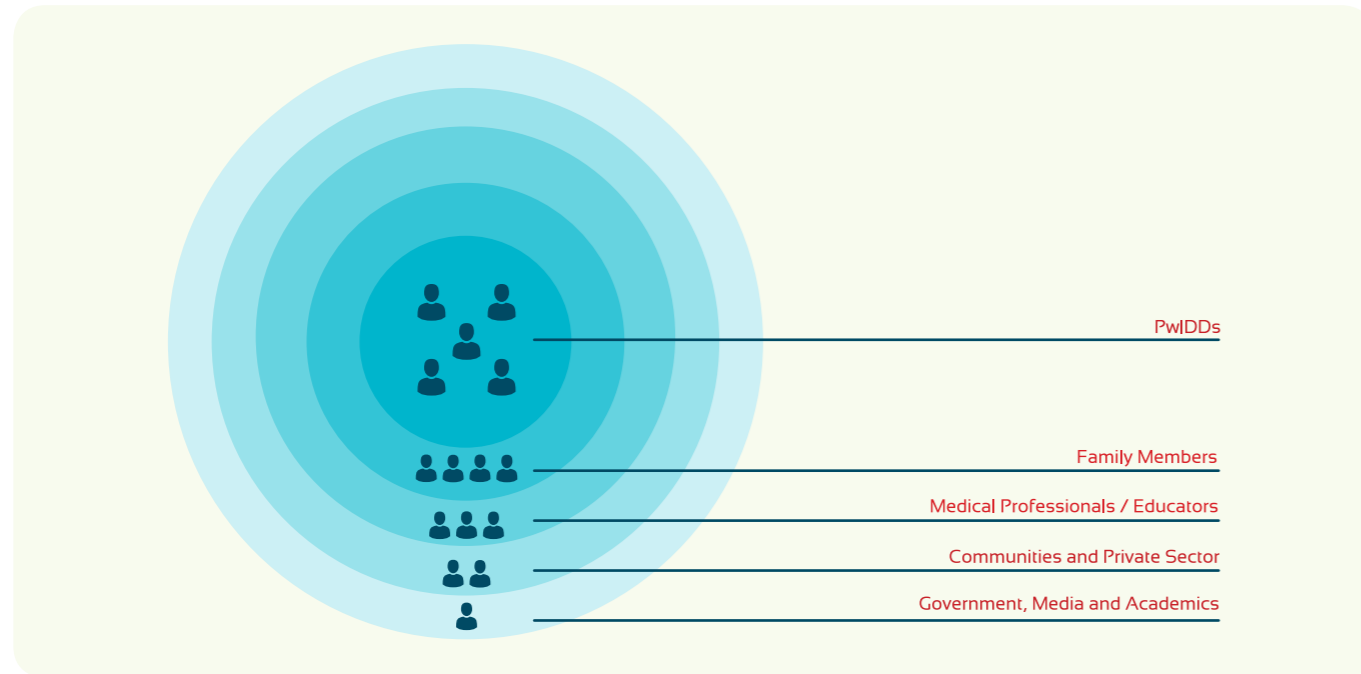
"For any action within the sector, PwDs should be at the forefront and their voices need to be heard; even when a PwD goes to the doctor with a care-giver, the doctor addresses the care-giver instead of the person himself/herself." "

- Nilesh Singit, Disability Rights Activist

While PwIDDs are the primary stakeholders in the sector, Dasra has identified six additional stakeholders that play critical roles:

- **Family members** are uniquely positioned to identify developmental delays in PwIDDs, ensure diagnosis, regular medical and therapeutic support, and round-the-clock care. If they are provided access to the right information and support, they can create a loving and nurturing environment at home for PwIDDs to ensure that these individuals achieve their full potential and live with dignity and confidence.

- **Medical professionals** can provide a range of services for PwIDDs, ranging from early identification and intervention during childhood, to physical, speech and/or occupational therapy throughout their lives. A responsive and far-reaching system of trained medical professionals can ensure timely support to PwIDDs that can lessen the severity of their disability and drastically improve the quality of their lives. Their families can also benefit from consulting mental health professionals, who can counsel them on how to accept and cope with the challenges of a loved one's disability.

- **Educators** are responsible for assessing the needs of a child with IDD and designing a customized education plan that focuses on his/her cognitive and adaptive functioning skills in the requisite measure. With the right tools and training, teachers in special and mainstream schools can meaningfully engage children with special needs in the classroom to ensure improved learning outcomes.

- While **corporates** like Bank of America are committed to providing equal opportunities to PwDs, creating large-scale employment opportunities for PwIDDs requires support from the private sector as a whole. If a majority of corporates establish inclusive workspaces with the requisite infrastructure and identify specific job opportunities for PwIDDs (repeatable and consistent tasks such as data entry and packaging are usually suitable), it will help them become economically independent and successful members of their community.

- The following ministries and departments of **the government** are also key stakeholders in the sector, which focus on different aspects of the lives of PwIDDs, as described in the table below.

Ministry of Women and Child Development	Provides information and runs programs around prenatal and neonatal care that can mitigate the onset of developmental disabilities in children.
National Institute of Open Schooling, Ministry of Human Resource Development	Has designed a flexible curriculum and provides educational certifications for students with special needs.
Disability Division, Ministry of Social Justice and Empowerment	Focuses on skill development programs and employment generation for all PwDs.
Rehabilitation Council of India (RCI)	Regulates and monitors services given to PwDs and standardizes the syllabus for training professionals who will work with them.
National Trust	Focuses on most of the aforementioned areas, with an emphasis on supporting adults with any of the following four disabilities – autism, cerebral palsy, mental retardation and multiple disabilities.

While the list of ministries above provides an indication of the kinds of government stakeholders involved in improving outcomes for PwIDDs, it is far from exhaustive. Some other departments that also work on issues related to the lives of PwIDDs include the Ministry of Health and Family Welfare, the Ministry of Skill Development and Entrepreneurship, the Ministry of Housing and Urban Affairs, the Ministry of Rural Development and the Ministry of Labour and Employment. If each of these branches consult each other and converge in order to develop integrated policies and schemes, it can ensure holistic, improved outcomes for PwIDDs.

- Finally, both **academia and the media** have significant roles to play in this sector. By studying programs and their impact, building data and gathering evidence on the trends in the sector, academia can steer programs for PwIDDs to more effective outcomes. By sensitizing the public to the challenges that PwIDDs face and showcasing stories of inspiring individuals, the media can influence mindsets and alter the narrative to dispel the stigma that surrounds them.
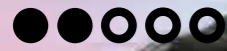
PRIORITY AREAS OF ACTION

As discussed in the previous chapter, PwIDDs face immense challenges in accessing their rights and entitlements. These range from social exclusion and lack of requisite services and infrastructure, to issues with policy implementation. In order to address some of these gaps, Indian non-profit organizations have spearheaded some innovative and impactful strategies to build a more inclusive India. Through engagements with sector leaders, experts and detailed secondary research, Dasra has identified four priority areas of action that have the potential to create catalytic impact in the sector.

1.
Strengthen timely identification and family centered early intervention services

2.
Equip educators with teaching strategies to cater to PwIDDs' needs

3.
Create employment opportunities and conducive work environments with PwIDDs

4.
Drive awareness and advocacy using evidence-based research

1. Strengthen timely identification and early intervention services

To help a child showing signs of developmental delay reach his/her full potential, it is important for the family to seek help as early as possible. Several trials conducted in different countries and across cultures indicate that timely identification and early intervention for children between the ages of zero and five can significantly improve their IQ, language, and adaptive and social behaviors.[45] At this age, a child's nervous system is still developing and hence she/he can respond positively to targeted support provided at early intervention centers.[46] The importance of these services has been re-iterated in the provisions of both the UN Convention on the Rights of the Child (Article 23) and UN Convention on the Rights of Persons with Disabilities (Article 26).[47]

Despite empirical evidence that establishes the importance of early intervention centers, access to and the quality of such services remain inadequate.[48] In order to address these challenges, developed countries such as Portugal have established government-led, community-based early intervention clinics across the country. Using a trans-disciplinary team of doctors, special educators and social workers, these clinics provide focused healthcare services to children while ensuring that families are actively involved in the child's treatment plan. This approach has helped put parents at ease and decreased the time between referral to the clinic and first contact with the family to less than one month.[49] This is in stark contrast to the situation in India, where the time between identification and intervention is almost two years.[50] An evaluation study found that more than 70% of the families using the early intervention centers in Portugal believed that having a consolidated center helped reduce family stress and strengthened their ties with the community.[51]

Therefore, it is essential to support organizations that run assessment clinics and family centered early intervention programs that empower families to make informed decisions about the services that their children may need.

"Early intervention is the most important step for good prognosis. The age of diagnosis has improved over the past 25 years. Earlier, PwIDDs would be diagnosed between 12 to 15 years of age, whereas now IDD is diagnosed in children between one and two years of age."[52]

- Dr. Kishore Kumar, Director, The Banyan

Uma Educational and Technical Society's (UETS) early intervention program adopts multiple models and a family centered approach for early diagnosis and treatment. Established in 1988, the organization setup its first early intervention center in East Godavari district of Andhra Pradesh. According to the founder, Mr. Reddy, "In our communities, disability is caused mainly due to social factors such as malnutrition, consanguineous marriage, etc. Therefore, we realized that educating and training families and communities is important to ensure that children are provided with the best possible support." As part of its community-based early intervention program, UETS' multi-disciplinary teams, comprising a child specialist, psychologist, physiotherapist, speech therapist and a social worker, visit villages and set up screening and assessment camps to identify development delays. These children are provided therapeutic services using locally sourced materials and families are provided with the required training to ensure continuity of therapy. For instance, for children from tribal communities that live in remote regions such as Rampachodavarm, the team substitutes parallel bars with bamboos during physiotherapy sessions.

Using effective patient management systems, UETS tracks each assessment and conducts follow-ups on a regular basis. Additionally, it provides services such as facilitating parent self-help groups, conveyance to and from its centers and midday meals that help families to attend therapy sessions regularly. Over the years, UETS has supported more than 6000 children through its early intervention centers and community-based program.

2. Equip educators with teaching strategies to cater to PwIDDs' needs

Children with IDD in India can currently avail one of three schooling options to obtain an education:[53, 54, 55, 56]

Inclusive Schools

- O The Right to Education Act (RTE), 2009, mandates free and compulsory education to all children from 6 to 14 years of age, including those with IDD.

- O The RTE Act is implemented by the Ministry of Human Resource Development (MHRD) through its *Sarva Shiksha Abhiyan* (SSA) scheme.

Special Schools

- O To ensure access to education for PwIDDs, non-profit organizations and state governments have established separate schools for children with special needs.

- O The Ministry of Social Justice and Empowerment (MSJE) oversees the operation of government-led special schools.

Home Schooling

- O Under the RTE Act, children with multiple disabilities or severe disabilities have the right to opt for home-based education.

- O States have adopted different ways to provide home-based support such as appointing resource teachers to visit homes of children with IDD, creating consolidated resource centers to provide part-time support to families or outsourcing the task to non-profit organizations.

For PwIDDs, a meaningful education can enable them to participate effectively in community activities and lead independent lives. However, educators across India (irrespective of the kind of school they teach in) continue to use traditional methods of teaching like lectures and written examinations that are not suitable for PwIDDs. Hence, for millions of children with IDD, the right to education is just a pipe dream.

> "In terms of schooling, there are two major barriers: a resistance to revisit the curriculum and a resistance to look beyond speech as a mode of communication. Unless our schools are comfortable with augmented forms of communication, they will not be truly inclusive."[57]
>
> - Dr. Reena Sen, Co-founder, Indian Institute of Cerebral Palsy

In order to ensure learning outcomes for children with IDD, individualization is crucial. Depending on the degree and nature of his/her disability, each child has different requirements. Teaching strategies need to account for these differences in skills, abilities and experiences. Hence, it is important to equip educators and parents with multiple teaching strategies such as the use of play-based learning, visual cues and positive reinforcements. They can then decide which strategy would be most effective to meet each child's social, emotional, behavioral, and intellectual needs. In order to help them measure progress and decide the most effective course of action, educators must also have access to adaptable syllabi and the knowhow to create individualized education plans (IEPs).

In Austria, a pilot project evaluated multiple interventions to identify which one was most effective at ensuring inclusive education for children. The study found that supporting teachers by providing pre-service and in-service training was one of the most impactful models to foster inclusion. The pilot scheme evaluated 290 integrated classrooms and deduced that integration can fail if the teaching style used in the classroom does not incorporate active learning and a willingness on the part of the teacher to work in partnership with the student and parent.[58, 59]

In addition to providing special educators with adequate support, studies show that children with IDD need to have access to appropriate assistive technology to effectively exercise their right to education. Recognizing the importance of these tools, the Government of India has adopted a scheme that makes assistive technology available free of charge, or at subsidized costs, to PwDs from low-income groups. Despite the existence of such schemes, children in India only have access to the most basic assistive technology devices, such as hearing aids and wheelchairs.[60] There is tremendous scope in our education system to introduce modern technology such as text-to-speech (TTS) software, talking book players, etc. For children with mobility challenges, the introduction of sip-and-puff systems for using computers or other technological applications by moving the device with his or her mouth could help them lead independent lives. Such assistive technology can help children with IDD in many areas, including word recognition, math, spelling and even social skills. Access to such technology has also been found to promote interaction among children with and without IDD.[61, 62]

CASE STUDY / URMI FOUNDATION

Urmi Foundation designs syllabi, learning and teaching materials for special educators to ensure quality education and therapeutic support for children with IDD from lower socio-economic backgrounds. "Before founding Urmi Foundation", said Sonalee Shyamsundar, "I did some research and found that most teaching tools for special educators in Mumbai are too technical for parents and teachers with limited medical training." Therefore, she ensured that the content used in the teaching tools was user-friendly. Urmi Foundation's teaching materials avoid using technical jargon and explain teaching methods and therapies to parents and teachers, so that they are able to support children with IDD in an effective manner. They also support teachers in applying these techniques by creating low cost training materials from easily accessible and affordable articles.

The impact of their intervention in schools has enabled the foundation to also play an important role in the community. They counsel parents and ensure that parents are active participants in their child's education. Today, the foundation has a team of 30 women, has adopted eight BMC special schools and nine community schools, and supports more than 2,000 beneficiaries in slum communities across Mumbai.

3. Create employment opportunities and conducive work environments for PwIDDs

There are three employment options for PwIDDs: [63,64]

Open Employment

O Open employment is when PwIDDs are employed in the open labour market with an employer who does not exclusively hire PwIDDs

O Also referred to as mainstream employment or supported employment (USA)

Sheltered Workshops

O Sheltered workshops are workspaces exclusively tailored to PwIDDs to help them develop trade skills in a supportive environment

O Some organizations also distribute profits from the sale of these products to PwIDDs based on their output and productivity

O Also referred to as sheltered employment

Social Enterprise Employment

O Social enterprises are for-profit organizations that aim to employ marginalized individuals including PwIDDs or empower them to set up their own businesses to become financially independent

O Also referred to as alternative businesses or social firms (US, UK)

A dearth of employment opportunities for individuals with intellectual disability is a major issue in the sector. A survey of 100 corporates across India, conducted by the National Centre for Promotion of Employment for Disabled People, revealed that the rate of employment of disabled persons was only 0.4% of the total work force.[65] As a result of bias and perception, even amongst the broader group of persons with disability, PwIDDs are less likely to be employed (irrespective of the severity of the condition).[66]

A survey of over 230 organizations conducted by the Institute for Corporate Productivity revealed that pre-conceived notions of the challenges of employing PwIDDs were 42% higher than those actually experienced by employers.[67]

In order to bridge the disparity in employment rates between individuals with and without IDD in India, we need to actively address the difficulties that PwIDDs experience in being gainfully employed. It is imperative that the government and committed corporates partner with non-profit organizations to co-create suitable job opportunities for PwIDDs. Such opportunities can help them become economically self-sufficient and live lives of equity, dignity and respect. While non-profit organizations can provide the technical skills required to support PwIDDs in the workplace, corporates and state agencies can use their finances and influence to create more inclusive job opportunities for PwIDDs.

A number of documented case studies reveal that providing employment to PwIDDs allows them to learn and use new skills, enjoy economic independence and develop self-confidence. It also gives them an opportunity to be active participants in their communities and serve as much needed role models for inclusion.[68]

Providing employment opportunities to PwIDDs is not only a civil rights issue but has proven to be a rewarding strategy for companies as well. The Institute for Corporate Productivity surveyed over 230 organizations that employ PwIDDs and found that this decision had a positive impact that led to improved culture, attracted better talent and increased customer satisfaction that translated into larger profits. Additionally, more than 75% of the respondents of the survey found that PwIDDs exceeded their expectations and proved to be highly motivated and dedicated employees with great attendance records, strong attention to work quality and high productivity.[69]

Ways in which corporates can enable non-profit organizations across the sector

1. **Create an industry-approved curriculum:**
   Corporates and non-profit organizations can partner to create an industry approved curriculum for skilling PwIDDs in particular tasks. This will help set standards for skilling programs by non-profit organizations and help PwIDDs become better equipped for the job market.

2. **Identify creative roles:**
   Due to pre-conceived notions, PwIDDs are hired for a limited number of restrictive roles. Corporates can ideate and brainstorm with non-profit organizations to think outside the box and identify different types of roles in design services, data entry, inventory management, customer management, etc., that could be suitable for PwIDDs.

3. **Provide pro-bono services to non-profit organizations:**
   Corporates can provide pro-bono services such as marketing, media & communications, technology, etc., to non-profit organizations and help them improve their products and services. For instance, non-profit organizations across the country have successfully created sheltered workshops that enable persons with moderate to severe IDD to be gainfully employed. Corporates can help non-profit organizations create large distribution networks and help them to leverage online platforms to sell their products.

4. **Build leadership capacity:**
   Investing in management training of founders and senior leaders of non-profit organizations can enable them to operate sustainable organizations that create long-term impact.

5. **Invest in organizations:**
   Corporates can either use their CSR budget or leverage creative funding mechanisms such as employee payroll programs, to invest in credible non-profit organizations conducting impactful interventions.

6. **Provide social capital:**
   Leverage networks to help organizations create a larger network of volunteers and encourage employees to volunteer in different non-profit organizations in different capacities.

Ways in which corporates can create employment opportunities and inclusive workplaces for PwIDDs [70]

1. **Create an Equal Opportunity Policy (EOP):**
   Corporates must create a policy that can guide all SOPs in the organization including HR policy, procurement, client management procedures, etc. to ensure inclusion. They should ensure that components of HR policies such as job profiles, performance appraisal systems, metrics, etc., are updated to promote and retain diverse teams. Research shows that introductory programs produce a positive impact on the experience of an employee with IDD.

2. **Invest in sensitizing and training staff members:**
   Staff members are instrumental in creating a safe and inclusive work environment. Corporates should partner with accessibility and inclusion consulting organizations and non-profit organizations to provide inclusion training to staff members and decreasing instances of bullying and harassment at the workplace.

3. **Provide accommodation to PwIDDs to ensure accessibility:**
   To be effective employees, PwIDDs may need certain assistive devices or modifications to the workplace or tasks assigned. For instance, assistive devices such as low-tech message boards, dictation software or mobility aids can make the workplace more accessible to PwDs.

4. **Build inclusive and safe physical infrastructure and services:**
   Corporates should ensure that the office entrance and amenities such as bathrooms and stationery, etc., are accessible and safe for a PwIDD. The aim should be to enable a PwIDD to do as many things as independently as possible. Similarly, they should also ensure that services and products such as digital properties and documents are inclusive and easily accessible to PwIDDs.

5. **Partner with non-profit organizations or disability consultants:**
   Creating an inclusive workplace is a social and legal decision, and hence, it is best to collaborate with a consultant or non-profit organizations to learn best practices and ensure implementation.

According to the International Labour Organization, economic losses resulting from exclusion of PwDs from the labor force are immense, ranging from 3% to 7% of a country's GDP.[71]

CASE STUDY / **AMBA**

AMBA is an example of how organizations have been able to effectively identify potential employment opportunities that not only account for the needs and abilities of adults with IDD but also add value to corporate processes.In 2004, Sugandha Sukrutaraj founded AMBA as a training and business hub that employs PwIDDs to perform visual and functional data entry for partner corporates. This not only allows corporates to outsource back-end tasks while enabling adults with IDD to develop and use employable skills but also provides a collaborative and safe working environment for adults who may not find the requisite support in conventional corporate environments.

At the core of AMBA's success is its use of a customized training curriculum and an effective peer-training approach. The curriculum adopts visual cues to teach PwIDDs how to convert physical forms into a digital format swiftly and efficiently. It also conducts exercises that involve consistent and repeatable tasks, thereby enhancing accuracy. Apart from data entry, the training enables PwIDDs to conduct a variety of back end tasks. Currently, trained personnel at AMBA are also performing back-end tasks for a camera based Artificial Intelligence solution. Through their peer-training program, AMBA empowers PwIDDs who have received training by promoting them to team leaders and supervisors, allowing them to pass on their knowledge and learning to new recruits in the best way possible. AMBA has a core team of 113 adults with IDD who drive different training modules across India. Today, AMBA not only employs more than 100 individuals in its core center in Bangalore but has also trained over 100 organizations across India, that are using this model to ensure sustainable employment for PwIDDs.

CASE STUDY / **Bank of America**

Bank of America's (BoA) US-based support services team has been providing meaningful employment to persons with intellectual disabilities for over 25 years. It acts as an in-house marketing and fulfillment (i.e. packaging, printing and data entry) operation that is aligned closely with BoA's core business functions. The team's competencies lie in: (i) fulfillment (ii) graphic arts/printing; and (iii) inventory management services. It currently comprises 300 individuals with intellectual disability who perform consistent, repeatable and operational tasks that are critical to BoA's operations. BoA has adopted the following actions to ensure the sustainability of the support services team:

- Recruitment and assistance: BoA partners with local agencies that help hire suitable candidates, provide job support after recruitment, and address all concerns during the term of employment.
- Competitive costs: The support services team's overheads are absorbed at the corporate level, and only direct supply costs are charged to customers. This not only enables customers to save money by utilizing support services but also ensures that the team gets a high volume and variety of work.
- Human Resources support: A committed employee relations team liaises with the support services team to address any challenges experienced by the employees.

4. Drive awareness and advocacy using evidence-based research

Recent advances in global policy and practices have encouraged India to adopt an evolved approach towards PwIDDs. Our current laws ensure that PwIDDs are recognized as individuals with rights who have been marginalized and stigmatized by society.

India ratified the UNCRPD in 2007 and passed the RPwD Act nearly a decade later in 2016, finally discarding the medical model of disability for the social model. This has changed the way our laws perceive disability – from an incurable, physical or mental impairment alone to a social condition that is caused by the interaction of environmental, social and biological factors.[72] However, the social model of disability needs to percolate from policy to practice. In many parts of India, intellectual disability is still considered to be the result of divine justice or punishment for sins committed in past lives and PwIDDs continue to be neglected and marginalized.[73] Lack of data, including on prevalence and intervention effectiveness, further impedes affirmative action.

> "The government should have a twin-track approach in which disability is a section for every law passed and policy enacted. For instance, schemes under the Mahatma Gandhi National Rural Employment Guarantee Act should have a component for disability. Issues of disability need to be visible in every aspect of life and only then there will be inclusion."[74]
>
> - Nilesh Singit, Disability Rights Activist

Studies have revealed that public attitudes towards PwIDDs have a significant effect on community integration.[75] Hence, IDD needs to be mainstreamed more effectively to influence increased acceptance of individuals with IDD in communities. One way to achieve this is to improve the quantum and quality of our academic, social and political discourse. For instance, in developed countries, disability studies focusing on interactions between the environment and the individual, is a vast area of teaching and research in several universities. This research creates data that fuels innovative solutions while debunking myths and misconceptions associated with IDD.[76] However, in India academic and field-based scientific literature on IDD is limited, thus creating a sector that continues to employ ineffective or poorly designed interventions.[77]

One example is Project Unify, an initiative of the Special Olympics to create a unified inclusion strategy for schools in the US. The organization conducted evaluation studies after the pilot stage and the first phase of implementation, which helped them understand the strengths and drawbacks of their inclusion program. The study also helped them re-visit certain aspects of their program to make it more effective. Additionally, they created playbooks that document and share the lessons learnt from this initiative. These playbooks highlight challenges, creative solutions and success stories of the program, helping other organizations learn from their experiences.[78]

CASE STUDY / SANGATH

Sangath is a child developmental clinic that provides primary services for children with diverse needs including developmental delays and disabilities. A key finding from its early years of providing center-based services was the alarming drop-off rate as parents stopped bringing their children back to the clinic after a few sessions. As Sangath investigated the reasons, it realized the need to work within the community in order to create sustained impact.

Through its interventions, Sangath aims to empower stakeholders including community workers, parents and teachers by equipping them with low-cost, scalable solutions that build on existing systems. It invests in research that tests proof of concept before implementation at scale across a community. For instance, it has initiated several studies to measure the clinical effectiveness and cost-effectiveness of a comprehensive intervention for autism in an Indian setting. Sangath aims to leverage this evidence to approach policy makers and advocate for the introduction of such interventions for all children with autism in the country. Today, Sangath is India's fourth leading Public Health Research Institute that reaches over 2000 children and families, conducting work across the country. Sangath has had representatives on key technical advisory bodies of the Government of India, including for the *Rashtriya Bal Swasthya Karykram*, as well as on international bodies like the World Health Organization's advisory group on autism and other developmental disorders.

Throughout their lives, adults with IDD need to have access to support that allows them to live with dignity and to participate in social activities as equals. These services could include a range of support, such as:

Providing residential support through independent housing or group homes

Assisting PwIDDs to undertake decision-making, self-care activities, household chores, mobility, etc.

Promoting participation in sports, creative arts, dance, music and field trips for increased social interaction

In developed countries such as Canada, the government, along with non-profit organizations, provides most PwIDDs with safe housing options for independent living and services that promote their social inclusion within the community.[79] However, in India, families continue to be the primary care givers for adults with IDD. Although the National Trust operates several schemes and services for adults with IDD, its scope and reach are limited.[80] Additionally, PwIDDs do not have sufficient options for independent living. Most residential institutions in India segregate PwIDDs from society instead of promoting their inclusion. They are often overcrowded and have unhealthy, abusive living conditions. A report by Human Rights Watch has documented the range of abuse, sexual, physical and mental, that women with IDD undergo in government residential care institutions in India.[81]

Although, adult support services are a priority area for the sector, we could not identify quality interventions that were practiced on a large scale. Therefore, we will not be discussing these services in detail in this chapter.

Walgreens, a Fortune 500 company that employs more than 180,000 workers, revealed that employing individuals with IDD had contributed to higher productivity in its distribution centers, higher retention rates, and increased customer loyalty, among other benefits.[82]

Efforts to drive change across these four priority areas for action need to be deployed collectively to improve outcomes across crucial life stages of PwIDDs:

○ By **strengthening timely identification and family centered early intervention services,** the impact and extent of developmental delays on PwIDDs can be reduced and controlled

○ By **ensuring educators are equipped with teaching strategies** to cater to PwIDDs needs, learning outcomes among persons with IDD can be improved

○ By **creating employment opportunities and conducive work environments** for PwIDDs, they can be provided with opportunities to be economically independent

○ By **driving awareness and advocacy using evidence-based research,** we can create a diverse and inclusive society in India where PwIDDs are treated with dignity and respect.

CHAPTER
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KEY INTERVENTIONS

This table draws linkages between the identified priority areas for action (the 'what') and the interventions that organizations are already delivering on the ground (the 'how') across the life stages framework.

Life stage of PwIDD	Priority Area for Action	Intervention
Birth and Early Childhood	Strengthen timely identification and family centered early intervention services	○ Provide diagnostic services and family centered early intervention care ○ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers (AWs) and pre-school teachers
Education	Equip educators with teaching strategies to cater to PwIDDs' needs	○ Deliver technical training to educators in special schools and inclusive schools ○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
Employment	Create employment opportunities and conducive work environments for PwIDDs	○ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising PwIDDs
Sector Support	Drive awareness and advocacy using evidence-based research	○ Conduct advocacy for legislative change and educate key stakeholders such as parents, families and community members to generate awareness ○ Build capacity of partner organizations and enable them to create sustainable entities ○ Conduct research to build data on developmental disorders and program effectiveness

A range of initiatives and activities are being undertaken by non-profit organizations and other stakeholders to improve services for PwIDDs. The following pages describe these critical interventions and analyze each intervention's impact and scalability on the basis of certain criteria.

ANALYSIS CRITERIA

IMPACT	SCALABILITY
O Proximity to target group O Duration of engagement O Evidence for effectiveness	O Resource intensity O Gestation period O Partnerships leveraged

In addition to the interventions highlighted in this chapter, here are three promising but less established efforts to improve outcomes for PwIDDs:

O Deliver remedial and counseling services to children with IDD in inclusive schools.

O Conduct counseling sessions for adults with IDD in mainstream employment settings.

O Provide legal aid and create platforms that give a voice to disability rights.

Intervention 1

Provide diagnostic services and family centred early intervention care

As family members of children with IDD interact closely with them on a daily basis, they are also most likely to be aware of their children's needs and abilities. Yet, medical service providers rarely obtain their inputs on the course of action being decided for their children. In order to bridge this gap, non-profit organizations operate holistic early intervention programs that not only involve families in deciding the plan of care but also integrate the emotional, social and cultural well-being of the child into decision-making and planning.[83] This intervention caters to children between the ages of zero and six years and typically involves:

O Community outreach and awareness sessions for families
O Diagnosis of children with IDD through standardized assessments
O Provision of therapeutic support such as physiotherapy, vision training, speech and communication, and group play and referral services
O Home management plans that teach parents effective techniques (i.e. toilet training, feeding, breathing and handling) to help with their child's development

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CASE STUDY / **The Association of People with Disability**

The Association of People with Disability (APD), India runs an early intervention program across Karnataka alongside six partner organizations. In addition to providing screening and diagnostic services to children with developmental delay, APD's program involves working very closely with parents to formulate individualized family support plans (IFSPs). Based on each child's goals, field staff provides need-based rehabilitation services that include comprehensive therapy, assistive and adaptive devices as well as guidance and support to families. It also facilitates access to various government-led social security schemes. These services are provided at the center, in homes and even at their sub-centers established in primary healthcare centers and government *anganwadis* (Integrated Child Development Centres). Sub-centers enable five to six families to come together on any given day, allowing parents to exchange their stories, knowledge and challenges and learn to support their children together. Building on its family-centered and holistic approach, the program also works to capacitate and sensitize key stakeholders such as frontline healthcare workers, doctors, nurses, parents, caregivers, and communities.

Family-centered care has demonstrated far-reaching benefits as it (i) improves the quality of services being rendered (ii) enables parents of children with IDD to understand their needs and deal with developmental challenges; and (iii) helps create a sense of community between families of PwIDDs. This intervention is high-impact because it involves working very closely with the primary stakeholder group – children with IDD, and their families through weekly sessions. However, since it is resource intensive and requires consistent touch points over six years of a PwIDD's life, it is low on scalability unless the organization can leverage government partnerships at a district or state level.

DASRA ANALYSIS

Intervention 2

Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers

Sustainable inclusion of PwIDDs depends, to a significant degree, on how trained professionals communicate about IDD and how effectively they support PwIDDs and their families. Yet, as discussed previously, there is a dearth of trained professionals who are qualified and sensitized to provide effective family-centered rehabilitative support. Therefore, a key intervention in the sector involves providing technical training, undertaking refresher courses and conducting workshops to improve the capacities of health professionals who work closely with PwIDDs. This kind of intervention typically involves the following activities:

- Provision of certificate courses and diplomas on rehabilitation therapy/clinical competencies for counselors, psychologists and social workers
- Sensitization of health professionals on the rights of PwIDDs under the UNCRPD so they are able to look beyond the disability
- Equipping *anganwadi* workers and pre-school teachers with strategies to identify developmental delays and build on the child's cognitive, numeracy and literacy skills

Intervention 3

Deliver technical training to educators in special schools and inclusive schools

Trained special educators are essential for schools to implement inclusive policies and practices as they determine how best to address the unique learning needs of PwIDDs. Therefore, an educator needs to understand the accommodations or support services that children with IDD may require. However, the number of trained educators in India is limited. In order to address the dearth of skilled professionals, non-profit organizations provide pre-service and in-service training to ensure the quality of educators working with PwIDDs.[84] This encompasses:

- Delivery of courses recognized by the Rehabilitation Council of India to train special educators
- Enhancement of skills of special educators who are already working with PwIDDs through workshops/short-term training
- Mentorship programs for new special educators
- Monitoring and evaluation of the training being administered through frequent refresher courses and check-ins with former trainees

CASE STUDY / Sethu

Sethu's training program aims to build inclusive, government-run pre-schools (*anganwadis*) by providing pre-school teachers and *anganwadi* workers and helpers of the Integrated Child Development Scheme (ICDS) with the tools and training required to assist children with special needs. The aim of the training sessions is to empower stakeholders with practical information that will allow them to reflect on their experiences, analyze the challenges they face and design contextualized solutions for children with diverse abilities and learning needs. The 3-10 day training programs adopt an interactive format and are carefully curated to help teachers and helpers understand the theory of child development, multisensory teaching techniques, classroom management techniques including handling difficult behaviors, etc. Sethu also conducts experiential workshops and re-fresher sessions aimed at sensitizing stakeholders such as therapists and doctors to the needs of children with IDD. Over the years Sethu has managed to train hundreds of pre-school teachers across all 12 *talukas* in Goa and plans to now train the *Mukhiya Sevikas* (supervisors) of the ICDS as Master Trainers, to cover 145 *anganwadis* under their care.

CASE STUDY / SOPAN

Over the last 25 years, Society of Parents of Children with Autistic Disorders (SOPAN) has grown from a local initiative into a nationally recognized organization that provides a wide range of high quality services to children with IDD. Rubina Lal, the founder of SOPAN, realized that there was a lack of quality training programs for special educators in India. In order to address this issue, she founded the Suvidya Centre of Special Education, a college affiliated with the University of Mumbai that conducts preparatory programs approved by the RCI for educators who teach children with disabilities. In keeping with the continuum of teacher preparation, Suvidya runs both initial teacher preparation and continuous professional development programs for educators who work with children with IDD. Their B.Ed. Special Education course with a focus on ASD was the first course in India that equipped educators with the skills to teach children with ASD in special and inclusive school settings. The center also conducts short-term capacity building programs to help in-service teachers, professionals, and parents of children with autism to understand the nature and needs of their children.

DASRA ANALYSIS

Non-profit organizations prepare and deliver contextualized courses to train health professionals in using appropriate communication techniques and terminology for interactions with PwIDDs and families of PwIDDs. While the intervention does not involve working closely with PwIDDs, it improves the quality of services being provided by professionals who are the first responders and influencers, and, in some cases, decision-makers for PwIDDs and their families. Since the intervention adopts a 'training of trainer' (ToT) model, it can easily be scaled effectively to promote inclusive and progressive medical services for PwIDDs.

DASRA ANALYSIS

Delivery of training for special educators is an important, medium impact intervention that is key to ensuring learning outcomes for PwIDDs. However, the success of the training courses depends upon the rigor and quality of teaching. If these aspects are accounted for, the intervention has the potential to be scalable as it builds expertise within the sector. To ensure that the intervention is sustainable and effective, non-profit organizations need to monitor their trainees and update training modules regularly.

Intervention 4

Equip educators in special and inclusive schools with specifically designed and standardized teaching tools

Each child with IDD may experience a range of developmental disabilities and it is usually up to the teachers to creatively adapt educational materials to suit the needs of the child. Some non-profit organizations develop standardized teaching tools to reduce this burden on special educators. These include the following:

- Creating contextualized, milestone driven curriculums, visual toolkits and other learning materials
- Conducting sessions to familiarize special educators with the teaching tools

For example, non-profits such as Com DEALL and Urmi Foundation have designed worksheets with defined milestones to help children with IDD develop language and motor skills, and cognitive and adaptive behaviors. Based on these worksheets, educators create individualized plans, in consultation with the parents, counselors and therapists that help determine the right educational goals and services for each child.[85]

CASE STUDY / Sol's Arc

Through innovative education research, Sol's Arc focuses on improving learning outcomes for children with IDD and ensuring that they acquire basic literacy and numeracy skills. It has developed internationally acclaimed, standardized, inclusive learning content based on the National Curricular Framework (NCF) to enable both mainstream and special schools to address special needs in their classrooms effectively. In addition to its prescribed curriculum and structured life skills program, Sol's Arc produces standardized learning materials and promotes the use of technology such as interactive boards and iPads. It has actively worked towards increasing the reach of its learning content to more than 2,00,000 children annually by serving as a consultant and training center for schools and other organizations.

DASRA ANALYSIS

This is a highly scalable intervention since it involves providing educators with tools that help them maximize the potential of their teaching strategies. To create the right tools, non-profit organizations need to carry out extensive, contextualized pilot and evaluation studies, making this a fairly resource-intensive intervention. However, once these tools are developed, they can be used across schools in India.

Intervention 5

Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising PwIDDs

PwIDDs are under-represented in typical workplaces, largely due to numerous physical and societal barriers that they experience in obtaining job opportunities.[86] Non-profit organizations are, therefore, providing PwIDDs with opportunities to be self-reliant, productive and empowered citizens of society through employability interventions. The key activities include:

- Imparting skill training to PwIDDs that enables them to secure mainstream or self-employment opportunities
- Operating sheltered workshops where PwIDDs can undertake small-scale economic activities, such as baking, weaving, packing and creating decorative items like candles and paper bags; profits from the sale of these products are distributed amongst the workshop staff
- Partnering with corporate employers and industry confederations to ensure that mainstream work spaces are conducive and enabling environments for PwIDDs

CASE STUDY / EnAble India

Enable India, established in 1999, is considered a pioneer in creating livelihood opportunities for persons with disabilities (including sensory, physical, and intellectual and developmental disabilities). Before Enable India started working for PwDs, these communities (especially those with severe disabilities) were only able to get jobs via reservations in public sector undertakings. Enable India opened up the private sector and helped companies see business value in hiring PwDs. It undertakes a wide range of interventions that cater to both employers and PwDs. It provides consulting services to corporates interested in becoming inclusive employers via its 'Enable Employers' program. Through its 'Enable Inclusion' program it helps public sector undertakings and government departments recruit, retain and upskill employees with disability (to meet their reservation quotas). It also has targeted services such as career counseling, job opportunities and employability training for PwDs. Enable's holistic approach to employability has allowed them to open 300 job roles for PwDs and coached 10,639 leaders all over India.

DASRA ANALYSIS

Creating employment opportunities for PwIDDs can ensure their financial independence, which in turn (i) empowers them to make their own decisions (ii) has a positive impact on their families (iii) and enables their social integration. These interventions also help to make workplaces more diverse and inclusive, thereby creating a positive work environment for all employees. Employability interventions are high-touch interventions that engage deeply with the target population over several months, if not years. While they are typically resource intensive, they leverage existing corporate and government infrastructure for employment opportunities, making them potentially scalable interventions.

Intervention 6

Conduct advocacy for legislative change and educate key stakeholders such as parents, families and community members to generate awareness

Advocacy, both within the community and with the government, can help create a diverse and inclusive society in India where PwIDDs are treated with dignity and respect. To this end, non-profit organizations typically undertake the following activities:

- Conduct community participatory programs such as public rallies, street plays, flash mobs, and live entertainment events to generate awareness and garner active involvement and support from people in the community
- Engage students from schools, colleges and offices through immersion visits, seminars and cultural events to sensitize them to the needs of PwIDDs
- Organize support groups for parents and organizations working with PwIDDs, to provide them with a safe space to voice their concerns
- Develop active partnerships with the media to mainstream the disability discourse through articles and campaigns
- Work closely with the government and contribute to the drafting of policies and provisions related to PwIDDs at a state and national level. Most non-profits establish resource centers where they undertake research on the legal rights of PwIDDs and work to ensure their effective implementation

CASE STUDY / PARIVAAR - National Confederation of Parents Organizations

PARIVAAR - National Confederation of Parents Organizations (NCPO) is a federation of over 260 parent associations and grass-root non-profit organizations that provides direct services to PwIDDs. Over the last 25 years, Parivaar has successfully advocated with the central and state governments to facilitate the enactment of enabling laws, provisioning of resources and pushed for schemes to improve the lives of PwIDDs. Its success is evidenced by milestone achievements like the formulation of the National Trust Act and its efforts towards including self-advocacy training in the national plan for integrating PwIDDs into mainstream society. In order to strengthen its advocacy efforts by identifying and empowering emerging advocates, Parivaar conducts regional and national parent meets and has formed the Self Advocates' Forum of India (SAFI) with more than 3000 members.

DASRA ANALYSIS

Successful advocacy at the national and international level has led to numerous progressive policies, including adoption of the UNCRPD in 2006, creation of the RPwD Act in 2016 and affirmative action in workplaces for PwIDDs. While such efforts for policy-level change do not affect PwIDDs directly and have a high gestation period, at their fruition they produce a transformative and sustainable impact that is unmatched in the long run. Furthermore, community awareness initiatives have the potential to be scaled, since they are not resource-intensive or time-consuming, allowing them to reach vast numbers of individuals in a short span of time.

Intervention 7

Build capacity of partner organizations and enable them to create sustainable entities

As the disability rights movement grows, several small community-based organizations (CBOs) have emerged across India to cater to the needs of PwIDDs. In order to ensure the quality of services being provided to PwIDDs across India, established organizations in the space have developed capacity-building programs targeted towards CBOs in rural, semi-urban and slum areas. These interventions involve:

- Community-based and classroom-based training programs that aim to strengthen the technical, operational and organizational capabilities of CBOs working for PwIDDs
- Needs assessments and hands-on support to design contextualized programs using an inclusive and rights-based lens
- Sensitization of social workers from these CBOs on issues of inclusion in order to ensure effective implementation of programming

CASE STUDY / Indian Institute Of Cerebral Palsy

Since its inception in 1974, the Indian Institute of Cerebral Palsy (IICP) has cemented its reputation as a leading specialist resource center for cerebral palsy. Its community-based rehabilitation (CBR) program does not provide direct services to PwIDDs but instead focuses entirely on building the capacity of partner organizations in West Bengal. The nature of support that IICP provides is determined by the needs of the organization. For instance, a budding institute would require support in setting up operations and designing its programs. An organization with an established presence in the community would need guidance on how to add a disability lens to its existing programs. IICP's CBR team connects with each organization at least once a month to understand its requirements and subsequently design and deliver relevant training. In addition, the organization runs technical training at its own headquarters to upskill individuals working directly with PwIDDs.

DASRA ANALYSIS

This intervention enables CBOs to campaign for change at local levels, create networks and stay abreast of sector-level trends. It is a medium-impact intervention, which does not engage with PwIDDs directly but improves the local support services available to them. There is, however, tremendous potential to scale such an intervention because it uses a ToT approach, has a low gestation period and is not resource-intensive – even a single expert trainer can help build the capacity of numerous organizations in a year.

Intervention 8

Conduct research to build data on developmental disorders & program effectiveness

Service providers in the sector (whether non-profit or state-led) require information on the prevalence of IDD, key gaps in service provision and on the effectiveness of different interventions to design effective services for PwIDDs. However, a dearth of accurate data on such issues impedes evidence-based, effective decision-making. Therefore, non-profit organizations have made significant efforts over the last decade to build data for IDD in India. Some of these interventions include:

- Conducting prevalence studies that aim to ascertain the incidence of IDD in specific communities or states
- Engaging with communities to determine the current state of services in the sector
- Undertaking empirical studies to evaluate the clinical effectiveness and cost-effectiveness of interventions
- Conducting research to tailor internationally accepted government and non-profit services for PwIDDs to the Indian context

CASE STUDY / **Amrit Foundation**

Amrit Foundation is an organization committed to increasing the availability of research-based evidence to communities. As part of their 'Patang Project', the organization carried out research to build evidence about the experience of caring for a child with intellectual disability in India. Using primary research, their study helped reveal insights on availability and accessibility to services, the interplay between service access and social characteristics, and the strategies that caregivers use to cope with the existing gaps in the system. Amrit has also created a one-stop online platform that houses a large database of service providers that work with children with IDD, making it easier for caregivers to find such services. Over the past six years, Amrit Foundation has expanded its network exponentially and is currently connecting PwIDDs to over 900 service providers across the country.

DASRA ANALYSIS

Generating such robust evidence can help organizations modify and improve their programming and can inform the interventions of other service providers in the sector. Although evaluating program effectiveness is a time and resource intensive intervention, it can affect PwIDDs significantly by improving the quality of services provided to them. Furthermore, leveraging government infrastructure to collect and interpret data around IDD in the country can increase the potential of carrying out this intervention at scale.

Each of the interventions described has the potential to be highly impactful for PwIDDs and to transform the sector. However, there have been limited efforts to replicate programming, identify best practices or even find linkages and opportunities for referral across service providers. The following chapter sets out Dasra's recommended strategies to bridge these gaps and develop a collaborative and supportive ecosystem for PwIDDs.

RECOMMENDATIONS

Based on research, expert interviews and thorough due diligence of non-profit organizations in the field, Dasra recommends the following strategies to stakeholders looking to create powerful and lasting change in the sector.

For practitioners

1. Mainstream issues of IDD for effective inclusion

While there is a tremendous amount of research and academic material on the benefits and strategies for inclusion, Dasra recommends a stronger push to bring it into every aspect of the disability ecosystem. In addition to bringing this lens to non-profit organizations' programs, this means advocating with the government for better, more equitable policies, corporates for more inclusive workplaces and communities for more sensitive treatment of PwIDDs. The media can also play a pivotal role by promoting and mainstreaming content around PwIDDs in an effort to battle the stigma associated with disability in India. The power of the media is reflected in the success of movements like Breakthrough's Bell Bajao campaign (to call on men and boys to take a stand against domestic violence) that reached over 130 million people in three years and trained more than 75,000 rights advocates to become agents of change.[87] Mainstreaming issues of IDD in a similar fashion could help propel rapidly the idea of inclusion from the discourse alone to the reality on the ground.

2. Enable self-advocacy

A call for more inclusive and better policies and treatment of PwIDDs must necessarily include more voices of self-advocates. Pioneers like Jeeja Ghosh have led the way in embodying the sector's motto of 'nothing for us without us' and represented the needs and challenges of PwIDDs at national and international forums. It is imperative to bring the voices of these self-advocates to the fore of mainstream discourse on IDD and create more platforms like the Special Olympics for them to showcase their potential and bring their perspective to government decision-making. Organizations should also focus on developing innovative means to identify and empower such leaders who are the most powerful spokespersons for the sector.

3. Promote a family centered approach

As primary caregivers, the families of PwIDDs not only play a crucial and constant role in the lives of PwIDDs but also in the sector as a whole – nearly 30% of organizations assessed by Dasra were started by parents of children with IDD.[88] A family centered approach recognizes the importance of the families' participation in the care of the PwIDD by including them in decision-making and training them in appropriate home-based therapies.[89] This approach also helps families understand the developmental needs of the PwIDD and ensures that their financial context is incorporated into the design of the rehabilitation program,[90] which is crucial to its success and sustainability. Focusing on families also means supporting them by providing information, counseling and access to the requisite government schemes and facilities. Organizations that adopt this holistic approach to programming for PwIDDs and their families should be encouraged, since they have the potential to influence their lives in the most meaningful and lasting manner.

4. Enhance adult support services

As PwIDDs transition into adulthood, their lives often take a turn for the worse as their primary care-givers (typically their parents) start to age and struggle to continue providing round-the-clock care. Support services at this stage are thus critical and can have a truly transformative impact on the overall quality of the lives of PwIDDs. Currently, however, government and non-profit interventions for adults (aside from creating employment opportunities) are limited to day care centers or group homes. There is a need for more research and analysis to find new ways to enable adults to live independently as part of their communities. One example of an organization that has initiated such an effort is Vidya Sagar, which has conducted research to understand the nature of the workforce required to facilitate a shift towards more inclusive adult support services. The organization found that increasing the quality and quantity of four types of professionals in particular could help achieve this shift in India – personal attendants, job coaches, independent travel trainers and group home managers.[31] If the government could subsidize training, incentivize individuals to enter into these professions and provide adults with IDD access to advanced and effective assistive devices, it could empower them to live and participate in mainstream society even in the absence of a primary caregiver.

For donors

4. Provide patient capital

Donors looking to support organizations working in the IDD space must decrease their focus on outreach numbers and instead redefine the way they measure impact. Nearly all programmatic interventions in this sector are resource intensive, often requiring daily engagement with the beneficiaries over several years to yield tangible outcomes. The nature of the sector, therefore, demands investing patiently and consistently over several years, without an expectation of immediate results. Donors should also support research and innovative interventions that seek to improve outcomes for PwIDDs in new, evidence-based ways.

Q&A with Mrs. Neerja Birla

What inspired you to work in traditionally underserved areas like mental health and intellectual disability?

My personal experiences and then having children of my own, were the driving force that led me to invest in the sector as a social entrepreneur, and approach it using the lens of education through the Aditya Birla Education Trust. Children with learning disabilities have always been a cause of great concern to me. I remember when my children were in school, I watched children who could not cope with the workload being singled out and even bullied. Therefore, one of my initiatives is the Aditya Birla Integrated School, which today caters to 154 children with intellectual disabilities and special needs. In the course of my work with both the schools that I look after, the Integrated School and Aditya Birla World Academy, I witnessed the lack of awareness and understanding of not just intellectual disability but also mental health issues. The natural next step was to launch Mpower, an initiative designed to create awareness, foster education and alleviate the stigma around mental health.

How do you aspire to create impact within these sectors through the Aditya Birla Education Trust?

My vision for the Aditya Birla Education Trust is that it addresses all these issues in a comprehensive manner and acts as an end-to-end service provider. The Trust is comprised of four initiatives, the Aditya Birla World Academy, The Aditya Birla Integrated School, Mpower and the Aditya Birla Education Academy. Each of these provides a unique service that is needed in the ecosystem, including education for children with and without intellectual disabilities, counselling and therapy for adults with mental health issues and even trainings for educators working in this space.

How important is collaboration in this space?

I believe the only way for social enterprises to grow and scale is through collaboration. Acting alone may eventually result in the same impact, but the time, effort and resources that one invests will be manifold. For instance, at Mpower, we are working with the Family Planning Association of India. They already have a huge network and we have the services. Our partnership means that we can reach their clientele, who in turn receive mental health services, which they previously didn't have access to. We are always looking for such partnerships and collaborations, in order to amplify the impact of our work.

Do you have a message for fellow social entrepreneurs and funders looking to enter this space?

When I began working in this space, it was a major risk. It is so niche that it took me some time to learn and understand its nuances. Moreover, very few people were interested in helping us. For instance, although we invited several media persons, the launch of our enterprise was covered by only two media companies. Regardless, we persevered, and Mpower today has more than 1000 clients, garnered over the last three years. Thus, I want all social entrepreneurs and funders to know that it is important to invest the time and capital and remain committed to the cause. We at the Aditya Birla Education Trust, are committed to creating powerful change and are slowly but surely witnessing the impact of our patience and dedication. Believe in your cause and success will be yours.

For the sector as a whole

5. Build a more cohesive ecosystem

Service providers and non-profit organizations in the sector tend to operate in isolation, focusing only on certain disabilities or services. Several studies have documented how the lack of inter-sectoral coordination and a community-level coherent strategy leads to fragmented and poor services for persons with disability.[92] Dasra's site visits further uncovered an overlap of efforts and strain on the limited human resources and infrastructure to cater to the needs of PwIDDs. In order to minimize this duplication of effort, these stakeholders need to communicate better with one another and develop referral systems that build linkages within the ecosystem. For instance, the World Bank recommends cementing the supply chain from primary health centers to national level medical and rehabilitation services.[93] The quality of services will also improve if the sector promotes sharing and learning from best practices and challenges faced by other organizations and service providers.

6. Integrate the work of diverse government departments

There are numerous branches of the government that work on issues related to PwIDDs, and their messaging can sometimes be contradictory. For instance, while the amendment to the Right to Education Act in 2012 specifically encourages children with IDD to study in mainstream schools, the Ministry of Social Justice and Empowerment promotes special schools for children with disabilities.[94] Furthermore, implementation is affected when the responsibility for service delivery does not lie with any single department. The 2013 *Rashtriya Bal Swasthya Karyakram* mandates District Early Intervention Centers,[95]but nation-wide implementation is a distant dream due to the lack of coordination between the National Health Mission, state governments, Ministry of Health & Family Welfare and district hospitals. There is a need for convergence between ministries and government departments for efficient and consistent IDD service delivery. Such convergence could be akin to that between the Department of Women and Children (DWCD) and the Department of Health and Family Welfare (DHFW). While both departments work on maternal and child health, they have streamlined their efforts to ensure minimal overlap, with the DWCD's *anganwadi* worker operating at the village level and working with the DHFW's auxiliary nurse midwife (ANM) who oversees 3-5 villages.[96]
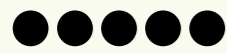
CHAPTER /5 ● ● ● ● ●

SECTOR SNAPSHOT AND ORGANIZATION PROFILES

This chapter captures key sector trends identified through Dasra's comprehensive landscaping and due diligence process (described in Appendix 1) and profiles ten organizations doing exceptional work in the space of intellectual and developmental disability. These ten organizations have been assessed on the basis of their models and programs and have been mapped to the priority interventions discussed in Chapter 3.

17 PUNJAB

17 RAJASTHAN

20 GUJARAT

18 WEST BENGAL

12 ODISHA

84 MAHARASHTRA

15 TELANGANA

13 ANDHRA PRADESH

45 KARNATAKA

38 TAMIL NADU

12 KERALA

Organizations engaged with through the due diligence process

405 Researched

147 Interviewed

14 Visited
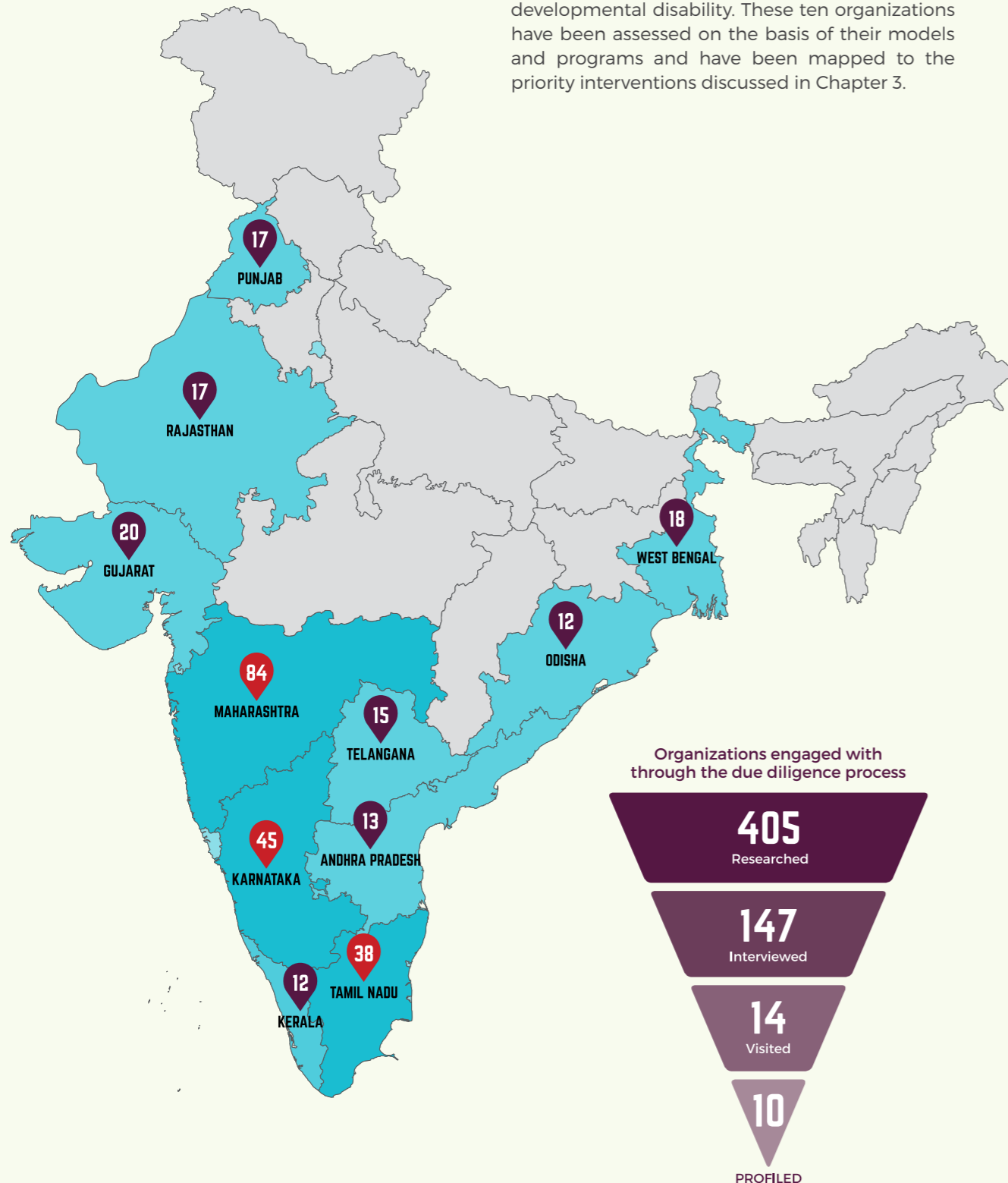
10 PROFILED

KEY TRENDS

PwIDDs face a shortage of adequate and quality services and hence, depend on non-profit organizations to access even their most basic rights.
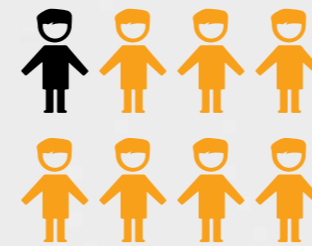
However, of the 405 organizations profiled

ONLY **35%** provide services exclusively to PwIDDs

One in eight children in India aged two to nine years has a neuro-developmental disorder

OVER **43%** were set up only in the last two decades

Among PwIDDs, persons with multiple disabilities find it even harder to get the requisite support.

Of all the types of intellectual and developmental disabilities, our analysis revealed that only 14% of the organizations provide services to persons with multiple disabilities.

42% INTELLECTUAL DISABILITY

23% AUTISM SPECTRUM DISORDER

17% CEREBRAL PALSY

14% MULTIPLE DISABILITIES
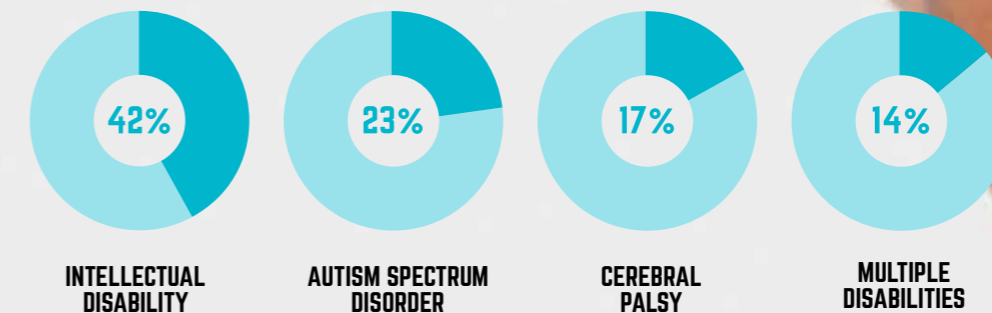
A larger number of non-profit organizations in metros have an online presence as compared to those in non-metros

50% of organizations headquartered in non-metros do not have an online presence, which limits accessibility of their services to persons with IDD and their families.
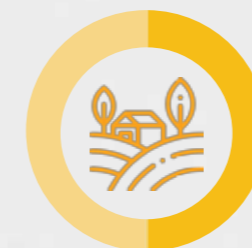
NON METROS - ONLINE 50%

METROS - ONLINE 85%

Mapping the key interventions to organizations profiled in the report

INTERVENTIONS	Action for Autism	Bethany Society	Indian Institute of Cerebral Palsy	Jai Vakeel Foundation	Latika Roy Memorial Foundation
Provide diagnostic services and family centered early intervention care	●	●	●	●	●
Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers		●		●	●
Deliver technical training to educators in special schools and inclusive schools	●	●	●		●
Equip educators in special and inclusive schools with specifically designed and standardized teaching tools				●	
Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising PwIDDs	●	●	●	●	●
Conduct advocacy for legislative change and educate key stakeholders to generate awareness	●		●		●
Build capacity of partner organizations and enable them to create sustainable entities	●		●		●
Conduct research to build data on developmental disorders & program effectiveness	●		●		●

INTERVENTIONS	Muskaan	Rajasthan Mahila Kalyan Mandal Sanstha	Satya Special School	Ummeed Child Development Center	Vidya Sagar
Provide diagnostic services and family centered early intervention care		●	●	●	●
Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers				●	
Deliver technical training to educators in special schools and inclusive schools		●			●
Equip educators in special and inclusive schools with specifically designed and standardized teaching tools					
Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising PwIDDs	●	●	●		●
Conduct advocacy for legislative change and educate key stakeholders to generate awareness	●			●	●
Build capacity of partner organizations and enable them to create sustainable entities		●			●
Conduct research to build data on developmental disorders & program effectiveness			●	●	

Action for Autism (AFA)

Website: www.autism-india.org **| Model:** Non-profit

![ACTION FOR AUTISM — National Centre for Autism India]

Organization overview:

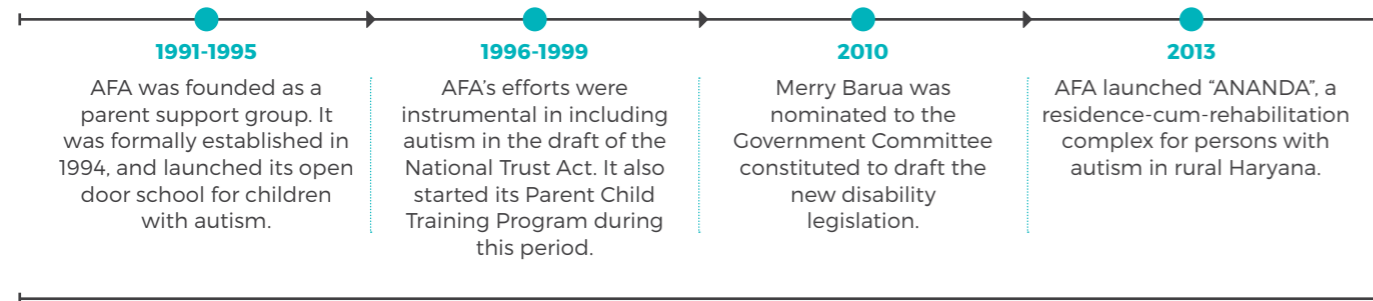**Founded:** 1991 **| Head office:** New Delhi **| Coverage:** New Delhi **| Full-time staff:** 61 **| Budget (2017-18):** INR 2.00 crores (USD 280,000)

AFA has spearheaded education, employment, training, research, policy and advocacy issues to support the rights of children and adults with ASD and multiple disabilities. AFA has pioneered the movement for autism in South Asia. It has influenced policy, promoted the demystification of professional knowledge, catalyzed educational inclusion, and most importantly enabled parents to become change makers.

How did it evolve?

1991-1995
AFA was founded as a parent support group. It was formally established in 1994, and launched its open door school for children with autism.

1996-1999
AFA's efforts were instrumental in including autism in the draft of the National Trust Act. It also started its Parent Child Training Program during this period.

2010
Merry Barua was nominated to the Government Committee constituted to draft the new disability legislation.

2013
AFA launched "ANANDA", a residence-cum-rehabilitation complex for persons with autism in rural Haryana.

Program overview:

Coverage: New Delhi **| Full-time program staff:** 40 **| Budget (2017-18):** INR 1.70 crores (USD 240,000)

The problem

There is lack of awareness and incomplete understanding of ASD, due to the dearth of simple, accessible information on the issue. As a result, children with autism are often misunderstood, even by their own families, and do not receive adequate support from them and the wider community.

AFA's approach

AFA aims to demystify knowledge about autism spectrum disorder and make it easily accessible to the public. It has a school for children with autism to equip them with basic knowledge and functional skills. It also runs programs to train and empower parents to better understand, manage and accept their autistic children.

What does it do?

AFA undertakes a number of programs, including:

- **Parent Child Training Program (PCTP):** This 12-week program is conducted thrice every year. About 10-15 parents participate in each session wherein they are trained alongside their children by experienced therapists. The main goal of the PCTP is to empower the parents to manage challenging situations and to work effectively with the child from a place of acceptance and understanding.
- **Open door school:** It has gained recognition as a model school for children with autism in India and the wider South East Asian region. It currently has six sections with children between the ages of three and 18 years. The school adapts and applies training techniques gathered from around the world to the Indian context.
- **Research:** AFA's focus is primarily on creating and gathering accessible and applicable research on issues related to ASD. It uses this research to inform and educate the public, advocate with the government and to modify and enhance its own programs.
- **Publications:** Autism Network, the AFA journal, has been in circulation since 1994, to disseminate research and make relevant information about autism available to the public.
- **Professional training:** AFA runs Diploma and B.Ed. teacher training programs in addition to several skill-enhancement programs through the year.

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ⭘ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ✔ Deliver technical training to educators in special schools and inclusive schools
- ⭘ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising PwIDDs
- ✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ✔ Build capacity of partner organizations and enable them to create sustainable entities
- ✔ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ⭘ AFA reaches more than 2000 beneficiaries every year through its programs. It has reached nearly 45,000 parents through the Autism Network over the years.
- ⭘ The Parent Child Training Program (PCTP) has been replicated in different cities in India, including Ahmedabad, Jalandhar, Jaipur, Indore and Baroda, as well as in neighbouring countries like Nepal and Bangladesh.
- ⭘ Two major successes of AFA's advocacy efforts are the inclusion of autism in two laws, viz., the National Trust Bill in 1999 and the Rights of Persons with Disabilities Act 2016, and the creation of a Diploma in Special Education (Autism Spectrum Disorder) by RCI in 2003.

What next?

- ⭘ The organization aims to create opportunities for white-collar jobs by advocating with equal opportunity cells in colleges and pushing for campus recruitments.
- ⭘ It plans to develop a residential program and build group homes for independent living.
- ⭘ It wants to leverage the 'sports for development' model to further help children with ASD and has already hired a staff member who specializes in training children for the Special Olympics.

Children with autism at the open door school engage in playtime activities.

Quality indicators

Leadership

Merry Barua, Director, AFA and National Centre for Autism
- ⭘ She is a founder member of the World Autism Organization in Luxembourg. She was nominated to the first Council and was elected Vice President.
- ⭘ She has served 3 terms on the board of National Trust.

Partners and Funders

United Way, Give Foundation, Ernst & Young, UCLA

Awards and Endorsements

- ⭘ Winner, The India NGO Award category 'The Rising Star' 2012 by Resource Alliance & Rockefeller Foundation
- ⭘ Winner, National Award in Best Service Institution Category for 'Outstanding performance in the field of empowerment of PwDs' by the Ministry of Social Justice and Empowerment, GoI (2011)

"I got so much help personally, morally, financially – in every aspect. I feel like somebody is with me all the time, and that gives me peace of mind. AFA has really helped me. My child has progressed a lot; his behavior has improved. AFA has also addressed some of his sensory issues. It is an all-in-one center – all kinds of help in one place."

- Mohana S Kumar (parent of a child enrolled at the open door school)

Voices from the ground

"The aim of the programs run by AFA is to demystify the professional concepts and to empower the parents, especially the mothers. The focus is the mother and child. We want the Parent Child Training programs to be replicated in order to create a ripple effect – increase awareness and change the belief and mindset of people."

- Indrani Basu, Head of Parent and Family Training

Voices from the team

Bethany Society

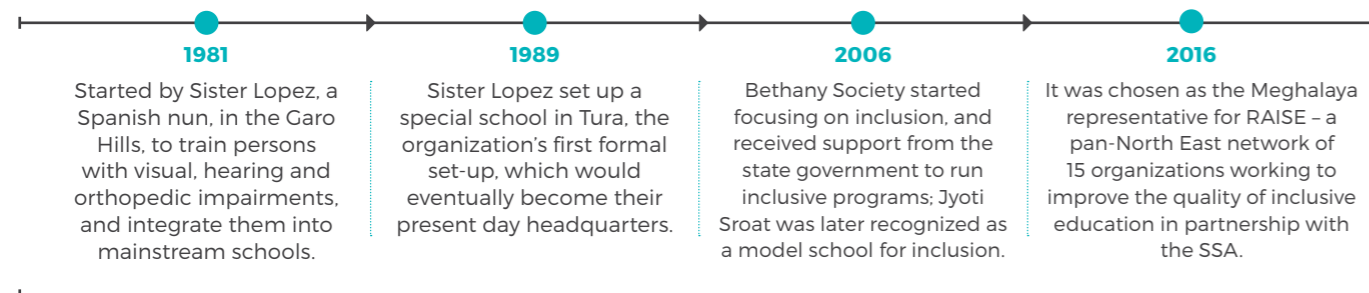**Website:** www.bethanysociety.org | **Model:** Non-profit

Organization overview:

Founded: 1981 | **Head office:** Tura, Meghalaya | **Coverage:** Meghalaya | **Full-time staff:** 125
Budget (2017-18): INR 4.00 crores (USD 565,000)

Bethany Society caters to two target beneficiary groups – PwDs and the rural poor. It is a secular organization, providing services to PwDs from birth till adulthood. With an emphasis on collaboration, every intervention strives to establish a community-based model and network. Inclusion and innovation are core aspects of the organization's approach towards improving the quality of life for PwDs.

How did it evolve?

1981	1989	2006	2016
Started by Sister Lopez, a Spanish nun, in the Garo Hills, to train persons with visual, hearing and orthopedic impairments, and integrate them into mainstream schools.	Sister Lopez set up a special school in Tura, the organization's first formal set-up, which would eventually become their present day headquarters.	Bethany Society started focusing on inclusion, and received support from the state government to run inclusive programs; Jyoti Sroat was later recognized as a model school for inclusion.	It was chosen as the Meghalaya representative for RAISE – a pan-North East network of 15 organizations working to improve the quality of inclusive education in partnership with the SSA.

Program overview:

Coverage: Meghalaya | **Full-time program staff:** 125 | **Budget (2017-18):** INR 4.00 crores (USD 565,000)

The problem

There is lack of quality services for Persons with Disabilities in the rural interiors of Meghalaya that can support and enable them to live fulfilled lives. There is also a lot of stigma associated with PwDs and, therefore, they are treated differently by members of the community.

Bethany Society's approach

Bethany Society aims to eradicate discrimination against PwDs by designing and implementing interventions with a prime focus on inclusion. Additionally, the organization focuses on building the capacity of communities and equipping them to become inclusive, rather than building institutions that isolate PwDs from them.

What does it do?

Bethany Society works with persons with disabilities, children, youth and women living in extreme poverty, with a special focus on remote, rural areas in North-East India.

- **Inclusive education:** As part of its focus on inclusion, Bethany Society has set up the Jyoti Sroat School, an inclusive school based in Shillong. Additionally, the organization aims to scale its efforts in inclusive education through the RAISE network.
- **Sustainable livelihoods for PwDs:** Keeping an agro-based and environment friendly theme at the centre, Bethany Society researches and tests potential employment-generating models for PwDs, which are easy, economic and environment friendly. They have also formed inclusive self-help groups and trained PwDs in farming, poultry etc.
- **Community-based rehabilitation:** Services provided through this program include early intervention, linking PwDs to government schemes and family counselling. The organization has also helped to build Disabled People's Organizations (DPOs) in the community for self-advocacy and empowerment.
- **Training and capacity building program:** It trains government and mainstream teachers in inclusion, NGOs in CBR, and has a center for RCI-certified courses (Foundation course and B. Ed in visual impairment).

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ✔ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ✔ Deliver technical training to educators in special schools and inclusive schools
- ○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ○ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ○ Build capacity of partner organizations and enable them to create sustainable entities
- ○ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ○ Through its inclusive school and CBR programs, Bethany Society reaches more than 500 PwIDDs annually.
- ○ Jyoti Sroat has been recognized as a model school by the Meghalaya State Government.
- ○ Bethany Society represents Meghalaya in the prestigious RAISE program and is at the forefront of designing and implementing the program due to in-house expertise in inclusion.
- ○ It has conducted access audits for 60 government buildings in Meghalaya and presented recommendations to make these buildings disabled-friendly.

What next?

- ○ For the rural livelihoods program, the organization is exploring the e-marketing potential of products made by PwIDDs.
- ○ it plans to invest in research and development for further innovations in sustainable agro-based livelihoods for PwDs, which are easy, environment-friendly and good sources of additional income.
- ○ The organization aims to invest in building the capacity of teachers and equiping them with the skills needed to use technology to deliver the state curriculum to all children, irrespective of disabilities.

Students in the Jyoti Sroat at an Annual Day event, in an inclusive setting.

Quality indicators

Leadership

Shirleen B. Sawkmie, President, Bethany Society
- ○ She is a member of the Governing Body of the Rehabilitation Council of India.

Carmo Noronha, Executive Director, Bethany Society
- ○ He is a part of the General Governing Body of the National Rural Livelihoods Mission.

Bertha Dkar, Board Member, Bethany Society
- ○ She has been awarded the Padma Shri in recognition of her efforts towards the education of children with disability.

Partners and Funders

Department of Education, Government of Meghalaya, 15 NGOs of the RAISE program, The Hans Foundation, APPI, Light for the World

Awards and Endorsements

- ○ Winner, National Award for Promoting Sustainable Livelihoods for PwDs from the Ministry of Social Justice and Empowerment, Government of India (2016)

> "My motivation to work comes from the community's support and their respect for the work we do. The biggest driving factor for me is when I see the individuals we work with go on to become independent, respected members of society. Recently, a boy who availed of our CBR program got employed in the local school. That, for me, was a moment of joy and pride, and a testament to the good work Bethany is doing."
>
> - Field Worker

Voices from the ground

> "Bethany Society's Theory of Change follows the hedgehog concept. We identify unique approaches for implementing interventions. Our expertise lies in inclusion. We focus on identifying the mission multipliers and teaching and training methods that are "Essential for some, Good for All". We strongly believe that if you have a good model that is in collaboration and not in competition with the government, it works."
>
> - Carmo Noronha, Executive Director

Voices from the team

Indian Institute of Cerebral Palsy (IICP)
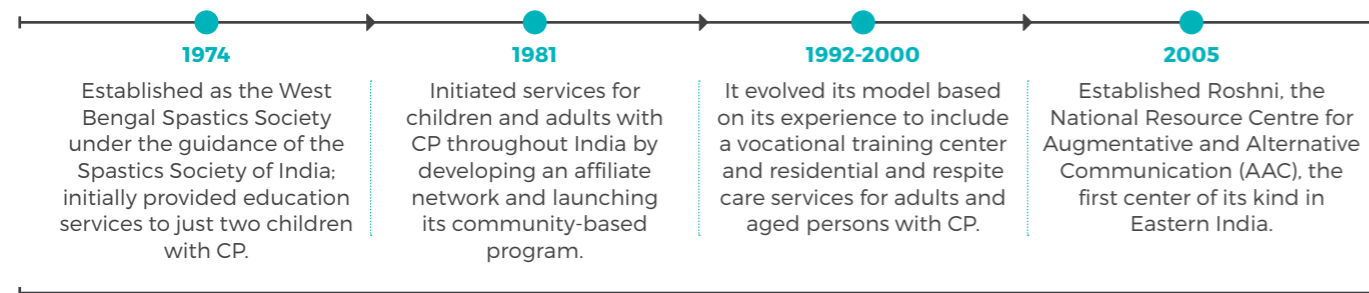
Website: www.iicpindia.org | **Model:** Non-profit

Organization overview:

Founded: 1974 | **Head office:** : Kolkata, West Bengal | **Coverage:** West Bengal | **Full-time staff:** 160
Budget (2017-18): INR 4.87 crores (USD 685,000)

IICP is a specialist resource center for cerebral palsy (CP) and other neuro-motor disabilities. It seeks to bring positive changes in the lives of all people with such disabilities through a range of policies and service provisions. These are designed to enhance their individual skills and knowledge, give them the opportunity to exercise their constitutional rights and fully participate and contribute to the community and country.

How did it evolve?

1974
Established as the West Bengal Spastics Society under the guidance of the Spastics Society of India; initially provided education services to just two children with CP.

1981
Initiated services for children and adults with CP throughout India by developing an affiliate network and launching its community-based program.

1992-2000
It evolved its model based on its experience to include a vocational training center and residential and respite care services for adults and aged persons with CP.

2005
Established Roshni, the National Resource Centre for Augmentative and Alternative Communication (AAC), the first center of its kind in Eastern India.

Program overview:

Coverage: West Bengal | **Full-time program staff:** 160 | **Budget (2017-18):** INR 4.87 crores (USD 685,000)

The problem

There are limited primary service providers for persons with CP in Eastern India. In the absence of professionals who understand their needs and can help educate, train and support them, they are isolated from mainstream society and find it difficult to lead meaningful, holistic lives.

IICP's approach

IICP provides a range of services that are designed to enhance the learning and adaptive skills of persons with CP and multiple disabilities. It has adopted the social model of disability, and uses either institution-based or community-based interventions based on the PwIDD's needs.

What does it do?

IICP provides a range of services and programs including:

- **Diagnostic clinic and early intervention services:** It runs a screening clinic for infants, many of whom are referred from hospitals as soon as they are discharged. The early intervention services include physical therapy, stimulation programs and family support.
- **Education:** IICP has a Centre for Special Education that provides a broad-based, holistic learning experience for children with CP regardless of the severity of their disability. It also uses AAC for students with complex communication needs.
- **Vocational Training:** In addition to a printing and catering unit, it runs a Computer Unit that offers courses in collaboration with Jadavpur University to train PwIDDs in basic software like Microsoft Word, Excel and PowerPoint.
- **Training:** With certification from Jadavpur University, IICP conducts a two-year B.Ed. degree in Special Education (Multiple Disabilities) among other programs.
- **Community-based rehabilitation:** It provides technical support and need-based training to community-based organizations in slums in Kolkata, rural districts of West Bengal and organizations in other states in India.
- **Research and advocacy:** IICP conducts research through clinical trials and studies, and advocates for the rights of persons with disability.

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ⭘ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ✔ Deliver technical training to educators in special schools and inclusive schools
- ⭘ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ✔ Build capacity of partner organizations and enable them to create sustainable entities
- ✔ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ⭘ The organization's direct service users for the year 2017-18 included 1665 children and adults with CP and multiple disabilities.
- ⭘ IICP is considered a pioneer and leading specialist organization in this field by the government, RCI and international partners. Dr. Sudha Kaul, Founder and Special Educator at IICP, was invited to contribute to the formulation of the Rights of Persons with Disability Act, 2016, in recognition of this leadership.

What next?

Over the next few years, IICP plans to:

- ⭘ Build its vocational training and residential service programs;
- ⭘ Focus on building the capacity of its staff members and find innovative ways to attract and retain talent; and
- ⭘ Develop new strategies to raise institutional funds beyond programmatic requirements.

Students from the Centre for Special Education participate in a race during IICP's annual sports day.

Quality indicators

Leadership

Dr. Sudha Kaul, Founder and Special Educator
- ⭘ She was a recipient of the Padma Shri in 2010 for her contribution to the disability sector.

Partners and Funders

Jadavpur University, National Trust, eight affiliate non-profit organizations across the country, Tata Trusts, Cipla Foundation, Goodricke Group

Awards and Endorsements

- ⭘ Winner, National Award for Best Institute for Disability from the Ministry of Social Justice and Empowerment
- ⭘ Winner, Outstanding Training Institute from RCI
- ⭘ Winner, Best Respite Care Services and Best State Nodal Agency Centre from National Trust

"I have been in this school since I was a child and apart from the subjects, I learned how to work with my friends and teachers, interact with visitors and arrange an event or program. I have had the opportunity to participate in various cultural programs. I am a member of the school band and perform as a percussionist. I will miss my friends when I leave school."

- Tanbir Hossain Safui, Senior Academics, Centre for Special Education

"It is a great privilege to serve with such motivated and dedicated administrative and support staff. I enjoyed every moment of it. I was made aware that every bit of our effort with the limited resources at our disposal went towards the betterment of our services to the children and their parents. And of course, I will cherish for a long time the experience shared with the children."

- Wing Commander AK Chowdhury, Former Administrative Officer

VOICES FROM THE GROUND

VOICES FROM THE TEAM

Jai Vakeel Foundation

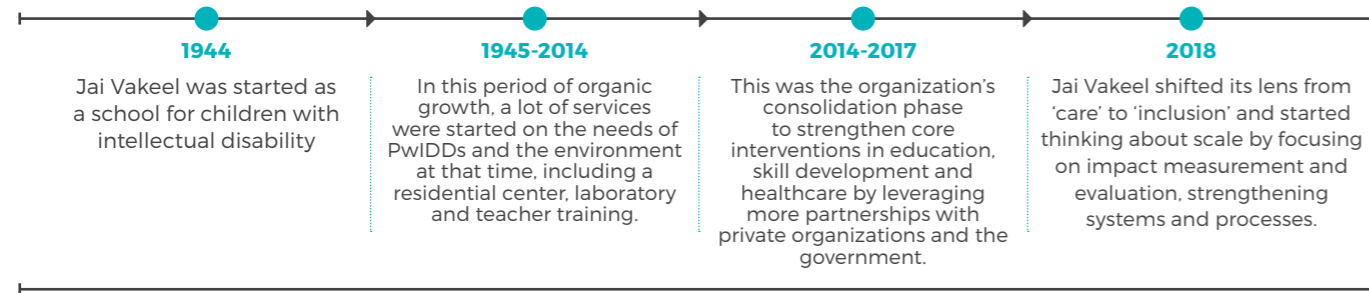**Website:** www.jaivakeel.org | **Model:** Non-profit

Organization overview:

Founded: 1944 | **Head office:** Mumbai, Maharashtra | **Coverage:** Maharashtra | **Full-time staff:** 217
Budget (2017-18): INR 11.70 crores (USD 1,650,000)

Jai Vakeel is one of the oldest non-profit organizations that focuses on PwIDDs and aims to integrate its students into mainstream society through holistic interventions in three areas: healthcare, education, and skill development. Started by a parent of a child with Down's Syndrome, its philosophy is to keep the child with IDD and the family at the center of everything it does.

How did it evolve?

1944	1945-2014	2014-2017	2018
Jai Vakeel was started as a school for children with intellectual disability	In this period of organic growth, a lot of services were started on the needs of PwIDDs and the environment at that time, including a residential center, laboratory and teacher training.	This was the organization's consolidation phase to strengthen core interventions in education, skill development and healthcare by leveraging more partnerships with private organizations and the government.	Jai Vakeel shifted its lens from 'care' to 'inclusion' and started thinking about scale by focusing on impact measurement and evaluation, strengthening systems and processes.

Program overview:

Coverage: Maharashtra | **Full-time program staff:** 217 | **Budget (2017-18):** INR 11.70 crores (USD 1,650,000)

The problem

In spite of their large numbers, there is a lack of interventions specifically focused on PwIDDs, which are tailored to their unique needs and are designed keeping their families in mind.

Jai Vakeel Foundation's approach

Jai Vakeel Foundation's solution is to develop a two-part intervention model. In the short term, the organization aims to improve outcomes for its students, thus creating proof of what is possible. In the long term, the goal is to increase awareness, sensitize the community and build capacity of others to impact lives at scale.

What does it do?

Jai Vakeel runs the following programs for PwIDDs:

O **Schooling programs:** Jai Vakeel operates four schools - two in Mumbai and two rural-based. A salient feature is the curriculum, which integrates academics, pre-vocational training, functional skills and therapies into a single learning outcomes framework.

O **Vocational training and employability:** Young adults, aged 18 and above, undergo a three-year vocational training. Three employment avenues are offered – open employment through partnerships, integration in family employment and sheltered workshops.

O **Rehabilitation center:** The center provides diagnostic services, early intervention therapies, parent training, counseling etc. Parent attendance is encouraged for all therapy sessions.

O **Respite services:** Respite care is also offered to persons with severe disabilities, in the form of part-time or temporary stay services, to offer parents some rest. Bi-annual medical camps are held in two districts of Maharashtra to provide a multidisciplinary intervention to children with neurological disorders and epilepsy.

Key interventions

✔ Provide diagnostic services and family centered early intervention care

✔ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers

O Deliver technical training to educators in special schools and inclusive schools

✔ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools

✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD

O Conduct advocacy for legislative change and educate key stakeholders to generate awareness

O Build capacity of partner organizations and enable them to create sustainable entities

O Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

O The organization reaches 3000 individuals and their families annually, 2200 through the medical camps and 800 through the healthcare, education and skill development program.

O Jai Vakeel has built the first of its kind, comprehensive, multi-sensory curriculum to help special educators teach children with different learning needs.

O It has one of the largest sheltered workshops with over 200 products being made and sold.

O 12 students have participated in the Special Olympics at the international level in different sports.

What next?

The organization has formulated Mission 2022, with intervention-specific focus areas, as mentioned below.

O **Healthcare services:** Building capacity of the team to enhance the partnership with the state government whereby Jai Vakeel provides training to the government's community-based medical staff, and provides awareness and therapy sessions at government-organized medical camps in rural Maharashtra to ensure impact on individuals at scale.

O **Education services:** By 2022, the organization aims to help build the capacity of others in the space and thereby affect more lives by demonstrating impact and sharing their proven model, best practices and making resources available.

Students in a Jai Vakeel physical therapy session.

Quality indicators

Leadership

Archana Chandra, CEO of Jai Vakeel,
O She, along with her husband, is one of India's most prolific givers and has featured in the Forbes Asia's Heroes of Philanthropy List.

Partners and Funders

La-Monnaie Skills, Teach India, Government of Maharashtra, Aditya Birla Group, Credit Suisse, Tata AIG, HT Parekh Foundation

Awards and Endorsements

O The 100% in-house built curriculum has been quoted as reference material by the Disability Commissioner in the Special School Code Book.

O Winner, 'National Award in public recognition of outstanding performance in the field of Handicapped Welfare' by the Research Society.

O The organization has been appointed as the State Nodal Agency Center for the third time by the National Trust.

'Jai Vakeel has been a GODSEND for us! My daughter Malti can do more than we ever dreamt of. Inspired by the foundation, she wants to work as a micro biologist.'

 - Parent of a child enrolled in Jai Vakeel's EIC Unit

"Jai Vakeel has always been a place parents and children with IDD have relied on, and come to for all their problems. As an organization, we have evolved to provide for every need of our children. The focus has been on holistic interventions, and not only education, or only therapy. Our end goal is inclusion, and inclusion needs an all-encompassing intervention."

- Archana Chandra, CEO, Jai Vakeel

Voices from the ground

Voices from the team

Latika Roy Memorial Foundation

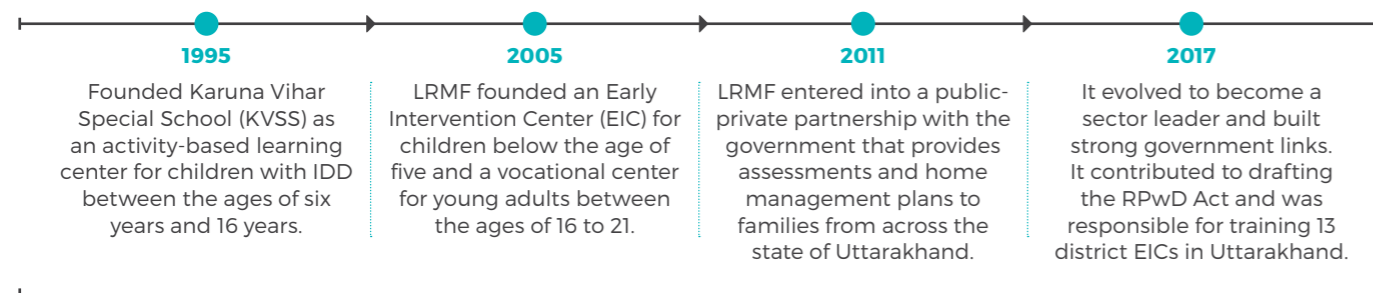**Website:** www.latikaroy.org | **Model:** Non-profit

Organization overview:

Founded: 1994 | **Head office:** Dehradun, Uttarakhand | **Coverage:** Uttarakhand, Uttar Pradesh and Himachal Pradesh
Full-time staff: 104 | **Budget (2017-18):** INR 4.00 crores (USD 555,000)

The Latika Roy Memorial Foundation (LRMF) has been a force for inclusion in North India for nearly 25 years. Founded in 1994 and based out of Dehradun, the organization works with children and young adults with disabilities. The foundation provides creative diagnostic services, education and therapy to children and adults, focusing on those that fall financially and socially outside the reach of mainstream education and support services.

How did it evolve?

1995
Founded Karuna Vihar Special School (KVSS) as an activity-based learning center for children with IDD between the ages of six years and 16 years.

2005
LRMF founded an Early Intervention Center (EIC) for children below the age of five and a vocational center for young adults between the ages of 16 to 21.

2011
LRMF entered into a public-private partnership with the government that provides assessments and home management plans to families from across the state of Uttarakhand.

2017
It evolved to become a sector leader and built strong government links. It contributed to drafting the RPwD Act and was responsible for training 13 district EICs in Uttarakhand.

Program overview:

Coverage: Uttarakhand, UP and HP | **Full-time program staff:** 104 | **Budget (2017-18):** INR 4.00 crores (USD 555,000)

The problem

Parents of children with IDD struggle to find quality services and trained professionals. This causes stress and alienates families, and perpetuates the myth that it is difficult for children with IDD to lead fulfilling lives.

Latika Roy Memorial Foundation's approach

LRMF provides specialized local services for children and vulnerable adults with intellectual and development disabilities and their families while also building the capacity of other organizations to provide such services. It uses a family centered approach in which it empowers parents to be partners in its quest for inclusion.

What does it do?

The Latika Roy Memorial Foundation provides the following services for children and young adults with intellectual and developmental disabilities:

○ **Early intervention center and child development center:** This center caters to infants with developmental delays and children between six and 14 who need functional education and therapy. It focuses on learning through play and trains parents to support their children more effectively.
○ **Special school (KVSS):** The school uses activity-based learning tools to provide educational services to children with special needs between the ages of 6 and 14.
○ **Center for vocational training (CVT):** The training center targets young adults between 14 and 21 years with disabilities. It provides these individuals with job training and life-management tools.
○ **Latika Vihar:** This center provides recreational facilities to persons with IDD and arranges for activities such as pottery classes, table tennis sessions, etc.
○ **Resource center and legal and advocacy unit:** The Resource Center provides information and support to people with disability, and other interested parties. It also offers courses on rehabilitation for professionals and parents.

Key interventions

✔ Provide diagnostic services and family centered early intervention care
✔ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
✔ Deliver technical training to educators in special schools and inclusive schools
○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
✔ Build capacity of partner organizations and enable them to create sustainable entities
✔ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

○ It assesses approximately 1000 new children annually, provides therapy, education and opportunities to over 260 children every day and follows-up with 500 families.
○ LRMF has sensitized almost 5000 people annually through training, workshops and awareness and outreach initiatives in remote locations across Uttarakhand.
○ LRMF's advocacy and legal unit is held in high regard in Uttarakhand. Apart from being asked to draft the rules for Uttarakhand under the RPWD Act, 2016, the team has intervened and helped more than 22 female survivors of sexual abuse get compensation due to them.

What next?

○ LRMF is looking to consolidate its operations in one campus as evidence of institutional maturity and to showcase the Universal Design for Learning (UDL) framework.
○ Its vision is to create a state-of-the-art 62000 square foot campus that will be a model of inclusion for the entire country and incorporate UDL features for children and people with disability. It has acquired prime real estate in Dehradun and has the pro-bono support of architectural and project management firms.
○ Consolidating its services will help it to increase the quality and reach of its services, decrease operational costs and showcase how architecture and design can reduce and even eliminate barriers for people with disabilities

Staff members celebrate with a child at Latika Roy Foundation's special school.

Quality indicators

Leadership

Jo Chopra, Founder and Executive Director, LRMF
○ Jo is a prolific writer who has written for publications such as the Wire, Mint, Dialogue, etc.
○ She has been a guest speaker at prestigious events including Ted Talks and conferences organized by Ashoka University and Dasra.
○ She is the recipient of several awards such as the CNN IBN Real Hero (2012) and the Times of India Icon Award (2017).

Partners and Funders

Doon Hospital, Ummeed Foundation, Teach for India, Gateway School, Tata Trusts, Sightsavers, BHEL, National Rural Health Mission

Awards and Endorsements

○ Winner, Laadli Award from Population First (2015)
○ Winner, Sightsavers International Innovative Project Award (2013)
○ Winner, NGO of the Year Award from National Trust (2012)

"When I first brought Simran to the EIC, she would not leave my lap. Now, 4 years later, her confidence and maturity are a source of pride for me. Today, she attends a mainstream school and is doing well there. The credit for her remarkable progress in development goes to the EIC staff"

- Simran's (child enrolled in EIC) mother

"At the Latika Roy Foundation, we truly believe in staff development. Most of my colleagues have been here for more than 10 years. Through those years, they have managed to evolve and train in multiple therapies allowing them to be better teachers and therapists. I joined LRMF as a volunteer 22 years ago and today I've done my B. Ed. from LRMF and become a special educator."

- Manju Subedi, Project Head, LRMF

Voices from the ground

Voices from the team

Muskaan

Website: www.muskaanthengo.org | **Model:** Non-profit

Celebrating Simple Joys
MUSKaaN
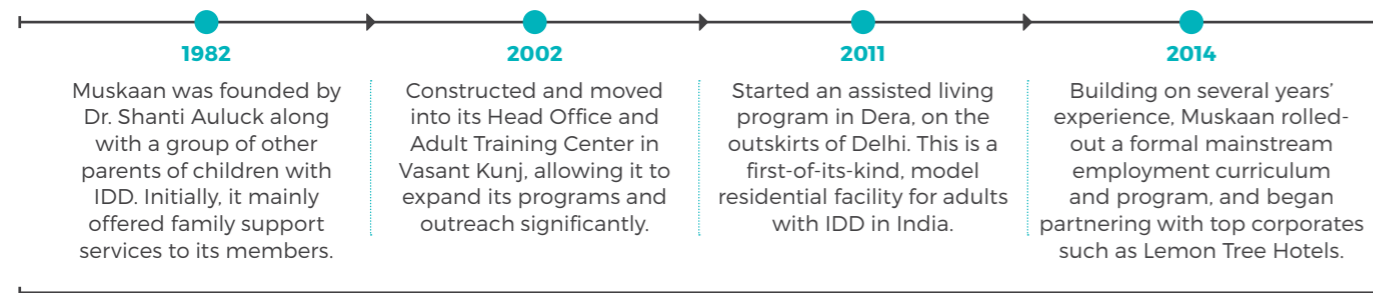*Spreading smiles among the differently abled*

Organization overview:

Founded: 1982 | **Head office:** Delhi, NCR | **Coverage:** Delhi, NCR | **Full-time staff:** 51
Budget (2017-18) INR 2.55 crores (USD 360,000)

Over the last 36 years, Muskaan has established itself as a thought-leader in India within the space of Intellectual and Developmental Disability (IDD). Muskaan seeks to empower children and adults with disability to live fulfilled, self-reliant and meaningful lives. It does this by providing comprehensive education and training, including vocational training and employment opportunities to PwIDDs.

How did it evolve?

1982
Muskaan was founded by Dr. Shanti Auluck along with a group of other parents of children with IDD. Initially, it mainly offered family support services to its members.

2002
Constructed and moved into its Head Office and Adult Training Center in Vasant Kunj, allowing it to expand its programs and outreach significantly.

2011
Started an assisted living program in Dera, on the outskirts of Delhi. This is a first-of-its-kind, model residential facility for adults with IDD in India.

2014
Building on several years' experience, Muskaan rolled-out a formal mainstream employment curriculum and program, and began partnering with top corporates such as Lemon Tree Hotels.

Program overview:

Coverage: Delhi NCR | **Full-time program staff:** 39 | **Budget (2017-18):** INR 2.41 crores (USD 340,000)

The problem

There is a severe lack of professional services for children and adults with IDD and their families, as well as limited general awareness on the issue. There is also limited focus on building long-term capacity of PwIDDs and enabling them to live self-reliant and dignified lives in adulthood.

Muskaan's approach

Muskaan believes that with the right training, PwIDD have immense learning potential and the capacity to be self-reliant and empowered. Muskaan adopts the life-span approach to understand the unique needs of every individual, and builds the confidence and skills required for the individual to be gainfully employed.

What does it do?

- **Adult training program:** It focuses on the holistic development of individuals over 16 years through life skills education, creative expression (arts and crafts), games and recreation, and vocational skills and computer training to empower them.
- **In-house supported employment:** Muskaan has nine vocational units that together train over 100 students in prevocational and vocational skills. The units include food processing, data entry, craft units, bakery and snacks, amongst others. The sales from products made at the unit contribute to approximately 30% of Muskaan's annual organization budget.
- **Supported mainstream employment:** The organization trains and facilitates the transition of PwIDDs into mainstream jobs with corporates.
- **Dera residential facility:** The 21-person facility is a participative and assisted living model where residents are engaged in making decisions related to their life and day-to-day living. It was set up under the Gharaunda scheme of the National Trust.
- **Family support services:** Services include short-term training programs, counselling and guidance, assistance in availing benefits of government schemes and workshops for parents.
- **Awareness & advocacy:** Muskaan reaches out to leading schools, colleges and offices in Delhi through immersion visits, seminars and cultural events.

Key interventions

- Provide diagnostic services and family centered early intervention care
- Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- Deliver technical training to educators in special schools and inclusive schools
- Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- Build capacity of partner organizations and enable them to create sustainable entities
- Conduct research to build data on developmental disorders & program effectiveness

FCRA ✔ 12A ✔ 80G ✔

What has it achieved?

- Since 2014, Muskaan has successfully placed and retained 26 students in mainstream jobs. It is the sole training and employment partner for Lemon Tree Hotels, Radisson, Four Point Sheraton and Country Inn and Suites. Muskaan has also placed students in Microsoft (Mumbai) and Jubilant FoodWorks Limited (Noida).
- Over the years, Muskaan has built very strong linkages with the government. It has participated actively with the Disability Rights Group, a cross disability network, for the development of the RPWD Act 2016 and Right to Education Act 2009. Muskaan has also played an active role in several expert committees formed by the government to guide policy and decisions such as the Planning Commission, RCI and National Trust.

What next?

- Muskaan plans to formally set-up and expand Muskaan Social Consultancy Services, an experiential program to spread awareness and sensitize corporates on IDD; it also plans to simultaneously build a steady and sustainable income stream for the organization through 2018-2020.
- It wants to expand its employability focus by starting an additional prevocational training program for children between 12 and 16 years.
- Muskaan wants to achieve scale by acting as a model institution for IDD in the country that educates civil society, trains other organizations, conducts professional training courses and advocates policy reform.

Adults working in the bakery at Muskaan's Supported Employment Centre.

Quality indicators

Leadership

Dr. Shanti Auluck, Founder
- She received the 'Distinguished Women Entrepreneur' national award from the Consortium of Women Entrepreneurs of India in 1999
- She was a member of the Planning Commission subcommittee for the 11th and 12th five year plans
- She is a governing body member of the Sector Skill Council for people with disability

Partners and Funders

MSJE, Delhi Social Welfare Department, Lemon Tree Hotels, Courtyard Marriot, Lady Sri Ram College, CBRE, Godfrey Phillips India Ltd, Bank of India, Magnetti Marelli Train India Pvt. Ltd. XL CATLIN, Competent Softwares Pvt. Ltd.

Awards and Endorsements

- Winner, Best Parents Association and Best Local Level Committee Award from National Trust (2011)
- Winner, Helen-Keller award by NCPEDP & Shell for creating employment opportunities for PwID (2011)

"What strikes me the most is the total accessibility to teachers and the principal. The teachers at Muskaan are completely committed to the individual needs of my daughter. She needed wings to soar high, and Muskaan gave her those wings. It has helped her become fearless and confident, and I have seen a tremendous change in her over the years. Seeing this change in my own daughter inspired me to help with the Life Skills Program (LSP)."

- Vandana Kumar, mother of Muskaan student (Punchika) and volunteer with the Life Skills Program

Voices from the ground

"At Muskaan, we have focused on empowerment and sustainability right from the start. We believe that to truly empower individuals we must focus on enriching adulthood – the longest span of life. Therefore, the need of the hour is to create adequate opportunities of employment, friendship building, health needs and safe and dignified living within or outside the family.

- Neera Chawla, Director

Voices from the team

Rajasthan Mahila Kalyan Mandal Sanstha (RMKM)

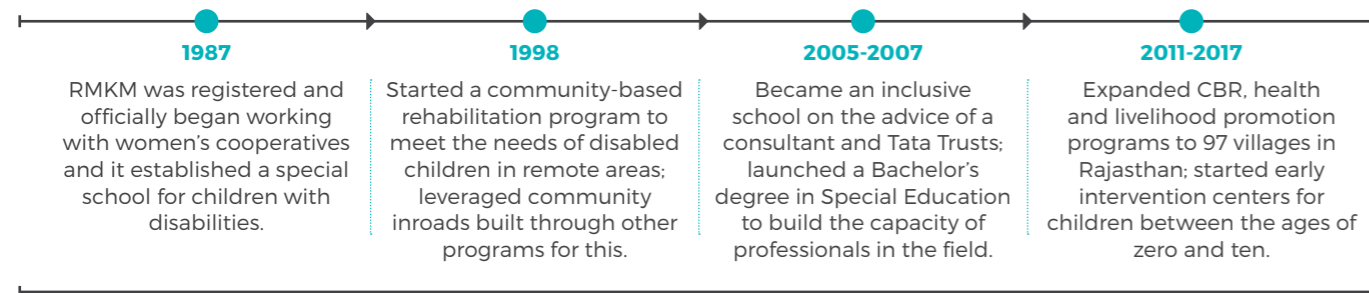**Website:** www.rmkm.org.in | **Model:** Non-profit

Organization overview:

Founded: 1987 | **Head office:** : Ajmer, Rajasthan | **Coverage:** Rajasthan
Full-time staff: 112 | **Budget (2017-18):** INR 2.75 crores (USD 380,000)

RMKM works to uplift rural communities in Rajasthan through formal education on skill enhancement, health, basic human rights and livelihood for independence and self-reliance. It seeks to partner with and empower individuals living below the poverty line, PwIDDs, women and the elderly.

How did it evolve?

1987
RMKM was registered and officially began working with women's cooperatives and it established a special school for children with disabilities.

1998
Started a community-based rehabilitation program to meet the needs of disabled children in remote areas; leveraged community inroads built through other programs for this.

2005-2007
Became an inclusive school on the advice of a consultant and Tata Trusts; launched a Bachelor's degree in Special Education to build the capacity of professionals in the field.

2011-2017
Expanded CBR, health and livelihood promotion programs to 97 villages in Rajasthan; started early intervention centers for children between the ages of zero and ten.

Program overview:

Coverage: Rajasthan | **Full-time program staff:** 58 | **Budget (2017-18):** INR 1.40 crores (USD 195,000)

The problem

The mother plays a pivotal role in taking care of a child with disability. However, in the rural areas of Rajasthan, there is limited access to medical practitioners, special educators and other support services that could ensure that the child is healthy and develops basic cognitive and functional skills.

RMKM's approach

RMKM is bridging this gap by providing a holistic range of services for children with disability and training both field professionals and parents on how best to care for the children. It believes that working with children with disability extends support to their mothers and eases the pressure on them as caregivers.

What does it do?

RMKM works in four key areas, namely education and inclusion, health, livelihood promotion and micro-credit, and human resources development. The services that focus on persons with disability include the following.

Education and Inclusion

- **Identification and early intervention:** RMKM has two early intervention centers. It also monitors children who were admitted to the Neonatal Intensive Care Unit of the government hospital for six months to identify any developmental delays.
- **Inclusive schools:** The organization runs two inclusive schools, for children with special needs and non-disabled children.
- **Day care and vocational training:** RMKM operates two vocational training centers for children with special needs that have five units each including woodcraft and vermin composting.
- **Community-based rehabilitation:** For families in remote villages and districts, the org runs a community-based rehabilitation program. The program focuses on the five aspects of the World Health Organization's CBR matrix – health, education, livelihood, social and empowerment.
- **Human resource development:** RMKM conducts special education training for government and private teachers. It also runs a Bachelor's degree and Diploma in Special Education (Mental Retardation) that is affiliated with the RCI.

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ○ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ✔ Deliver technical training to educators in special schools and inclusive schools
- ○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ○ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ✔ Build capacity of partner organizations and enable them to create sustainable entities
- ○ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ○ The organization provided services to more than 1600 children with disabilities in the year 2017-18 alone. It also linked over 2000 children with disabilities to more than 20+ social security schemes (including pensions, disability certificates, road and railway concessions, housing loans and NREGA cards) in the same period.
- ○ RMKM's inclusive schools train and prepare children with an inclination for sports to participate in the National Special Olympics-two such children with intellectual disabilities have won gold medals for roller skating.
- ○ It was the first organization in North India to adopt a 'Reverse Inclusion' model for its special school in 2006.

What next?

Over the next three years, RMKM plans to:
- ○ Systematically scale its CBR program from its current presence mainly in Central Rajasthan to 10 districts of the state, thereby reaching 5000 children with disabilities.
- ○ Build an early intervention center in Rajasthan on land provided by the government in a specially designed building with complete access for the disabled.
- ○ Develop a sensory park that will serve as a training area for children and young adults with autism, visual impairments and multiple disabilities.

A special educator teaches a child with disability at Minu inclusive school with the help of innovative tools.

Quality indicators

Leadership

Kshama R. Kaushik, Secretary and Chief Functionary
- ○ She graduated from TISS with an MA in Social Work; holds a B.Ed. in Special Education

Partners and Funders

Childline India Foundation, Vibha Inc, Sense International India, APPI, Give India, Perkins International, Rehabilitation Council of India, National Trust

Awards and Endorsements

- ○ Winner, Social Achievers Award from G.I.P. Foundation (2017)
- ○ Winner, State-Level Best Organization in the field of Mental Retardation (2009)
- ○ Winner, Best NGO from Ministry of Women and Children Development (2005)
- ○ Winner, Sulakshana Ram Janam Pandey Award for rehabilitation from NASEOH (2017)

"My son was born with intellectual disability, and I couldn't understand how to help him. He would lie in bed all day, unable to sit up, drooling and crying. The CBR sir has been a blessing. He worked with him consistently for the last four years, doing physical therapies and exercises to stimulate his mind. Today, he studies in a regular school alongside non-disabled children. Look, he can write his name in Hindi and knows basic multiplication!"

- Mother of Bhupendra, a beneficiary of the CBR program in Ajmer city

Voices from the ground

"There is so much stigma attached to these children. Our mission is to do everything in our power to reduce this stigma, and partner with experts, government bodies and other non-profit organizations to spread the idea of inclusion. For us, inclusion is not just an articulation or philosophy – it is a spirit and action."

- Kshama Kaushik, Secretary and Chief Functionary

Voices from the team

Satya Special School

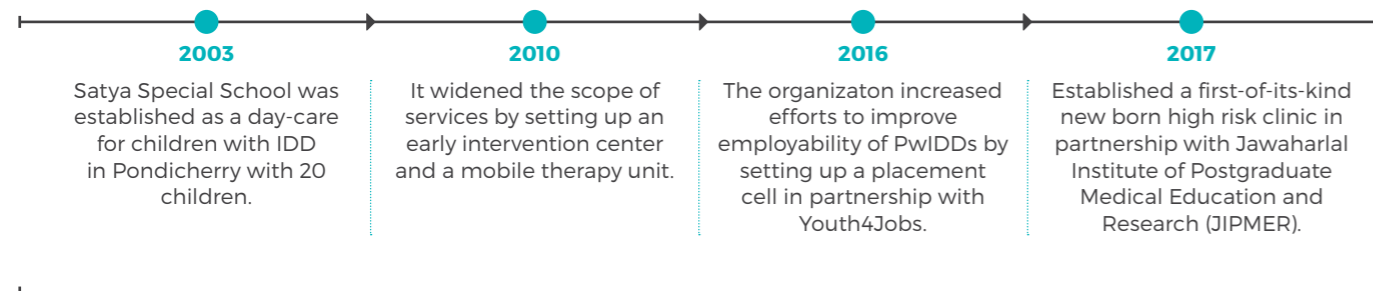**Website:** www.satyaspecialschool.org **| Model:** Non-profit

Organization overview:

Founded: 2003 **| Head office:** Pondicherry **| Coverage:** Pondicherry **| Full-time staff:** 125
Budget (2017-18): INR 2.78 crores (USD 400,000)

Satya Special School aims to create a rehabilitation system that improves life outcomes for children with intellectual and developmental disability (IDD) and ensures social inclusion. It provides free, quality rehabilitation services to vulnerable children with special needs in Pondicherry and aims to reduce social stigma.

How did it evolve?

2003
Satya Special School was established as a day-care for children with IDD in Pondicherry with 20 children.

2010
It widened the scope of services by setting up an early intervention center and a mobile therapy unit.

2016
The organizaton increased efforts to improve employability of PwIDDs by setting up a placement cell in partnership with Youth4Jobs.

2017
Established a first-of-its-kind new born high risk clinic in partnership with Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER).

Program overview:

Coverage: Pondicherry **| Full-time program staff:** 125 **| Budget (2017-18):** INR 2.78 crores (USD 400,000)

The problem

Children with IDD from socio-economically backward groups lack access to basic rehabilitative and educational services. They also experience acute isolation and social stigma within their communities. Further, government support is limited and fragmented.

Satya Special School's approach

Satya Special School seeks to rehabilitate children with IDD into the community by providing a range of services. It provides diagnosis, early intervention, day care, therapy, inclusive education and vocational training to PwIDDs within Pondicherry.

What does it do?

Satya Special School provides a range of services across six urban and three rural centers. The organization's services can be broadly described under the following headers.

- **Diagnosis and early intervention:** Through its center in JIPMER hospital, it helps identify newborns at risk for developmental delays and, through its early intervention center, assesses each child, and provides therapies (including physiotherapy and neuro development therapy) to 150 children per month. This helps build their life skills and promotes over-all development.
- **Community Based Rehabilitation (CBR):** It conducts CBR by providing mobile therapy services (for e.g., physiotherapy, speech therapy) for rural children with special needs across 44 villages.
- **Education and daycare:** It provides daycare, functional academics training, therapeutic facilities and educational facilities to persons with IDD through its centers. Children are referred to different centers based on the nature of their disability (i.e., multiple disabilities, autism, extent of ID, etc.)
- **Sports and recreation:** The organization also provides a platform for children with special needs to learn arts, dance, yoga and sports. Four children from Satya have won Special Olympic awards.
- **Vocational and employability training:** The organization also runs vocational training, placement and BPO training centers for IDD youth.

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ○ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ○ Deliver technical training to educators in special schools and inclusive schools
- ○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ○ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ○ Build capacity of partner organizations and enable them to create sustainable entities
- ✔ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ○ Over the last 15 years, Satya Special School has impacted directly the lives of 2600 persons with IDD and indirectly, the lives of 83,975 individuals (including families of PwIDDs).
- ○ It identified 2500 newborns with developmental delays and provided rehabilitation and counseling services to 50% of the cohort through its New Born High Risk Clinic at JIPMER from 2017-18.
- ○ The organization has distributed 550 aids and appliances to children with special needs from 2015-18.

What next?

- ○ The organization aims to expand its work in early intervention and education by building networks and providing technical support to organizations in other parts of India.
- ○ It wants to build its employability and vocational training programs and increase focus on the branding and marketing of its products.
- ○ In the long run, it wants to also provide assisted living facilities to adults with developmental disabilities and respite care homes for children with IDD.

Children learning about photosynthesis at Satya Special School's Alternative Inclusive Center for Education.

Quality indicators

Leadership

Chitra Shah, Director, Satya Special School
- ○ She is an alumni of the Madras School of Social Work
- ○ She is a member of ther National Action And Coordination Group, Puducherry UT for Child Rights and Abuse, the State Advisory Council for Right For Education and the Act Implementation Group of the District Level Committee, Puducherry UT.

Partners and Funders

University of Oregon, USA, Tata Institute of Social Sciences, JIPMER, The Hans Foundation, CIAI, Give India, Sri Aurobindo Society

Awards and Endorsements

- ○ Winner, World Cerebral Palsy Day Major Award, 2018
- ○ Winner, Special Jury award from Adapt Achievement Awards, Making a Difference category, 2018
- ○ Winner, Puducherry State Award for Best Institution Working with PwDs, 2018

"Before I brought my grand-child to Satya Special School, he couldn't move and sat at home alone all day; he had gained a lot of weight. Now he plays and interacts with other children and has access to the therapies and exercises he needs to progress and improve his motor skills."

- Grand-parent of a student with IDD, Satya Special School

VOICES FROM THE GROUND

"When families have PwIDDs, they only see the things they cannot do and how these kids do not measure up to other typical children. At Satya Special School, we focus on showcasing the amazing things that children with special needs are able to achieve so their parents stop seeing them as liabilities and feel proud of them."

- Chitra Shah, Director, Satya Special School

VOICES FROM THE TEAM

Ummeed Childhood Development Center

Website: www.ummeed.org | **Model:** Non-profit

Organization overview:

Founded: 2001 | **Head office:** Mumbai, Maharashtra | **Coverage:** Pan-India and International
Full-time staff: 70 | **Budget (2017-18):** INR 8.01 crores (USD 1,150,000)

Ummeed's vision is to help children with developmental disabilities and those at risk reach their maximum potential and get integrated in society. The organization provides a range of specialized services, including clinical services and training, research and advocacy.

How did it evolve?

2001
Ummeed Childhood Development Center was set up for developmental pediatric assessment and therapies.

2007-2008
It established the Early Intervention Center (EIC) and started training in mental health and child development.

2012
The organization developed advocacy focused and other training programs across audiences and disciplines.

2017
It launched Ummeed Training Center (Center of Influence); expanded training repertoire and reach.

2018
Developed the first online training program, through international collaboration.

Program overview:

Coverage: Pan-India | **Full-time program staff:** 70 | **Budget (2017-18):** INR 8.01 crores (USD 1,150,000)

The problem

Children and families from low resource backgrounds lack quality services, facilities, information and support to intervene at early ages and work towards optimal child development. The larger IDD space in India does not adequately promote inclusive communities.

Ummeed's approach

Ummeed provides specialized care for developmental disabilities and supports children and their families through clinical services and an early intervention center. It aims to influence the ecosystem by training parents, professionals, teachers, community workers and creating more awareness, research and advocacy.

What does it do?

Ummeed provides the services mentioned below.

- **Clinical services:** The aim is to support children to manage their disabilities through direct clinical services and help families in their journey towards acceptance and empowerment. Clinical services include developmental assessments, autism interventions, occupational therapy, testing services, counseling and mental health services, speech therapy, remedial education and social work support.
- **Training services:** The aim is to build an ecosystem of trained professionals and community workers who can help families prevent, diagnose, and manage developmental disabilities effectively. Training services include mental health programs, autism intervention training programs, early childhood development and disability programs, school inclusion programs, know your rights workshops and other skill building and sensitization workshops.
- **Research and advocacy:** Ummeed partners with national and international organizations (such as WHO, UNICEF, Rehabilitation Council of India) to foster research, promote child development and create awareness on developmental disabilities. In addition, they actively participate in international committees, national groups and task forces, as well as advocate for inclusive schools and communities.

Key interventions

- ✔ Provide diagnostic services and family centered early intervention care
- ✔ Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers
- ✔ Deliver technical training to educators in special schools and inclusive schools
- ○ Equip educators in special and inclusive schools with specifically designed and standardized teaching tools
- ○ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD
- ✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness
- ○ Build capacity of partner organizations and enable them to create sustainable entities
- ✔ Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

- ○ Till date, Ummeed has served over 11000 children and families through their direct clinical services and trained over 4000 participants, 80 teachers in 17 Brihanmumbai Municipal Corporation (BMC) special schools and 25 pediatricians/psychologists/neurologists through various training programs
- ○ Over 10 countries including Iran and Bangladesh are represented in the outreach of all their training programs.
- ○ Collaborated with Yale and Ankara Universities to develop an International Guide for Monitoring Child Development

What next?

- ○ Ummeed plans to develop multiple long-term partnerships with community-based organizations, non-profits working in the disability space, and schools to promote child development, early intervention, and support inclusive practices.
- ○ It plans to extend its influence outside Mumbai and make training more accessible through online modules and training trainers. The team will invest in a communications and awareness strategy to make the cause more visible at scale.
- ○ Ummeed will invest in impact measurement and dissemination on topics such as family centered practices and participation-based outcomes, narrative practices, best practices for school inclusion, etc.

Children and their parents in a therapy session at Ummeed's clinic.

Quality indicators

Leadership

Vibha Krishnamurthy, Founder, Ummeed
- ○ She is a member of expert committees on disability and early childhood development at WHO, UNICEF, Rehabilitation Council of India and National Trust.
- ○ She is the president of the International Developmental Pediatrics Association

Partners and Funders

Mental Health Foundation, Yale University, Ankara University, Narrative Practices Adelaide, World Health Organization, International Developmental Pediatrics Association, Echo India, Cipla Foundation, APPI, Reliance, Tata, Deutsche Bank, Bajaj Finance

Awards and Endorsements

- ○ Winner, Best NGO of the year, Tata Housing Development Company, 2017
- ○ In 2016, approved for providing the IAP Fellowship in Developmental Pediatrics.
- ○ TedX Talk in 2018 by Raviraj Shetty from Ummeed

"The EIC did Subhan a lot of good. He was now much more confident, adored by his teachers and friends. His speech improved and expressions became clearer. His social interactions became praise-worthy. I no longer wanted to hide myself or my son from the glaring eyes of the world. I was not embarrassed to seek help from people around. I did not mind telling them that he was a 'special' child. I felt happy, as I was a 'Special Mother'."

- Mother of a beneficiary, Early Intervention Center, Ummeed

"With Ummeed, we are building a "center of excellence" and a model that can be replicated in other parts of the country. Ummeed functions as a facilitator of care for developmentally disabled children, putting the family first and providing care regardless of parents' ability to pay. One of our biggest challenges has been generating awareness among financially marginalized families and encouraging them to find their way to appropriate services. To overcome this challenge, we liaise with other organizations already working with these communities."

-Vibha Krishnamurthy, Founder, Ummeed

Voices from the ground

Voices from the team

Vidya Sagar

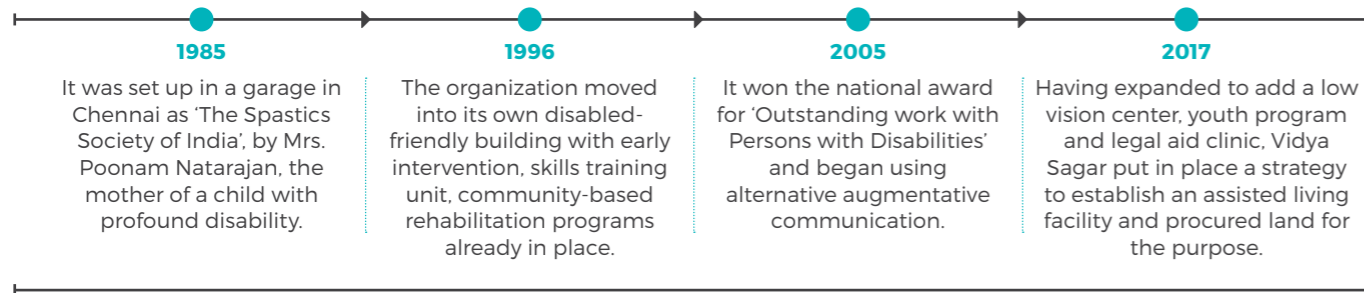**Website:** www.vidyasagar.co.in | **Model:** Non-profit

Organization overview:

Founded: 1985 | **Head office:** Chennai, Tamil Nadu | **Coverage:** Chennai | **Full-time staff:** 103
Budget (2017-18): INR 2.80 crores (USD 396,000)

Vidya Sagar is a rights-based organization working with persons with multiple disabilities in the areas of rehabilitation, special education, inclusion, training and advocacy, for the last 33 years. The organization has pioneered many interventions that are suited to Indian conditions and adopts a life span approach, supporting persons with disability from infancy to adulthood.

How did it evolve?

1985	1996	2005	2017
It was set up in a garage in Chennai as 'The Spastics Society of India', by Mrs. Poonam Natarajan, the mother of a child with profound disability.	The organization moved into its own disabled-friendly building with early intervention, skills training unit, community-based rehabilitation programs already in place.	It won the national award for 'Outstanding work with Persons with Disabilities' and began using alternative augmentative communication.	Having expanded to add a low vision center, youth program and legal aid clinic, Vidya Sagar put in place a strategy to establish an assisted living facility and procured land for the purpose.

Program overview:

Coverage: Chennai, Tamil Nadu | **Full-time program staff:** 103 | **Budget (2017-18):** INR 2.80 crores (USD 396,000)

The problem

Persons with profound multiple disabilities are often denied basic rights and are one of the most marginalized communities. There is a lack of organizations providing integrated services to cater to the varied needs of such individuals.

Vidya Sagar's approach

Vidya Sagar seeks to empower PwIDDs by providing them with the tools required to lead an independent life. The organization has adopted a holistic framework, creating programs that focus on early intervention, rehabilitation, education, training, inclusion and advocacy.

What does it do?

Vidya Sagar runs various programs supporting the different needs of PwIDD during their life time.

O **Rehabilitation:** Conducts holistic assessment and goal setting for every walk-in, provides advisory and referral services and early intervention, and trains the primary care-giver to effectively meet the special needs of the person with disability.

O **Education:** Fulfils the education needs of children with severe and multiple disability from the first to the twelfth grade through the Centre for Special Education, by adapting and modifying the state curriculum to ensure inclusion.

O **Vocational training:** Offers training courses in weaving, papermaking, tailoring, etc., and develops units of PwIDDs who work in production units using the skills.

O **Partnerships:** Develops in-house software and devices with partner organizations, made available at reasonable rates, to solve complex needs of the students.

O **Capacity building:** Works to build the technical capacity of partner organizations in rural, semi-urban and slum areas. Conducts training courses to enhance the skills of professionals working with PwIDDs.

O **Advocacy:** Provides legal aid through the state legal services authority, creates awareness on legal rights, runs issue-based campaigns and undertakes policy level work with local governments.

Key interventions

✔ Provide diagnostic services and family centered early intervention care

O Deliver technical training to key professionals including medical health professionals, *anganwadi* workers and pre-school teachers

✔ Deliver technical training to educators in special schools and inclusive schools

O Equip educators in special and inclusive schools with specifically designed and standardized teaching tools

✔ Operate workshops with market linkages or partner with corporates to create inclusive workplaces that employ peer groups comprising persons with IDD

✔ Conduct advocacy for legislative change and educate key stakeholders to generate awareness

✔ Build capacity of partner organizations and enable them to create sustainable entities

O Conduct research to build data on developmental disorders & program effectiveness

What has it achieved?

Vidya Sagar has been successful in improving the lives of over 700,000 beneficiaries. Over the years it has:

O Successfully partnered with Indian Institute of Technology, Madras, to create patented technology aids at affordable prices to enhance alternative augmentative communication;

O Pioneered the inclusion of low vision training across all their programs involving direct work with PwIDDs;

O Built the capacity of 34 organizations in rural and semi-rural areas across Tamil Nadu, Kerala and Andaman & Nicobar Islands through their community-based rehabilitation program, which has had an impact on over 75,000 people.

What next?

O To scale up their lifespan approach, the organization has developed a five-year plan to operationalize a 24x7 assisted living facility for PwIDDs, with continued focus on individuals with profound disability. This will enable the organization to ensure infancy to end of life care for PwIDDs. A plot of land has already been assigned to Vidya Sagar in Karambakkam, Chennai, to construct this facility. The organization will have to raise INR 20 crores for construction and an estimated INR 50 lakh per month for the maintenance of the facility.

O It plans to increase the effectiveness and outreach of the existing programs by hiring more training support persons, i.e., special educators, occupational therapists, vision therapists and speech therapists.

Advocate Ummul Khair inaugurating the legal aid clinic

Quality indicators

Leadership

Poonam Natarajan, Founder, Vidya Sagar

O She is the ex-Chairperson of the National Trust, Ministry of Social Welfare; Member of the 'New Law Committee' formed to harmonize national legislation with the Convention on the Rights of Persons with Disabilities.

Partners and Funders

Indian Institute of Technology, Madras, Anna University, Chennai, Rehabilitation Council of India, Perkins School for the Blind, Boston, APPI, Tata Trusts, Larsen & Toubro Limited

Awards and Endorsements

O Vishwanathan Anand, Indian Chess Grand Master is the global ambassador of Vidya Sagar

O Winner, National Award for outstanding work with persons with disabilities, 2005

"I have always wanted to write and tell stories about people who have overcome their disabilities and have been included in society. It was at Vidya Sagar that I found the support system to translate my dream of becoming an author into reality by using text-to-type software"

- Anjana, Ex-student and Author of Evolving Angel

Voices from the ground

"We are a rights based organization with a lifespan approach. We want to break the institutional way of thinking and empower individuals with intellectual and developmental disabilities to lead independent lives by creating a strong support system consisting of their family, institutions and community"

- Radha Ramesh, Director

Voices from the team

Appendices

Appendix I

Dasra's expertise lies in recognizing and working with non-profit organizations that have the potential to create impact at scale. Dasra strongly believes that the strength of an organization comes from its people, and has ingrained this philosophy in its due diligence process. Consequently, an organization is assessed not just on the basis of its program but also on the potential of its leadership and management team.

In order to identify such organizations, Dasra follows a comprehensive three-stage due diligence process.

Phase I – Sector Mapping

○ The process involves undertaking exhaustive sector mapping and compiling a list of non-profit organizations working in the sector.
○ Based on quantitative and qualitative secondary research, references from previous experience, and inputs from sector experts, the work carried out by the organizations is categorized under specific interventions.
○ Organizations having programs with the most scalable and impactful interventions are screened from this universe against criteria such as program focus, outreach, team, budget, scale, impact and growth plan.

Through sector mapping for this report, Dasra mapped 405 non-profit organizations across India.

Phase II – Detailed Assessment of Organizations based on phone calls and site visits

○ Dasra conducts a detailed assessment on the screened organizations by making a one to two day site visit to understand the work being done on the ground and spend time with the leadership and management team of the organization
○ An organization profile is prepared to capture the current work and achievements of each organization and provide a sense of the future growth of the organization as a whole
○ Organizations are evaluated using the Dasra Capacity Assessment Framework (DCAF), a tool that Dasra has developed to assess organizations against three key areas – leadership potential, organization strength and program effectiveness.

Dasra conducted phone calls with 147 non-profits that work to improve outcomes for persons with intellectual and developmental disabilities and identified 14 organizations on which detailed diligence was conducted through site visits to these organizations.

Phase III – Final Shortlisting

○ Dasra Capacity Assessment Framework (DCAF) and organizational profiles are used to evaluate the program strength, organization potential, and areas where Dasra can add value through its capacity building support
○ Members from Dasra's advisory research and diligence team and senior management participate in the shortlisting process alongside the Bank of America team to identify 8-10 high impact and scalable non-profit organizations to be profiled in the report

Ten non-profit organizations were shortlisted to be profiled in this report, based on their institutional capacities and impact in the sector.

Dasra re-engages with the final shortlisted organizations to create robust growth plans, and works with the organizations to explore funding opportunities. Dasra also offers peer learning and capacity building opportunities to these organizations through Dasra's customized and cohort driven workshops.

Appendix II

EXPERT	ORGANIZATION
Amba Salekar	Equals Centre for Promotion of Social Justice
Bhargavi Davar	The Bapu Trust
Chandra Sengupta	Indian Institute of Cerebral Palsy
Iona Kundu	Mentaid
Jeeja Ghosh	Indian Institute of Cerebral Palsy
Jo Chopra	Latika Roy Memorial Foundation
Kishore Kumar	The Banyan
Merry Barua	Action for Autism
Neerja Birla	Aditya Birla Education Trust
Nilesh Singit	Equal Opportunity Consultant
Poonam Natarajan	Vidya Sagar
Rajan Mani	Disability Law Initiative
Ram Lakhan	Jackson State University
Reena Sen	Indian Institute of Cerebral Palsy
Rukmini Datta	Cipla Foundation
Shanti Auluck	Muskaan
Shrirang Bijur	PARIVAAR
Sudha Kaul	Indian Institute of Cerebral Palsy
Suneeta Singh Sethi	Amrit Foundation
The Late Javed Abidi	National Centre for Promotion of Employment for Disabled People
Vibha Krishnamurthy	Ummeed Child Development Center
Ziaa Lalkaka	H. T. Parekh Foundation
Zirak Marker	Mpower and Aditya Birla Integrated School

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