



**Project:** Comprehensive Special Education and Rehabilitation Services to Persons with Deafblindness and their Families

Project Location: Guwahati, Assam & Sri Ganga Nagar, Rajasthan

**Project Timeline**: July 2024 to June 2025

**Project Report:** July 2024 to February 2025



Submitted to

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Submitted by

Sense International India

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### Introduction

Deafblindness is a complex and challenging condition encompassing hearing and vision loss. This dual sensory impairment significantly impacts how children perceive and interact with the world around them. For children with deafblindness and multiple disabilities, everyday activities, from communication to mobility and learning, are shaped by barriers that others may not face. These children require specialized support to ensure they have opportunities to thrive and develop essential life skills. Without the support of family, community, and rehabilitation professionals, these children would lead extremely isolated and restricted lives. As Helen Keller poignantly said, "Blindness separates people from things; deafness separates people from people." With deafblindness, a child is often excluded from family, community, and their surroundings. Their world becomes limited to what they can experience through their fingertips.

The project title "Comprehensive Rehabilitation and Educational Services for Children and Young Adults with Deafblindness and Multiple Disabilities in Shishu Sarothi, Guwahati, Assam' and "Comprehensive Rehabilitation and Educational Services for Children and Young Adults with Deafblindness and Multiple Disabilities in Nav Chetna Society, Sri Ganganagar, Rajasthan" are designed to enhance the quality of life for children and adults with deafblindness and multiple disabilities (MD) by developing specialized interventions. Our goal is to empower these children and adults to engage meaningfully with their surroundings, fostering independence, social inclusion, and holistic development. In 1st year (2023-24), 96 children and adults in Guwahati and 29 in Sri Ganganagar were enrolled and received necessary services through centre and home-based programme. The 2<sup>nd</sup> phase of the project started in July 2024 to strengthen the services, continue provision of services to the existing enrolled service users and expand reach to more persons with deafblindness and MD in need.

Partner organization Shishu Sarothi in Guwahati, Assam is capacitated to work as the Deafblind Regional Centre (DbRC) in Northeast region and Nav Chetna Society is capacitated to work as the Deafblind Resource Centre for Ganganagar district.

Recognizing that persons with deafblindness and MD often require a multi-faceted approach, the project thrives on collaboration with families, educators, healthcare professionals, and community stakeholders. This holistic approach ensures that children and adults receive the comprehensive care and support they need. Families play a vital role in understanding their child's needs and are integral in implementing personalized interventions. Educators and other rehabilitation professionals, working in tandem, help tailor strategies that align with the child's needs, creating an environment that fosters learning, growth, and development.

At Sense International India, we are deeply committed to fostering the holistic development of children and adults with deafblindness and MD. Through the project, we aim to build the capacity of key stakeholders, equipping them with the necessary skills and knowledge to create a more inclusive society for people with disabilities. This capacity-building effort focuses on empowering educators, healthcare professionals, and caregivers with the tools they need to identify, understand, and address the specific needs of children with deafblindness.

A key component of the project involves providing technical expertise to partner organization. This collaboration ensures that partner project teams are well-prepared to offer targeted interventions for both children and adults with deafblindness and MD. By equipping the partner team with specialized knowledge and practical tools, we ensure that individuals with deafblindness and MD receive the personalized care they deserve. Looking ahead, Sense International India remains committed to expanding the reach and scope of this project.

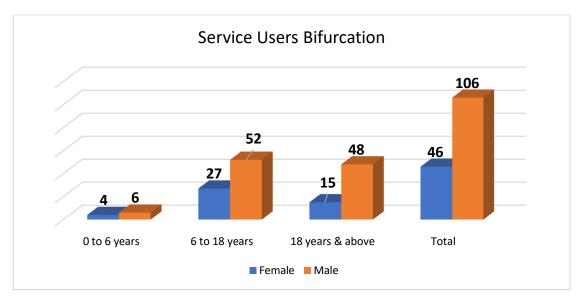
## **Specific Objectives of the Project:**

Specific objectives aligned with the overall goal of the projects are as follows:

- Strengthen Shishu Sarothi as a Deafblind Regional Centre (DbRC) in Northeast and Nav Chetna Society as Deafblind Resource Centre in Sri Ganganagar, Rajasthan.
- 500 persons, including 125 children and adults with deafblindness & MD and 375 parents and siblings to be directly impacted by the project in Guwahati, Assam.
- 200 persons, including 50 children and adults with deafblindness & MD and 150 parents and siblings to be directly impacted by the project in Sri Ganganagar, Rajasthan.
- Provision of need-based early intervention services to 21 children with deafblindness and Multiple Disability (MD) of age group 0-6 years in the community.
- Ensure that 91 children with deafblindness and MD of age group 6-18 years receive educational/ prevocational training through Centre-based / Home-based services along with medical and nutrition, therapy and rehabilitation support services.
- Provision of prevocational/vocational training /counselling services to 63 adults with deafblindness and MD of age group 18 and above as per their potential and aspirations.
- Advocate with the government's departments for the need for 'Integrated/ Inclusive' education and linking children and adults with disabilities with welfare schemes and programmes.
- Build the capacity of partner organizations professionals to work with children with deafblindness and MD ensuring the sustainability of the project.
- Build the capacity of 525 caregivers/ parents and siblings to work with children with deafblindness and MD.
- Strengthen network development of adults with deafblindness, parents and special educators to take advocacy initiatives.
- Sensitization of professionals from NGOs, other disability-based organizations, Anganwadi and ASHA workers to create a referral network and work with children with deafblindness and MD ensuring the sustainability of the project.

## **Project Reach:**

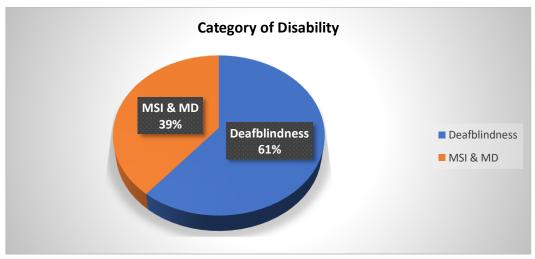
Currently the project reach stands at 152 children and adults with deafblindness and MD. The details of service users are given below-



Graph 1: Bifurcation of children and adults on basis of age and gender

Partner	0-6 years	6-18 years	18 years and
Organizations			above
Shishu Sarothi,	10	55	48
Assam	(6M & 4F)	(34M & 21F)	(35M & 13F)
Nav Chetna	-	24	15
Society,		(18M & 6F)	(13M & 2F)
Rajasthan		,	
Total	10	79	63
	(6M & 4F)	(52M & 27F)	(48M & 15F)

Table 1 Partner-wise breakup of service users



Graph 3- Bifurcation of children and adults based on the category of disability

## **Key Achievements:**

The project addressed the multifaceted needs of persons with deafblindness and MD and ensured sustained and continuous support. Through comprehensive support systems, including functional activities, personalized education plans, and mobility training, the project is helping children and adults in developing the skills needed to lead independent and engaged lives. Furthermore, by fostering partnerships with families, educators, and other stakeholders such as ASHA workers, Anganwadi workers, we are laying the groundwork for a future where children with deafblindness can fully participate in their communities and enjoy a fulfilling life. We are impacting the lives of 608 children and adults with deafblindness and MD, parents and family members across Guwahati, Assam and Sri Ganganagar, Rajasthan. Below are some of the key achievements-

#### 1. Education and Rehabilitation Services

- 152 children and adults (106M, 46F) with deafblindness and MD received educational and tailored rehabilitation services as needed.
- 16 (10M, 6F) new children and adults with deafblindness and MD were identified and enrolled under the project through surveys and referrals from sensitized stakeholders during the project period.
- 25 children and adults (21M, 4F) from low-income families received medical support, leading to improved health and greater participation in project activities.
- 34 children and adults (19M, 17F) underwent functional/clinical vision and hearing assessments, which guided the development of personalized intervention plans.

- 16 individuals (14M, 2F) with deafblindness and MD were provided with assistive devices, including CP chair, wheelchairs, MSIED kit, Braille Kit, walker and smart canes supporting them in mobility and improved hearing abilities.
- 17 service users received consistent, center and home-based physiotherapy services to improve their physical mobility and overall well-being.
- 1 adult with deafblindness supported with a seed grant to start income generation activity of running a general shop. The adult with deafblindness will not only gain financial independence, reducing reliance on family members but will become more active in the community through socialization and develop



A student attending home based educational session

business skill. Income generation application of 2 more adults with deafblindness and MD is under consideration.

4 exposure visits/outings were organized for children and their caregivers, offering them
opportunities to relax and engage in learning experiences in an open, outdoor environment.
The visits included trips to culturally significant sites, a garden, and an adventure camp. In total
44 children and caregivers participated in the outings.



Student with deafblindness/MD participating in an adventure camp, Assam

#### 2. Sensitization of stakeholders

• Two Regional Trainings on Deafblindness and Multiple Disabilities were organized during the project period. These sessions targeted rehabilitation professionals and trainees, including special educators, therapists, and special education students from the Northeast and North regions. A total of 64 professionals and students from Tripura, Meghalaya, Assam, Rajasthan, Punjab, Haryana, and Delhi participated in the training. The sessions greatly enhanced participants' awareness and understanding of deafblindness and multiple disabilities, while also improving their knowledge and skills in inclusive education, sensory integration activities, functional assessments, communication skills (such as Braille and Sign Language), and curriculum adaptation. Additionally, the training has strengthened networking among participants and organizations.

'I learned about deafblindness and how to adapt the curriculum as per child needs.'

### Ms. Bonkima Chakraborty, Tripura

 45 professionals from 20 disability-based organizations and other institutes in Nagaland, Assam, and Sri Ganganagar were reached out to and sensitized on deafblindness and MD. The visits focused on strengthening networking and disseminating information on the project and services provided by the partner organizations. As a result of sensitization, the project teams received referrals of 3 children with deafblindness/MD.

'As a professional for person with hearing impaired, we use sign language but for the deafblind tactile sign is used, this will help us in communicating with a deafblind person. I gained information on different modes of communication and hand under hand & hand over hand.'

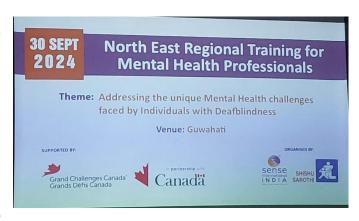


Ms. Amongla Ao, NGO professional, Nagaland



Rehabilitation professionals from North and Northeast attending regional training on deafblindness and MD

- District-level training on deafblindness and MD for Anganwadi workers was organized by Nav Chetna Society on 9th Dec. In total 43 Anganwadi workers attended the training. The training aimed at equipping participants with knowledge of deafblindness and skills to identify children with the possibility of deafblindness. The project team through regular follow-up will support the trained workers in the identification of children with deafblindness and MD in their respective communities.
- A Northeast Regional Training for Mental Health Professionals was organized by Sense India in Guwahati, Assam, and attended by 24 mental health professionals from the region. The training participants with valuable provided insights into the unique mental health challenges faced by individuals with deafblindness. As result, the professionals are now equipped to



support individuals with deafblindness using suitable approaches and implement tailored mental health interventions that address the specific needs of this population. Additionally, the training sensitized the professionals to offer informed support and resources to families and caregivers, considering the regional and cultural context.



Mental health professionals attending training

## 3. Capacity building of project staff to work with children and adults ensuring the project's continued effectiveness

13 team members including 7 members from Shishu Sarothi, Assam and 6 from Nav Chetna Society encompassing project coordinators, special educators, vocational trainer, community-based rehabilitation workers (CBR), and finance members received guidance and need-based training to work with the children and adults, project implementation and financial management through onsite visits, mentoring visits, and project monitoring and evaluation visits. Through visits, the teams were trained in the setting of routine and timetable in home-based, classroom management, involvement, planning a theme base curriculum at the centre, developing individualized education plan using S.M.A.R.T. goals, preparation of need-based teaching learning material, and documentation of the project activities and project finances.



Ms. Rosa Wahlang, mentor interacting with a student

'The rapport and the trust that has been built by the educators and field workers with not only the immediate family but with the neighbors of the beneficiaries is something remarkable.'

Rosa Wahlang (mentor to project partner Shishu Sarothi, Assam)

• A 4-day National Training for special educators and parents/caregivers from 29th July to 1st August 2024 was organised by Sense India in Ahmedabad, focusing on both the mental health and sexual and reproductive health rights (SRHR) of persons with deafblindness and MD. The training aimed to equip participants with strategies to address the unique mental health and SRHR needs faced by persons with deafblindness and MD. Participants were empowered with knowledge on stress management, mental well-being, self-care, and the importance of promoting autonomy and respectful relationships. The training was attended by 4 members from partner organization Nav Chetna Society, Sri Ganganagar including 2 caregivers, 1 adult with deafblindness, and a special educator. Key topics covered during the training included: Sexuality and SRHR, Mental Health and Emotional well-being, Roles of mental health professionals and mental, neurological and substance abuse disorders.

"I found the training incredibly important for my grandson, as it gave me valuable guidance on both sex education and mental health. From this training, I realized that we must openly discuss the topic of sex with our children and educate them so that it doesn't negatively impact their health and mental health. This topic should be openly addressed with everyone, so children with special needs can understand it and take care of their mental health. I also learned that it's essential to make parents aware of the importance of protecting their children's privacy."

P. K. Verma, Caregiver, Sri Ganganagar

• 2 officials (1M, 1F) from Nav Chetna Society participated in ICEVI conference held in Ahmedabad from 13<sup>th</sup> to 16<sup>th</sup> Nov. The conference also included a pre-conference session themed "Importance of Independent Living for Persons with Deafblindness." During the event, the participating officials attended presentations by speakers from various organizations, where they gained valuable insights on topics such as transition planning, income generation activities undertaken by adults with deafblindness, and livelihood development. The conference provided the platform to the officials to interact with professionals from across India.

'The sessions in the conference were very informative. I could understand the importance of sex education, assessments and early intervention for persons with deafblindness. I tried to link the experiences and information shared by the presenters with children and adults we work with.'

Ms. Gurpreet, Project Coordinator

'During this training I gained information on national policies promoting inclusive education, ensuring that students with disabilities have equal access to quality education.'

Mr. Om Prakash Baweja, Caregiver

# 4. Capacity building of caregivers/ parents to work with children and adults ensuring the project's continued effectiveness

The project team at the ground level sensitized 402 parents and family members as per the needs of the child. Caregivers/parents receive continuous guidance both through centre and home-based visits to the service users. Caregivers were involved in the centre and home-based sessions which ensured their hands-on training to conduct the activities, understand the child's needs, as well as share their feedback with the team. Some of the basic aspects in which caregivers received training and guidance are as follows-

- Conducting activities of daily living in a manner that the child learns steps and tries to complete
  activities with minimal/ no support such as brushing, bathing, buttoning cloths, wearing own
  clothes, toileting, identifying own clothes, applying oil-talcum powder, menstrual hygiene, etc.
- Conducting independent living skills activities- engaging and guiding child/adult in household work such as shopping from nearby shop, cleaning room, identifying own utensils, cleaning table after lunch/dinner, washing utensils, washing own personal garments, buying groceries and making simple dishes.
- Training on basic stretching, sensory stimulation, and speech exercise- Caregivers of children
  and adults in need of therapy were also trained on basic stretching exercises, correct
  positioning, sensory stimulation activities which can be repeated at home with the use of
  available resources within home.



A caregivers sharing her experiences with other caregivers during network meeting

### 5. Support Network and Advocacy

A strengthened network of caregivers and adults with deafblindness is essential to provide ongoing support, promote inclusion, and ensure the empowerment of persons with deafblindness and MD.

• The North Regional Network Meeting, held on September 25th and 26th, 2024, brought together participants from various organizations in the Northern region, including 2 caregivers, 1 special educator, and an adult with deafblindness from partner organization Nav Chetna Society. During the meeting, the participating members shared updates related to the local network. Additionally, they gained insights into Rights of Persons with Disabilities (RPWD) Act 2016, covering topics such as disability certification, high support needs, universal design, and reasonable accommodation. Members from the Udaan network group were informed on key rights related to the mentioned in the Act, while caregivers and special educators were engaged in activities around the A-Z booklet on the RPWD Act developed by Sense India. The event also included discussions on mental health, with network members from all participating organizations and siblings joining in the initial conversations.

The engagement of caregivers in the meeting enhanced their understanding of the legal framework protecting persons with disabilities. This boosted their confidence in advocating for necessary accommodations, certifications, and rights on behalf of the persons with deafblindness and other disabilities. As caregivers and special educators participated in discussions and activities related to the RPWD Act and mental health, they can apply the new information to improve their service delivery, ensuring that children and adults with deafblindness and MD receive appropriate supports in various settings.

The inclusion of mental health discussions helps to broaden the understanding of the complex needs of individuals with disabilities. Siblings' involvement in mental health discussions lead to better understanding among siblings of the challenges their family members face, which can improve the emotional and social support they provide.

## **Impact Stories from Ground**

### Dikhita Baishya: A Journey of Resilience, Growth, and Ambition

Dikhita Baishya, a bright and ambitious young girl, was born on February 23, 2012. She lives with her parents and her younger brother. Her father works as a daily wage laborer, and her mother is a homemaker. Dikhita's story began with a challenging start, as she was diagnosed with multiple disabilities—low vision with cerebral palsy. Her disability was identified when she was six months old.

Dikhita's journey took a positive turn when she was enrolled in the Mukul Madhav Foundation-supported project at Shishu Sarothi, Guwahati on March 10, 2024. Before joining the project, Dikhita faced several difficulties. She struggled to write properly, had no knowledge of sign language, and her balance was poor.



She had never received physiotherapy interventions, which further hindered her progress.

Once she was enrolled in the project, Dikhita began to receive physiotherapy sessions aimed at improving her motor functioning and balance. In the current project period, she showed remarkable improvements. She was soon able to walk unaided and began engaging in various activities. Dikhita also learned basic sign language, including the alphabet and numbers, and she can now express her needs using sign language, gestures, and color and fruit signs, which she also uses at home. Along with her motor development, she gained confidence in socializing and performing basic activities of daily living.

Some of her major achievements include learning basic sign language, improving her motor skills, and developing better balance. She has started to follow basic instructions.

Her educator is pleased with Dikhita's progress, particularly in terms of her motor skills and balancing. The team sees her as a bright child with big aspirations. They plan to continue her therapy and special education to improve her ADL skills and further support her development.

Dikhita's mother, shared how, after enrolling Dikhita, her daughter became more engaged in her studies and showed a growing interest in learning. Dikhita's family despite living in a distant area, actively participates in the parents' meetings and ensures that Dikhita receives exposure to various opportunities. Her parents express their desire for Dikhita to grow up and lead a successful career. As

for Dikhita, despite her multiple disabilities, she has a clear aspiration to become an IAS officer one day, which reflects her determination and ambition.

The project team has set specific goals for Dikhita over the past three months, which include enhancing her communication skills (particularly in sign language), improving her academic skills (such as counting, understanding color concepts, and the alphabet), and increasing her self-awareness (particularly body parts). Going forward, the action plan is to continue developing these skills and expand upon them.

### Sewa's Path to Progress



Sewa doing activity on pegboard for improving attention span

Sewa Singh is a 14-year-old boy with multiple disabilities (low vision with intellectual disabilities) living in Sri Ganganagar. Before enrollment in the project for children and adults with deafblindness and MD, Sewa showed concerning behaviors; he often ran away from home, impulsively picked up garbage or food from the ground to eat, and displays aggression towards his peers and family members.

Sewa was enrolled in the Mukul Madhav Foundation supported project at Nav Chetna Society after a survey. Under the guidance of dedicated professionals, especially his special educator, Sewa has started to receive the necessary support to thrive after proper clinical and functional assessments. His individualized education plan was formulated and the team started the intervention with him.

The programme focused on creating an inclusive and nurturing environment that caters to his unique needs. The special educators started to engage him in educational activities and peer learning activities. He gradually started to shift his behavior towards the children in the centre in a positive manner.

In the first few months of the programme, Sewa shows remarkable improvement in his behavior. He now attends school regularly and sits comfortably in his seat without attempting to escape. He has started to engage positively with his peers and family and no longer runs away from home or school. Sewa began to eat independently, and has stopped his previous habit of picking up food from the ground.

As Sewa continues his journey, he also discovered interests in activities such as playing with blocks and playing on slide on the playground. His ability to communicate has improved significantly and has learnt to express himself through gestures and responds appropriately when spoken to.



His mother expresses her satisfaction with his progress, stating, "He has started doing activities on his own and has begun sitting in one place. He does not even try to run away from home or school anymore. I am proud of how he has started eating food on his own and responding to those around him."

With continued guidance and resources, Sewa looks forward to achieving more milestones, including learning personal hygiene skills and basic sewing as vocational training. His parents are now hoping to see Sewa as an independent person.

## Programme plan till March 2025

Apart from the regular activities, following major activities will be implemented till March 2025.

- 1. Capacity building of project coordinators, caregivers, special educators and adults with deafblindness and MD through theme-based National training scheduled from 17<sup>th</sup>-20<sup>th</sup> March 2025.
- 2. National conclave of network.
- 3. District-level training of ASHA and Anganwadi workers in Guwahati, Assam
- 4. Assam state-level sensitization of NGO professionals.
- 5. Seed grant to 2 adults with deafblindness and MD to start their income generation activity.

### Financial Overview:

Payment released by MMF during the relevant period	For Shishu Sarothi- INR 1395910/-	
	For Nav Chetna Society	
	INR 1436774/-	
Actual Expenditure Incurred till December	For Shishu Sarothi	
2024	INR 1612401/-	
	For Nav Chetna Society	
	INR 1217226/-	

## Sustainability plan

To ensure the continued impact and benefits of the project beyond the implementation period, Sense International India continues to build the capacity of project team and organization in aspects covering working with persons with deafblindness and MD, project management, and fundraising. Apart from organization development, the project team at ground level is training caregivers through both centre and home-based visits to ensure sustained work with the children. Stakeholders such as health workers at the grassroots level, Govt. officials, and rehabilitation professionals from other like-minded organizations have been networked to create awareness on deafblindness and MD, linking service users with welfare schemes and creating a network of referrals.

## **Project Photographs**



Individualized sessions with the children at center and clinical vision assessment









Centre and home based services on therapy, orientation and mobility, computer skills and communication