

Project: Comprehensive Rehabilitation and Educational Services for Children and Adults with Deafblindness and Multiple Disabilities

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

Project Report: July to December 2023









Report Submitted to

Mukul Madhav Foundation

Submitted by

Sense International India

INTRODUCTION

Deafblindness is a combination of sight and hearing loss that affects a person's ability to communicate, access information, and get around. It's also sometimes called "dual sensory loss". Because of the impairment of two key senses through which one learns i.e. vision and hearing as well as the challenges it poses for a person in day-to-day life deafblindness is a unique and complex disability.

For a person with deafblindness and multiple disabilities (MD), life is challenging until communities, rehabilitation professionals, and most importantly family members come together to support them. The road to inclusion and realization of basic rights is long and requires support from different sections of society. The support can be in any form or at any level. Be it equipping them with skills to earn a livelihood or creating an inclusive education setup etc. Communities can come together to encourage families and persons with deafblindness/multiple disabilities rather than stigmatizing them. Dedicated rehabilitation professionals can guide families and help persons with deafblindness to become independent in their lives. Family members at their level develop their skills and knowledge to work with persons with deafblindness/MD.

The project 'Comprehensive Rehabilitation and Educational Services for Children and Young Adults with Deafblindness and Multiple Disabilities' supported by the Mukul Madhav Foundation aimed at providing key rehabilitation services to children and adults with deafblindness and multiple disabilities in Guwahati, Assam, and Sri Ganga Nagar, Rajasthan. The project started in July 2023 with 91 children and adults with deafblindness and MD and by the end of Dec. 2023, the project reach stands at 108 children and adults.

The project not only catered to the specialized needs of children and adults with deafblindness and MD, but it also developed and enhanced the skills of other stakeholders including caregivers/ parents, and rehabilitation professionals from govt./non-govt. organizations to understand deafblindness and work with persons with deafblindness/MD.

With its technical know-how in the field of deafblindness and MD, Sense International provided technical support to the partner organizations i.e. Shishu Sarothi in Guwahati, Assam, and Nav Chetna Society in Sri Ganga Nagar, Rajasthan. The project teams at partner organizations were trained to identify and work with children and adults with deafblindness and MD through training at different levels.







PROJECT ACHIEVEMENTS

- 108 children and adults with deafblindness and MD received continued need-based rehabilitation and education services.
- 17 new children and adults with deafblindness and MD identified and enrolled under the project through surveys and referrals from sensitized stakeholders during the project period.
- 23 service users from low-economic families received regular medical and nutrition support leading to better health and active participation in the activities.
- 11 service users received need-based assistive devices that supported them in mobility, learning braille, improved vision, and maintaining proper posture.
- Motor skills development in 24 service users receiving regular physiotherapy leading to better balance, and achievement of development milestones such as sitting, improved grasping, etc.
- 15 service users underwent clinical vision/hearing/IQ assessment resulting in better understanding among the project team about the extent of impairment in the assessed child and preparing an intervention plan based on the assessment report
- 50 adults with deafblindness/ MD received pre-vocational and vocational training as per their potential and capacity along with other rehabilitation services.
- 2 adults with deafblindness/MD received a seed amount to start income generation activity
- 30 service users along with their caregivers got an opportunity to participate in an exposure visit/outing and enjoy the day out. The visit also created awareness among the public on the rights of persons with disabilities to recreational avenues
- 133 Samagra Shiksha educators were sensitized on deafblindness leading to a better understanding of deafblindness, correct assessment of children, and curriculum adaptation.
- Govt. officials participating in Assam State level advocacy meeting have assured support to partner organization Shishu Sarothi for revision of disability certificate of service users who were earlier issued single disability certificate.
- 102 rehabilitation professionals from different NGOs in Assam, Sri Ganga Nagar, and Tripura were sensitized on deafblindness and MD. The sensitization has supported the project teams in getting referrals and expanding services to persons with deafblindness
- Sense India has built and enhanced the capacity of project teams at partner organizations to work with children and adults with deafblindness and MD. In total, 10 rehabilitation professionals including project coordinators, special educators, community-based rehabilitation workers, and vocational trainer were trained through onsite visit training, Monitoring and evaluation visits, and national and regional level training.

PROJECT ACTIVITY REPORT

Sr. No.	Targets for the relevant period	Activities undertaken during the relevant period	Deviation from the targets, if any, and reasons for the same.
1	Target(s) met in the relevant period as mentioned in the Implementation Plan / Schedule I	Shishu Sarothi 13 (8M, 5F) children and adults with deafblindness and multiple disabilities were identified and enrolled during the project period. Nav Chetna Society 4 (M) children and adults with deafblindness and multiple disabilities were identified and enrolled in the project. 2. Provision of need-based services to enrolled service users- Shishu Sarothi- * 84 (57M, 27F) service users received rehabilitation and education services based on their needs and the intervention plan prepared. * 15 (10M, 5F) service users from low-income families received nutrition support to meet their nutritional requirements. * 6 (3M, 3F) service users received assistive devices. 4 service users received a braille slate and 2 received spectacles. * 13 service users received regular need-	the same.
L		based therapy i.e.	

- physiotherapy/occupational therapy and speech therapy.
- * 39 (29M, 10F) adults with deafblindness and multiple disabilities received training in developing pre-vocational & vocational skills based on their potential and capacity.
- * 6 (5M, 1F) service users underwent needbased clinical assessment. 3 service users underwent a clinical hearing assessment and another 3 service users underwent a clinical vision assessment
- * The team reviewed individualized education plans (IEPs) of 37 service users and 2 new IEPs were prepared.
- * 15 students and their caregivers participated in an exposure visit/ outing to an ancient temple in Hajo. The students explored the temple and enjoyed the day with their caregivers.
- * 2 adults with deafblindness received a seed amount of 25000/- to start income generation activity.

Nav Chetna Society

- * 24 (19M, 5F) service users received rehabilitation and education services based on their needs and the intervention plan prepared.
- * 5 (4M, 1F) service users from low-income families received nutrition support to meet their nutritional requirements.
- * 3 (3M) service users on a need basis received medical support.
- 5 (4M, 1F) service users received assistive devices. 1 service user received a walker, 3 received a calliper and 1 received a CP chair.
- 9 (6M, 3F) service users underwent needbased clinical assessment. 5 service users underwent a clinical hearing assessment, 2 service users underwent a clinical vision

- assessment and 4 service users underwent the clinical psychological test.
- * 11 service users received regular physiotherapy.
- * The team reviewed Individualized Education Plans (IEPs) of 14 service users and 1 new IEP was prepared by the team members.
- * 15 service users with their caregivers visited the Hindumalkot India- Pakistan border for an exposure visit. Apart from exploring the area under the guidance of BSF officers, children enjoyed the day out with their caregivers and participated in recreating activities organised for them.

3. Capacity building of deafblind resource center professional

 A 3-day National Training on Deafblindness with a focus on "Understanding Mental Health Needs and Addressing them through Individualised Education Program" was organized from 23rd to 25th August, Ahmedabad.

The sessions for adults with deafblindness/MD focussed on their orientation to the concept of 'stress' and developing their capacity to express their emotions to family members and their educators. Different stress management techniques were introduced to the adult trainees.

Caregivers/ parents and special educators' learned to address the mental health needs of their children under the different dimensions of mental health.

Special educators were trained to integrate the mental health component into Individualized Education Plans (IEPs) of children and use different intervention strategies to assess and plan intervention under the mental health area of the IEP.

2 special educators, 2 caregivers/parents, and 1 adult with deafblindness with an interpreter from partner organizations supported by the Mukul Madhav Foundation attended the National Training.

 A 5-day Regional Training on Deafblindness was organized by the National Association for the Blind, Delhi (Deafblind Regional Centre- North Region).

The training aimed at building capacity and enhancing skills of rehabilitation professions in areas of understanding deafblindness, conducting functional assessment of children, developing IEPs, and training participants in orientation and mobility, sensory integration activities, sign language, teaching strategies, and curriculum adaptation.

Mr. Amit, CBR worker from Nav Chetna Society attended the training.

Monitoring & Evaluation Visits

- * Mr. Ritesh Daniel, Sr. Officer- Accounts, Sense India visited Nav Chetna Society, Sri Ganga Nagar for the project finance monitoring & and evaluation on 5th & 6th Sept. During the visit he reviewed the finance-related documents and guided the project partner in financial management. Key suggestions to partner organizations are as follows-
- Bills & and vouchers should have the signature of the accountant and project coordinator
- * Asset tagging is suggested to the partner
- Partner organizations need to strengthen their internal control system

- * Ms. Kanu Priya, Senior Specialist-Capacity building conducted a 2-day monitoring and evaluation visit at both the partners' locations- Shishu Sarothi, and Nav Chetna Society. During the visit, she met children and adults receiving services and interacted with caregivers. The visit also focussed on documentation review and discussion regarding challenges faced by the team in the implementation of the activities. The following suggestions were given during the visit to the project teams-
- * Project teams to create a WhatsApp group of Samagra Shiksha educators, Anganwadi, and ASHA workers trained for easy follow-up and communication with the sensitized officials.
- * Referral records from different sources to be maintained and updated.
- * Visits organizations working on child rights, street children, health care, education, etc. for sensitization.

Onsite Training Visits

* Ms. Mercy Chingnunmuang, Sr. Trainer-Capacity Building, Sense India provided 3 days of onsite training support to the project team at Shishu Sarothi from 13th to 15th Dec. And Mr. Rashmikant Mishra, Lead Trainer-Capacity Building, Sense India provided 3 days of onsite training support to the project team at Nav Chetna Society from 27th to 29th Dec. During the visits both the trainer observed sessions conducted by the respective teams and provided needbased training the project teams based on their observation and assessment conducted.

Key suggestions given to the project teams during the visits are as follows-

* Focus on age-appropriate goals

- In-house training should be planned weekly. Staff who all the attending training should share the knowledge with others
- Pre-requisite skills should be developed before planning IGA
- * Listing out the areas wise activities

• Mentoring Visit at Shishu Sarothi

Ms Rosa Wahlang, a senior professional in the deafblindness field visited Shishu Sarothi for mentoring on 19th-20th Oct. During visits, she observed the team conducting sessions with selected children and provided child-specific suggestions to the team. Some of the suggestions given are as follows-

- Conduct functional assessment on areas of communication, social skills, academics, and pre-vocational skills (problem-solving, time management, organizational skills, critical thinking- for Syed Abdulla Amin)
- * Motivate parents or family members to understand about sign language as a form of communication for their son, and how their involvement can help in improve his communication and learning. (For Rakesh Ali's family)
- Establish routines around daily activities and decide ahead of time what words and concepts you want to focus on during each routine. (For Rizwan)

4. Stakeholders Sensitization

Shishu Sarothi, Assam

 96 Samagra Shiksha (SS) educators were sensitized on deafblindness and trained on curriculum adaptation, inclusive education, screening, and assessment through State Level Training on 10th August. Feedback from two participants is as below;

"After participating in this training I have gained basic knowledge of 'Modes of Communication' & assess vision/hearing" -

Ms Binita, SS Educator

"Participating in this training makes me aware of the ways I can help students with deafblindness"

Ms Mrinal Kalita, SS Educator

 39 NGO professionals from 4 NGOs in Assam were sensitized on deafblindness and MD on 7th Dec 23, aiming at creating a referral network and expanding services to children with deafblindness and MD. Partner organization also received a request from another NGO named Morigaon Mahila Mehfil for sensitization.

> "After participating in this training I have gained basic knowledge of Deafblindness and got ideas to do functional assessment"

> Ms Wahida Rahman (Director, Morigaon Mahila Mehfil)

 42 rehabilitation professionals from 11 NGOs in Tripura were sensitized on deafblindness and MD on 22nd Dec. The sensitization also focused on collaboration with NGOs to expand services for children with deafblindness and MD in the State of Tripura.

> "Participating in this training makes me aware of the ways I can help students struggling with Deafblindness"

Ms Sreelekha Ray (Director-Voluntary Health Association of Tripura, VHAT)

- 36 Anganwadi centers were covered under an awareness drive on deafblindness and multiple disabilities. In total 412 Anganwadi workers and parents were sensitized on deafblindness and disability as a whole
- 60 members from SB Deorah College- Guwahati, Ulubari including teaching faculty and students sensitized on the importance of sign language on the occasion of International Sign Language Day
- Assam state-level advocacy meeting on 21st Nov. provided an opportunity for Govt. officials from different departments and parents to discuss and resolve challenges faced in accessing services by persons with deafblindness. In the meeting following key officials attended the meeting-
 - * Ms Rashmi Baruah Gogoi, Joint Director (Social Justice and Empowerment)
 - * Mr Nilakshi Barman, Counsellor (RRC)
 - * Mr Nilotpal Kalita, State Coordinator (UDID, Assam)
 - * Ms Sangita Sharma, Off Asst. (Guwahati Nodal Office)
 - * Ms Sanyukta, Physiotherapist (RRC)
 - Ms Ketaki Bardalai, Executive Director, Shishu Sarothi
 - * Mr Parag Namdeo, Head-Network & Advocacy (Sense International India)
 - Ms Shrutilata Singh, Sr. Specialist-Network Support (Sense International India)

Post the advocacy meeting the project team at Shishu Sarothi received support to revise the disability certificate of children with deafblindness/ multiple disabilities who were earlier issued single disability certificates. The revised and correct disability certificate will enable the children to avail more services they are entitled to.

Ms. Rashmi Baruah Gogoi, Joint Director (Social Justice and Empowerment) sought support to sensitize health department officials on deafblindness and correct assessment.

Nav Chetna Society

- 21 NGO professionals from 10 NGOs were sensitized on deafblindness and MD on 21st Sept.23, aiming at the creation of a referral network and expansion of services to children with deafblindness and MD.
- 37 Samagra Shiksha (SS) educators were sensitized on deafblindness and MD. The training focused on curriculum adaptation, inclusive education, screening, and assessment. This training was conducted on 27th December.

5. Network development of adults with deafblindness, parents, and special educators

Shishu Sarothi

A local network meeting was organized on 31st
 August. 12 caregivers (4M, 8F) attended the
 meeting. Parents and the project team discussed
 about timetable of students, the development of
 students, the introduction of the annual report
 card of students, activities and action plans, etc.

		Project team members who attended national			
		training on deafblindness shared their learnings and experiences with caregivers. During the meeting, caregivers were oriented to different relaxation techniques with tips to manage their stress.			
		Nav Chetna Society			
		3-day North Regional Network Meeting was			
		organized from 24 th -26 th July 23, aiming at building the capacity of network members in SRHR (Sexual and Reproductive health), mental health, and experience sharing by network members.			
		4 caregivers and 1 special educator from Nav Chetna Society participated in the training and built their understanding of SRHR-related issues.			
		The participants also learned different methods through which young adults can be oriented to SRHR-related topics such as menstrual hygiene, menstrual pain, myths related to menstrual, balanced diet, use & disposal of sanitary napkins			
		 2 local network meetings were organized during the project period. A total of 25 caregivers (7M, 18F) attended the meeting. Caregivers were briefed on the Mukul Madhav Foundation- supported project followed by a discussion on the role of network members. Parents were also motivated to join Sense India's National Network 			
2	Payment released by MMF during the relevant period	Total payment released- INR 31,46,000/-			
3	Actual Expenditure Incurred during the relevant period	Actual expenditure- INR 28,74,262/-			
4	No of Beneficiaries Details of the project	Total service users – 108 (76M, 32F) service user			
	at this stage.	Shishu Sarothi, Guwahati- 84 (57M, 27F) service users			

		Nav Chetna Society, Sri Ganga Nagar- 24 (19M, 5F) service users			
			0 to 6 years	6 to 18 years	18 years & above
		Shishu	6	39	39
		Sarothi	(5M, 1F)	(23M, 16F)	(29M, 10F)
		Nav	1	12	11
		Chetna	(M)	(9M, 3F)	(9M, 2F)
			7	51	50
		Total	(6M, 1F)	(32M, 19F)	(38M, 12F)
7	Any other remarks				

CHALLENGES ENCOUNTERED

Teams at both project locations faced different challenges when working with service users and implementing activities. Some of the key challenges faced by the teams are as follows-

1. The project team at Shishu Sarothi faced a challenge in providing more service hours to children with deafblindness and MD due to distance and transportation problems.

As service users live far from the centre with both parents either engaged in daily living work or household chores they couldn't visit the centre regularly. Also keeping in view the distance and number of service users assigned to each team member, it was challenging for the team to give equal time to all the service users.

The project team encouraged caregivers especially grandparents, wherever possible to bring the child to the centre. Also during home visits, the visiting team member ensured that at least a caregiver sits during the sessions and is trained in conducting the activities.

2. Identification of children with deafblindness posed a major challenge for the project team at Nav Chetna. Reluctance from family members to disclose the presence of a family member with a disability during the survey, ignorance among caregivers about dual sensory impairment such as deafblindness leading to the issuance of only a single disability certificate, etc. are some of the factors affecting identification.

The partner organization is creating awareness on deafblindness through networking with govt. officials and community awareness programs. Caregivers of existing enrolled children are roped in to share their experiences with new parents and guide them. Team members encourage caregivers of children identified to visit the center, observe sessions, and guide them in availing welfare schemes

3. Team members faced a challenge in getting a few children's clinical vision/ hearing assessed. At times children did not cooperate during the assessment as a result another date was allotted for the assessment. Ensuring parents' availability for the next date assigned for assessment was another challenge faced by the teams.

The teams sensitized medical practitioners on the condition of the child assessed for better understanding coordination during assessment. The team is allotted a time slot when patient turnover is low so that doctors can give more time to children referred by partner organizations. Parents as well as project teams now also prepare the child for assessment in advance.

IMPACT STORIES

7-year-old Sanjib Bishwa from Guwahati has deafblindness. With continuous one-on-one sessions with CBR worker Sanjib has become calm, learned to socialise and can navigate his way indoors. He is now able to perform basic activities such as brushing his teeth on his own.





21-year-old Vinay from Sri Ganga Nagar has deafblindness and cerebral palsy. He has achieved an important milestone of toileting with support. Earlier Vinay could not express his need to go to the washroom and used to defecate in his clothes. But with regular sessions on activities of daily living and orientation and mobility, he has learned to navigate his way to the washroom.

15 years old Sudip from Guwahati has deafblindness. With continuous sessions, he has learned to socialize and has been trained in basic orientation and mobility. He now shows interest in his activities. As a result of regular physiotherapy, he can walk with the support of a cane. He has also learned the basic concept of braille.



"I am very happy to see him develop specially his Braille skills and basic orientation. He uses tactile sign/body language at home too and he points out touches the objects he needs. He has become very calm and expresses more than before now"

Ms Rita Bala Roy (Sudip's mother)



10-year-old Aishwarya from Sri Ganga Nagar has deafblindness with cerebral palsy. With regular centre based services there has been considerable improvement in Aishwarya's behaviour. She now has started to participate in activities. Tries to greets when someone says hello and has started to pay attention to what the other person is saying

		Shishu	Sarothi	
S.No.	Name of the child(ren)	Activity	Nature of setting	Impact/ Benefits
1	Arman	Cognition & Communication (identification of fruits, colors, sign language)	Centre based	He can now identify 10 types of fruits and 10 types of vegetables name with sign language. He can identify 4 colors and also can sign A-Z.
2	Siba Mahato	Academics	Centre based	He can write numerica numbers 1-50 and can also sign 1-20 in sign language
3	Ananta Raj	Academics	Centre based	He can identify, write, and sign numbers 1-10.
4	Rizwan Choudhury	Fine motor activity	Centre based	There is improvement in Rizwan's grasping skills. He is learning to hold and release objects.
5	Sanjib Biswas	Mobility	Center Based	He can independently move around inside the house and known place using landmarks and cues.
		Nav	Chetna Society	
S.No.	Name of the child(ren)	Activity	Nature of setting	Impact/ Benefits
1	Yuvraj	Sensory stimulation activity and mobility	Center-based	With regular sessions there is an improvement in Yuvraj's tactile perceptions. He also tries to walk with support.
2	Cheenu	Gross motor skills	Centre based	Cheenu now tries to si without a belt.
3	Mamta chug Pre Braille activity		Home based	Mamta now understands the concept of Braille dots and has learned to write A to D in Braille.

4	Dhaanu	Receptive	Center based	Dhannu has started to
		Communication		follow instructions.
		and Fine motor		As a result of activity with
		skills		Thera putty her grasping
				power has improved