

Educational Services for Children with Deafblindness and Multiple Disabilities in Vadodara, Gujarat

From Isolation to Inclusion

Our vision is of a world in which all children and adults with deafblindness can be full and active members of society.

Introduction

Deafblindness – a unique disability, causing extreme challenges

95% of what we learn is through our eyes and ears. Imagine what it is like to be a person with deafblindness. Deafblindness combines varying degrees of both hearing and visual impairment. All individuals who are deafblind experience extreme challenges with communication and mobility; as well most have additional physical and medical conditions. Persons with deafblindness face neglect and discrimination owing to their inability to communicate and relate to the world. They are thus denied the basic human rights of education, medical care, amongst other needs that are taken for granted by most of us. The condition of deafblindness poses additional challenges when it is clubbed with other disability conditions like intellectual, cerebral palsy, autism to name a few. Most often they are with associated disabilities.

Sense International India

Sense International India (also known as Sense India) is the only national-level organisation supporting specialised educational and rehabilitation services which enable children and adults with deafblindness to overcome the challenges caused by deafblindness and become an integral part of their society. Sense India's key objective is to provide the information, guidance, support, and training needed along with being committed to helping persons with deafblindness and multiple disabilities and their families by raising awareness and campaigning for rights, opportunities, and services throughout the nation. Sense India has specialised expertise in domains of communication, mobility, accessible information, assistive devices and rehabilitation building capacity of persons with deafblindness. With its unique technical know-how of the last 23 years in the field of deafblindness and multiple disabilities, Sense India uses a multi-pronged approach. This includes technical assistance to its partner NGOs and direct training of their staff to work with children and adults with deafblindness and multiple disabilities in the community.

This well planned consistent efforts of expanding services with the help of a network of grass-roots organisations and building their capacity on deafblindness had enabled Sense India to **reach out to more than 78,000 individuals with deafblindness** in the last twenty-three years. The partnership approach of directly working with local organizations has resulted in the **setting of 59 projects in 23 states** and is one of the most cost-effective and innovative models of service delivery.

Due to our nation-wide initiatives, **Sense India is accredited to the United Nations** and has consultative status on deafblindness. **Sense India has started to assist in South-Asian countries** based on expertise in the field of deafblindness in India. Our **vision** is of a world in which all children and adults with deafblindness can be full and active members of society.



After we identified Sufiya and enrolled her at our care centre in, we helped her learn how to wear hearing aids and glasses. We helped her train in functional academics and gradually Sufiya became independent in her daily activities, learnt numbers and alphabet and started to interact more with her classmates at school. Sufiya is now in the 3rd grade and loves going to school

Project Need in Vadodara

There are an estimated 1,650 children and adults with deafblindness and multiple disabilities living in Vadodara district itself, but there is only one specialist centre to fulfil the needs of these children and adults with deafblindness located in Vadodara city. Sense India has established a centre in Vadodara with its partner organisation to cater to the needs of children with deafblindness and multiple disabilities. Currently, we have been able to reach out to only 20 children with deafblindness and multiple disabilities, but there is a dire need to expand our current services. There is a need to build the capacity of local CSO and community so that they are capacitated to address the needs of persons with deafblindness and multiple disabilities and their families. In the process, the community will also get sensitised towards the need for inclusion of persons with disabilities in the society.

Proposed Project

Currently, in the Vadodara city, we are reaching out to 20 children with deafblindness and multiple disabilities. Through the project, we would like to expand our reach and include an additional 15 children with deafblindness and multiple disabilities and provide them with the required needs-based individualised education and rehabilitation support services. The centre will be developed as model centre for children with deafblindness and multiple disabilities where their specific needs will be address and supported to become and independent and contributing member of their society. CSOs associated with disability work will also be trained towards the needs of persons with deafblindness. Sense India will provide capacity building training to its partner organisation and project staff for better quality care and services to children with deafblindness and multiple disabilities. Training will be provided to parents as well to support the education of their children and advocate for their rights with the government. An integral part of the project will be training the government's *Samagara Shiksha (SMSA) Abhiyan* teachers for identification and inclusion of children with deafblindness and multiple disabilities in mainstream schools.

The proposed project's work will focus on the development of required educational service infrastructure, maintaining the established deafblind education and rehabilitation services and strengthening the formation of local parent's and other network groups for the sustainability of the needs-based specialised educational services.

Project Implementation Plan

The activities carried out through the project will be as follows:

- Identification of children with deafblindness and multiple disabilities

- Through Community based Rehabilitation Workers, linkages with *Anganwadi*, primary health centres and hospitals. We aim to identify 15 children with deafblindness and multiple disabilities in the year
- Centre and home-based services for 35 children with deafblindness and multiple disabilities (20 existing children and 15 new identified in the year) to become independent
 - **Clinical & Functional Assessments:** Clinical and functional assessment helps the professionals to understand the degree of disability of each child identified in the project. Clinical assessments are done by medical/para-medical professionals whereas functional assessments are done by special educators. Each child undergoes functional assessments as soon as they are identified. However, the clinical assessments are done in the first two-three months after the identification, depending upon the convenience of the child.
 - **Development of an 'Individual Education Plan' (IEP) for each individual:** Individualised Education Programme (IEP) is prepared through a team effort to provide quality services for children and adults with deafblindness and multiple disabilities. The IEP is prepared based on the clinical and functional assessment of each child. As an initial part of developing the IEP, rehabilitation professionals along with parents considering the interest and need of the child, identify the annual goals and develops teaching strategies to attain the plan. IEP is mandatory for all the children availing services by Sense India.
 - **Therapeutic Services:** Therapeutic Intervention includes both physiotherapy and speech therapy. The children with deafblindness receive the therapies as per their need. Most of the children with deafblindness and multiple disabilities have complications concerning their health, which requires proper therapeutic intervention. The years of experience of Sense India have proved that therapies help children with deafblindness and multiple disabilities in the prevention of any secondary disability.
 - **Provision of Aids and Assistive Devices:** Assistive devices enable the children with deafblindness and multiple disabilities to improve their functional skills in the areas like communication, orientation & mobility.
 - **Training:** Training in mobility, communication abilities, sensory awareness, daily-living skills, social and wherever possible, vocational skills.
- Work with the government's education department the need for 'Integrated/ Inclusive' education to be made available for children with deafblindness under *Samagra Shiksha Abhiyan* (SMSA)– the 'Education for All' programme of the government. We aim to train 10 government teachers in the year
 - Sensitisation of state SMSA officials, through meetings and school visits
 - SMSA teachers will be trained to identify and include children with deafblindness in schools.
- Build the capacity of project staff to work with children with deafblindness. 4 project staff members will be provided capacity building training in the year.
 - Mentoring support by Sense India's qualified and experienced staff will include onsite and field visits by Sense India trainers
- Capacity building of parents of children with deafblindness and multiple disabilities. We aim to train at least 70 parents in one year to provide better education support and advocate for the rights of persons with deafblindness and multiple disabilities.

- Promote sharing and networking activities among parents/ families, teachers and NGOs¹ at the local, regional and national level. 1 local group of parents will be provided support to advocate for education and other rights of their children with deafblindness and multiple disabilities
 - Parents/ families of children with deafblindness and their teachers will be motivated to join the national network of families: Prayaas; the network of teachers: Abhi Prerna; and the network of young adults with deafblindness: Udaan

The project is designed based on the needs expressed by persons with deafblindness and their families. The approach reflects the immediate and future expectations of people with deafblindness and their families, obtained through regular interviews, interactions in their familiar settings and consultations within their communities.

Impact Measurement

Short to Medium-term impacts	Means of Impact Measurement
Proper screening for correct diagnosis and 35 children receiving need specific services based on her/his individualised educational plan (IEP)	Number of children screened and the number of children receiving needs-based independent living training; Documentation of diagnosis and assessment of each child under the project – assessment documents of newly identified children and need assessment document of existing children; Maintenance of individual educational plan (IEP) in the child's file and its regular reporting to the project coordinator.
Enhancement of the skills and knowledge of 4 project staff to work with the child with deafblindness more effectively,	Number of children receiving services versus enrolled at the centre; Improvement in quality of services to the child; Pre-training and post-training tests results
Enhancement of the skills and knowledge of 70 family members to work with a child with deafblindness and multiple disabilities more effectively	Number of family members trained to address the needs of persons with deafblindness and multiple disabilities; Number of parents joining the network groups Advocacy initiatives taken by parents at the local level Better compliance of child's follow up plan at home; Parents' active involvement in the team meetings and their feedback on training of persons with deafblindness and multiple disabilities and its outcome.
Enhancement of the skills and knowledge of 10 SMSA teachers to work with a child with deafblindness and multiple disabilities effectively,	Number of children enrolled by SMSA; Pre-training and post-training tests results No. of children identified and referred from teachers trained to the project for assessment and further intervention

¹Establishing network with NGOs working with persons with disabilities is one of the major focus and project aim of Sense India. This network will be helpful in creating larger support and referral system for persons with deafblindness.

Long term impacts	Means of Impact Measurement
35 Children who receive the services are showing progress on their growth and developmental milestones.	Documentation & Reporting of the progress of each child – in terms of success “Stories of Hope”
Enhancement of the capacities of partner organisation to continue services for children more effectively,	Partner willingness to integrate deafblind work in their larger organizational work
Increased awareness of deafblindness in community and referral to the centre on time	Number of children diagnosed as “deafblind” at the end of the project; and Number of referral received at the centres

Project Outputs and Outcome

- Need-based individualised education, therapy and rehabilitation services to 35 (20 enrolled + 15 new to be identified) children with deafblindness and multiple disabilities
- Capacity building of 70 parents/family members of children with deafblindness and multiple disabilities to provide quality care to their family members and advocate for their issues
- The capacity of our partner organisations will be built on deafblindness and related issues. 4 project staff members will be provided with the capacity-building support, ensuring the long-term sustainability of the work
- Training and capacity building of 10 government teachers associated with the Inclusive Education for All initiative, for identification and inclusion of children with deafblindness and multiple disabilities in mainstream schools
- A support group of parents and teachers will be formed at each of the project locations to advocate for the rights of persons with deafblindness and multiple disabilities

The long-term impact envisaged by Sense India for the project is for the centre to be well-known in Vadodara district for any children diagnosed with deafblindness to be referred there. The children provided education and allied services at the centre will become functionally independent and certain children through Sense India’s training initiatives with government’s *Samagara Shiksha* teachers will be able to enrol in mainstream schools and complete their education in inclusive setups. The parents/family members provide training through the project, will work on spreading awareness in the community on deafblindness and become a self-sustainable group advocating for the rights of their children and persons with deafblindness in general. The children who otherwise would have completely missed out on education will get educated through their centre and will look forward to becoming micro-entrepreneurs through Sense India’s vocational training project for young adults with deafblindness and multiple disabilities or find other meaningful employment opportunities and become productive members of the society.

Budget

The total project cost is **INR 8.11 Lakhs** for one. Detailed breakup of the budget is shared in the attached excel sheet.

Please note that at the time of submission of the project proposal, we had shown tentative funding of INR 2.5 Lakhs, and hence requested the remaining amount of 5.7 Lakhs from Asha for Education. We have not received the grant of INR 2.5 Lakhs, and hence we are requesting the total budget amount i.e. INR 8.11 Lakhs.

Contact Details for this Project:

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