

Frequently Asked Questions

Who are Anganwadi Workers and Samagra Shiksha educators? Are they local groups/organizations that Disha works with?

- Anganwadis- Anganwadi centres were started by the Indian government in 1975 as part of the Integrated Child Development Services program (ICDS) to combat child hunger and malnutrition. Anganwadis are the focal point for implementation of all the health, nutrition and early learning initiatives under ICDS at community level. Six key services like Supplementary Nutrition, Immunization, Health check up, Referral Services, Nutrition and Health Education and Pre-school Education are provided to children in age group of 06 Months to 06 years, pregnant women and lactating mothers through Anganwadi centres.

Anganwadi Workers (AWW)- The Anganwadi worker is a functionary of ICDS in charge of managing the Anganwadi.

Since Anganwadi workers through Anganwadi centres provide basic health care services within community. These workers have valuable information related to health of children living within the assigned communities. Anganwadi workers are helpful in getting information related to number of children in 0 to 6 years age, children with disabilities/ in risk of getting disabled, information related to pregnant women with rubella infection or with any other conditions that's increases risk of child being born with disability. They can refer children with deafblindness/ other disabilities and their caregivers to Disha Charitable Trust.

- Samagra Shiksha Abhiyan (SSA)- Ministry of Human Resource Development, Government of India in 2018, launched Samagra Shiksha as an Integrated Scheme for School Education. Samagra Shiksha aims to provide inclusive and equitable quality education to all children from the age of 4 to 18 years and at all levels of school education from Pre-school to Senior Secondary in the country in accordance with UN Sustainable Development Goals (SDG-4) for Education.

(SMSA) recruits special educators to implement the programme, these special educators are trained in different specialised stream like special education in intellectual disability, special education in deafblindness, special education in visual impairment etc. and are registered under Rehabilitation Council of India (RCI) Act. These educators are trained to provide quality education who are enrolled under SMSA.

Since these educators are working in govt. schools hence project team at regular basis follow ups with them for referrals and builds their capacity to work with children with deafblindness, adapt regular curriculum as per need of deafblind children, create inclusive setup within classroom and school etc.

Annual Report 2021 - Project Objectives 1: What is the graph about?

The graph shows age wise distribution of children and adults enrolled under the project. Of the total 26 children and adult provided services in year 1 of the project. Majority are in 0-18 years age group whereas 2 service users are 18 years and above.

Age and other details of new identified children/adults?

Sr. No.	Name of service users	Sex	Age
1	Jhanvi	F	13
2	Ananya	F	6

3	Zainab	F	16
4	Jamila	F	16
5	Ejaj Khan	M	17

What is an IEP?

The term 'IEP' refers to Individualised Education Programme. The IEP for a child with deafblindness is a written plan describing the specific education and related services designed to meet the unique educational needs of a student with deafblindness. It contains objectives and goals (both short term & annual goals) based on the child's present level of educational performances, it specifies the educational placement, settings and describes the related services and support which is necessary for the child to benefit from the special education program.

A multidisciplinary team comprising of professionals such as special educators, vocational trainers, physiotherapist-speech therapist-occupational therapist, the child's parents and the child (where appropriate) meet to develop the IEP. The team discusses and focuses on the specific information about the child's strength, needs, concerns as well as parents' ideas for enhancing the child's education. Results of evaluations and assessments of the child, both formal and informal, are considered to form the base for the IEP.

The IEP as a document is extremely need based and considers the child as a whole, taking into account various areas of development.

How often do the sessions happen with parents and children?

20 service users are able to visit the centre thrice in a week. These service users come under direct services as they receive six hours of service in a week. Parents are provided hands on training during one-to-one sessions with the children.

3 service users receive support services as per their needs. Under support services the team works with specified number of service users once or twice in a month as they require less support or live far from the centre. The team supports them in linking with govt. schemes and provide guidance to their caregivers whenever required.

How did Sense come to know about Disha? or How does Sense look for organizations like Disha?

Some of the Sense India's partner organizations act as Deafblind Regional Centre (DbRC). These DbRCs are none other than Sense India long associated partner organizations whose capacity has been built to a level that they can guide and support other organizations on deafblindness in their respective region.

Blind People's Association (BPA) is the DbRC for west region. It is through BPA, Disha Charitable Trust came in contact with Sense India. Before initiation of any project with Disha, their team has been part of many trainings conducted by BPA and Sense India.

How does Sense look for organizations like Disha? –

- As Sense India is pioneer and well-known organization in the field of deafblindness in India, organizations who are interested in working for rehabilitation of persons with deafblindness directly contact Sense India.
- Sense India team also come across many disability-based organizations through its DbRCs. These organizations are network member of DbRCs like Disha Charitable Trust.
- Through participation in numerous government/ non-government consultations, meetings, advocacy initiatives etc. Sense India team also come across many disability-based organizations or organizations with prior experience in

implementing disability projects. Whenever Sense India has opportunity to expand its work, we contact these organizations.

How are the children identified? Is there any other type of outreach done?

Children are identified through many sources which also ensure reach to maximum children. Some of the sources we have shared in previous call i.e., through referrals from SMSA educators, local NGOs and anganwadi workers (govt. appointed) community-based health workers. Other sources of identification are as follows: -

1. Survey by the project team
2. Referrals from parents of children with deafblindness already enrolled under the project or from parents of children with other disabilities that the organization is working with.
3. Referral from nearby govt. hospitals and primary health care centers.
4. Referrals from private medical/ paramedical practitioners who knows that particular organization is working on deafblindness/ disabilities.
5. The organization can also organize community sensitization meetings and may get referral from sensitized community members. But this was difficult to do so in pandemic times due to restrictions in gathering and risk of Covid itself.

How is the staffing done at Sense?

- Sense India recruits' staff on the merit basis being an equal opportunity organization, Sense India encourages qualified persons with disabilities, women candidates and transgender to apply.
- The post for the job vacancy is posted on Sense India website, social media handles and other job portals. Interested candidates can apply by submitting their CVs and cover letter. If the candidate is shortlisted, there are informal and formal rounds of interviews. The panels grade the candidates as per skills for their job requirement. The candidate who has been selected by most of panel members is finalized and offered the post.

How is the training activity/education for children decided?

- Sense India understands that as each child has varying degree of deafblindness, so their needs too vary from each other. Therefore, after the identification, the project team at partner organization plans clinical assessment of the child with the doctors to understand extent of impairment and simultaneously does children functional assessment to know the child's residual vision and hearing capacity.
- After the assessments are done, the team consisting of special educators, therapist (physiotherapist, speech therapist, occupational therapist) and caregivers develop the IEP (Individualized Educational Plan) for the child. IEP is a specialized curriculum with annual goals covering different aspects such as activities of daily living, academics, communication etc. The annual goals are further divided into short term goals which can be modified as per the child's response to the activity and their performance.
- The activities of the child are planned keeping in mind their age, their needs and the goals set for them in the IEP. If the child is between 0-6 years of age, then focus is on early intervention, if the child is between 6-18 years of age, focus is on educational intervention and prevocational training and if beneficiaries is above 18 years, the focus is on vocational training for income generation activities. Therapy sessions such as physiotherapy, occupational therapy or speech therapy are decided as per the need of the child/ adult.

Could you elaborate more about the difference in content and quality between training over a video call vs center-based training?

- Centre based training is considered as a traditional or conventional form of training where the child and educator meet each other in person. It is considered a more effective way of interacting with children with deafblindness as they are able learn by touch. As we know that the children with deafblindness have vision and hearing impairment and therefore they rely on smell or touch to identify any object or person better. Learning through tactile approach is one of the best ways to learn for persons with deafblindness.

- The pandemic in the year 2020 forced us to keep safe distance from one another. The educators started taking video and audio calls for the activities of the children. In online mode parents/caregivers stepped into shoes of special educators and conducted activities with their children. The video calls give the flexibility to the parents and the educator to interact with each other and the child at a convenient time. With the video recordings shared by the educators, the parents are regularly able to observe and learn how to do activities with their child. Hence, the child is able to get a holistic experience by learning from both the educators and their parents.
- Content for online and centre-based activities is same. On the basis of goals mentioned in each child's IEP sessions are conducted. The difference is that in centre based activity it is professionally trained special educator/therapist working one to one with the child. Whereas in online mode the parents based on special educator/therapist instructions work with the child. Though parents have been trained prior to pandemic but they are not professionals thus the quality of service that child gets from parents may not be as per the quality of service that one gets in the centre. For example, at home parents may not be able to do therapy that a professionally qualified physiotherapy or speech therapy is able to do at centre. So, parents are trained in only basic exercise/ sitting position that is not harmful for the child and can be repeated at home.

What does parent training include?

Sense India believes that the capacity building of the children is not complete without the support from their parents. Therefore, one of the major focusses of Sense and its project partners is the capacity building of the parents and family members of children and young adults through trainings, online courses, network meetings.

Training sessions/ workshops revolve around developing parents' capacity and skills in following areas:

- Understanding deafblindness as disability and specialized need of children with deafblindness
- Understanding children behavior
- Making child independent in activities of daily living like eating food, brushing, toileting, personal grooming- wearing cloths, bathing, applying oil/talcum powder

- Helping child to acquire independent living skills in personal care including sexual health, home management, financial management (money concept), time management (time concept & discipline), leisure & recreation, socialization, mobility, vocational training
- Developing self and children communication skills especially in terms of learning sign language
- Developing understanding on different teaching strategies
- Govt. schemes, services and different Acts for welfare of persons with disabilities/ deafblindness
- Basic strengthening exercises, yoga, massage therapy and positioning that can be repeated at home

Parents are encouraged to attend online or offline trainings, online courses on deafblindness/sign language and network meetings of the Prayaas group (National Level Sense India Parents Network Group) and local network group (at partner level) to increase their knowledge, and awareness on deafblindness, rights of persons with disability, issues and challenges faced by the persons with deafblindness and how to overcome those, income opportunities for young adults with deafblindness.

Difference between National Training on Deafblindness and Regional Training on Deafblindness

National Training on Deafblindness is an annual training organised by Sense India aimed at building and enhancing caregivers and special educators' capacity to work with children and young adults with deafblindness/ multiple disabilities. During the training separate sessions for caregivers and special educators are organised covering following key areas: -

For Special Educators

- Developing IEP and evaluation of children
- Research in the field of deafblindness
- Inclusive education curriculum adaptation for children with deafblindness/ multiple disabilities

For Caregivers

- Understanding communication skills and sign Language for persons with deafblindness

- Identifying behavioural issues in person with deafblindness especially children and behaviour modification techniques
- Understanding sexuality and social-emotional needs of persons with deafblindness

Regional Training on Deafblindness is a 5 days annual training organised by region specific Deafblind Regional Centre (DbRC). Under this project team members primarily special educators and community-based workers/field workers along with educators from other local partner organisation where children with deafblindness/ multiple disabilities have identified in the region, participate in capacity building sessions like understanding deafblindness and various intervention strategies. These sessions cover vast areas to work with children and young adults with deafblindness which includes below mentioned key topics: -

- Orientation on deafblindness as disability
- Functional assessment- Practicing functional vision and hearing assessment
- Teaching strategies and developing IEP
- Practicing developing orientation and mobility in children with deafblindness/multiple disabilities
- Developing communication skills in children with deafblindness/multiple disabilities
- Braille and sign language practice sessions
- Technology and its use for persons with deafblindness
- Session on basic therapy, positioning and sensory stimulation activities
- Policies and legislations for persons with disabilities with focus on deafblindness

Who creates IEP for the Children?

IEP (Individualised education plan) is an important document when it comes to working with children with disabilities. IEP for each child is unique and gives bird eye view of the goals prepared for the child. IEP is prepared by team of rehabilitation professional with support from child's parents. The team consists of: -

- Special Educator
- Vocational trainer (if child – young adult can participate in pre- vocational and vocational training)
- Therapists such as physiotherapist, occupational therapist, speech therapist

- Parents (feedback from parents/caregivers is valuable while preparing IEP. Involvement of parents in preparing IEP helps them to develop their understanding on the goals set and support the child to achieve goals sets.)
- Child with disability (if possible, even children for whom IEP is prepared can also be involved in preparing IEP which ensures that their view is also taken into making plan for them, however this is very difficult to do due to severity of disability in the service users.)

What is National Conclave of Network?

There is little awareness regarding deafblindness. As a result, the most appropriate support deafblind people, families and practitioners will receive will be from people in the same situation. Networking is a vital tool in providing mutual support, information exchange and learning. Sense India has helped develop national networks of families names as 'Prayas', teachers named as 'Abhi Prerna' and deafblind adults named as 'Udaan', which are a playing an important role in advocacy and are a strong support group for partners.

During National Conclave of Network also referred to as National Meeting of Networks, representative caregivers, adults with deafblindness and educator from local network groups across India come together to share updates about their network groups and learn from good practices/initiatives taken by another network group. This annual event provided platform to the network members to interact as well as learn from other States representatives network members.

Also during conclave separate capacity building sessions are organised for caregivers and adults with deafblindness which aims at understanding their level of knowledge and simultaneously develop their understanding on different aspects such as role of network group, disability laws-policies, rights of persons with disabilities, need for vocational skill building and income generation for adults with deafblindness, sexual and mental health for persons with deafblindness and other key issues.

What happens in local network meeting?

During local network meeting parents/caregivers, project team and adults with deafblindness (if any in the project) share their views, experiences, good practices, plan covering following areas-

- Dissemination of information related to schemes/services provided by govt. dept or other disability-based organization which can be availed by children-young adult with deafblindness
- Dissemination and sharing of learnings from workshops, trainings, meeting with govt. officials attended by caregivers and project team with fellow network members
- Sharing of procedure followed by caregivers in applying for any schemes including documents kept ready by the caregivers and right authorities to approach. This helps other caregivers in hassle free applying for the documents and schemes
- Sharing of grievances related to difficulty in availing any schemes and how caregivers and project team as network group can advocate with concerned officials to ensure that children receive services without any difficulty
- Sharing good practices with other parents/caregivers to motivate them especially parents of new identified children. This also provided moral support to the caregivers to work with the child for sustained improvement.
- Sharing of challenges faced by caregivers in working with children at home and looking at possible alternatives to resolve the challenges
- Dissemination of project activities updates, action plans and upcoming events by the project team.

Measure the work through pre training and post training results, please provide details of tests that are conducted?

- During national level trainings and regional level team from Sense India and DbRC conducts pre-test in beginning of the training and a post-test after completion of training. The questionnaires used in these tests are set of close ended questions with options, fill in blanks and true/false statements related to the different topics covered during the trainings. Analysis of pre and post-test marks obtained by each participants give Sense

India team better view about the increase in level of understanding and areas that need further trainings. The impact observed during the onsite training/mentoring and according to the need observed, more trainings are designed for the same.

Role of Project Coordinator

- Responsible for smooth functioning of the project and execution of activities as per project objectives ensure minimum organizational programme management standards
- Monitor day to day functioning of the project staff members, planning their tour programmes, evaluating their progress, etc.
- Establish and strengthening rapport with the family members of the children and adults with deafblindness/ multiple disabilities and other stakeholders such as medical & paramedical professionals, govt. officials, aganwadi & ASHA workers, regular school teachers, Samagra Siksha educators, NGOs etc.
- Responsible for compilation and dissemination of information and submissions to relevant agencies.
- Undertake regular field visits to review project progress, monitor and assist project staff on programme management and compliance with project objectives
- Responsible for documentation of project activities including case study, success stories, good practices and maintenance of documents.
- Preparation of quarterly narrative report based on project activities and timely submission of the narrative report, financial report and other information as required by Sense International India and donor organization
- Responsible for logistic arrangement and organise capacity building trainings for the project staff with regards to deafblindness/ multiple disabilities, organization policies, disability laws and policies etc.
- Facilitate meeting of network groups of family members and educators of children with deafblindness and adult with deafblindness
- Sensitize govt. officials and CSOs on deafblindness and multiple disabilities. Create synergizes between govt. machinery and project to ensure maximum benefit to the service users under the project
- Ensure protection of children and vulnerable adults with deafblindness/multiple disabilities against any form of abuse and in case of abuse report it to organization designated Child Protection Officer or concerned authority

- Organize and facilitate visits from officials from Sense India and other donor agencies
- Any other work concerning the project assigned by the director

Role of Special Educator

Key Duties and Responsibilities: -

- Support team in identification and enrolment of persons with deafblindness/multiple disabilities
- To work hands on with children and plan proper Individualised Education Programme (IEP) and activities as per the need of the child
- Responsible for maintenance of children IEP and other other documents such as
- To establish and strengthen rapport with the family members of the children and adults with deafblindness/ multiple disabilities identified and enrolled under the project
- To conduct functional assessment of children and support team in clinical assessments of children with disabilities
- To work closely with the project team on various events, awareness campaigns, conduct trainings and workshops
- To share a quarterly progress/impact report of children with project coordinator
- To modify classroom and home setup to help children participate in school/home activities
- Conduct regular home and centre visits, community-based programme for children with deafblindness/ multiple disabilities
- To support team in organising sensitization and training programme for government officials, civil society organization etc.
- Participate in capacity building training programmes organised by Sense International India and share learnings with other team members
- Ensure protection of children and vulnerable adults with deafblindness/multiple disabilities against any form of abuse and in case of abuse report it to project coordinator or organization designated Child Protection Officer
- To take initiatives independently as well as work as part of the team

4 project staff members will be provided with capacity building support, ensuring long term sustainability of the work.

These project staff members are from partner organization Disha Charitable Trust only. SII team will build capacity of Disha's project staff through onsite training, mentoring, Regional and National Level trainings.

In a year 2 each onsite visits, mentoring and project M&E are planned for partner organization. Regional, National level events are annual event i.e., conducted once in a year.

Out of 24 students, currently how many are affected by deafblindness? As in the site visit there were some children at the centre with autism/other disabilities too.

Out of total 24 students, 15 service users have deafblindness and multi-sensory impairment and other 9 service users have multiple disabilities. Thus, under the project we have children with deafblindness and children who have either visual or hearing impairment along with other sensory issues or disabilities that cause severe communication, developmental and educational problem.

Disha's also work with persons with autism and intellectual disabilities. During virtual site not all children were from Asha for Education supported project. Children and young adults from other projects run by Disha were also getting services.

Note:-

In multi-sensory impairment we include children and young adults with either vision or hearing impairment along with other sensory issue with a combination of tactile+ vestibular + proprioceptive.

In multiple disabilities we include students who have vision or hearing impairment along with any one or more than one of the 21 disabilities (as mentioned on the Right of Persons with Disabilities Act, 2016), causing severe communication, developmental, and educational problems.