

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

January 2021- April 2021

Submitted to Asha for Education

Submitted by Sense International India



LEARNING THROUGH TOUCH

Executive Summary

Disha Charitable Trust with support of Asha for Education and Sense International India is implementing project 'To provide Centre based education and rehabilitation services for children and young people with deafblindness and multiple disabilities in Vadodara, Gujarat'. The project started in 2021 with 20 children with deafblindness and multiple disabilities. We identified 3 children with deafblindness, however, 2 children dropped out from the service due to family moving to their native place. Under the project currently services are being provided to 21 children.

The project focused on identifying the unreached children with deafblindness, multi-sensory impairment and multiple disabilities in Vadodara district through survey and networking visits. The identified children were provided specialized education through home-based and centre-based services as per their individual needs. Parents were also trained for the provision of better services to their children and support them in their daily activities and education as well as to make them more independent. With its technical know-how in the field of deafblindness, Sense International India built and enhanced capacity of project team to work with children and adults with deafblindness.

Till March 2021, children were either given home-based or centre-based support, however, with the pandemic taking over the country, a new medium was explored to connect the child with their educator. The educators started audio or video calls to take sessions with the children and their parents.

After initial hiccups of adapting to this new mode of communication, the children and parents are now comfortable engaging and doing activities online. With the efforts of the rehabilitation professionals, parents have also started taking more interest in participating with the child as they become the primary person to connect physically with the child every day. In difficult times, especially for persons with deafblindness and multiple disabilities and their caregivers, engaging with their educator and performing activities with them on regular basis has been a silver lining. Besides the sessions, parents and educators connect with their respective network groups online. These modes of participation have given them hope that they are not alone.

The services provided under the project proved to be eye opener for many parents who had given up hope of education for their children with deafblindness. As children and adults with deafblindness achieved delayed development milestone, attended academic session with project team, became independent in daily living, parents are hopeful about better future for their children.

Project Objective	Annual Target	Achievement till date
1. Identification of children with deafblindness and multiple disabilities	15	3 service users with deafblindness identified
2. Centre and home-based services for 35 children with deafblindness and multiple disabilities	35 (20 existing children and 15 new identified in the year) to become independent	21 children and adult received need-based services
3. Sensitization and building capacity of 10 govt. teachers	10 educators	Due to continuous pandemic its difficult for project staff to go for networking and meetings with SMSA educators
4. Build capacity of project staff to ensure project sustainability project staff to work with deafblind children	4 project staff	3 project staff have been trained and their capacity have been built in developing IEPs and child safeguard issues.
5. 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.	70 parents	42 parents have been sensitized as per their child needs and guided to work with children in home setup with the available resources.

Project highlights for reporting period

1. 3 new children and adults with deafblindness identified and enrolled for necessary rehabilitation services through referrals for sensitized parents and community members
2. 21 children and adults with deafblindness received educational and rehabilitation services through project
3. 2 clinical hearing assessment conducted. Post assessment the service users are diagnosed with mild to moderate hearing impairment.
4. 8 children attended general medical checkup organized within Disha's premises
5. Individual educational plan for 7 children reviewed by the educators and new/modified goals planned for the children based on their progress and parents feedback
6. 12 children received physiotherapy, occupational and speech therapy on need basis. Out of 12, 3 children received both speech therapy and physiotherapy.
7. 18 NGO officials sensitized on deafblindness
8. 2 sensitization meeting conducted for parents

9. 2 children linked with travel concession certificate, 3 children received disability certificate and 2 availed disability pension.

PROJECT OBJECTIVES AND OUTCOME

1. Identify 15 new children & young people with deafblindness & multiple disabilities in a year

In the reporting period through surveys and referrals 3 service users with deafblindness and multiple disabilities were identified. New identified service users and their family members received necessary guidance and training on different aspects of rehabilitation like vocational activities, activities of daily living (ADL), orientation and mobility techniques (O&M), developing independent living skills, personal grooming, physiotherapy etc. In total 21 service users have been supported directly through centre based, home based, support- based services and online platform.

Due to pandemic project staff could not do networking visits but are in contact with Anganwadi staff of Makarpura and Rasulji chawala area. They have identified one child with suspected deafblindness, the team will conduct functional assessment of the child through home visit once situation gets better in the district.

	6-18 years		18 years and above		Total	
	M	F	M	F	M	F
No. of service users	14	5	1	1	15	6
Total Reach- 21 (excluding 2 dropout)						

Dropout: 2 children dropped out in the reporting period due to migration to native villages and project staff is unable to contact family members of the children.

2. Centre and home based services to 35 children with deafblindness and multiple disabilities

Under the project 21 service users received direct services through centre and home-based services Following services were provided to the services users:-

- Children enrolled under the project received need-based services as per individualized education programme prepared for each service users. IEPs of 7 children receiving direct services through have been prepared and regularly reviewed by the project team.

- 2 clinical hearing assessments were also conducted to ascertain the extent of impairment in the children and adults. The results from clinical assessment assisted the educators in preparing rehabilitation plan for the children in need.
- 8 children attended general medical checkup organized within Disha's premises and parents were guided by the medical practitioners regarding medicines to be followed
- Pandemic period is been utilized by project team to guide the parents to apply for important disability related documents and schemes online. In reporting period Parents of 2 children received travel concession certificate, 3 children disability certificate were issued and 2 children availed disability pension.
- 12 children received physiotherapy, occupational and speech therapy on need basis. Out of 12, 3 children received both speech therapy and physiotherapy.

Sr.	Name of the children	Activity	Nature of setting	Impact/Benefits
1.	Archana Sutaria	Cognition (vehicles, fruit and vegetable identification)	Home based work with online consultation	Archana has started to identify vehicles. She can now differentiate between road, waterways and airways She has also learnt trees/plant name and she knows which gives flowers and fruit. She is slowly learning about household items made out of wood.
2.	Noman Momin	Cognition (identification of basic household items and food items)	Home based work with online consultation	Noman understands the concept of edible and not edible food. He has started to identify roti, biscuits, wafers. He also identifies spoon, glass, plate without any support.
3.	Shivam dhobi	Cognition (identification of basic household items and vegetables)	Home based work with online consultation	Shivam has started to recognize vegetables like tomato and potatoes. He also identifies spoon, glass, plate but need some verbal prompt.

Impact (Physiotherapy/Occupational Therapy/ Speech Therapy)				
Sr.	Name of the children	Activity	Nature of setting	Impact/Benefits
1	Mayur Chauhan	Exercise for Neck & shoulder, simple stretching and strengthening exercise	Home based work with online consultation	Mayur's neck and shoulder girdle movements have improved and there is improvement in his limbs muscle tones
2	Raiyan Patel	Physical Exercise to improve knee and lower limb strength	Home based work with online consultation	With regular therapy and guidance to parents there is considerable improvement in his mobility and walking posture He is able to wear pants with physical prompt and is able to remove his T-shirt on his own.
3	Vatsal Rathod	Simple movements for neck, shoulder, elbow, hand, fingers. Practice to sit	Home based work with online consultation	He needs mother's assistance while doing exercises, but his overall mobility has improved.

3. Sensitize and build capacity of 10 govt. educators

As a result of ongoing pandemic, project team is unable to network with SMSA authorities for sensitization. The team is looking into possibility to organizes an online session but it is subject to approval from the dept.

4. Build capacity of project staff to ensure project sustainability to work with deafblind children

Project staff capacity has been built in developing individual education plan and weekly reporting format through quarterly calls. On the basis of guidance from Sense India, weekly time table has been shared with the parents and Disha's project staff is able to guide the parents in conducting activities at home with available resources.

As result of capacity building of Disha's team members, they are conducting sensitization meetings for NGOs and other stakeholders independently. In the reporting period 18 NGO officials from local NGO named 'Sahaj' were sensitized on deafblindness with focus on identification of children with deafblindness and their assessment.



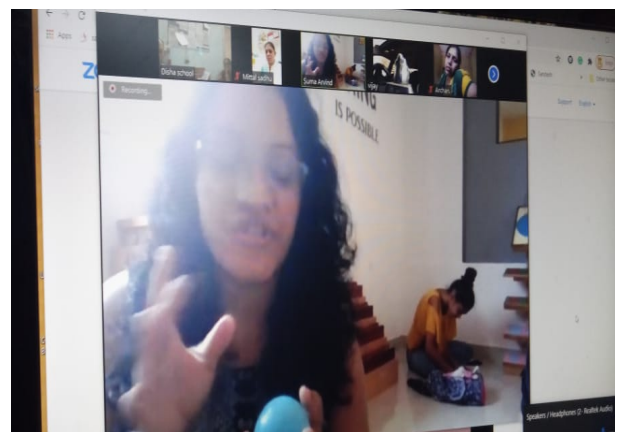
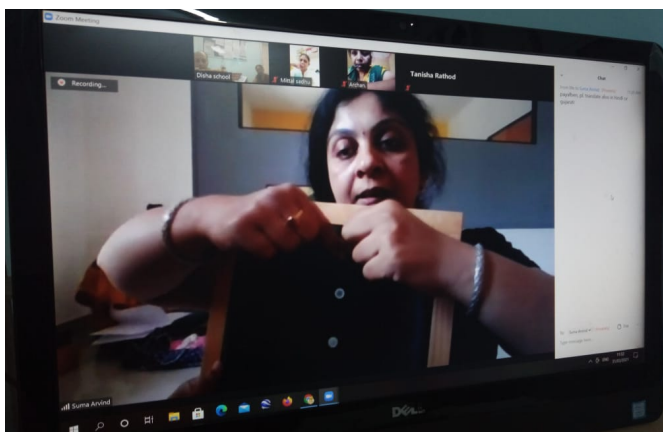
NGO sensitization by Disha's team member

5. Capacity building of parents of children with deafblindness and multiple disabilities

In the reporting period 2 online meetings were conducted with the parents i.e. on 23rd March and 31st March 2021. Apart from regular guidance to the parents on conducting activities with the children, 8 parents were part of these meeting. The meetings aimed at orienting and sensitizing parents in following areas: -

- Childcare and home-based Activities
- Supporting child in activities of daily living training
- Developing teaching learning material at home

Through medium of centre based and home-based services prior to pandemic and online sessions during pandemic, the project team is able to sensitize 42 parents in the reporting period.



Online training to parents on ADL activities and use of resources available at home

Challenges faced during Covid 19 Pandemic

The changing times call for new pedagogy to be adopted to help children to learn, explore and move ahead. With beginning of lockdown numerous educational institutions shifted to online classes to reach to its pupils. As children without disabilities continued their studies through online mode, parent of children with disabilities were in distress about their child future. Children with disabilities is one of

the groups which faced brunt of the lockdown as many of them needed regular therapeutic services and their parents could not step out of their homes. Many parents through WhatsApp group and webinars shared increased behavioural problem in the child with deafblindness and multiple disabilities due to disruptive rehabilitation services.

Challenges faced by project staff, caregivers and persons with deafblindness during lockdown period:

- With project staff and their immediate family members getting affected due to Covid 19 at same time, it was difficult for the respective team member to continue providing services to children.
- As result of travel restriction project activities were severely affected. Both the centre and home-based services need to be closed. This also affected identification of children as project team was unable to go for survey and networking visits.
- Due to lockdown, therapeutic services were disrupted. This affected children with deafblindness who have other disabilities also like cerebral palsy for whom regular therapeutic intervention was very necessary. Though online sessions were conducted but parents cannot do all the exercises as it needs to be conducted by trained specialist only.
- Educators have to plan sessions keeping in view free time available with the parents and in some cases sessions have to be postponed as parents were not available even when time was fixed with them.
- To conduct activities at home, family members faced challenge to make teaching learning material as per requirement of activity and child's current level of understanding. Adding to this space constraint to conduct the activities also posed challenge.
- Attention span of the student with deafblindness while working on an online mode was another key challenge faced by educators.

Step taken to mitigate the challenges

To ensure that children receive continuous support and stay in touch with the project team, Sense India guided the project team to conduct sessions through audio and video calls, wherever possible with support from family members. children and young adults with deafblindness received services through online platform and audio mode.

- Weekly report format was shared with the coordinators to help them update about the weekly sessions conducted with the child and family highlighting the challenges as well as parents' feedback. This enabled educators to keep track of children getting the services as well as monitor the child progress.
- Guidelines for educators and parents to work with children in home setup were shared by Sense India team for educators and parents to refer to. Apart from guidelines, time table for the children was prepared and shared with educator. The time table was modified as per the children needs and shared with parents too. This helped parents to engage children in meaningful age-appropriate activities.

- For children in need of therapy, pictures and videos were shared with parents to do basic strengthening exercises at home. Therapist conducted online sessions with parents and for parents who did not have smart phone guidelines were shared over calls.

Key sessions conducted by project team through online

Educational/Academic Sessions

- Writing activity- alphabets and words writing
- Practicing braille and sign language
- Reading activity
- Basic arithmetic problems – one-digit additions/subtractions
- Identifying fruits-vegetable- household items-body parts
- Language development session through poems, storytelling etc.
- Revision of curriculum followed in school
- Understand concept of time and money

Independent living skills sessions

- Home management- washing and peeling vegetables, watering plants, preparing bed, cleaning wardrobes, folding cloths, cleaning room

Activities of daily living

- Sessions on personal grooming like applying hair oil, combing hairs, identifying face cream etc.
- Session on menstrual hygiene- use of sanitary napkins
- Sessions on brushing and eating food with minimum support
- Session on clothing- identifying own cloths and wearing them, zipping and buttoning shirts etc

Therapy Sessions

- Session on neck positioning and back muscles
- Sitting up and half kneeling with support
- Assisted trunk activation on wedge
- Position to improve muscles tone, neck and trunk control activities on the swiss ball,
- Standing with support
- Sensory stimulation activity
- Speech therapy- repeating words, sounds etc.



Children and parents engaged in activities through online sessions

DISCOVERING THE SELF

Excluded from children of his own age and remained confined within his home, Mr. Mustakbhai and Ms. Fariyal only son Noman has fought his own war. Residing in Vadodara, Gujarat, Noman has multiple disability (deafblindness with intellectual disability and cerebral palsy) as a result of epileptic episode as an infant. Noman was enrolled in project for children and adults with deafblindness and multiple disabilities in a quest to bring him at par with every other child of his age.

Before availing rehabilitation, services Noman was very sensitive. He never allowed anyone to touch him. Due to severity of the multiple disabilities and parents' limitation to provide him necessary intervention at the right time Noman would spend his days crying. He was unable to sit independently, leave alone walk on his own and was also unable to hold objects in his hand. Due to inability to walk, he became dependent on his parents to carry him around.

Educators and therapist developed IEP and encouraged his parents during meetings to support the team in their plans prepared.

With dedicated efforts network partner team, the tables have turned today as Noman has developed by leaps and bounds in various aspects. Much to the delight of rehabilitation team and family members, Noman has started to participate in activities. His concentration span has improved. At present he stays calm and participates in activities. His family members were overwhelmed to see him take steps with support of wall and are now hopeful that their son will walk without support one day. Noman now is not irritated while wearing spectacles and wears them regularly. During pandemic Noman has started to understand the concept of edible and not edible items. He has started to identify roti, biscuits, wafers. He also identifies spoon, glass, plate without any support. As per his physiotherapist Noman's muscle tone has improved and weight bearing has also increased on the affected side of his body.



Noman attending function prior to onset of pandemic

Over few months Noman has started to use his remaining vision to explore objects. His educators have been assisting in developing plan to improve his communication skill and will work towards making Noman independent in activities of daily living. In Noman's mother words "**Noman ab diwar ke sahare chalta hai aur mujhe asha hai ki ek din vo appne aap chalega**".