MAPPING THE SERVICE JOURNEY

of Children with Hearing Impairment from Initiation to Successful Integration into Mainstream Schools

SAVE The Children India
FOUNDED BY MRS. VIPULA KADRI IN 1988

A RESEARCH STUDY

on Dhvani Early Intervention Program of Save The Children India

Report submitted by:

BASIC PARADIGM

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Acronyms

ABR	Auditory Brainstem Response
ADHD	Attention Deficit Hyperactivity Disorder
ADIP	Assistance to Disabled Persons
AIISH	All India Institute of Speech and Hearing
ANC	Ante Natal Care
ANM	Auxiliary Nurse Midwifery
AVT	Auditory Verbal Therapy
AYJNISHD(D)	Ali Yavar Jung National Institute of Speech and Hearing Disability(Divyangjan)
BCC	Behaviour Change Communication
B. ED	Bachelors in Education
BERA	Brainstem Evoked Response Audiometry
CT	Computerized Tomography
dB	Decibels
DIC	District Intervention Centre
ENT	Ear, Nose, Throat
FGD	Focus Group Discussion
GOI	Government of India
HI	Hearing Impairment
HR	Human Resource
IDI	In-depth Interviews
IEC	Information, Education, Communication
IGNOU	Indira Gandhi National Open University
IQ	Intelligence Quotient
MDG	Millennium Development Goals
MIS	Management Information System
MRI	Magnetic Resonance Imaging
NGO	Non-Governmental Organization
NHM	National Health Mission
NITI	National Institution for Transforming India
NPPCD	National Program for Prevention and Control of Deafness
OAE	Oto Acoustic Emission
PIB	Press Information Bureau
PWD	Persons with Disabilities
R&D	Research & Development
RBSK	Rashtriya Bal Swasthya Karyakram
RCI	Rehabilitation Council of India
SDG	Sustainable Development Goals
STCI	Save The Children India
TV	Television
UN	United Nations
WHO	World Health Organization

Executive Summary

Save The Children India implements 'Dhvani', a program on early intervention for children with hearing impairment. The 'Early Intervention Program' for children with hearing loss was setup in 2010 recognizing the need for early identification and interventions with children with hearing loss. Since its inception, the program has focused on providing critical services of testing, diagnostics, therapeutic intervention delivered by a team of professionals with the aim of enabling the mainstreaming of the child by the time s/he is ready to enrol in primary school.

The basic philosophy of the program

The program contributes to the lives of the parents and families that discover their child's hearing abilities at the earliest, especially at birth, in first three months after birth or in infancy. The families are provided timely access to comprehensive services for their children from professionals on early development, communication, and language, resulting into the same quality of early life experiences as their hearing peers.

A family-centered philosophy that nurture the capacities of children to enable them to be at par with other children provide the foundation for programs and practices in early intervention. Children with hearing impairment benefit from an understanding that they are part of a larger community who share similarities in ways they acquire information, communicate, and socialize with others.

Increased opportunities for children to acquire language during the early years and enabling them with communication skills means indicates that the families can be assured of mainstreaming and integration to regular schools. Early identification of hearing abilities signifies that more children are using hearing devices such as hearing aids and/ or cochlear implants, during the early months of life when the brain is most receptive to environmental stimuli.

The professionalism reinforced by the program

Apart from all the responsibilities that the professionals at the intervention center shoulder, one of the key responsibility is to ascertain that the families maintain realistic expectations regarding the outcomes associated with different technologies, so that the focus remains on the child's acquisition of age-appropriate language and other developmental milestones. The program has focused on contributing to the change from the "wait and see" mentality to one of "assess, support, and monitor" to ensure age-appropriate development and mainstreaming. Services are provided by a team of specialists or by one specialist in consultation with others. The frequency and intensity of the services are directly related to the needs of the child and the family.

About the Study

A study to map the service journey of children treated from initiation into the program to successfully being integrated into mainstream schools was undertaken to help understand the key levers necessary to replicate this model and advocate for better policies around education of children with special needs.

This study was funded with seed funding provided by the Global Challenges Research Fund India Project at Canterbury Christ Church University. This initiative intends to support capacity building towards research informed practice in relation to the UN Sustainable Development Goals in India.

Objectives

- To study, assess and map the services offered by Dhvani Program
- To closely map the journey of a child to understand key levers, challenges and best practices

Methodology

While a set of qualitative methods have been used, a detailed analysis of quantitative data from the MIS of the project has also been analyzed for better understanding. The qualitative data collection entailed:

- In-depth-interviews (IDIs) of: a. service providers involved in the program ecosystem; b. government officials; and c. senior management professionals of STCI
- Focus group discussion (FGD) of the program implementation team
- Interviews of the parents for documenting case studies for documenting the overall care pathway the child was provided with.

Evident challenges at the level of parents/families and at the systems level

- Lack of discussion on complications in previous pregnancy and if there is any complication reported then no action taken by parents and families
- Age of marriage, age of first pregnancy, family planning counselling and birth spacing
- Access for ANC services is still a challenge
- Lack of access to active screening at birth for any hearing impairment so the delay in detection which affects the outcome of the interventions
- Lack of community-based referral mechanism and no training program in place for community level workers for screening and referral
- Lack of IEC activities with especial focus on hearing impairment, its implications on life of any individual, importance of early detection and interventions and stigma & discrimination
- Due to non-availability of large IEC program the knowledge and awareness is limited to small geographical boundaries

Enablers that contribute today

- Thorough counselling and explanation about the program, investigations and interventions, discussion on developmental milestones by Dhvani team
- The early intervention under Dhvani is being done by multi skilled dedicated team like audiologist, auditory verbal therapists, speech therapist and mainstreaming specialist and other experts

- Participation of parents in the entire process of intervention improve the compliance of intervention and empowering the parents
- Detection of hearing impairment at young age is the very important milestone of the entire process
- Team of multiple disciplines that ensures quality of care during and post-surgery period
- Ensuring access to funding support is the most attractive aspect of the program as cochlear implant is very expensive surgery and it is difficult for the poor patient to deal with it.

Aspects that have the potential for future contribution

- Using existing community-based platforms like immunization camps for implementing community-based screening programs for early detection of hearing impairment in children
- Providing services close to the residence of kids and through tele-practice improves the compliance of intervention and reduce the possibilities of dropout rate
- Collaboration with the Government of India sponsored largest public health program which covers the disease, deficiencies, defects at birth and developmental delay of zero to 18 years of children and adolescents.
- Ongoing Post Graduate Diploma Auditory Verbal Therapy (PGDAVT) course at AYJNISHD, Mumbai to develop the human resource for enhancing the capacity of system to address the hearing impairment.

Recommendations

The study clarifies that 'Dhvani' as a program has come a long way in establishing itself as a scalable and replicable model. However, there are few areas which have both a scope and potential to strengthen itself, wherein it can be comprehensive enough from two perspectives: one is focusing on multi-dimensional aspects; and two is to engage with and involve multiple stakeholders. With this perspective, a set recommendations that emerge pertain to: systems and service delivery; demand generation; and policy advocacy.

Systems and Service Delivery

Contributing to service strengthening

While STCI itself is providing a set of services through its program and the established center for more than a decade, a step further in strengthening the other services around this intervention will prove to be helpful, this can be achieved by way of:

- Creating network of various service providing institutes, hospitals, non-government organizations so as to increase service accessibility and screening programs for early detection and helping in developing a timely intervention plan.
- Facilitation or starting of community and home-based active screening program at birth for early detection of hearing impairment
- Initiating IEC (Information, Education and Communication) and BCC (Behaviour Change Communication) programs for each group including parents, family, community and health care providers to improve early detection, decrease dropout during the entire journey of intervention and adherence to the intervention protocols.
- There should be mechanism for institutional partnerships with institutes like TISS, Nirmala Niketan and other academic bodies, especially those that are dealing with social aspects of disability. This will also ensure more human resource availability, will help in expanding

the reach of STCI in identifying gaps in service provision at the government level and will also provide an opportunity in conducting research on these aspects

Facilitating establishment of robust referral mechanism to improve reach and track drop-outs

Of all the children that have enrolled and participated in the intervention, proportion of dropout during the intervention journey is 23%, so it is important to identify, assess and document reasons of case dropouts throughout the service journey and program. The ways and means of doing this may entail:

- Developing individual care plans and track the specific needs and challenges of parents and of children.
- A community-based referral mechanism which involves community level workers for screening and referral
- There should be a back-tracking system in place to identify dropout cases and to engage with those parents and children.

Demand generation and community based systems

Creating mechanisms for demand at community level

- Culturally sensitive, community-based, collaborative, and developmentally appropriate services are key aspects of any program intervention that focuses on addressing a specific disability. While STCI has effectively worked on these aspects, a need for nurturing community based support mechanism which involves parents, families, community leaders and volunteers to help reduce stigma, increase awareness of screening, and help in understanding the implications on life of any individual if interventions are delayed.
- Engagement with various government schemes to leverage the existing community-based platforms.
- Creation of and capacitating community level cadre will ensure expansion of reach.

Policy Advocacy and Enabling Environment

Vision and positioning of Dhvani-STCI as thought leader

- Professional organizations with special interests in programs for children both globally and nationally have successfully developed position statements, knowledge and skills documents, and reports addressing the issue. STCI should consider taking up this role, as the organizations that have field programs are best suited to do so, and STCI is not an exception.
- An interdisciplinary, team-based approach facilitates collaboration among professionals providing support to families and strategies of engagement that will enhance their children’s development serves can be a precursor to establishment of a network, as Dhvani will serve as a role-model for other organizations of the network that may be focusing on either hearing or any other disability of young children.

- Based on the learning and a decade long implementation experience, STCI should take a role of mentor to enhance the capacity of local organizations and their community-based staff for implementing community-based program on screening for hearing impairment.
- An effort to improve donor engagement specifically for community-based campaigns and implementation support to mainstream the agenda of early detection and intervention will help in taking the cause to the next level.
- Partnerships and collaborations with academic institutions like social work, business management and paramedical colleges will help in leverage both human resources as well as multi-faceted experience and expertise for Dhvani program and will also help in furthering the agenda of addressing hearing impairment.

Advocacy at the highest level

- Advocacy to be done at the highest level, such as the Ministry of Health and Family Welfare, Government of India for the inclusion of record keeping of pregnant mothers with focus on any associated risk for hearing impairment needs to be done. While STCI now has the newborn screening facility, it should collaborate with both state and city governments for screening at community level as well. The other mechanism could be to collaborate with government/ public hospitals for screening at birth within the facility, including display of IEC materials at the health facilities for the parents to get educated about newborn screening and its benefits.

1. Introduction

Overview

Each of the sense organs in the human body enables a crucial function. Any defect in one or more of these sense organs can affect the entire body and overall growth, especially in children. Hearing loss is one of such concerns observed in children. For a growing child, speech and hearing are more important than an adult as those are the instruments of learning to understand language and speak, playing and building social skills during the developing years. If a child suffers from hearing loss and it goes undetected or untreated, there is a lot that the child misses out on. Delay in treatment or action can lead to delay in speech and/or language development, social behavioural issues and academic difficulties.

According to the World Health Organization (WHO), 60 per cent of childhood hearing loss can be prevented. The temporary hearing loss in many children can be restored with medical treatment or minor surgery. If a child has sensorineural hearing loss, mostly it is permanent. However, thanks to the advances in medical science, almost all kinds of hearing impairments can be treated if timely identified. *Early intervention remains key for better outcomes.*

Auditory impairment is one of the more widely occurring sensory deficit in human beings around the world. While it may not affect mortality, hearing loss can prove to be a severe deficit especially in infants and children adversely affecting the development of speech and language abilities. This can be highly detrimental to the child's social, educational and economic standing well into their adulthood. Further to this, there remains a huge gap with regards to the human resources in healthcare domain in India to meet this massive health challenge. When it comes to childhood speech and language development, as well as overall health and well-being, there is no question that hearing ability plays a critical role. From delays in the development of both receptive and expressive language to communication difficulties with peers leading to poor self-esteem, hearing loss has a direct effect on life outcomes.

A person who is not able to hear as well as someone with normal hearing – hearing thresholds of 25 dB for adults and 15 dB for children or better in both ears – is said to have normal hearing.

Efforts to ensure early intervention

The most effective treatment is achieved through early diagnosis and intervention. Newborn screening at birth or screening in first month to identify children with potential hearing loss. When identified, the children can be further assessed with a series of audiological tests and radiological assessment of the inner ear structures. The Joint Committe of Infant hearing (JCIH) 1-3-6 guidelines highlights- (screening completed by 1 month, audiologic diagnosis by 3 months, enrollment in early intervention by 6 months).

Further to this, the early intervention journey with the child and the parents/ care-givers/ family members is embarked. The early intervention programs and efforts focus on: help the child with his speech and language skills; helping the parents understand child's hearing loss and listening needs; supporting the families in helping their child; and keeping track of child's overall progress to ensure her/ his integration into mainstream school.

Save The Children India

Save The Children India (STCI) is a not-for-profit organization which works with vulnerable children – particularly those with disabilities and those vulnerable to trafficking – to enable them to live independent, dignified lives and achieve their full potential.

Established in 1988 by a leading influencer in Mumbai, the late Mrs. Vipula Kadri, STCI has three core verticals in the organization – Education, Disability, and Anti-trafficking.

The Education programme includes work on Early Childhood Education through a *Balwadi* (early childhood education) programme and improved learning for children in Primary School through Remedial programmes. The Anti Trafficking vertical works on Prevention, Protection, Prosecution and Policy. In urban pockets the Prevention programme includes skilling as a strategy and in rural pockets; the focus is on a Safe Village campaign that involves multiple stakeholders. The Disability programme includes a school for the hearing impaired and a school for the mentally challenged, as well as an early intervention for those with hearing impairment, called Dhvani.

Dhvani Program

STCI's program '**Dhvani**' which means 'sound' in Hindi is a program on early intervention for children with hearing impairment. Dhvani–Early Intervention Program for children with hearing loss was setup in 2010 recognizing the need for early identification and interventions with children with hearing loss. Since its inception, the program has focused on providing critical services of testing, diagnostics, therapeutic intervention delivered by a team of professionals with the aim of enabling the mainstreaming of the child by the time s/he is ready to enroll in primary school.

The center is situated in Save The Children India's campus at Bandra-Kurla Complex in Mumbai and provides quality service to hearing impaired infants & children where all testing & therapeutic needs are fulfilled under one roof.

STCI also runs a Special School for children with hearing and intellectual disabilities, with the aim of integrating them into mainstream schools in the future. The Dhvani Program has been running for about 10 years now and offers diagnosis, pre-and post-cochlear implant management, therapy and support to hearing impaired children and their parents.

The children enrolled in the **Dhvani Early Intervention program** are referred by various professionals and hospitals. Once the child comes to Dhvani center, the core services extended at minimal costs include – a **Comprehensive Audiological Evaluation, Auditory Verbal Therapy** (AVT) and **School readiness** so the child can easily cope with the requirements of a mainstream educational institution.

> Whatever the origin of hearing impairment, screening children to identify this disability should be done as early as possible in order to ensure all hearing-impaired children benefit from interventions from a very young age. Early intervention is one of the major factors influencing the quality of oral language and all subsequent milestones that emanate from this ability.

2. Situation Analysis

Burden (Global [1], India and Maharashtra)

Over 5% of the world's population – or 466 million people – has disabling hearing loss[i] (432 million adults and 34 million children). It is estimated that by 2050 over 900 million people – or one in every ten people – will have disabling hearing loss. 60% of childhood hearing loss is due to preventable causes. Worldwide, it is the second leading cause for "Years lived with Disability" the first being depression. [2]

In India, as per WHO estimates about 63 million people (6.3%) suffer from profound hearing loss.[3] Four in every 1000 children suffer from severe to profound hearing loss. With over 100,000 babies that are born with hearing deficiency every year. The estimated prevalence of adult-onset deafness in India was found to be 7.6% and childhood onset deafness to be 2%.[1] [4]The NSS report (76th Round_ Disability in India_ July to Dec 2018)surveyed disability in Indian households and found that hearing disability was the 2nd most common cause of disability and top most cause of sensory deficit.

> Newborn hearing screening is just the beginning of a journey for infants and their families. The itinerary for this journey is packed with visits to the paediatric audiologist for hearing evaluations, developmental assessments by an interdisciplinary team of professionals, investigations of assistive technologies, programs and services, and the gathering of information about communication opportunities. The journey can be smooth or rocky depending upon the quality of the Early Intervention program and the effectiveness of the professionals and services provided.

In Maharashtra, the total estimated persons with hearing disability (2016) is estimated to be 4.7 lakh (male – 2.6 lakh and female 2.08 lakh) and disability in speech is estimated to be 4.7 lakh (male 2.6 lakh and female 2.1 lakh) [5]. Prevalence[ii] of hearing disability[iii] in Maharashtra was calculated to be 179 (2002). The prevalence rate of hearing disability was higher in rural Maharashtra (215) as compared to that in urban Maharashtra (127) for both the sexes. At the State level, about 41 per cent had profound, 39 per cent had severe and rest 20 per cent had moderate hearing disability.[iv] 7 percent of the persons with hearing disability were born with and its onset is reported to be nearly 2 percent in all age groups till mid-teens (20 years) which is a matter of great concern for society.[6]

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[1] https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss

[2] Impact of Indian public health standards for rural health care facilities on national programme for control of deafness in India: The results of a cohort study Sanjeev Davey, Chaitanya Maheshwari, Department of Community Medicine, Muzaffarnagar Medical College and Hospital, Muzaffarnagar, Uttar Pradesh, India

[3] State of Hearing and Ear Care in the South East Asia Region. WHO Regional Office for South East Asia. World Health Organization.

[4] Singh V. Hearing in India: All aspects. Otolaryngol Online J. 2015;5:1–31. [Google Scholar] [Ref list]

[5] Disabled Persons in India, Social Statistical Division , Ministry of Statistics and Programme Implementation GOI (2016)

[6] A Report on 'Disabled Persons' based on data collected in state sample of 58th round of National Sample survey (July – Dec, 2002), VOL. I, Government of Maharashtra.

Impact of Hearing Loss

Out of every 1000 children born in India, there may be 5–6 such children who cannot hear properly. Because of lack of visual indicator, most hearing-impaired children who are not screened at birth are not identified until between 1½ and 3 years of age, which is actually well beyond the critical period for healthy speech and language development. The prevalence of speech and language delay was found to be 27% under 3 years of age. Overall, 3% to 10% of children are affected by speech delay. Boys are 3 to 4 times affected more than girls. Hearing, Speech and language disorders needs early intervention. Hearing disability along with delay in speech and language skills results in cognitive impairments including lower IQ score, slower information processing skills and poorer literacy skills like reading and spelling. Thus, leading to psychosocial deficits in these children which is persisting till adulthood.[7]

The impacts of hearing loss are broad and can be profound. They include a loss of the ability to communicate verbally with others, delayed language development in children, which can lead to social isolation, loneliness and frustration, particularly among older people with hearing loss. Many areas lack sufficient accommodations for hearing loss, which effect academic performance and options for employment. Children with hearing loss and deafness in developing countries rarely receive any schooling.

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[7] Study of Incidence and Type of Deafness in Children Withdelayed and Non Development of Speech in Apediatric Tertiary Health Care Centre Among 5500 Childrenover 5 Years ; Author: Poulomi Saha, Kapildev Mondaland, Pallab Kumar Majumder

3. Initiatives taken by GOI and Maharashtra

Policy Environment for Disability in India

The Constitution of India ensures equality, freedom, justice and dignity of all individuals and mandates an inclusive society for all including Persons with Disabilities (PWD). A number of International commitments and guidelines came into effect in the recent past targeting the welfare of the disabled persons. The Sustainable Development Goals (2015) pledges for 'leaving no one behind'. Recognizing that the dignity of the human being is fundamental, the SDGs wish to see the Goals and targets met for all nations and peoples and for all segments of society and to endeavour to reach the furthest behind first. In India, NITI Ayog oversees the implementation of SDGs from policy perspective.

Hearing Screening for Early Identification

In India, generally hearing screening facility is available to newborns brought into tertiary hospitals. A centralized hearing screening facility for universal screening program was conceptualized and established in Cochin. The program initiated by the Indian Academy of Pediatricsin 2003 is one of the largest programs with a unique centralized screening facility. It includes 20 major hospitals in Cochin, Kerala (South India), with maternity units.

In 2006, the Government of India initiated efforts toward prevention and control of HI, in which neonatal hearing screening at a grass-roots level was envisioned as National Program for Prevention and Control of Deafness (NPPCD).

In 2013, the Government of India launched **Rashtriya Bal Swasthya Karyakram (RBSK).** This initiative involved child-health screening and early intervention services for children 0–18 years of age, for defects at birth (including congenital hearing loss), disease, deficiencies, development delays, and disabilities. Under RBSK, children undergo community-level screening by mobile health team comprising a medical officer, paramedics, and nurses at Anganwadis. Screening is also conducted at government-aided schools and at public health facilities such as primary/composite health centers and district hospitals, by existing health personnel such as medical officers, nurses, and auxiliary nurses. Children diagnosed with illnesses receive follow-up services at tertiary level at no cost. NPPCD and RBSK are significant milestones in the implementation of systematic nationwide hearing screening programs.

Intervention for Identified Population

Medical intervention: There are about 600 district hospitals in the country but not all may have ENT specialists nor infrastructure for audiological assessment. The scenario is expected to improve as NPPCD has made budgetary provisions to meet the deficiencies and a 'medical kit' for grass root workers to attend to the ear problems.

Aids, appliances and cochlear implant: The Scheme of Assistance to Disabled Persons (ADIP) of Ministry of Social Justice and Empowerment, Government of India, provides Rs. 10,000 for aids and appliances. In the case of multiple disabilities, the limit will apply to individual items separately in case more than one aid/appliance is required.

The Ministry of Social Justice and Empowerment empanels an Institute of national stature from each zone to recommend children eligible under the Scheme for cochlear implant, with a ceiling of Rs.6.00 lakh per unit to be borne by the Government. The Ministry also empanels the Institutes in the zones for surgery, for providing cochlear implant. Further, for Cochlear Implant under ADIP scheme, a dedicated website www.adipcochlearimplant.in has been developed wherein all information is available for access by the public. The provision of Cochlear implantation is also made under RBSK scheme of National Health Mission.

Auditory and speech-language training

Certificate courses for the caregivers (of children with developmental disabilities) has been launched by AIISH, Mysore and IGNOU in collaboration with the RCI. To meet the special needs of the age group 0 to 5 years, orientation programs of one-month duration aimed at manpower development are conducted at seven centers across the country by Ali Yavar Jung National Institute of Speech and Hearing Disability (Divyangjan) [AYJNISHD(D)], Mumbai in collaboration with Balavidyalaya, Chennai.

4. Dhvani Program

Dhvani Departmental Process Overview: This incorporates all the processes that are followed throughout the journey of any child who is enrolled in the program:

New case process

When a new case approaches Dhvani, the need for the child is established. If a child is referred only for certain audiological tests then those tests are done, reports are produced and the child is referred back to the referring professional.

If a child is referred for further intervention, then according to admission criteria, the decision of enrolling the child into an early intervention program is taken by staff and parents. If the child is older than 3 years, then referred to the appropriate program. Once enrolled, the detailed case history is taken and previous medical and audiological reports are collected from parents/caregivers. After this, audiological and habilitation processes are followed.

Audiology process

Appropriate audiological evaluations (Otoscopy, Immittance Audiometry and Baseline Audiogram) are done. This is followed by ear mold making, hearing aid trial and fitting. Hearing thresholds using hearing aids in each ear are checked. Audiometric results are explained to parents in a language that is understood by them. Simultaneously, the child is referred for HRCT scan and MRI of cochlea and cochlear nerve and reports are explained to the family. Child's hearing status is constantly monitored throughout this process. Child who is getting access to all the speech and environmental sounds using hearing aids will continue to use hearing aids and hearing aid benefit is closely monitored at regular intervals through different audiological tests. Children who don't seem to be benefiting from the good quality hearing aids follow the cochlear implant process.

Cochlear Implant processes (Pre-implant and post-implant process)

This is a step-by-step guide for all the steps to be taken to do cochlear implant surgery and audiological management following that. It starts with collecting all the necessary assessment reports (medical, radiological, audiological, ect.) and consultation with an ENT surgeon is done. The family undergoes systematic counselling sessions where they get complete understanding about device, funding, post implant process, etc. Once a final decision is made by the family, further procedure is started.

After the surgery, during the healing period parents get accustomed to the external part i.e. speech processor, its parts and accessories. Once the wound is completely healed and checked by an ENT surgeon, the processor is switched on and the child starts hearing. Through multiple testing and MAPping (programming of processor) sessions the child is given the best possible access to speech sounds. Parents are trained to take good care of device through care and maintenance sessions. Child continues to attend regular audiology and therapy sessions at Dhvani.

Even after mainstreaming, both hearing aided and cochlear implanted children continue to attend audiology sessions for monitoring purpose. Regular care and maintenance sessions are arranged for both the groups.

Habilitation Process

Initially, the child after being enrolled in the early intervention centre, is provided with an orientation session, days and times are decided for the entire intervention duration, along with the language which will be best for the child to pick up faster as he/she grows up. Some of the children are referred only for evaluation and after that process is completed, they are sent back to the referring centre/professional. There are also baseline assessments done, to explain the results to the parents who are in distress, feel lost and especially have no idea to understand the child in the start. It also gives an understanding of the current level of functioning of the child in the areas of audition, receptive language, expressive language, speech, cognition and social communication. Most of the children that are referred are 2.5 years or younger than that, but some children also belong to the age-group 2.5 to 5 years, these are enrolled for Aural-Oral Rehabilitation, and as time progresses, are referred to a Special School.

After the assessment, there are goal plans to understand what the child could achieve in the next 3 or 6 months. The first long term plan of every child is made for 3 months. Also for very young babies below two years of age 3 months goals are set since they undergo rapid development. Once the child and family are settled in the program 6 monthly goals are made. If there is a red flag case monthly goals are set and progress is monitored. According to the goals set, weekly lesson plans are drafted in order to teach the child. Habilitation sessions are executed once or twice in a week depending on the requirement. While only dealing with the hearing impairment, the child is also referred for other assessments, such as occupational therapy if a child is having attention issues during sessions, or even referred to an ophthalmologist or a neurologist to understand all aspects of the child, other than the hearing impairment. In order to understand the child better, there are occasional referrals to psychologists as well.

After reviewing and monitoring the progress of a child every 3 months or 6 months an evaluation is done whether the child would benefit from auditory verbal strategies. Once it is confirmed that the AVT method is suitable for a child, the family continues to attend till the child develops age appropriate listening and spoken language. At an appropriate stage the child begins to attend school readiness sessions as a preparation to attend regular school. There is also a family meeting after 6 months, to discuss the progress of the child and the recommendations for the next 6 months.

While all of the processes are followed diligently, every child's candidacy towards a Cochlear Implant is also monitored, which would enable her/him to learn and process sounds much better, which also strengthens their speech. Once a child is suitable for a Cochlear Implant, there are additional processes in place, such pre-implant process and post implant process, for the optimal and best usage of the implant for the child.

With the help of further goal setting sessions and annual assessment, the child is then graduated from the program, after which the child is still monitored for the next 2 years, after being mainstreamed in a regular school.

For a child, not suitable for AVT, a red flag assessment is conducted, followed by counselling the parents to make them understand the scenario completely. The child is then referred to a suitable program.

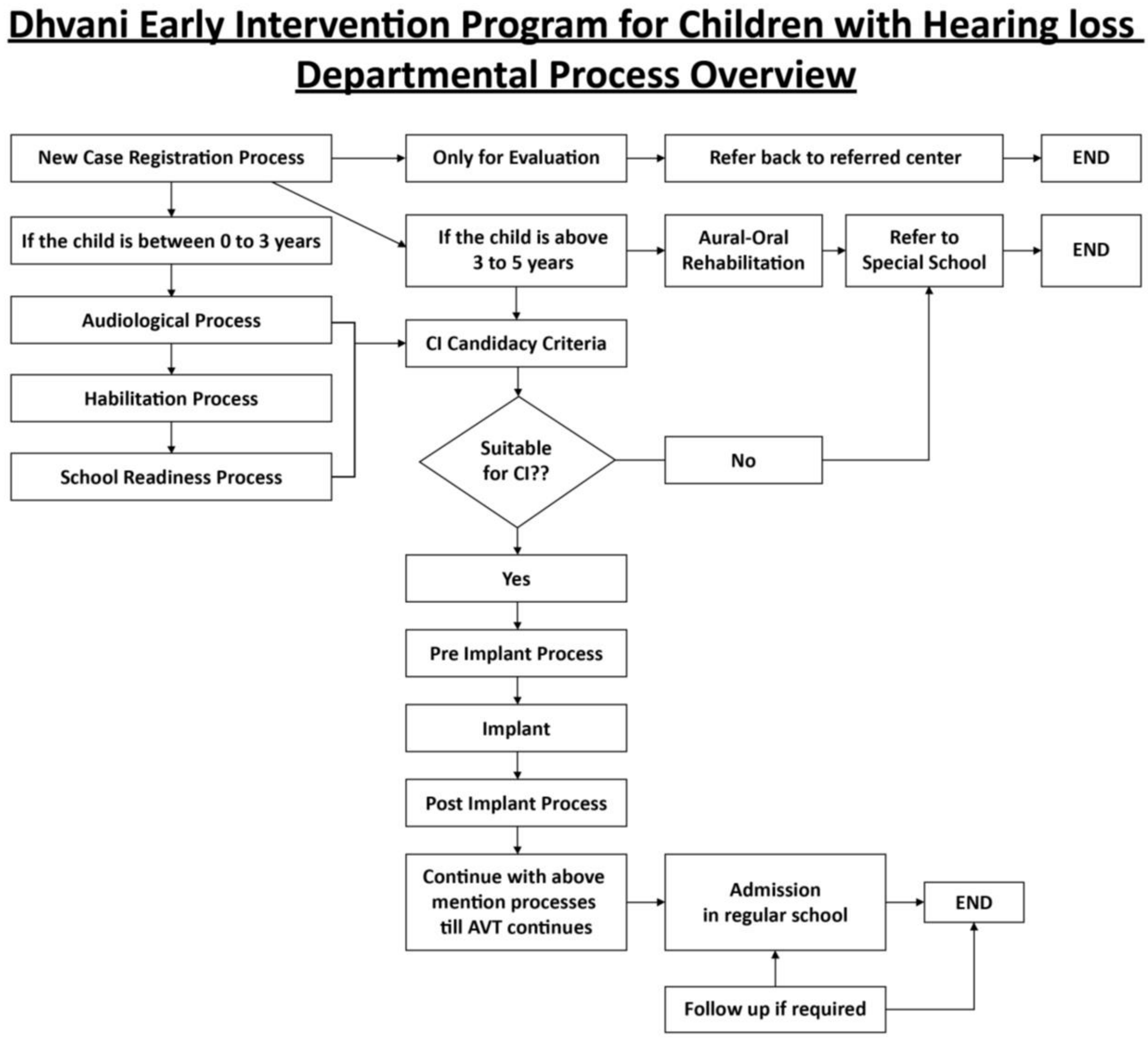
Also during the habilitation process from enrollment to graduation, a set of records and documents is also used to encompass the child's progress in the program, which would enable Dhvani to better set the sessions for the coming months and also acts as a record in order to help the program assess what impacts most.

School Readiness

Once a child achieves a certain level of language proficiency, s/he starts attending school readiness sessions to prepare them for regular schooling. Pre-reading, pre-writing and math skills are worked upon. Simultaneous mainstreaming is done where children attend regular school as well as school readiness sessions at Dhvani. Before taking admission in any school, mainstream specialists would do a school visit and the school management is made aware of the needs of a child with hearing difficulties. Once a child graduates from the program, parents visit mainstream specialist for monitoring purposes.

If significant gap is found in chronological age and language age which can not be bridged using listening and spoken language approach and if the child is in need of remedial education strategies along with needs of developing language and communication using other modes, then he/she is referred to oral-aural school.

Figure 1 Dhvani Master Process



Record-keeping and documentation of early intervention

New case Registration

Sr. No.	Document	Purpose
1	New case entries in excel sheet	To keep record of demographic and contact details
2	Case History Form	Medical and developmental details of the child

Audiological Formats

Sr.No.	Document	Purpose
3	Audiogram	Report explains type and degree of hearing loss
4	Audiology Assessment Report	Audiological progress monitoring & recommendations for parents
5	Speech Evaluation Report	Progress monitoring of child undergoing articulation therapy

Habilitation Formats

Sr.No.	Document	Purpose
6	Assessment Report	Progress monitoring of child undergoing auditory verbal therapy
7	Long Term Goals	Plan of goals to be achieved for a child in next 3 or 6 months.
8	Weekly lesson plan	Plan of goals to be achieved weekly.

School Readiness Formats

Sr.No.	Document	Purpose
9	School Readiness Progress Report	School Readiness Progress Monitoring & recommendations for parents

Miscellaneous

Sr. No.	Document	Purpose
10	Attendance Sheet	To record attendance in each dept
11	Home Visit Record Form	Details of child’s residence and environment
12	Family Meeting	Documenting meeting agenda, MOM and action plan
13	Feedback Form	Feedback from parents recorded after workshops

5. Research study

The Dhvani Early Intervention program sources cases through their partnerships with maternity hospitals and healthcare providers and the process starts with screening of children which may be done at their state-of-the-art screening facilities and involves initial and follow up counselling of caregivers and parents to prepare them for what's to come should the child be diagnosed of hearing impairment. The core services that they provide at minimal costs include – a Comprehensive Audiological Evaluation, Auditory Verbal Therapy and School readiness so the child can easily cope in a mainstream educational institution.

The key highlights of the program are:

- Once enrolled, it takes anywhere between 2-4 years of duration for one child with hearing impairment (HI) to complete the program.
- Most of the children are integrated into mainstream schools though few do need support from special school (due to various reasons) and then integrated to regular school.
- There is parallel integration too, where the children attend 'Dhvani' and regular school simultaneously.

Studying the program holistically so as to map the service journey of children treated from initiation into the program to successfully being integrated into mainstream schools can help understand the key levers necessary to replicate this model and advocate for better policies around education of children with special needs.

Objectives of the study

- To study, assess and map the services offered by **Dhvani Early Intervention Program of** Save The Children India to its beneficiaries (children and their families)
- To closely map the journey of a child through the Dhvani Early Intervention program to understand key levers, challenges and best practices

Methodology

While a set of qualitative methods have been used, a detailed analysis of quantitative data from the MIS of the project has also been analyzed for better understanding. The qualitative data collection entailed:

- In-depth-interviews (IDIs) of: a. service providers involved in the program ecosystem; b. government officials; and c. senior management professionals of STCI
- Focus group discussion (FGD) of the program implementation team
- Interviews of the parents for documenting case studies for documenting the overall care pathway the child was provided with.

Sampling

For case studies

From the list of total 35 children (successful intervention list), **a total of 7 families with 8 childre**n were selected based on defined criteria, specifically the children graduated in the last 3 years of program to avoid loss of information due to large time gap.

For the IDIs and FGDs: the study participants were:

Type of Stakeholder	Method	Numbers
Project Management team	IDI	2
Project implementation team	FGD	1
Doctors/ service and care providers	IDI	3
Government officials	IDI	2
Total: 7 IDIs and 1 FGD		

6. Dhvani Early Intervention program for children with hearing loss: Implications for the Sustainable Development Goals

Persons with disabilities were not referenced in the Millennium Development Goals (MDGs) and as a result were excluded from many important development initiatives and funding streams around the world.

The 2030 Agenda for Sustainable Development is the world's globally agreed plan for peace and prosperity for all on a healthy planet. But this vision of a better future can only be achieved with the full participation of everyone, including persons with disabilities. Upholding the rights and ensuring the full inclusion of the world's 1 billion persons with disabilities is not only a moral imperative, but a practical necessity.

Despite the strong commitment expressed by the international community for inclusive and sustainable development, persons with disabilities continue to face significant challenges to their full participation in society. These include negative attitudes, stigma, discrimination and lack of accessibility in physical and virtual environments. Our shared duty is to tackle prejudice and misinformation and find new approaches and tools to work for and with persons with disabilities.

SDG	Indicator/s	Implications
Ending poverty and hunger for all persons with disabilities (Goals 1 and 2)	Social protection for persons with disabilities	• Persons with disabilities are more likely to live in poverty than persons without disabilities due to barriers in society such as discrimination, limited access to education and employment and lack of inclusion in livelihood and other social programmes. • National data on income poverty disaggregated by disability remain scarce, but available data show that the proportion of persons with disabilities living under the national or international poverty line is higher, and in some countries double, than that of persons without disabilities.
Ensuring healthy lives and promoting well-being (Goal 3)	Coverage of essential health services amongst the disadvantaged population	• Persons with disabilities generally have more health-care needs than others – both standard needs and needs linked to impairments – and are therefore more vulnerable to the impact of low quality or inaccessible health-care services than others. • Lack of financial resources, lack of access to and accessibility of medical facilities and transport, as well as inadequate training of health personnel to accommodate persons with disabilities remain major challenges.
Ensuring inclusive and equitable quality education (Goal 4)	- Children who are developmentally on track in health, learning and psychosocial well-being, by sex - Schools with adapted infrastructure and materials for students with disabilities	• Persons with disabilities remain less likely to attend school and complete primary education and more likely to be illiterate than persons without disabilities. Available data reveals that, on average, one in three children with disabilities of primary school age is out of school, compared with one in seven children without disabilities. • 34 out of 193 United Nations Member States guaranteeing in their constitutions the right to education for persons with disabilities or providing protection against discrimination based on disability in education.
Achieving gender equality and empowering all women and girls	Equal opportunity to both girls and boys	• Women with disabilities are often subjected to double discrimination due to their gender and disability status and continue to be at a disadvantage in most spheres of society and development. Available data suggests that the gap is stark compared with men without disabilities: women with disabilities are three times more likely to have unmet needs for health care; three times more likely to be illiterate; two times less likely to be employed and two times less likely to use the Internet.

with disabilities (Goal 5)		- Many countries still address gender and disability issues separately without focusing on the intersection between the two, but there are increasingly positive initiatives. For instance, in Latin America, 17 out of 20 countries include disability in their national gender plans.
Reducing inequalities (Goal 10)	Addressing discrimination prohibited under international human rights law Providing equal opportunities	- Combating discrimination is key to reducing inequality for persons with disabilities. Discrimination is a major cause of exclusion of persons with disabilities. In some countries, more than 50 per cent of persons with disabilities have experienced discrimination. - Ensuring access to assistive technology is crucial to enable the independent living of persons with disabilities and their ability to fully participate in society. Available evidence shows that in several developing countries more than half of the persons with disabilities who need assistive products are not able to receive them, mainly because available products are inadequate, unaffordable or no transport is available to the providers of these products.
Promoting peaceful and inclusive societies for sustainable development, providing access to justice for all and building effective, accountable and inclusive institutions at all levels (Goal 16)	Addressing challenges of children aged 1-17 years who experience any physical punishment and/or psychological aggression by caregivers	- Persons with disabilities experience a heightened risk of violence, in part as a result of stigma, discrimination and exclusion from society. Likewise, women and girls with disabilities experience higher exposure to sexual violence compared to women without disabilities and men with and without disabilities.

7. Study Findings

A. Findings from the quantitative data:

1. A total of 301 children's data was captured between 2012-2020. Out of these 53% or 160 children were male children and the remaining 47% or 141 were female children.
2. Out of the 225 children (Table no. 2) that were registered, 137 children (60.89%) were of the age 3 or below, and some were even below the age of 1 year, which is 40 children (17.8%).
3. Out of all the different age groups, children 6 years of age or below were primarily identified with severe hearing disability and were enrolled for the 'Early intervention program', 57 children, 96.6% (out of those enrolled within the intervention).
4. As for the outcomes of children provided 'short-term intervention' or 'consultation only':
    a. Children enrolled within the short-term intervention either successfully completed their intervention (101 children, 95.3%) or after testing they were found to have normal hearing sensitivity. (5 children, 4.7%).
    b. Those children who only required 'consultation' either didn't enroll (79 children; 59.8%) or were referred to another appropriate program (50 children, 37.9%).
5. For the children provided 'early intervention':
    a. Out of the 21 children (33%) who were successfully mainstreamed, 11 children were 2 year of age or below, while another 8 were within 2.1 – 3 year of age. Thus, registration at young age showed improved chances of mainstreaming the children.
    b. 11 children (17.5%) were provided significant interventions, but didn't continue/ complete the intervention due to different reasons and additionally 15 children (23.8%) dropped out right from the start of intervention.
    c. When looking at the age of the children who dropped out at start or after significant intervention, most of them were below 2 years of age (6 children below 1 year of age; 12 children 1-2 year of age)

Data Coverage and details

A total of 301 children/ individuals were registered within the project between 2012 – 2020 (*Table 1*), out of which 53% (160 cases) were male while remaining 47% (141 cases) were females.

Table 1: Year wise and Gender wise total cases registered

Year of Registration	Male		Female		Total	
	Count	Column N %	Count	Column N %	Count	Column N %
2012	14	8.8%	13	9.2%	27	9.0%
2013	19	11.9%	15	10.6%	34	11.3%
2014	25	15.6%	17	12.1%	42	14.0%
2015	7	4.4%	9	6.4%	16	5.3%
2016	21	13.1%	26	18.4%	47	15.6%
2017	24	15.0%	20	14.2%	44	14.6%
2018	21	13.1%	17	12.1%	38	12.6%
2019	26	16.3%	18	12.8%	44	14.6%
2020	3	1.9%	6	4.3%	9	3.0%
Total	**160**	**100.0%**	**141**	**100.0%**	**301**	**100.0%**

Year of Registration	Male		Female		Total	
	Count	Column N %	Count	Column N %	Count	Column N %
	53%		47%		100%	

The key data captured for each child/ individual were:

- Age at the time of registration**
- Type of intervention provided or enrolled under
- Outcome of the intervention
  - Some additional details on outcomes (remarks/ details)

*(**76 cases were found to be missing data on date of birth, thus age during registration couldn't be calculated)*

To analyse the overall data captured, the study has presented key finding based on the individual data points and has highlighted any association if present between the different data points.

Age at the time of Registration

Looking at the age at the time of registration (*Table 2; Graph 1*) most of the registered cases were that of children ages 6 years or below (199 cases; 88.4%), out of which 106 were male child (53%) and 93 were females (47%). There were 25 children (11.1% of total) aged between 6.1 (6 years and 1 month) to 18 years of age enrolled within the project and one girl above 18 years of age (27 years and 8-month-old) (*Graph 1*).

Thus, the data reflects that most of the children were being registered at a very early stage, and some even before 1 year of completed age (40 children, 17.8% of total; *Table 2*), hence children with potential hearing disability were being recognized and referred at an early stage for interventions.

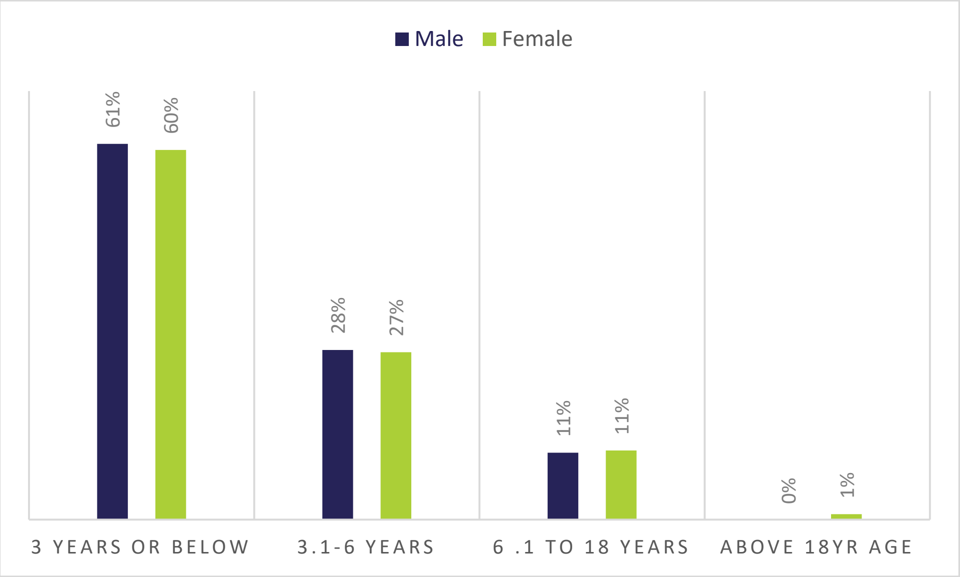
*Table 2: Age at the time of registration in the Project***

Range of Age at Registration	Male		Female		Total	
	Count	Column N %	Count	Column N %	Count	Column N %
Less than 1-year age	21	17.60%	19	17.90%	40	17.80%
1 to 2yr age	26	21.80%	25	23.60%	51	22.70%
2.1 to 3yr age	26	21.80%	20	18.90%	46	20.40%
3.1 to 4yr age	18	15.10%	17	16.00%	35	15.60%
4.1 to 5yr age	10	8.40%	6	5.70%	16	7.10%
5.1 to 6yr age	5	4.20%	6	5.70%	11	4.90%
6.1 to 7yr age	2	1.70%	3	2.80%	5	2.20%
7.1 to 8yr age	2	1.70%	2	1.90%	4	1.80%

8.1 to 9yr age	3	2.50%	3	2.80%	6	2.70%
9.1 to 14yr age	5	4.20%	3	2.80%	8	3.60%
14.1 to 18yr age	1	0.80%	1	0.90%	2	0.90%
Above 18yr age	0	0.00%	1	0.90%	1	0.40%
Overall Total	**119**	**100.00%**	**106**	**100.00%**	**225**	**100.00%**
Sub –Total						
3 years or below	73	61.34%	64	60.38%	137	60.89%
3.1-6 years	33	27.73%	29	27.36%	62	27.56%
6 .1 to 18 years	13	10.92%	12	11.30%	25	11.10%
Above 18yr age	0	0.00%	1	0.90%	1	0.40%

***Data presented for 225 cases instead of 301 as data on DOB is missing for 76 cases*

Graph 1: Age at Registration



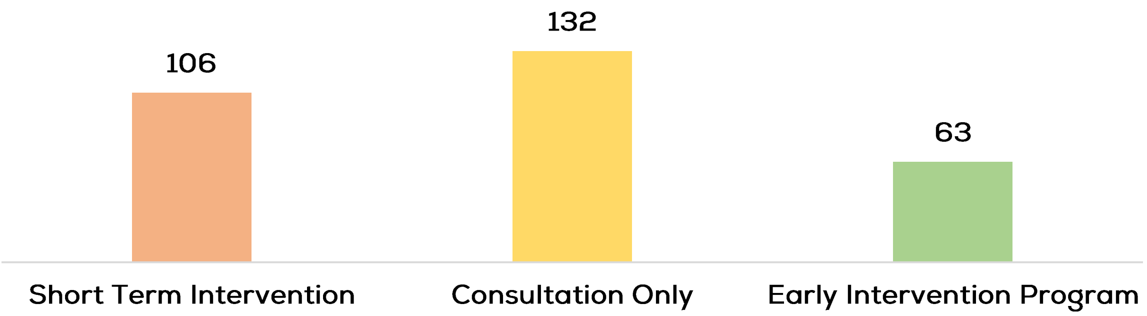
Type of Intervention Provided

To all the children enrolled within the project, 3 main type of interventions were provided, these were:

- Short-term intervention
- Consultation only or
- Early intervention program.

Looking at the different types of intervention most of the children were provided 'consultation only' (132 cases; 59%; *Graph 2*), followed by 106 children (47%) enrolled in the 'short-term intervention', and 63 children (28%) were enrolled in the 'early intervention program'.

Graph 2: No of children provided different interventions



Looking at the type of intervention provided against the age of registration (*Table 3*), mostly children 6 years old or younger were enrolled for 'early intervention program' (57 cases) in comparison to rest and across all the age groups 'consultation only' was the primary form of intervention.

Thus, based on the data mostly children 6 years or below were eligible for the early intervention based on their age of detection and severity of hearing impairment.

*Table 3: Type of Intervention against age***

Range of Age at Registration	Short Term Intervention		Consultation Only		Early Intervention Program	
	Count	Column N %	Count	Column N %	Count	Column N %
6 yr or Below	36	80.0%	106	87.6%	57	96.6%
6.1 to 18 yr	9	20.0%	14	11.6%	2	3.4%
Above 18yr age	0	0.0%	1	0.8%	0	0.0%
Overall Total	**45**		**121**		**59**	
	20%		***54%***		***26%***	

***Data presented for 225 cases instead of 301 as data on DOB is missing for 76 cases*

Outcome of interventions

All the children who were enrolled under different interventions as detailed above, had several different outcomes. Based on the project data the key outcomes observed were:

- Children were currently enrolled within the program (on-going intervention),
- Dropped out of intervention,
- Were successfully mainstreamed within education,
- After testing they were found to have normal hearing,
- Did not get enrolled in the program,
- Were referred to either, another appropriate program; or, another oral-aural school; or, to another centre,
- Completed the short-term intervention, or
- Significant intervention was provided

Outcome of children provided with 'Short-term' interventions

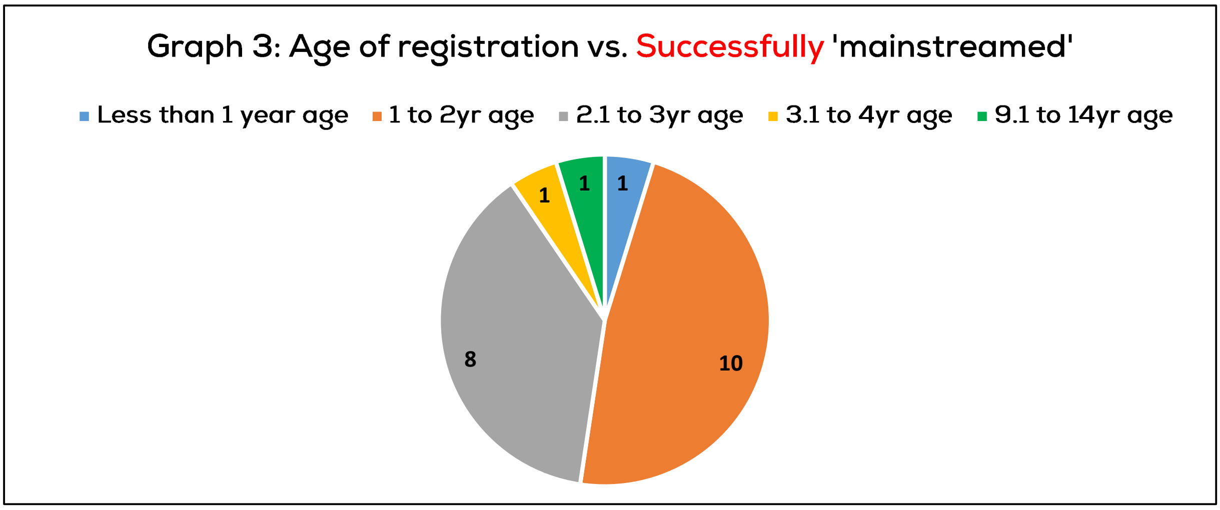
Looking at the some of the critical outcomes (*Table 4*) against the intervention provided, most of the children who were provided 'short-term intervention' successfully completed their interventions (101 children; 95.3% of children were provided with the specific intervention), and the remaining 5 children were tested to have normal hearing sensitivity, hence, the project team helped out all the children under this intervention.

Outcome of children provided with 'Consultation only' interventions

For children selected to be provided 'consultation only', most of the children 'did not enrol' (79 children; 59.8% of children out of total provided this intervention), while the remaining majority (50 children, 37.9%) were referred to 'another appropriate programme' (*Table 4*).

Outcome of children provided with 'Early Intervention Programme'

Children who had major hearing problems were enrolled within 'early intervention programme'. Out of the total children enrolled, 33.3% (21 children) were successfully mainstreamed within the education system, while another 11 children (17.5%) are 'currently undergoing intervention'.



Graph 3: Age of registration vs. Successfully 'mainstreamed'

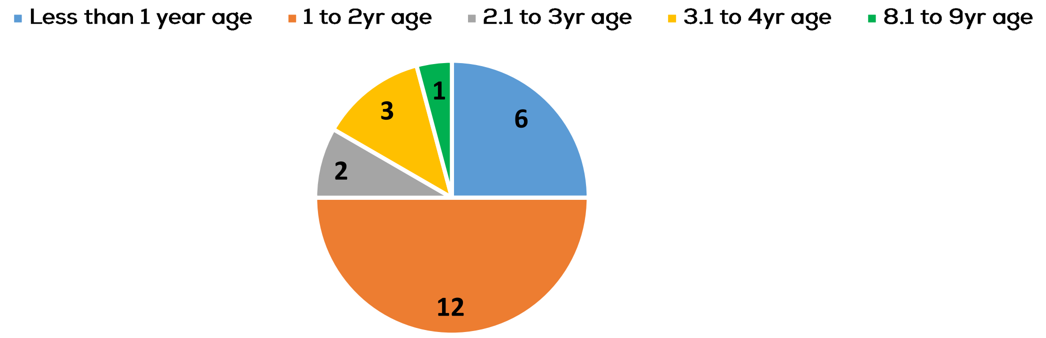
Looking at the age of registration for the children who were successfully 'mainstreamed' (21 children total), 11 were below 2 years of age, and another 8 were between 2.1 – 3 year of age (*Graph 3*), thus, overall early registration of children under the intervention showed improved chances of being mainstreamed.

Out of all the children enrolled for 'early intervention', 11 children (17.5%) were provided with significant intervention for their hearing impairment but ultimately discontinued the intervention for various reasons, additionally, another 15 children (23.8%) also dropped completely out of the intervention from the start (Table 4).

Table 4: Outcomes of Interventions provided

Outcome		Intervention Category							
		Short Term Intervention		Consultation Only		Early Intervention Program		Total	
		Count	Column N %	Count	Column N %	Count	Column N %	Count	Column N %
Currently in Programme		0	0.0%	0	0.0%	11	17.5%	11	3.7%
Dropped Out		0	0.0%	0	0.0%	15	23.8%	15	5.0%
Mainstreamed		0	0.0%	0	0.0%	21	33.3%	21	7.0%
Normal Hearing		5	4.7%	0	0.0%	0	0.0%	5	1.7%
Not Enrolled		0	0.0%	79	59.8%	0	0.0%	79	26.2%
Referred to	Appropriate Programme	0	0.0%	50	37.9%	0	0.0%	50	16.6%
	Oral Aural School	0	0.0%	1	0.8%	4	6.3%	5	1.7%
	Other Centre	0	0.0%	2	1.5%	1	1.6%	3	1.0%
Short-term Intervention Complete		101	95.3%	0	0.0%	0	0.0%	101	33.6%
Significant Intervention Done		0	0.0%	0	0.0%	11	17.5%	11	3.7%
Overall Total		**106**	**100.0%**	**132**	**100.0%**	**63**	**100.0%**	**301**	**100.0%**

Graph 4: Age wise dropped out of early intervention programme



Looking at the age of children who dropped out (whether from start or after providing significant intervention) (*Graph 4*) most of them were of 1-2 years of age (12 children) and 6 children were of children below 1 year of age, this is a loss, in case they had remained enrolled in the programme, they could have been provided the appropriate treatment/ support required from a very early age and could have successfully entered mainstream education in the future.

B. Findings from the qualitative data:

Interview with parents on the entire journey of the child

Chronic illness or complications during antenatal period or delivery

- All the parents interviewed, except one informed that the mother did not have any history of chronic illness that she herself had, or any of the family member had in the past, or any complication at the time of delivery.
- One parent shared about having a history of complication in the earlier pregnancy, the one immediately before the conception of this child. The previous pregnancy had resulted into an abortion and some medication was given for the constant head-aches the mother had for a duration of 5-6 months.
- The age of the mothers during pregnancy was as follows, most of them were in their early 20s except for one who was in her mid-20s.
- None of the parents spoke about any other members in the family having hearing impairment before the birth of this child.

Care during ante-natal period

- Out of all the parents, only one mother had not had a single antenatal check-up, as she was in the village throughout the 9 months of her pregnancy and she did not access any services therein.
- The other parents expressed that the mother had all the check-ups done at the required time, and also took all the necessary steps guided by the doctor during pregnancy

Timing and process of discovering the child's hearing problem

> *In Hinduja Hospital, we met Dr. Kirtane, who suggested about Dhvani program, and we coincidentally met Akanksha ma'am as well in the hospital. And since then, we started going to Dhvani Center.*
>
> *Mother of a child*

- The parents informed that most of them discovered that the child has a hearing loss, during the very first year after child's birth or just when the child was a year old.
- In case of one family, both the children were detected with hearing impairment, first child was detected at the age of 1 and half years, and the second child was detected at the age of 3 and half years.
- The reasons were varied. Some found out because the child would not respond to her or his name; also at times would not respond when nobody was around.
- Two of the parents shared about finding it out when they visited the doctor for treating the child for common cold or mild fever.
- One parent also talked about visiting the doctor to assess the milestones when the child completed one year of age.
- In case of the parent with both hearing impaired children, while the parents were very conscious, there was delay in detection of hearing impairment in the second child, the reason the second child was detected late, at the age of 3 and a half years old, was due to the fact, that initially there was no sign of impairment, but after their doctor explained that hearing diminishes over time, she was then tested and confirmed to be impaired.

- The parent explained that the child had fallen off a ladder once, and after going to the doctor, they had found out that he wouldn't respond to anyone around him. It was then that they took him to the ENT specialist.
- A child was diagnosed with pneumonia when she was 6 months old, and the parents thought that hearing impairment was an after effect of the medications given to her, as she was the first child, so they didn't think that response was affected.
- The tests done on the children were majorly, Brainstem Evoked Response Audiometry (BERA) tests, CT scan and MRI to determine the hearing loss.

The immediate pathway followed by the parents

- Most parents sought immediate tests for confirmation of the impairment and its intensity.
- After the confirmation, they were suggested by the hospital doctors to visit Dhvani center for further help.
- Parents also visited hospitals, primarily, Hinduja Hospital and Ali Yavar Jung National Institute for Speech and Hearing Disabilities. A parent also took the child to Nanavati hospital for a second opinion, both the reports had the same result.
- One parent talked about meeting the parents of a girl-child with hearing impairment, who was already going to Dhvani center. A recommendation from them helped the parents in deciding to approach Dhvani team.
- Another parent met a girl who had implants for the past 10 years, and after meeting her, they went to Hinduja Hospital, and then Dhvani. They never imagined that their child would be able to hear or speak, they thought it would be her way of life going forward. This was when the parents had already started to look for funding for the child's implant surgery.
- 2 parents even sought help from AliYavar Jung National Institute for Speech and Hearing Disabilities, Mumbai as well.

Understanding about 'hearing loss affecting ability' of the child

- While all parents were concerned at the time, their experiences differ. One parent expressed that there was another child in the house as they lived in a joint family, and she always felt that her child was behind in understanding, and all the other aspects. She also feels that if given the right guidance and support, the child can do much more than other children.
- Another parent had no idea what is to be done, as it was the first encounter in the family.
- A parent had already given in and thought that this would be the life of the child going forward.

> *For the first time, we could not believe that she would be able to hear, like even with the help of hearing aids or the implant, like other normal children are able to hear and speak, because we were so depressed from the time we came to know about her impairment and felt that her life would be like this forever.*
>
> *Father of a girl child*

The stigma and discrimination faced by the child

- Regarding the overall treatment of the child by parents, family members, neighbors, and friends, the parents revealed that both understanding and support existed in general and there was no ill-treatment or any kind of traumatic experience the child had to go through.
- One parent talked about the training she had to extend to all her family members and neighbors with regard to: how to talk to the child, how not to shout/talk aloud as the child can hear normally with the help of the hearing-aid; and how not to use gestures, but talk normally as with others.
- The parent also expressed that even the neighbors or relatives were very supportive, whoever knows about his impairment treats him normally. However, people who meet him for the first time first ask how they are supposed to initialize the conversation and in time they also become normal with him.
- The parent also expressed that sometimes in school, other children out of curiosity ask him about the hearing aid, nobody passes negative comments but children their age are curious to know about something they don't usually encounter.
- One parent expressed about an incident where the child was being referred to as '*behera* (deaf in Hindi)' by one of his peers, and this was a little challenging for both the child and the parents to deal with, as the child continuously questioned the mother if he was really 'deaf' and why is he being teased by his friend.
- Another parent informed that although the tests were clear to indicate that the child had impairment, the family members were still wanting to wait and watch and continued to say that 'some kids start talking late, some kids start talking after 4 years'.

The initial experiences after enrolment in Dhvani program

- The parents informed that during the process of enrollment, no fees was taken and hearing aid were also provided on a temporary basis to understand the depth of the hearing loss, and to determine the plan of action for the child in terms of surgery.
- During the process, a parent revealed that after the enrollment, the initial 3 sessions were counseling for them. This was because of the grief at the time surrounding them about their child, as they felt lost, seeing their child not respond to sound at the time. One of the Dhvani staff then explained to them how there will be change, and even gave examples of children who have mainstreamed.
- The parents shared about an overall orientation and a session plan that was extended at the center, immediately after the enrollment.
- The session plans also had certain exercises/ sessions to be taken at home as well as during the holidays
- There was constant interaction with the staff especially for the help they needed during the home sessions
- Parents revealed about their encouragement when they saw the results in the response from the child in the first 6 months after they enrolled.
- After the enrollment, there were home programs provided, a list of activities was also given.
- Some parents were already told how long the therapy will go on, and when will they start seeing the results depending on the child's current condition and rate of progress.
- The therapist also gave a complete timeline of post-surgery sessions.

> *Our daughter was three and a half years old, when we found out about her impairment, initially we didn't see a problem, but when doctor suggested that we should test her also (due to a particular cochlear deformity there is a progressive nature of hearing loss), and when we tested her she did have impairment, but now with Dhvani's help, we are able to help her overcome.*
>
> *Parents of two children (a girl and a boy) with hearing impairment*

Understanding of development milestones in the child

- Most of the parents talked about the child speaking at-least one word in the first 6 months; 2 to 3 words or even small sentences in the next 6 months
- On the recommendation of a staff member, the parent also enrolled the child in school early, it helped as he was interested in activities as well, and it would help in the long run.
- Even the difference between physical age and the hearing age was explained.
- One child was an exception as she took much more time, as her hearing impairment was detected when she was already three and a half years old.

The overall journey

- Most of the parents are very grateful for all the efforts the Dhvani team made to help their child graduate to a normal school
- One of the parents suggested that if the staff strength is increased, more children would be helped.
- Parents expressed that they never felt anything was missing in the entire pathway that they followed during two to three years of intervention at Dhvani center
- One of the parents had few grievances. He informed that the child felt pressurized to perform at par with the school entrance standards.
- The same parent also shared that the names and addresses of the organizations that were shared with them by Dhvani team for funding support were wrong, and this resulted in a lot of delay in accessing necessary help.
- Amongst all the 8 children that have been focused upon in this study, 7 are already in the mainstream school, except for 1 child, who is younger in age and is on the pathway to normal school.

Exclusive impact or influence the program has made

- One of the parents revealed about the influence and the impression the program interventions as well as the Dhvani team could create on her mind. She made an in-depth study of the hearing loss her child was facing and also gauged the efforts that were needed to help her child so as to overcome the impairment. She also found out what are the challenges of the other parents and the help they need in training and helping their child. This resulted in her decision of taking this up academically, wherein she enrolled herself and completed her Bachelors in Education *B.Ed* - Hearing Impaired. She also worked with Dhvani team for 6 months when one of the staff was on maternity leave. She has started reaching out to parents of children with hearing impairment and is able to share the best possible strategies to help their children cope up with the impairment.
- Another parent felt that Dhvani program is comprehensive and it provides steady inputs and support for the child to improve, learn and grow.

Discussions on planning and implementation with program implementation team

Chronological Journey of the Program~~Project~~

- The team shared about 'Dhvani' as a dream of STCI's founder, Mrs. Vipula Kadri. STCI already has a special school known as Special Care Centre, for a couple of years. The team also shared, 'Our founder then realized that there was need for this kind of care. Unfortunately, she passed away before her dream could reach execution, but her daughter took over this project.'
- They also shared, 'it is our baby as we have worked with it since its inception. Initially, it was just the two of us, then we were up to three, Audiologist, therapist and a mainstreaming specialist and since last 4 years, we are now a team of 4.
- The children referred earlier were slightly older, and now we are getting young babies, and the actual early intervention takes place much effectively. We have been improvising, according to the need of our beneficiaries, to make it more meaningful and valuable for the families and children who come in for intervention.
- Mapping services and school readiness services and assessments using standardized assessments were introduced in the due course.
- So, the journey of the program and the journey of the child has semblance, where in things have progressed from non-hearing child to a confident person who can lead a normal life.
- Now 'Dhvani' also does newborn/infant hearing screening activities in the community.

Staff structure

- Currently there are 5 staff members, consisting of Audiologists, therapists and mainstreaming specialists. While, the present staff is able to extend all the services, it is not sufficient enough and needs to be expanded, especially due to increase in early interventions and emerging therapies.
- The staff is however well trained and up-to-date with the latest knowledge and techniques.

Awareness in the community

- So as to ensure awareness in the community, regarding the importance of screening, developing speech and language and extending education, Dhvani team has co-ordinated with Vasai Virar Municipal Corporation where the team participates in the immunization camps. The team also conducts two types of tests: AABR (automated auditory brainstem response); and OAE (Otocoustic Emissions testing)

> *Our entire role as a team in this identification process starts with community awareness, awareness about having screening done, importance of normal hearing for developing speech and language and for education.*
>
> *Quote: Member of project implementation team*

Beneficiary identification

- The children are mostly referred are already diagnosed or are diagnosed at Dhvani using state of the art facilities
- Since 2019, there is an in-house hearing screening program in place, which is the first step in depicting hearing loss. The children who do not pass the screening test, undergo re-screening, and if it still has the same result, then they go for a diagnostic test.
- As the organization caters to a lot of families that belong to lower socio-economic strata, these families prefer some place for interventions and support with nominal costs and the

doctors also advice that it is close to their residence, as both the family and the child have to attend at-least 3 times a week for a duration of 2-3 years.

- During the COVID-19 pandemic, the organization started with tele-practice and it has now turned out to be a major service, as the intervention is not interrupted. This tele-practice will continue for the families who are not able to travel to the center to avail habilitation services due to genuine reasons.
- As a part of state of the art facilities especially for testing babies, the program has invested in having insert earphones which enables to get ear specific hearing thresholds.

Beneficiaries accessing services

- Geographically, most of them originate from Mumbai, but there are a few who come from around Mumbai or outside Mumbai.
- A few international enrolments have also come in past.

Age-appropriate efforts for mainstreaming

- All the processes mentioned above are followed for successful mainstreaming of the hearing-impaired children.
- The parent has to be involved in every session.
- Work on audition, receptive and expressive language, speech and cognition are all necessary aspects so they be mainstreamed and are on par with peers.

The stigmas and taboos

- Even wearing the device is seen as a taboo because of how the society looks at the children, hence parents do not let the child wear it for longer periods of time.
- There is also relatively larger blame on the mother when the child is born with a disability.
- Also seen is the hesitation of the parents for the surgery, and the biggest stigma is the 'wait and watch' 'some children speak late' where most of the time for development is lost.

Challenges in collaborating with external agencies and in referral

- One of the challenges is the scarcity of special schools, where travel time and cost is a big hurdle.
- Another issue is the time consumption on back and forth paperwork and funding while the child loses quality time.

Benefits of collaboration and referral

- One of the beneficial aspects is tele-practice, where Dhvani can help children around Mumbai, outskirts or even children in different cities as well.
- Spreading awareness through collaboration on a larger level will benefit as well.

Understanding of and linkages with Dhvani program

- The service providers expressed that the work done by Dhvani team is excellent, as they detect the hearing impairment in the children at a very young age.
- All of the service providers have informed that the steps taken by Dhvani are excellent. After the child is tested, they are started with the intervention by Dhvani team.
- One service provider explained the concern in the following manner: "My role is to get introduced to the patient once her/ his initial information is taken, and when she/ he is ready to take the further steps, specifically for cochlear implant surgery . So assessing fitness, intellectual assessment, developmental assessment before the surgical process, support needed during surgery, post-surgery, are all the aspects that I look into. The children are also sent to me for behavioral issues which emerge because of their access to new sounds, and a new environmental sense.

> *Not being able to hear, understand, speak and communicate hampers the opportunity for proper education and also to hold jobs. The ear only transmits the sound, the brain interprets it. Children can pick up languages fast, because that area of the brain, which is meant to listen to the sound and understand, to create voice and speech, is sort of blank when a child is born, so there are areas of the brain that gradually open up. They open very fast for the first 2 years, they open up later on as well, but not at the same rate. The older they get, the more the delay. A child can still benefit at the age of 5, but the benefit would have been more, had it been earlier. After certain age, the capacity to hear becomes less and less as time progresses.*
>
> *Quote from a service provider associated with Dhvani Program*

Services provided by them or their institutes

- The overall services provided by the hospitals and private providers are: detection of the child's hearing loss, with the help of OAE and ABR.
- Referring the child for early intervention by or before 6 months, and if need be, cochlear implant surgery.

Specific roles and responsibilities

- With regard to role and responsibility of a good centre, a provider shared that it is to detect the impairment in the child, and this can be done as early as when the child is one day old, with the help of OAE. If it comes as a referral, then an ABR is done. Then the 1-3-6 process is followed, detection by 1 month, diagnosis by 3 months and intervention by 6 months. However, today it is advocated that it is important to ensure that intervention takes place as early as possible, so as to ensure that the child is at par with other children.
- One of the providers explained that in the country, blindness and other aspects are given more importance, although deafness is a silent killer.

Intervention Pathway

- Every child is fitted with hearing aids, those who do not get enough benefit with the hearing aids especially children with severe to profound hearing loss are checked for candidacy for cochlear implant surgery
- For cochlear implants, certain parameters need to be in place. Starting with the ENT or medical consultation to make sure there is no outer ear or middle ear pathology in the child's ear, such as fluid or perforation to reduce chances post implant infection. The audiological assessments are done to know child's hearing status. Then the next parameter is the radiological investigation to see if the cochlear nerve is present for the implant. The last of all is a pediatric consultation, where the pediatrician confirms if the child is suitable for an implant or not, based on physiological and mental makeup.
- There are also other tests done, to make sure there no other complications before or after the cochlear implant surgery, such as tonsils or adenoids, if yes, they are treated first, to avoid swelling later. The next step is therapy, which is not only for the child but also parents, the initial sessions are focused more on the child as to explain that there is a device on the ear and to adjust to it.
- There is also an extensive program for the parents, to not only adjust themselves to the child's needs, but also to help enable others around them for an optimal environment for the child to grow normally.

Collaboration with the internal teams

- One of the important aspects that requires collaboration is for testing, wherein other agencies or clinics can be collaborated with for testing the children, this will reduce our time for detection, and we can directly focus on intervention, therapy or surgery, as suggested.
- There are also co-morbidities in children, such as Autism, ADHD, cerebral palsy, etc. which if referred to a pediatrician would significantly help the child's growth and intervention way forward. Hence collaboration with the pediatricians and other specialists is needed.
- In bigger hospitals, collaborations with the doctors from other departments is a process that is usually followed. But not all of the doctors and specialists can come at one place or be together at the same time. The general process is to send the child for consultation to each specialist one by one, based on the needs of the child and the requirement of the tests.

Collaboration with other stakeholders

- Accessing the government schemes for cochlear implants is necessary and should be further looked into.
- Quality control could be an aspect which would be beneficial through external collaboration, asking for assistance in areas out of their forte.
- While collaborating with the Dhvani program, one of the felt needs is of a social worker with psychology background who can go to the field and intervene at the location, which would further enhance the effects of therapy.

Interviews with Project Management representatives

The evolution of the program

- Need to bring about social development perspective as compared to medical
- One of the biggest evolutions of the program is the partnership with Hinduja Hospital, and also the partnership with Cochlear India. The kind of partnership STCI has had with Cochlear India and the number of cochlear surgeries it has been able to set up for children who might never have had access to this otherwise.
- When Dhvani enrolls a child for intervention, efforts are made to ensure that the child is graduated from the program, which means that the child is ready to go to a mainstream school and has an age appropriate language.
- For outreach, we need new equipment, plus Dhvani has not been very aggressive with early detection because the hearing screening equipment is new and they need to understand it more and better. Going forward, Dhvani wants to target work with more minorities, and develop communication about it.
- Dhvani now wants to expand as they have been a clinic for the past 10 years, and they want to expand to be able to provide access to more children and families.

Efforts for policy-advocacy

- The management representatives in the past 9 months have been building towards advocacy, where, firstly, they want to formulate a research study, train more community workers of other NGOs and work to upscale the economy during rollout.
- The top one is how to bring in the development sector outlook to the program, as it has a more clinical outlook. Other is the communication of the program to the wider audience and the importance of it.
- One of the first things the Dhvani team has done is to formulate a research question for a study, as there is no independent study done so far. There is no way to do advocacy without that.
- They have spoken with three NGOs to collaborate and train their community workers of their programs, and scale up the newborn screening component by partnering with other NGOs.
- Partnerships within the organization with other programs are encouraged, as this will increase the denominator in Dhvani and will help in the operationalization through partnerships.
- A factor pertaining to economy of scale is important to be looked into when such models have to be scaled up elsewhere.

Training

- The management explained that there is no specific training for the staff, particularly because they are experts in their individual fields. The staff also knows the clinical processes very well.
- The management also informed that the staff learn from each other, while also attending webinars and events. They also from time to time, update themselves with new knowledge about the fields they are from, in order to best provide services to the children.
- The management however, is looking for a senior advisor from a technical standpoint to come in and guide the staff furthermore about aspects not related to their fields.

Funding availability

- The management believes that Dhvani is a one-stop place for everything the child requires to further grow and be able to hear, and speak, and there is everything readily available at the centre except for the surgeries.
- However, the struggle of the families in order to even maintain the equipment has to be tackled. Also, the fact that when the parents come with the child, they are at the centre for the entire day rendering their day's wage unearned. Hence, Dhvani takes very minimal cost from the parents to access the services.
- In order to acquire funding for a child's cochlear implant or to purchase a hearing aid device, Dhvani approaches the trusts, such as Tata Trusts to enable the operation to function at subsidized rates.

Interviews with Government Officials

Programs and schemes

- Under the Ministry of Social Justice and Empowerment, the government of India is conducting a post graduate course in Auditory verbal therapy at Ali Yavar Jung National Institute of Speech and Hearing Disability, Mumbai to develop the human resource for enhancing the capacity of systems to address hearing impairment. It is a national level course run by the University of Mumbai. And courses are mainly focusing on Audiology & Speech Language Pathologies and special education programs. So manpower development in listening & learning to speak, professional therapy with the perspective of child needs, areas of speech development in any language through listening and learning to speak. This course is first of its kind in the world and is also appreciated in the UN.
- The work and the aspects related to the course and how it is being imparted has been presented at the UN level because it is now a national level subject.
- AYJNISHD also provide help in development of communication material especially with focus on hearing and speech related problem.
- Through this institute measures are taken to provide doorstep and outreach services to various corners of the country (from Nagaland to Rann of Kachchh, from Kanyakumari to Srinagar and Tribal belts). The children with hearing problems are identified and referred for various services such as hearing aids, implants, learning through listening and speech therapy and rehabilitation.
- Rashtriya Bal Swasthya Karyakram (RBSK), an initiative of Ministry of Health and Family Welfare, government of India is meant for screening over 27 crore children from 0 to 18 years for 4 Ds - Defects at birth, Diseases, Deficiencies and Development Delays including Disabilities. Children diagnosed with illnesses receive follow up including surgeries at tertiary level, free of cost under the National Health Mission (NHM).

Benefits of these programs

- Most people are unaware of the fact that the government is doing a lot of things at the community level also. Especially the role RBSK (Rashtriya Bal Suraksha Karyakram) team plays at all levels. RBSK teams are trained in early identification of developmental delays.
- All services are free. Travel cost, in case of children coming from far off locations are also borne by the government, hearing aid for trial, and the cochlear implant surgery as well as some support that may be required post-surgery is also extended free of cost.
- The teams travel to the remotest locations in the country, currently for the entire state of Maharashtra there are 1195 teams
- Through research and development schemes of AYJNISHD, special children are provided hearing aids, setting up of identification centres, free schools, education, professional & technical team of professionals for audiology, psychology, and other rehabilitative services. Audiometric assessments are also carried out at the institute and therapies like multimodal therapy, and individualized training programs are extended.
- The institute also develops communication products like banners, posters, protocols to disseminate for awareness programs related to hearing and speech disabilities.

Special efforts for early detection of hearing impairment

- Children are identified in the District Early Intervention Centers (DEICs) as well.
- Right now, the functioning teams of RBSK are around 1195 teams, in every team, there are 2 doctors, a female and male, one ANM and a pharmacist. There are more than one teams in one block. These personnel are provided with a doctor and a vehicle. Their advanced touring programs are planned well in advance.

Referral mechanism

- The referral mechanisms include the specialist services for the child, and also cochlear implants or surgeries or any other follow-up thereafter.

Evident gaps

- Although the RBSK program in Maharashtra has 1195 teams, they are still less and need to be increased. At times, this number also poses scarcity of HR.
- Even 1195 teams are less, and the difficulty in adding more teams is due to the fact that the salaries are less, or there are no other incentives to the team members. While other programs have more salaries, they switch out and join those programs when there are newer advertisements, which in turn hurts the team structure as less people join and more people leave.
- Monitoring of the vehicles provided to these teams are a must as these are not fit as per the norms, and the teams face a challenge when they have to travel to remotest locations

8. Challenges and Enablers

Challenges

- The quality of antenatal check-ups, no discussion was undertaken on complications in previous pregnancy and if there is any complication reported then no action was taken
- Age of marriage, age of first pregnancy, family planning counselling and birth spacing
- Access for ANC services is still a challenge
- No access of active screening at birth for any hearing impairment so the delay in detection which may affect the outcome of the interventions
- Lack of community-based referral mechanism and no training program in place for community level workers for screening and referral, if it is there, so the quality of its implementation is still a challenge
- Lack of IEC activities with especial focus on hearing impairment, its implications on life of any individual, importance of early detection and interventions and stigma & discrimination for deaf and dumb individuals
- Lack of dedicated cadre and community based program to address the hearing impairment program in a public health approach
- It shows that the communication with kids by program professionals is still a challenge area, we need to revisit the BCC strategy and approaches that is currently in use by the program
- Due to non-availability of large IEC program the knowledge and awareness is limited to small geographical boundaries

Enablers

- Thorough counselling and explanation about the program, investigations and interventions, discussion on developmental milestones
- The early intervention under Dhvani for children with hearing loss ~~hearing impaired children~~ worked as trigger for the mother's empowerment in terms of their education and keenness towards the studies related to hearing impairment therapies
- Program implementation is being done by multi skilled dedicated team like audiologist, auditory verbal therapists, speech therapist and mainstreaming specialist and other experts
- Using existing community-based platforms like immunization camps for implementing community-based screening programs for early detection of hearing impairment in children
- Providing services close to the residence of kids and through tele-practice improves the compliance of intervention and reduce the possibilities of dropout rate
- Participation of parents in the entire process of intervention improve the compliance of intervention and empowering the parents
- Detection of hearing impairment at young age is the very important milestone of the entire process
- Government of India sponsored largest public health program which covers the disease, deficiencies, defects at birth and developmental delay of zero to 18 years of children and adolescents.

- Team of multiple disciplines to ensure the quality of care during and post-surgery period
- Ensuring access to funding support is the most attractive aspect of the program as cochlear implant is very expensive surgery and it is difficult for the poor patient to deal with it.
- Ongoing Post Graduate Diploma Auditory Verbal Therapy (PGDAVT) course at AYJNISHD, Mumbai to develop the human resource for enhancing the capacity of system to address the hearing impairment.

9. Discussion

A couple of aspects have been discussed below that the study reflects with regard to Dhvani program

Basic philosophy and non-negotiables

- Parents and families that discover their child's hearing abilities at the earliest, especially at birth, in first three months after birth or in infancy have the potential to provide them with the same quality of early life experiences as their hearing peers.

- Families that access timely and comprehensive services from professionals knowledgeable about early development, communication, and language are more likely to witness greater progress in many areas of development than those without similar opportunities.

- A family-centered philosophy and professional organizations that nurture the capacities of children to enable them to be at par with other children provide the foundation for programs and practices in early intervention.

- Children with hearing impairment benefit from an understanding that they are part of a larger community who share similarities in ways they acquire information, communicate, and socialize with others.

- Increased opportunities for children to acquire language during the early years and enabling them with communication skills means indicates that the families can be assured of mainstreaming and integration to regular schools.

- Early identification of hearing abilities signifies that more children are using hearing devices such as hearing aids and/ or cochlear implants, during the early months of life when the brain is most receptive to environmental stimuli.

Professionalism reinforced

- Apart from all the responsibilities that the professionals at the intervention center shoulder, one of the key responsibility is to ascertain that the families maintain realistic expectations regarding the outcomes associated with different technologies, so that the focus remains on the child's acquisition of age-appropriate language and other developmental milestones.

- The program has focused on contributing to the change from the "wait and see" mentality to one of "assess, support, and monitor" to ensure age-appropriate development and mainstreaming.

- The quality of early education and developmental services centers on the quality of the providers.

- The services delivered mirror the needs of the children and their families

- Services are provided by a team of specialists or by one specialist in consultation with others. The frequency and intensity of the services are directly related to the needs of the child and the family.

10. Recommendations

The study clarifies that 'Dhvani' as a program has come a long way in establishing itself as a scalable and replicable model. However, there are few areas which have both a scope and potential to strengthen itself, wherein it can be comprehensive enough from two perspectives: one is focusing on multi-dimensional aspects; and two is to engage with and involve multiple stakeholders.

With the above perspective, a set of key recommendations emerge:

Systems and Service Delivery

Contributing to service strengthening

While STCI itself is providing a set of services through its program and the established center for more than a decade, a step further in strengthening the other services around this intervention will prove to be helpful, this can be achieved by way of:

- Creating network of various service providing institutes, hospitals, non-government organizations so as to increase service accessibility and screening programs for early detection and helping in developing a timely intervention plan.
- Facilitation or starting of community and home-based active screening program at birth for early detection of hearing impairment
- Initiating IEC (Information, Education and Communication) and BCC (Behaviour Change Communication) programs for each group including parents, family, community and health care providers to improve early detection, decrease dropout during the entire journey of intervention and adherence to the intervention protocols.
- There should be mechanism for institutional partnerships with institutes like TISS, Nirmala Niketan and other academic bodies, especially those that are dealing with social aspects of disability. This will also ensure more human resource availability, will help in expanding the reach of STCI in identifying gaps in service provision at the government level and will also provide an opportunity in conducting research on these aspects

Facilitating establishment of robust referral mechanism to improve reach and track drop-outs

Of all the children that have enrolled and participated in the intervention, proportion of dropout during the intervention journey is 23%, so it is important to identify, assess and document reasons of case dropouts throughout the service journey and program. The ways and means of doing this may entail:

- Developing individual care plans and track the specific needs and challenges of parents and of children.
- A community-based referral mechanism which involves community level workers for screening and referral
- There should be a back-tracking system in place to identify dropout cases and to engage with those parents and children.

Demand generation and community based systems

Creating mechanisms for demand at community level

- Culturally sensitive, community-based, collaborative, and developmentally appropriate services are key aspects of any program intervention that focuses on addressing a specific disability. While STCI has effectively worked on these aspects, a need for nurturing community based support mechanism which involves parents, families, community leaders and volunteers to help reduce stigma, increase awareness of screening, and help in understanding the implications on life of any individual if interventions are delayed.
- Engagement with various government schemes to leverage the existing community-based platforms.
- Creation of and capacitating community level cadre will ensure expansion of reach.

Policy Advocacy and Enabling Environment

Vision and positioning of Dhvani-STCI as thought leader

- Professional organizations with special interests in programs for children both globally and nationally have successfully developed position statements, knowledge and skills documents, and reports addressing the issue. STCI should consider taking up this role, as the organizations that have field programs are best suited to do so, and STCI is not an exception.
- An interdisciplinary, team-based approach facilitates collaboration among professionals providing support to families and strategies of engagement that will enhance their children's development serves can be a precursor to establishment of a network, as Dhvani will serve as a role-model for other organizations of the network that may be focusing on either hearing or any other disability of young children.
- Based on the learning and a decade long implementation experience, STCI should take a role of mentor to enhance the capacity of local organizations and their community-based staff for implementing community-based program on screening for hearing impairment.
- An effort to improve donor engagement specifically for community-based campaigns and implementation support to mainstream the agenda of early detection and intervention will help in taking the cause to the next level.

- Partnerships and collaborations with academic institutions like social work, business management and paramedical colleges will help in leverage both human resources as well as multi-faceted experience and expertise for Dhvani program and will also help in furthering the agenda of addressing hearing impairment.

Advocacy at the highest level

- Advocacy to be done at the highest level, such as the Ministry of Health and Family Welfare, Government of India for the inclusion of record keeping of pregnant mothers with focus on any associated risk for hearing impairment needs to be done. While STCI now has the newborn screening facility, it should collaborate with both state and city governments for screening at community level as well. The other mechanism could be to collaborate with government/ public hospitals for screening at birth within the facility, including display of IEC materials at the health facilities for the parents to get educated about newborn screening and its benefits.

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[i] Disabling hearing loss refers to hearing loss greater than 40 decibels (dB) in the better hearing ear in adults and a hearing loss greater than 30 dB in the better hearing ear in children.

[ii] The prevalence rate i.e. number of persons with hearing disability per lakh population

[iii] Inability of a person to hear properly was considered as hearing disability. For the purpose of the survey, hearing disability was judged taking into consideration the ability of the better ear. In other words if one ear of a person was normal and the other ear had total hearing loss, the person was judged as normal in hearing, Hearing disability was judged without taking into consideration the use of hearing aid.

[iv] A person was considered as having very severe hearing disability, if he/she could not hear at all or could hear only loud sounds. Severe hearing disability exists if a person could hear only shouted words, while moderate hearing disability was reported when disability was not severe. Persons with moderate hearing disability usually would ask to repeat the words spoken by the speaker or like to see the face of the speaker during conversation. Depending upon the extent of person's inability to hear properly, the degree of hearing disability has 19 been classified into 3 categories such as, profound, severe and moderate