

MAPPING

THE SERVICE JOURNEY
of children
with Hearing
Impairment
from initiation
to successful
Integration
into
Mainstream
Schools



A RESEARCH STUDY

on Dhvani Early Intervention Program
of Save The Children India



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Overview

Save The Children India implements 'Dhvani', an early intervention program for children with hearing impairment. This 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.

Basic Philosophy of Dhvani program

The program works with children, and parents who discover their child's hearing challenges at an early stage of childhood i.e. at birth, in the first three months after birth, or in infancy. The families are provided 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. 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. Early identification of hearing abilities ensures 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.

RESEARCH STUDY

Implications for the Sustainable Development Goals Leaving no-one behind.

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.

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 for replication of this model and advocacy 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.

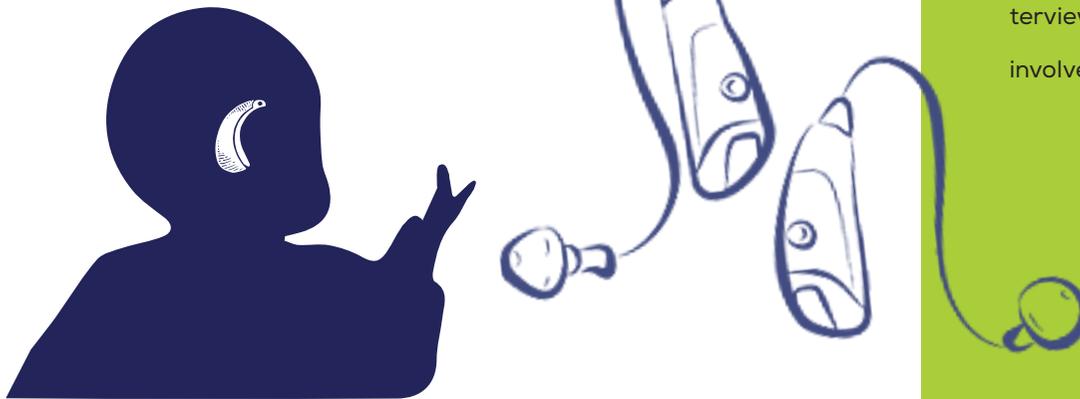
Objectives

- 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 analysed 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.



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 to 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 absence of training program 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
- Limited knowledge and awareness among communities

Potential Contributions from Dhvani

- Parent-friendly counselling and explanation about investigations and interventions, discussion on developmental milestones
- A multi skilled dedicated team that includes audiologist, auditory verbal therapists, speech therapist and mainstreaming specialists, and counsellors
- Participation of parents in the entire process of intervention to improve compliance of intervention and empower parents
- Detection of hearing impairment at a very young age
- Close coordination with the Cochlear surgery team to ensure quality of care during and post-surgery period
- Ensuring access to funding support for Cochlear implants

Potential Areas for Programme Development

- 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 children and through tele-practice improves the compliance of intervention and reduces the possibilities of drop out
- Collaboration with the Government of India sponsored largest public health program which covers the disease, deficiencies, defects at birth and developmental delay of those aged zero to 18 years
- Ongoing Post Graduate Diploma Auditory Verbal Therapy (PGDAVT) course at AYJNISHD, Mumbai to develop human resources to enhance the capacity of the system to address hearing impairment.



Recommendations

The study clarifies that 'Dhvani' as a program has come a long way in establishing itself as a high quality, scalable and replicable model. However, there are few areas which have both potential for strengthening, thus adding value from two perspectives:

1. Focusing on multi-dimensional aspects
2. Engaging with and involving multiple stakeholders.

Additionally, recommendations pertaining to systems and service delivery; demand generation; and policy advocacy have been laid out below.

Systems and Service Delivery



Contributing to Service Strengthening

While STCI itself provides a set of services, strengthening the other services around this intervention will prove to be helpful. This can be achieved by way of:

- Creating a 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, to help expanding the reach of STCI in identifying gaps in service provision at the government level. Additionally, there is the possibility of 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
- 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. There is a need for nurturing community based support mechanisms which involve 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



Policy Advocacy and Enabling Environment



Vision and Positioning of Dhvani-STCI as Thought Leader

- STCI to work on developing position statements, knowledge and skills documents, and reports addressing the issue of hearing loss, and thus convert its experience into usable knowledge for the sector
- An interdisciplinary, team-based approach facilitates collaboration among professionals providing support to families and strategies of engagement that will enhance their children's development. This serves as a precursor to the establishment of a network, as Dhvani will serve as a role-model for other organizations that may be working 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 programs 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 leveraging 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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