



**Challenges faced by
children who are Deaf
or Hard of Hearing**

Awareness regarding appropriate early interventions methods for deaf child to facilitate learning



Challenges faced by children
who are Deaf or Hard of Hearing



Post the diagnosis of deafness, **early and appropriate intervention methods** can facilitate a deaf child's learning of language and comprehension from a very young age.

This sets a strong foundation for their social, emotional and intellectual development.

Challenge

- **Less than 5% of doctors** are informed about different intervention options for the Deaf.
- Many doctors do not inform parents about the importance of language development through Sign Language and don't include it as an option.
- Most screening centres in India suggest Cochlear Implants as the only solution.



Oral Language Development

For a child with hearing loss if detected early, oral language development will happen only if :

- (a) good hearing aid or cochlear implants are given
- (b) Regular speech & language therapy
- (c) one of the parents/grandparents commits lot of time to working with the child

Right now, there is no integrated solution for all of this and hence, parents are often left to coordinate for all of these by themselves.



Indian Sign Language

ISL is a visual language which enables early language acquisition and communication development amongst deaf children.

Learning sign language in the early years can lay a strong base for teaching the child a second language and reap the benefits of a bilingual education. Sadly, most hearing parents are unaware of the benefits of learning sign language for their child.



ADIP Scheme

To promote independent functioning and to assist physical and social rehabilitation for PwD, the Government of India has rolled out the **ADIP scheme (Assistance to Disabled Persons for purchase/ fitting of aids and appliances)**, wherein free and discounted assistive aids and devices are distributed to disabled persons.

Following benefits have been proposed for persons with hearing impairment:

1. Hearing aids at discounted prices (depending on the family income)
2. Financial support (upto Rs. 6 lakhs) for cochlear implant surgeries
3. Rehabilitation Support – travel cost for child and escort (Rs. 250 per person per day) and boarding lodging cost (Rs. 100 per day for 15 days)



Cochlear implants

- Work when administered with extensive speech therapy support.
- Parents often miss out continued speech therapy as they stay in far off locations and/or have limited access to therapists.
- If suggested, parents need to be guided on how they can practice speech therapy with their child at home.



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“Believing that implants will help the child in developing language, most parents put all the eggs in the same basket and soon realize that the child has significant language delays. Further, inability to communicate manifests itself in frustrations and behavioural problems. An implant can never replace normal hearing and make an unintelligible speech into a clear one. It is important to remember that there is a critical period of language development and sign language comes naturally to deaf children. Contrary to the popular belief that sign language interferes with the child’s academic success and acquisition of either language , it instead enhances the development of spoken language and literacy”.

Disability Expert on Cochlear implants and language literacy

Challenges with Cochlear Implants

Challenge

Post surgery therapy and follow-up is challenging for parents

- Difficult for parents to miss a day's wage, and travel to therapy centers.
- Lack of resources in government hospitals
- Private therapy centers closer home expensive
- Availability of therapies in small towns is limited.

Impact

Abandoning of the device even though the ADIP scheme greatly subsidize costs for surgeries & instruments.

Families invest cost, time and effort for procuring & fitting of the device

Solutions

Tele-therapy from community centers and Aangan Wadis

Video or App with step by step written guides to assist parents in administering therapies at home.

Online and telephone assistance for challenges faced and methods of resolution.

Challenges with Cochlear Implants

Challenge

External components of the Cochlear Implant device **needs frequent replacement or repair every 2-3 years. They are expensive and** not available easily.

Impact

Abandoning of the device due to hassles of procuring and high cost of the repair.

Solutions

Local availability at affordable prices will facilitate better usage of the devices



Parent Awareness

Parents, if guided appropriately on how to assist their children with therapies, using an accessible language at home and generating visual learning stimuli, can be instrumental in supporting their child's cognitive growth. It is important to figure out ways in which parents can be more involved in the intervention process.

**“Parents do not
have information
available to make
informed choices...”**

”...They should be allowed to evaluate and choose between oral and sign language intervention for their child. Parents of other deaf children and deaf adults can support the new parents in this process. New trends do not even demand the parents to choose. Why choose? Why not both the languages? We need experts to guide parents to follow the sign/bilingual approach from early years.”

- Dr. Surinder Randhawa , Deaf Educator



Deaf Role Models

The people who guide parents at DIECs are mostly doctors and audiologists. What is needed is deaf role models and sign language interpreters who can lead by example and help parents look at early intervention in totality and not in independent silos comprising of cochlear implants, sign language training, bilingual education etc.

- Ashish Doval, Project Coordinator , Early Intervention , Haryana



Sign Language Awareness

We cannot deny the fact that Deaf children need exposure to sign language (their primary language) even if they get a cochlear implant. A holistic development is possible only through a Bilingual approach.

- Atiya Hajee, Senior Sign Language Interpreter & Project Coordinator Digital Sign Language Lab.

“Deaf children need language and not (just) speech”.

“More than 90 % of deaf children face language deprivation, since they get delayed and inadequate language input in the critical years of language acquisition”.

-Pallavi Kulshresth ,Academic Head, HWSTSHI

“Early intervention program for children using sign language and counselling for parents on the need for bilingual education (first language being sign language for a fully deaf children) is important”.

- Deaf Educator and Entrepreneur

This is Sudip and Nishtha's story...

Sudeep and Nishtha stay in a small village in Manesar with their parents. Their father is a poor farmer with family income less than 20,000 / month. They are the only deaf children in their extended family.

Sudeep's father was in denial when his son's hearing impairment was confirmed at the age of 5. Since there was no family history of deafness, no assessment was done when Sudeep was born. At Nishtha's birth , the family was more aware and her deafness was confirmed within 6 months of her birth.

Their father got to know about ADIP scheme (Assistance to Disabled Persons for purchase/ fitting of aids and appliances) during a camp which was organized in their district. He was told about the surgery and how it will enable his children to hear and speak. Cochlear Implants were done for Nishtha and Sudeep in a Government Hospital in Gurgaon in Jan 2019.

What happened?

The family was not aware about the intervention needs post the operation. The surgery went off well but when he realized that speech therapy is a must for which he needs to visit private clinics, he didn't have a choice but to sell his land. Every time he took his children, it meant loosing on a days daily wage.

They needed minimum 3 sessions a week for at least 6 months. Travelling 150km one way every alternate day took a toll on their resources and very soon they lost the steam and despite best efforts, both the children are unable to hear and speak.

Now, Sudip and Nishta go to the same government school where they were enrolled in before their surgery. They can hear sounds but they are jarring to the ear and make no sense. They are unable to communicate and do not make sense of conversations around them. In addition to this, their father has to bear the regular expense of maintaining their cochlear implants

This is Fauzia...

Female, 19, Mumbai.

Fauziya was born in a rural area. When she was 7 months old, her mother realized that she was not responding to sounds. Her parents took her to a doctor in Siliguri where they were assured that she will start speaking over time. They were asked to make her sit in front of the television, put food items and daily objects in front of her and ask her to say their names aloud. This continued for two years until they moved to Mumbai and took a second opinion. Though the doctors advised that she needed to go to a special school for deaf, her parents chose to keep her home and work on speech therapy with her. After wasting 3+ years, her parents finally sent her to a deaf school. Their limited understanding of deafness and subsequent delay in accepting her disability led her to waste crucial years of language development which despite her best efforts has had a lasting impact on her.



Some possible solution ideas:

1. Parents should be made aware of **Pros/Cons of different intervention methods** for their child at the screening centres.
2. All District Early Intervention Centres must have **sign language interpreters** and deaf role models who can guide the parents.
3. **Parent awareness toolkit available in-person or remotely** on how to help their child at home (learning basic sign language, visual flashcards and aids such as stickers that can be put on everyday objects to learn new words, audio adjustments to be made in the house, etc.

Some possible solution ideas:

4. **Toolkits/trainings for Doctors/medical professionals at screening centers** to deal with the parents with empathy, provide them with the right information, and involve them in the intervention process.
5. A **database of parents and deaf adults** can be maintained, to share their experiences and help parents decide the best way ahead for them.

Helpful Readings

- Advantages of Early Visual Language <https://drive.google.com/file/d/1mDudSl5tu848ONnphj6TGCFhIH4llWY1/view>
- Deaf children need language, not (just) speech <https://drive.google.com/file/d/1xXxiq7uDBLTYiSW2FcorNmyqWF548y-T/view>
- Gallaudet University Research Briefs: https://drive.google.com/file/d/1u4HLHdAAyodq_QLIT2F_qT8w8qVR07yV/view
- <https://drive.google.com/file/d/1ohrUxcgqLY-GcT8EXYg7cY8zjUDpdh3M/view>
- <https://drive.google.com/file/d/1wvsoBV3RH4KNq22bK5gCHop6yUCTaA9e/view>
- https://drive.google.com/file/d/1Q02VYpIXtd9k7t1filbV0v-1ZY_b4iFn/view

