# ORIGINAL RESEARCH ARTICLES

# Hearing, Speech and Language Outcomes in Children with Cochlear Implants: a Comparison between ADIP Scheme and Self-Financed Scheme

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## *ABSTRACT*

***Purpose:*** *Cochlear implants (CIs) are of immense benefit to children with severe to profound hearing impairment. While cochlear implants under the Government of India supported ADIP scheme cost a lot to the public exchequer, parents spend considerable amounts on CI surgery under the self-financed scheme. This study aimed to find and compare outcomes of cochlear implants in children who availed of the ADIP scheme and those who were implanted under a self-financed scheme. The secondary aim was to elicit the views of parents on the challenges their wards faced under the ADIP scheme for cochlear implants.*

***Method:*** *The study focused on twelve children who received cochlear implants under the ADIP scheme and twelve children who received implants under a self-financed scheme at a tertiary care health centre. The baseline for measurement of various outcomes was a minimum of six months post implantation. Cochlear implant outcomes were compared using MAIS/IT-MAIS, SIR, CAP, and ISD tests. Interviews were also conducted with the parents of children who received cochlear implants under the ADIP scheme, for information regarding the challenges they faced.*

***Results:*** *There was a significant difference ($p<.05$) between the two groups in the scores of CAP and reception, speech, and cognition subsections of the ISD scale. The scores of the ADIP group were significantly lower in these domains. The possible reasons might be a lack of funds, not visiting the therapy centre regularly, loss of wages during a visit to the therapy centre, lack of family support, and insufficient time to repeat therapy activities at home. There was*

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*no significant difference in age, CI age, and CI usage duration between the two groups.*

***Conclusion and Implications:*** *Compared to children implanted under the self-financed scheme, children implanted under the ADIP scheme are significantly lacking in a few domains of communication skills. The efficacy of the ADIP scheme for cochlear implantation can be evaluated and policy change can be advocated based on this study. The study has outlined some modifications to this welfare scheme in order to fill the observed lacunae and widen the scope of its reach.*

***Key words:*** *ADIP scheme, self-financed, outcomes, cochlear implants, challenges*

## INTRODUCTION

Hearing impairment is the most prevalent sensory disability (Mathers et al, 2003). More than 466 million people are reported to have moderate to profound hearing loss; many more have mild hearing loss and ear diseases such as otitis media (WHO, 2008). As per the NSSO survey, 291 persons per one lakh population currently suffer from severe to profound hearing loss in India (National Sample Survey Office, 2003). Four in every 1000 children suffer from severe to profound hearing loss, with over 100,000 babies born with hearing deficiency every year in India. Hearing impairment has a significant impact on both children and their families. This is seen in every aspect of their lives, including cognitive, communication, psychosocial, educational, personality development, and financial condition.

Cochlear implantation has been widely used to recover or obtain audition for clients with severe to profound hearing loss. A cochlear implant can effectively stimulate the auditory pathways with electrical pulses, even in cases of severe to profound hearing loss. In the case of children, electrical stimulation of the cochlea can more effectively activate the central auditory pathway, which will provide auditory perception and enable the development of speech perception skills (Miyamoto et al,1995; Geers,1997; Skarzynski et al, 2012).

Cochlear implants are costly devices, with prices ranging from INR 500,000 up to 1,400,000 in India. The cost of surgery and therapy makes the implantation procedure an expensive affair. However, the benefits to communication and other domains of quality of life make it a panacea for severe to profound hearing-impaired children. In India, the central and state governments have started

welfare schemes for hearing-impaired children belonging to economically weaker sections of the population.

Assistance to People with Disability for Purchase/ Fitting of Aids and Appliances (the ADIP scheme) - for cochlear implant - is an ambitious welfare scheme for the hearing-impaired population under the Ministry of Social Justice and Welfare, the Government of India (AYJNISHD(D)). The scheme aims to provide cochlear implants to hearing-impaired children from poor economic backgrounds and to support implanted children with auditory verbal therapy (AVT) for two years through empanelled rehabilitation centres. Children under five years of age with severe to profound hearing loss, whose family income is less than INR fifteen thousand per month, and who have no associated disorders are eligible for cochlear implants under the ADIP scheme. To avail of this, parents need to submit documents such as their income certificate, child's birth certificate, hearing handicap certificate, detailed IQ assessment report, audiological assessment reports (Pure tone audiometry, Impedance audiometry, Otoacoustic emission, Auditory brainstem response report, hearing aid benefit report), speech-language assessment report, ENT examination report and radiological report (CT scan and MRI scan to rule out cochlear malformations).

The scheme targets the implantation of 500 children per year, with a ceiling of INR 6 lakhs per unit. The Standing Committee on Social Justice and Empowerment (2017-18) observed in its report that during three initial years (2014 - 2017) only 975 cochlear implant surgeries were conducted across the country, which is far less than the target of 500 implant surgeries per year(Sharma, 2018). Thus, it appears that the ADIP scheme is still struggling to reach out to a large portion of the economically weaker section.

While cochlear implants under the ADIP scheme involve high costs to the public exchequer, parents spend a considerable amount of money on the procedure under the self-financed scheme. Having to pay INR 5 - 14 lakhs for a device, in addition to the costs of investigation, pre-surgery vaccination, hospitalisation, and medicines, places a heavy financial burden on the family. Hence there is a need to study the hearing, speech, and language outcomes in children implanted under the ADIP scheme and compare them with children implanted under the self-financed scheme.

## Objective

The present study aimed to find and compare hearing, speech, and language outcomes of children with cochlear implants under the ADIP scheme and those implanted under the self-financed scheme. The secondary aim of the study was to elicit parental views on challenges in the ADIP scheme for their wards with cochlear implants. The efficacy of the welfare scheme can be evaluated, and policy change can be advocated based on the findings of this study.

## METHOD

### Study Participants

Twelve children implanted under the ADIP scheme and twelve children who received implants under a self-financed scheme at a tertiary care health centre were included in the study. Informed consent was taken from all the participants. The surgeries were performed between 2016 and 2018. Six months post-implantation was taken as a baseline for measurement of outcomes. The parents of children who received cochlear implants under the ADIP scheme were also interviewed to get information regarding the challenges they faced.

### Study Tools

Outcome measurement of cochlear implants was done by administering different tools.

Hearing outcomes were assessed using MAIS/IT- MAIS and CAP scale.

- MAIS (Robbins et al, 1991 ) / Infant-Toddler - Meaningful Auditory Integration Scale or IT-MAIS (Zimmermann-Phillips et al, 2001) - MAIS is a structured interview schedule designed to evaluate the use of conversational listening skills in school-age children. IT-MAIS is the modified MAIS to be used on very young children.
- Categories of Auditory Perception or CAP (Archbold et al, 1995) – This test has 1 to 12 levels to measure auditory skill development. The 12$^{th}$ level is the highest level where the child may use the phone with an unfamiliar speaker.

Speech outcomes were evaluated using the Speech Intelligibility Rating test.

- Speech Intelligibility Rating scale or SIR (Allen et al, 2001) – It categorises

the child's speech intelligibility from 1 to 5 (where 5 is the highest level of intelligibility when the speech is entirely intelligible).

ISD was used to assess speech-language development.

- Integration Scale of Development or ISD (Cochlear) - The scale is helpful to assess speech-language development in six domains: audition, receptive language, expressive language, speech, cognition, and pragmatic skills.

**Ethics Approval**

All procedures performed with the participants were in keeping with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

## RESULTS

The details of children in the ADIP group and self-financed group have been summarised in Table 1 and Table 2.

The ADIP group consisted of 12 children (seven females and five males) with a mean age of 5.64 years (SD 2.29). The mean implant age and implant usage duration were 4.55 years (SD 1.42) and 1.6 years (SD .57). The self-financed group consisted of 12 children (seven females and five males) with a mean age of 5.76 years (SD 1.75). The mean implant age and implant usage duration were 4.57 years (SD 1.71) and 1.32 years (SD 0.67).

**Table 1: Details of ADIP Group**

| S N | Age (yrs) | Gender | Age at implant (yrs) | Implant usage (yrs) | CI company |
|---|---|---|---|---|---|
| 1 | 7 .6 | F | 5.5 | 2.1 | Cochlear |
| 2 | 7 | F | 5 | 2 | Cochlear |
| 3 | 7.83 | M | 5.83 | 2.1 | Cochlear |
| 4 | 6 .5 | F | 4.42 | 2 | Cochlear |
| 5 | 7 .1 | F | 5.58 | 1.5 | Cochlear |
| 6 | 6.1 | M | 4.58 | 1.5 | Cochlear |
| 7 | 7 | F | 5.75 | 2 | Digisonic |
| 8 | 4 | M | 3.08 | 1.9 | Digisonic |
| 9 | 9 | F | 6 | 1.75 | Cochlear |

| | | | | | |
|---|---|---|---|---|---|
| 10 | 3 | M | 2.5 | 0.91 | Cochlear |
| 11 | 3 | M | 2.8 | 0.83 | Cochlear |
| 12 | 3.8 | F | 3.6 | 0.58 | Cochlear |

**Table 2: Details of Self-Financed Group**

| SN | Age (yrs) | Gender | Age at implant (yrs) | Implant usage (yrs) | CI company |
|---|---|---|---|---|---|
| 1 | 6.41 | F | 5 | 1.41 | Cochlear |
| 2 | 7 | M | 5.67 | 1.33 | Advanced Bionics |
| 3 | 6 | F | 5.25 | 0.75 | Medel |
| 4 | 3.25 | M | 2.91 | 2.58 | Advanced Bionics |
| 5 | 5 | F | 2.25 | 2 | Medel |
| 6 | 5.92 | F | 3.9 | 2.1 | Advanced Bionics |
| 7 | 8 | M | 7.3 | 0.58 | Advanced Bionics |
| 8 | 3.5 | F | 2.84 | 0.66 | Cochlear |
| 9 | 5.5 | M | 3.92 | 1.58 | Medel |
| 10 | 3.75 | M | 3.16 | 0.58 | Medel |
| 11 | 5.83 | F | 5.16 | 0.75 | Advanced Bionics |
| 12 | 9 | F | 7.5 | 1.58 | Medel |

In the ADIP group, the cochlear implant brands were Cochlear (n=10) and Digisonic (n=2). In the self-financed group, the cochlear implant brands consisted of Cochlear (n=2), Advanced Bionics (AB) (n=5), and Medel (n=5).

A t-test was carried out to determine the mean difference in age, implant age, and implant usage duration between the ADIP group and the self-financed group. As shown in Table 3, there was no significant difference between the two groups on any of these measures.

**Table 3: Comparison of Age, Cochlear Implant Age, and Cochlear Implant Usage Duration between the ADIP Group and Self–Financed Group on independent t-test**

| S N | Name of the Variable | ADIP Group | Self-Financed Group | t-test (p-value) |
|---|---|---|---|---|
| **1** | **Age** | 5.64(2.29) | 5.76(1.75) | 0.3(.88) |
| **2** | **Age of Implantation** | 4.55(1.42) | 4.57(1.71) | -0.3(.97) |
| **3** | **CI Usage Duration** | 1.6(0.57) | 1.32(0.67) | 1.09(.3) |

For statistical analysis, the scores on the ISD scale were taken as a mean of the age range obtained from the scale. The mean scores of different tests in the ADIP group and self-financed group are given in Table 4. When both the groups were compared using an independent t-test, there was a significant difference ($p<.05$) between the two groups in the scores of CAP and reception, speech, and cognition subsections of the ISD scale. The scores of the ADIP group were significantly lower in these domains. There was no significant difference between the two groups on the domains of MAIS/IT-MAIS and SIR and audition, expressive language, and pragmatics domains of the ISD scale.

To find the difference in CI outcomes between two groups based on age (less than vs. more than five years), gender (male vs. female), cochlear implant age (before vs. after three years), and cochlear implant usage (less than vs. more than one year), independent t-test was carried out. There was no significant difference ($p>0.05$) between the groups based on gender, age, cochlear implant age, and cochlear implant usage duration. Hence, the difference between the ADIP group and the self-financed group may not be attributed to gender, age, age of implantation, and cochlear implant usage (see Table 4).

**Table 4: Comparison of Test Results of Children with Cochlear Implants under ADIP and Self-Financed Scheme on independent t-test**

| S N | Name of the Test | | ADIP Group (Mean) | Self-Financed Group (Mean) | t-test(p-value) |
|---|---|---|---|---|---|
| 1 | **MAIS/IT-MAIS** | | 28.25 | 32.42 | -1.65(0.11) |
| 2 | **SIR** | | 2.33 | 2.91 | -1.38(0.18) |
| 3 | **CAP** | | 4.25 | 6.5 | **-2.94(0.007)** |
| 4 | **ISD** | Audition | 15.13 | 20.25 | -1.72(0.1) |
| 5 | | Reception | 14.1 | 20.38 | **-2.14(0.04)** |
| 6 | | Expression | 12.33 | 17 | -1.8(0.08) |
| 7 | | Speech | 12.12 | 17.4 | **-2.2(0.04)** |
| 8 | | Cognition | 24.25 | 34.63 | -3.13(0.005) |
| 9 | | Pragmatics | 24.625 | 32.75 | -1.89(0.072) |

**Parental Perceptions about Challenges in ADIP Scheme**

The parents of children with cochlear implants were asked about the difficulties faced during pre- and post-implant procedures under the ADIP scheme. The challenges have been discussed below.

- **Awareness** – The parents came to know about the ADIP scheme very late, and by the time the applications were accepted and surgeries were performed, the child was over five years of age. Hence the average implant age for children was more than five years. Most parents came to know about the ADIP scheme either through the tertiary centre (n=9) or from the special educators (n=2). One parent came to know about the scheme through a local hospital. Most physicians, including ENTs, are either unaware or reluctant to inform the parents about this central government scheme. Many audiologists do not notify the parents about the scheme as they are not interested in dispensing the costly devices and want their clients to continue using hearing aids. So, even when the hearing aids are not beneficial, parents keep waiting for improvement in their wards' auditory and language skills, and thus precious time is lost.
- **Documentation** – All the parents mentioned that documentation was a tedious job. Getting the disability certificate, IQ certificate, and income certificate took a lot of time and effort. Obtaining an income certificate was difficult for parents working as labourers or in some low-profile jobs. In places like Chandigarh, the officials refused to issue a disability certificate as there was no such provision for these daily wage workers. AYJNISHD (D), Mumbai (the nodal agency supervising the ADIP scheme), needs a detailed psychological report rather than IQ scores. It is not easy to obtain this as most hospitals do not issue detailed IQ reports for young children. Getting a disability certificate at the civil hospitals was difficult due to the lack of human resources at many centres. The parents had to visit many centres to obtain these mandatory documents, and consequently precious time was lost.
- **Delay in Cochlear Implant approval** – After sending all the required documents, there was a gap of 3-6 months to get the approval from the headquarters (AYJNISHD (D), Mumbai). This could be due to a large number of applications from across the country.

- **Hearing Aid trial** - Four parents found it challenging to get the powerful digital hearing aids for the three-month trial period. Most of them used body-level hearing aids before cochlear implants. There is no provision for dispensing hearing aids and batteries to poor clients during hearing aid trials under the ADIP scheme for cochlear implants.
- **Post-implant Rehabilitation** – Seven implantees found it challenging to take the AVT therapy from qualified audiologists, mainly due to the distance to the therapy centre from their homes. One implantee could not visit the therapy centre regularly due to a lack of family support and financial issues. One family relocated to stay close to the therapy centre.
- **Availability of Accessories and Servicing –** Some parents had difficulty procuring cochlear implants accessories, like batteries and cables. For Digisonic instruments, there were no local dealers for accessories. There was also a concern about the accessory cost and recurrent cost of batteries. There was no backup for these expenses. The parents felt that the government should provide financial assistance to meet these costs as well.
- **Cochlear Implant Company Support –** Initially, it was difficult to map the processor for the first Digisonic implanted child in this study, as she would not cooperate. It took about three months to find the child's behaviour threshold. The mapping centre could not get the necessary support from the company.
- **Non-availability of Habilitation Programme in Hindi –** Parents reported that the respective cochlear implant companies failed to provide adequate AVT materials and troubleshooting methodology in the Hindi language, which could be used as a guide at home.

## DISCUSSION

The study results suggested that auditory and speech-language skills had developed in cochlear implanted children in both the ADIP and self-financed groups. There are comparable studies that propose a growth in receptive vocabulary in CI children right after the initial fit or with increasing hearing age (Robbins, 2004). Schramm et al (2010) found that progress in hearing and language development assessed by questionnaires in 60% of CI children was nearly comparable to the development of their normal-hearing peers. Different factors affect the outcomes in CI children. This includes the hearing loss duration,

hearing aid use, residual hearing, pre-operative speech recognition, implant age, parent support, speech therapy, etc., (Rubinstein et al, 1999; Green et al, 2007; Carlson et al, 2011; Lazard et al, 2012; Blamey et al, 2013; Holden et al, 2013; Plant et al, 2016). The implant brand, number of electrodes inside the cochlea (Gifford et al, 2013), and residual hearing preservation (Aschendorff et al, 2007; Skinner et al, 2007; Finley et al, 2008; Wanna et al, 2014) are device and surgery-related factors.

Significant differences were observed under the domains of audition, reception, speech, cognition, pragmatics skills, and CAP test, between self-financed implanted children and children implanted under the ADIP scheme. Poor scores in the ADIP group may be attributed to scarce financial resources (reducing to and from visits to the intervention centre), lack of parental education, and lack of awareness, leading to less stimulation and support at home. Parents under the self-financed scheme are more motivated to improve the communication abilities of their implanted wards. They attend the therapy sessions regularly and devote extra time to repeat the therapy activities at home. Thus their children with implants get more support from the family.

The caregivers who availed of the ADIP scheme perceived the following challenges: lack of awareness, delay in cochlear implant approval, unavailability of enough AVT centres, lack of finance for hearing aid trial, etc. Post-implant service is also considered critical. It is the responsibility of the implementing agency to take care of the service and repair of these instruments. All the parents were satisfied with the ADIP scheme and even suggested spreading more awareness among the masses. They also mentioned empanelling more AVT centres with qualified audiologists, which would help the children to attend regular therapy sessions. Some parents suggested prioritising the post-implant service. Also, habilitation material in the Hindi language was required.

The ADIP scheme has been introduced keeping in mind the majority of the population in India, i.e., the lower-middle and low-income group. The impact of this scheme is directly linked to general awareness about the programme among the masses. The ADIP programme has been widely accepted, and professionals and parents have duly recognised its benefits across the country.

There is scope for improvement in the ADIP scheme, as summarised below.

1. **The maximum age criteria -** It should be raised from 5 to at least 7 years. Children with hearing impairment are identified late due to the non-

availability of hearing care services in far-off places, especially in rural areas. By the time they are referred to an ADIP recognised centre, it is already late.

2. **Duration of rehabilitation services** - Provision for AVT is limited to two years under the scheme. However, it has been noticed that many clients either miss the sessions due to various reasons or need support beyond two years. Hence the free AVT sessions may be allowed for at least three years, with frequency increased from three to five sessions per week.

3. **Assistance for accessories** – These families need support beyond the standard warranty period provided by the cochlear implant companies. The accessories, including the rechargeable batteries and cables, need an extended warranty of at least five years. There should also be a provision for the replacement and repair of parts of implants and batteries free of cost.

4. **Candidacy for bilateral implantation** – Sometimes, the family can get the first implant under different schemes like Sarva Shiksha Abhiyan, MP fund, etc. However, they are not candidates under the ADIP scheme for the second implantation. This needs to be revised.

5. **Cochlear Implants for children with additional disabilities –** Though cochlear implants have a guarded prognosis in cases of cochlear anomalies, the children still do better than those with other modes of amplification and should be included in the candidacy criteria under the ADIP scheme.

## CONCLUSION

The ADIP scheme for cochlear implants is an appreciable advance that has allowed hearing-impaired children from a lower socioeconomic background to develop auditory, speech, and language skills and join the mainstream. However, compared with children who received implants under the self-financed scheme, children with implants under the ADIP scheme are significantly lacking in a few communication skills. The lacunae in this ambitious welfare scheme need to be dealt with so that the large hearing-impaired population in India may benefit.

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