



Rehabilitation of hearing impaired children in India – An update

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Introduction:

The prevalence of deafness in India is fairly significant. It is the second most common cause of disability. Approximately 63 million people (6.3%) in India suffer from significant auditory loss.¹

Rehabilitation of hearing impaired children in India remains a challenging task. Early detection and intervention are the mainstay of this initiative. This article does not purport to detail the clinical aspects and surgical management of hearing handicapped children. We discuss here the resources and options available in India for the education of deaf children and the role of the Government bodies in rehabilitation. Awareness about education and rehabilitation of hearing handicapped is low among the general public and even among the medical fraternity.

Definitions and Terms

The Rehabilitation Council of India Act, 1992², has defined "hearing handicapped" as - hearing impairment of 70 decibels and above, in better ear or total loss of hearing in both ears.

The legal definition of "hearing disability" in India as per the Persons with Disability Act³ (PWD), 1995 is – "a hearing disabled person is one who has the hearing loss of 60 decibels or more in the better ear for conversational range of frequencies".

The latter definition is at variance with the former. There exists a need to clarify which of the two is a valid definition.

The term 'deaf' is being replaced by the term 'hearing impaired'.⁴ 'Hearing challenged' is an alternate appropriate term. An individual who is hard of hearing since birth was earlier termed 'deaf and dumb'. In today's age of political correctness, these individuals have been redesignated as "congenitally deaf".

The word 'deaf,' when spelt with a small 'd' refers to hearing loss and when spelt with a capital 'D', refers to the Deaf Community⁴. The Deaf Community is an invisible minority community worldwide, as deaf persons can only be identified after personal interaction with them.

Habilitation is a process by which persons born with impairments learn life skills⁵.

Rehabilitation refers to a process by which persons readapt to society after acquiring impairment.

Deaf Community in India

Deaf persons live scattered worldwide. The Deaf Community in India is not an organized entity. They lack a sense of common identity.

Early diagnosis and intervention for rehabilitation of deaf children

Early identification & timely intervention with appropriate support from the family and community is the key to management. Early diagnosis and suitable amplification is mandatory for speech training. Shortly after birth, every neonate should be screened by OAE (otoacoustic emission) testing. All cases detected by OAE testing should be tested further by BERA (Brainstem Evoked Response Audiometry) testing. Speech training should be initiated as early as two years of age with an amplification device such as bone conduction hearing aid. Surgery, where indicated should be performed after careful assessment of each case. Cochlear implant surgery has evolved in recent years and many centres in India are conducting this operation with fairly good outcomes. However, the cost of the implant being prohibitive, not many can afford to avail of this facility.

Indian Sign Language

The ability to communicate is the essence of human existence. The mother tongue is easily learnt by hearing children. In India, almost every state has its own language which is the mother tongue of a hearing child. The deaf child fails to learn the mother tongue. Thus there exists a lacuna in the early speech development at home for the child born with hearing impairment.

Sign language is the equivalent of oral language for those who are deaf. Gestural communication develops at home which is a type of self developed sign language. This form of communication in the home environment takes the place of the mother tongue and this has given rise to the term “homesign” language.⁶

A homesign language was developed in Botswana for preschoolers. It was designed with the motive of improving deaf education as it facilitates the learning of the second sign language formally taught in the classroom. It is based on the theory that learning a second sign system is additive to the mother tongue. In Botswana, deaf children begin communication in the school by use of homesign. In school, they are then taught Botswana sign language, which is based on English.

For several years there was no uniform Indian Sign Language (ISL). Vasishta et al.⁷, reported that ISL is a language in its own right and is indigenous to the Indian subcontinent. Earlier ISL was not included as part of the curriculum in teacher training programmes. Ironically, teachers of the Deaf had to resort to learning sign language from their own students for the purpose of communication. Courses and teaching aids for ISL instruction were not available, nor were there any avenues for training ISL instructors.

The Indian sign language is based on an English platform. English is not the lingua franca in most homes in India. There is no sign language based on any regional Indian language. The problem of how to provide access to Indian Sign Language for deaf people in rural areas of the Indian subcontinent⁸ is difficult to tackle, given the magnitude of the task.

Special schools vs Inclusive schooling

A special school for the deaf has the following advantages⁴:

1. It provides a venue for free communication and social interactions between deaf persons.
2. It is a “home away from home” for deaf children and provides a comfort zone.
3. It inculcates a sense of identity.
4. It provides role models for deaf children.
5. It provides the opportunity to participate in sports and other activities among peers.

Inclusive schooling or mainstream schooling, seeks to address the learning needs of all, with a specific focus on those who are vulnerable to marginalization and exclusion. It implies all young learners, with or without disabilities, should be able to learn together through access to common schools with an appropriate network of support services

It is postulated that a child with disability can be educated in a general school only and not in special school. Even those children who are admitted to special schools for training in plus curriculum skills should be transferred to general schools once they acquire daily living skills.

Research has shown that inclusive education results in improved social development and academic outcomes for all learners⁹. It leads to the development of social skills and better social interactions because learners are exposed to real environment in which they have to interact with other learners each one having unique characteristics, interests and abilities. The non-disabled peers adopt positive attitudes and actions towards learners with disabilities as a result of studying together in an inclusive classroom. Thus, inclusive education lays the foundation to an inclusive society accepting, respecting and celebrating diversity.

Initiatives by the Government of India

The last decade has seen the passing of many a legislation on disability by the Government of India.

- The Rehabilitation Council of India Act(1992)²

A Rehabilitation Council of India was set up to promote and regulate training of rehabilitation professionals in the country

- Persons with Disability Act (1995)³

The Persons with Disabilities Act, 1995 includes hearing impairment in the list of disabilities covered and defines hearing impairment (vide supra). The Act endeavors to promote the integration of learners with disabilities in mainstream schools. It includes a section dealing with reduced syllabus for disabled people and issuing a concession of a single language for the hearing impaired student. It has set up the Ali Yavar Jung National Institute of Hearing Handicapped (NIHH)¹⁰.

Among the several facilities at this institute, the following are noteworthy:

(i) Training of Personnel at NIHH

It was only as late as 2001, when a proposal for starting ISL classes and an interpreter training programme at NIHH was initiated. In March 2001, the first national workshop on sign language in India, sponsored by the Rehabilitation Council of India was held. An ISL Cell was established at NIHH, in May 2001 and subsequently, sign language training commenced in formal manner on a ongoing basis.

(ii) Facility of Hearing aid sale at the Institute has been provided.

(iii) A Directory of Rehabilitation Resources for persons with hearing impairment in India – consisting of details of Schools for the Deaf, Acts, Concessions, Schemes of the Government of India, is available at the Institute.

- National Programme for Prevention and Control of Deafness (2006)¹¹

National Programme for Prevention and Control of Deafness was launched with the long term objective to prevent and control major causes of hearing impairment and deafness, so as to reduce the total disease burden by 25% of the existing burden by the end of eleventh five year plan. The pilot project was completed in 2008. As per NSSO survey, currently there are 291 persons per one lakh population who are suffering from severe to profound hearing loss (NSSO, 2001). A large percentage of these, are children aged from 0 to 14 years. These hearing impaired young Indians, contribute to a loss of national productivity. Rehabilitation programmes reaching all over the country, particularly the rural areas is the need of the hour.

OBJECTIVES OF THE PROGRAMME

1. To prevent the avoidable hearing loss on account of disease or injury.

2. Early identification, diagnosis and treatment of ear problems responsible for hearing loss and deafness.
3. To medically rehabilitate persons of all age groups, suffering with deafness.
4. To strengthen the existing inter-sectoral linkages for continuity of the rehabilitation programme, for persons with deafness.
5. To develop institutional capacity for ear care services by providing support for equipment and material and training personnel.

STRATEGIES

1. To strengthen the service delivery including rehabilitation.
2. To develop human resource for ear care.
3. To promote outreach activities and public awareness through appropriate and effective IEC strategies with special emphasis on prevention of deafness.
4. To develop institutional capacity of the district hospitals, community health centers and primary health centers, selected under the project.

Components of the Programme

- 1) Manpower training and development – For prevention, early identification and management of hearing impaired and deafness cases, training would be provided from medical college level specialists (ENT and Audiology) to grass root level workers. The training of PHC doctors and health functionaries would be provided by Rehabilitation Council of India.
- 2) Capacity building – for the district hospital, community health centers and primary health center in respect of ENT/ Audiology infrastructure.

3) Service provision including rehabilitation – Screening camps for early detection of hearing impairment and deafness, management of hearing and speech impaired cases and rehabilitation (including provision of hearing aids), at different levels of health care delivery system.

4) Awareness generation through IEC activities – for early identification of hearing impaired, especially children so that timely management of such cases is possible and to remove the stigma attached to deafness.

The programme is expected to generate the following benefits:

- i. Various services like prevention, early identification, treatment, referral, rehabilitation etc. for hearing impairment and deafness at the primary health center / community health centers / district hospital level.
- ii. Decrease in the magnitude of hearing impaired persons.
- iii. Decrease in the extent of ear morbidity or hearing impairment in large number of cases.
- iv. Improved service network for the persons with hearing impairment in the districts.
- v. Awareness creation among the health workers/grassroot level workers who function within the community, through the primary health centre medical officers and district officers.
- vi. Community participation to prevent hearing loss through panchyati raj institutions, mahila mandals and village bodies.
- vii. Capacity building at the district hospitals to ensure better care.
- viii. State of the art department of ENT at the medical colleges.

However despite efforts by the government and the non-government sector, educational facilities need to be made available to a large proportion of persons with hearing disability.

- Sarva Shiksha Abhiyan(SSA)¹² - has been implemented by the Ministry of Human Resource Development for children with special needs (CWSN).The Emphasis is on inclusion or mainstreaming CWSN into formal elementary Schooling. SSA ensures that CWSN are provided education. All CWSN need not Be deprived of the right to education and they are taught in an environment, Which is best, as per their needs. All CWSN should be placed in schools of the neighborhood with along with provision of all necessary support services.
- Persons with Disabilities Act, 2011. -Working Draft (9th February, 2011 version)³
All persons with disabilities have a right to be provided aids and appliances of recognized quality at an affordable cost along with the requisite training to utilize it. Every person with disability has the right to be informed of the various rehabilitation options and make the final decision on the course of rehabilitation.
There shall be constituted for the purposes of this Act, a Fund to be called the National Fund for Persons with Disabilities

Summary

The government has enacted legislation and set up bodies like Rehabilitation Council of India and institutes like NIHH for training personnel for the education and rehabilitation of deaf children. These measures focus on inclusive schooling as a means of integration of deaf children in the community. However, the advantages of special schools for deaf

children cannot be ignored. The task of educating and rehabilitating deaf children is a formidable one. The decision whether to opt for special school or mainstream schooling should be left to the parents of the deaf child. Suitable counselling centres should be set up to advise parents to take an informed decision regarding the same. More special schools as well as training institutes for educators of the deaf are the need of the hour. Public awareness campaigns should be initiated by voluntary organizations so that facilities provided by the government are broadcast and thereby availed by all in need.

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