

Deafness in India

Welcome to the world of deaf

Deafness means loss of hearing and it may be partial or total. Hearing impairment cannot be seen and hence its effects are not visible to others, so deaf suffers in silence. Unlike blindness, deafness often provokes ridicules rather than sympathy. A deaf person is so isolated from family and friends and greeted by unsympathetic attitude he/she is often depressed and needs psychological counseling. The consequences for a child born with hearing loss are quite severe. It is well established that a child with hearing loss cannot develop speech and language abilities. This puts the child at a disadvantage in school, higher education, and limits future professional opportunities. The problem of the child deaf from the birth is quite different from that of the adult who has become completely deafened after school age or in adult life. The hard of hearing person whose deafness has developed slowly over the years is different again. But, for all of them, the handicap is the same – the handicap of the silent world, the difficulties of communicating with the hearing and speaking world.

The WHO definition of “deafness” refers to the complete loss of hearing ability in one or two ears. The cases include in this category will be those having hearing loss more than 90 dB in better ear (profound impairment) or total loss of hearing in both the ears. The WHO definition of “hearing impairment” refers to both complete and partial loss of ability to hear.^[1]

In India, “hearing handicapped” as defined by the Rehabilitation Council of India Act., 1992, is – hearing impairment of 70 dB and above, in better ear or total loss of hearing in both ears. This law is applicable to only those persons with severe hearing impairment whose hearing loss is 70 dB and above. A person with hearing levels of 61–70 dB, (although suffering from severe hearing impairment, as per the WHO classification), is automatically excluded from the hearing handicap category.^[2] Section 2 (i and iv) of the persons with disability act., 1995, (PWD) states that “hearing impairment” is a disability and a “person with disability” means a person suffering from not <40% of any disability as certified by a medical authority. In addition, in Section 2 (i) “hearing disability” has been redefined as – “a hearing disable person is one who has the hearing loss of 60 dB or more in the better ear for conversational range of frequencies.” This is a step in the right direction, as all person with severe hearing impairment is now included in the hearing handicapped category.^[3]

The Ministry of Social Justice and Empowerment, Government of India, notified guidelines for evaluation of various disabilities and procedure for certification vide notification

no. 16-18/97-NI dated June 1, 2001. Procedure for calculating hearing disability is based on pure tone thresholds as well as speech discrimination score in order to arrive at the percentage of the disability. The minimum degree of disability should be 40% in order to be eligible for any concessions/benefits.

The statistics are staggering - 360 million people in the world suffer from disabling hearing loss. This constitutes a substantial 5.3% of the world’s population. The prevalence and incidence of hearing impairment in India also are substantially high. The high burden of deafness globally and in India is largely preventable and avoidable. The prevalence of deafness in South-East Asia ranges from 4.6% to 8.8%.

Going through the deaf history of India, of particular interest is the article “the deaf and the blind in India.” This article was published in the silent worker, vol. 33 no. 2 (November 1920). It is photo-illustrated and has interesting historical facts, such as in 1920 there were 10 schools for the deaf in India. In India, 63 million people (6.3%) suffer from significant auditory loss. 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%.^[4] The National Sample Survey 58th round (2002) 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. In urban areas, loss was 9% of all disability and in rural areas, it was 10%. It was estimated that the number of person with hearing disability per 100,000 persons was 291; it was higher in rural (310) compared with urban regions (236). In the same survey, about 32% of the people had profound (person could not hear at all or could hear only loud sounds), and 39% had a severe hearing disability (person could hear only shouted words). The survey results revealed that about 7% of people were born with a hearing disability. About 56% and 62% reported the onset of hearing disability at ≥60 years of age in the rural and urban areas, respectively. The incidence of hearing disability during that year was reported to be 7/100,000 population. The magnitude of milder degrees of hearing loss and unilateral hearing loss would be larger than these estimates for bilateral hearing loss.^[5]

Hearing impairment is a serious but grossly neglected condition in India. The country also suffers a huge economic impact due to lost productivity, higher unemployment, and lower wages for the hearing impaired. The real issue in India is the woeful inadequacy of facilities of any type for the deaf. The government of India has recently signed and ratified

the United Nations Convention on Rights of People with Disability. This shows the desire to conform to international norms and appear progressive. It is a very positive move and seen by all as a wonderful step in the right direction. However, despite good intentions, the lack of services and facilities continues to plague the Indian deaf community. The Government of India has launched the National Programme for Prevention and Control of Deafness (NPPCD). Since the program is also being implemented at the primary healthcare level, it envisages a reduction in the burden of deafness and prevention of future hearing loss in India. India celebrates the International Week for the Deaf in September, and September 26 is recognized as the “Day of the Deaf” in India.

The major causes of hearing loss and ear diseases in India have been listed by the WHO survey. Ear wax (15.9%) was the most common cause of reversible hearing loss. Noninfectious causes such as aging and presbycusis are the next most common causes of auditory impairment in India (10.3%). Middle ear infections such as chronic suppurative otitis media (5.2%) and serous otitis media (3%) are other leading causes of hearing loss. The other causes include dry perforation of tympanic membrane (0.5%) and bilateral genetic and congenital deafness (0.2%). Approximately 50% of all cases of congenital hearing loss are attributable to environmental factors, such as congenital hyperbilirubinemia, ototoxic medication exposure, neonatal hypoxia, viral infections, and meningitis. The other 50% of cases are thought to be inherited, i.e., of genetic causes. Of these hereditary cases, approximately 30% are classified as syndromic. About 400 named syndromes are associated with hearing loss, the associated auditory features being quite variable – sensorineural or conductive, unilateral or bilateral, and progressive and stable. This small subset of hearing loss patients (15% of all patients with hearing loss) is the group most readily diagnosed by physicians due to recognizable features other than hearing loss. The other 70% of hereditary cases are classified as nonsyndromic. This group is the otherwise perfectly normal child with the exception of hearing loss.^[1]

With increasing noise pollution, ototoxic drugs, ototoxic chemicals the incidence of old age deafness is on increase. The WHO estimates 360 million individuals in the world have disabling hearing loss, of which 91% are adults and only 9% are children. Disabling hearing loss is >40 dB hearing loss in better ear in a person above the age of 15 years and >30 dB in better ear below the age of 15 years. Noise-induced hearing loss is 100% preventable, but once the patient had it, it is for life time. With the increasing life span, we expect the prevalence of deafness as high as 40% above the age of 75 years. The worst part of this deafness is it affects speech frequencies hence only 20% will be benefited even with the best possible hearing aids. This huge population of senior citizen will be a big liability and great national loss. Hence, we have to make all the efforts.^[6] Further, use of headphones and mobile may further add to the magnitude of the problem.

It has been noted by the WHO that half the causes of deafness are preventable and about 30%, though not preventable, are treatable or can be managed with assistive devices. Thus, about 80% of all deafness can be said to be avoidable. It has also been stated by the WHO that there is a shortage of human resources to address the issue of deafness. The estimated number of ear, nose, and throat (ENT) specialists and otologists in India are 7000 and 2000, respectively. The audiometrist: Population ratio was found to be 1:500,000 and the ratio of speech therapists to the deaf population was 1:200. There is also a maldistribution of personnel with more people located in urban than rural areas. Human resource analysis revealed that there is a need to enhance the skills and working capacity of practicing doctors and other personnel.^[7]

It is important to note that without hearing a child cannot develop speech and language. Hence, the aim should be to recognize deaf child before the age of 1 year because from 1 to 3 years onward babies start hearing the speech. Unfortunately, hearing loss is often not detected until a child is 2, 3, or even 4 years old, especially in rural areas due to the poor awareness about deafness and its relation with speech and language development as well as lack of infrastructure such as the nonavailability of ENT surgeon, audiologist, audiological equipment, and speech therapist.

Parents can assess hearing of their child at home by the following manner [Table 1].

A probable strategy to ensure that children with hearing loss are identified and treated early is to ensure that every baby is screened for possible hearing loss at the birth in hospital. Early detection and consequent treatment lead to better speech development in children, enhanced scholastic achievements in school, and limitless professional opportunities. This strategy has been implemented in countries such as USA, Singapore, Australia, UK, and many more. India does not have such a program in place. There is clearly a need for a “universal newborn hearing screening” program in India. Neonatal and infant hearing screening programs can eventually improve the linguistic and educational outcomes for the child. The importance of a screening program is to provide effective treatment at the earliest opportunity, thereby reducing

Table 1: Hearing milestones

Shortly after birth	Startle reflex, i.e., closing of eyes on exposure to loud sound
By 1 to 3 months	Children notices sudden prolonged sound
By 4 months	Baby turns his/her eye toward the sound
By 7 months	Turns the head towards the familiar voice or sound from across the room such as mother’s voice, cup and spoon sounds
By 9 months	May babble loudly and tunefully such as Ma Ma, and Ba Ba
By 12 months	Responds to his/her own name or other familiar sounds from 13 th to 24 th month - articulate speech with ability to answer question

suffering due to the impairment. I urge every parent to screen their newborn babies for hearing [Table 1]. I also exhort the pediatrician community in India to give hearing screening the same level of importance as vaccination. Thus, focus should be on Early Detection of Newborn Hearing Loss and Intervention.

A cochlear implant is probably one of the best inventions in the recent history of medical science for bilateral severe-profound deaf. It is the first device that can restore one of the five senses. Currently, the central government and a few state governments offer financial assistance to children who need a cochlear implant. Defence organization DRDO is working on an indigenous cochlear implant which will be of approx. One lakh rupees, thus increasing the affordability, as cost is still a limiting factor in our country. A universal newborn hearing screening program will only bolster such government initiatives by enabling the hearing impaired children access to cochlear implants sooner. The sooner a child gets access to hearing, the better are his/her chances of getting fully integrated into mainstream society.

Considering the enormous impact of deafness on the social, economic, and productive life in India due to its burden and also gaps in human resources to meet this health challenge, primary healthcare remains the strategy of choice for the provision and implementation of prevention of deafness and hearing loss in India. The Government of India initiated the NPPCD in 2006. It was initially started as a pilot project and was implemented in 25 districts in 10 states and 1 union territory. It was upscaled to include 203 districts in all states and union territories in the eleventh 5-year plan (2007–2012). The NPPCD was launched with the long-term objective of reducing the total disease burden of hearing impairment and deafness by 25% at the end of the eleventh 5-year plan. The program aims to cover three levels of prevention and care: Primary, secondary, and tertiary ear care by provision of an appropriate response at these levels. It aims at preventing avoidable hearing loss on account of disease or injury, identifying early and treating major ear problems, and medically rehabilitating persons with deafness of all age groups. It envisages strengthening existing intersectoral linkages and developing institutional capacity for ear care services. For the prevention of auditory impairments, it promotes outreach activities and public awareness through innovative and effective information, education and communication strategies. The program has been integrated along with the umbrella health mission of the government of India – the National Rural Health Mission (NRHM) – at the state and district levels. Under the NPPCD, funds for the execution of the program are given to the state health society and program committee of NRHM to carry out various activities through district health societies. The role of the state committee is to function as a supervisory and monitoring authority for smooth conduct of the strategies to prevent and control deafness.^[4]

Table 2: Management of deafness

Tier I (primary care)	Awareness for prevention and early detection of deafness and minimum intervention for treatment at the block level hospitals
Tier II (secondary care)	Detection of deafness and treatment of curable causes including microsurgery and rehabilitation as far as practicable at the subdivision and district level hospitals
Tier III (tertiary care)	Specialized treatment modality - means most modern specialized treatment modalities available at the city hospitals (e.g., Medical College Hospitals, Advanced Corporate Hospitals) for the hearing handicapped providing microsurgical facilities, availability of cochlear implantation surgery and selection and distribution of highly efficacious modern hearing aids

There is an increase in old age deafness, up to 40% senior citizen above the age of 75 have a disabling hearing loss out of which only 20% are expected to be benefited with hearing aid. Hence, all efforts should be made to prevent age-related hearing loss by avoiding noise, ototoxic drugs chemical, and by changing diet and lifestyle.^[6]

Management protocol for deafness should be in three-tier system [Table 2].

A future hope lies that after mending hearts and restoring vision, stem cells may now be used to restore hearing in deaf people.

In the years to come, institutional building as well as team building may be key elements that could influence the early detection and rehabilitation scenario. Teams comprising medical experts, experts from basic and hearing sciences, and technology may work together to evolve strategies that could pave the way for addressing issues in hearing impairment from different perspectives. A radical change may emerge from such an endeavor as the scenario would then be shaped by the collective efforts of many disciplines of science and technology – a consortium that rarely operates in India.

“DON’T BE DEAF FOR THE DEAF”

So, let us see the deaf with smiling, sympathetic approach, medical expertise, and modern technologies but early detection of deafness is absolutely necessary to minimize deaf cases in our country.

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