

HEARING IMPAIRMENT



Chapter 1

Introduction

The Ear and Its Work

The sense of hearing provides a background, which gives a feeling of security and participation in life. It plays a critical role in the development of speech and language and in monitoring one's speech.

The ear is a complex, but delicate structure designed to perform a variety of functions: to be able to hear very soft sounds over a wide frequency range as well as withstand the very loud sounds, to discriminate between sounds that vary in pitch and loudness; to be able to locate the direction of arrival of a sound and in the presence of noise, to be able to switch on and off a sound of interest.

The human ear perceives simple tones in the range of 20 to 20,000 Hz and also complex signals such as speech and music. Both types of signals are used in the assessment of hearing loss.

Impact of Hearing Impairment

Consequences of hearing impairment will depend on the ear/s involved, the degree and the type of hearing loss and the age of onset.

Hearing impairment leads to loss of normal verbal communication. Due to distortion of sounds, differentiation of environmental sounds, including speech, is difficult; making sounds louder does not improve the clarity or quality of sound. Similarly, recruitment, which is an abnormal growth in loudness, a characteristic of

damage to the inner ear, makes it difficult to tolerate loud sounds.

For children with hearing impairment, congenital or acquired before development of speech and language, normal speech development is interfered with.

With unilateral hearing impairment also, there is difficulty in localizing sound, reduced speech discrimination. Lower speech and language development in children has significant effect on their educational, linguistic and auditory perceptual development.

The hearing-impaired persons have in common, their difficulty in hearing spoken and other sounds. They also depend on what they see which they supplement to what they hear.

Assessment

Hearing sensitivity of each ear is measured separately and the severity/degree of hearing impairment/ hearing loss is generally classified in seven categories as per Goodman's (1965) classification and an additional category - slight hearing loss is added between the normal hearing and mild hearing loss especially when assessing the hearing sensitivity of young children. Table 1 shows the classification of severity of hearing impairment.

Table 1: Classification of Severity of Hearing Impairment

<i>Classification</i>	<i>PTA range in dBHL</i>
Normal Hearing	-10 to 15
Slight Hearing Loss	16 to 25
Mild Hearing Loss	26 to 45
Moderate Hearing Loss	46 to 55
Moderately-severe Hearing Loss	56 to 70
Severe Hearing Loss	71 to 90
Profound Hearing Loss	91 and more

The level of normal conversational speech is approximately 65dB SPL. Thus, for a person with hearing impairment of 60dBHL or more, verbal communication would be difficult. This level of hearing impairment has been equated as 40% hearing impairment as in Persons with Disability (Full Participation, Equal Opportunity and Protection of Rights) Act, 1995. The definition of hearing disabled as stipulated in the PWD Act, 1995 is a person who has a minimum of 60dBHL of hearing impairment in the better ear in speech conversation frequencies.

Percentage of Hearing Disability (Threshold + Speech Discrimination Score Based)

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 1st June 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.

Issue of Disability Certificate

The certificate of disability is to be issued by a medical board consisting of at least three members, of which one shall be an otolaryngologist. Percentage of disability can be determined considering Pure Tone Average and Speech Discrimination Score as shown in Table 2.

Table 2: Percentage of Disability

<i>Category</i>	<i>Type of Impairment</i>	<i>PTA of Better Ear in dBHL</i>	<i>Speech Discrimination Score of Better Ear</i>	<i>Percentage of Disability</i>
I	Mild	26-40	80-100%	< 40%
II(a)	Moderate	41-60	50-80%	40-50%
II(b)	Severe	61-70	40-50%	51-70%
III(a)	Profound	71-90	<40%	71-100%
III(b)	Total	>91	Very Poor	100%

To obtain Speech Discrimination scores, specialized skills, instruments and standardized tests are required. Neither the range of instruments

nor standardized tests for speech discrimination in various languages are presently available in all centers in the country.

Chapter 2

Historical Perspective

Historical developments have been dealt with comprehensively in the *Disability Status Reports* published by the RCI, in 2001 and 2003. Since then, significant events such as establishment and support of early identification and early intervention centers by the AYJNIHH, Mumbai and the Disability Helpline initiated during 2004-05 are worthy of mention.

Establishment of Early Intervention Centers and Training of Personnel

A collaborative project by AYJNIHH, Mumbai and Balavidyalaya, Chennai on 'Early Identification and Early Intervention towards Inclusive Education of Children with Hearing Impairment (0 to 5 years)' was initiated in 2002. An urgent need was felt to lower the age of identification of hearing impairment and strengthen intervention service delivery. If a larger number of children with hearing impairment acquire abilities ensuring their success in mainstream education, they pave the way for more severely affected children to avail the services of special schools. The gains shown by children who have gone through the process of early intervention in India were convincing enough to start a greater number of early intervention programs on a pilot project basis. However, the diploma and degree courses in special education do not focus enough on aspects of habilitation with very young children with the exception of the Diploma in Training Young Hearing Impaired Children which is available only in three centers in India. This would

mean that any effort to initiate early intervention services should be accompanied by short term training programs for qualified professionals. These programs should be aimed at equipping rehabilitation professionals to handle aspects especially pertinent to very young children. Keeping these issues in view, the project was evolved. The project was conceptualized in two phases:

Phase I: Training of manpower to enable them to handle very young children.

Phase II: Running the early intervention programs.

Under the project, it was decided that a one-month orientation program would be given to already qualified professionals to work with children in the age range of 0 to 5 years. Seven centers were chosen to run the project, namely AYJNIHH, Mumbai; its four regional centers at Secunderabad, Delhi, Bhubaneswar and Kolkata; Balavidyalaya, Chennai and NISH, Trivandrum. A training package with curriculum specified, video films and manual was evolved. The uniformity of execution across centers was ensured through a program for Training of Trainers (TOT). Two representatives from each of the seven centers attended the TOT program. Each center was directed to periodically conduct one month orientation programs with an aim to have at least 5 per year with ten trainees per batch. Special schools

already running programs for pre-school children and institutions conducting diploma and degree courses in special education were approached and encouraged to depute professionals/suggest candidates from among past students of degree and diploma courses. Interested fresh and or unemployed special educators were also enrolled.

The seven centers under the project were already providing diagnostic and or intervention services for children in the 0 to 5 year age group. Thus it was decided that for the second phase, it would be ideal to run the intervention programs under close supervision of these centers. Each of the centers could appoint a teacher/speech-language pathologist and audiologist who had undergone the one month orientation program. If a center had more than 25 children, two teachers could be employed. The center could also appoint two ayahs/helpers. Until now, the focus was on the 0 to 2.5 year age group. This was reflected in the orientation programs as well which focused only on this age group. The next stage of orientation programs to handle the 2.5 to 4.5 year age group will be launched in the near future. The project is being monitored by an advisory group consisting of senior professionals.

Since its commencement in the year 2002, nearly 100 rehabilitation professionals have been trained through orientation programs to equip them to handle the 0 to 2.5 year age group. Nearly 150 children with hearing impairment under the age of 2.5 years have received intervention at the seven centers under the project. AYJNIHH plans to increase the number of intervention centers by training more professionals and also by providing technical as well as financial assistance to the extent possible.

Disability Helpline

Frequently due to lack of awareness among the persons with disabilities and the community, the early identification and rehabilitation processes are delayed. Also the benefits of services offered by Government and Non-Government organizations for the rehabilitation of persons may not be availed of by the target group on account of lack of information. The Disability Line launched by AYJNIHH, Mumbai in 2005 was envisaged to bridge this gap to some extent by enabling the public to have easy access to information regarding disabilities, the services available in their neighborhood as well as the schemes and concessions offered by the Government.

Specifically, the Disability Line provides information about:

- Different types of disabilities.
- Diagnosis and intervention strategies.
- Diagnostic and therapy centres.
- Educational opportunities and Special schools.
- Vocational training and job opportunities.
- Special Employment Exchanges.
- Government Schemes and facilities.
- Organizations working for PWDs.
- Prevention and management of disabilities.

- DRS/NHFDC forms by fax.

Disability Help Line has presently been implemented in Maharashtra, Goa and Delhi Telecom Circles and can be accessed by dialing the following telephone numbers:-

Maharashtra/Goa : 022-26404019/24/43
or 155206

Delhi : 011-29825094/95

The implementation of Disability Line for UP, MP, Bihar, Tamil Nadu, Assam & West Bengal are in the pipeline. It would be possible to cover the whole country in a span of five years or so.

Thus the Disability Helpline would help overcome the barrier of lack of information which has blighted many lives in the past.

The most promising development in recent years is the coming together of a diverse group of professionals, parents/caregivers, policy makers, lay persons and the hearing-impaired themselves in the prevention, diagnosis/identification and management of hearing-impairment. Such a scenario portends well for persons with disabilities as well as for the professionals in the various spheres of rehabilitation.

Chapter 3

Manpower Development

Introduction

Manpower in the field of Speech and Hearing consists of professionally qualified persons who are involved in a spectrum of activities related to persons with impairment—hearing and/or communication employed in diverse settings—hospitals, rehabilitation centers, special schools, regular schools, speech and hearing centers, training and research institutions.

Training Programmes

Training programs available at various levels are discussed below:

Under-graduate: B.Sc. (Speech and Hearing), AST, BASLP.

Post-graduate: M.Sc.(Speech and Hearing), MASLP, M.Sc. Speech-Language Pathology, M.Sc. Audiology.

Admission Requirements

Those who have successfully completed pre-university (10+2) in the science stream are admitted to the B.Sc. course.

To the two-year program, MASLP, candidates with B.Sc. (Speech and Hearing) or equivalent from a recognized institution are admitted. Admission requirements have moved from performance at the Bachelor's level to the entrance test conducted by the respective universities.

Variations

Variation in the eligibility for admission at the under-graduate level among universities exists; Physics, Chemistry and Biology combination is compulsory at the 12th standard level, but other combinations are also acceptable.

Variations in post-graduate program earlier affiliated to the Mumbai University, shifted in 2006 to Maharashtra University of Health Sciences, Nashik provides for specialization either in Audiology or Speech-language Pathology, in part II (Final year).

Since 2003, M.Sc. (Speech and Hearing) affiliated to Mysore University has been replaced by Master's degree in Audiology or Speech-language Pathology, a pattern also followed both at Mangalore and Bangalore Universities.

Training institutions being required to follow the norms of the affiliating universities, variations among different programs are seen in depth of information, method of teaching, differences in the pattern of examination and in following the semester system as against the annual system. These are also true of the Master's level programs.

The Bachelor's program currently runs for four years; during the first three years the focus is on preparing theoretical knowledge base and providing insights into developing requisite clinical skills followed by the internship year.

Despite the uniformity maintained due to RCI regulations regarding minimal infrastructure facilities, there still exists inter-program variability due to the differences in budgetary allocation and availability of funds in the various institutions. The national institutes have larger budgets thereby enabling state-of-the-art facilities for their trainees. The programs that have to depend on their own resources are not able to provide similar facilities.

Internship

Introduction of internship as per the RCI guidelines, prior to the award of degree, is a progressive step, which has the merits of creating parity among the various degree courses and providing services in the rural areas. Institutional variations in the settings, in the placement duration, payment of stipend, are in need of further regulations.

Recent years have witnessed a global shift in the perception and treatment of Persons with Disabilities towards a human rights perspective. This has influenced the various training programs bringing about modifications, time and again, in the type and content of courses in Speech and Hearing, both at the B.Sc. and M.Sc. levels.

Doctoral Program

The Ph.D. program in speech and hearing was available so far only at AIISH, Mysore affiliated to the University of Mysore. Some candidates have also got their doctorates in allied streams such as Linguistics and Psychology from other Universities/institutions. In spite of interest in pursuing doctoral degrees, the fact that full-time candidates only were being accepted by University of Mysore, and availability of guides were limitations.

The demand for professionals with doctorates is on the increase with the advent of many new training programs and the recruitment rules for teaching institutions. The next doctoral program in speech and hearing has commenced at AYJNIHH, Mumbai from the year 2007 with affiliation to Maharashtra University of Health Sciences, Nashik.

Diploma in Hearing, Language and Speech (DHLS)

Earlier known as Diploma in Management of Communication Disorders (DMCD) and also Diploma in Communication Disorders (DCD), it is a one-year course post higher secondary school certificate qualifying them to assist the speech and hearing professionals and to take up routine clinical activities. This program is being conducted in about 15 institutions in different parts of the country.

Contrary to the course objectives, most of the products are found to be self-employed or working in private ENT setups as speech and hearing professionals. This may possibly be because the government does not include the post of speech and hearing assistant in their grant-in-aid schemes for schools for the deaf or the mental retardation or the spastics.

Wherever possible and feasible, the DHLS personnel may work as substitute teachers or teacher aides in schools. The syllabus and the examinations currently conform to RCI regulations.

The AIISH, Mysore plans to launch the DHLS program through the distance mode, simultaneously in five different locations in the country.

Diploma in Hearing Aid and Ear Mould Technology

The RCI has standardized a training program in ear mould making and hearing aid technology for those successful at higher secondary level. A one-year course, started at AIISH, Mysore since 2002-03, generates skilled personnel. AYJNIHH, Mumbai also conducts a similar, short duration program for educators and personnel working in special schools.

Disparity Between Available and Requisite Manpower

About 25 institutions offer Bachelor's degree and about 10 institutions offer Master's degree in Speech and Hearing across the country. Approximately 750 candidates graduate at different levels each year which is woefully short compared to the needs of manning training programs, furthering the growth of the profession, providing services. The skewed distribution, geographically, of available professionals in the country and on account of emigration of the professionals overseas, the shortage felt is more acute. There is economic factor also, the cost per trainee being approximately Rs. 3 lakh/student (Savithri, 2003).

The magnitude of brain drain among speech and hearing post-graduates is reported to be 48% (Nambiar and Shah, 2006). The reasons cited being better financial gains (62%), better career prospects (62%), and better academics. Whereas 50% went abroad seeking employment, about 30% left for higher education, and other 20% for personal reasons.

An increasing number of training programs are coming up in smaller towns of the country, sometimes in the same State where two or more training programs already exist. The courses must also be designed to meet the needs in the country

rather than duplicating without review the curricula followed in other countries. These issues need to be addressed by the professional associations and the relevant policy making forums.

A close evaluation of training programs must be undertaken periodically in the light of current potential employment opportunities.

Resources for Training

Shortage of human resources to man the training programs is a major challenge. Fresh graduates with little or no experience are recruited to provide training to the new entrants.

Published resource material used for the training programs are mainly from the West, which cost substantially. Availability of Indian editions and an increasing number of Indian journals coming up in the field of speech and hearing and allied disciplines has reduced the budgetary burden.

Programs attached to medical institutions such as TNMC, Mumbai; SRMC, Chennai; and MAHE, Manipal have access to extensive medical literature.

Access to the main university libraries by the speech and hearing trainees being limited, the respective programs have to have their own libraries. Many institutions have also provided computer and internet facilities to the trainees thereby increasing the resource base.

Continuing Education

Continuing Education (CE) is the key for ensuring that professionals adapt to new developments, which will lead to the growth of the profession with consequential benefits to the individual and to the society.

CE may be obtained through workshops, seminars, symposiums and conferences conducted by institutions, by the professional associations at the State and the National levels. These may be RCI approved CE programs of three or five day-duration since it is mandatory for the professionals to attend such programs for the renewal of their RCI registration.

Career Prospects

Currently, a professional in the area of speech and hearing is able to find employment in a variety of settings, unlike in the past. However, there is a distinct difference in the number of opportunities and the type of work available to those with interest in Audiology and those affiliated to Speech-language pathology. The latter can practice at lower investment since infrastructure requisite is less, but is more man-hour intensive, while the practice of Audiology requires considerably more financial investment, but less manpower dependent.

In spite of the absorption of our graduates in jobs in diverse settings, the jobs are isolated and the one or two persons employed there have to attend to all aspects of the discipline. In some instances, the rigorous training imparted to the trainees is not being fully utilized for want of the requisite infrastructure including audiometric rooms and test instruments. A lack of awareness about the diverse role the speech and hearing professional plays in diagnosis and management, may lead to their being treated as technicians, often in a subordinate position without acknowledgement of their role as competent members of an interdisciplinary diagnostic management team.

Remuneration

Professionals whose work includes a wide

range of duties such as teaching, clinical supervision and/or clinical services do not get comparable remuneration. Also employment settings dictate the salary structure and not the duties or the academic qualifications.

Possessing higher than the requisite academic qualifications does not guarantee better remuneration for the individual professional, irrespective of how earned while on the job or on study leave. This leads to dissatisfaction/ frustration leaving little motivation among the professionals who have aptitude and abilities to improve their qualifications and skills.

Our training programs are well received both in the country and outside; programs in other developing countries have looked for support from our programs. Many professionals, products of our programs, have been admitted into doctoral programs in specialized streams earning accolades. The American Speech-Language-Hearing Association takes cognizance of the course work completed in India for purposes of Clinical Certification, both in Speech-Language Pathology and Audiology.

Manpower in Special Education of the Hearing Impaired

Special education can be thought of as a means of secondary and tertiary prevention of impairments that eluded primary prevention. The aim of the special educators is to enable the children with hearing impairment to realize their full potential, so that they can achieve a respectable place in society and enjoy a better quality of life.

Special educators have traditionally been primarily placed in special schools for children with hearing impairment. In the prevailing conditions, there are various types of educational programs

available in India for children with hearing impairment as given below:

- (1) Early Childhood Education or Early Intervention programs (Pre-school Education) for infants and younger children (0 to 5 years) with varying degrees of hearing impairment.
- (2) Special school programs for children with substantial degree of hearing impairment.
- (3) Integrated education programs for children with milder degrees of impairment in a regular school set up.
- (4) Inclusive Education under the Sarva Shiksha Abhiyan Scheme where children with impairment of different types and degrees are educated in regular schools with normal peers.
- (5) Apart from this, persons with disability within age group of 14-35 are given the opportunity for education through National Open School (NOS).

Thus, it can be seen that there is change in the focus of education from segregation to inclusion, and late intervention to early intervention. A numerical increase is seen in the special educators working as early interventionists, resource persons in regular schools and itinerant teachers in inclusive education.

Teacher Training Programs and other technical services for the deaf in the country received a boost with the establishment of Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH) in Mumbai in 1983. At that time, only eight centers were conducting teacher training programs as reported by Dr. Rita Mary (1993). Besides conducting D.Ed. [now D. S. E. (H.I.)] and B.Ed. (H.I.) at its headquarters

in Mumbai and regional centers in the north (NRC), south (SRC) and east (ERC), AYJNIHH also has collaborative centers, involving the State Governments and the NGOs.

Recognition of the dearth of master trainers to be appointed as faculty at these centers and the poor quality of the model teaching schools, prompted negotiations with the Universities of Osmania (Hyderabad) and Calcutta, for commencement of the B.Ed. (H.I.) training program at the SRC and the ERC of AYJNIHH, in addition to the programs conducted at Mumbai since 1997. This enabled several schools to upgrade their D.Ed. training levels. The M.Ed. (H.I.) program was started at AYJNIHH from 1995-96, and is affiliated to the University of Mumbai.

The training programs in Special Education for the Hearing Impaired are regulated by the RCI. Presently there are two centers offering M.Ed.(H.I.), 15 offering B.Ed. (H.I.) while 38 offer D.S.E. (H.I.) and three centers offer D.T.Y. (H.I.). In spite of the many special educators trained at various levels, a wide gap exists between supply and demand.

Keeping this in view, NCERT through its Regional Institutes started Multi-category Teacher Training Programs, which includes orienting the regular school teachers to categories of impairments and the modifications required for teaching such children. Such teachers were then enrolled in Integrated Schools under I.E.D.C. (Integrated Education of Disabled Children Scheme) and P.I.E.D. (Project Integrated Education for the Disabled).

Distance Education

RCI has also recognized technical expertise of the Madhya Pradesh Bhoj (Open) University (MPBOU) for conducting the B.Ed. Special

Education program through the distance mode. Other Universities have also begun to show interest in running similar programs.

Resources for Training

As most trainees in these courses, especially the diploma courses, are from vernacular medium with poor knowledge of English, their limited experience in using reference material, utilization of the resource material from Western countries poses a major limitation. Short duration of the programs is an added constraint.

RCI has invited experts in the respective subject to prepare requisite material in language easy to understand. Some experts have also taken an initiative in developing resource material in regional languages such as Marathi, Tamil, Telugu, etc.

Research

Since the M.Ed. program has been introduced, there has been an increased focus on

conducting applied research in the field of education of the hearing impaired. However, many graduate level teacher training programs do not include sufficient input to the teacher trainees about research and documentations. Systematic orientation towards research would bring about fruitful outcome.

Conclusion

There is a need to gear the training programs to meet the specific needs of the multi-lingual and multi-cultural population of the country. In spite of the big strides in the past several decades, much needs to be done especially to retain the professionals to provide quality services in the cause of which there has been a heavy investment. If emigration is a problem, so is professional mortality and seeking other vocations within the country.

Chapter 4

Incidence and Magnitude of Hearing Impairment in India

The National Sample Survey Organization (NSSO) and Census of India, defined hearing disability in a manner not requiring services of professionals, standard test procedures and a test environment meeting stringent criteria.

Hearing Disability (NSSO Perspective)

In the International Year for the Disabled Persons, the NSSO undertook during the second half of 1981, the most comprehensive survey in its 36th round for collecting information related to persons with disability.

In 1991, the NSSO with an extended definition of disability, conducted its 47th round of survey in July-December 2002, on the specific request of the Ministry of Social Justice and Empowerment, Government of India. Its 58th round of survey was conducted adopting a stratified multi-stage sample design methodology. It included information on physical and mental disability, socio-economic characteristics of the disabled persons, such as age, literacy, vocational training, and the cause, age of onset of disability, marital status, educational level, living arrangements and activity status.

As this was one of the more comprehensive surveys, defining disability was done in a very careful and guarded way to minimize the bias on the part of the investigators and the respondents. The definition of disability and each type of disability was carefully agreed upon by a group with experts in their respective areas.

Hearing disability was defined as a person's inability to hear properly. As non-medical investigators/non-professionals conducted the survey, hearing disability was assessed based on the quantum of impairment in the better ear. If a person reported normal hearing in one ear and total loss of hearing in the opposite ear, normal hearing was the verdict for the purpose of the survey.

Usage of hearing aids was not taken into account in assessing hearing disability. A person was stated to have profound hearing impairment if he/she could not hear at all or could only hear loud sounds (such as thunder) or used only gestures to communicate.

If a person could only hear when the speaker shouted or could hear only if the speaker was sitting in front, hearing loss was considered severe.

Moderate hearing disability was the verdict, if a person having hearing loss did not fit either in profound or severe category. Such a person would ask for repetitions when spoken to or would like to see the face of the speaker. In other words, if the person reports difficulty in conducting conversation due to hearing problems, he was considered to be in the moderate category of hearing disability.

Hearing Disability (Census of India, 2001 Perspective)

Interest in enumerating the number of persons with hearing impairment began in 1876

in India. In the past counting of such people did not indicate adopting a clear definition.

The recent head count conducted by Census of India, 2001 defined persons with hearing disability as those who cannot hear at all (deaf) or can hear only loud sounds which clearly excluded people who had hearing impairment but who could hear through use of amplification devices. However, the Census did include as disabled, people who could not hear with one ear but his/her other ear was functioning normally.

The Magnitude of the Problem

As on 1st March 2001, India's population stood at 1,027,015,247 and projected population in 2016 would be 1,263,543,000 (Census of India, 2001). With the present set of concept of hearing disability, the Census of India, 2001 counted 1,261,722 people in whom hearing disability existed (Males 53.4% and Females 46.59%).

A majority of persons with hearing disability were identified in rural India (81.06%) except in

the Union Territory of Chandigarh, Delhi, and Daman and Diu.

NSS 58th Round of Survey estimated persons with disability to be 18.49 million (1.8 per cent of the total population). Ten per cent of the persons with disability are likely to have hearing disability of moderate to profound degree. This number is likely to go up if we add lower degree of hearing disability.

Prevalence and Incidence of Disability

A broad idea about the magnitude of disability can be known if we compare the prevalence of disability as found in National Sample Surveys conducted at different points of time. Tables 1 and 2 show that there is a significant decline in the prevalence and incidence of disability including hearing disability. This can be attributed to the general growth in health, education and infrastructure sector.

Table 1: Prevalence Rate of Disabled Persons Per 100,000 Persons (Hearing Disability)

NSS	36th Round 1981	47th Round 1991	58th Round 2002
Rural	1844 (573)	1995 (467)	1846 (310)
Urban	1420 (390)	1579 (339)	1499 (236)

Table 2: Incidence Rate of Hearing Disabled Persons Per 100,000 Persons

NSS	36th Round 1981	47th Round 1991	58th Round 2002
Rural	19	15	8
Urban	15	12	7

The incidence is almost the same in both the rural and urban India. The incidence is also observed to be higher among males than females as is the prevalence rate.

The rates among males are 9 and 8, as against 7 and 6 among females, respectively, in rural and urban areas.

Conclusion

Persons with hearing impairment constitute a significant portion of our population who can be contributing citizens. Efforts made to provide diagnostic and therapeutic services and the efforts put forth to mainstream them will create an inclusive, barrier-free and rights-based society for persons with disabilities.

Chapter 5

National Program of Prevention of Hearing Impairment in Operation

A national program on prevention of hearing impairment carried out will discharge our responsibilities as well as comply with the stipulations in the Persons with Disability Act, 1995.

Measures stipulated in the Act to be taken for prevention and early detection of hearing impairment include conducting surveys to determine the underlying cause of disabilities; utilizing various methods to prevent disabilities; screening of children at least once a year; providing training to staff at the primary health centres; taking steps for prenatal, perinatal and postnatal care of children; educating the public and creating awareness through mass media.

Some or all of the above activities are being carried out in different centres across the country.

Surveys to Determine the Cause of Disabilities

Data has accrued on the hearing status of adults. But there is dearth of information on the incidence and prevalence of hearing impairment, among infants and children. Through questionnaires alone, valid and reliable information on hearing loss cannot be garnered. Only surveys where competent persons have evaluated the infants or toddlers would provide the numbers with hearing-impairment in this age group.

Methods to Prevent Disabilities

The most effective way to carry out prevention is through public education. Educating different target groups on the causes of hearing impairment creates greater awareness among them. The increased awareness should help in preventing hearing impairment.

As the manpower directly dealing with the needs of the hearing impaired is comparatively less, availing services of allied professionals becomes necessary in creating the country-wide awareness. Existing grass root level personnel working in the Departments of Health, Education, and Woman and Child, is being used effectively in educating the general public on prevention of hearing impairment.

While the nomenclature varies depending on the State involved, the function or job description of these personnel is by and large the same. This group of enthusiastic individuals could be empowered to function more effectively with the right kind of encouragement.

It is imperative that a prevention program should *provide immunization* for expectant mothers, infants and adolescent girls to such conditions as maternal rubella, measles and meningitis.

It is important to reduce the incidence of hearing problems in children since its effects are more devastating especially on their

communication abilities which in turn would affect their school performance. Being the future citizens of the country, they should be given the necessary help at the earliest.

While the above measures may reduce the occurrence of hearing problems, this would not totally eliminate the problem. Hence, it is essential to carry out tests to identify the presence of a hearing problem. These tests should be carried out at the earliest to enable early rehabilitation both in terms of fitting appropriate amplification devices and providing speech and language therapy. Early rehabilitation is required since there is a critical age for speech and language development. The later the hearing impairment is identified, the gap to be bridged between normal and hearing impaired individuals would be more. Further, the psychological stress in such individuals would be less since they would have better speech and language skills, which in turn would enable them to succeed in inclusive set ups. Children with good speech and language would also find it easier to find appropriate job placements later in life. Not only it is important to identify hearing loss early in individuals with a congenital hearing loss but also in those with an acquired hearing loss since hearing is required for monitoring of speech.

At the program on “National Consensus on Prevention, Identification and Management of Hearing Impairment” held at the All India Institute of Speech and Hearing, Mysore, in 2005, various experts involved with hearing conservation, representing government and the non-government sectors, gave their viewpoints.

Personnel Involved in Prevention

The consensus among experts was that prevention of hearing impairment should be carried out at the doorstep of each household by

grass root level workers, such as, Anganwadi workers, Accredited Social Health Activists (ASHAs), traditional birth dais and Auxiliary Nurse Midwives (ANMs) or Multipurpose Health Workers (MPHWs). In the absence of these in the locality, the responsibility would be taken by Education Guarantee Scheme (EGS) teachers or Lower Primary School (LPS) teachers who would be supervised by a medical officer at the Primary Health Centre (PHC) (Figure 1).

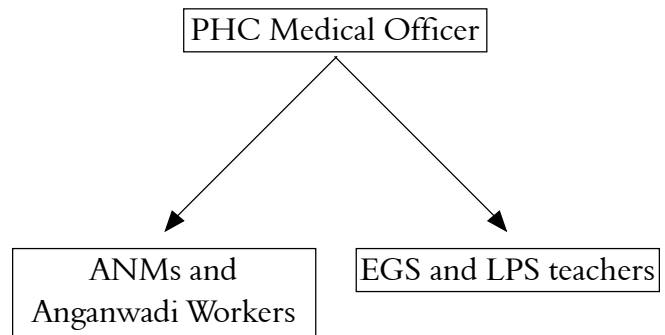


Figure 1: Allied personnel involved in the prevention of hearing impairment

Training of the Professionals

Figure 2 shows the personnel involved in the cascading of information to the grass root level workers.

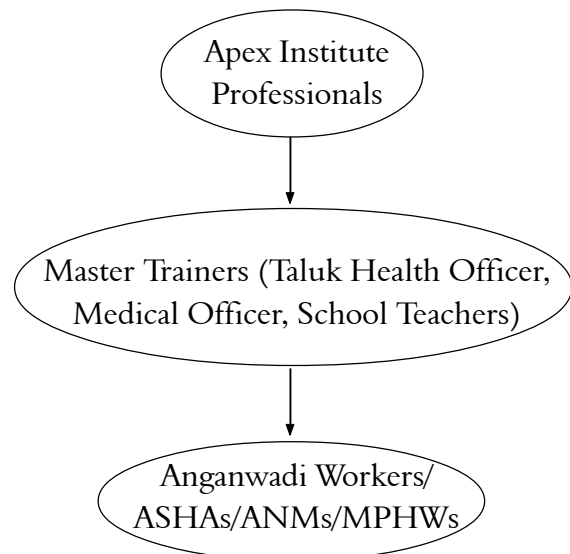


Figure 2: Personnel involved in cascading of information to the grass root level workers

Number of Professionals to be Trained at a time

Figure 3 depicts the number of professionals to be trained at a time.

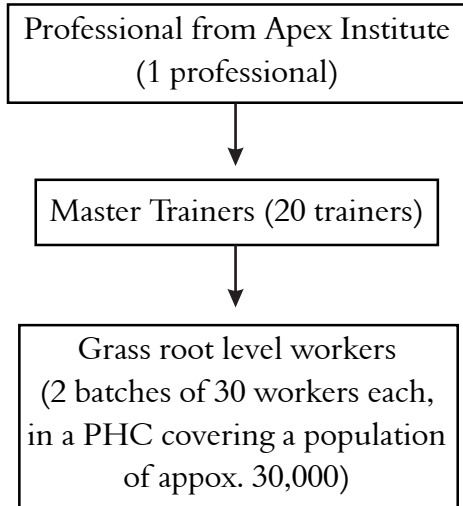


Figure 3: Professionals and the number to be trained in a session

Duties of the Professionals

The qualified speech and hearing professionals, from the apex centres, would orient the master trainers on prevention of hearing problems as well as on basic evaluation to be carried out by the grass root level workers. The evaluations would include: administration of the high risk questionnaires, carrying out behavioral observations and orientation to audiological tests requiring instrumental usage. The duties of the speech and hearing professionals and the others involved would be as follows:

Duties of the Medical Officer

- (a) Get himself trained on the hows of early identification of hearing impairment.
- (b) Train and orient the grass root level workers.
- (c) Monitor the activities of the ANMs/anganwadi workers.

- (d) Determine whether in a given case is at risk for a hearing loss using the high risk register for medical professionals.
- (e) Practice early medical remedy in cases of external and middle ear infections.
- (f) Suggest appropriate referrals as and when required.

ASHAs / ANMs / Anganwadi workers / EGS and LPS teachers must

- (a) Get trained on early identification of hearing impairment.
- (b) Orient the general public on how to prevent a hearing loss:
 - (i) Inform them about possible causes of hearing loss.
 - (ii) Educate them about immunization and also administer vaccinations on infants, adolescent girls and expectant mothers.
- (c) Determine whether a given case is at risk for hearing loss using the high risk register for medical professionals.
- (d) Screen for hearing loss through behavioural observation audiometry.
- (e) Suggest appropriate referrals as and when required.

The “High Risk” babies should be identified at birth and screened immediately. They should be asked to follow-up regularly subsequently for 2 to 3 years.

It is essential that there is co-ordination among all the professionals associated in the prevention and identification of hearing loss since best results are an outcome of team efforts. Figure 4 provides an illustration of the linkage between the professionals that are involved.

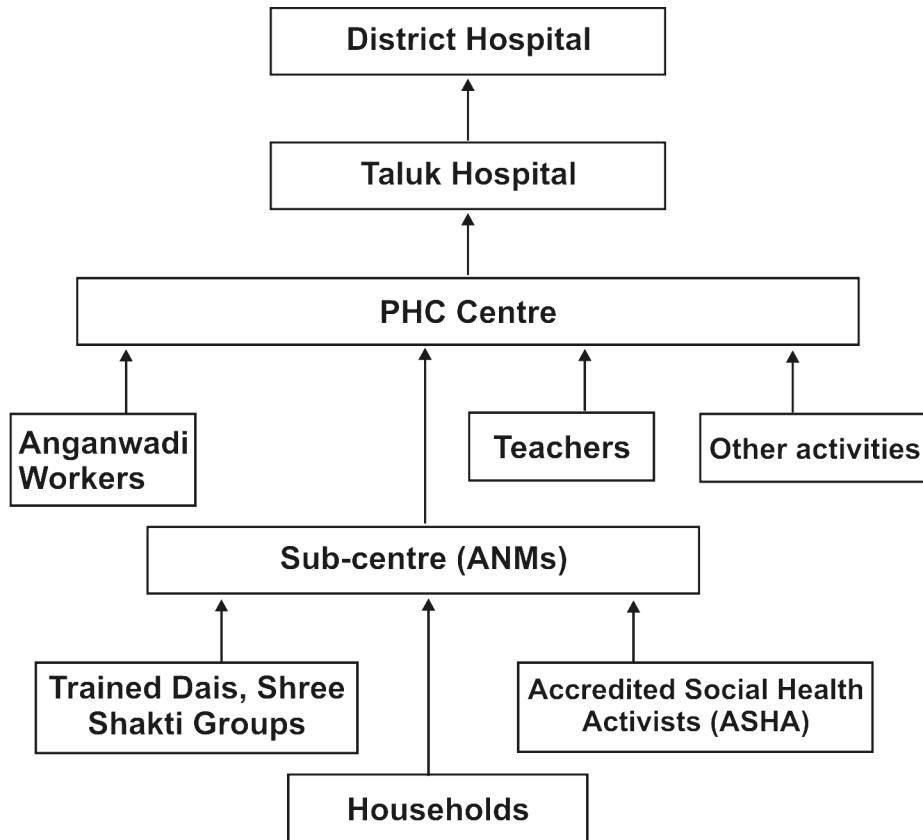


Figure 4: Illustrating the linkages among the professionals

Protocol to be Used for Infant Screening

Due to cost factor, the protocol that is currently suggested for prevention and identification is restricted to using simple behavioural techniques. However, in due course, it is proposed to use the protocol developed by

Yathiraj, Vanaja and Manjula based on the literature. All children who might have a hearing loss should be identified by the age of 3 months irrespective of whether or not they are at high risk (Figure 5).

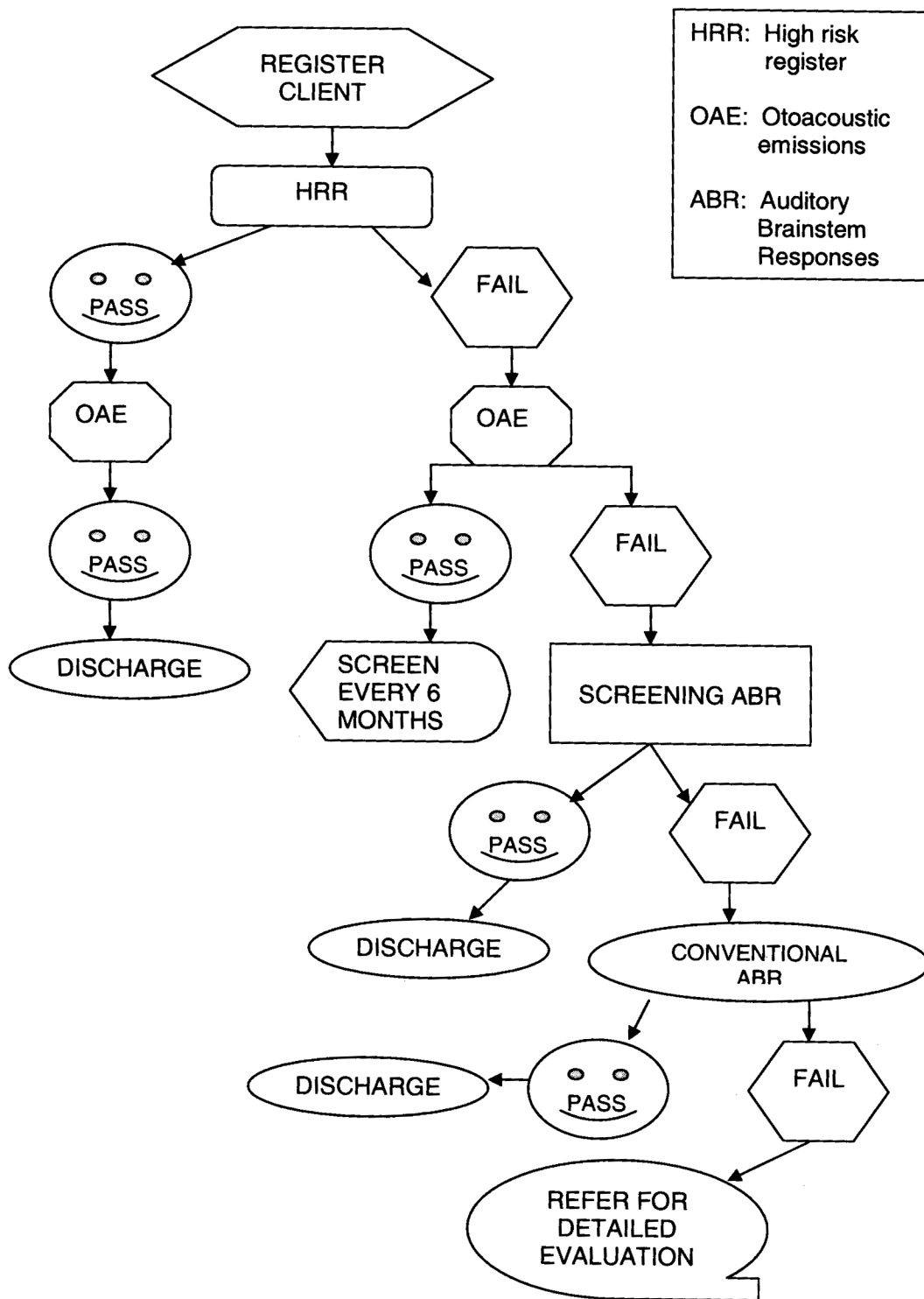


Figure 5: Flow chart of the test protocol suggested to be used for infant hearing screening

Protocol Used for Screening School Children

It is also necessary to identify school-going children with hearing impairment. Hearing loss in school-going children can be identified by the teacher by using a checklist regarding the signs and symptoms of hearing loss. In addition, it is recommended that Ling's 6 sound test may be used. Teachers can carry out this test with minimal training. For children who can read, the test can be carried out in small groups. They could be asked to select the correct sound (phoneme) from a group given in a print form. For younger children, the script could be associated with pictures such "aaaah" with sweets or "iiiiii" with brushing the teeth. Depending on the region where the test is being administered, the choice of phonemes would vary.

Frequency and Media to Train the Professionals

Once in two years, refresher programs should be conducted in the local language using minimum technical terms for the master trainers and their support staff using audio-visual aids and demonstration of the test procedures. Using the materials available at the national institutes, the training sessions should follow a test module, which incorporates pre- and post-evaluation of the trainees' understanding of the disorder, its assessment and management.

Currently, the All India Institute of Speech and Hearing, Mysore, has put in place the infant screening program at a few districts in the southern states. Team effort is a necessary ingredient for the success of a program purporting to identify hearing loss where every member and all concerned work in co-ordination.

Chapter 6

Early Identification and Intervention

Section I

Hearing Screening for Early Identification

The issues in early identification to be addressed are (i) population/location of screening, (ii) technique/tools for screening, (iii) human resources for screening, (iv) cost, (v) challenges in screening, and (vi) intervention for the identified.

Population/Location of Screening

The larger projects/services have dealt with both universal hearing screening as well as screening only those at high risk.

Under the Project of Prevention of Deafness undertaken at All India Institute of Speech and Hearing, Mysore, funded by the Ministry of Health and Family Welfare, Government of India, Yathiraj et al. (2002) reported screening of 28,750 infants over a period of five years.

Under its Child Care Center, the Indian Association of Pediatrics (IAP), Cochin branch initiated in 2002, a newborn hearing-screening program of high-risk babies. Screening is carried out using portable automated OAE equipment in all the NICU (Neonatal Intensive Care Units) of 19 hospitals with a higher number of deliveries. Those failing the first screen have a repeat screen four weeks later, followed by ABR if they failed again.

Basavaraj and Nandurkar (2007) reported on screening 353 at-risk, 276 high-risk and 77 at-no-risk neonates and infants aged 1 day to 9 months at a tertiary hospital in Mumbai. The HRR criteria

given by Joint Committee on Infant Hearing (2000) was used to develop and evaluate an infant hearing screening module to identify bilateral severe to profound hearing loss. Behavioral, TEOAE and ABR techniques were compared with the involvement of the mother/caregiver for behavioral screening and the nurse for both behavioral and TEOAE screening.

They reported that 25% of the babies were not available for screening due to various reasons. For screening no-risk babies, the parents as well as hospital staff were non-cooperative. Suitable location for screening (with ambient noise with <45 dBA) was available near the NICU, but not in the general ward/nursery.

Nagapoornima et al. (2007) reported a large scale incidence study among neonates in the Indian context. They examined the incidence of hearing impairment in a cohort of 1,769 (at risk 279 and at-no-risk 1490) neonates who sought care at a tertiary hospital in Bangalore over a period of 3.5 years. They screened both neonates as a non-randomized cohort from a population of 8,192 neonates seeking care at that hospital. The HRR criteria were as per the American Joint Committee statement on Infant Hearing Screening (2000). TEOAE Screening was used at the first level by 6 weeks of age. The failed neonates underwent a second screen within 3 weeks of first screen. ABR and BOA confirmed hearing loss on second failure. The authors reported a general incidence of 5.65 per 1000 screened. Further, the incidence in high-

risk infants was 10.75 per 1000 whereas that for no-risk infants was 4.70. Their results show that screening only the 'at risk infants' may result in missing out 70% of the newborns with hearing impairment.

Mathur and Dhawan (2007) report about TEOAE screening of 1000 randomly selected neonates in the first 48 hours of life in a tertiary hospital. Those failing the first screening were re-screened using TEOAE at three weeks, three months and six months of age. Infants who did not 'pass' at these stages were subjected to ABR and oto-endoscopy. They recommend the TEOAE screening at three months of age as the pass rate of TEOAE at 48 hours was only 79%, which increased to 97% at 3 months.

Apart from these, neonatal infant hearing screening programs are under way in several other tertiary hospitals such as Sri Ramachandra Medical College, Chennai, Post-graduate Institute of Medical Education and Research, Chandigarh, All India Institute of Medical Sciences, New Delhi, etc. and as part of training programs in some training institutions.

Technique/Tools for Screening

The technique/tools used for hearing screening have a lot to do with the population and funds available for screening. The objective of the screening also determines the technique and tools used. From the abundant literature available on hearing screening programs undertaken in USA, UK, Australia and other developed countries, it is evident that the objective of screening is to identify all degrees and types of hearing loss in each ear. In India, one may have to work out the requirement bearing in mind the infrastructure facilities available for follow up.

Behavioral Observation Technique

Behavioral Observation Technique continues to be used even though they do not provide ear specific results for screening as reported by Anupriya (2001), Yathiraj et al. (2002)), Basavaraj and Nandurkar (2007), Nagapoornima et al. (2007).

Checklists

Hearing screening checklists have been used to obtain the report of the caregivers regarding the auditory behavior of their children. One such checklist is incorporated in the Interactive Voice Reception System (IVRS) of the Disability Helpline launched by Ali Yavar Jung National Institute for the Hearing Handicapped, Mumbai.

In the website www.checkhearing.nic.in, Basavaraj et al. (2006) have incorporated four such check lists for four different age groups. The checklists have been validated and they report the overall sensitivity and specificity of the checklists as 82% and 75%, respectively.

HRR

High Risk Register (HRR) continue to be used as a screening technique. Several versions of HRR specific to Indian population have been reported in *RCI Disability Status reports (2000 and 2003)*. Several projects use the HRR of American Joint Committee on Infant Screening (2000) as a benchmark HRR.

OAE

A variety of makes and models of OAE such as, fully automated, hand held screening instruments, diagnostic instruments are available (see Table 5 for details). Thus, OAE screening has been used widely in the developed countries

reporting very high sensitivity and specificity for both TEOAE and DPOAE measures. However, the same has not been documented in the Indian studies.

ABR

Automated ABR has been used for screening in the last decade. Portable instruments with automated ABR and OAE are available. The sensitivity and specificity of ABR has been documented to be very good. However, ABR has been used more as a second step for the confirmation of hearing loss in the screening process.

Human resource for screening

Human resource is directly related to the tools used, but the validity of screening results in relation to different categories of human resources is lacking apart from sporadic published/unpublished reports.

Basavaraj and Nandurkar (2007) studied the feasibility of utilizing mothers/care-givers and nurses in hearing screening and report no significant differences between the mother/caregivers, nurses and audiologists in carrying out behavioral screening in case of bilateral severe to profound hearing loss; also there was no significant difference between the nurse and the audiologist when automated TEOAE was the equipment in use.

HRRs especially those developed for medical and non-medical persons (Anitha, 2001) can be administered by a whole range of personnel including trained volunteers.

Hearing checklists are being used under the project 'Prevention of Deafness' at AIISH, Mysore since 1995-96 to identify school children with hearing loss. Checklists are available on the website www.checkhearing.nic.in which can be used by caregivers, pre-school/school teachers and also for self-assessment by the older group.

Behavioral screening is carried out by trained technicians or audiologists especially if the tool is a kit of noise makers. Training is also required to develop the skills to observe the auditory behavioural response.

A checklist to screen school children under the scheme of Sarva Shiksha Abhiyan of Ministry of Human Resource Development, Government of India is also available.

Attempts have been made to sensitize the caregivers about the normal developmental stages of auditory behaviour by means of handouts. The Disability Helpline of AYJNIHH, Mumbai provides this information through its IVRS.

OAE screening is mainly done by audiologists. Nurses have been trained to use the automated OAE in projects (Basavaraj and Nandurkar, 2007). The scenario is same as for ABR screening.

Besides the techniques/instruments mentioned in Table 1, high risk registers and check lists to be used for various age groups have been developed and are in use.

Table 1: Hearing Screening Tools/Methods

Sl. No.	Source of stimuli	Frequencies (in Hz) covered	Type of Response	Tester	Approximate cost (in Rs.)
1.	A set of noise makers with a combination of the items mentioned below: i) Drum ii) Metal Khanjeera iii) Jingles iv) Squealer (high frequency) v) Wooden rattle vi) Steel bell	i) 800-1700 Hz (peak at 800 Hz) ii) 1140-7360 (peak at 2500 Hz) iii) 800-1700 (peak at 6080 HL) iv) Maximum between 4 and 8 kHL v) 900 to 1600 Hz vi) >4000 Hz	Behavioral (eye blink, startle, facial grimace, localization, etc.)	Trained Personnel	1000-1500
2.	Hand held audio screeners i) Pure tones (discrete and/or sweep frequency) ii) NBN (discrete and/or sweep noise) iii) Environmental sounds	i) 500 Hz, 1 kHz, 2 kHz, 4 kHz ii) Center frequency of 500 Hz, 1 kHz, 2 kHz, 4 kHz iii) Variable frequency	Behavioral (involuntary response, viz., eye blink, startle, facial grimace, localization). Behavioral response as in play/standard audiometry if the subject is old/intelligent enough and without associated problems	i) Professionals— audiologists ii) Trained Personnel	i) 1250 to 2500 for indigenous one (available at AYJNIHH, Mumbai) ii) 20,000-40,000 for the imported ones.
3.	Portable screening audiometers	500 Hz, 1 kHz, 2 kHz & 4 kHz	Behavioral (conditioned responses)	-do-	25,000 onwards
4.	Handheld Tympano-meters	NA	Physiological measure, viz., tympanogram	i) Audiologists and Otolaryngologists ii) Automated ones may be used by technicians	1.2 lakhs onwards
5.	Handheld Immittance meters	NA	Physiological response Tympanogram & presence/absence of Acoustic reflex	-do-	2.0 lakhs onwards

6.	Immittance Audiometer	NA	Physiological response, Tympanogram Acoustic threshold	Audiologists & Otolaryngologists	2.3 lakhs onwards
7.	OAE screener				
	i) TEOAE	Clicks to elicit OAE in frequency bands of 1 kHz, 1.5 kHz, 2 kHz, 2.8 kHz & 4 kHz, (may vary from make/model to make/model)	Physiological response TEOAE	i) Audiologists & Otolaryngologists ii) Nurses	1.3 lakh onwards
	ii) DPOAE	1 kHz, 2 kHz, 2.5 kHz, 3 kHz, 4 kHz & 6 kHz	DPOAE Automated equipment gives result as pass /refer	-do-	3.0 lakh onwards
8.	Diagnostic OAE with TEOAE/ DPOAE options	-do-	Physiological response TEOAE/DPOAE	Audiologists & Otolaryngologists	4.5 lakhs onwards
9.	Automated ABR	<ul style="list-style-type: none"> • Clicks • Tone bursts of 500 Hz, 1 kHz, 2 kHz & 4 kHz 	Result as pass/refer	Audiologists & Otolaryngologists	2.0 lakhs onwards
10.	Diagnostic ABR	<ul style="list-style-type: none"> • Clicks • Tone bursts of 500 Hz, 1, 2 & 4 kHz 	Physiological response indicating ABR wave form to assess threshold of hearing	-do-	4.5 lakhs onwards
11.	ASSR	AM/FM frequencies of 500 Hz, 1, 2 & 4 kHz	Physiological responses indication Threshold of hearing at the respective frequencies	Audiologists	7.0 lakhs onwards

Instruments with a combination of the above are also available.

High Risk Register/Checklists for Screening Developed in India between 2000 and 2007

- (1) HRR for Medical persons (Anitha, T., 2001)
- (2) HRR for Non-medical persons (Anitha, T., 2001)
- (3) Hearing Screening Checklist (Basavaraj et al. 2006)
 - (i) 0-2 years
 - (ii) 2-6 years
 - (iii) 6-18 years
 - (iv) 18+ years
- (4) The Screening Checklist for Auditory Processing (SCAP) (Yathiraj & Mascarenhas, 2002)
- (5) Self Assessment Hearing Handicap : Short-form scale (Vanaja, 2000)
- (6) Checklist for identification of hearing impairment in school going children, Department of Audiology, AIISH, Mysore

Challenges in Screening

Challenges in undertaking newborn/infant hearing screening are: the lack of awareness in both the public and the professionals regarding the importance of early identification of hearing impairment; high levels of ambient noise in the test areas in hospitals; deliveries at homes especially in rural areas with the assistance of dais/other attendants; poor follow-up bringing the initial efforts to nought; and scarcity of technical manpower.

Hearing Screening in Schools

As part requirement of the clinical work of under-graduate programs (in Speech and Hearing), the school screening has received a

fillip. Government of India Gazette notification of June 2001 with respect to disability screening and certification has recommended including 500 Hz, 1, 2 and 4 k Hz for hearing screening at 25 dBHL. The Non-Government Organizations (NGOs) such as Rotary, Lion, Jaycee Clubs continue to participate in arranging school screening programs. However, documentation/publication of reports on school screening program continues to be minimal.

The introduction of Sarva Shiksha Abhiyan (Education For All) of Ministry of Human Resource Development in the year 2001 has sensitized the primary and secondary school authorities under the State Governments to arrange hearing screening, the school teachers being trained to identify hearing impairment in children besides other disabilities. Budgetary provision has been made for such activities as well as for the intervention of the children identified with disabilities.

Identification of Auditory Processing Disorders in school-going children needs urgent attention. The screening checklist developed by Yathiraj and Mascrenous, 2002 is not used as widely as desirable due to lack of awareness of the condition by parents and teachers.

Identification of Noise-induced and Age-related Hearing Loss

No significant progress has been made in screening industrial workers and others for suspected noise induced hearing loss. The same is the status with regard to age-related hearing loss.

People seeking training or employment in the aviation sector are referred to institutes/hospitals for audiometry. Self-assessment questionnaires (Vanaja, 2000) developed can be put to use to cover larger population.

National Programme for Prevention and Control of Deafness (NPPCD)

The Ministry of Health and Family Welfare, Government of India in 2006, launched the pilot phase of the National Programme in Prevention and Control of Deafness. One of the objectives is early identification, diagnosis and treatment of hearing loss.

In the first phase, a pilot project is being conducted in 25 districts in 10 States and 1 union territory for two years, from 2006 to 2008. It is proposed to expand this programme, in a phased manner, to include a total of 203 districts covering all the States and Union Territories by 2012. Table 2 shows distribution of the same.

Table 2: States/Union Territories, Medical Colleges and Districts Covered under the Pilot Phase of NPPCD

<i>Sl. No.</i>	<i>State/UT</i>	<i>Medical College</i>	<i>Districts</i>
1.	Andhra Pradesh	Osmania Medical College/ Govt. ENT Hospital, Hyderabad	<ul style="list-style-type: none"> • Mehboob Nagar • Nalgonda • Hyderabad
2.	Assam	Guwahati Medical College, Guwahati	<ul style="list-style-type: none"> • Kamrup • Sonitpur • Nalberri
3.	Gujarat	Govt. Medical College, Jamnagar	<ul style="list-style-type: none"> • Jamnagar • Rajkot • Bhavnagar
4.	Karnataka	All India Institute of Speech and Hearing, Mysore	<ul style="list-style-type: none"> • Mandya • Hubli • Hassan
5.	Manipur	RIMS, Imphal	<ul style="list-style-type: none"> • Imphal
6.	Sikkim	Sikkim Manipal Institute of Medical Sciences, Gangtok	<ul style="list-style-type: none"> • Gangtok
7.	Tamil Nadu	Christian Medical College, Vellore	<ul style="list-style-type: none"> • Vellupuram • Vellore • Thanjavur
8.	Uttarkhand	Himalayan Institute of Medical Sciences, Dehradun	<ul style="list-style-type: none"> • Haridwar • Dehradun • Narendernagar
9.	Uttar Pradesh	King George Medical University, Lucknow	<ul style="list-style-type: none"> • Barabanki • Gorakhpur
10.	Delhi	Lady Harding Medical College, Delhi	<ul style="list-style-type: none"> • North west • West
11.	Chandigarh	Govt. Medical College, Chandigarh	<ul style="list-style-type: none"> • Chandigarh

Section II

Early Intervention for the Identified Population

The fact that early identification not followed by intervention is of no consequence needs no elaboration.

The services/facilities available for early intervention in the country is covered under the following: (i) Medical intervention, (ii) Aids, appliances and cochlear implant, and (iii) Auditory and speech-language training.

(i) Medical Intervention

Accumulated wax and otitis media are two conditions that require medical intervention in school children. Follow up data is not available to the extent desirable. Otolaryngologists being available only at the district hospitals, the PHC doctor manages the ear/conductive hearing problem at the primary center. Anganwadi workers and other grass root level health workers are trained to handle acute ear pain, foreign body in the ear canal, etc.

There are about 600 district hospitals in the country but not all may have ENT specialists nor infrastructure for audiological assessment. The scenario is expected to improve as NPPCD has made budgetary provisions to meet the deficiencies and a 'medical kit' for grass root workers to attend to the ear problems.

(ii) Aids, Appliances and Cochlear Implant

Fitting appropriate hearing aids are a crucial step in initiating successful intervention especially in children with pre-lingual hearing impairment.

The status of availability of 'state-of-art' hearing aids of all styles, makes and models (digital

and analog) in the Indian market have improved to a great extent with the liberalization of the import policies. It is estimated that about 1.85 lakh hearing aids are distributed/sold annually. Of these, about 1.25 lakh body level aids are distributed under the ADIP scheme. The rest are either assembled or imported for sale in the country.

The Scheme of Assistance to Disabled Persons (ADIP) of Ministry of Social Justice and Empowerment, Government of India, provides Rs. 8,000 per aid per ear for the beneficiary. Binaural aids are provided to school-going children which may be replaced with new hearing aids every two years. Income for eligibility for fully and partially subsidized aids currently is Rs.6,500 p.m. and Rs.6,501 to Rs.10,000 p.m. respectively. A solar battery charger with two AA rechargeable batteries are also included for the beneficiaries. Other appliances such as the auditory trainers, tape recorders and assistive listening devices are not provided under the ADIP scheme.

The cost of hearing aids is reimbursed for employees under ESI and CGHS schemes. Some of the State Governments have also made provision for distribution of free/subsidized hearing aids. SSA has budgetary provision to provide hearing aids to the school going children. Of late, Ministry of Health and Family Welfare, Government of India under NPPCD has finalized the rate contract for Behind-the-ear (BTE) hearing aids.

The hearing aid manufacturers are continuing to bring out new models by incorporating advanced technology. The Government sector has not made any significant contribution in developing indigenous hearing aid.

Center for Design of Advance Computing (CDAC), Trivandrum under a project funded by Ministry of Information and Technology has developed proto types of digital body level hearing aids along with indigenous programming system. This project is in collaboration with AIISH, Mysore.

Hearing aid analyzers, which help in monitoring the quality of hearing aids are available in the institutes offering speech and hearing courses as it has been made mandatory to have them as per the RCI requirement. Apart from these training centers (which are about 30 in number) these equipments are available with the hearing aid manufacturers and some special schools.

Assistive Listening Devices (ALD) such as TV listening aid, alarm devices, telephone listening aid are not as widely used as would be desirable, though a few companies deal with these devices.

Cochlear implant is not an option by choice, but in terms of candidacy and cost (varying from Rs.5 lakhs to Rs.10 lakhs). Among the elite hearing impaired, cochlear implant is picking up well, especially in the prelingually deaf. Marketing strategies and the outcome of cochlear implant in the implanted children seem to have contributed to the popularity. Three popular brands of cochlear implant (Nucleus, Medel and Clarion) are marketed in the country.

AFMC, Pune and INS Ashwini Hospital, Mumbai have made provision for free cochlear implant for their beneficiaries. Certain corporate houses also have donated funds to some private hospitals to help the economically weaker section. The outcome of cochlear implant is good (especially with the pediatric population) wherever a team of professionals is involved.

The network of hearing aid dealers of the

major hearing aid manufacturers in the country have provision to supply the spares for the hearing aids (such as cords for body level aids, prebent tubes for BTE aids) as well the repair of the hearing aid. Repair facilities are available at the major training institutes, some NGOs and private practitioners. *Directory of Services* published by AYJNIHH, Mumbai provides more information on this issue.

Ear Moulds

The ear mould is the final link between the hearing aid and the ear. Custom made ear mould are prepared only at institutions in cities and by some NGOs and private practitioners. District Disability Rehabilitation Centers (DDRC) of Ministry of Social Justice and Empowerment has facilities for custom ear mould (website: www.socialjustice.nic.in). Facilities to make soft ear molds are available at some centers and with the hearing aid manufacturers/distributors.

(iii) Auditory/Speech-Language Training

Available services are comparatively more in the urban than the rural sector; the caregivers from the latter sector can avail of demonstration therapy, with the objective of facilitating home training. Several early intervention centers run by parent groups continue to offer quality services. Special educators are also involved in auditory/speech-language training though it remains the domain of the speech-language pathologists/audiologists.

Recognizing the importance of auditory/speech-language training for the cochlear implant recipients, the team approach has had a positive impact on the caregivers. An increasing number of special educators and caregivers have benefited from the workshops/training programs in auditory/verbal therapy organized by the manufacturers/distributors of cochlear implants.

Certificate courses for the caregivers (of children with developmental disabilities) has been launched by AIISH, Mysore and IGNOU in collaboration with the RCI.

To meet the special needs of the age group 0 to 5 years, orientation programs of one-month duration aimed at manpower development are conducted at seven centers across the country by AYJNIHH, Mumbai in collaboration with Balavidyalaya, Chennai.

Availability of affordable educational material such as picture story books, puzzles, audio/video tapes, educational toys, attractive stationery items has improved due to the access, through internet, to pictures/material. Indigenously developed software and websites are also available for auditory training and speech-language training.

Chapter 7

Educational Services for Children with Hearing Impairment

Introduction

Education of children with hearing impairment in India is just a little over a hundred years old.

After Independence, improvements were seen with the establishment of many new schools in the 1950s and many programs based on the new technology came up in the 1960s.

The sixties saw the establishment of the All India Institute of Speech and Hearing in Mysore where facilities for diagnosis of hearing impairment in infants and young children were available. Initially, the Institute also provided children with body worn, pocket model hearing aids through an Indo-Danish Aid program. Young children were diagnosed and fitted with suitable hearing aids. This paved the way for the establishment of the new era schools that used the latest technology available for educating infants and young children with hearing impairment.

For the first time in the country, schools were created for early intervention. Infants and young children used individual hearing aids which facilitated development of early verbal language. They could be integrated into regular school.

Parents of hearing-impaired children were the first ones to start these Early Intervention programs. As contribution of the parents and family members gained importance, they were motivated to take an active role in the education of the hearing impaired infants and young children.

Educational Provisions Available Today

Schools

At present, over 500 schools for the hearing-impaired children are available in the country. The Government established and administers some schools whereas the NGOs run many others.

Most of the schools, still residential, admit children aged 5 years and above who spend the entire school year in the hostels; they go home only during summer vacation. Provision of vocational courses and sheltered workshops facilitates spending almost the entire lifetime of some students in these schools.

Schools do not go beyond 8th standard in some States such as West Bengal. Beyond this, the National Open School is the option.

Schools go up to Higher Secondary level in some States like Tamil Nadu and Maharashtra with variation in the syllabus for the hearing-impaired students; same syllabus as in the regular education system in Tamil Nadu; separate syllabus with a waiver for some subjects in Maharashtra.

Colleges

Two colleges for the Deaf, one in Chennai, Tamil Nadu affiliated to the University of Madras and another in Valakam, Kerala conduct degree courses in Commerce and Art subjects; a third program is under the Indira Gandhi National Open University, New Delhi.

The Early Intervention Centres are able to motivate the family members to take part in the education of hearing impaired children which helps them develop early verbal language skills. In some cases, parents and family members have assumed the responsibility of educating hearing impaired infants and young children with help from sources such as ENT clinics, speech and language professionals and special educators. They help the children develop early verbal language skills and join mainstream schools.

Percentage of Children Having Access to Education

Assessing the percentage of children who have access to education is difficult as the exact number of children with hearing impairment is not available. The population of children with hearing impairment from birth to 14 years is estimated to be around 3,07,600. Their educational status in India is as follows:

Graduation and above	:	0.9%
Higher Secondary	:	1.1%
Secondary	:	2.5%
Middle School	:	7.6%
Primary School	:	19.5%
Without any schooling	:	68.8%

The survey shows that only 31% of the hearing impaired children get enrolled in any school and only one-third of them continue after primary level. The 0.9% of the high achievers includes children from special schools as well as the children who get mainstreamed directly or from early intervention programs.

Possible reasons for low enrolment of children in schools may be:

- (1) There is not enough number of schools to enroll all the children.

- (2) A majority of schools are situated in cities and big towns.
- (3) Not enough awareness about the availability of educational services.
- (4) Poor economic background of those living in urban slums and rural areas.

The high dropout rate of children can be due to: poverty, lack of awareness, illiteracy among parents and family members, and lack of good educational system.

Qualitative Aspects of Education Imparted

There was no uniformity in the training offered to teachers of the hearing impaired. Recently, the Rehabilitation Council of India has revamped the training courses. However, the educators are faced with many problems which are discussed below.

Hearing Aids

- In the ADIP schemes of the Ministry of Social Justice and Empowerment, Government of India, only those hearing aids approved are distributed which limits the choice.
- Many parents in the economically weaker sections are not able to meet the recurring expenses: replacement of cells multiple times in a month, broken cord and damaged receivers, replacement of ear moulds as and when the child outgrows them.
- Suitable hearing aids are not available to all the children enrolled in the schools. Hearing aids of high-end technology are expensive. The cells required are very costly and available only in metro cities.
- Lack of adequate repair services locally.

- Downtime is more when the children in some schools are allowed to use the hearing aids only inside the classrooms.
- Poor knowledge in maintenance and troubleshooting of hearing aids.
- Lack of periodical review and replacement of hearing aids, which may not be meeting the child's needs for various reasons.
- Deprivation of effective hearing aid usage due to improper choice of hearing aids, use of rundown cells and damaged accessories.

Family/Child Related Factors

- Even in case of day scholars, the schools do not receive family support due to poverty/illiteracy/lack of motivation of the family members.
- When the medium of instruction in the school is not the mother tongue, the child is being taught in a language which precludes communication at home between the family members and the child.
- Many special educators face tremendous pressure in the classroom. Enrolled late, children between 4 years and 10 years are admitted into the preparatory classes.

Teachers

- The teachers also have to deal with children who have already acquired secondary disabilities due to late start. Frustrated children end up with behavior problems. Some children suffer from additional disabilities and there are no specific counselors to provide help in these areas.

- Teachers in the pre-schools are not really equipped to help children with hearing impairment. The duration of training programs conducted is too short to be of real benefit.
- The children admitted are heterogeneous with respect to hearing loss, intelligence, age and family background. Hearing loss may range from moderate to profound. Intelligence may range from borderline to superior. Even with a small class of 8 to 10, the special educator finds it extremely difficult to do justice to every child on account of the heterogeneity of the children.
- Low salary scales results in schools not being able to recruit better teachers.

Schools

- Many schools are not able to develop the initial linguistic skills of the pupils as they are forced to follow the textbooks, i.e., teach academic skills primarily. As a result children develop rote memory without actually internalizing the inputs given by the teachers. This ultimately reflects in poor social and psychological maturity of pupils.
- The sign language used by some of the special schools is not well developed.
- In the residential set up, the students do not receive any input after school hours.

Hearing impairment is different from other disabilities. Given an early start, the atrophy of residual hearing can be averted and the children can be helped to develop early verbal language skills which in turn would enable them to be mainstreamed from first standard onwards.

Meeting the Educational Needs of Children with Multiple Disabilities

Educating children with multiple disabilities is a difficult task. In India training programs to train teachers to help children who are 'deaf-blind' has only recently begun.

As on date, there are no recognized programs to train teachers to help the hearing impaired child with additional problems such as mental retardation, autism spectrum disorder, learning difficulties and spasticity.

Conclusion

As children with disabilities are likely to suffer from more than one disability, new training programs have to be developed to enable teachers to handle children with more than one disability.

Improved efforts at the planning as well as at the implementation level is likely to bring about the necessary improvement in the education of children with hearing impairment and other disabilities.

Chapter 8

Parental and Community Attitude Towards the Disabled

Introduction

The earlier the parent/family accept the fact of impairment and follow a well-planned rehabilitation program under professional supervision, the better are the chances for the child and the family to lead a more normal life.

Parental attitudes towards disability include *inter alia* acceptance, rejection, indifference and overprotection.

Acceptance

Some parents are able to accept the sensory impairment and show love and concern by looking for ways and means to help their child. With this positive attitude, they soon learn how much they themselves can do to help their child and how much their child is capable of achieving. The other family members may follow suit. Thus, the parental attitude of acceptance helps the child to achieve his potential.

Rejection

There are parents who consider it a stigma affecting social status and prospects of the other family members if their child has a disability. They are averse to acknowledging the presence of such a child in their family, providing the bare necessities of food, shelter and clothing. Some parents send their disabled child to an institution and wash their hands off him/her.

Indifference

In some cases, parents/family accept the disabled child and try to find ways to help. They show their love and concern for the child, but they find it difficult to treat the child on par with other children in the family. This not only hampers the all round development of the disabled child, but may also lead to additional problems.

Overprotection

Some parents work towards the development of the child, but feel the need to shelter and protect because of the disability. Overprotection denies the child the opportunity to achieve his potential in various areas of development.

Social Attitude Towards Disability

There has been a change in the societal attitude towards the disabled because of greater awareness regarding the needs of the disabled and their capabilities, and due to increased literacy, especially among women.

The attitude of the parents goes to make that of the community towards the disabled child. If there is parental willingness to provide the child with his requisites including emotional support, and providing opportunities for realizing his potential, the community and society at large would follow suit.

The Changing Scenario

Gender inequality perceived among the hearing handicapped is changing in the present day as women are being given priority in many areas. Much importance is being given to their education especially to the disabled girl child. DPEP has a separate intervention cell to ensure equal opportunities to the girl child in the classroom and in society.

The latest draft of the National Policy on Disabilities has a separate section on women with disability which is a major development for improving the status of the disabled girls.

Under the scheme of assistance to disabled persons for purchase/fitting of aids/appliances (ADIP scheme) the Government endeavors to provide persons with hearing impairment with aids and appliances at minimum cost. One of the conditions is that 25% of aids/appliances should be provided to female children/women.

In the Scheme of National Scholarship for Persons With Disabilities, 500 awards given through institutions are equally distributed between the male and female students with disability for pursuing higher and technical education.

Two important schemes, 'Sarva Shiksha Abhiyan' and 'Mahila Samakhya', are being implemented by the Department of Elementary Education and Literacy; these primarily aim to reach the girl child including the disabled ones.

The Women and Child Development Department operates programs for persons with disability. Besides coordinating the implementation of the PWD Act, 1995, it also supports their

economic empowerment through provision of loans through NHFDC for self-employment and micro-finance for self-help groups. Implementation of schemes for special schools, scholarships/stipends to students with disability, and pension to severely disabled persons are other responsibilities of the Department.

Marital Status of Disabled Women

The marital status of a girl often determines her position in society and family. Motherhood also plays a crucial role to determine her social status.

For women with disabilities, finding a suitable life partner poses difficulties. Hence marriage and motherhood seem beyond their dreams. The disabled women are perceived as potential burden on the family as they may not be expected to earn their livelihood and be economically independent and/or contribute to the family income.

Conclusion

A person's success depends on the opportunities available to him or her. This is very true for children with disability. If children with disability are identified at a very young age and provided early intervention, they will develop optimally and reach their potential for development enabling them to become contributing members of society.

Parents of hearing impaired persons and the community play a major role in empowering them through providing a strong and stable foundation. With the focus on their abilities and acknowledgement of their right to lead fulfilled lives, undoubtedly much can be achieved.

Chapter 9

The Role of Government and NGOs in C.B.R. and Other Programmes Developed in the Country

Introduction

Rehabilitation of persons with disabilities has gained momentum in India during the last decade with several states as well as the Union Government launching programs for their benefit. Community Based Rehabilitation and Integrated Child Development schemes are two major thrust areas in this endeavor.

Community Based Rehabilitation

Community based rehabilitation for persons with disabilities (PWDs) was initiated in the developed countries by the World Health Organization in 1983. The initial medical focus shifted to the social sphere later.

W.H.O. suggested that the program be integrated into the already established Primary Health Care System in rural areas. Accordingly, intervention activities were shifted from institutions to the community, the family members and community volunteers, a move which minimized many difficulties/obstacles such as travel and expenses, associated with institution based activities.

Since medical rehabilitation alone was not sufficient to complete the rehabilitation process, C.B.R. programs added interventions such as education, vocational training, social rehabilitation and prevention. Thus, C.B.R. today follows a social rather than a medical model.

C.B.R. attempts to restore or maximize the

full potential and functions of PWDs in their natural environment within the family and the community. Its objectives are: to empower PWDs and the communities, to encourage PWDs achieve their potential, to remove physical barriers, social and physiological building strategies for sustainability. It also aims at changing negative attitudes, addressing human rights issues and sharing information, promoting social integration and learning from communities (Hartley, 2002).

Role of the Government in Promoting C.B.R.

To facilitate smooth operation of the C.B.R. programs, the Government must set up management structures which include policy-making and planning, decentralization, putting in place appropriate administrative infrastructures. Onward referral systems, provision of resources, training personnel, monitoring and evaluation are other aspects to be covered.

The Government must formulate new policies, promote/review existing ones to rectify any deficiencies in available health services and educational facilities and in vocational opportunities that affect the lives of the persons with disabilities.

By formulating a detailed policy statement, the Government puts down the goals to be achieved, changes to be implemented, identify personnel responsible, a time frame for changes to be brought about and a commitment made to

provide the resources. The Government must use an affirmative strategy to promote participation of the disabled.

The Government must mobilize resources through central and local government bodies, communities and non-government organizations. Some of these resources are – funds, personnel, equipment, transportation, physical structures, statistical services, research activities and information availability.

One of the key features of C.B.R. program is decentralization. It must be followed by change of attitudes. Those responsible for decentralization must ensure that the plans and issues concerning the disabled are streamlined at district and lower levels of the local government.

All stakeholders have to be involved in sensitization of the technical personnel, political and district level authorities to increase awareness and appreciation of the issues that the persons with disabilities have to face.

The training of the persons with disabilities is essential in building their confidence, capacities and capabilities towards realizing their potential and in actively participating and demanding that attention be paid to the issues that affect them.

Training of families and communities has raised awareness on causes, management and prevention of disabilities and has contributed towards a change in attitude and increased awareness concerning the provision of resources.

The Government must ensure that treatment, education, employment and legal services are operating efficiently. The central and the state level governments have created several referral options – major hospitals, special schools and vocational rehabilitation centers. The Government also monitors and evaluates community-based programs.

Due to financial constraints, the government has not been able to extend the C.B.R. programs throughout the country. Secondly, census data for ease of planning and resource allocation for the disabled has not been adequate (Hartley, 2002).

Role of NGOs in C.B.R. and Other Similar Programmes

The efforts of the NGOs have undoubtedly increased community awareness about the important issues in CBR programmes.

The fundamental difference between the NGOs and the Government agencies is that the NGOs focus on the efforts made by the people themselves to organize and set up sustainable institutions, whereas the Government focuses on delivery of goods and services. The NGOs have a propensity to work in small locations, achieving impact on the ground, as compared to the Government services that usually address the needs of the majority with lesser attention given to the members of civil society, who may have no voice.

International donors and the Government should incorporate the capacity of the local NGOs into their plans and programs so that their activities can be complementary.

With the current privatization strategies in the developing countries, NGOs should build skills that enable them to compete with the private sector in contracting Government jobs. While the private sector may have better skills in bidding for Government jobs, the NGOs have wider experience in working with communities.

Local NGOs have made efforts to make good the gaps in promoting the participation of the identified stake holders, e.g., persons with disabilities, their parents, the local community, etc., to redress issues of access to C.B.R. services for people with disabilities through various strategies

that may include (a) Resource mobilization, (b) Community mobilization and sensitization, (c) Community education and training, (d) Attitude and behavior change, (e) Capacity building, (f) Mechanisms for social and economic empowerment, (g) Research and information dissemination, (h) Networking, lobbying and advocacy. Through their participation, local NGOs have served as links between the grass root level and the international organizations, which have fostered the development of C.B.R.

Local NGOs have the potential to serve as important instruments and catalysts for social change. For this to happen, there must be a quantum shift in how C.B.R. is perceived and the roles played by the professionals, disabled activists and the community members involved. A holistic approach is required to effectively address the felt needs of the disabled and the problems and challenges faced by them and their families.

Participation by local NGOs has been very crucial in the implementation of C.B.R. programs, though the government may take on more responsibilities. The NGOs must share their expertise in working in a complementary and coordinated way and not to compete in the implementation or fund raising for C.B.R. programs in the developing countries (Thomas & Thomas, 2003; Hartley, 2002).

Schemes Undertaken by State Governments for Disabled People

Among the schemes initiated by the various State Governments for the welfare of the disabled persons, some are nationwide and some are state-specific.

Provision of scholarships and reservation of 2-3% seats in I.T.I's (e.g. Delhi) and 3% jobs is a

common feature across several Indian States/UTs: Kerala, Assam, Bihar, Chandigarh, Dadra & Nagar Haveli, Daman & Diu, Orissa, Andaman & Nicobar Islands, Goa, Punjab, Haryana, Andhra Pradesh and Delhi.

Aids and appliances are provided fully free of cost by the States of Punjab, Orissa, Delhi, Mizoram and Goa.

C.B.R. programmes are successfully run in the States of Andhra Pradesh and Karnataka, but no details are available about other states.

The Andhra Pradesh Government provides 3% seats in Government B.Ed. Colleges, language exemption and grace marks for the deaf. The Government of Kerala provides grant-in-aid to voluntary organizations, financial assistance to the handicapped and distress relief fund to the disabled for medical and surgical purposes. Vocational training centers for the disabled are also provided.

Rehabilitation centers at regional, district levels, besides vocational training centers have been started by the Government of Orissa.

The Government of Punjab provides loans (Rs. 2 lakhs) for self-employment, financial incentives for marriage and exemption in medical examination fee.

The Delhi Government allots D.D.A. shops and unemployment allowance to the disabled.

The Government of Karnataka sanctions maintenance/conveyance allowance, and bus concessions to the disabled and grant-in-aid to the NGOs. Running schools for the hearing impaired, establishment of a Braille press and a "sound" library are a few more end-results of its thoughtfulness.

The Mizoram Government has training centers, which impart training to persons with

disabilities in different trades like tailoring, knitting and shoe-making to enable them to earn their livelihood. It provides allowances and pensions to the disabled.

The Government of Goa rewards a normal person for accepting a person with disabilities as a life partner. Assisting voluntary organizations for setting up special schools, providing financial assistance to institutions for taking up detection, intervention and prevention of disabilities are a few more of the endeavors of the Government of Goa.

The Gujarat Government has special schools where vocational training is provided for children with impairment, hearing and visual.

Persons with disabilities are eligible to receive free vocational training and free Braille books, book allowance and exemption in payment of examination fee from the Himachal Pradesh and the Tamil Nadu Governments, respectively (Menon, 2001).

Central Government Schemes for the Rehabilitation of Disabled Persons

The Ministry of Social Justice and Empowerment, Government of India, under its scheme to promote voluntary action for persons with disabilities provides grants to the NGOs. This is implemented under the heads of salaries, infrastructure development (Hostel + School), rental costs, maintenance grant, stipend to students, transport allowance, grant for vocational training, sports equipment as well as grant for P.T. / O.T. / Speech therapy equipment/special education material, and grants for seminars, workshops and rural camps.

C.B.R. is an important project initiated by the Ministry of Social Justice and Empowerment, involving such diverse manpower as rural rehabilitation volunteers, C.B.R. personnel,

workers for the mentally retarded, social workers, therapists, social educators and vocational trainers.

Also included are legal literacy and counseling projects, environment-friendly and eco-promotive projects for persons with disabilities.

The ADIP scheme for purchase/fittings of Aids and Appliances is implemented by the Ministry of Social Justice and Empowerment. Disabled individuals also get scholarships for pursuing education from 9th standard to such courses as M.A., L.L.M.

The National Handicapped Finance and Development Corporation (NHFDC) promotes self-employment among individuals with mental retardation, cerebral palsy and autism. Loan assistance for self-employment in small business for the disabled, and loan assistance for agricultural activities are available through the NHFDC.

In early 1985, the Government of India launched the District Rehabilitation Center (DRC) Scheme to provide services to those with locomotor disabilities, speech and hearing and the visually impaired, the mentally handicapped and those with multiple handicaps, operative in 11 different locales in the country. The themes are: prevention, early detection, medical intervention, surgical correction, fitment of artificial aids and appliances, therapeutic services inclusive of physiotherapy, speech therapy and occupational therapy, vocational training, provision of educational services in special and integrated schemes, community and family counseling.

At the village level the Integrated Child Development Scheme (I.C.D.S.) functionaries like teachers and local health workers, undertake the work of disability prevention. They refer cases to Primary Health Center (PHC)/Community

Health Centre (CHC)/District Centre of Voluntary Organization which have specialized rehabilitation personnel. Both medical and paramedical personnel are being trained in disability intervention.

Direct services to the handicapped persons at the headquarters in conjunction with the local hospital authorities are sometimes arranged, courtesy District Rehabilitation Centers.

Composite Rehabilitation Services

The 107 Composite Rehabilitation Service Centers located in 107 districts in the country promote early detection and prevention of disability, fitment of aids, follow-up and repair of assistive devices. Vocational training and gainful employment is also intended. There are also Training Centers for Adult Deaf, mostly at the trade-man level.

Regional Rehabilitation Centers for the Spinal Injured

These have been taken up on 90:10 Centre-State sharing basis to establish four regional centers (RRC's) for the spinal injured, who require treatment, long term specialized rehabilitation services and management for life. Equipment for these centers is being received from Italy.

National Program for Rehabilitation of Persons with Disabilities

A State sector scheme, it has provision for two community based rehabilitation workers at each Grampanchayat and two multipurpose

rehabilitation workers at the block level. Its focus is on prevention, early detection and information dissemination, utilizing the services of professionals such as the physiotherapist, the occupational therapist, the orthotic and prosthetic engineers. The states of West Bengal, Kerala, Tamil Nadu and Andhra Pradesh run this program.

Child Guidance Centers

All the child guidance centers provide centre based bio-psychosocial intervention with multidisciplinary teams in place. They reach out to children with developmental difficulties, academic problems, learning disability, hyperactivity, autism spectrum disorders and behavior problems. Some child guidance centers have trained manpower such as grass-root level workers (Bal Sevikas) and school teachers to become force multipliers for supportive interventions for children (Singh, 2004).

Conclusion

Although several states, union territories and the Government of India have implemented several programs/schemes for the disabled, the consequent benefits have not accrued to all those in need and not in all states. Further, there is also variation in the types of benefits.

Community based rehabilitation is still in its infancy. It needs to be implemented in all the states of India. A broad based strategy is needed to get benefits of these schemes to reach persons in every state.

Chapter 10

Research and Development

Introduction

In a multilingual and multicultural country where a new profession has arrived, R & D activities are both a necessity and an opportunity. A large population, illiteracy and initially non-existing, but later progressing to inaccessible services, brought out the resourcefulness of the involved and the concerned.

Need for Research and Developmental Activities

On account of the multidimensional facets of hearing impairment, R & D activities call for in-depth studies, both inter and multi-disciplinary. This calls for synchronized development in the core discipline as well as in allied disciplines.

Achievements in technology, bio-technology, information technology, and digital technology have ushered in developments in accessibility to digital programmable hearing aids, cochlear implant surgery, related rehabilitation technology and auditory genetic diagnosis.

Exploration of indigenous technology and techniques is crucial to bring benefits of technological advances within the reach of the economically weakest among the disabled to meet their needs, whether for identification/diagnosis or habilitation/rehabilitation. Use of locally available research tools and materials for the development of appropriate aids and appliances in the Indian context must be expedited so that for want of the

diagnostic tools, diagnostic protocols are not compromised.

Manpower Development

In human resource development, content of training programs as well as different levels need to be evolved to meet unique needs in the country. For instance, are all the courses stacked presently for earning the degrees, graduate/undergraduate, appropriate for our needs? Is uniformity in the admission requirement for the courses in terms of the level completed, the subjects studied, age limits justified? Would it be appropriate to introduce an element of aptitude in the selection of candidates to reduce mortality before or after completion? In view of the needs, can we sandwich courses which utilize the services of the trainees appropriately so that manpower at several levels is available instead of or in addition to the diploma/certificate courses?

It must be inculcated early in the trainees so that their efforts be it in the preparation of their project work, dissertation or doctoral thesis should be relevant to our developing economy.

Client Requirement

Exploring alternate sources of funding for clients should be an area of concern. In Denmark every person is provided customized services through CBR. In the U.S. almost 70% of the population is covered by insurance.

Areas Investigated

The broad scope of research activities that impinge either directly or indirectly in the area of hearing impairment could be delineated as below:

In the early days of the arrival of the speech and hearing profession in the country, of necessity, efforts were directed at increasing awareness of the problem among the allied professionals and the lay public, adapting the procedures, the techniques the professionals had acquired during their training overseas, etc. Simultaneously, clinical services, which served as practical training ground for the trainees, were provided.

Early Identification

Identifying school children with hearing and speech problems (Nikam & Dharmaraj, 1971) and infant screening in the maternity hospital projects were taken up in the late 1960s at AIISH, Mysore. Subsequently, utilization of state-of-the-art instrumentation/technology such as impedance, ABR and Otoacoustic emission were notable. Projects at the Master degree level and other studies with the specific objectives to evaluate the different screening techniques have been taken up.

Attempts were made to develop a mass hearing-screening test for use over the radio and T.V.

Presently, the manpower involved in early identification includes also professionals, allied professionals—medical, non-medical, grass root level workers—anganawadi workers, ANMs, etc.

Tests/Questionnaires

Paper and pencil tests for self-assessment, questionnaires for early identification of noise-

induced hearing loss have also been developed.

Preparation and maintenance of high risk registers, and infant cry analysis (Gopal, 1992) were other attempts at early identification of hearing impairment.

Location

Site for screening activity is varied: Hospitals, district hospitals, PHC Centers, schools, etc., are the varied sites for screening activities.

Development/Adaptation of Diagnostic Test Materials

Studies especially devolving from Masters' dissertations were directed to the development of test material and tests for speech audiometry (Mayadevi, 1976). Interest in this area led to the development of tests of SRT and speech discrimination in several Indian languages. Adaptations of English language test material for Indian population also drew attention.

Some investigators directed their efforts at development of tests for the detection of central auditory processing disorders. Some explored construction of their own tests or tried adaptation of existing ones meant for other purposes.

Development of Norms

Norms established for different auditory disorders were incorporated into routine testing procedures and were also used by allied professionals such as ENTs, neurologists.

Public Education/Orientation

This is an area which continues to be in the forefront of the R & D. Pamphlets, slogans, lectures, printed articles are employed widely. Much scope is there for improvement. Firstly, the objective is to be defined. It seems little thought

goes into making the printed material suitable/attractive for specific target groups. Secondly, what are the objectives? Is it to increase awareness, to achieve what purpose - is it to increase referrals from the target group, to bring down the prevalence/incidence, to increase the number of satisfied hearing aid users, to organize self-help groups and similar objectives? Thirdly, after determining the target group, the appropriateness of the presentation/material is to be examined. Is it to be the printed material (hand outs, articles, and posters), an audio-visual presentation, talk by a professional/affected individual/parent, prominent personality, theater, music or other? The time and place—a social-religious occasion, organized camps, mass gatherings such as exhibitions, fairs, are yet to be evaluated for their suitability and cost effectiveness. Lastly, how is the success to be measured?

Amplification Devices

Early attempts at manufacturing hearing aids resulted in crude trouble prone instruments. With the passing of time, research activities led to sophisticated indigenous technology including noise suppression circuits. FM systems, programmable/digital hearing aids have appeared in the Indian market.

Ear mould technology too underwent a metamorphosis resulting in improved acoustic signal output and flexibility for tailoring hearing aid responses to individual needs (Babu & Chitre, 1973). The advent of BTEs and ITEs in the 1980s provided impetus for further developmental activities though research efforts in this direction were only sporadic.

Utility of various hearing aids for different clinical groups was explored. Follow up studies revolved around acceptability, care and

maintenance, the costs involved and electro acoustic characteristics of hearing aids over time (Pandalay & Murthy, 1972). Surveys of the status of the instruments and their accessories were also topics of interest.

Methods of hearing aid evaluation and selection were debated as technology made rapid strides. Computerized instrumentation for measuring and determining hearing aid benefits for the user was an alternate. Studies conducted examined the issues from various viewpoints, related to hearing aid fitting using different instrumentation.

Assistive Listening Devices

Assistive listening devices appeared on the Indian scene in the late 1980s. Developmental activities using indigenous technology resulted in cheaper and more suitable devices for local consumers. Examples are the doorbell alarm, vibralarm, telephone amplifier, telephone ring indicator and tactile aids. In recent times, the advent of SMS facility for mobile phone users has enabled the literate hearing impaired to experience the joy of instant communication.

The multilingual culture and ethos of India has always posed special challenges to professionals involved in assessment and remediation of speech-language disorders. The multiplicity of languages has called for the development of tools in various languages, adaptation of western tests, investigations on the acoustic aspects of individual languages, as well as attention to speech perception (Oyer, Richard, Rajaguru & Kapur, 1972).

Speech-language characteristics of the clinical population, especially the hearing impaired, has been an area of avid interest to researchers. Much effort has also gone into treating speech and

language defects in such persons and in development of tools to measure the outcome.

Research Strategies

Diverse strategies have been employed. Surveys have been conducted for the study of noise pollution in cities. Incidence and prevalence of hearing disorders amongst children and adults in rural and urban areas have also been surveyed.

Efficacy of tactile aids as compared to hearing aids, are studied using an experimental approach as also the effect of extended frequency amplification on speech discrimination ability of children with hearing impairment. Single case studies are the choice in describing the outcomes of specific treatment approaches or to highlight the difficulties encountered in differential diagnosis.

Settings

Varied settings are desirable as per the objective. Investigations of language acquisition among typically developing children take place in the natural, home environment. However, the efficiency of auditory site-of-lesion test is always evaluated in an environment where acoustic/temperature/humidity conditions are under control.

Effects of noise on hearing, hearing screening tests may be studied in a lab or in the field such as a school, factory or a hospital. The purpose dictates the choice of environment for recording speech samples.

Smaller towns may provide quiet rooms for a variety of purposes.

The Scenario Today

The Persons with Disabilities Act, 1995 states that the appropriate Government and local

authorities shall promote and sponsor research, inter alia, in the following areas:

- (a) Prevention of disability.
- (b) Rehabilitation including community based rehabilitation.
- (c) Development of assistive devices including their psycho-social aspects.
- (d) Job identification.
- (e) On site modification in offices and factories.

Recent literature shows that effort has been expended on empowerment of mothers, prevention of hearing loss, and the training and employment of persons with hearing impairment. At the Ali Yavar Jung National Institute for the Hearing Impaired, R&D projects completed till date include:

- (1) Know your hearing sensitivity online.
- (2) Socio-economic impact and additional cost incurred in the upbringing of persons with hearing impairment in India.
- (3) Developing modified school text books for children with hearing impairment.
- (4) Gender differences in providing rehabilitation services to persons with hearing impairment.
- (5) Standardization of Indian Adaptation of Grammatical Analysis of Elicited Language - Pre-sentence Level (GAEL - P) Test in Marathi.
- (6) Disability line for the Persons with Disabilities.
- (7) Brain Drain... Is it affecting speech and hearing services in India?
- (8) Development of software and conventional kit of 'Language

Improvement Indicator' - an educationally relevant language assessment tool to be used for teachers of the students with hearing impairment.

Conclusion

The current scenario of research in India leaves much to be desired. Research has for long been relegated to the back burner due to the heavy caseload engaging the attention, time and energy

of the professionals. It seems the opportunity provided thus for collating, analysis and interpretation are not utilized fully. Poor efforts at documentation and publication leads to a tremendous loss both for the professionals as well as the advocates of the hearing impaired.

In keeping with the trend worldwide, there is need to strengthen evidence based clinical practices besides other thrust areas.

Chapter 11

Vision of the Future

The future beckons..... and a new age. Advances in many fields have contributed in no small measure to development in the field of rehabilitation. The spillover may be expected to benefit the disabled sectors well into the next decade. The major thrust of developments would include the following.

Prevalence Rate of Disability

As a result of intense preventive initiatives, medical intervention, better access to health care and nutrition and an increased general awareness, the prevalence rate has shown a marked downward trend. There is also a decline in the prevalence rate of hearing and speech disability from 467 to 342 in rural areas and from 339 to 254 in urban areas from 1991 to 2002.

With the availability of more sensitive tools, an increase in the geriatric population *inter alia* the demand for identification, diagnosis and management of the hearing-impaired is more likely to increase over the next two decades.

International Classification of Functioning, Disability and Health (WHO, 2002)

Assessment of the effect of disability in the context of personal and environmental factors should be addressed besides evaluating the nature and extent of the impairment suffered by an individual. Defining disability along the ICF guidelines needs to be hammered out. Efforts are already on to incorporate the ICF perspective in the curriculum as has already been done in

countries such as USA, Australia, Indonesia and Thailand. Similar strategies would need to be used by other countries.

Self Help Group (SHG), and Women with Disabilities (WWD)

The Biwako Millennium Framework (BMF, 2002) has placed greater emphasis on empowering the PWDs and WWDs. Self Help Groups hasten successful empowerment. A very successful model has been created through a World Bank assisted project called “Indira Kranthi Pathan” (previously called ‘Velugu’) in Andhra Pradesh. The package for the trainers includes: to resolve conflicts, to sensitize and mobilize the society, to identify income generating avenues within the local community, to enable convergence to services, etc. There is need to further consolidate the course design, and research the issues from various perspectives.

The Aging Society

Over 6% of India’s population is above the age of 60 years; a sizeable number of them may actually have a long term disability or chronic conditions during some periods, before the end comes.

The foreseeable solution to meeting the long-term care needs of PWDs during the Baby Boom Aging Wave is to concentrate on the comprehensive, community based provider systems, including home care, and congregate living scheme. The need to develop infrastructures and means to support the needs for expanded care

will be challenges faced by societies. Meeting these needs in institutional settings is precluded by prohibitive costs and practical barriers besides contradicting the wishes of the people to be served. The training programs and services provided must be sensitized to meet the needs of the senior citizens.

Capacity Building in Research Related to Services and Technology

A lot is done and but more is needed. Our production capacity for aids and appliances is less than 10%. Little R & D has gone into the application of electronics: strategies must be evolved to sift material, technologies, user comforts, need, demand, marketing, production, distribution, monitoring and evaluation. India has a first and also a third world. The needs of both these worlds along with the emerging sequences of development have to be anticipated and faced. A welfare state needs to augment human resource oriented technology to help persons with disabilities to be employed. The technological applications for employability of the disabled, prevention of disabilities through industrial accidents, and also Virtual Reality technology need to be augmented to achieve Social Justice.

Research and investigations should be undertaken to generate statistics about the employment status of persons with disability (Abdul Kalam, 2004). This is especially required for those who become disabled due to accidents and other disasters.

Adaptive research with a view to develop cost

effective, user friendly and durable aids and equipments for disabled persons with the help of various technological institutes should be undertaken in the areas of enhanced personal mobility and verbal/non-verbal communication. Design changes in articles of common usage should be encouraged. The key to maximizing effectiveness of research is the dissemination and sharing of information on the research outcome.

Phenomenal amount of work and experimentation is happening within the teaching community. Documenting the innovations and findings, in addition to undertaking research activities, need to be encouraged amongst the teachers. Many training programs do not have the input and wherewithal for research and documentation. Hence orientation for research and refresher courses would bring out fruitful researches and documentation, which would help fellow professionals to reduplicate the success of others and find solutions to their failures.

Conclusion

In the years to come institutional building as well as team building may be key elements that could influence the rehabilitation scenario. Teams comprising of 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.

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