

Assessing Parental Role as Resource Persons in Achieving Goals of Early Detection and Intervention for Children with Hearing Impairment

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ABSTRACT

Early detection and intervention for any degree of hearing loss is critical to the linguistic, social and educational development of children with auditory deficit. Since parents and family members are in a position to identify hearing loss at an early stage, they can play a vital role in achieving the goals of early identification and intervention for their children.

Purpose: *This study was conducted to determine the age at which parents and significant others begin to suspect hearing impairment in their children, and to advocate for using them as resource persons in the early detection of hearing loss.*

Method: *Parents of children with hearing impairment were retrospectively surveyed and interviewed to determine the age at which suspicion, diagnosis, fitting of amplification and initiation of interventions occurred.*

Results: *Interviews revealed the average age to be 16.5, 24.3, 31.7 and 33.4 months, for suspicion, diagnosis, fitting of amplification and initiation of early intervention for hearing loss respectively. The obtained age of suspicion is lower than the age of identification of hearing loss reported in Indian literature. The current study found delays in diagnosis and fitting of amplification, both of which are essential to initiate early remedial programmes which facilitate development of speech and language skills in children with hearing impairment. Surprisingly, it was found that these delays were caused by professional failures.*

Conclusion: *It is emphasised that parents are in the best position to detect hearing problems in their children, and can be effectively utilised as manpower/ equal partners in achieving the goal of early identification of hearing loss. The study outlines appropriate ways and means to facilitate early identification and*

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provide effective intervention for children with hearing impairment.

Implications: *In the absence of a universal hearing screening programme for newborn infants, parents can be used as manpower/resource persons to identify children with hearing impairment.*

Key words: *hearing loss, early detection and intervention, diagnosis, amplification, language remedial programme.*

INTRODUCTION

Hearing loss in children has a serious impact if left undetected and untreated. It leads to delayed development of speech and language skills, social and emotional problems, academic under-achievement, and interferes with quality development of the child (Markowitz & Larson, 1989; Northern & Downs, 1991; Arehart et al, 1998; Marschark, 1998; Dalzell et al, 2000; Wake et al, 2005; JCIH, 2007). With the recent advancement in rehabilitation technology, it is unnecessary for the child to suffer these consequences (Marttila & Karikoski, 2006). By detecting hearing loss as early as at the newborn stage, effective treatment which significantly reduces the disabling condition can be employed (Northern & Hayes, 1994; Carney & Moeller, 1998; Nicholas & Geers, 2006). Many research studies have demonstrated that early identification and intervention for hearing-impaired children results in improved speech and language development, communication skills, better social adaptation, enhanced academic success and increased lifetime earnings (Yoshinaga-Itano et al, 1998; Yoshinaga-Itano et al, 2000; U.S. Bureau of Census, 2000).

Unfortunately, despite the benefits of early identification and intervention, the average age at which identification of hearing loss takes place in India is rather late. A report by the Rehabilitation Council of India (2000) titled "Status of Disability in India – 2000" indicates that the average age of identification of children with severe to profound hearing loss is 5 years. Basavaraj et al (1984) reported a similar age of identification of hearing loss in Bangalore, India. This is much later than it should be for the development of communication required for linguistic, social and cognitive development in a child (Schlesinger & Acnee, 1984; Northern & Hayes, 1994; Harrison & Roush, 1996; Kittrell & Arjmand, 1997; Yoshinaga-Itano et al, 1998; Yoshinaga-Itano et al, 2000; U.S. Bureau of Census, 2000; Nicholas & Geers, 2006).

The Persons with Disabilities Act of India (Ministry of Law Justice and Company Affairs, 1996) guarantees early identification and intervention of disabilities. In spite of this provision in the Act, it is surprising that only few sporadic programs have been implemented on this aspect. At the same time, there is insufficient manpower to support such a programme. Although professionals are essential to design and implement early identification and intervention programmes (Arehart & Yoshinaga-Itano, 1999), parental involvement in the programme is an important determinant of its success in promoting the communicative abilities of the child (Reamy & Brackett, 1999). Thus, the objective of the present study is to explore and focus on the effectiveness of parents in detecting hearing loss and providing early intervention services to facilitate better development of communication skills in young children. The hypothesis is that parents, especially the ones who are well-informed and spend quality time with their children, are in the best position to detect hearing loss and could be used as a resource to achieve the goals of early detection and intervention for infants and young children.

METHOD

Participants

The study was conducted at Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH) based in Mumbai, India. The parents of 110 boys and 98 girls with confirmed severe to profound hearing loss, ranging in age from 8 months to 96 months (mean age 36.1 months), participated in the study. Participants who had attended the 1-day monthly training programme during the years 2010-11 and 2011-12, were interviewed retrospectively. The programme was specially designed to educate parents of hearing-impaired children about hearing loss, assessment, prevention and management. 103 mothers and 84 fathers responded to the questionnaire.

9 parents could not answer the questionnaire because of certain constraints. Another 12 were excluded because of limited data. The majority of the participants (70%) were from the municipal limits of Mumbai city, 21% were from adjoining districts and 9% from other parts of Maharashtra state. 21% of the participants had at least primary education and 79% had education up to secondary level and above (Table 1).

Table 1: Educational Background of Respondents

	Average Age	<Primary	Primary	High school	Pre-university	Under Graduate	Post Graduate	Doctorate
Father	39.04 yrs	18	16	13	18	12	06	01
Mother	33.16 yrs	20	23	33	21	05	01	00

Materials

A questionnaire was developed (Appendix I) to obtain information from parents and families regarding early identification and intervention for hearing loss in their children. The aim was to elicit information about the ages of suspicion, diagnosis and intervention for hearing loss, reasons for delay in diagnosis such as parental and professional failures to identify hearing loss, and reasons for delay in fitting amplification and facilitating speech and language programmes. Those who suspected hearing loss had got it diagnosed and provided intervention. The survey also contained questions about the parents' level of education, socio-economic status, and about the professionals they had consulted for early identification and from whom they were receiving the early intervention programme. At the interview, the participants were also asked about the duration of early intervention services provided and the present status of their children.

Data Collection and Analysis

The interview survey was conducted with the help of trained volunteers, under the supervision of the author. One or both parents responded to the questionnaire. Two sittings were required as all the participants did not respond to every question at the first sitting. The obtained data was analysed using Statistical Package for Social Sciences.

RESULTS

A total of 177 questionnaires were descriptively analysed because many participants did not respond to every survey question. The results from 135 participants indicated that hearing impairment was suspected at an average age of 16.5 months (Table 2). The ones who first had doubts about the child's hearing ability were the parents in 95 cases (70.37%), the grandparents in 20 cases (14.82%), General Physicians in 2 cases (1.48%), ENT Specialists in 8 cases (5.92%), Audiologists in 6 cases (4.44%) and Paediatricians in 4 cases (2.96%). Among

these 135 participants, 7(5.18%) reported that friends and others had questioned the hearing status of their children.

Table 2: Mean Ages (in months) of Suspicion of Hearing Loss by Family Members, Relatives, Professionals and Others

Suspicion of Hearing Loss	Obtained Responses	Mean	Median	Range	Standard Deviation
Father	32	11.1	10.2	00 - 30	08.79
Mother	63	12.5	11.0	00 - 18	09.17
Grandparents/Relatives	13	11.2	10.5	00 - 21	10.22
General Physician	02	28.0	28.0	24 - 25	17.33
ENT Specialist	08	20.3	19.5	00 - 29	07.43
Audiologist	06	8.7	7.0	00 - 16	09.19
Paediatrician	04	18.4	21.5	00 - 24	14.24
Friends/Others	07	22.5	24.2	00 - 39	11.67
Total	135	16.5	18.6	00 - 39	17.71

While 68 parents revealed that non-responsiveness to name call and environmental sounds were the primary reasons that led to suspicion, 27 parents stated that doubts had arisen due to noticing delay in speech and language as compared to the peer group, and finding their children staring at the face of the speaker. Professionals suspected hearing loss due to the presence of risk factors such as meningitis and congenital factors among 6% of the children for whom data was available. The age of suspicion (detection) in the joint family was found to be lower than in the nuclear family. Socio-economic status had no impact on the early detection of hearing loss. However, the educational background of parents and family members had a positive impact on early detection. The average age of confirmation of hearing loss was found to be 24.8 months, the age at which these children were fitted with hearing aid was 31.7 months, and initiation of language intervention programme was 33.4 months (Table 3).

Table 3: Mean Ages (in months) of Suspicion of Hearing Difficulty, Diagnosis, Fitting of Amplification and Initiation of Early Intervention Programme

Events	Obtained Responses	Mean	Median	Range	Standard Deviation
Suspicion of Hearing Loss	135	16.5	13.2	00 - 21.2	9.2
Diagnosis of Hearing Loss	139	24.3	21.0	1.5 - 23.0	8.70
Fitting of Amplification	165	31.7	26.5	2.5 - 26.6	11.5
Initiation of Early Intervention	67	33.4	24.2	1.0 - 37.7	14.1

It was found that the average delay between suspicion of hearing loss and diagnosis was 7.8 months, between diagnosis and fitting of hearing aid was 4.9 months, and between diagnosis and intervention was 1.97 months (Table 4). The participants reported that 97 children (54.80%) were diagnosed with hearing impairment by an Audiologist, with 17.4 months and 26.3 months being the average age of identification and fitting of hearing aids respectively. 61 children (34.46%) were diagnosed by an ENT specialist, with 18.6 months and 22.6 months being the average age of identification and fitting of amplification respectively. The remaining 19 children (10.73%) were fitted with hearing aids by hearing aid dealers and dispensers at an average age of 33.40 months.

Table 4: Average Ages (in months) of Delay in Suspicion of Hearing Difficulty, Diagnosis, Fitting of Amplification and Initiation of early Intervention Programme

Delay between Events	Obtained Responses	Mean	Median	Range	Standard Deviation
Suspicion - Diagnosis	78	7.8	4.25	00 - 35	7.79
Suspicion - Amplification	102	10.2	8.75	00 - 31	8.15
Diagnosis - Amplification	97	6.3	5.25	00 - 09	8.21
Amplification - Intervention	59	5.7	3.50	00 - 21	7.13

95 parents reported both the ages of suspicion and confirmation of hearing loss. Of these, 67 reported a delay of about 7 months between suspicion and confirmation of hearing loss, while 28 indicated a delay of more than 7 months, with 51 months

being the longest period of delay. Among the latter group, 21 explained that professionals had advised them not to worry, to wait till the child started going to school and/or that a few children start speaking late; 5 children were categorised as hyperactive and 2 were labelled as mentally/developmentally slow. Majority of the participants were of the opinion that professionals were responsible for the delay in diagnosis and in providing and guiding them towards early intervention services. The delay between diagnosis and intervention was unreasonably long, with 5.7 months as the average.

105 parents waited for approximately 6 months to obtain hearing aids, while 17 months was the longest waiting period for those who wanted to avail of the Government of India's subsidised scheme for aids and appliances. Those who bought the device from a hearing aid dispenser did not receive any training, as neither the Audiologist nor the hearing aid dealer had any facility for very young children and provided no information to the parents. Children from urban areas were fitted with hearing aids at a younger age as compared to children from rural areas.

At the time of the survey, 67 children were undergoing the language remedial programme. Though these children were diagnosed at the age of 17.5 months, intervention services were initiated at an average age of 28.2 months. While 23 children, a sizeable number, were attending preschool programmes at the age of 28.4 months, 17 were enrolled in Parent- Infant Programmes at an average age of 19.87 months. Speech and language pathologists at the AYJINHH centre were giving therapy to 13 children, and special educators were helping 5 children at home, at an average age of 37.2 months. 65 parents reported that their children could speak using two-word phrases, with a maximum vocabulary of 25-35 words. Majority of the children undergoing the language remedial programme came from joint families or nuclear families and had no other siblings. Those who attended the speech and language remedial programme were from better socio-economic backgrounds than the others.

DISCUSSION and CONCLUSIONS

There were encouraging results related to the ages of suspicion, diagnosis, fitting of amplification and initiation of language remedial programmes for children with severe to profound hearing loss. The current study found lower average ages of suspicion and identification of hearing loss than the figures reported in the Status of Disability in India -2000 (Rehabilitation Council of India, 2000).

The study results are consistent with the findings of Kittrell and Arjmand (1997) who reported 20.2 months as the average age of diagnosis. Arehart et al (1998) observed a similar age of identification. However, the study differs from the findings of Harrison & Roush (1996) which reported that children with a similar degree of hearing loss with risk indicators were identified at an average age of 12 months, and children with no risk indicators were diagnosed at 13 months of age. Nevertheless, with respect to delay in early intervention services, the findings of the present study are consistent with the findings of Harrison & Roush (1996) and Arehart et al (1998) which have reported delays of more than 1 year.

Early Detection, Diagnosis and Intervention for Hearing Loss

The study aimed to explore and emphasise parental contribution in the detection of hearing loss. The analysis has indicated that 68% of parents suspected hearing loss at the mean age of 12.46 months and had approached professionals for confirmation and intervention; unfortunately, the diagnosis and intervention were made available at an average age of 24.36 months and 28.36 months respectively. Reportedly, the primary reason for parents and family members to suspect hearing loss was their child's failure to respond behaviourally to environmental sounds and name call, as well as delayed speech and language development. The parents cited several reasons for delay, the most common one being the professional's failure to corroborate their suspicion and to give proper advice. Most of the parents were unaware that hearing loss could be identified in young children and intervention provided to them. Further, parents had visited the professionals at least 3 - 5 times before hearing loss was confirmed. This indicated that although parents were certain about their child's problem, they had waited patiently for the professional to conduct the necessary tests to confirm and categorise the hearing loss. Thus, it can be concluded that parents are in the best position to identify hearing loss in their children, and professionals need to be more responsive to parental concerns. Also, professionals must hasten the diagnostic and intervention processes so that the gap between diagnosis and intervention is reduced. This will be of more benefit to the children.

Initiation of Language Remedial Programmes

67 children in the survey were attending language remedial programmes. The parents reported 28.36 months as the average age for initiation of intervention. The observed delay between diagnosis and intervention was unreasonably long

(5.7 months. The shortest period that elapsed between fitting the hearing aid and the intervention programme was 2.1 months. 45% of these children were referred to early intervention programmes when they were aged between 3 to 5 months. Hence, it is reasonable to suppose that these children could be diagnosed and fitted with amplification at an earlier age if only parents and professionals had information and knowledge about developmental schedules of speech and hearing skills, the presence of risk indicators and the availability of resources and services. It has also been observed that the level of family education, socio-economic background, family size and other factors have an impact on early detection of hearing loss and provision of early intervention services for young children.

Those whose children were not attending any remedial programme cited reasons such as finance, family size (having more than one child in a nuclear family) and non-availability of services near their residence.

Though the present study found that the age for early suspicion and identification of children with severe to profound hearing loss was lower than the reported ages in Indian literature, it remained very far from the optimal age essential for speech and language development, which is under 6 months, as recommended by Yoshinaga-Itano et al (1998) and Position Statement 2007: Joint Committee on Infant Hearing (JCIH, 2007). Thus, early identification and intervention for children with hearing impairment is of critical importance, and in this regard a Head Start Programme must be started, employing all available means and methods.

Considering the scarcity of professionals, the author recommends that the family, especially the parents, are in the best position to identify hearing impairment in their children and can be used as a resource.

Limitations

The study sample may not represent the overall population as the participants were educated people and the majority belonged to the metropolitan city of Mumbai. Moreover, the survey was conducted for children with severe to profound hearing loss, and listening deficiencies for this group are easily identifiable. The results may also be limited because they are based on parents' reports of events that had occurred months and even years prior to the investigation. Furthermore, despite

being careful, the responses could have been influenced by the opinion of other parents who participated in the survey.

RECOMMENDATIONS

These suggestions are made in the absence of any dedicated national programme for identification of hearing loss. The present study reveals that about 70% of parents suspected hearing loss in young children by observing their auditory and delayed speech and language behaviour. These findings support the idea that parents are efficient and effective in observing the developmental behaviour of their children. Therefore parents, in particular those who spend quality time with children, can be utilised for the early identification and intervention programmes. Educating parents to identify the cardinal signs of hearing loss and training them in aspects of rehabilitation may help in lowering the ages of identification and can make intervention programmes more effective.

Clearly, if the goal of identifying hearing loss is to be on par with other developing countries, a nationwide awareness and educational programme for parents, caregivers and professionals must be initiated in a committed manner. To achieve this goal, the following recommendations are made:

- On discharge from the maternity home, every parent and family member should be given the developmental schedules of speech, language and hearing, along with the addresses of rehabilitation centres.
- Pamphlets describing the behaviour that signals the presence of hearing problems and the consequences of late identification should be distributed to local clinics, primary health centres and district hospitals.
- Parents, caregivers and medical professionals should be educated to spot behaviour that identifies hearing loss. Parental education and participation may help in lowering the early ages of identification and can facilitate intervention programmes.
- Representations about the need and procedures for early identification of hearing loss should be made at professional meetings of family doctors, Paediatricians, and ENT specialists.

- Orientation programmes should be organised to update the high-risk register for hearing disability and to expose primary and child healthcare professionals to use developmental screening tools to detect the disability.
- Most importantly, in the absence of trained professionals and appropriate laws, many people who lack essential knowledge and skill and are involved in providing services to hearing-impaired children, should be given the necessary training to meet the needs of the population under discussion.

In view of the study findings, the author believes that at present it is best to involve parents in the rehabilitation processes for children with hearing impairment.

ACKNOWLEDGEMENT

The author would like to thank Professor R Rangasayee, Director of AYJNIHH, Mumbai, for his constant support and encouragement, as well as Chandrahas Chandanshive for his suggestions and feedback regarding this article. The author is also very grateful to all those who participated in the study.

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APPENDIX

Assessing Parental Roles Resource Persons in achieving Goals of Early Detection and Intervention for Children with Hearing Impairment

QUESTIONNAIRE FOR PARENTS

NAME: _____ AGE/SEX: _____

ADDRESS: _____ CONTACT NO: _____

1. Could you please provide the following information?

	FATHER	MOTHER
NAME		
AGE/SEX		
EDUCATION		
OCCUPATION		
INCOME		

2. What is the age and sex of your child?

Male/Female

Age _____ years _____ months

3. Who suspected the hearing difficulty in your child?

Father/ Mother/ Grandparents/ Relatives/ Others

4. How many hearing-impaired children have you?

5. What is the hierarchy of your hearing-impaired child among your children?

6. How old was the child when you suspected the hearing loss?

1st child _____

2nd child_____ (Please mention the age of the child).

7. Who identified hearing loss in your child?
 Father/ Mother/ Grandparents/ Relatives/ Friends/Others/
 General Physician/ ENT/ Paediatrician/ Audiologist
8. What made you suspect the hearing difficulty in your child?
 - Child was not responding whenever called
 - Child was not developing speech and language
 - Any other
9. Whom did you consult about the hearing difficulty of your child?
 - GENERAL PHYSICIAN
 - ENT
 - PAEDIATRICIAN
 - AUDIOLOGIST
 - ANY OTHER
10. What did your consultant say about your child's hearing and about your suspicion?
11. At what age and who confirmed the hearing loss of your child?
12. Do you think that the consultant delayed in confirming the hearing loss in your child? Yes/No
13. What is the degree of hearing loss in each ear of your child?
 Right Ear _____dBHL Left Ear _____dBHL
14. At what age was the child fitted with hearing aid?
15. Is your child attending any language remedial programme? Yes/No
16. What type of language remedial programme is your child receiving and where?
 - Parent – Infant Programme

- Preschool Programme
 - Speech and Language Therapy
17. Since how long has your child been receiving a language remedial programme?
- Please mention in months.
18. Who is providing the Speech and Language Therapy Programme to the child?
- Speech and Language Pathologist.
 - Special educator
 - Any other
19. What is his/her present status?
- Does not speak at all
 - Speaks a few words
 - Speaks in phrases/sentences
20. Do you think that your child could have made more progress if he could have been identified with hearing loss earlier and have been fitted with hearing aid along with speech and language training?