

Parent Empowerment in Early Intervention Programmes of Children with Hearing Loss in Mumbai, India

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ABSTRACT

Purpose: *Since families are perceived to be active agents in the early intervention programmes of young children with disabilities, professionals ought to treat parents as equal partners and keep them informed and involved in various aspects of the intervention. This study aimed to explore the areas in which parent empowerment is currently being facilitated in the early intervention centres for children with hearing loss.*

Method: *A qualitative research with conversational analysis was the approach used. Focus group discussions with the two primary stakeholders, namely parents and special educators, were held separately at five sites in Mumbai, to gather their views on the existing areas of empowerment. It was also decided to explore the felt needs of parents in this regard. Space & Person triangulation was used to ascertain the credibility of the data.*

Results: *Conversational analysis yielded 4 themes with respect to parents: Parental knowledge, involvement, support and needs.*

Conclusion and Implications: *The study highlighted the gaps in parent empowerment in the programmes undertaken by early intervention centres. A recommendation is made to develop a common framework for empowering parents. It is envisaged that such a framework will bridge the gap between what currently exists for parents, their felt needs, and current global practices. This framework could also assist in measuring family empowerment outcomes.*

Key words: *Early intervention programmes, children with hearing impairment, parent empowerment, parental knowledge, parental involvement, parental support, parental needs*

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“When parents become involved, children do better in school, and they go to better schools.”

—Anne T. Henderson

INTRODUCTION

Deafness is the second highest birth anomaly in India (Garg et al, 2009). WHO (2009) estimates that 1 - 5 neonates and infants out of every 1000 babies have congenital or early childhood onset of sensory neural deafness of a severe to profound nature. Deafness is referred to as ‘hearing impairment’ in the Persons with Disabilities Act (1995) of Department of Empowerment of Persons with Disabilities in India. This is a hidden disability with many visible effects. Children born with severe to profound deafness, or those who acquire it within the developmentally critical phase of 0 - 5 years, fail to acquire spoken language which in turn affects their communication and further literacy skills. This is because neuroplasticity is most in the first 3 ½ years of life, during which period the major milestones of language are achieved. Hence, Mundkur (2005) observes that screening and timely intervention for hearing loss should be considered a neurodevelopmental emergency (Cole and Flexer, 2011). Guralnick (2001) defines early intervention as a system designed to support family patterns of interaction that best promote child development. As young children spend the greater part of early childhood with their parents, it makes sense for the parent to assume the role of the child’s first teacher. In the case of children with hearing impairment, it is all the more important that parents are encouraged, involved and trained to develop communication skills and handle the hearing devices of their children. A growing body of research suggests that family-centred models are more humane and more respectful for the dignity and involvement of parents which leads to better child outcomes (Carpenter, 1997). Thus, for parents to build their knowledge, skills and confidence as primary language facilitators, early intervention centres need to support and inform them in ways that are practical, accessible, and relevant.

Rationale of the Study

Parent training in early intervention programmes is the key (Kaiser and Hancock, 2003) to success. This is because 92% of deaf and hard-of-hearing (DHH) children are born to hearing parents (Mitchell and Karchmer, 2004). This creates a language “mismatch” between the parent and the child (Spencer and

Lederberg, 1997) where the child is not using the same language or modality to access language as hearing children of hearing parents do (or deaf children of deaf parents). Lederberg et al (2013) also observed that many families are unaware of the importance of their role in facilitating language development for their DHH children. Families may perceive that they are incapable of building language effectively in DHH children or that it is the job of the interventionist or the teacher to build language, rather than the job of the parent (Gioia, 2001; Stabbart and Alant, 2008). To help parents realise their roles and duties, they need to be informed so that they develop self-confidence and participate in the intervention programmes for their young children.

Appreciating the importance of parental participation, the IDEA Act of Department of Education USA, (2004) suggests a family-centred intervention in natural environments and has made Individualised Family Service Plan (IFSP) mandatory (Bruder, 2010). However this is not the case in India, as policies and legislations have not yet made it obligatory to have an IFSP. A survey of the early intervention practices for deaf children in India by Gathoo (2012) documents that although the centres insist on parents' participation, they do not have any mechanism to facilitate or measure family participation. Gowramma (2012) also observed that measuring family outcomes is not a practice in educating young children with hearing loss in India. Being cognisant that empowering parents is cost-effective and parents participating in their child's intervention have better outcomes (Kaminiski et al, 2008), the present study was conceptualised. The purpose was to identify the current practices of parent empowerment in the early intervention programmes for children with hearing loss in the Indian context.

Statement of Purpose

The purpose of the study was to conduct a baseline study on practices of parental empowerment in the early intervention centres. The views on the existing areas of empowerment were gathered from two primary stakeholders, namely parents and special educators. It was also decided to explore the felt needs of parents in this regard.

Objectives

1. To explore the current areas of parent empowerment in the early intervention programmes of children with hearing loss.

Research questions:

- 1a. What information pertaining to managing hearing loss is provided by the early intervention centres?
- 1b. Describe the involvement of parents in the intervention sessions?
- 1c. In what way do the early intervention centres support the families?
2. To describe the felt needs of parents in early intervention programmes of children with hearing loss.

Research question:

- 2a. What are the needs of parents of children with hearing loss?

METHOD

A qualitative research with conversational analysis was used as an approach for the present study.

Research Sites

Five early intervention centres in Mumbai, catering to the needs of children with hearing loss who were below 5 years of age, were chosen. Centres from the city as well as the suburban areas were included in order to obtain views from different areas of the metropolis. The centres were attached to special schools for children with hearing impairment.

Sample

Purposive sampling technique was used to select 50 parents and 30 special educators from these 5 early intervention centres for children with hearing loss. The 50 participating parents included 43 mothers and 7 fathers of children with hearing impairment. Their socio-economic background was more or less the same as they belonged to the lower socio-economic bracket. The 30 special educators who participated in the study were female teachers who had a professional qualification and work experience of 5 years in early intervention.

Data Collection

With the permission of the centre heads and participants, focus group discussions were held separately with 10 parents and 6 special educators at each of the five sites. Discussion protocol, consisting of research questions covering the major

objectives of the study, was used as a tool for data collection. Informed consent was obtained to audio-tape the proceedings of the focus group discussions. The participants were assured that their identities would be kept confidential.

Validity of Data

The technique of space & person triangulation was used to judge the credibility of data collected through focus group discussions. According to Dipeolu (2010), triangulation is equivalent to reliability in a quantitative research. It involves using multiple data sources in an investigation to produce deeper understanding. In the present study, this was achieved by asking the same questions to the two groups of participants, namely, parents and special educators from different early intervention centers. The information and views obtained from the recruited participants were transcribed into text and later coded and categorised. Five themes which emerged describe the current focus of parent empowerment and felt needs of parents in early intervention centres for children with hearing impairment. (See Table 1 below)

Data Analysis

The audio data was transcribed into a written format. The data was treated as under:

- Division into text
- Coding
- Identifying themes

Table 1: Themes and the Underlying Codes

	Current areas of Parent Empowerment			Felt needs of Parents
Themes/ Categories	Theme 1 Parental Knowledge	Theme 2 Parental Involvement	Theme 3 Parental Support	Theme 4 Parental Needs
Codes	1a.Disability certificate, schemes, concessions and facilities	2a.Parental involvement in instructional practices	3a.Financial support	4a. Parental need for information
		2b.Listening, language & speech development	3b.Skill development	
		2c. Volunteering		

RESULTS and DISCUSSION

Results pertaining to current areas of Parent Empowerment

Theme 1: Parental Knowledge about Service Delivery

1a. Disability Certificate, Schemes, Concessions and Facilities

As per the Persons with Disabilities Act (1995) of Department of Empowerment of Persons with Disabilities in India, children with disabilities are entitled to facilities and concessions in academics, public transport and other aspects pertaining to financial support. These are granted in accordance with the degree of hearing loss as documented in the child's disability certificate.

The parents were asked about the information provided to them by the early intervention centres pertaining to managing hearing loss. The first topic that they raised was about concessions and facilities. Parents mentioned that they had been informed about the disability certifying agency and were aware that in Mumbai the disability certificate was issued by J.J. hospital, while the civil hospital issued certificates in the adjoining Thane district. A few parents added that they were updated about the online mode of disability certification and knew about the renewal requirements after every 5 years. They also discussed travel concessions. Parents seemed to know that their child was eligible for 50% concession while travelling by train, though no concession was available for an accompanying person. They were also aware that there was no travel concession on the local BEST bus service, but travel concessions were available on outstation State Transport buses.

In Mumbai, most parents of children with disabilities use public transport to commute to the early intervention centres. It was therefore rather surprising that none of them mentioned their concern that the parent accompanying a young child did not getting any travel concession. In fact, travelling to the early intervention centres on a daily basis would be quite expensive for them. It was expected that parents would talk about sensitising the government agencies to the fact that these concessions were essential for them to escort their young children, between 0-5 years of age, for early intervention sessions. They seemed to have accepted their situation since free travel was available for all children up to 5 years of age. It is to be noted that parents' discussions centred only on travel concessions. They seemed unaware about academic concessions being offered at a later stage in schools for children with disabilities.

In sharp contrast to parents, the teachers' group discussion focussed on academic facilities and concessions. The teachers in general mentioned that their programmes were child-centred, with the focus on the child and not the parent. At one site, teachers also justified why they did not provide information about facilities and concessions to parents. They felt that since many of the parents were illiterate, they would not understand the procedure of certification and the system of concessions and facilities; hence their special schools assist the parents.

Researchers' Perspective

Focus group discussions with parents revealed that they were highly motivated and attended the early intervention centres on a regular basis. However, these centres were not empowering parents with the skill of advocating for their rights. Majority of the parents seemed to have accepted the fact that only their children would be eligible for travel concession after the age of 5 years. They did not seem to think the family was entitled to travel concessions. Most of them belonged to the lower income group, so it must have been difficult to buy 2 tickets on a daily basis to accompany their young children to the centre. The early intervention centres could promote advocacy regarding the issue of facilities and concessions.

Focus group discussions with the teachers at various sites indicated that they withheld some information about academic concessions and facilities. Though the intention was to make the children proficient in academics and less dependent on facilities and concessions, another perspective is that parents have the right to be given complete information. If they themselves are not aware about academic or any other concessions given to their children by law, they will find it difficult to advocate for the rights of their children after transitions. Rappaport (1981), Dunst (1985), and Turnbull et al (2000) have presented the concept of 'collective-empowerment' in early intervention. They reported that being in possession of information has the potential to change power dynamics so that the decision-making process is based as much as possible on fully informed participants, as opposed to a process in which power is based on who owns the resources. This inadequacy of information leads to the feeling of 'powerlessness' among parents. They emphasised that power has to be shared equally by families and professionals. Thus how, and to what extent, information is made available to families becomes a critical component of empowerment in early intervention.

On consolidating results about service delivery, it appears that it is not legally

binding on the early intervention centres to provide information to parents. Information is provided to parents at the discretion of the centres.

Theme 2: Parental Involvement

2a. Parental Involvement in Instructional Practices

Classroom observation of instructional practices is one of the widely used strategies for parent empowerment. When the parents in the current study were asked about their classroom observations, many of them reported that it was made mandatory by their centres. Enquiries about the nature of the activities they were involved in revealed that there was no uniformity in the type and duration of activities organised for parents. At some centres parents reported that only the parents of newly enrolled children had obligatory classroom observations and these were gradually reduced as the children settled down in school. Almost all centres required parents to maintain a diary of observation, to note down the teaching strategies. Parents also mentioned that in general the teachers would invite them for a discussion every Friday, to talk about topics for the following week's sessions and to share what had already been taught in the class.

When the teachers were asked about parents' classroom observations and participation, many of them emphasised that this was done so that the parents could make children revise the lessons taught in school. They felt that classroom observation was sufficient for parents to know about the instructional strategies; they did not feel the necessity to discuss or plan the learning outcomes of children as this was the professionals' job. This result is in congruence with a study conducted by Gowramma (2007) which identified several barriers to effective parental participation. Significant among these was the lack of information about planning educational goals.

2b. Parental Involvement in Listening, Language and Speech Development

Parents were asked about the method/approach for language development that was followed by their centres. Majority of them reported using the natural conversational method. They said that as per the centre's instructions, there was more emphasis on the use of communicative language. When asked about any specific techniques used for language development, they reported 'play' as a technique used for developing language at home. Parents indicated that they picked up various aspects and strategies by observing the teachers. They also

reported that they had observed the teachers undertaking speech correction and auditory training activities for their children. Later, they were asked to correct speech or develop listening skills at home by using similar strategies. They reported that no formal training sessions were organised by their centres on topics like 'language development strategies' or 'milestones to be achieved by their children'.

Focus group discussions with the teachers suggested that their centres occasionally organised lectures on developing conversational skills in children. At one site, teachers emphasised that line drawings were taught to parents so that they could depict the events. Parents were also encouraged to read newspapers to the children. No systematic efforts to train parents on ages and stages for language development were being undertaken at these early intervention centres.

2c. Parental Involvement in Volunteering

On being asked about volunteering at their child's centre, parents said that they participated in the activities that were planned and organised by their centres. The centre assigned them specific volunteer work like preparing salad, distributing milk, bananas and lunch plates for the students, and other play activities. Parents at one site reported that they are sometimes asked by the centres to conduct sessions which were generally the revision or follow-up of the content already taught by the teacher. Parents opined that they did not feel confident to introduce a new concept or a new topic.

When teachers were asked their opinions regarding volunteer activities, the opinions were divided on allotting teaching assignments to parents. Some special educators opined that parents were capable, while others felt parents should only be assigned duties at lunch time or free play activities. One suggestion that emerged during teachers' focus group discussions was that encouraging volunteering of parents as proxy teachers is beneficial, as this helps to get feedback about their teaching strategies and would in turn help to improve their teaching skills.

Researchers' Perspective

The researcher's findings, collated under the theme 'Parental Involvement', may be seen with reference to 'Partnership Model of Empowerment' of Hanvey and Philpot (1994), opining that the 'parent empowerment' practiced in early intervention centres are professional-directed services. The two-way relationship

fostering partnership is the essence of 'equality' which the teachers undertake. In the present study, it was found to be practised in some aspects of developing listening, language and speech of children with hearing impairment.

Empowerment theorists also recognise that collective action must grow out of living experiences shared by individuals who are willing to work together to address a common social problem. The process of individuals sharing information and collective experiences related to a social problem is called raising critical consciousness (Lee, 1994). The findings of the present study, under the theme voluntarism, also show that some effort is being made in this regard. Teachers do provide opportunities for parental networking and voluntarism but this needs to be done in a more systematic way.

Theme 3: Supporting Families

3a. Financial Support

Caring for children with special needs requires more effort and resources than caring for a child with typical needs (Floyd and Gallagher, 1997). In addition to the responsibilities of growth and development, parents of a child with disability are also burdened with additional responsibilities, such as teaching specific skills and practising rehabilitation programmes. For this reason, the parents of such children require additional support (Roberts and Lawton, 2001; Emerson, 2003).

In the present study, parents reported that they had received advice on ways to generate the additional funds required to support expenses of travelling and maintenance of batteries for hearing aids. A few parents said that their early intervention centre had provided them with a list of donors (individuals as well as institutes) who were willing to provide assistance for the cause of hearing impairment. Usually, the social workers in these centres helped the parents in fund-raising to buy hearing aids for their children.

When the teachers were asked about the kinds of financial support provided to the parents in early intervention centres, majority of them indicated that funding was provided only for buying hearing aids. The early intervention centres would sponsor hearing aids for needy children. However, in the case of cochlear implant surgery, they referred the parents to hospitals and these hospitals gave the parents a list of donors.

3b. Skill Development

At the focus group discussions, parents revealed that short-term professional training courses in mehendi designs, facial make-up, making small purses, phenyl-floor cleaner and pickles, were arranged and facilitated for them by the early intervention centres. At one site, a one-day workshop on self-employment, titled 'Gruhaudyoj', was organised for mothers of young children. At another site, the teachers said that they had actually appointed a few mothers as 'sevikas' (meaning helpers) when their regular non-teaching staff were on leave. Teachers also mentioned having organised 'Anandamelava', a fun-fair, for parents to generate income.

Researchers' Perspective

The researcher felt that since the parents in the study sample belonged to the lower socio-economic group, the need for financial resources would be felt. Procurement and maintenance of hearing aids would be a difficult task. This would have led to suggestions for relaxation of criteria for financial concessions and for more skill development programmes for livelihood.

Results pertaining to Felt Needs of Parents

Theme 4: Parental Needs

4a. Parental Need for Information

The felt needs focussed around educational planning and outcomes. During the focus group discussions, parents expressed the desire to know about various schemes, concessions, and facilities available for their children with hearing loss, eligibility for availing of these schemes, and the procedures to be followed. They were also keen to have more information about amplification devices and the care and maintenance required. Some parents felt that Auditory Verbal Therapy (AVT) was only for children with cochlear implants but they realised during the discussions that AVT could be used as an approach for hearing aid users as well. Other needs expressed were: information about developmental milestones, 'time management' and school readiness strategies.

Researchers' Perspective

The focus group discussions clearly suggest that skill development programmes

for parents of young children with hearing impairment can be developed. It has also highlighted the fact that almost all early intervention centres insist on parents' participation but family outcomes are not measured (Gathoo, 2012).

Conclusion and Implications

The present study highlighted the lacunae in terms of parent empowerment at these early intervention centres. It appears that parent empowerment is not a structured or a formal component of the early intervention programmes but is the initiative of an individual centre to engage parents in the activities that the centre considers important. There is a need for a more structured effort to be made regarding family empowerment. The underlying feeling was that parents wanted to be heard and involved in the decision-making process for their children.

The way forward would be to develop a common framework for empowering parents. This could bridge the gap between what already exists for parents, their perceived needs, and global practices. The components of the framework could be developed on various domains such as : (1) Disability-related domain - comprising of information on hearing assessments, facilities, concessions, service delivery; (2) Developmental domain - involving knowledge of critical period, developmental milestones and deviations; (3) Partnership domain - involving knowledge about language planning, teaching collaboratively, transitioning; and, (4) Advocacy domain - involving articulating needs of the child, shared decision-making, networking and mentoring. Such a framework could also be used to measure outcomes of family empowerment.

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REFERENCES

- Bruder MB (2010). Working with families of young children with special needs. New York, NK: The Guilford Press
- Carpenter B (1997). Families in context: Emerging trends in family support and early intervention. London: David Fulton.

Cole E, Flexer C (2011). *Children with hearing loss: Developing listening and talking*. Birthtosix. (2nd ed.), San Diego, CA: Plural Publishing.

Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (1995). Available at <http://disabilityaffairs.gov.in/content/page/acts.php>. [Accessed on 2 May 2014]

Dipeolu A (2010). Methods used to validate qualitative research. Available from <http://docslide.us/documents/methods-used-to-validate-qualitative.html> [Accessed on 16 April 2016].

Dunst CJ (1985). Rethinking early intervention. *Analysis and Intervention in Developmental Disabilities*; 5: 165-201. [https://doi.org/10.1016/S0270-4684\(85\)80012-4](https://doi.org/10.1016/S0270-4684(85)80012-4)

Emerson E (2003). Mothers of children and adolescents with intellectual disability: Social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. *Journal of Intellectual Disabilities*; 47(4-5): 385-99. <https://doi.org/10.1046/j.1365-2788.2003.00498.x>

Floyd FJ, Gallagher EM (1997). Parental stress, care, demands and use of support services for school-age children with disabilities and behaviour problems. *Family Relations*; 46(4): 359. <https://doi.org/10.2307/585096>

Garg S, Chadha S, Agarwal AK (2009). Burden, prevention & control in India. *Natl Med J India*; 22: 79-81. PMID:19852345

Gathoo V (2012). *Early intervention of children with hearing loss. Status of disability in India -2012*. New Delhi: Rehabilitation Council of India.

Gioia B (2001). *The emergent language & literacy experiences of three deaf preschoolers*.

Gowramma IP (Unpublished). *Analysis of stress among parents of children with hearing impairment*. M.A-Psychology thesis. University of Madras, Chennai, India.

Guralnick M (2001). A framework for change in early childhood inclusion. In M.J Guralnick (Ed). *Early Childhood Inclusion: Focus on Change*. Baltimore, Maryland: Paul H. Brookes.

Hanvey C & Philpot T (1994). *Practising social work*. Routledge: London. <https://doi.org/10.4324/9780203421697>. PMID:8154906. PMCid:PMC1061015

Kaiser AP, Hancock TB (2003). Teaching parents new skills to support their young children's development. *Infants & Young Children*; 16: 9-21. <https://doi.org/10.1097/00001163-200301000-00003>

Kaminski JW, Valle LA, Filene JH, Boyle CL (2008). A meta-analytic review of components associated with parent training program effectiveness. *Journal of Abnormal Child Psychology*; 36: 567-589. <https://doi.org/10.1007/s10802-007-9201-9>. PMID:18205039

Lederberg AR, Schick B, Spencer PE (2013). Language and literacy development of deaf and hard-of-hearing children: Successes and challenges. *Developmental Psychology*; 49(1): 15-30. <https://doi.org/10.1037/a0029558>. PMID:22845829

Lee J (1994). *The empowerment approach to social work practice*, New York.

Mitchell RE, Karchmer MA (2004). Chasing the mythical ten percent: Parental hearing status of deaf & hard of hearing in United States. *Sign Language Studies*; 4(2): 138-163 <https://doi.org/10.1353/sls.2004.0005>

Mundkur N (2005). Neuroplasticity in children. *Symposium on Developmental and Behavioural Disorders. Indian Journal of Paediatrics*; 72(10): 855-857. <https://doi.org/10.1007/BF02731115>. PMID:16272658

US Department of Education, (2004). *Building the legacy: IDEA 2004*. Available from: <http://idea.ed.gov/part-c/search/new>. [Accessed on 10 May 2012]

Rappaport J (1981). In praise of paradox: A social policy of empowerment over prevention. *American Journal of Community Psychology*; 9:1-25. <https://doi.org/10.1007/BF00896357>

Roberts K, Lawton D (2001). Acknowledging the extra care patients give their disabled children. *Child Care Health and Development*; 27: 307-319. <https://doi.org/10.1046/j.1365-2214.2001.00178.x>

Spencer PE, Lederberg AR (1997). Different modes, different models: Communication & language of young deaf children & their mothers. In LB Adamson & MA Ronski (Eds.), *Communication & Language acquisition: Discoveries from atypical development*. Baltimore: Brookes: 203- 230. PMID:9201472

Stabbort C, Alant E (2008). Home based literacy experiences of severely to profoundly deaf preschoolers & their hearing parents. *Journal of Developmental Physical Disabilities*; 20: 139-153. <https://doi.org/10.1007/s10882-007-9085-1>

Turnbull AP, Turbiville V, Turnbull HR (2000). Evolution of family partnerships: Collective empowerment as the model for the early twenty- first century. In J.P Shonkoff & S.J Meisels (Eds) *Handbook of early childhood intervention* (2nd ed). Cambridge University Press: 630-650. <https://doi.org/10.1017/CBO9780511529320.029>

World Health Organisation (2009). *Newborn and infant hearing screening: Current issues and guiding principles for action*. Available from: http://www.isa-audiology.org/pdf/Newborn_and_Infant_Hearing_Screening.pdf. [Accessed on 23 May 2012].