

Caregivers' Involvement in Early Intervention for Children with Communication Disorders

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ABSTRACT

Purpose: *Since very young people benefit from early identification of communication disorders, the primary caregivers (generally the parents) become the fulcrum of the intervention services provided. This article deals with the measures taken to empower caregivers, as part of the early intervention services offered at the All India Institute of Speech & Hearing (AIISH) in Mysore city in India, and the impact this has had on their wards' progress.*

Method: *A survey was conducted among the caregivers of 205 clients who availed of early intervention services. Five-pronged data were collected, pertaining to family demographic details, early intervention measures for their children with communication disorders, type and intensity of caregiver empowerment measures provided along with early intervention services, resultant caregiver participation in the education and training of their wards, and the consequent development in children with communication disorders. The mutual influences among these factors were analysed using simple correlation measures.*

Results: *The findings revealed that informal, but continuous and consistent efforts to empower parents, such as counselling and guidance, had a better impact. Empowered caregivers in turn contributed towards the education and training of their children with communication disorders, resulting in improved development of their wards' communication skills and academic achievements.*

Conclusion: *The evidence adds strength to recommendations that caregiver empowerment and participation need to become integral components of early intervention services for young children with special needs.*

Key words: *caregiver, empowerment, parental participation.*

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INTRODUCTION

Difficulties in communication have an adverse impact on all aspects of an individual's life, starting with the fulfilment of basic needs and extending to the realms of education, employment, and participation in family and community life. The nature and severity of the difficulty, as well as the time of onset, have a crucial influence on the intensity of the impact. Difficulties in communication may arise from the presence of disabilities that are sensory, intellectual, emotional-behavioural, or motor in nature. These disabilities may occur at birth or at early developmental stages, or even later in life. The impact is profound and enduring when they occur early in an individual's life. In such situations, early identification as well as timely intervention could go a long way in easing the adverse effects and enabling near-normal development (Downs and Yoshinaga-Itano, 1999; AYJNIHH, 2000; Watkin et al, 2007; Yoshinaga-Itano, 2003; Vohr et al, 2008). In congenital or pre-lingual occurrences of communication disorders, since the affected individuals are very young children the onus is on parents or other primary caregivers to provide for early identification and timely intervention.

Relevance of Early Intervention to Caregivers of Children with Communication Disorders

Early intervention services are vitally important for parents and families of children with communication disorders. In several instances, families of these children experience emotional turmoil and face social isolation, along with the practical difficulties of managing their children. There is evidence that these challenges affect family dynamics, which in turn compound the children's difficulties. Therefore, caregivers and families have to be at the centre of services organised for young children with communication disorders. Other valid reasons for inclusion of caregivers as integral participants in the rehabilitation process of young clients are that they are better aware, though informally, of their child's abilities and limitations; spend maximum time with their child and have more frequent interactions; happen to be the natural and first teachers of their wards; supposedly have the best intentions; and are better disposed to expend their resources for the development of their child (Girolametto et al, 2001; Girolametto and Weitzman, 2006; CDI, 2010).

Involvement of caregivers in the early intervention process generally begins with clearing up misconceptions about their child's disorder or disability, accompanied by counselling and guidance to overcome their emotional turmoil. They are then

educated about consequent implications and necessary interventions, so that they are able to make crucial decisions about their child's rehabilitation. Ultimately, the parents are empowered to acquire knowledge and skills to support the intervention process. Systematic and committed efforts on this front have resulted in caregivers improving their attitudes vis-à-vis themselves and their children, as well as capacitating them to train and teach their wards (Beckman-Bell, 1981; Tanock and Girolametto, 1992; Baxendale and Hesketh, 2003; Girolametto et al, 2003).

Caregivers' Influence on Early Intervention for Children with Communication Disorders

Apart from the benefits of involvement for caregivers themselves, it has been found that they can influence the early intervention process for their children with communication disorders. Evidence suggests that caregivers' knowledge and attitudes towards their children's education are strong indicators of their contribution to their children's education and progress (Stephens and Slavin, 1992). Field studies in India in particular and the Asian region in general (Fan and Chen, 2005; Kumar and Rao, 2009), reaffirm the conviction that better educational status of caregivers leads to improved knowledge, attitudes and expectations among them. This has led to better rehabilitation efforts on their part, as well as better outcomes. Along with these indicators, evidence from developed communities (Ritter-Brinton, 1993) shows that the family ambience, in terms of fluency of communication maintained at home with the children who have difficulties in communicating, endorses the positive influence of rehabilitative as well as educational efforts. Beyond awareness and attitudes, size of the family (Mortimore et al, 1988), and socio-economic status (Kurian, 1978; Sharma, 1980; Desjardin, 2005) are also said to positively influence the rehabilitative prospects for children with special needs.

More than just education and economics, tangible involvement in the rehabilitation process is found to create a positive and more enduring impact. This would involve extending and monitoring learning at home, constant interaction with the service providers, and participation in training and/or educational processes (Epstein, 1987; Yathiraj, 1994).

For nearly 5 decades the All India Institute of Speech and Hearing (AIISH), based in Mysore city in India, has been a pioneer in the south-Asian region, by extending early identification and timely intervention for young children with

communication disorders. Majority of these young clients and their caregivers access AIISH from places beyond Mysore and in some instances from even outside India. In many cases, after successful early intervention, they have returned to their home states which did not have the necessary ongoing support services. Hence, early intervention services for communication disorders at AIISH have always insisted on empowerment of caregivers and their continuing involvement in the rehabilitation process.

Between February 2010 and February 2012, an AIISH Research Fund (ARF) sponsored follow-up study titled 'Efficacy of Multidisciplinary Preparatory Services at AIISH in Mainstreaming Children with Communication Disorders' was undertaken, to appraise the efficacy of the early multidisciplinary preparatory services provided. While the major focus was on the impact of early intervention measures on educational rehabilitation, the study also shed light on caregiver empowerment measures embedded in the course of early intervention services and subsequent developments. This article highlights the findings of these investigations.

METHOD

Participants

The original study covered 205 children with communication disorders who had received early intervention services at AIISH since 2003. The caregiver-participants in the investigation included a natural parent of each child-participant. Figure 1 provides demographic details of the participants, as well as the nature of special needs among their children. Majority of the participants (51%) had completed school education, while around 27% had 10+2 or equivalent qualifications, and 19% had completed higher education in colleges. Six caregiver-participants (approximately 3%) had professional qualifications, while there was 1 participant (approximately 0.5%) who was illiterate. Income-wise, majority of the participants (approximately 60%) were from middle-income groups, while about 27% and 12% of the participants were from lower and higher income groups, respectively. Majority of the 126 parents who participated in the study had children with the sensory problem of hearing impairment, 40 had children with multiple special needs, and 32 had children with intellectual disability. There were 4 who had children with autistic spectrum disorders, and 3 had children with cerebral palsy.

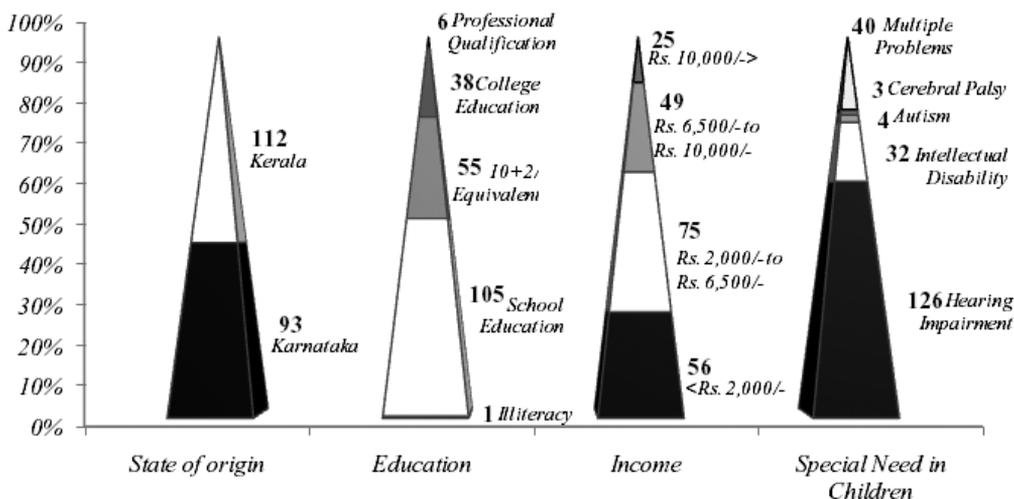


Figure 1: Details of the Participants

Tool

The researchers compiled and utilised a 20-item tool to collect essential information from the participants. The composition of the items are as follows: (1) four items focussed on the demographic information of caregivers and their families (2) four items on the type and intensity of caregiver empowerment measures that supplemented early intervention services at AIISH, and (3) three items on their current participation in the education and training of their wards. The items probed the type of empowering measure, and the number, frequency and/or duration of the activity, as well as the nature of support offered by the caregiver towards the education and training of the ward; and the frequency of those measures were also recorded. (4) Four other items were utilised to collect information about the early intervention-related data such as age of identification, age of intervention, range of services and duration of services, and (5) another five items for information on the current level of receptive and expressive communication skills, as well as school performances of the children including performances in core-curricular subjects (in terms of marks and/or grades obtained), participation in co-curricular activities and social integration at school (which were graded on a 5-point Likert's scale by concerned educators).

Procedure for Data Collection and Analysis

Data on family status, caregiver empowerment and participation in the education and training of their children were collected through face-to-face interviews

with the caregiver-participants. Information about nature and range of early intervention services were collated from clinical records, while data on the school performances of the children were collected from the respective school teachers.

The influence of independent variables, such as the demographic status of caregivers as well as the nature of caregiver empowerment measures on dependent variables, namely, dimensions of caregiver participation in training and teaching their wards with communication disorders, and consequent outcomes in terms of development of communicational skills and school performances, were correlated using appropriate statistical measures.

RESULTS

Influence of Familial and Caregiver Factors on Early Intervention

The major factors that were considered were type of family (nuclear or joint), number of siblings, level of caregiver education and caregiver income. The influence of these factors on the age of identification of the communication disorder, age of commencing rehabilitation intervention, and the range (number) as well as duration of intervention services received, was analysed. The results are presented in Table 1.

Table 1: Correlation of Early Intervention (EI) Parameters and Environmental Factors

S. No.	Influential Factors / Early Intervention Status	Age of Identification	Age of Intervention	Range of Services	Duration of Services
01.	Type of family	-0.009	-0.035	+0.110	+0.085
02.	Number of siblings	-0.010	+0.144	-0.125	+0.071
03.	Caregiver education	-0.192**	-0.069	+0.097	+0.036
04.	Caregiver income	-0.085	-0.044	+0.125	-0.070

* - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$; no* - no statistical significance

Larger or joint families exhibited positive correlation with the age of identification as well as intervention, and range as well as duration of services, though this was not significant. More number of siblings for the child with communication disorders related negatively with age of identification, but positively with age of

intervention. It is also related negatively to range of services and positively with the duration of services.

Both the educational ($p < 0.01$) and socioeconomic status of the caregivers exhibited negative association with age of identification and intervention. Better caregiver education was also connected with increased range as well as duration of services. On the other hand, caregivers from higher income groups were associated with increased range, but decreased duration of services.

Outcomes of Caregiver Empowerment through Early Intervention Services

The next stage involved discovering how caregiver empowerment efforts promoted their contribution to the education and training of their children. For this purpose, 3 major measures of caregiver empowerment, namely: support through regular counselling and guidance, information dissemination and training through brief programmes like workshops, and detailed formal training through courses like 'Certification Course for Caregivers of Children with Communication Disorders' (C4D2), 'Diploma in Training Young Deaf & Hard of Hearing' (DTYDHH), etc., were recorded in terms of frequency, number and duration, respectively. The relationship of these factors to the present day contribution of caregivers, such as frequency of home training in academic subjects, home training in communication skills and preparation of special teaching-learning materials for home training, were investigated.

Table 2: Correlation of Nature of Caregiver Empowerment with Caregiver Participation in Education / Training of their Children with Communication Disorders

S. No.	Nature of Empowerment / Caregiver Participation	Training in Communication	Home Training	Material Preparation
01.	Counselling & guidance	+0.330***	+0.418***	+0.337***
02.	Workshops	+0.192**	+0.143*	+0.163*
03.	Formal training	+0.200**	+0.219**	+0.173*

* - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$; no* - no statistical significance

The results show that all efforts at caregiver empowerment had positive and, most often, a significant impact on the various modes of caregiver contribution

towards the education and training of their wards. Informal and ongoing support like counselling was found to have a more enduring effect. Further, the influence of various types of empowerment efforts, as well as the on-going contributions of caregivers in the development of communication and in school performances, were assessed. The results are shown in Tables 3 and 4, respectively.

Table 3: Correlation of Nature of Caregiver Empowerment and Contribution to Communication Skill Development in their Wards with Communication Disorders

S. No.	Influential Factors Early Intervention	Status /	Listening Skills (only for CWHI ^o)	Speech-Language Skills
01.	Nature of caregiver empowerment			
	(i) Counselling & guidance		+0.114	+0.112
	(ii) Workshops		+0.172*	+0.154
	(iii) Formal training		+0.018	+0.010
02.	Nature of caregiver contribution			
	(i) Home training		+0.427***	+0.482***
	(ii) Training for communication skills		+0.344***	+0.436***
	(iii) Teaching-learning material preparation		+0.342***	+0.387***

* - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$; no* - no statistical significance

^o CWHI – Children with Hearing Impairment

Table 3 reveals that the nature of all efforts to empower caregivers as part of the early intervention programme, as well as caregivers' participation in their children's education and training, have positively correlated with the development in listening, speech and language skills, and at a statistically significant level ($p < 0.001$).

Table 4: Correlation of Nature of Caregiver Empowerment and Contribution to School Performances of Wards with Communication Disorders

S. No.	Influential Factors / Early Intervention Status	Core-curricular Performance	Co-curricular Participation	Social Integration in Learning Environment
01.	Nature of caregiver empowerment			
	(i) Counselling & guidance	+0.165*	-0.031	+0.054
	(ii) Workshops	+0.227**	+0.200**	+0.211**
	(iii) Formal training	+0.131	+0.080	+0.021
02.	Nature of caregiver contribution			
	(i) Home training	+0.580***	+0.275***	+0.319***
	(ii) Training for communication skills	+0.510***	+0.217**	+0.262***
	(iii) Teaching-learning material preparation	+0.412***	+0.168*	+0.211**

* - $p < 0.05$; ** - $p < 0.01$; *** - $p < 0.001$; no* - no statistical significance

Results on Table 4 demonstrate a similar trend regarding influence of caregiver empowerment-related factors on their wards' school performances, which were compiled in terms of scores achieved in core-academic subjects, grading of participation in co-curricular activities, and rating of social integration in the learning environment. Of all the efforts to empower caregivers, participation in workshops had brought about a more significant cascading impact ($p < 0.01$) on all aspects of school performances.

In terms of caregiver contribution, regular home training showed substantial impact ($p < 0.001$) on performance and participation in the core and co-curricular aspects of education, as well as integration in the learning environment. Training in communication skills was also found to have all-round, positive and significant influence on school performances, more so in academic subjects and social integration. The development and use of special teaching-learning materials in the home training process complemented these outcomes.

DISCUSSION

Factors Influencing Trends of Early Intervention

As inferred from Table 1, larger or joint families were supportive of the process of early identification and intervention, as well as in seeking systematic and sustained intervention services, as indicated by the positive relationship between these factors. Caregivers with more children have been able to identify problems earlier, which may be due to experience gained from child-rearing. However, it was found that the added responsibility of rearing more children tends to delay the age of seeking intervention. Caregivers with more children sought fewer intervention services, while at the same time they opted for sustained services.

Caregivers' educational status also seems to have an all-round constructive influence, with better education being responsible for lower ages of identification and intervention, as well as opting for comprehensive and extended services. This supports earlier findings of Kumar and Rao (2009) that better educational status of caregivers has led to positive intervention trends among children with special needs. However, caregivers' socio-economic status seems to have exerted mixed influences, with reduced age of identification and intervention, and increased range of services, but reduced duration of services. This finding is almost in accord with several earlier studies like those of Kurian (1978), Conrad (1979), Sharma (1980), Stephens and Slavin (1992), and Kumar and Rao (2009) which confirmed that caregivers' socio-economic status always influenced better intervention for children with special needs. However, the mixed influences could also be the result of well-off caregivers seeking private services outside the institute, which were not recorded in this study.

Influence of Caregiver Empowerment in Early Intervention

As mentioned earlier, caregiver empowerment has been an integral aspect of early intervention service delivery at AIISH. Some of the activities carried out on this front are the ongoing counselling and guidance, knowledge and skill disseminating seminars and workshops, as well as formal training programmes like the indigenous 'Certificate Course for Caregivers of Children with Communication Disorders (C4D2)', and the 'Diploma in Training Young Deaf and Hard of Hearing (DTYDHH)', with special preference given to caregivers. According to Table 2, all three measures of counselling and guidance programmes like workshops, as well as formal training programmes,

have helped to prepare caregivers to support their children with adequate home training for academic and communication skill development, as well as to sustain such training by the preparation and use of special materials. In particular, the influence of regular counselling and guidance, though provided informally in many instances, seems to have had a more significant impact on all three fronts, followed by formal training programmes, and orientation programmes and workshops.

The empowerment measures and the consequent caregiver contributions were found to influence early communication skill development, in terms of listening and speech language skills as well as current school performances, as is evident from results on Tables 3 and 4. Support to caregivers in the form of counselling and guidance as well as programmes like workshops, seems to have made a more significant impact compared to formal training programmes. This could be considered a slightly skewed impression as there were few caregiver-participants who had undergone formal training programmes, leading to the distorted representation. Among caregiver contributions, they seemed to be more adept at home training for communication as well as academic skills, along with preparation and use of relevant teaching-learning materials, which in turn have had a significant impact on their wards' performance in curricular and co-curricular activities, as well as on the social front at school. All these add to the conviction that caregiver empowerment and participation should form an integral component of any and every early intervention measure (McNuty et al, 1983; Shankoff and Hauser Cram, 1987; Yoshinaga-Itano et al, 1998).

CONCLUSIONS

At AIISH, caregiver empowerment is a vital component of early intervention measures for young children with communication disorders. Transfer of necessary knowledge, skills, and moulding of attitudes are promoted through regular sessions of counselling and guidance, organisation of frequent seminars, workshops, etc., as well as by conducting formal training programmes. These were found to have equipped caregivers for better home training and participation in school activities, which in turn had enhanced the school performances of their wards. Apart from these, other family dynamics like educational and socio-economic status of the caregivers and size of families were also found to exert considerable influence on the development and education of these children.

ACKNOWLEDGEMENT

This research article is the outcome of a project titled 'Efficacy of Multidisciplinary Preparatory Services at AIISH in Mainstreaming Children with Communication Disorders', undertaken with AIISH Research Fund under the supervision of the former Director of AIISH, Dr. Vijayalakshmi Basavaraj.

The authors would like to thank Prof. S R Savithri, Director of All India Institute of Speech and Hearing, Mysore, for endorsing the original research and for her encouragement while writing this article. They acknowledge with deep gratitude the encouragement, guidance and support extended by Dr. Vijayalakshmi Basavaraj, former Director of AIISH as well as the Principal Investigator of the ARF Project which led to this article. They also thank Prof. K S Prema, Head of the Department of Special Education, and Dr. S P Goswami, Head of the Department of Clinical Services at AIISH, for extending permission and support at the respective departments to carry out research. Thanks also to co-investigators Ms. Alavi Ummathoor and Mr. K K Sulaiman, SSA – Inclusive Education Project Officers of Malappuram and Wayanad districts of Kerala, and project staff Mr. H P Ananthapadmanabha and Mr. K V Viswanathan.

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