Original Article

Parental satisfaction with early intervention services for children with visual impairments and multiple disabilities in Greece

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Abstract:

Early intervention programs offer important services for families of young children with disabilities. Recently in Greece, visually impaired children with multiple disabilities participate in early intervention services. This study was designed to estimate families' perceptions concerning the effectiveness of early intervention services and determine whether specific characteristics of the families are associated with parents' satisfaction. Participants complete a modified version of the Project Dakota assessment of program effectiveness and also they were asked to fill a questionnaire including personal characteristics of each family such as: Parent's education level, severity of child's visual impairment, time participation in the program. The results revealed high scores in all domains of parents' satisfaction. Characteristics of the child and parents were not related to parental satisfaction. Results suggest that this specific program provides important support for families of children with visual impairments and multiple disabilities.

Key words: Early Intervention, Children with visual impairments and multiple disabilities, Families.

Introduction

Early Intervention (EI) is a composition of services for very young children and their families which are provided in order to ensure and improve personal development, to strengthen the adequacy of the family and promote the social integration of families and children. The most important characteristics of EI are the early age of the child and the combination of services provided. The EI philosophy stresses the importance of interaction of different services involved on child development with the active participation of parents (Chen, 1999; Hospers-Blauw & Algra-Hadders, 2005; Iversen, Shimnel, Ciacara, & Prabhakar, 2003).

According to literature, EI results in significant benefits for children. More specifically EI supports the communication, play and behavior of children. Greatest impacts are mention when parents are involved in the intervention and when children are younger than 3 years (Bailey et al., 2005; Hospers-Blauw & Algra-Hadders, 2005).

An important criterion for the success of EI, is the forming of partnerships with families and working collaboratively with them. Service providers and family members learn from each other and use shared strategies in their interactions with their child. A true team approach is created where parents and EI providers develop interventions to promote the child's development. Given that families know their child the best, they have the information needed to guide the EI provider in the development of an effective and individualized educational program. (Chen, 1999; McWilliam et al., 1995, Horn, 2012).

Moreover, when EI providers listen carefully to families concerns about their children and respond by providing strategies then families are supported in caring for them. As a result, parents learn to read their child's communicative signals and interact in more developmentally facilitative ways (Brooks-Cuun, Berlin, & Fulgui, 2000; Chen, 1999; Ozkan & Sucoglou, 2011; Pechat, Lefebvre, Proulx, & Reidy, 2004). Therefore, it is essential for services of EI to be evaluated consequently. Regular assessment provides feedback for the appropriate design of EI programs in order to support each child needs and each family priorities.

In more detailed, a child's disability is often associated with significant stress for parents. Difficulties in finding appropriate and affordable child care, lack of knowledge, inability in allocation of time are some of the common problems which increase emotional stress. EI can help by providing support and information so that parents will feel able to respond to the needs of their child and to encourage it to become autonomous in all daily activities such as eating, dressing and bathing (Kaaresen, Rouning, Ulvund, & Dahi, 2005; Ozkan & Sucoglou, 2011). Moreover, EI can provide the appropriate guidance to the parents in order to have access to all social

services and information regarding their rights and their children's facilities (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004; Bailey et al., 2005; Bailey et al., 2011).

The important role of the family contributed to the change of the philosophy of EI service which altered from child centered to family centered (Iversen, Shimnel, Ciacera, & Prabhakar, 2003; Mahoney & Filer, 1996). Intervention within the home environment was considered a first step towards creating with families a positive working alliance which allowed parents to engage in their children's development. In home environment parents feel they have better control and EI providers become more familiar to family culture and living conditions (Dunst, 2009).

Although the role of the family has been recognized in the field of EI, limited number of studies has assessed the satisfaction that parents feel with the services that EI provide (Favez, Metral, & Govaerts, 2008; Rodger, Keen, Braithwaite, & Cook, 2006). According to Favez, Metral, and Govaerts (2008) satisfaction refers to a global, positive, one-dimensional appraisal of a situation taken as a whole, or it can be considered domain specific. Three main characteristics influence parent satisfaction. The first one refers to the quality of EI services, the second one to the structural aspect of EI services and the third one to the relationships between parents and professionals (Summers, Hoffman, Marquis, Turubull, & Poston, 2005; Ziviani, Cuskelly, & Feeney, 2010).

Parent satisfaction constitutes a key component of any evaluation of early intervention services. Rating parent satisfaction reveals important information about components of service or relationship quality that need to be maintained or improved in order to fit in parent's culture and expectations (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004; Favez, Metral, & Govaerts, 2008; Summers, Hoffman, Marquis, Turubull, & Poston, 2005; Ziviani, Cuskelly, & Feeney, 2010). Satisfaction depends not only on ethnic background but also on demographic and socio-economic variables (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004; Britner & Philips, 1995).

Although measuring parent satisfaction is a key element for evaluating the quality of EI services, research on this particular field is limited. Moreover, a number of problems reveals when measuring satisfaction as perceptions of satisfaction are subjective and affected by emotions (Alisauskiere, 2007; Ziviani, Cuskelly, & Feeney, 2010). Most satisfaction inquiries are carried out with parent reported questionnaires or with telephone interviews. Research indicates that the majority of parents who participate in EI programs report high levels of satisfaction concerning the quality of EI services (Bailey, Hebbeler, Olmsted, Raspa, & Binder 2008; Lanners & Mombaerts, 2000; McNaughton, 1994). According to parent's perceptions, staff's willingness to provide them with useful and clear information about their child's development increases their confidence in their ability to support their child and family (Iversen, Shimnel, Ciacera, Prabhakar, 2003; Raspa et al., 2010).

Parent's experiences at the end of EI indicated that most of them felt competent in caring for their children, advocating for services and gaining access to formal and informal supports. As a result, parents became more optimistic about the future (Alisauskiere, 2007; Bailey et al., 2005).

In Greece the only home based intervention program which offers EI services to children with visual impairment and multiple disabilities is a non-profit "Association of Parents and Friends of People with Visual Impairments and Additional Disabilities, Amymoni". The fundamental objective of this program is the timely evaluation and optimization of each child as well as support, information and guidance for parents.

The main areas which are supported are body perception, orientation, mobility, daily skills and counseling to families. Providers inform parents about their child development and assist them to gain access to community recourses. Moreover, they create a collaborative team with each expert who provides services for the child and with parents be active participants. Particular emphasis is placed on visual perception which is reinforced through visual stimulation. The child is encouraged to make the best use of his functional vision in his daily life. Until now there is no study that has estimated parent's perceptions about EI services in Greece which creates a significant gap in assessment and adjustment of the program. There is an overall lack of data available on the subject of parental satisfaction with home based intervention. As there is no other association which offers EI services to children with visual impairment and multiple disabilities in Greece it is essential to rate parent's satisfaction in order to evaluate the effectiveness of the intervention program. Therefore, it is important to examine parent's views of their partnership with EI providers because cooperation between parents and EI providers is critical for the success of EI.

The purpose of this study was to examine the satisfaction level of the parents whose children participate in the specific EI program. The study was concerned with two objectives: a) to determine whether services were responsive to family needs and priorities, and b) to identify whether specific characteristics of the families were associated with parent satisfaction.

Method

Participants

The sample consisted of 15 mothers of children up to age of 5 years (mean age 4.1) with impaired vision and additional disabilities. Participants were recruited from the EI program which operates in Thessaloniki.

Procedure

Parents' perceptions of EI services were assessed using a modified version of the Project Dakota. The specific instrument provides a complete picture of parental satisfaction and the effectiveness of the EI services rendered to their child. Project Dakota was used in previous studies to examine the effectiveness of EI services in meeting the needs of families (Iversen, Shimnel, Ciacera, Prabhakar, 2003; Kjerland & Kovach, 1990).

The instrument contained 36 questions in five subscales: (1) program and staff responsiveness, (2) growth in knowledge and skills in helping the child, (3) growth in understanding normal behavior and problems, (4) utilization of community resources, and (5) building a support system through participation in the program. The survey was scored using a four-point Likert scale with responses ranging from strongly disagree to strongly agree.

Parents were also asked to complete a questionnaire including basic characteristics of families including demographics, severity and cause of the child's disability and the time participate in EI program. Participants were told that the survey was voluntary and that all information would be kept confidential.

Statistical Analyses

The survey was analyzed using the SPSS 20 statistical package. Frequencies and means were used to describe parents' perceptions of the program effectiveness in meeting family needs. Non-parametric test were used to assess differences in satisfaction related to (a) parents education level and (b) children's characteristics such as the level of visual impairment, the cause of disability, and the years of EI.

Results

Participants characteristics

Characteristics of the respondents and their children are represented in Table 1.

Parents: All the participants were female, with mean age 37.6%. The majority of them had a high school education or more. More than half of the parents reported staying at home (66.7%) and 3 (20%) working part time.

Children: Most of the children were participating in the EI program for four years (46.7%). They all had a serious visual impairment. According to parent's reports, 46.7% of the children had partial visual impairment, 40% had light perception and 13.3% were totally blind. Prematurity was the main cause for children's visual impairment and additional disabilities (40%).

Table 1. Characteristics of Parents ($n=15$), children ($n = 18$)

Measure	
Age of parents, Mean	37.6 (range 21 □ 54)
Female, N (%)	15 (100%)
Education, N (%):	
Less than high school	3 (20%)
High school diploma	5 (33.3%)
Associates or bachelors degree	7 (46.7%)
Mothers work status, N (%):	
Home	10 (66.7%)
Part time	3 (20%)
Full time	2 (13.3%)
Time participate in the EI program, N (%)	
One year	1 (6.7%)
Two years	2 (13.3%)
Three years	5 (33.3%)
Four years	7 (46.7%)
Visual impairment, N (%)	
Total visual impairment	2 (13.3%)
Light perception	6 (40%)
Partial visual impairment	7 (46.7%)
Cause of visual impairment, N (%)	
Prematurity	6 (40%)
Prenatal causes	4 (26.7%)
Perinatal causes	3 (20%)
Postnatal causes	1 (6.7%)
Unknown etiology	1 (6.7%)

Parents perceptions of program effectiveness.

Descriptive statistics were used to examine parent satisfaction. Dakota scores for the total sample are presented in Table 2. Responses were categorized as either agree or disagree. These scores are the mean values of items from each subscale that received ratings from 1 to 4 with values closed to 4 indicating more satisfaction. As indicated in Table 2, parents were satisfied with EI program in all the domains.

Table 2. Parents' mean responses for each subscale of the modified Dakota assessment.

Responsiveness	Growth Knowledge	in Growth Understanding	in Utilization of Community Recourses	Building a Support Network
3.41	3.17	3.5	3.48	3.22

Parents' specific characteristics associated with parents' satisfaction

No statistically significant differences were found when comparisons were made among the three levels of education (elementary, high school, university) and each mean score of parent's satisfaction sub-categories (responsiveness, growth in knowledge, growth in understanding, utilization of community, and building a support network). Table 3 presents the findings from the Kruskal-Wallis test.

Table 3. Parents' satisfaction scores according to education level

	Responsiveness	Growth Knowledge	in Growth Understanding	in Utilization of Community Resources	Building a Support Network
Level of Education	$H(2)=2.049,$ $p=.359$	$H(2)=4.452,$ $p=.108$	$H(2)=.725,$ $p=.696$	$H(2)=.606,$ $p=.739$	$H(2)=1.161, p=.560$

Children specific characteristics associated with parents' satisfaction

No statistically significant differences were found when comparisons were made among the three levels of visual impairment (total visual impairment, light perception, partial visual impairment), the five levels related to the cause of the disability (prematurity, prenatal causes, prenatal causes, postnatal cause, unknown etiology) and the four levels related to the years of participation in EI program (one year, two years, three years, four years) and each mean score of parents' satisfaction. Table 4 presents the findings from the Kruskal-Wallis test.

Table 4. Parents' satisfaction scores according to children characteristics

	Responsiveness	Growth Knowledge	in Growth Understanding	in Utilization of Community Resources	Building a Support Network
Visual Impairment	$H(2)=1.539,$ $p=.673$	$H(2)=3.101,$ $p=.376$	$H(2)=2.226,$ $p=.527$	$H(2)=1.382,$ $p=.710$	$H(2)=.348, p=.951$
Cause of visual impairment	$H(2)=6.518,$ $p=.259$	$H(2)=3.904,$ $p=.563$	$H(2)=3.559,$ $p=.614$	$H(2)=5.700,$ $p=.337$	$H(2)=1.161, p=.489$
Years of EI	$H(2)=1.659,$ $p=.646$	$H(2)=2.536,$ $p=.469$	$H(2)=1.792,$ $p=.617$	$H(2)=1.712,$ $p=.634$	$H(2)=2.211, p=.530$

Discussion

In Greece, until now the context and effectiveness of EI programs have not been evaluated. As it was referred, there is only one home based intervention program which offers EI service for children with visual impairment and multiple disabilities. It must be underlie, that for the first time Greek parent's perceptions of EI program have been estimated.

According to the literature, parent's satisfaction constitutes a key element for EI program assessment. Parent's opinions provide valuable insight on the impact of EI and feedback for the improvement of the services offered. Parent's satisfaction levels, demonstrate the weak and strong points of the program. As a result, EI providers are able to examine the quality of the program and adjusted it according to the needs that arise (Iversen, Shimnel, Ciacara, & Prabhakar, 2003; Ziviani, Cuskelly, & Feeney, 2010).

The majority of literature examines the effect of EI programs on children with developmental disabilities or on children who are at risk. There are only a few studies that refer to children with visual impairments and multiple disabilities. Visual impairment in combination with other physical or developmental disabilities affect seriously children's development. Moreover parents often feel incapable of caring their children and support their growth (Chen, 1999). As this group of children comprise a diverse population is

important to evaluate the effectiveness of EI program. Parent's perceptions reveal important information about the efficacy of the EI services. Measuring and assuring parent satisfaction result in important family outcomes such as increased empowerment, enhanced parent self-efficacy and active involvement with EI program (Summers, 2005).

This study examined parent's perceptions regarding the effectiveness of the EI program on specific domains. Results of this study are consistent with past studies which refer to high levels of parental satisfaction as far as concerned the effectiveness of specific EI programs which mostly refer to parents of children with developmental disabilities (Favez, Metral, & Govaerts, 2008; Iversen, Shimnel, Ciacara, Prabhakar, 2003; Lanners & Mombaerts, 2000; McWilliam et al., 1995). According to the literature, EI services were responsive to families concerns and needs. Bailey et al. (2005) report that most parents believed, that their family was better off as a result of EI. Moreover they felt optimistic about the future. In this study, the results show that all the parents evaluated the EI as satisfactory. High scores on parents' responses indicated that EI services are the appropriate in meeting and supporting families' needs.

The questionnaire Project Dakota used for this research examined parental satisfaction in five domains: program and staff responsiveness, knowledge and skills in helping the child, understanding normal behaviour and problems, utilization of community resources and building a support system through participation in the EI program. According to this study, high levels of parental satisfaction were scored in all the domains. In contrast, Iversen, Shimnel, Ciacara, and Prabhakar (2003) refer that parents report lesser parental satisfaction in learning how to develop strategies and set goals to help their child, learning strategies to discipline and set limits for their child. Similar findings are mentioned in Bailey et al. (2005) study where parents felt less positive in their ability to deal with their child behavior. Different results are reported in Raspa et al. (2010) study as parents scored themselves high on the items that measured their ability to help their child develop and learn. One area that most studies report less satisfaction is access and utilization of community recourses (Bailey et al., 2005; Iversen, Shimnel, Ciacara, & Prabhakar, 2003, Lanners & Mombaerts, 2000; Raspa et al., 2010). Almost all the studies agree that providers and staff of EI services respect and support their families (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004; Bailey et al., 2005; Favez, Metral, & Govaerts, 2008; Raspa et al., 2010).

Most studies have investigated the relationship between demographics features of the families and parental satisfaction. Race, ethnicity, family income, educational levels are the variables that mostly the researchers have studied (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004; Bailey et al., 2005; Mahoney & Filer, 1996; Raspa et al., 2010).

The results of the study show that satisfaction is not related to parent's educational level. Similar findings are reported in past studies who found no differences with regard to parental education (Bailey et al., 2005; Iversen, Shimnel, Ciacara, & Prabhakar, 2003). In contrast, Bailey, Hebbeler, Scarborough, Spiker and Malik (2004) refer that families with less educated mothers were more likely to report negative experiences.

As it was mentioned, children with visual impairments and multiple disabilities comprise a minority population with a variety of characteristics that affect differently every child. A final area of concern was the association between children's characteristics and parental satisfaction. According to the results of this study the severity of visual impairment was not related to parental satisfaction. To our knowledge, there are no other studies who have researched the same issue. Favez, Metral, and Govaerts (2008) compared different kind of disabilities in relation to parents' satisfaction. According to their results, parents of children with sensory-motor and cognitive difficulties were more satisfied than those of children whose behavioural difficulties were the core problems. No relationship was found between the time participation in EI program and parental satisfaction. One possible explanation should be the small sample of the study and the short time in which the specific EI program operates. Our results are inconsistent with the findings of Raspa et al. (2010) study. According to these results, child's age and the amount of time spent in EI were statistically significant associated with family outcomes. The younger the child or the longer the child was in EI, the higher the family outcome.

Conclusions

The results of this study clearly show that parents who participated in EI program are very satisfied with EI services. The high degree of satisfaction demonstrates the importance and the necessity of the active parent participation. This suggests the need to estimate frequently parents' perceptions in order to examine and improve the effectiveness of EI services.

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