

Original Articles/นิเมนธ์ต้นฉบับ

Family-centered Early Interventions for Pre-School Children with Developmental Disabilities: A Systematic Review

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Abstract

Context: Early intervention is very important for young and at-risk children with developmental disabilities. A major goal of early intervention is to reduce the likelihood of disabilities or causes of delays of the very young children. The presence of a disabled child often has a profound effect on the structure of his/her family. The entire family often appears to need intervention as well as the disabled child. As a result, family-centered early intervention has become a critical type of service delivery. Many interventions for these children have been proposed and studied, but there is currently no consensus regarding which interventions are most effective.

Objective: To systematically review evidences regarding family-centered early interventions for children aged 6 years or younger with disabilities.

Methods: The publication including NIH, MEDLINE, EMBASE, PsycInfo, and ERIC databases from 1985 to 2013 using the terms *children with disabilities, intervention/early intervention, and family* have been searched. Using data analysis software program, XSight, has been employed to assess each study against predetermined inclusion/exclusion criteria. Then, the data has been extract regarding the participant and intervention characteristics, methodology, and outcomes and assigned overall quality and strength-of-evidence ratings on the basis of predetermined criteria.

Results: With the total of twenty studies included as an assumption that the development needs of preschool children with developmental disabilities can be met by enhancing the families' effectiveness of early intervention in caring for and managing these children, evidence supports the home visiting and professionals consultation program as the most effectiveness of all family- centered early interventions.

Conclusion: Although children with developmental disabilities or at-risk are currently receive treatments and cares during many years in life. The family- centered early interventions are probably the most important programs as these may reduce the likelihood of disabilities at the very young ages.

Keywords: Early intervention, children with disabilities, family-centered

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Introduction

Although the early years are important periods of development for children without disabilities, these years are even more critical for children with disabilities or at-risk especially developmental disabilities. Early intervention is apparently important for young children who have disabilities as "there is consensus among early childhood experts that the earlier intervention is begun, the better"(1). The purpose of early intervention for disabled children is to produce gains in their development and prevent the development of secondary disability conditions. Many researchers have found that early intervention results in substantial and immediate benefits for children with disabilities including improved cognitive⁽²⁾, language⁽³⁾, social-emotional⁽⁴⁾, and motor skills⁽⁵⁾. Additionally, effective early intervention can accomplish long-term changes that reduce the likelihood of social dependence, institutionalization, and the need for special classrooms once the children reach school age⁽⁶⁾.

Once the importance and necessity of early intervention are realized for young children with special needs, a model of intervention could be selected, and then implemented. These models are not only directed at the child but rather the whole family. Family involvement is a fundamental premise of early intervention⁽⁷⁾. Four basic assumptions that comprise the basis of family involvement in intervention including the need to provide support for family members, recognition of the unique needs of individual families, the need for parents to have full membership in the interdisciplinary team, and the need to help parents teach and manage children⁽⁸⁾. Nonetheless, each family member influences the other, especially in the families of children with disabilities, so the intervention should not focus exclusively on the child but instead on the entire family. As a result, families themselves have been viewed as important part of the process. In order to understand these different needs and to help families to deal with the problems they encounter, family-centered interventions are emphasized and have become the mainstream of early intervention.

Although there have been previously reviews of early interventions for many types of children with disabilities⁽⁹⁻¹¹⁾ especially those with emotional and behavioral problems, there have been many new conclusions and studies in recent years, the family-centered early interventions are still infancy. Moreover, an updated review is required in order to support the effective family-centered early intervention programs. In this systematic review, findings from studies published in peer-reviewed journals are examined. The purpose of this present study was to examine the most effective family-centered early interventions for children with developmental disabilities that can be drawn from research conducted to date.

Method

The following databases were searched for peerreviewed papers from 1985-2012: NIH, MEDLINE, EMBASE, PsycInfo, and ERIC using the terms young children with disabilities, intervention/early intervention, and family. Additional sources of information were the state of Maryland (Maryland Bureau of Disability Services, Maryland Administrators of Services for Children with Disabilities); U.S. Department of Health and Human Services (Administration on Intellectual and Developmental Disabilities); the state of West Virginia (Legal Aid of West Virginia- Family Advocacy, Support, and Training (FAST) Services); the state of New York (Center for Disability Rights); the state of New York (Department of Health); the state of New York (Center for Independence of Disabled); the state of New York (State Office for People with Developmental Disabilities); National Research Council (2009); the State of Maine (Maine Administrators of Services for Children with Disabilities); and National Institutes of Health (NIH). The inclusion criteria for the review were: (a) NIH certified home-based or family-centered early intervention programs; (b) case-control



comparison study of early intervention for young children with special needs; (c) age at start of intervention of children with disabilities less than 6 years (pre-school period); (d) intervention minimum 10 hours per week; (e) duration minimum 6 months; (f) adequate data on Bayley⁽¹²⁾ or other standard measures^(13,14) to allow calculation of extent of gains.

A data spreadsheet was formatted to record study identification, author, title, populations, interventions, results/outcomes (Table 1) by using XSight program. Due to the heterogeneity of the retrieved studies in terms of intervention approach and study design, the results were reported as a best-evidence synthesis of findings. Using this paradigm, all studies meeting the review criteria could then be considered. These were grouped in a table of included studies (Table 1).

Results

In total, sixty-seven studies that met the search term combinations were identified. Some studies were excluded from the review which indicated clearly that the study was early intervention, but not family-centered or home-based, the use of pharmacological interventions or clinical trial studies. Abstracts of review papers were checked to find more accurately studies that matched the study criteria. Twenty studies that appeared to meet criteria for inclusion were initially identified; 6 of these were overviews of research in the area or commentaries on previously published studies; 5 were a mix of early intervention and other clinical interventions. The following summaries of the existence studies are based on comparisons of the published group means.

Home visiting

The home visiting service consists of a variety of professionals/qualified staff (e.g., speech therapists, physical therapists, occupational therapists, social workers, consultants, nurses) who routinely visit families'

homes for the purpose of delivering intervention that meet the children with disabilities and their families' needs⁽¹⁵⁾. In addition, several studies indicated that home visits are an effective service of family-centered early intervention⁽¹⁶⁻¹⁸⁾.

The intervention involved teaching mothers about toddlers' development and child raring skills, as well as instructing mother on games and exercises to facilitate the cognitive, motor, and social development of their children. One of the studies revealed that infants in the experimental group obtained significantly higher Bayley mental score (16) which means that those young children showed improvement in one or more of the developmental areas (e.g., cognitive, physical, social) after the home visiting services. Some of the studies showed a higher degree of involvement and greater emotional and verbal responses to their children. One of the studies found that mothers in the intervention group were more likely to provide appropriate and effective playing methods to the child's physical and temporal environment than mothers in the control group.

The reasons behind the assumption that made home visiting effective were the interventionists educated the mothers about developmental milestones and demonstrated to the mother caretaking, sensory motor/cognitive, and interaction exercises, then invited them to perform the exercises. At four months, mothers in the intervention group rated their toddlers' temperaments more optimally, expressed more realistic developmental milestones and child raring attitudes, and received higher rating on face-to-face interactions. At eight months, the intervention group obtained significantly higher Bayley mental, home environmental, and temperamental scores⁽¹⁹⁾.

Parent groups

Parent groups are a parent-oriented approach that emphasizes the availability of effective and appropriate services and supports to parents⁽²⁰⁾. These



TABLE 1 Summary of studies of family-centered early intervention

Author, date	Sample size	Intervention	Results
Affleck, et al., 1989	94 mothers	 Comparative study (parent training & relationship-focused) Hospital-to-home transition program 	- Mothers increased sense of control, positive mood, and responsiveness
Bailey, et al., 1998	114 mothers	- Questionnaires - Home visiting	- Family-focused intervention should be the of early intervention programs
Barrera, et al., 1986	59 preterm infants 24 full-term infants	Developmental programming interventionParent-infant intervention	- Significantly higher Bayley metal scores in both groups
Bibby, et al., 2002	66 children	Home visitingParent groups	- Progress for 60 children across 12 months was found for mental age (5.4 months), adaptive behavior (9.7 months), and language (5.1 months)
Boettcher, 2003	Focus group	Home visitingConsultation program	- The child with autism and her sibling showed decreases in their disruptive behaviors and the family experienced other family-wide collateral positive effects from this proactive intervention approach
Bradley, et al., 1991	152 families of children with disabilities	Home visitingConsultation program	- Significant positive correlations between parenting and both marital quality and social support (especially perceived helpfulness, instrumental support from father, involvement in social groups, and emotional support network)
Caro, et al., 1991	16 families of moderate to severe disabled children	- Home visiting	 Acquisition of functional skills by families increased Parental knowledge increased Accelerated rates of progress by disabled children
Field, et al., 1980	150 mothers	- Biweekly, home-based, parent-training intervention	Higher scores on DevelopmentalBehavior Checklist at 4 monthsHigher HOME scores at 8 months
Gresham, et al., 1998	Comprehensive report to NIH	- Early intervention program (EIP) in general	- EIP claims to produce recovery from autism in 47% of the cases and to greatly reduce its severity in an additional 42% of case



TABLE 1 Summary of studies of family-centered early intervention (Cont.)

Author, date	Sample size	Intervention	Results
Hazell, et al., 2002	1, 412 families	- Survey	- Parents of children manifesting
		- Clinical services	disruptive behavior reported a high
		- Home visiting	level of family stress
		- Parent-child group	- Consultations by health care profes-
		- Consultation program	sionals reduced the stress level (35%)
Koegel, et al., 1996	2 focus groups	- Parent group (Parent	- Parent-child interactions rated as
		intervention program)	happier, the parents more interested
			in the interaction, the interaction less
			stressful, and the communication style
			as more positive.
Krauss, et al., 1993	150 mothers	- Home visiting	- Maternal support/ peer helpfulness
		- Questionnaires	enhanced
		- Parent group	
Marshall, et al.,	85 mothers	- Consultation programs	- The positive behavior of disabled
2002			children increased
Mesibov, et al.,	23 mothers	- Hospital-to-home transition	- Positive impacted on children with
1993			mental retardation
Nurconbe, et al.,	78 mothers	- Hospital-to-home transition	- Satisfied mothers toward child-rearing
1984		program	- Higher Barley scores after 8 months
		- Consultations	
Rauh, et al.,1988	25 Low-birthweight	- Hospital-to-home transition	- Mothers had higher scores on self-
	infants	program	confidence and role satisfaction
	28 mothers	- Consultations	- At 36 months, children had higher
			developmental scores
Rosnick, et al., 1989	107 Low-birthweight	- Hospital-to-home transition	- Significantly higher Bayley scores at
	infants	program	1 and 2 yrs old
		- Consultations	- Significantly lower incidence of
			developmental delay
Ross, 1984	40 preterm infants	- Home visiting	- Significantly higher Bayley scores
Scarr-Salapatek,	30 Low-birth weight	- Home visiting	- Significantly higher scores on neuro-
et al., 1973	infants	- Hospital-to-home transition	logical and developmental status at
		program	4 weeks
		- Consultations	- Significantly higher scores on intelli-
			gence scales at 1 yr
Weiss, 2002	120 mothers	- Parent-child group	- Both hardiness and social support
			were predictive of successful
			adaptation



groups bring together parents of children with disabilities for resource and information gathering, sharing of feelings and concerns, and mutual supports. Some of the parent groups are led by a service provider, others by an experienced parent, while some are led jointly by both. One of the study found that most of the parent groups were structured to enable parents to identify concerns or issues they wanted to discuss⁽²¹⁾. The array of issues covered in the groups included information sharing, emotional support, discussions about parenting skills and techniques, advocacy training, and management of family-level impacts of raising a child with disability. A central goal of the parent groups is to enhance the social support network of families having children with disabilities (20).

The benefits of parent groups have been examined by several investigators (20,22,23). One of the studies found the relationship of support group participation to maternal levels of stress and depression by interviewing mothers of children with variety of developmental delays. In the study, the support group gave parents concrete help with specific behavioral problems involving their children. Moreover, the support group stressed problem-solving approaches concerning how mothers interfaced with the outside world such as extended family. Finally, the support group made an active effort to promote networking among group participants (22). Another study found that the fathers who participated in support groups were less depressed and utilized more problem-solving skills than those who did not participate (23). There is also evidence that parent groups are associated with benefits for some participants, especially those who feel in need of support and who have the skills to interact effectively in a group setting (20). Furthermore, mothers who felt that they benefited from parent groups commented that groups reduced their sense of social isolation, provided a forum for sharing their pride in the children's progress, allowed them to share resources and ideas, and provided them with a nice break, and a way to make friends. However, those who felt parent groups were not beneficial pointed out that they resented the forced atmosphere. Some felt uncomfortable when listening to other parents whose problems were different from or more severe then their own⁽²⁴⁾.

Parent-Child groups

Terms used to describe parent-child group varied in the studies that were reviewed. In addition to parent-child group, terms used to describe this approach included parent-child group, parentchild activities or parent-infant early intervention programs^(10,26). A common assumption held by this approach is that parents should and can be taught to play a more direct and explicit didactic and therapeutic role with young children with disabilities (27). The main purpose of this approach is to facilitate enjoyable parent-child interactions by involving parents in children's daily activities, and training parent to become the agent of intervention by helping them develop the necessary skills and attitudes (10,26).

According to Maryland Administrators of Services for Children with Disabilities, the approach helped parents as: (a) reduction of the risk of parental alienation from the child, (b) improvement parental selfconfidence, (c) increase in intervention time for the toddles, and (d) provision of a broader base of information on which to plan objectives and evaluate progress. Although not normally a prevalent approach, and few research studies were found, parent-child group interventions are still suggested in family-centered practices ad listed among the ranking of helpfulness of early intervention services (28,29).

Hospital-to-Home transition

The hospital-to-home transitional program is an intervention for families having disabled newborns that occurs before and after the hospital discharging. The delivery of a hospital-to-home transitional service usually begins in the hospital after the infant is born and follows up several weeks or months at the infant's home. It is based on an assumption that biomedical risks interact with environmental inadequacies, which will depress infant development⁽³⁰⁾. The main goals of this approach are to reduce the parental stress of caring for their low-birth weight infants⁽³⁰⁾, to improve parents' adaption to their highrisk infants⁽³⁰⁻³²⁾ and to enhance parents' abilities in facilitating the infants' development by providing them with a favorable development environment⁽³¹⁾.

One of the studies conducted a three-month transitional program with mothers of low-birth weight infants. The intervention consisted of eleven sessions with a trained pediatric nurse. Seven sessions were conducted in the hospital during the week prior to the infant's discharge, and four sessions were conducted at home during the three moths following discharge. Mothers were taught how to be more sensitive and responsive to their infant's physiological and social signals. Maternal outcomes indicated that the intervention group was more confident in, more satisfied with, and more favorable toward, child rearing than the control group. Moreover, follow-up data indicated that the intervention and control lowbirth weight groups began to show divergent Bayley scores after twelve months, and significant differences favoring the intervention group were found at 36 and 48 months in cognitive development (31).

Consultation program

The consultation program is a service that makes available a broad range of supportive resources to parents who have problems in rearing their children with disabilities. This approach allows parents to tell the consultant the problems or to decide specific topics for discussion. If parents express no concerns or problems, the consultant may play an active role in suggesting topics for consultation sessions, based

on their assessment of the child's development and behavioral characteristics as well as observations of parent-child interactions⁽³³⁾.

The general goals of consultation services including: (a) assist parents' adjustment to their stresses in rearing a child with disability; (b) encourage mutually enjoyable parent-child interaction; (c) develop parents' abilities in interpreting their children's behavior cues; (d) improve parents' observational and problem-solving skills; and (e) enhance parents' sense of self-efficacy and control over the child's development (30,33,34).

Studies of consultation programs in familycentered early intervention per se have been limited. One of the studies included consultation programs in their intervention by using home-based services delivered to parents of developmentally disabled children. Every treatment family was seen by a singlefamily consultant for home intervention that permitted the family to discuss their concerns about their child. Analysis of variance showed the following main effects of the consultation program: (a) treatment mothers were more emotionally and verbally responsive and showed more responsiveness during interactions, (b) treatment mothers showed positive parent-child interaction; and (c) treatment mothers gave evidence of grater involvement with the problem-solving skills (31,35).

In many studies that investigated parents' perception of early intervention, data analysis indicated that most parents viewed the early intervention services as quite helpful and were satisfied with the improvement in their children's development (24-26,36-39). The data in these review studies also suggested that if the early interventions were implemented, at least five areas would benefit to children: motor development, behavior, communication, cognition, and selfhelp. In terms of benefits for themselves as parents, both mothers and fathers rated learning techniques for working with their children as most beneficial fol-



lowed by learning about their child's developmental problems^(24,25,39).

In addition, the reviewed studies also reported that parents' weighting of perceived benefits varied in response to certain child and family characteristics^(5.11,20,39). For example, mothers who had severely disabled children indicated less benefit in learning techniques and more in meeting their family members' needs when compared with those mothers of children who had moderate or mild levels of disabilities (40). Mothers having only one child and mothers employed part-time viewed program services as more of a necessity their children and less for themselves than did other mothers (41,42). However, full-time mothers attributed relatively more program services as benefiting their family as a whole rather than individual children or parents (40,42). Fathers of children with Down syndrome rated themselves as having received more benefits than other fathers (23).

Finally, parent's overall rating of program help-fulness were associated with certain changes in their own or their children's outcomes. For example, mothers rated early intervention services as more help-ful when parenting stress decreased, but no relation was found between perceived helpfulness and child outcomes. On the other hand, fathers usually gave higher ratings of helpfulness to early intervention services when these services were the source of social support, when the negative impact on the family decreased, and when their child gained more in cognitive skills. These findings indicated that mothers who had a child with disability were eager to eliminate the parenting stress, while fathers were more concerned about gains in their children's development.

Conclusions and Recommendations for Future Research

With an assumption that the developmental needs of young children with developmental disabilities can be met by enhancing the families' effective-

ness in caring for and managing these children, early intervention for young children with disabilities and their families has been altered from primarily individual, child-focused service models to multifaceted family-centered models over the past decade⁽⁴³⁾. The data presented in this review suggest many aspects, since each child with disability is unique and each special need has to be met in order to accommodate the child.

As noted previously, every family is unique with different characteristics. Children with disabilities in different families may influence, either positively or negatively, other family members. The parents, especially mothers, are usually the person who is affected first and directly by the birth of the disabled child. The non-disabled siblings may also be influenced directly by the presence of their disabled sisters or brothers or indirectly through their parents. By reviewing studies, one can described certain family/parent characteristics, which may affect family functioning and child development.

In an effort to facilitate the development of young children with disabilities, a number of early intervention programs have been designed and implemented (see Table 1). The reviewed studies showed effective intervention models include home visiting, parent support groups, parent-child group activities, consultation programs, and hospital-to-home transition.

Home visiting, as a procedure to deliver services to families with young children with disabilities, has a long history within early intervention^(20,21,39). According to the findings of research reviewed, it is apparent that home visits are very beneficial to very young children with disabilities and their families. However, some suggestions may be worth mentioning in order to maximize the effectiveness of home visiting services: (a) the schedule for home visiting should be convenient for parents to involve in the intervention, as well as the siblings or other important family member⁽²⁰⁾; (b) home visiting programs

need to address the issue of a fair degree of advanced training to adequately prepare the professional service providers.

Parent groups have been proven to be more effective for parents who have a high need for support (22,38); in contrast they may have an adverse effect on parents with a low need for support (29). The finding suggests that families' needs should be examined before providing parent group services so that these programs can best match individual needs and maximize the effectiveness of services. A suggestion for the future study of parent groups is to examine the long-term effects of parents' child-rearing skills relating to children's outcomes.

With the belief that early intervention is very important in parent-child relationship, parent-child group activities have been increasingly emphasized in family-centered early intervention. The reciprocal parent-child interactions are considered to be the basis for socioemotional development (25), cognitive development, and acquisition of early communication patterns⁽²⁶⁾. However, there are some suggestions for parent-child group programs (37). First, a variety of feasible activities and natural settings must be designed and chosen. Second, the most available participation time must be scheduled. Third, parent-child activities should be extended to be family-child activities by involving other family members. Finally, parent-child group activities should be included as a part of community activities instead of inclusively for children with disabilities and their parents.

Hospital-to-home transition programs have been proven to produce beneficial early effects upon the general adaption to mothering by the women involved (27,28). Most studies of transition interventions focused on certain populations such as mothers who have preterm infants. The future research should concern more about the adequate follow-up. Transition programs themselves should involve more fathers in the intervention. One can see whether or not the observed treatment effects might translate into meaningful academic advantages for those who receive the intervention during their school years. Further, researchers should make efforts on future studies to replicate the intervention program on different types of children.

Consultation programs are essential within family-centered early intervention to help parents solve the problems arising when rearing a young child with disability. Since consultants may be challenged by various problems that parents confronts, consultants should be well trained and experienced in nursing, social work, and early childhood special cares.

By reviewing the goal, delivery and intervention setting of home visiting and consultation programs, family-centered early intervention can be strengthened by effectively combining these two approaches. From the reviewed studies, with more studies one can hope to see the effectiveness of family-centered early interventions in helping parents learn problemsolving skills, enhancing cognitive and behavioral abilities, and reducing the stress in rearing their disabled young children better in the future.

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