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FAMILY CENTERED EARLY INTERVENTION SERVICES

ABSTRACT

Family centered early intervention services are explored in this article. In attempting to argue for a renewed focus on early intervention programs, this article addresses four major points concerning family centered early intervention: family centered perspectives, ecological perspective, family systems theory, and family centered service delivery. This article also discusses what is required to achieve an adoption of family centered values and practices in early intervention and provides recommendations for early intervention practitioners.

Keywords: Early Intervention, Family-Centered Services,
Young Children With-Disabilities, Home-Based Intervention

AİLE MERKEZLİ ERKEN MÜDAHALE HİZMETLERİ

ÖZET

Bu makalede aile merkezli erken müdahale hizmetleri incelenmiştir. Erken müdahale programlarında yeni bir odağın gerekliliği üzerine oluşturulan bir girişimle, bu makalede dört önemli nokta ele alınmıştır: aile merkezli yaklaşımlar, ekolojik yaklaşımlar, aile sistemleri teorisi ve aile merkezli hizmetlerin aktarımı. Bu makalede ayrıca erken müdahalede de aile merkezli değerlerin ve uygulamaların benimsenilmesinde nelerin gerekli olduğu tartışılmış ve erken müdahale uygulayıcılarına tavsiyelerde bulunulmuştur.

Anahtar Kelimeler: Erken Müdahale, Aile-Merkezli Hizmetler,
Erken Çocuklukta Özel Gereksinimleri Olan Çocuklar,
Eve-Dayalı Eğitim



1. INTRODUCTION (GİRİŞ)

Early intervention consists of a variety of services intended to meet the diverse needs of infants and toddlers with developmental delays or disabilities and their families [1]. According to Thurman [2] "Early Intervention may be defined as an array of services that is put in place through a partnership with families for the purpose of promoting their well-being and the well-being of their infants, toddlers, and young children whose development may be at risk due to a combination of biological and environmental factors".

For infants and young children, the first few years of life provide a unique opportunity to capitalize on developmental forces to significantly reduce, if not prevent, disablement through primary, secondary, and tertiary prevention. In any early intervention program, the primary prevention level is to reduce the occurrence of developmental disability through reduction of risk factors such as low birth weight, malnutrition and family awareness that child development can be influenced by their efforts. At a secondary prevention level, the goal is to reduce the extent of manifested childhood disability and shorten its duration. Infant stimulation and remediation programs operate at this level. In tertiary prevention, the aim is to prevent or reduce complications of disability that lead to a need for institutionalization [4].

Participation in early intervention services is comprised of on-going assessment and intervention provided by multidisciplinary teams of providers (i.e., education specialists, speech-language, physical therapist, social workers..etc.) in concert with parents. Additionally, these services require the involvement of a host of professionals from many disciplines such as special educators, speech and language pathologists, audiologists, occupational therapists, physical therapists, psychologist, social workers, nurses, and nutritionist [3].

The early intervention service system in developed countries prior to the enactment of the law, known as the education of the Handicapped Act Amendments of 1986 in the U.S., was child-centered, provided a fixed package of services delivered separate and sometimes insufficient therapies from independent disciplines, and placed children in segregated programs. In child-centered approach the child is often treated as a separate and distinct entity with minimal emphasis on the family or other groups affecting the family. Since 1986 this amended version of IDEA in the U.S., however, the focus has widened to include the family. This movement towards a more family-centered approach grew out of a growing dissatisfaction with the lack of involvement of individuals and families in determining policy and practice guidelines that directly impacted them. Some additional reasons included limited success of parent-assisted models for promoting parent participation; development of theories about the roles of parents and families in children's development; increasing awareness of complex family issues surrounding the care of children with disabilities; and heightened sensitivity to the moral and legal rights of parents to be treated as full partners in all decisions and activities carried out on behalf of their children. Furthermore, the emergence of family centered early intervention approach occurred alongside, and in many ways supported or prompted the changes in special education legislation, with the result being improved access to services for infants, toddlers, and preschool children with disabilities and the



rising importance of the role of their families within service delivery models.

2. RESEARCH SIGNIFICANCE (ARAŞTIRMANIN ÖNEMİ)

Universally there is an increased awareness of the early years as a crucial period for promoting physical, mental, and psychological growth of children. Early Intervention services in Turkey have incorporated several early intervention models such as Small Steps and Portage into early intervention services. The Small Steps and Portage approach build on assessing the child's status on a checklist of major developmental domains. The intervention approach for children involves visits to a child's home by a trained professional to recommend skills that could be worked with the child by the parent. Thus, these models utilize a "cookbook" approach in which a home visitor teaches the parent by modeling the program with the child and mother tries to teach the child each day and keeps a record of child's progress. Even though the program centered approach has been criticized for its ineffectiveness to create a change atmosphere for families; costs of family centered early intervention services pose a serious constraint for Turkey. Furthermore, the program centered early intervention services are not available to all families of children with disabilities in Turkey since the population is large and resources are limited.

Each year thousands of Turkish families across all over the country learn that their young child, aged birth to three, has a developmental delay or disability, or may be at risk for developing such a delay or disability. This can, obviously, be a difficult time for families, a time when they may be asked to absorb new information, to make important decisions, all at a time when they may be worrying about their young child and working to continue their day to day family routines. Some parents go through periods of disbelief, depression and self blame whereas many parents experience helplessness, feelings of inadequacy, anger, shock, and guilt. The early intervention experience can offer families hope, reassurance, and a positive perspective at a time which could be potentially stressful, and frightening. Because early interventions are often a family's conduit to information related to their child as well as a link to constructing an optimistic view of the future. This article provides important information about a paradigm shift in the early intervention services in the U.S. and developed countries. Using information provided in this article, Turkish home visitors may reflect upon their practices to become more aware of their strengths and needs in the area of family centered early intervention services.

3. FAMILY CENTERED PERSPECTIVE (AİLE MERKEZLİ YAKLAŞIM)

Professionals working with young children with special needs have witnessed significant philosophical shifts in the field [5]. Parents and family members are no longer considered only the recipients of professional instruction but are viewed as having the strength and capacity to decide their own intervention plans. Families now collaborate as equal partners with professionals, and their needs drive the service delivery. "Professionals are seen as the agents and instruments of families, and intervene in ways that maximally promote family decision making, capabilities, and competencies" [6]. In other words, family-centered services are now intended to improve the ability of families to



cope with the unique needs of their infants and toddlers with developmental delays or disabilities [7]. Specifically, services are designed to assist families in coping with the challenges of having children with developmental delays or disabilities, empowering families to work collaboratively with early intervention service providers, and supporting families as they make decisions about their child's services [8 and 9].

In the past, early efforts for parent involvement were dominated by a clinically-oriented educational and therapeutic service model [10]. Based on this model, the child was the focus of intervention services. Therefore, professionals designed specialized instructional and therapeutic activities to address the child's developmental needs only. Children's levels of exposure to clinical settings were considered factors contributing to their typical development and progress. The process of family involvement in such a professionally driven model involved requested parents to observe in such settings and to create conditions and implement activities at home that replicated and supported clinical intervention activities.

The rationale for family-centered services is built upon the premise that children and families are integrated; intervention with children will influence the family. Involving the family makes for more powerful intervention services [11]. Moreover, current understanding of family-centered services involve a strong collaboration between families and professionals, while providing services that meet the unique needs of the child and family. This collaboration serves to empower the family and work with the individual strengths of the family. According to Trivette, Dunst, Boyd, and Hamby [12], supporters of the family-centered philosophy view professionals as instruments to be used by families, and interventions that are individualized, flexible, responsive, and maintain and strengthen family functioning. Furthermore, acceptance of individual differences is valued in family centered philosophy because it encourages a more productive approach to intervention in which professionals do not try to change children and their families, but instead build on the strengths that children and families bring to programs [13]. In addition, from the family empowerment perspective, partnerships are valued over paternalistic approaches. Forming partnerships with families conveys the belief that partners can share knowledge, skills, and resources in a manner that benefits all participants as a result of a cooperative arrangement [13 and 14]. Professionals who promote family empowerment do not mobilize resources on behalf of families, but rather they create opportunities for families to acquire competencies that permit them to mobilize the resources and support necessary to cope, and grow in response to their children's disabilities.

4. THEORETICAL PERSPECTIVES (TEORİ YAKLAŞIMLARI)

Presently early intervention services in developed countries are intended to be family-centered, individualized, integrated, transdisciplinary and inclusive. The importance of these principles are based on an established literature base from ecological theory [15] and family systems theory [16]. Ecological theory demonstrates the relationship of the family to the larger social environment [15] whereas the family system framework represents the interactive and dynamic qualities of families [16]. These different theoretical bases have contributed to the movement towards family-centered early intervention



and provided system frameworks for a better understanding of the functioning of the child, the parents, and the family.

4.1. Ecological Perspective (Ekolojik Yaklaşım)

The ecological perspective incorporates a child's total environment or ecology when assessing, planning, and educating children and families. Bronfenbrenner's model [15] provides perhaps the most comprehensive foundation for understanding the application of the ecological perspective to early intervention. Bronfenbrenner [15] argues that human growth and development are a result of the progressive, mutual accommodations between an active, growing human being and the changing properties of the immediate settings in which the developing person lives. This progress is affected by relations between these settings and by the larger contexts in which the settings are embedded.

Bronfenbrenner's [15] ecological systems theory illustrates a system or categorizing levels of influence on child development, from proximal to distal variables. There are proximal factors directly impinging on the child, such as parent-child interactions, versus those impacting families, through whom these more distal variables, such as the affects of resources, social networks, or social policies, are mediated. Bronfenbrenner [15] proposed the following four hierarchical levels of influence on a child's development:

- the microsystem,
- the mesosystem,
- the exosystem, and
- macrosystem.

These four levels of influence consist of interactions of the child and family in a range of settings from immediate to cultural settings [18].

Several central assumptions of Bronfenbrenner's conceptualization of the ecology of human development are relevant to the evolution of the way professionals work with families. Bronfenbrenner emphasized the transactional nature of the relationship between individuals and their environment [19]. Professionals who adopt the ecological perspective view children as part of a broader world including the family system [14, 20, and 21]. In other words, adopting and implementing this perspective in early intervention requires a shift from a child-centered approach to a family-centered approach. Thus, ecological theory contributes to early intervention services by providing a blueprint for understanding the child within the context of the family and how the family can impact the child's development.

4.2. Family Systems Theory (Aile Sistemleri Teorisi)

Family systems theory recognizes that the family is a system and that actions affecting any one member affect all of the members [22]. The family systems perspective examines the individual structure, roles, values, beliefs, stresses, coping strategies, resources, and social support networks of each family [23]. It puts primary importance on the interactional nature of the family unit. The family systems theory is an appropriate framework to use especially when exploring the needs of low-income, rural families who have children with disabilities. As individual family members interact with other members of the family and the services, resources and supports in the community, the needs of the entire family are impacted. Families of children with disabilities who



live in rural communities may experience isolation, an unwillingness to accept services, difficulty accessing appropriate services, and limited options for service provision [24 and 25]. From that perspective, family centered services should strengthen a family's ability to meet their own needs and be supportive of each aspect of their caregiving role [26 and 27], including providing information so families can make decisions and access a variety of formal and informal community resources [28 and 29].

In family systems theory, the family is seen as consisting of a series of sub-systems whose roles change over the life-cycle of the family [23]. Families are also viewed as interacting with the environment. They have boundaries that regulate the amount of influence they will allow from the environment. Because of the interactional nature of the families, early intervention services have begun to shift from the child as the exclusive focus of intervention to incorporating entire family as recipients of services. Furthermore, researchers and practitioners recognize that all members in a family function as interdependent parts of a system [22]. Their development is interdependent on each other. In examining such relationships, researchers and practitioners have developed strategies aimed at reducing possible stresses caused by various issues within a family, and at improving a family's coping ability and skills to meet the special needs of their children.

In addition to the grounding in theoretical models, recommended practices from Division of Early Childhood (DEC) of the Council for Exceptional Children also advocate for high-quality, family centered services that are delivered in a comprehensive and coordinated manner [30]. DEC "recognizes that the family is constant in the life of a child and the purpose of early intervention is to enhance the capacity of the family to facilitate their child's development" [31]. The National Association for the Education of Young Children (NAEYC) in the U.S. further endorses this position [32].

5. FAMILY CENTERED SERVICE DELIVERY (AİLE MERKEZLİ HİZMET AKTARIMI)

In the study of early intervention services for families of children with developmental concerns, one of the most vigorous debates has been continued on the kinds of services that are most helpful for families. Despite the widespread acceptance of and commitment to family-centered early intervention on a philosophical level, the implementation process lags behind [33]. Indeed, observation-based research reveals that the majority of home visitors' time consists of child-focused instruction with the home visitor in the role of teacher primarily in the presence of mothers and children. In a review study Dunst [26] concluded that the early childhood professionals are considerably weaker with regard to the participatory component of being family-centered. Even though the existing empirical research lags behind that of the theoretical work on the effectiveness of family centered practice in early intervention, evidence suggest that parents of children in early intervention programs did not experience responsive practice, nor were they provided complete and unbiased information needed to make informed choices and decisions [34 and 35]. The process is often hampered by the lack of a clear picture of what works best for families and by an inability to translate what we do know about working with families into practice [11]. Therefore, it is essential that the early intervention profession continue to work to



understand family-centered philosophical approach as it translates into everyday practice.

Although some researchers have argued that direct training of parents is the key factor for having successful outcomes in early intervention, some argued that existing research fails to support link between direct teaching of parents and intended outcomes. According to Mahoney and colleagues, intervention effectiveness can be improved only when interventions change mothers' attitudes of relating to or caring for their children [26]. A theoretical perspective by Kurt Lewin posits that change can only be possible if a person motivated to change, and has, therefore opened him or herself up to new learning process [27]. The basic argument in Kurt Lewin's Change Theory is that all forms of learning and change can lead to discomfort by admitting that we are imperfect and fail to meet our creative potential. Therefore, a person can resist a learning process or change by ignoring disconfirming information and blaming outside factors for adapting poorly in life. What can break that defensive cycle is creating a sphere in which a learner can feel psychologically safe and his or her self esteem is not under attack. In order to create a sphere by which means a person can feel ready to change, a learning process should be presented to a person with an opportunity to control and predict the direction of learning. Furthermore, for change to occur, learning process should be presented as a means of broadening and empowering a person's cultural and personal resources not through destruction of these meanings. Finally a role model can introduce the learning process to a person step by step with an insight to the person's personal and cultural meanings and an ongoing support throughout managed learning. In accordance with Lewin's change theory, Results of a recent study which explored family-professional talk during the home visits of 15 families of young children indicated that verbal behavior from the professional predicted greater verbal behavior from the families. When professionals praised, encouraged, were accepting of the families' ideas, and asked questions, families participated more in family-professional talk (36). In another study McWilliam, Tocci, and Harbin [34] studied the characteristics of service providers who aligned closely with the best practices definitions of family centered practice. Underlying components of service providers philosophies included: a primary concern with the family, a non-judgmental mindset, and optimistic view of children's development, and enthusiasm for working with families.

Furthermore, it is critical for practitioners to begin with an understanding that the level of stress experienced by parents is quite different for families in which children with special needs are being raised. Such stress would be a result of the increased caretaking demands that such children impose on their parents. In addition, child care may create a significant problem to socially isolated and economically disadvantaged families. In order to create "growth promoting climate", early interventionist must begin with unconditioned respect, empathy, acceptance, and understanding, motivating parents by helping them recognize the power that they have on their children's growth. Parents who believe they can make a difference are more likely to engage actively in an early intervention program. Parents with high level of involvement and high level of self-efficacy can gain necessary knowledge and skills that allow them to understand and extend the intervention with their child [38].



Overall, in order to achieve and maintain the collaboration of parents, practitioners need be well knowledgeable, creative and flexible to create a program that addresses every family's needs and strengths though which parents can feel comfortable implementing in and strengthen and develop their key role in their child's development. The families then will be empowered in making decisions about their child's live and thus will be in advocating for their child's rights. Rather than utilizing a "cookbook" approach by envisioning families as having similar characteristics, becoming sensitive to each family's uniqueness and recognizing their strengths and weaknesses and challenges that they face, are the key dynamics that lead to target the individual needs of families and provide the appropriate support that each family deserves.

In addition, a Socratic style of questioning can be used to encourage parents' involvement and self-awareness. Such questioning leads to active parental involvement in the discussions, rather than placing parents into passive listener or observer position by exposing them to professional lecturing. One of the important advantages of using a Socratic style questioning is that a practitioner can help parents become more aware of their interaction styles with their child and their unique strengths by responding to questions that lead parents to recognize their significant impact on their child's developmental growth. This sense in turn is translated into higher levels of inter-personal trust and self efficacy and thus be more effective in promoting their children's development.

6. CONCLUSION (TARTIŞMA)

Based on emerging best practices, early intervention services are unique for their singular focus on the relationship between providers and families for accomplishing mutually established goals. As such, the primacy of the family is the interactions process [11]. Early intervention services have been described as a complex series of interactions and transactions centered around the accomplishment of two basic tasks: nurturing and enhancing the development and behavior of the infant or toddler with a disability and supporting and sustaining their families. Providing early intervention services implies providing services that are sensitive to the concerns of families, that build on family strengths, that seek to enhance family adaptations, and that create within families new capabilities to support and facilitate infant and toddler development and prevent developmental problems [11].

Mahoney and colleagues [37] posit that one of the primary needs that all children require from their family is unconditional love. Unconditional love is the knowledge that someone loves you with all your frailties as well as your strengths. This is the kind of love that is supposed to be given between parents and child, whether the child has a disability or not. Parents has to develop a genuine respect for their children with disabilities, which includes valuing them as whole and complete and worthy of unconditional love. This includes the parents' ability to communicate appreciation and respect for the child' unique, often different-looking ways of doing things [37].

Finally, McCollum [40] pointed out that we have lost sight of the fact that the family's most important role in children's development occurs in their direct interactions with the child. In order to improve the relations between the child with disabilities and his/her parents, professionals need to focus on family-identified needs, concerns, and



priorities instead of professionally-identified needs and concerns as the primarily targets of intervention. In addition, professionals need to recognize the family's rightful role in deciding what is most important and in the best interest of the family unit and its members. Responsive and truly individualized interventions address family needs and aspirations by promoting the family's ability to first identify and meet their needs in a way that makes them more capable and competent. As Guralnick [41] explains, "the early years constitute a unique opportunity for influencing child development and supporting families, an opportunity that may well maximize long-term benefits for all concerned" (p.3).

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