A PARADIGM SHIFT IN EARLY INTERVENTION SERVICES: FROM CHILD-CENTEREDNESS TO FAMILY CENTEREDNESS

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Abstract

Early intervention is an integrated service available to the families and their children, between birth and three years of age, for whom there are developmental concerns due to identified disabilities and/or various circumstances. Current early intervention practice has been called to move away from a practice in which therapeutic and educational services are designed only for the child, to a practice that emphasizes support of the strengths and effectiveness of families to facilitate the child's growth. Family-centered services characterized, primarily by a fundamental respect for families; attention to family-identified concerns, priorities, and resources; recognition of the family as the ultimate decision maker; and collaboration between families and professionals. This article reviews and integrates available evidence about theoretical and empirical background relating to family-centered practice and discusses information relating to the implementation of family-centered early intervention services.

Key words: Early intervention, family, family-centered services, young children with disabilities, at-risk children, Home-based intervention, early intervention service delivery, ecological theory.

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Özet

Erken Eğitim Hizmetlerinde Bir Paradigma Değişimi: Çocuk-Merkezcilikten Aile Merkezciliğe

Erken eğitim, 0-3 yaşları arasında, gelişimi çeşitli faktörler nedeniyle risk altında olan çocuklara ve ailelerine verilmek amacıyla desenlenen entegre edilmiş hizmetler bütünüdür.Günümüzdeki erken eğitim uygulamalarının, sadece çocuk için desenlenen terapiye dayalı eğitim uygulamalarından çıkarılarak, ailelerin çocuklarının gelişimini desteklemeleri için etkililiklerinin arttırılmasına dayalı bir sisteme geçilmesi gerektiği desteklenmektedir. Aile merkezli hizmetler, temelde aileye saygıyı ön plana alan, ailenin kaygılarını, önceliklerini ve kaynaklarını dikkate alan, aileyi nihai kararı veren bir birim olarak kabul eden, ve aile ile erken eğitim çalışanlarının işbirliğine dayalı olan bir hizmet şekli olarak betimlenir. Bu makele, aile merkezli uygulamaların teoriye dayalı ve deneysel kanıtlarını ve aile merkezli erken eğitim programları ile ilgili var olan bilgileri derler ve entegre eder.

Anahtar Sözcükler: Erken Eğitim, aile; aile-merkezli hizmetler, erken çocuklukta özel gereksinimleri olan çocuklar, risk altında çocuklar, eve-dayalı eğitim, erken eğitim hizmet aktarımı, ekolojik teori.

The early intervention field is not always clear in defining its terms when it discusses early intervention and research involving family reporting. However one of the most widely accepted definition of early intervention is that early intervention is an integrated developmental service designed for families of children, between birth and three years of age, for whom there are developmental concerns due to identified disabilities, or whose typical development is at risk due to biological, medical or environmental factors. Its is an individualized program of coordinated services and supports that promotes the child's growth and development and supports families during the critical early years.

Early intervention services are designed to provide therapeutic services to ameliorate developmental delays (i.e., speech, language, motor, and cognitive delays) at the earliest point possible. Participation in early intervention services in 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. Two fundamental assumptions form the basis of early intervention. The first concerns the need for interdisciplinary activity. Since the problems confronting infants and toddlers with disabilities and their families are so diverse, the range of services required to meet these needs must reflect this diversity. Therefore, early intervention incorporates a host of service providers from a variety of disciplines and theoretical orientations including

education, social services, occupational and physical therapy, medicine, and speech and language pathology. The second assumption is that the needs of infants and toddlers enrolled in early intervention programs can only be fully appreciated and understood within the context of the child's family. In other words, the current rationale includes not only the goal of enhancing children's development, but also the goal of supporting families, even if that support is not aimed directly at "enhancing the capacity of families to meet the special needs of infants and toddlers with disabilities (Mahoney & Wheedon, 1997).

Family-Centered Perspective

Since the late 1980's, the field of early intervention in the U.S and developed countries has been undergoing a philosophical shift in how practitioners view and interact with the families of infants and toddlers with special needs. There has been movement away from child-centered service provision to family-centered practices: families are viewed as experts on their child and have a role in the early intervention system, formulating goals for their children and themselves (Mahoney & Bella, 1998). The service system prior to the enactment of the law was child-centered, provided a fixed package of services, delivered separate and sometimes insufficient therapies from independent disciplines, and placed children in segregated programs. Presently, under the reauthorized legislation, services are intended to be family-centered, individualized, transdisciplinary, and inclusive.

The catalyst for this shift was the enactment of legislation known as the education of the Handicapped Act Amendments of 1986 in the U.S. This law established early intervention services for young children with disabilities under age of three and their families. It propelled the movement from childcentered to family-centered service provision by encouraging the active participation of families in the early intervention system. In addition, there has also been a shift in the thinking about the role of the early intervention professional and their interactions with families; professionals are no longer seen as working with families, but are viewed as working for families (Bailey et al., 1998; Zipper, Hilton, Weil, & Rounds, 1993). Families are now seen as the ultimate decision-makers for their children and for themselves (Baird & Peterson, 1997).

The practice of family-centeredness has also evolved from an integration of child and family experiences. Family-centered practices have emerged from a history of research in Early Intervention, Early Childhood Education, and Early Childhood Special Education. Historically familycentered services meant parental involvement in activities that professionals

selected. However, reauthorization of Individuals with Disabilities Act (IDEA) in 1997 in the U.S. strongly encouraged professionals in the field of early intervention to increase their knowledge and competency in the principles of family-centered services. Three objectives for parents and family involvement have summarized in the act: first, to broaden early intervention services to include both family and child, and to help them adjust and cope with the stress and demands associated with children with disabilities; second, to support and respect family decision-making with family-identified priorities, concerns, and service outcomes included in the Individuated Family Service Plan (IFSP); and third, to promote family strength and to consider parents as full partners in the early intervention process to care and manage their child's development, versus expecting professionals to dictate services and activities (Mahoney & Filler, 1996).

Researchers and practitioners have summarized a number of reasons for such change (Dunst et al., 1991; Dunst, Trivette, & Deal, 1988; Mahoney & Filler, 1996). These reasons include 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 fully partners in all decisions and activities carried out on behalf of their children. Nevertheless, after the enactment of legislation known as the education of the Handicapped Act Amendments of 1986, research has focused on defining family-centered practices. Conceptualizations have evolved over time and include encouraging the family to be active decision makers (Bailey et al., 1986), attending to family concerns even though they may not involve the child (Dunst, Johanson, Trivette, & Humby, 1991), helping families create informal support networks (Dunst, Trivette, & Deal, 1988), recognizing family strengths (Bailey & McWilliam, 1993), and allowing families to decide on their level of involvement (Vincent & McLean, 1993).

In addition, services are selected in collaboration with families and focus on the concerns, priorities and available resources of the family in relation to the child's needs, parents are involved in the process of assessment, development of the Individualized Family Service Plan (IFSP) and on-going programming. The IFSP is to contain information about family resources, priorities, and concerns and the designation of a service coordinator who serves as a services coordinator for the family. This document serves as the blueprint for mobilizing services that are designed to meet the family's needs (Dunst & Deal, 1994). Due to the fact IFSP's

theoretically guide services and correspond with actual practice, there should be evidence of family-centeredness throughout the documents.

The family's growth toward independence in planning for the child's continuing and changing needs is supported. Family members are encouraged to be active participants in every component of early intervention service delivery. On an individual level, family members are involved in determining and participating in services for their child and family. On the program level, families are encouraged to advise and participate in the development and monitoring of policies, procedures and practices.

Theoretical Perspectives

Family-centered early intervention has its theoretical basis in an ecological framework (Bronfenbrenner, 1979) and a family systems theory (Minuchin, 1974). This frame of reference views the family as embedded in larger social context. It draws attention to the interactions between families and the larger social contexts. It also recognizes the importance of the family for the development of children, including those with disabilities.

Ecological Perspective

Although there are a multiplicity of early intervention programs that target families and their children, Bronfenbrenner's (1979) work on the ecology of human development has provided the theoretical underpinnings for many of the models of early intervention. Bronfenbrenner (1979) proposed a theoretical framework of human development that views the child within a system of interconnected levels of the surrounding environment. The environment consists of subsystems arranged like a series of concentric circles or nested structures. Bronfenbrenner takes a system approach to the ecology of the child and explains how the microsystem, mesosystem, exosystem, and macrosystem interact and influence a child's development. The microsystem refers to the immediate environment of the child that might include, for example, such as the home or school. A child's family is the immediate context for his/her development, the micro system. The layers of the social system influence one another as they interact. The mososystem refers to the interaction between two Microsystems, such as the home and school. The exosystem is an environment in which the child is not involved but, nonetheless, is influenced by, such as the parent's workplace. Finally, the macrosystem is the broader ideology, laws, and customs of the culture in which the child' ecology is rooted. Thus, Bronfenbrenner's theory of human ecology allows us to go beyond the traditional definition of the

environment by taking into account the multiple, interconnected systems that influence the child.

From Ecological Theory Perspective, adapting to having a child with exceptionality is affected by ecological influences within the family and within society. Culture and value, components of the macrosystem, and family structure, a component of the microsystem, must be acknowledged when utilizing a family-centered approach. Indeed, society imposes restrictions that make the disability more difficult than it need be (Turnbull, Blue-Banning, Turnbiville, & Park, 1999). Knowledge of this theoretical framework allows professionals to consider problems from all levels, the micro, meso, and macro. Using Bronfenbenner's ecological perspective, major emphasis can be shifted to "fixing" the various contextual environments of the child and family to provide adequate resources, accommodations, and support rather than focusing on "fixing" the child (Turnbull, Blue-Banning, Turnbiville, & Park, 1999).

Family Systems Theory

Another prevalent theory found in the literature concerning early intervention is the Family System Theory. According to family systems theory, the family is viewed as a growing and ever changing system that has its own structure, resources, functions, and interactional patterns (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986). This theory encompasses the belief that any actions affecting one member affect all other members of the family (Minuchin, 1974). Family systems theory influenced the shift in the focus of early intervention services from the child to the family (Wehman, 1998). 25 to effectively meet the needs of a child with disabilities, the needs of the entire family must be addressed. The theory implies that in order to be more sensitive and effective in helping the child and the family, a professional's knowledge needs to be extended to examine events and interactions within and around the family. This theory also calls attention to the interdependence and mutual influence of the child and other family members, to the degree of influence the family will allow the early intervention system to have on their lives, and to the family's reaction to having a child with a disability (Shonkoff, Hauser-Cram, Krauss & Upshur, 1992).

Family-Centered Service Delivery

Early intervention policy, programs, and providers advocate that home visiting services should be family-centered, that is, aimed at promoting families' capacities to care for their children as the primary influences on their children's development. Family-centered services are provided by

embracing an approach that includes (a) establishing the family as the locus of intervention services and using family needs to guide service delivery (Dunst, Johanson, Trivette, & Hamby, 1991), (b) focusing upon relationships (e.g., home visitor to parent, and parent to child) as the medium for the intervention process (Kelly & Barnard, 1999), and (c) concentrating upon outcomes that strengthen family functioning such as the quality of parentchild interactions, parent understanding, parent efficacy, the emotional wellbeing of family members, and child adaptive capacities (Weston, Ivins, Heffron & Sweet, 1997). In order to move toward a consistent focus upon family involvement, family services, and family outcomes in early intervention, early interventionists need to better apply the theory and practice of family-centered home visiting. One example of the development of a working model to explain home visiting and its impact is based upon the collective work of Dunst & Trivette (1996), Mahoney et al. (1999), and McWilliam, Tocci, & Harbin (1998). There are five elements to this model. (1) Each family has a unique constellation of beliefs, supports, and values that shape and inform the caregiving environment for its children. (2) When an infant with disabilities is born, the family may have needs for various kinds of information, resources, referrals, and assistance. In addition, the infant may need special medical care and various kinds of therapies. (3) Family-centered home visits that are focused on assessing and addressing individual family strengths, needs, concerns, and resources can enhance family functioning and support family members as they seek to provide a good caregiving environment and needed services for their infant. (4) As a result of family-centered home visits, family members learn new information about their baby's developmental needs and gain new attitudes and skills to use in guiding the development of that child. Family members become more self-competent in caring for the infant's needs. Family members expand their abilities to use support and resource networks in order to function well together. The expected outcome is that the infant experiences optimal development. Similarly, the family experiences optimal functioning.

In this model, a hypothesis about pathways to optimal child and family outcomes is linked with an intervention focus that is based upon strengthening the family's abilities to provide a caregiving environment that maximizes developmental opportunities for an infant with disabilities. Home visitors often use play activities to convey developmental information to parents in spontaneous and natural ways. Inviting parents to participate in simple play is an effective tool to discuss parenting issues and children's development. By being active participants in play activities, parents enjoy their child's development, and develop positive feelings about contributing to their child's learning. In fact, parents learn and remember information

better when it is associated to a particular context, such as ongoing discussions or activities (Klass, 1996).

Bailey et al. (1998) suggested that the essence of the family-centered approach resided within the relationship between families and professionals. They further suggested that a new relationship between families and professionals should be forged. This new relationship should recognize the need for an individualized approach to accommodate the preferences of individual families as well as value and support families in ways that meet the individual needs of families. Family centered approach requires not only changes in the attitudes of professionals toward parents , but also a fundamental shift in the focus of early intervention from working directly and exclusively with the child to collaborating with families by providing an array of supports responsive to their needs and priorities. This shift was expected to enable parents to become more effective at promoting the development and well being of their children (Dunst, Trivette, & Deal, 1988).

In other words, moving from a professionally centered or child-centered approach to a family centered approach often requires a major reconceptualization of the early intervention service delivery system (Murphy et al., 1995). This reconceptualization includes the way professionals work with families as well as the way parents interact with professionals. Based on the family empowerment perspective, acceptance of individual differences is valued because it encourages a more productive approach to intervention in which professional do not try to change children and their families, but instead build on the strengths that children and families bring to programs (Dunst & Trivette, 1994). Furthermore, Johnson-Martin, Goldman, and Gowan (1989) point out that families want professionals to provide effective support; that is, delivered though the quality of the relationship between the professional and family. Some characteristics of this relationship include trust, respect, communication, and a collaborative attitude (Turnbull & Turnbull, 1997). Because forming relationship 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 (Dunst, 1985; Dunst & Trivette, 1994). In addition, a sensitivity to the cultural and social traditions of a community is an essential element in family-centered early intervention programs because the community is integral to the life of the family and child. Familycentered programs area based on the awareness that parents are products of their culture. As such, their child rearing patterns reflect their cultural customs and traditions.

In family centered early intervention services, professionals are encouraged to change their beliefs, attitudes, and skills to meet such ideological shifts and practices. These changes have created challenges for early intervention professionals who have limited training in working with families and accustomed to interacting only with a child whose parents passively participate. Bailey, Mcwilliam, and Winton (1992) summarized three major challenges in implementing family-centered practice: (1) difficulty transitioning from traditional child-focused practice to a practice of servicing the whole family as well as the child; (2) professionals' lack of training and skills working with families; and (3) lack of clearly defined guidance in implementing family-centered practice.

Positive communication skills are important aspect of a parentprofessional partnership. The more accurately professionals and families communicate their thoughts and feelings, the more successful the relationship will be, thus creating an empowering context for all involved (Turnbull & Turnbull, 1997). Communication should flow not only from professionals to parents in the form of information about diagnoses and services, but also from parents to professionals in the form of sharing information about the familial, religious, and cultural environment in which family members are involved. This exchange of information should result in a discussion about

the type of resources and services that might match the needs of the family and child. It is from this kind of bidirectional communication process that family members should gradually feel more empowered to exercise control of the early intervention process (Brown et al., 1991).

CONCLUSION

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 (Harbin, McWilliam, and Gallagher, 1998). Indeed, observationbased 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. 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 (Bailey et al., 1998). It is essential that the early intervention profession continue to work to understand family-centered philosophical

approach as it translates into everyday practice. There is a significant need for early interventionists to identify, develop, and reflect upon their own effective service delivery strategies for facilitating family-centered early intervention. Early interventionists can build their own internal working models of their home visiting beliefs, roles, and activities that reflect family-centered practices. As home visitors planfully support each family's capacities to care for their children, they can bring more awareness and decision-making skills to their experiences with families as well as to more fully understand and support families' progress in their journeys.

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