Family-Centered Early Intervention for Infants and Toddlers With Disabilities

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Almost 300,000 children in the United States from birth to 3 years of age are affected by a developmental disability. Disabilities have a lasting effect on a child’s development and, in turn, may have a psychosocial impact on the child’s family. In addition, the limitations of a child with a disability are often related to family members’ stress, depression, and feelings of helplessness. Accordingly, not only do children with disabilities have special needs, but also families have unique needs as well. This review article describes the value of a family-centered approach to early intervention services for infants and toddlers and their families. Authors also describe barriers to the implementation of family-centered care and the role that social workers may play in addressing these barriers.

KEYWORDS developmental delay, disabilities, early intervention, family-centered care, infants, toddlers

Part C of the Individuals with Disabilities Education Act (IDEA, 2004), also known as the Early Intervention Program, was passed to allow states to provide educational and therapeutic services to infants and toddlers with disabilities (Bailey, Hebbeler, Scarborough, Spiker, & Malik, 2004). Although the term early intervention is used disparately among scholars and other stakeholders, here it will refer to the services offered through Part C of IDEA. Part C early intervention is not only designed to improve developmental outcomes for young children with disabilities, but also includes information and recommendations on how to work with families in a systematic and...
comprehensive fashion (Block & Block, 2002). This type of practice is called family-centered care (FCC) and is applied in many therapeutic realms related to the treatment of disabilities (Dunst, Trivette, Davis, & Cornwell, 1988). As the number of children with disabilities rises, the influence of the family and the use of FCC become more essential. The purpose of this article is to describe the following: FCC within early intervention, especially in health care settings; its relationship to the service provision process known as the Individualized Family Service Plan (IFSP); and its relationship to the practice of therapeutic services and service coordination by early interventionists. We also describe barriers to the implementation of FCC and the role that social workers may play in addressing these barriers.

THE NEED FOR FAMILY-CENTERED EARLY INTERVENTION FOR YOUTHS WITH DEVELOPMENTAL DISABILITIES

According to the U.S. Census Bureau (2005), 228,000 children from birth to 3 years of age are affected by a disability. Despite current intervention strategies to reduce the prevalence of disabilities, the number of children with these conditions increases significantly for children between the ages of 3 and 5 to 475,000 children (U.S. Census Bureau, 2005). Additionally, disability affects between 2% to 10% of the child population younger than age 15 in the United States (Merrick & Carmeli, 2003; U.S. Census Bureau, 2006). Developmental disabilities include severe, chronic disabilities that begin any time from birth through age 21 and are expected to last for a lifetime (National Association of Councils on Developmental Disabilities, n.d.). More specifically, an infant or toddler with a disability is a young child experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: (1) cognitive development; (2) physical development, including vision and hearing; (3) communication development; (4) social or emotional development; or (5) adaptive development, including fine and gross motor skills (IDEA, 2004). Although speech delays are the most common developmental issue among infants and toddlers, many children have more severe disabilities requiring a range of medical and rehabilitative services (Hebbeler et al., 2007). Diverse individual and contextual factors are associated with severe disabilities, including prematurity and low birth weight (Lorenz, Wooliever, Jetton, & Paneth, 1998), maternal age (Saller & Canick, 2008), heredity (Freitag, 2007), and poverty and child abuse (Smith, 2002).

Extreme prematurity is especially linked to cerebral palsy and mental retardation (Marlow, Wolke, Bracewell, & Samara, 2005). Children with these health conditions are often delayed in their ability to carry out activities of daily living. For example, infants may not have the ability to alert parents when they are in need of simple care-taking tasks such as feeding. Toddlers
may have multiple issues such as severe speech, fine motor, and gross motor delays, making it difficult for them to walk, feed themselves, and play with other children (Mathews, 2005). Disabilities have a lasting effect on a child’s development and, in turn, have a psychosocial impact on the child’s family. Children with severe and multiple disabilities often have a total dependence on parental assistance for everyday tasks (e.g., feeding, bathing, grooming) (Roberts, Arthur-Kelly, Foreman, & Pascoe, 2005). Although disability does not always have a negative impact on families, many families of children with severe and multiple disabilities experience great physical and psychological stress (Skok, Harvey, & Reddihough, 2006). Some research suggests that parents, siblings, and other family members of youths with a disability are at an increased risk for depression and reduced quality of life (Blacher, Neece, & Paczkowski, 2005). Accordingly, not only do children with disabilities have special needs, but families have unique needs as well. Families often require financial, social, psychological, and other family support services (Canary, 2008). A family-centered approach to working with youths with disabilities and their families may help social workers and other health professionals better meet the diverse needs with which these families may present.

Family-centered care is based on practice principles that are designed to enhance self-determination of parents of youths with a disability, parent–provider collaborative decision-making processes, and parent self-efficacy (Dunst et al., 1988). Allen, Petr, and Brown (1997) reiterated the dimensions of family-centered practice as: centrality of the family (the staff member cares about the entire family, not just the child with special needs), informed decision making by families (the staff member makes it clear that the family, not the professional, is responsible for deciding what is done for the child and family), and a strengths perspective (the staff member understands that parents know their child better than anyone else does). In family-centered practice, providers assume the role of facilitator and collaborator, not of expert whose knowledge exceeds that of the parents (Block & Block, 2002).

Aspects of service delivery that reflect FCC in the medical setting include time spent with child, provider listening carefully to family, sensitivity to family values and customs, provider giving appropriate information to the family, and provider helping family feel like partners in child’s health care (Ngui & Flores, 2006). Families engaged in FCC are more likely to be satisfied with the care they receive from their health care professional and, in turn, are more likely to follow through with recommendations from the pediatrician, including referrals for continued therapy for children with profound disabilities (Ngui & Flores, 2006).

Early Intervention Services for Youths With a Disability

The IDEA directs that Part C (Early Intervention) evaluation and treatment services meet the needs of each family. Consequently, a family-centered approach
to service provision is essential. Early Intervention (EI) is a federal program that allows states to provide services to infants and toddlers, aged newborn to 3 years, with developmental disabilities (Bailey et al., 2004). Such services include special education; physical, occupational, and speech therapy; parent training; vision, nursing, and health services; and assistive technology. Children are to be evaluated and provided services in the most natural and least restrictive environment, usually at home, daycare, or in an early childhood center (Stremel & Campbell, 2007). However, children with severe and multiple disabilities, especially children born prematurely, often receive services in health care settings such as hospitals and/or outpatient clinics.

Once a family is deemed eligible for services, an IFSP is developed. The IFSP process involves evaluating the needs of the family as a whole as opposed to child-focused assessment, which evaluates the individual needs of the child apart from the family. Family-centered assessment entails working with families to develop goals that are consistent with their environmental, social, and cultural needs. Using this approach, professionals assist families in making informed decisions about their child's needs and focus on the family's strengths and ability to encourage the child's developmental progress (Allen et al., 1997).

The IFSP also includes specific information about the child's current milestones in the five areas of development. In addition, family goals may include participating in play groups to enhance parent–child relationships and social skills, applying for Supplemental Security Income (SSI) to enhance an inadequate household income, or taking part in parent training to develop appropriate parenting and disciplining techniques. Families of children with multiple and severe disabilities often have several goals addressing child and family outcomes, developmental needs, and family concerns. A family's services should reflect the IFSP goals and involve educating the parents about specific activities that will enhance the child's development in a particular area, such as gross motor functioning (Zhang, Fowler, & Bennett, 2004). According to IDEA, the IFSP must include a statement of the specific early intervention services that the child and family are receiving, including (1) the frequency, intensity, and method of delivering the services; (2) the natural environments in which early intervention services will be provided; and (3) a justification of the extent, if any, to which the services will not be provided in a natural environment.

Barriers to Implementing Family-Centered Care for Youths With Disabilities

DIVERSITY

Families of children with multiple and severe disabilities may have different concerns, opinions, and needs depending on their cultural backgrounds. In a
study by Hwa-Froelich and Westby (2003), Asian parents considered obedience and respect to be primary goals in child-rearing and disagreed with EI professionals who considered independence and self-esteem to be more important. Parents in this research believed that encouraging children to obey teachers and therapists was essential. They also believed that educating children was difficult if children were not first taught to respect their elders. It is critical to take a family’s values, customs, and beliefs into consideration when seeking to engage parents in the goal-setting process.

Additionally, EI professionals may suggest changes in daily routines or schedules or ask parents to implement daily programs that alter family habits, always noting, however, that families develop their own routines and schedules. Family systems are complex, and many factors contribute to the family’s adherence to or involvement in a particular treatment. In true family-centered assessment and treatment, providers do not expect families to follow a schedule that is either unrealistic or interferes with customs and rituals (Segal & Beyer, 2006).

Barriers Related to Information Sharing and EI Documentation

Although the EI system is governed by policies that direct providers to use family-centered practices (e.g., IDEA), not all EI and other health care providers use such practices. Barriers often exist in health care and other systems that interfere with the assessment and treatment of families. A qualitative analysis of barriers to family-centered services for infants and toddlers with developmental delays found that professionals experienced pressure to provide services that would be reimbursed by private insurance companies or Part C funds, instead of services the family needed (Shannon, 2004). It was also found that providers did not offer information on the existence of family programs, because Part C funding was linked to individual children as opposed to the family as a whole. Some family participants also felt that professionals kept information from families because they did not want to encourage families to request all possible services (Shannon, 2004). This type of practice could limit a family from being well informed about EI and other related programs. Other barriers to FCC surfacing in this research related to how some professionals perceived families who held divergent views on practice decisions. These families were viewed as resistant or unmotivated instead of empowered stakeholders working on behalf of their children’s needs. Such perceptions are not congruent with a family-centered philosophy insofar as it is the professional’s responsibility to develop and implement a treatment plan that addresses needs identified and prioritized by the family.

Other research has revealed that, in some cases, EI services lack a family-centered approach to goal setting and assessment. Sabatino (2001), for example, found that of 160 EI case records, 28 contained an Individualized Education Program (IEP) (generally geared toward child-centered care)
instead of the IFSP. Additionally, less than one half of the IFSP records contained family-centered assessment and outcome data including information regarding family resources, including those for extended family, family priorities, family concerns, and family outcomes. Without discussing this information with families, it is impossible for professionals to truly provide family-centered services.

Barriers Embedded in Health Care Settings

Early Intervention Program referrals often originate from the primary health care setting (Franck & Callery, 2004). However, Hendrickson, Baldwin, and Allred (2000) identified barriers in health care settings that may prevent children from receiving EI services. Two major barriers included a lack of primary care provider knowledge of the developmental delays the child was experiencing and a lack of referral information from the primary care provider for families. However, children who received FCC were more likely to (1) receive developmental assessments at the pediatrician's office, (2) to be referred for EI services, and (3) to receive preventive services including immunizations (Halfon et al., 2004).

The Role of Social Workers in Providing Family-Centered Early Intervention Services

Social workers may be able to help address barriers to providing FCC for youths with disabilities and their families. Social workers are uniquely trained to use a strengths-based, person-in-environment lens to discuss evaluation, psychosocial assessment, treatment issues, and concerns. Furthermore, social workers are equipped with the skill set to fill diverse roles to help empower families; they may serve as an empathic supporter, teacher/trainer to parents with little knowledge of the EI system or developmental disabilities, consultant to other early interventionists, enabler, mobilizer for agencies in the community, mediator between disagreeing family members and/or therapists, and advocate (Collins, Jordan, & Coleman, 1999). More specifically, social workers are also able to work with families on the primary objectives relevant to FCC that include helping family members (1) manage daily living activities; (2) learn appropriate problem-solving skills; (3) learn effective conflict resolution skills; (4) communicate individual wants, needs, and desires; and (5) access concrete resources during times of stress (Collins et al., 1999).

Recommendations to Enhance Family-Centered Early Intervention Services

Although social workers have basic assessment skills and the necessary knowledge of resources to implement FCC, additional social work education
is needed regarding EI systems and processes, early childhood typical and atypical development, family dynamics, and disability policy (Block & Block, 2002). Yet developmental disability content is often not formally included in social work education. In their review of the literature, Malone, McKinsey, Thyer, and Straka (2000), for example, found that social work graduates had little desire to work with individuals with developmental concerns, a finding that was attributed to the lack of curriculum content on disabilities. Other studies have similarly reported on the low representation of disability content in social work education. DePoy and Miller (1996) found only 4% of the social work programs in the United States offered disability-specific concentrations, and fewer than one half of the accredited programs in the United States offered courses related to working with infants and toddlers in the 1990s (Bishop, Rounds, & Weil, 1993).

Including disability and EI content in an overcrowded curriculum, however, may be a difficult task. Gourdine and Sanders (2002) discussed the possibility of using field placements to educate students about disability policy and practice, but they also noted that this method of integrating new content into the curriculum may not be sufficient to produce a majority of well-informed social workers and a minority of leaders in the area of disabilities. One effective way to encourage and support students to grow in their leadership relates to offering an interdisciplinary program on disability studies in which interested students could take courses inside, as well as outside, their schools of social work. This appears to be one of the most appropriate means of producing developmental disabilities scholars and practitioners (Gourdine & Sanders, 2002).

Another way to increase knowledge and expertise in disability studies and EI would be to implement an infusion model to help integrate this content into the general curriculum. This approach has been successfully implemented in some programs for aging content (Cummings, Cassie, Galambos, & Wilson, 2006). Continuing education support should also be available to social workers throughout their careers to enhance their capacity to provide family-centered services. Trainings on how to successfully navigate EI systems are especially needed because social workers must be able to explain these complex systems to families of youths with disabilities. Regular supervision is also critical to assist EI social workers with problem solving, minimizing countertransference, EI system navigation, and other issues that arise in their clinical and case management relationships.

CONCLUDING REMARKS

Providing FCC to families of infants and toddlers with disabilities is an essential component of high-quality early intervention services. It allows families to make informed decisions about their child's evaluation and treatment
processes and encourages the early interventionist to acknowledge the family as the expert of the child’s development. Although individual and contextual barriers to FCC persist, social workers possess to varying degrees the basic skills and expertise needed to promote the use of FCC in EI services. However, to more fully develop social workers’ capacity to address these barriers and fill a leadership role on early intervention teams, greater education on disability content and FCC is essential.

REFERENCES


