Educational & Developmental Intervention Services (EDIS) Personnel Development

KIT

Keeping In Touch

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ENSURING THE GENUINE APPLICATION OF FAMILIY-CENTERED PRACTICES

Resource Article

What contributes to positive outcomes for young children with disabilities? Certainly intervention with the child plays an important role, but it has become increasingly apparent that additional factors contribute significantly to these outcomes. Davis and Gavidia-Payne conducted a study examining the roles of child, family, and professional support characteristics in family quality of life (FQOL) in families of children with disabilities.

The authors surveyed 64 families participating in 14 Early Childhood Intervention Centers located in greater Melbourne, Australia. The survey packets contained questionnaires for the families to complete, including the *Beach Center FQOL Scale* (Beach Center on Disability, 2003*)* which includes sections on Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support. Also included was the *Measure of Process of Care* (MPOC-56) (King, Rosenbaum, & King, 1995) which includes subscales on Enabling and Partnership, Providing General Information, Providing Specific Information about the Child, Coordinated and Comprehensive Care of the Child and Family, and Respectful and Supportive Care. Lastly, the *Child Behaviour/Needs* subscale of the *Parenting Hassles Scale* (Gavidia-Payne, Matthews, Hudson, Richdale, & Nankervis, 2003), was included. This scale yields a score measuring frequency of stressor and perceived intensity. Additionally, families were asked to rate their perceived satisfaction with support from family members outside their immediate family as well as their friends using a scale from 0-10 (not at all helpful to extremely helpful). Demographic information collected included items such as child's diagnosis, age of child, type of intervention program, parent education, parent employment, and family income. The packets took less than 30 minutes to complete and were returned to the authors via post.

Results suggest child characteristics and FQOL were inversely related to child behaviors (i.e., child hassles). In other words, when child behaviors were viewed as more intense, lower scores of emotional support were found. Interestingly, the severity of the child's diagnosis was not significantly correlated with FQOL. However, this study consisted of relatively few children whose parents

Resource Article (continued)

considered their child’s disability to be severe (15.6% of the children) and none considered the disability as very severe.

Family characteristics associated with FQOL included social supports, income, and professional supports. Descriptive analysis suggested families rated support from extended family members as more helpful than that of friends. The authors found that “…the presence of social support was significant predictor of parental well-being as characterized by less depression and stress in families of children with disabilities” (p.160). Family income was one of the family characteristics significantly correlated with FQOL. Families with higher income reported greater satisfaction with quality of life, probably due to greater resources and access to services. When considering satisfaction scales, families were more satisfied with their physical/material well-being and least with their emotional well-being. However, when support from extended family members and professional supports were taken into consideration, family income was no longer a significant predictor of positive family outcomes. Professional support was described as providing services in a respectful and supportive manner, actively including parents in intervention, providing general information and delivering services in a coordinated and comprehensive way. Interestingly, the authors reported, “…professional support was found to be one of the strongest predictors of FQOL” (p. 161).

Families of children with disabilities have unique needs and challenges. As early interventionists we know that helping the child involves much more than child-centered intervention. In order to build family capacity to help families meet the needs of their child and family it is essential to design support from a family systems perspective and provide the right mix of informational, material, and emotional support.

Davis, K. & Gavidia-Payne, S. (2009). The impact of child, family and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disabilities, 34*(2), pp. 153-162.

What do the data say?

What is the intent of IDEA Part C?

Let’s first look back before moving forward. The year 1975 was the turning point for children with disabilities, with the celebrated signing of the Education for All Handicapped Children Act (EHA) (PL 94-142) by President Gerald Ford. This legislation was viewed as a civil rights act for all persons with disabilities and the beginning of the end of institutional settings.

In 1986, EHA was amended to include a separate part of the legislation to assist states with establishing a comprehensive, interagency, multidisciplinary system of services and supports for families of infants, toddlers with disabilities or conditions that have a high probability of resulting in later delays if early intervention services were not provided.

Congress established the program of early intervention for “handicapped infants and toddlers” in recognition of “an urgent and substantial need to:

- enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay,

What do the data say?

- to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after handicapped infants and toddlers reach school age,
- to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential for their independent living in society, and
- to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps."(EHA, 20 U.S.C. § 631(a) (1986) http://files.eric.ed.gov/fulltext/ED314927.pdf

In 1991, Congress directed the Department of Defense (DoD) to provide early intervention services for eligible infants, toddlers and their families. Since the establishment of early intervention in 1986 the original law has been amended several times. Currently the section that governs early intervention is found in Part C of the law now called the Individuals with Disabilities Education Improvement Act IDEA 2004

In section 631 (a) of the IDEA statute (2004), the following purposes point out the focus of services and supports for infants and toddlers with disabilities and their families." Congress finds there is an urgent and substantial need to:

- to enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life;
- to reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;
- to maximize the potential for individuals with disabilities to live independently in society;
- to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and
- to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural children, and infants and toddlers in foster care." (IDEA, 20 U.S.C. § 631(a) (2004) http://idea.ed.gov/download/statute.html

Looking at the Congressional findings that help drive early intervention there notable differences between the 1986 and 2004 Congressional findings. One is that the current law expressly acknowledges "the significant brain development that occurs during a child's first 3 years of life." Another is that Congress added a finding, that specifically addresses minority, low-income, inner city, rural, and infants and toddlers in foster care. Another significant and important change is the use of person first language, infants and toddlers with disabilities versus the 1986 reference to handicapped infants and toddlers.

In shaping this legislation parents, professionals, and other advocates worked to ensure that crucial themes provided the foundation for the services and supports the law set out to provide. These themes included viewing infants and toddlers as whole individuals whose needs must be met by service strategies that cut across the traditional disciplines, programmatic and funding categories; appreciating that the development of infants and toddler can best be understood and promoted within the context of the family environments; and that early intervention is most effective when parents are respected and empowered as consumers and as active team members collaborating with professionals. (Pletcher & Younggren, 2013, p. 10). Notice also that the critical importance of family and the focus on enhancing their capacity to meet the needs of their infants and toddlers with disabilities remains as a critical component of early intervention.

Consultation Corner

From January through July 2015 we are excited to have Peggy Gallagher and Eileen Kaiser as our consultation corner experts addressing the topic

"Ensuring the Genuine Application of Family-Centered Practices"

This family I'm working with just started getting additional therapy (speech and OT) for their child outside of early intervention (EI). Now that they are busy with that, I'm feeling a bit left out.

It's natural to feel a bit left out if others are now involved in supporting the child and family and you, as the provider, have been less involved in the decisions to make that happen. Always remember, though, that at the end of the day, it is the family members who will live with this child for 24 hours a day, 7 days a week, for perhaps the rest of the child's life. When you consider this, you can appreciate how parents may want to be sure they've done everything possible to help the child improve at an early age. It may be important to find out why the family members feel that they need to go outside of the EI system for additional therapy. Are they feeling that they are not getting the support needed to address their outcomes? Did the medical doctor recommend therapy and not know or understand what goes on in the EI system? Or is the family not happy with the EI services as outlined on the IFSP? Perhaps they heard from another parent or received feedback from friend receiving services under a different service delivery model. Do the family members believe that "more is better" and think that the more services of any kind that the child has will help "fix" the child? We recall a situation in which a child was receiving so many therapies every week that the family had little time left to spend just being a family doing everyday things. In fact, the infant sibling spent so much time in a baby carrier during her brother's many sessions that she ended up having developmental delays perhaps in part due to the limited opportunities she had to move around to explore. More does not mean better.

As you support families in EI it's important that the team (including the family) keeps abreast of the services received and needed so that the family's priorities are addressed and the child's progress is optimized. It's equally important that the family understand the EI service delivery model, including why and how a primary service provider approach is used. It is also helpful to discuss the importance of natural environments. Identifying and enhancing learning opportunities in the daily routine gives the child many more opportunities to practice functional skills than getting a half hour or hour of therapy in a clinical setting one or two days a week. For example, having Rosie practice putting on her coat repeatedly at the OT clinic will most likely not be as motivating as when she practices putting her coat on so she can play outside with her neighbor friend.

Getting different services in different ways from different providers is often not optimal for the child or family. For instance, a family we know was involved in a State's EI system and had a speech language pathologist who worked with two year old Ishmael at child care. Their health insurance also paid for 2 days a week "treatment" with a speech pathologist at the private hospital near their home. Ishmael was getting three days a week of speech therapy, two days with intensive training with one therapist and one day with a therapist who was working with the child care teacher to expand the child's language. Ishmael seemed to be confused and his language was not improving. Additionally, the family was not confident in what they could do to help Ishmael. One of the reasons may have been that the therapists did not know what the other was doing or working on with Ishmael and neither understood the natural opportunities for learning that occurred in the context of a typical day for the family.

The family is really the only entity that knows everything going on with the child, so, as a provider, it's important to discuss with them how important it is to coordinate services and have providers who collaborate and communicate. Share with the family the importance of both the family and providers establishing relationships with one another for the benefit of the child and family. As a primary provider, you can help foster this collaborative effort. One solution may be to conduct periodic collaborative

Consultation Corner (continued)

sessions with the family. For example the EI primary provider may join a family at a hospital-based therapy session. Doing so facilitates collaborative understanding of what's happening and minimizes the family having to decipher information or input received from different providers. You may also want to check to be sure services are not being duplicated; more is not better, especially if services are fragmented.

Other strategies that can be useful in helping providers collaborate are scheduled phone calls to discuss the child's progress, journals that can be carried around with the child with providers sharing intervention strategies and child progress, or using other electronic means, including video clips, for sharing information. Inviting outside providers to IFSP meetings or at least seeking their written input for the meeting can also be very useful. Parents can also ask for written reports from outside providers and then share these with their EI team who can help coordinate all services. Of course, all information that is shared must be at the consent of the parents as confidentiality is of utmost importance.

It may also be useful to remind parents of the importance of the team approach. All therapy associations support the idea of a team approach and services in the natural environment, though therapists may not have been necessarily trained in a collaborative approach, especially if they didn't complete a practicum with younger children. Share therapy association position papers with the family and the other therapists as follows:

ECTA http://ectacenter.org/topics/natenv/natenv_position.asp (All 3 associations)

These position papers emphasize the importance of services being family centered and team-based.

The role of the speech-language pathologist includes "…consultation with and education for team members, including families and other professionals…" Position statement: Roles and Responsibilities of Speech-Language Pathologists in EI: © Copyright 2008 American Speech-Language-Hearing Association; Retrieved from http://www.asha.org/policy/PS2008-00291.htm

"A collaborative early intervention team offers the expertise and perspectives of all its members to achieve family centered outcomes". AOTA Practice Advisory on the Primary Provider Approach in Early EI, January 2014 Retrieved from http://www.aota.org/-/media/Corporate/Files/Practice/Children/AOTA-Advisory-on-Primary-Provider-in-EI.pdf

"AOTA endorses the concepts of collaboration, teamwork, and family-centered care." AOTA Practice Advisory on Occupational Therapy in EI, July 2010 Retrieved from www.aota.org

"The team consists of the child, parent(s), caregiver(s), and others with specialized expertise (these may include physicians, teachers, social workers, psychologists, occupational therapists, speech-language pathologists, and, of course, physical therapists)." APTA Fact Sheet: Team-based Service Delivery Approaches in Pediatric Practice l© Copyright 2010. Developed by the EI Special-interest Group of the Section on Pediatrics of APTA http://www.pediatricapta.org/consumer-patient-information/pdfs/Service%20Delivery.pdf

DEC Recommended Practices http://www.dec-sped.org/recommendedpractices

"Practitioners representing multiple disciplines and families work together as a team to plan and implement supports and services to meet the unique needs of each child and family."

"Practitioners and the family work together to create outcomes or goals, develop individualized plans, and implement practices that address the family's priorities and concerns and the child's strengths and needs. "

In sum, please don't feel slighted if families decide to seek outside services for their young child. You want to help foster life-long advocacy for family members and promote their vision to do what they think is best for their child. Yet, do try to give information on the importance of coordinated services and help them think through that more is not always better. EI services must reflect the family's preferences and your role is to support the child and family in achieving the outcomes that they have selected.

On the WWW

The Exceptional Parent has a new interactive website. Check it out at

http://www.eparent.com/

Exceptional parent is a resource that has been around since 1971. The new website includes digital versions of the Exceptional Parent magazine. Each month the resource includes a section on military families that you might find helpful to review and share with families. The new interactive sits also includes information about specific disabilities as well healthcare, parenting, wellness, and the military!

Toward the bottom of the website be sure to check out the list of "helpful links." You can also link to archived editions of the Exceptional Parent publications. Each edition is filled with useful topics and resources and each edition includes a United States Military Section.

Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for KIT readers.

In line with the focus on *Ensuring the Genuine Application of Family-Centered Practices,* readers are invited to receive continuing education contact hours for reading the monthly KIT publications (January through June) and completing a multiple-choice exam about the content covered in these KITs.

KIT readers will receive the exam in July 2015. There is no need to register for the CEUs. Rather, if you are interested complete the exam online at www.edis.army.mil

Upon successful completion of the exam, you will receive a certificate of non-discipline specific continuing education contact hours.

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