KIT

Keeping In Touch

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Educational & Developmental Intervention Services (EDIS) Personnel Development

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ENSURING THE GENUINE APPLICATION OF FAMILIY-CENTERED PRACTICES

Resource Article

In her article, ‘Training in Infant Mental Health: Educating the Reflective Practitioner,’ Weston (2005) addresses the challenges encountered by providers as they face developmental complexities and disparate family situations. She also proposes ideas for reflective practice. With specialty training in content areas such as speech and language, physical motor, and education, early intervention providers have a wealth of knowledge to share with and teach families in response to the priorities the family identifies for their work with early intervention. Recognizing the diversity of families of children with developmental delays and disabilities and their dynamic and individual circumstances, a finessed approach to intervention is often needed. Providing emotional, informational, and material support (McWilliam & Scott, 2001) is integral to early intervention. Yet, when infant mental health issues emerge, early intervention providers face the challenge of carefully tuning into the fine distinctions of a particular family’s situation that may be beyond their area of expertise and familiarity.

Weston refers to the work of Schon, specifically the notion of “naming and framing” as fundamental to the process of reflective practice because it allows the provider to organize and define perceived factors involved in complex family situations. Naming and framing in a sense, characterizes or categorizes the issue, helping to ‘set the problem’. This can be done with regard to an individual child. For example, understanding that a child has Down syndrome, has been born premature or was the result of a traumatic birth helps to better understand the child, what the family has gone through, and what intervention approaches may be useful. Naming and framing the type of work being done with families may also be useful. Weston describes three different types of work: 1) Promotion, which is providing education and awareness-raising about infant mental health issues; 2) Relationship-based preventative intervention, is delivering a services to children and families with a focus on parent-child interaction with a clear understanding that the relationship between provider and parent affects the process of intervention; and 3)

Resource Article (continued)

Treatment, which is providing interventions designed to strengthen the infant-parent relationship.

Weston refers to the work of Pawl (2000) and Pawl, St. John, and Pekarsky (1999) in which several overarching ideas and sensibilities are said to positively contribute to the work between providers and families regardless of discipline: 1) Trust in parents: trusting that parents have investment in the wellbeing of their infant; 2) Mutual clarity: working with families toward a mutual understanding of the purpose of the work being done; 3) Hearing and representing all voices: being aware of and attempting to represent all voices involved, including the infant's; 4) Hypotheses, not truth: knowing that technical knowledge may not sum up the situation in its entirety; 5) Maintaining an appropriate role: understanding and respecting boundaries; 6) Knowledge, beliefs, biases and meanings: being aware of and understanding how our own systems of beliefs may affect our work; 7) Inclusive interaction: being able to relate to others while being aware of our own feelings and reactions.

Weston provides ideas for promoting reflective practice in the field of early intervention. Naming and framing (i.e., problem setting) is a means to help providers characterize a situation so they can better consider it and the surrounding contributing factors. Embracing the sensibilities listed by Pawl will facilitate the relationship based work between providers and families. Early intervention providers are not being expected to dismiss their unique background, training, and experience. However, given the unique and relationships based work of early intervention it benefits early intervention providers to expand their awareness of family complexities and engage in reflective practices to facilitate optimal care for families and their children.

Weston, D. R. (2005). Training in infant mental health: Educating the reflective practitioner. Infants & Young Children, 18(4), 337-348.

What do the data say?

What are differing levels of stress in babies?

Early childhood science has helped us learn the critical importance of the first three years of life. During this time the brain undergoes significant developmental change crucial for all future learning. It is during this time that the baby's brain architecture in being formed through a process of developing and pruning neural connections. This is an ongoing process that begins before birth and continues into adulthood, but it is incredibly rapid during the first three years when the brain plasticity and capacity for change is greatest. Just as positive experiences contribute to healthy brain development and learning, adverse experiences are harmful for brain development and learning. The length and magnitude of adverse experiences have a compounding negative influence that can derail healthy brain development early in life.

Children do experience stress as part of growing and developing, and some degree of stress is normal. In fact there is positive stress that helps babies learn ways to cope with stress. Yet, all stress is not positive and some stress can be devastating. The landmark resources provided by the Center on the Developing Child at Harvard University (http://developingchild.harvard.edu/key_concepts/toxic_stress_response/) help us understand different types of stress and the influences on early brain development.

What do the data say?

Positive stress is short-lived and is “characterized by brief increases in heart rate and mild elevations in hormone levels.” Some children experience this when separating from caregivers for brief periods of time, or learning cope with the frustration of not getting what they want immediately. Within the context of healthy supportive relationships, positive stress is not alarming or adverse to a baby’s brain development. The supportive relationship is a critically important factor that buffers stress from becoming unhealthy.

Another more concerning level of stress is referred to as tolerable stress; this type of stress “activates the body’s alert system to a greater degree as a result of more severe, longer-lasting difficulties, such as the loss of a loved one, a natural disaster, or a frightening injury.” If this type of stress is time-limited and supported with the nurturing relationship of an adult the brain is more able to recover. Of course what is tolerable to one child may be overwhelming to another and supportive nurturing relationships are critically important.

The highest and most concerning level of stress is toxic stress. This type of stress is longer lasting and influences a “prolonged activation of stress response systems without the nurturing support of a protective relationship.” It is this type of long-lasting stress that can accumulatively disrupt early brain and child development. Toxic stress includes long term exposure to physical or emotional abuse, chronic neglect, caregiver substance abuse or mental illness, or combined hardships such as poverty, poor health and nutrition, or repeated conflicts. Reduced exposure to toxic stressors is an essential component to remediating the adverse effects on brain development.

Babies show stress differently depending in part on the stress and the supportiveness of their relationships. Behavioral indicators of possible stress in infants and toddlers include uncontrollable crying, feeding problems, trouble sleeping, more frequent or more elaborate temper tantrums, regression, or other self-stimulatory or harmful behaviors. Granted observing a child demonstrate any one of these behaviors does not necessarily mean that he is experiencing toxic stress. But it is important to be mindful of extreme behaviors and behavioral changes you and primary caregivers observe. Remember too that babies can sense stress that parents or primary caregivers are experiencing. So working toward alleviating parent and primary caregiver stress is an important part of alleviating stress in young children.

Positive influences on early brain development include supportive, stable, responsive, nurturing relationships and favorable interactions with primary caregivers, and environments that are safe and free of harmful factors. As early interventionists supporting families of young children with disabilities it is important to remind ourselves of the environmental and relational components essential to children’s healthy development. It is also important to understand the differing degrees of stress and the dramatic influence stress can have on early childhood brain development. We know that development occurs within the context of relationships so helping families facilitate safe, supportive, nurturing relationships and environments is key to children’s positive learning and early brain development.

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”

I feel like we spend most of our time addressing the challenges with the older kids while the baby, eligible for early intervention, only gets the last 15 minutes of our visits.

One of the foundational premises of early intervention is that of the family as true partners with professionals. Bronfenbrenner (1977) reminds us that the child can be thought of as in the center of a series of concentric circles, with family members and community members beyond that, all supporting the child and family. It’s helpful to think of the family in a broad context which includes parents, but also grandparents, brothers and sisters, cousins, aunts, uncles, etc. All these family members have a stake in supporting the child with disabilities, perhaps none more so than the siblings. After all, the sibling relationship is one of the longest lasting relationships of our lives. Turnbull, et al. (2011) remind us that the family is a system that incorporates many subsystems such as the sibling relationship and the parental relationship.

In the scenario above, it seems as if issues with the siblings are foremost on the caregiver’s mind. Making and taking time to address family priorities beyond the infant or toddler with a disability is part of early intervention. Perhaps the sibling issues are normal developmental issues which may be addressed with early intervention support or may require helping the family make a referral to a counselor, behavior specialist, school personnel, or others depending upon the situation. On the other hand, if the issues concern the young child with disabilities, perhaps some of the literature and discussion related to siblings of children with disabilities would be useful to review.

For siblings, there can be both positive and negative outcomes associated with being in a family of a child with disabilities. On the one hand, siblings may experience feelings such as resentment (perhaps due to the extra time parents spend with the child), embarrassment, or concern over the future or a lack of information. For example, Josh may no longer be able to participate in playing soccer because it is too difficult for the parent to get him to practice because of the younger child’s needs. This may lead to feelings of resentment even though Josh understands that his baby sister has special feeding requirements during that time. Or Rahema may be embarrassed to invite friends over to her house because she is worried that her brother with Autism Spectrum Disorder may pull her friend’s hair. Siblings need to be supported in understanding how to cope with their own feelings and given strategies to solve the issue if possible. Early intervention providers can help brainstorm with the parents to come up with solutions. Providers can also share information to explain the disability to the sibling, but also to help the sibling explain the disability to others. Some siblings also report feeling guilt that they do not have a disability or worry that the disability may be contagious (Gallagher, Powell, & Rhodes, 2006).

Yet, siblings can also feel a great sense of compassion, understanding, and gratefulness for what they’ve learned and for their deep love of their sibling with disabilities. In fact, most siblings experience all these feelings at various points in time (Gallagher, Powell, & Rhodes, 2006). Outcomes for siblings are dependent on many variables such as the overall number of children in the family, the socioeconomic status of the family, as well as the parents’ expectations and feelings. Research has shown that having more children in a family is somewhat easier for siblings, since the expectations and extra caregiving needs can be spread across several children. In the same manner, families of higher income have more resources to help care for the child with special needs; they may, for instance, be able to pay for respite to take care of the child with special needs or help to take care of the siblings, so that siblings’ lives can remain minimally affected by any extra demands of the child with disabilities. Again, providers can ask about such needs and help point to resources to support the family.

Early intervention providers can be great sources of support for families who want to facilitate positive relationships with siblings when one of them has a

Consultation Corner (continued)

disability. It is so helpful for the child with disabilities to experience the normal give and take of a sibling relationship since they may not be able to experience that with typical peers. Siblings can be terrific role models for language and social interactions. An important survey of mothers of children in early intervention (Kresak, Gallagher, & Rhodes, 2009) found that when there were outcomes for siblings on the IFSP, siblings were more often included by the provider in sessions. On the other hand, parents reported that outcomes related to siblings were not often included in the IFSP. Parents suggested there were many ways that providers could include siblings during ongoing intervention visits. One way is to understand what the children do together and what they find challenging and use that information to explore ways to enhance or build enjoyable learning opportunities. Intervention might include helping sibling learn about turn-taking in conversation and how to tune into their sibling's nonverbal cues so they can respond to and avoid "talking" for the younger child with special needs. Siblings can also be amazingly helpful in teaching social skills and sharing playful interactions that are filled with positive learning experiences. Work with parents to help siblings know how they can be part of early intervention and what is or is not expected of them. See the January 2015 KIT Resource Article for further information.

One of the overarching goals parents recounted was the need for support in talking to the siblings about the disability. This echoes what siblings have said (Gallagher, Powell, & Rhodes, 2006) which is the need for information about the child's disability, specifics such as the label, prognosis, and implications, services the child will receive and by whom, as well as the child's future. Early intervention providers can refer parents to sibling resources such as Sibshops www.siblingsupport.org/sibshops https://www.google.com/maps/d/viewer?ie=UTF8&msa=0&z=3&hl=en&mid=zocxqr6MWiW4.kKx2opEXv-QQ (map showing US states and other countries that have Sibshop programs) or the Sibling Leadership Network (www.siblinglleadership.org). Sibshops can be valuable sources of support for siblings as they get children together to talk about their common experiences of living with a child with disabilities. There are also helpful role modeling sessions on how to talk to your friends about your sibling with a disability, or how to ask questions of your parents, as well as separate sessions for parents. Additionally, there are many books about disabilities that can facilitate healthy family discussions. Gallagher, Powell, and Rhodes (2006), for instance, share a long list of related literature and media. When giving information, providers and parents must be open and honest with siblings about the disability, while crafting the information and answers given, so they are appropriate to the age of the sibling.

In summary, it is important to remember that when one person in the family has a developmental delay, the entire family is affected. The purpose of early intervention is to support the family, not just the child with the delay. Early intervention providers offer informational, emotional, and material support (McWilliam & Scott, 2001) to help the family identify strategies that can be used throughout the day to help the child make progress in development (IDEA 2004). Siblings are present for many aspects of the family's daily routine and it is important to understand the development enhancing role they naturally play in day to day actions and interactions and how they might also help with embedding strategies. Recognize the siblings' role by offering praise for their actions that contribute to improvement in the child's skill level. Inclusion of siblings in sessions and support for the parents about how to answer siblings' questions can lead to positive outcomes for all.

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Kresak, K., Gallagher, P., & Rhodes, C. (2009). Siblings of infants and toddlers with disabilities in early intervention. *Topics in Early Childhood Special Education, 29*, 3, 143-154.

McWilliam, R. A., & Scott, S. (2001). A support approach to early intervention: A three part framework. *Infants and Young Children, 13*(4), 55-66.

Turnbull, A., Turnbull, R., Erwin, E. J., Soodak, L. C., & Shogren, K. A. (2011). *Families, professionals, and exceptionality*. Boston, MA: Pearson.

On the WWW

This month the www resource is the Center for Parent Information and Resources (CPIR).

http://www.parentcenterhub.org

This is a central clearing house of resources for parent training. Their focus is to share materials to support families, increase coordination of parent training efforts, and increase the knowledge and capacity of Parent Centers. Resources are organized around key topics, Parent Center practices, including family-centered services, as well as a set of resources around early intervention.

The site has a tab that makes it easy for families to locate Parent Centers in their state, which includes the contact information and local Parent Center website. As families are moving around the states Parent Centers can be helpful sources of information about services, resources, and advocacy. Included at the following link is a brief review of what Parent Training and Information Centers (PTI) offer and how they work. http://www.parentcenterhub.org/wp-content/uploads/repo_items/bp3.pdf

Every state has at least one PTI, so please share the link with families to help them get connected.

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.

KIT Newsletters are available online at **www.edis.army.mil**

Thank you for your continued interest in the KIT.
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