KIT

Keeping In Touch

MAY 2015

Educational & Developmental Intervention Services (EDIS) Personnel Development

Inside this edition

ENSURING THE GENUINE APPLICATION OF FAMILIY-CENTERED PRACTICES

Resource Article

Families of children with disabilities must sort through medical and educational information. In doing so they must consider varying types of services while also advocating for their children. At times this process can be slowed by a family who may not seem to understand the extent of their child's needs or who is resistant to what is proposed by an array of providers. In these situations, professionals are often heard commenting, "the family is in denial" to summarize the situation. What this says about the family is not nearly as insightful as what it says about the professionals suggesting this state of awareness.

In their article, Working With Families: Rethinking Denial, Gallagher, Fialka, Rhodes and Arceneaux, encourage professionals in the helping field take a closer look at their own ideas and perceptions when they come across families they consider to be in denial. They propose this is an important juncture in the helping relationship with a family, a point in which the professional can step back, reflect upon what the family is going through, and consider how to best provide support.

Elizabeth Kubler-Ross provided a significant way in which to *Death and Dying* (1969). In writing this book, she worked with those directly involved with the terminally ill. She theorized five stages of grief that one generally experienced when faced with a loved one's passing: denial, anger, bargaining, depression, and acceptance. While this construct has been helpful in describing different stages of grief, the application to the field of special needs is not always on point. Perhaps a more appropriate way to consider the grief of a parent with a child with special needs may face is that of Miller (1994), who suggests four elements of adaptation: surviving, searching, settling in and separating. Miller describes the progress through these four elements as being dynamic and circular with some lasting for brief periods and others longer.

What does it mean when a professional describes a parent as being "in denial"? Some may use this description when a parent is resistant to information surrounding a child's possible diagnosis, diagnosis, or as they make plans for the future, such as in writing IEP goals. Others may, more acutely, understand this to be a period in which there is disagreement

Resource Article (continued)

between the parent and professional. The disagreement could arise for any number of reasons (e.g., misunderstanding information, lack of desire to progress with proposed intervention, needing more time to process information, etc.). Interestingly, when the father of a child with a disability was asked about the early years of his child with special needs and whether or not he considered himself to be 'in denial' during that period, he responded, "No, I wasn't in denial. I was in hope" (p. 9).

The authors suggest an overall reconsideration of the notion of denial and instead seeing it as a point at which to regroup, assess and connect with families. Toward this end, they provide some helpful suggestions to contemplate when working with families whom they perceive may be in denial:

- **Support parent's hopes and dreams for their child.** Consider reframing *in denial* with *in hope*. Be encouraging and hopeful with families. Hope often gives families energy they need to take the next steps.

- **Suspend judgment of families and their behavior.** Judgment at any time can interfere with the helping relationship between providers and parents.

- **Be patient. People need time to find their own personal way through unexpected events.** Meet families where they are; realize that integrating new information can take some families longer than others.

- **View this time as an opportunity to strengthen trust.** Step back and consider what can be helpful to a family and how to provide it. Encourage the parent to discuss their concerns, doubts, and worries.

- **Educate other professionals and family members to rethink denial.** Encourage others to reconsider their idea of denial and contemplate how to be supportive of families.

As early intervention providers support families of young children with developmental delays and disabilities it is important to practice these points. In your work with families share information openly and honestly and be respectful of parents' responses. Practice empathy recognizing that you may not completely understand the family's unique circumstances.

Gallagher, P. A., Fialka, J, Rhodes, C., & Arceneaux, C. (2002). Working with families: Rethinking denial. *Young Exceptional Children, 5*(2), 11-17.

What do the data say?

Do you ever wonder about the demographics of the military and DoD families you support? In 2013 the Office of the Deputy Under Secretary of Defense (Military Community and Family Policy) published a profile report of the military community. As an early intervention provider supporting military families the following questions and answers can help you understand the demographics of the population you support. The full report is available online at: http://download.militaryonesource.mil/12038/MOS/Reports/2013-Demographics-Report.pdf

Q: What are the different Active Duty Service branches?
A: Army, Navy, Marine Corps, Air Force, and the Department of Homeland Security's (DHS) Coast Guard.

Q: How many people make up the military personnel?
A: In fiscal year (FY) 2013 the military personnel was over 3.6 million strong. DoD Active Duty personnel was 1,370,329 strong.

Q: What service branch has the largest number of Active Duty members?
A: In FY 2013 the Army had the largest number of Active Duty with 528,070, followed by the Air Force (326,537), the Navy (319,838), and the Marine Corps (195,848).

Q: What are the rank ratios across the services?
A: Across the services there is one officer for every 4.7 enlisted personnel. In the Air Force it is 1:4, in the Army it is 1:4.3, in the Navy it runs 1:4.9, and in the Marine Corps it is 1:8.2.

Q: What is the gender distribution?
A: Women make up 14.9 % and men make up 85.1 % of the DoD Active Duty force. In FY 2013, 16.4% of the Active Duty women were officers and 14.5% were enlisted, yielding an overall ratio one female officer for every 4.2 female enlisted members. Comparatively, the ratio of male officers to enlisted

Q: What is the race/ethnicity distribution?
A: Using the OMB directives just less than one-third (30.7%) of the Active Duty members identify themselves as a minority (i.e., Black or African American, Asian, American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, muli-racial, or other/unknown).

Q: Where is the Active Duty population?
A: The three primary areas where Active Duty personnel are assigned are in the U.S. and its territories (87.2%), East Asia (6.8%), and Europe (4.9%). The ten states with the highest Active Duty populations are (in order) California, Virginia, Texas, North Carolina, Georgia, Washington, Florida, Hawaii, Kentucky, and Colorado. Collectively, these states make up 69.9% of the personnel stationed in the U.S.

Q: What is the age make up of the Active Duty population?
A: The average age of the Active Duty force is 28.6. Active Duty officers are on average 34.8 and Active Duty enlisted are 27.3.

Q: What is the education level of the Active Duty population?
A: Most (83.2%) officers have a Bachelor's degree or higher while fewer (6.5%) enlisted members have a Bachelor's degree or higher.

Q: How many Active Duty members are married?
A: Just over 50% (55.2%) of Active Duty military members are married. In FY 2013, 69.7% of officers reported themselves as married compared to 52.2% of enlisted personnel.

Q: What are the ages of military children?
A: Nearly 50% (42.7%) of DoD military personnel have children. The largest percentage of children (37.4%) is between the ages birth and 5 years of age, followed by 30.8% between the ages 6 and 11, and 24.7% between 12 and 18 years of age.

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 one family I work with has it so together. I feel like they have all the strategies and they just tell me what they are doing. I don't feel like I'm doing anything. Yet, this other family I work with seems to be in such denial about their child's delay. They just don't want to work on anything.

It's interesting how families can differ in how they perceive and accept ideas and supports from others. In the first case, the family members may indeed know how to strategize on all the IFSP outcomes, are aware of what support they need, and are able to plan for their child and family with seemingly little help from early intervention providers. It may be that the child is making great progress and the family no longer needs early intervention. Consider that your job may be complete and that it's time for the child and family to "graduate" from early intervention! After all, an ultimate goal for early intervention is that family members have the confidence and competence in working with their young child with special needs. If this is the case, perhaps it is time to ask the parents to be involved in advocacy or leadership efforts on behalf of other families of children with special needs. There may be opportunities for leadership. Perhaps as part of the local interagency coordinating council (LICC), support groups on base, or other advocacy groups found in the U.S. The following is a link to a list of advocacy organizations: http://www.connectwc.org/advocacy-organizations.html

It is worth checking, however, to be sure that all members of the family are indeed comfortable with IFSP strategies and progress or whether it may just be one of the parents or caregivers. Are there other members of the family who do not feel as confident and competent in achieving the outcomes for their child and family? For instance, maybe the stay at home parent is the only one who has ever met with the early intervention providers and is feeling very competent about her skills in working with her daughter, but the spouse who spends long hours at work remains worried about why Lara isn't talking. It may also be time to update the IFSP, think of new outcomes, or assure that the outcomes the child has accomplished are generalizable to all settings. The IFSP can be modified at any time. Another possibility might be that the child and family have accomplished their IFSP outcomes in one setting but generalizability to other settings and persons has not yet occurred. Work with family members to discuss different aspects of routines and figure out where else skills can be embedded across the child's day. For example, Filiz is doing great walking up stairs in her home, but has difficulty transferring this type of movement to the slide on the playground. It may also be helpful to physically join the caregiver and the child in activities occurring throughout the household, planning your sessions at different times of the day to see different routines. The framework for Reflective Questioning by Rush and Shelden (FIPP CASE Tools, September 2008, Vol. 4, No.1) can be a helpful way to think about awareness, analysis, alternatives, and actions [http://fipp.org/static/media/uploads/casetools/casetool_vol4_no1.pdf]The TaTICS checklist for Key Indicators of Family-guided Routines-based Intervention developed at Florida State University offers away to evaluate whether outcomes desired by the family are occurring throughout the day during different routines (http://tactics.fsu.edu/pdf/HandoutPDFs/TaCTICSHandouts/Module4/KeyIndicators.pdf).

In the second scenario above, it is important to think about the use of the term "denial". In an article we wrote on Rethinking Denial (Gallagher, Fialka, Rhodes, & Arceneaux, 2002) we offer a discussion on reframing the concept of denial, a term often used by professionals when they think the parents do not understand or accept the child's limitations. The term grew out of a linear model of grief shared by Kubler-Ross (1969) in her work on death and dying. Even though many professionals have been taught that the stages of grief must be similar for parents who are accepting the fact of their child's disability, parents we talk to do not support this notion of linearity in their feelings. Rather, they report experiencing many feelings such as joy, acceptance, frustration, anger, etc., sometimes all at once, and do not feel that they are "stuck" in any one stage such as denial. Most parents of young children will tell you that they know very well that their child has limitations and disabilities, but that sometimes they don't want to discuss it with others. In many cases "denial" as a term is used to convey a feeling that the parents aren't doing their part because they can't accept that their child has disabilities. Often, this couldn't be further from the truth. In fact, almost every parent of a

Consultation Corner (continued)

young child with disabilities that we've talked to does in fact understand in their heart of hearts that their child is not reaching developmental milestones nor is on target with typical children. They may not be ready to discuss this with others, including providers or even their spouses, but they do know and understand that their child is not developing as others are. Harry (1997) suggested that professionals sometimes use the term "in denial" in a judgmental way, often when the parents don't agree with the professional on what outcomes to work on or what strategies to use. Rather than putting the "blame" of not working on activities on the parents, an early intervention provider should instead encourage the parents to have hope. After all, especially in early intervention, parents may have just been given a diagnosis for their child or may not have one yet. They don't yet know or understand this new world of disabilities they've been thrust into. The parents didn't volunteer for this role, as professionals did. They may need time to pause or process the world of disabilities. They need to feel hopeful that their child will grow and develop and have friends and go to birthday parties and be a child like other children. The parents are the ones who will be with the child throughout the years of schooling so who better to be a "cheerleader" for the child than the parents! You as the early intervention provider can encourage and support them in this role. Parents need to be optimistic and "in hope" for their child's future. Help parents explore their dreams and goals. Be honest and give them information, encouragement, and optimism. Give them time to process this new world. For "over time, most parents rebuild their hopes and dreams for their child, learn to adapt to the circumstances in their lives, and remain steadfast in their concern for and commitment to their child with disabilities" (Gallagher, et al., p. 17).

It's helpful also to remember that many other things could be going on in the life of the family than just the fact that their child has a disability. For instance, has the spouse just recently been deployed or even injured in the line of duty, are there aging grandparents who need their support, or did one of the parents just get a new full-time job? Just because parents or caregivers don't seem to follow through on your suggestions or seem to be as involved as you would like them to be, doesn't mean they don't care or aren't concerned. We as professionals have dedicated our lives to this field but there are times when we need to put our priorities in perspective. It may be time to engage other community resources. It may be time to talk to a trusted colleague if you need to reflect on your worries and plan a way ahead. Try hard not to "label" parents. No one can walk in their shoes or understand their deepest dreams and desires for their child. Find ways to truly listen to the parents and hear their hopes and dreams for their child so you can support those. Reviewing the TaTICS checklist on Implementing Information About Adult Learners in Family-guided Activity Based Intervention (Florida State University, 2010) can help you reflect on your own practice regarding your interactions with this family (http://tactics.fsu.edu/pdf/HandoutPDFs/TaCTICSHandouts/Module3/AdultLearner.pdf)

It is often useful to start with small steps with parents. Start with something you know they already do with the child. Use that routine to embed a strategy and once that is accomplished and the parents feel comfortable, you can move to the next step. Help the parents feel a sense of accomplishment and hope, even if it is just with one routine. You want them to feel that "I can do this!" Another helpful strategy is to link parents to other parents who also have a child with disabilities. Help parents make these connections in your local community or in the U. S. connect families with a **Parent Training and Information Center** (PTI) to offer families support and information. Many States also have a **Community Parent Resource Center** (CPRC), which offers the same type of support and training to parents of children with disabilities. (http://www.parentcenterhub.org/find-your-center/)

Early intervention personnel may also have to "sell" the importance and efficacy of early intervention. Sharing the impact and effectiveness of starting early can be so helpful. In some cases, one parent might understand and appreciate this importance but the spouse or partner does not. We know of a father who constantly seemed to put up roadblocks to the early intervention provider's visits, saying "there is nothing wrong with my son; I don't want these people in my house". In this scenario, helping both parents understand the importance and effectiveness of early intervention is the key. Each family that you meet will be unique and will have varying needs of support. It is important to accept families as they are and take the steps that help build the family's confidence in their ability to advocate for their child and create learning opportunities that help the child progress in development.

Harry, B. (1997). Leaning forward or bending over backwards: Cultural reciprocity in working with families. *Journal of Early Intervention, 21*, 62-72.

Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.

On the WWW

This month the web resource is the Clearinghouse for Military Family Readiness

http://www.militaryfamilies.psu.edu/

This clearinghouse is designed to provide assistance to military families and professionals by researching and linking evidence-based resources in a searchable database. Also included are webinars, virtual learning communities, and opportunities to interface with others.

The Clearinghouse evaluates programs and links reliable resources. For example, there are resources organized around families with special needs, child development, domestic/interpersonal violence, education and schooling, family relations, mental health, military lifestyle and many more.

If you can't find what you are looking for there is also a live chat option where you can chat with someone to receive the targeted resources you are searching for.

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.
Please share your KIT questions/ideas via email to
EDISCSPD@amedd.army.mil