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#### **Keeping In Touch**

JANUARY 2019



## Resource Article

Shifting perspectives on denial is a good place to start our new KIT series on *Understanding Early* Intervention Service Coordination Essentials. Service coordinators are typically the first early intervention providers to meet newly referred families. Service coordinators are responsible for connecting families other providers, helping families tell their stories, and assisting them throughout their early intervention journey from entry through exit.

As you think about service coordinators and other providers meeting and working with families children with voung delays developmental disabilities, you might recall having heard someone comment "the family is in denial." Take a moment to let that sink in; "the family is in denial." What does that mean to you? What does it convey to you about the family? How does the statement influence your feelings about the family?

In their article, Working With Families: Rethinking Denial, Gallagher, Fialka, Rhodes, and Arceneaux (2002)explore the implications of denial and suggest the need for reframing being in denial to being in hope (p. 4). Their article opens with a reminder of Helen Keller and her mother's optimism and persistence. Helen Keller's mother believed that Helen had great potential if only she could just be reached. Her mother knew of the limitations and challenges Helen faced but did not let them overshadow her dreams and exploration of possibilities that might help Helen. Is that denial? Or is that hope? Certainly, there were professionals who did not share or believe in the wishes Helen's parents had. Just think about how Helen's life (and ours) would be different if her parents' dreams had successfully squelched. If her parents were regarded as being in denial and not afforded the opportunities to partner with professionals acknowledged their beliefs, who

#### Resource Article (continued)

supported their optimism, and who shared informational, material, and emotional support to help them make informed decisions in a way that empowered them without silencing their hopes and dreams.

Denial, as a label for a parent of a child with a delay or disability, implies that the parent is not being realistic about their child. This can happen when parents are judged from the professional perspective, when the parent and professionals are at odds about a diagnosis, a child's potential, or some other aspect of the child's development or intervention needs. Gallagher et al., caution professionals not to pass judgement, but rather to reframe and consider the realities the family might experiencing. Reframing requires stepping back and considering others' perspectives. It means practicing empathy and working side by side with families to understand where they are in their feelings and understanding of their child's abilities and future. In doing so it is also important to acknowledge that the stages of grief are not predictable and linear. In fact, Gallagher et al. highlighted that "parents report they sometimes experience feelings such as guilt, acceptance, despair, or denial all within a period of five minutes of dealing with their child with special needs" (p. 2). Pinpointing parents to stages of grief is

therefore not helpful and can hinder the development of a supportive relationship with the family.

professionals rethink denial To help Gallagher et al. recommended several practices. One is to support the dreams parents have for their children. Engage them in conversations and exploration about their hopes and dreams as well as their fears and questions. Share your expertise and experience, but also acknowledge the possibility that being in hope can actually help parents. Be mindful about going down the judging path. Rather, work acknowledge to understand parents' actions and behaviors. Listen and keep a focus on building a supportive relationship. Practice patience, parents need time to trust the relationship. They need time to share and take in all they are hearing and experiencing. Each family will be on their own time table and there will likely be ups and downs along the way. Use the time needed to build the trust and to grow together in the relationship to support the family. And help others to rethink Acknowledge that being in hope is good and parents' behaviors others might have regarded earlier as denial might be a part of a much deeper and optimistic function that helps parents build their own acceptance, advocacy, and encouragement for child and family.

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

Online republication available at: <a href="https://www.danceofpartnership.com/Denial">https://www.danceofpartnership.com/Denial</a> Article.pdf

# What do the data say?



To start this KIT series on service coordination let's review a few questions about service coordination.

#### What is service coordination?

Early intervention involves a coordinated system of family-centered, culturally competent, comprehensive, multidisciplinary, interagency early intervention services for infants and toddlers with disabilities and their families. This requires the commitment and dedication of all service agencies and providers to "cooperatively and collaboratively plan, implement, and evaluate services that enhance the capacity of families to meet the special needs of their child" (RTC, 2002 p. 1). To do this, the law requires the appointment of a service coordinator to assist families with accessing services and assuring them of their rights and procedural safeguards. Service coordination is a mandated service provided at no cost to families.

### What are the requirements of service coordination in early intervention?

Service coordination is a requirement under the Individuals with Disabilities Education Act (IDEA, 2004) established to ensure coordination of for infants services and toddlers with developmental delays or disabilities across agencies and systems. Early intervention is not nor was it initially intended to be a silo of services. Rather, as stated in IDEA, early intervention represents a "statewide, comprehensive, coordinated. multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families" (IDEA, 2004 20 USC § 1431 (b)(1)). Service coordinators not only coordinate and collaborate with other early intervention providers and staff, they must also interface with multiple community agencies in support of infants and toddlers with developmental delays or disabilities and their families. Service coordination begins with the early intervention referral and intake process and continues through the transition out of early intervention. Every child and family receives service coordination to the extent needed by their family.

#### What are the desired outcomes of service coordination?

Beyond considering the functions and activities of service coordination, it is important to understand the desired results of service coordination. The Research and Training Center (RTC) on Service Coordination sought the answer to this question through extensive research (see http://www.uconnucedd.org/projects/rtc/rtc.html). Their results revealed nine interrelated outcomes of high quality service coordination. These nine outcomes are stated below (Bruder, 2010 pg. 95).

- Families have access to support, information, and education to address their individual needs.
- Families are able to communicate the needs of their child.
- Families make informed decisions about services, resources, and opportunities for their child.
- Agencies and professionals are coordinated.
- Children and families receive quality service.
- Children and families participate in supports and services that are coordinated effective, and individualized to their needs.
- Families acquire and/or maintain a quality of life to enhance their well-being.
- Families meet the special needs of their child.
- Children's health and development are enhanced.

Service coordination is a essential and empowering component of early intervention and with the right attention and effort it can help families achieve

Bruder, M. B. (2010). Coordinating services with families. In R. A. McWilliam (Eds), Working with Families of Young Children with Special Needs (pp. 203-236. New York: The Guilford Press.

Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. § 1400 et seq.

RTC - Research and Training Center in Service Coordination. (2002). Briefing Book Site Visit – Tuesday, August 6, 2002.



# Consultation Corner

Please welcome our consultation corner experts for this KIT series on

**Understanding Early Intervention Service Coordination Essentials** 



Sarah Nichols is a Professional Development Specialist and National Consultant for the Early Intervention Training Program at the University of Illinois. Sarah began her career in early intervention

in 2000 as a dedicated service coordinator in the Illinois Early Intervention System. In that role, she partnered with thousands of families helping them navigate early intervention processes and link with varied resources. Since becoming a statewide trainer and professional development specialist, Sarah has co-led all training and development for service coordinators in Illinois and co-leads an Illinois Service Coordination Community of Practice and a forum for service coordinator trainers across Illinois. Sarah also leads a National Service Coordination Training Workgroup and National Service Coordination Leadership Institute comprised of stakeholders from across the nation who share an interest in empowering, supporting and preparing service coordinators. As a result of this work, service coordinators across the nation have had the opportunity to participate in National Webinars. This work is also facilitating National Recommended development of Knowledge and Skills for Service Coordinators and a National Service Coordinator Community of As a member of the Council for Practice. Exceptional Children (CEC), an active member of the Division for Early Childhood (DEC), Sarah is the Professional Development Strand Leader of the DEC Personnel Preparation Committee and a former Co-Leader for the DEC Professional Development Special Interest Group (DEC PD SIG).

Maria Kastanis has worked in Early Intervention for 18 years. Currently, she is the Assistant Director of the Illinois Early Intervention Training Program at the University of

Illinois. Maria began her career in Early Intervention



as a Service Coordinator. As she advanced her knowledge, skills and leadership abilities she became a lead service coordinator responsible for training and supporting new and experienced service coordinators. Maria is a certified trainer in the Routines-Based Interview and a strong proponent of family engagement. Maria believes service coordination is the glue that holds the Individualized Family Service Plan together. Maria is a co-leader of the Illinois Service Coordination Community of Practice and a forum for service coordinator trainers in Illinois which provide a platform that connects those with a shared interest in service coordination across the state on a quarterly basis. Maria is a member of the National Service Coordination Training Workgroup, has co-facilitated two national service coordination webinars and actively participates in National Service Coordination Leadership Institute activities with fellow Professional Development Specialists, Training and Technical Assistance Providers, Part C Administrators, and Program Supervisors from across the nation. Maria is member of the Council for Exceptional Children (CEC) and an active member of the Division for Early Childhood (DEC).

#### **Consultation Corner** (continued)

As we roll out this series on service coordination we invite you to complete a quick knowledge check. Please review the ten true and false questions below. Then after answering the questions check your answers by looking at the box on the bottom of this page.

Be sure you complete your responses before peeking to the bottom of the page  $\odot$ .





- 1. TRUE or FALSE Part C of the Individuals with Disabilities Education Act (IDEA) specifically requires the provision of service coordination at no cost for all families eligible for early intervention.
- 2. **TRUE or FALSE** The primary responsibility of service coordinators in early intervention is to complete the program paperwork.
- 3. TRUE or FALSE An outcome of service coordination is for families to make informed decisions about services, resources and opportunities for their child.
- 4. TRUE or FALSE The service coordinator is the decision maker when it comes to deciding upon services and supports for families.
- 5. TRUE or FALSE The service coordinator makes sure team members are working with one another and that everyone is working towards the same goals.

- 6. TRUE or FALSE The service coordinator does not need to be knowledgeable about community resources outside the Early Intervention System.
- 7. TRUE or FALSE Service coordinators need to be flexible and culturally sensitive so they can build relationships and partnerships that empower families.
- 8. TRUE or FALSE Service coordinators have a responsibility to explain families their rights, and ensure their understanding of their rights, so they can make informed decisions.
- 9. TRUE or FALSE Part C of IDEA mandates that the model of service coordination is the same across all states.
- 10. TRUE or FALSE Service coordinators ensure policies and procedures are followed and that families are active participants throughout the early intervention process.



- 1. TRUE
- TRUE
- TRUE
- 7. TRUE
- 9. **FALSE**

- **FALSE**
- **FALSE**
- **FALSE**
- TRUE
- 10. TRUE



#### On the WWW

Service coordinators are responsible for many aspects of early intervention including connecting families with varied resources and facilitating the provision of high quality services in accordance with required timelines and processes. The types of resources service coordinators need are limitless. So there is no single or set of online sites that can provide all that might be needed. But there are some very robust resources that can be very useful for early intervention providers and service

coordinators. A go to resource that all early interventionists should be aware of is the Early Childhood Technical Assistance Center (ECTA). The home page is <a href="http://ectacenter.org/">http://ectacenter.org/</a> This site includes extensive resources related to Part C early intervention and 619 programs for children with disabilities. This site includes information about IDEA, interrelated systems key to quality programs and services, as well as information about state contacts and quality practices. If it is not already on your favorites list you'll benefit greatly by adding it to your go to list of resource links.



# 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 **Understanding Service Coordination Essentials**, readers are invited to receive continuing education contact hours for reading the monthly KIT publications (January through May and completing a multiple-choice exam about the content covered in these KITs.

KIT readers will receive the exam for this series in June 2019. 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.



