



Resource Article

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edition
**ENSURING THE
GENUINE
APPLICATION
OF FAMILY-
CENTERED
PRACTICES**

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We kick off our new KIT series, *Ensuring the Genuine Application of Family-centered Practices in Early Intervention*, by considering how to include siblings of children with special needs in our work with families.

In their article, "Siblings of Infants and Toddlers With Disabilities in Early Intervention," Kresak, Gallagher, and Rhodes (2009) examined Individualized Family Service Plans (IFSPs) to determine whether or not siblings were included in the goals; if so, how were siblings included in services; and if not, how would families want them included.

Results, from the sibling questionnaire completed by 87 families participating in Part C services in a southeastern state, suggested that 25.3% of respondents had IFSP goals including the siblings of their child with special needs. When they were asked in what capacity siblings were included on the IFSP goals, 38% were categorized as "play and interaction" (e.g., "play and interact with toys and games with sibs") and 19% as

"communication." Samples of goals involving siblings included: "to interact with him in the yard," "to like him," and "to better understand his sister's condition." Another theme listed was having siblings help in the feeding, dressing and walking/crawling of the child with special needs.

For those families who did not have goals including siblings, nearly half (48.3%) reported they would like them included. Families came up with many ways the siblings could be included in services: more interaction between their children, for siblings to learn more about the disability, to learn about ways siblings could join in and participate in services, to improve basic care and communication, and to learn about emotional issues (e.g., patience and dealing with frustrations regarding the child). Roughly half (50.6%) reported early intervention providers involved siblings during services. The following were some responses: included sibling in exercise/therapy, provided education to siblings on how to play/interact with child, provider asked and

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answered questions with sibling about the child with special needs. Parents also reported siblings had many questions about their brother or sister (e.g., "Why can't he talk?" "Can't the doctor take away the extra chromosome?" "Why doesn't she walk like me?").

When considered in sum, nearly 75% of families expressed a desire for all of their children to be involved in the early intervention process of their child with a disability or delay (25.3% of families currently had IFSP outcomes including siblings plus the 48.3% who stated a desire to have siblings included on the IFSP).

The results of this study suggest that not only do parents want the brothers and sisters of their child with special needs to be a part of early intervention services, but they also suggest some important ways to do so. Individually, early intervention providers can do a lot to include siblings. As we gather information about daily routines, providers can ask specifically about siblings. We can talk with siblings to gain their ideas on how to help their brother or sister; this also provides some insight on their perspective of the disability. As we prepare to write the IFSP, we may need to prompt parents to include siblings (e.g., "How would you like to include his brother/sister?").

Efforts can be made to include siblings during our visits, and we can provide additional information/education about the child's disability. At the program level, early intervention programs can develop opportunities with the goal of supporting brothers and sisters of children with special needs. SibNight is just such a program (Munch & Levick, 2001). It's designed for children ages 3 to 16 years who have a sibling in the neonatal intensive care unit. Early intervention programs can also offer trainings for providers on ways to include siblings in their work with families.

Early intervention has historically touted the importance of family-centered practice. And the results from this study remind us to have a more comprehensive understanding of family by considering how to include the siblings of a child with disabilities as part of early intervention.

Kresak, D, 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.



What do the data say?

What are the outcomes of early intervention for families?

To answer this question we will look at the Federal outcomes measurement requirements and data from the 2012 Part C Annual Performance Report (APR) Indicator Analysis compiled by the Early Childhood Technical Assistance Center (ECTA). All states, including the DoD EDIS early intervention programs, are required to collect and report on the outcomes of early intervention for families. The measurement indicator the states and the DoD use is the percent of families participating in Part C who report that early intervention services have helped the family (A) know their rights; (B) effectively communicate their children's needs, and (C) help their children develop and learn.

A central role of early intervention is the provision of family-centered support and empowering families. By measuring these family outcomes programs, families, as well as community, state, and national stakeholders can understand the results of early intervention for participating families and take action to improve or sustain quality practices that result in positive outcomes for families.

State early intervention programs use family surveys to collect data for this indicator. While there is some variation in the actual survey and survey approach employed, all states report on this indicator. The DoD programs use the Early Childhood Outcomes (ECO) Family Outcomes Survey (FOS) 2006 edition. Of the 56 states reporting data for the 2012 APR 26 states (46%) either used the original (2006) FOS (14 states) or the revised (2011) FOS (11 states). The remaining states used the NCSEAM Family Survey, variations of that, or state-developed surveys. The average

response rates, based upon the states that reported this information, was 39.9% with response rates ranging from 7% to 100%.

The results of state reporting on family outcomes are quite positive and the collective trend over the past reporting years is stable. During the 2012-13 reporting the national mean for the outcome "early intervention services have helped the family know their rights" was 87% with a range from 51% to 99%. With regard to the outcome "early intervention has helped the family effectively communicate their children's needs" the mean was 88% and the range was 51% to 99% and for the outcome "early intervention has helped the family help their children develop and learn" the mean was 90% and the range was 51% to 100% and for the outcome.

The DoD programs also celebrate positive results with regard to these family outcomes. In the reporting year 2012-13 96.3% of families reported high attainment in the outcome "early intervention has helped the family know their rights"; 98.2% of families reported high attainment for the outcome "early intervention has helped the family effectively communicate their children's needs"; and 98.5% reported high attainment for the outcome "early intervention has helped the family help their children develop and learn."

Measuring family outcomes is one critical aspect of understanding the results of early intervention services. Analyzing these data in light of other data programs collect is important for informing state and local program improvement initiatives to ensure the highest quality of support and family-centered early intervention services.

For more information on family outcomes and analysis of these data visit (<http://ectacenter.org/eco/pages/tools.asp>).



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”

Dr. Peggy Gallagher is Professor and Coordinator of the Early Childhood Special Education program at Georgia State University in Atlanta, GA, USA. She began her teaching career as an infant/toddler teacher and also taught preschoolers and elementary aged children with disabilities. She has directed Project SCEIs (Skilled, Credentialed Early Interventionists), Georgia's personnel preparation program in Early Intervention, for 20 years. Her research interests are in working with families of young children with special needs, including grandparents and siblings, as well as inclusion for young children with special needs.

Eileen Kaiser has been involved in the field of early intervention for over 20 years. She started her career in early intervention in Sarasota, FL as a teacher in a site-based program for infants and toddlers with developmental delays. After moving to the Atlanta area, she started working with Georgia's Babies Can't Wait (BCW) early intervention program as a special instructor providing services in natural environments. Over the years she has worked in a variety of roles for BCW, including evaluator, Early Intervention Specialist, and State CSPD Coordinator. Eileen had the opportunity to collaborate with Dr. Gallagher as the Assistant Director for the Project SCEIs personnel preparation program for early intervention providers. Currently, she works as a project coordinator for a research project for the Infant-Toddler Community Outreach program at the Marcus Autism Center, which is affiliated with Emory University and a part of the Children's Healthcare of Atlanta organization. The project is funded by a five year NIH Grant, with the aim of involving community systems in the screening and

referral process for toddlers in the hope of reducing the age of identification of Autism Spectrum Disorder (ASD) to 18 months of age. Leading to more timely early intervention for children with ASD and their families.

Over the next several months, Peggy and Eileen will explore the following provider shared situations in light of the genuine application of family-centered practices. This month we also invite you to review the following provider reflections and think about how you might respond if this was you or perhaps a colleague. Think about the situations from both the provider and family viewpoints. Then over the next several Peggy and Eileen will help us reflect and explore strategies for resolving or easing these situations.

• I leave the visit feeling like we talked about all the same old strategies. They are good strategies, but it seems like our visits are in a rut.

• I feel like the family could see great progress with their child's challenging behavior if they would just be more consistent with the strategies we've come up with.

• 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.

• This one family I work with has it so together. I feel like they have all the strategies and they just tell me. I don't feel like I'm not 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.

• A family I'm working with just started getting additional therapy (speech and OT) outside of early I'm feeling a bit left out.



On the WWW

In line with this KIT series on family-centered practices, our web resource this month is the Center for Parent Information and Resources.

<http://www.parentcenterhub.org/>

This link brings you to a host of resources for parents. The resource section is neatly organized by topics with several links in Spanish as well.

It includes topics such as descriptions of various types of disabilities, family capacity building, as well as multiple family support resources. One of the many links you and the families you support may find helpful is Great Start! Parent Empowerment Training Series. Check it out at

<http://factoregon.org/events/online-learning-opportunities/>



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

