



TECSNews— For the Allied eHealth Resource Network

Special points of interest:

- Strategies for Involving Families

- Working with Latino/Hispanic families
- Information from Providers

- A SC Family's Perspective
- Baby Net Policy Update from Provider Relations

For All Providers Working with 0-3

Issue 6

November 2007

Strategies for Involving Caregivers in Part C Services— Overview and New Information



Early intervention is what happens between visits of the early interventionist

R.A. McWilliam

As we increasingly look for ways that caregivers can participate in their child's development, it is helpful to review some of the strategies that we already use and learn new ones. This issue includes some considerations and strategies— from the practice literature, providers, and a family with a child with special needs— when guiding caregivers' participation in IFSP services.

Considerations to remember as we involve families and other caregivers more often...

Families want to learn about ways to help their child now and in the future (see p. 10). Since they may be dealing with several issues and responsibilities, feeling overwhelmed, or lacking in confidence, it can be helpful to provide families with information:

- that is short and clear— providing the most important information first, saving the less immediate issues for later visits; and repeating the information as well (Florida First Steps).
- provided verbally and in writing (McCormick, 2006).
- followed up by asking family members to paraphrase what you have said (e.g., what are the important points you'd like to remember, etc.)— to ensure no misunderstandings (Florida First Steps)
- that incorporates the family's suggestions— developing a "common vision" with the family and being "responsive" are key (McCormick, 2006).

We do more for the child when we inform parents (D. Stout, more on p. 10)

Continued on p. 2

About this issue

This issue spotlights strategies to use when supporting families— it introduces new strategies and reviews ones that we frequently use. *The articles include examples and considerations for involving caregivers more often, from the professional literature, other states, providers, & a family member from South Carolina.* This issue has information on working with children & families who are Latino/Hispanic, the Family Survey being conducted in SC, "play-based, family-involved" therapy ideas, routines-based assessment for planning intervention, the definition & role of special instruction, and more. *Be sure to read insights from a parent of a child with autism on p. 10.*

Finally, mark your calendars for **May 22, 2008, for the 1st annual SC Early Intervention Providers Conference!** Also, see the many new products on the TECS website at <http://uscm.med.sc.edu/tecs/>, & visit the provider & service coordination blogs!

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Strategies for Involving Caregivers in Part C Services— Overview and New Information

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More considerations for involving families and other caregivers...

- Try to include a routines-based assessment approach— the format of routines-based assessment leads to child and family-level goals and objectives that are functional and consistent across environments (McWilliam & Clingenpeel, 2003) (see p. 12 for more specifics about this strategy).
 - Provide support to families— interact and present information in a manner that is positive, responsive, friendly, sensitive, and oriented to the whole family (McWilliam & Scott, 2001)
 - Build on existing preferences and practices at home and other usual settings— use information from families; for example, by involving the caregiver, who typically prepares food and feeds, so that he can discuss how he adjusts food preparation, positioning, etc., to accommodate the child's eating needs during family meals, etc. (Sandall et al., 2005)
 - Listen to families— provide them with information based on their interests such as learning how to interpret research results, finding and connecting with parent education activities and resources, learning about various treatment approaches of interest to families, etc. (Sandall et al., 2005)
 - Provide information to families in a way that “matches the family's style of understanding and process—ing....” (Sandall et al., 2005)— so the family is a primary consumer and the child is the ultimate beneficiary of services.
- To promote team collaboration, remember to:
 - ◇ Keep an open mind to alternative solutions
 - ◇ Elicit participation, input, and consensus from others
 - ◇ Compromise for the sake of productivity
 - ◇ Solicit and make use of feedback
 - ◇ Communicate understanding and acceptance of the opinions of family and other team members (McCormick, 2006).

The family is a primary consumer and the child is the ultimate beneficiary of services (McCormick, 2006)

Research-based practice recommendations for new service delivery strategies warrant our careful review and consideration, especially at a time of reduced budgets, personnel shortages, and inconsistent access to services. This will involve challenges to work through, but the outcome should be quality services for more children with special needs. Continue to visit your professional association websites to keep abreast of emerging issues and solutions in early intervention.

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*May 22, 2008 is the first annual
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A Few More Ideas for Involving Caregivers, & Everyday Routines & Materials

Adapted from FACETS, a joint project of Kansas University Affiliated Program and Florida State University (<http://tactics.fsu.edu/pdf/HandoutPDFs/TaCTICSHandouts/Module4/Intervention.pdf>)

Not all care providers will be comfortable with various strategies. It helps when strategies for families to use are selected based on child and family preferences, their environment, as well as their goals.

It is also important to give caregivers choices of strategies they wish to use, and then follow up later by asking them how comfortable they felt with the teaching strategy they selected.

Not all care providers will be comfortable with various strategies.

General Principles: Within routines and play activities, the following may help caregivers facilitate successful practice and learning at home. These can also be thought of as “family objectives” to help address their child’s IFSP goals.



Children learn best when...	Caregivers can be involved by...
interaction between caregiver and child match the child’s current developmental level	learning/using strategies to communicate and interact with the child at the child’s level
they are actively engaged— we know that they learn as they look, touch, taste, climb, etc.	encouraging their child to look, taste, touch, climb, tell, throw, poke, smell, etc. (see p. 8 for more ideas from providers)
receive attention from a caring, interested adult— this can provide the interest to interact and the reinforcement for trying	interacting in a manner that is approachable, responsive, attentive, and fun— example: making diaper time fun, encouraging reaching for mom’s mouth, eyes, etc.
they initiate the interaction or activity— participation initiated by the child often results in longer attention to the activity, increased opportunities to practice skills, and decreased need for external reinforcement. <i>However, to be effective, the environment or routine may need to be arranged to attract the interests of the child.</i>	helping caregivers start with where the child is engaged— example: the child likes playing with a ball; so the caregiver can begin to practice skills such as turn-taking or sitting during ball play

The framework of a familiar and predictable routine supports learning new skills. Specifically, the child can focus attention on the specific requirements of the skill rather than dividing attention between the activity, the environment, and the skill. Using these and/or other strategies, caregivers can be involved with the development of their child.

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for the newsletter and website!

Cultural Competence— definition, resources, and considerations when working with Latino/Hispanic families, by Gina Crosby-Quinatoa, M.S.P., CCC-SLP

Important information
for all therapists

Gina Crosby-Quinatoa, M.S.P., CCC-SLP is a certified bilingual speech-language pathologist. She is the Director of the Hispanic/Latino Initiative at the University of South Carolina Speech & Hearing Research Center. She can be contacted at (803) 777-2671 or crosbye@gwm.sc.edu.

The United States is one of the most culturally, ethnically, racially, and linguistically diverse countries in the world (ERIC, 2001). As we have seen over the last 10 years, South Carolina's diversity is beginning to reflect similar immigration changes.

Given this increase of immigration and such diversity in S.C., it is likely that early childhood service providers (e.g. special instruction provider, speech pathologist, occupational therapist, physical therapist, etc.) will work with families from cultural, ethnic, and linguistic groups that differ from their own. The information provided in this article is to help early childhood service providers become more sensitive to cultural differences and develop effective skills for working with families from diverse backgrounds and identities.

First, culture will be defined and examples will be given; next guidelines and resources on how to become cultural competent will be provided; and last a comparison of beliefs, values, and practices of the Latino/Hispanic family and the mainstream culture will be made, with considerations to keep in mind when working with Latino/Hispanic children and families.

1. What is culture? *Culture is the sum of all the forms of art, of love, and of thought, which, in the course of centuries, have enabled man to be less enslaved. –André Malraux (as quoted in Lynch & Hanson, 1999, p.3)*



One's culture is the framework that guides and bounds life practices. It affects:

- ✓how one meets and greets strangers, friends, and family members
- ✓the stories one tells and how one tells them
- ✓the ways one uses touch, silence, eye gaze, distance and humor during interactions with intimates, new acquaintances, or professionals
- ✓preferred ways to start and stop conversation, shift topics as well as the appropriateness or significance of various conversation topics
- ✓how one reveals feelings and with whom
- ✓the questions one asks, how one asks them and if/how one answers questions posed by others
- ✓how one learns and how one demonstrates this learning
- ✓how one measures success, what one perceives as problems, the ways one deals with these perceived problems
- ✓who one lives with and how, the ways one raises their children, care for aging parents, share decision-making with spouses, extended family, and community members
- ✓how one perceives ability and disability (Kohnert, 2007)

2. What is a cross-culturally competent service provider and how does one achieve cultural competency?

A culturally competent service provider is one who is aware of his or her beliefs and values which are unique to that individual and are understood, protected and respected. A culturally competent service provider brings awareness of his or her own culture and cultural biases to his/her work. In order to be culturally competent, one must evolve through a process by which one develops an understanding of self, while developing the ability to develop responsive, reciprocal and respectful relationships with others.

Being cross-cultural is to have the ability to respond optimally to all children, understanding both the richness and the limitations of the socio-cultural contexts in which children and families as well as the service providers themselves may be operating (Barrera & Kramer, 1997). There are several resources (e.g. checklist) that can be used to determine if cross cultural competency is being used in one's service and practice. They include:

<http://www11.georgetown.edu/research/gucchd/nccc/>

http://www.asha.org/NR/rdonlyres/E7805A1A-CCD2-4A35-B84A-ED889318EFA0/0/personal_reflections.pdf

<http://www.asha.org/about/leadership-projects/multicultural/self.htm#ccc>



Considerations when working with Latino/Hispanic Families, continued from p. 4

3. How do the beliefs, values, and practices of the mainstream culture compare to the beliefs, values, and practices of the Latino/Hispanic family? *

Latino/Hispanic Culture	Mainstream Culture
Collective Orientation	Individual Orientation
Interdependence	Independence
Collective, group identify	Individual identity
Emphasis on group effort (cooperation)	Emphasis on competition
Not as direct. Saving face is important	Being direct
Relaxed with time. Time is not always essential.	Time sensitive. Timelines used.
Emphasis on interpersonal relationships	Emphasis on task orientation
Spiritual/magical belief orientation	Rational/empirical orientation
More recent agrarian influence	More urbanized/industrialized mode
Tendency toward more patriarchal family structure	Tendency toward more democratic family structure
More relaxed with child development	Strong expectations for child development. Parents follow
More overt respect for elderly	Less value/respect toward the elderly
Nuclear and extended family is very important	Nuclear family system more pronounced
Death more ritualized	Death less ritualized

(Lynch & Hanson, 1999)

Examples of performance and practices of Latino/Hispanic children/families, from the field (Langdon, 2008):

- ◇ It is not uncommon for young children of Hispanic backgrounds to lag behind in the performance of everyday skills such as knowing how to button jackets, tie shoes, or cut food— because parent, caregivers, and even older siblings have done it for them.
- ◇ In many daily situations, parents and caregivers may not always comment on or make verbalizations about ongoing events. More directives are given on what the child should do.
- ◇ Parents sometimes feel that play is only appropriate among children and should not take place in an educational setting.
- ◇ Hispanic children are taught to be respectful of adults and not interrupt conversations.
 - ◇ Many Hispanic parents do not ask their children to repeat facts or to foretell what they will do.



Things to keep in mind.....

What would be considered inappropriate when working with a Hispanic/Latino Family?

- ◇ Speaking to the wife before the husband when both are present
- ◇ Not asking whether the father is in agreement with the recommendations or plans, even if he is not at the session or meeting
- ◇ Declining a beverage or food offering
- ◇ Beginning on work or tasks immediately, before any informal and relaxed exchange with the client has taken place.
- ◇ Using teasing to break the ice

*The information provided is not meant to serve as a comprehensive description of the Hispanic/Latino family. There is much variation within subcultures and within families themselves. It is to provide basic information based on historical background, values and beliefs often shared by members of this cultural community.

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Family-Centered Principles— a resource for Part C providers

by Kristie Musick, M.Ed., Director, Team for Early Childhood Solutions

Family-Centered Principles are a set of interconnected beliefs and attitudes that shape directions of program philosophy and behavior of personnel as they organize and deliver services to children and families. Core to family-centered services is sensitivity and respect for the culture and values of individual family members and each family's ecology, as members define the people, activities and beliefs important to them. The purpose of early intervention is to achieve family outcomes as well as child outcomes. Preschool special education services must also include family involvement as well as accomplish child outcomes.

Formal definitions of "Family-Centered services" exist in the fields of social services, child welfare, developmental disabilities, early childhood and children's health care. While the definitions are different there are common words and descriptions among them all, and include the following key descriptors: strengths based, consumer driven, family systems, family support, empowerment, proactive service delivery, promotion, competency focused, partnerships, collaborative relationships, family driven.

The following principles guide how early intervention services are to be conceptualized, planned, and implemented. For additional information, visit the National Early Childhood Technical Assistance Center at <http://www.nectac.org/topics/families/families.asp>*

- Recognize that families are the constant in the lives of their young children.
- Provide opportunities for families to make good decisions (give families the resources and information that they need to make decisions on their own).
- Include families as full partners in each step of the IFSP process (e.g. assessment, planning, implementation, and review) and transition from early intervention supports.
- Structure the IFSP so that families determine the priorities for their young children.
- Provide services that enhance families' capacity to support their child's development.
- Share unbiased and complete information with parents about their child's care and development on an ongoing basis in an appropriate and supportive manner.
- Respect families' cultural and linguistic diversity and styles of interaction, communication, and learning.
- Base support and intervention on a sound understanding of how young children develop and how families systems function.
- Encourage and facilitate family-to-family contact and support.
- Remain flexible, accessible, and responsive to the unique needs of a family.
- Recognize that families have a wide range of strengths, concerns, emotions, and aspirations beyond the health, educational, and developmental needs of their children with disabilities.
- Acknowledge that because no one agency, discipline, or professional can provide all of the information, knowledge, and services needed to support young children with disabilities and their families, practitioners need to be dedicated to collaborating and consulting across programs.

Adapted from Family-Centered Care for Children Needing Specialized Health and Developmental Services (Bethesda: Association for the Care of Children's Health (ACCH), 1994) and Guidelines and Recommended Practices for the Individual Family Services Plan, 2nd ed. (Bethesda: ACCH, 1991).

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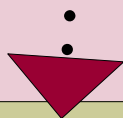
Occupational Therapy and Family-Centered Care

By Lesly S. Wilson, PhD, OTR/L

Occupational therapy (O.T.) practitioners are specifically supported under Part C of the Individuals with Disability Education Act (IDEA) and have been noted to play a critical role in facilitating and helping children identified with developmental concerns. They work closely with families to achieve the Part C goal of “enhancing the capacity of families to meet the special needs of their infants and toddlers with disabilities” (IDEA, 2004). The IDEA family-centered care concept views families as the constant in an IFSP team process and the most important element in the development of a child, as they identify needs and care for their child.

The expertise that occupational therapists contribute include evaluating and treating motor (movement), cognitive (thinking, reasoning), social-emotional and behavior development. Occupational therapists are frequently a part of the Individualized Family Service Plan (IFSP) team process, designed to serve as a road map for determining appropriate services and support, service providers, and goals for treatment. The Office of Special Education Programs (OSEP) has determined that family involvement should be specifically captured by assessing family outcomes that focus on how families perceive that early intervention services have helped them. Occupational therapy practitioners, who promote individualized treatment planning, have always recognized the value of family involvement in early intervention service delivery (Hanna & Rodger, 2002).

Occupational therapists typically use the collaborative approach, termed family-centered care, and focus on implementing services that promote function through adaptation, compensation and remediation techniques with family support (Stephens & Tauber, 1996). However, occupational therapy practitioners frequently encounter challenges to implementing family-centered care. The following are some of the *challenges* presented by families as identified in the literature, with potential solutions:



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Challenge: Families' lack of participation in treatment planning.

Potential Solutions: Providers can--

1. Include family in the treatment planning process and any adjustments to the plan,
2. Work on the concerns of the family,
3. Consider the priorities of family concerns, and
4. Consider the family resources.

Challenge: Inability to follow through with home programs in daily routines.

Potential Solutions:

1. Thoroughly assess family daily routines and natural environment during assessment,
2. Consider culture aspects of family,
3. Consider how to include other siblings in activities,
4. Develop home programs that can easily be incorporated in daily routines and child's natural environment,
5. Consider the family resources.

Challenge: Unfamiliarity with early intervention services.

Potential Solutions:

1. Encourage review of the *Family Guide to the BabyNet System* (<http://www.scdhec.net/health/mch/cshcn/programs/babynet/docs/BN013-Family%20Guide%20Rev.%209-18-2007.pdf>)
2. Encourage review of the *BabyNet Notice of Child and Family Rights* ([http://www.scdhec.net/health/mch/cshcn/programs/babynet/docs/App%206%20Procedural%20Safeguards%20\(08-06\).pdf](http://www.scdhec.net/health/mch/cshcn/programs/babynet/docs/App%206%20Procedural%20Safeguards%20(08-06).pdf)).
3. Review your team member role with families, and
4. Encourage questions and communication from families regarding concerns or uncertainties.

Although challenges occur for practitioners, it is helpful when we include families in treatment planning and ongoing processes. *The Family Guide to the BabyNet System* clearly identifies that families offer resources, priorities, and concerns to be included in the treatment planning process. The family resources are the strengths, abilities and supports that families can use to help their child. *The family priorities are the outcomes that you want most from the early intervention services.* The family concerns are the issues or needs that the family wants to work on with their child; goals and activities should be developed based on the family resources, priorities and concerns. The *BabyNet Notice of Child and Family Rights* should be shared with families as it provides further support that language, education, and culture barriers must be considered and provided for during the treatment planning process.

We should continue to explore solutions to the challenges that arise when planning and implementing services and support for families and children. Occupational therapy practitioners offer tremendous benefit to children and families with developmental disabilities, which should not be hindered.

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Play-Based, Family-Involved Therapy

By Leila Bressler, M.Ed., CCC-SLP and Sarah Dissa, M.A., CCC-SLP

Information
for
everyone!

The authors are independent BabyNet contractors who devote their practice to young children, birth to three years of age, and their families. For additional information, they can be contacted at FHAFNER@sc.rr.com.



As Speech-Language Pathologists, we know that children with language delays need to see, hear, feel, touch, smell, and taste language. Toys that address all of their senses are a must. *Fun and appropriate toys can often be as simple as the food in your fridge or the pots and pans in your cabinet. Children learn through play in their natural environments; therefore, we believe that speech therapy should be a play-based, family-centered experience.*

Therapy begins with a team including parents, therapists, and other early interventionists, who develop an Individual Family Service Plan (IFSP). The IFSP includes the goals to be targeted during a therapy visit. It is important to remember that early intervention is a team process, and decisions are made by the team. Therapy takes place in the child's natural environment (NE), whether it is home, daycare, or a family member's house. *And therapy ALWAYS involves toys!*

The toys and therapy strategies are selected with each child's goals and family input in mind. For example, a child targeting imitation would benefit from playing with favorite toys that make environmental sounds, such as animal sounds and transportation sounds. A child targeting oral motor skills would benefit from using their tongue and lips with toys and items at home such as whistles, recorders, bubbles, and straws. A child learning sign language benefits from the family who wants to learn and use sign language.

Sometimes we use theme-based therapy strategies (holidays, seasons, farm animals, transportation) to promote family involvement outside of the therapy session. We provide language ideas such as vocabulary words, creative snacks, books, and activities related to a theme and goal. At the end of each session, we review the daily note with the parent and often give a handout or home program for parents to continue skills during the week.



Parents continuously ask us how they can best provide a language-rich environment for learning while playing. We have found that the *Early Language Development* by Linda Mahwhinney is a particularly helpful resource for parents. This book includes handouts with topics such as for facilitating Eye Contact, Turn-Taking, Sound Imitation, Expanding Sentences, Block and Puzzle Play, Reading Skills, and Daily Routines. Additionally, we also offer videos, websites, handouts, and educational toys to assist in family learning.

As providers of early intervention, we have been given the opportunity to impact the life of a child and a family in a significant way. We must be ready to be creative in meeting the needs of each child and family and are often the best resources ourselves. Most importantly, it is important to remember to make learning language fun and motivating for our children and their families!



** For ideas on adapting toys such as by modifying items or using items from around the house for different purposes, see websites such as http://www.asu.edu/clas/tnt/home_files/i_play.html (from Tots-n-Tech, an inter-university collaboration between Thomas Jefferson University and Arizona State University).

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Special Instruction— information to know



Special Instructors - The “Other” Providers by Suzan Albright, M.Ed., TECS Training Coordinator

As members of IFSP teams, families, therapists, and other providers, frequently find themselves working with other early intervention personnel who are referred to as “the E.I.” or “the early interventionist.” Occasionally, that person may mistakenly be perceived as a “therapist.” Often in South Carolina, the same person is also called the “service coordinator.” The purpose of this article is to bring some clarification to the meaning of special instruction and to share information about the providers of that early intervention service.

Special instruction is one of the early intervention services available under Part C of the Individuals with Disabilities Education Act (IDEA). Understanding that service and the providers of that service requires a look at the federal law. According to the IDEA regulations (CFR 303.12 (13)(i-iv), special instruction includes:

- i. The design of learning environments and activities that promote the child’s acquisition of skills in a variety of developmental areas, including cognitive processes and social interaction;
- ii. Curriculum planning, including the planned interaction of personnel, materials, and time and space, that leads to achieving the outcomes in the child’s individualized family service plan;
- iii. Providing families with information, skills, and support related to enhancing the skill development of the child; and
- iv. Working with the child to enhance the child’s development (CFR 303.12 (13)(i-iv)).

That description implies that providers of special instruction must have knowledge of early childhood development and strategies for promoting it. While all areas of development are important considerations for all early intervention service providers, “cognitive processes” and “social interaction” are *specifically* mentioned in the service definition. Therefore, special instruction might be one of the appropriate IFSP services where a child’s assessment results or diagnosis indicate concerns in one or both of these developmental areas.

Furthermore, the definition suggests that providers of special instruction services must be able to plan effective use of all that is available within the child’s natural environment in designing interactions that will lead to achievement of specific IFSP goals, and must be able to assist families to enhance their child’s development. Thus, by definition, special instruction involves services that are integrated throughout the day and are “family-centered,” as are all IFSP services.

The term “early interventionist” is nonspecific and is not used within Part C to identify any service provider. In many states there are some agencies that have historically provided disability services and have used the term “early intervention” to refer to their entire early childhood program, which may include children who are not eligible for or are not receiving Part C early intervention services. Those agencies may have employees who are providing special instruction services to some children and families, but may also work with children who are not Part C recipients. Regardless of which agency employs them, providers of special instruction services for a child and family who are receiving that service as one of their IFSP services under Part C are appropriately referred to as “*special instructors*” to distinguish their role in the implementation of the IFSP.

Special instruction is not a therapy and special instructors are not therapists. Special instructors are not members of any single discipline, but may come from various professional backgrounds. For example, under South Carolina’s current early intervention personnel standards, special instruction providers may hold at least a Bachelor’s degree in any of the following areas: Child and Human Development, Education (elementary, early childhood, special education, or early childhood special education), Family and Consumer Sciences, Licensed Practitioner of the Healing Arts, Psychology, Public Health, Social Work, or Sociology (BNPPM, Personnel Qualifications, Table 1). So, the term “special instructor” designates a role within the early intervention system, rather than a professional discipline.

In South Carolina, special instructors have duties beyond those prescribed in federal regulations. Their responsibilities include:

- administration of curriculum-based developmental assessments (CBAs),
- ensuring that special instruction activities address identified areas of need, and coordination of all activities related to IFSP goals (BNPPM, CSPD: Staffing, p. 8).

For many children and families who are receiving service coordinator *and* special instruction in South Carolina, both of those services may be provided by the same individual.

References:

BabyNet Policy and Procedure Manual

<http://www.scdhec.net/health/mch/cshcn/programs/babynet/policy.htm>

Code of Federal Regulations 303.12 (13) (i-v)

http://www.access.gpo.gov/nara/cfr/waisidx_02/34cfr303_02.html

Individuals with Disabilities Education Act of 2004

<http://idea.ed.gov/explore/view/p/%2Croot%2Cstatute%2CI%2CA%2C602%2C>

A Parent's Perspective— Looking back to see what we can learn

Denice Stout found time during her busy day, as mother and teacher, to look back to when her son was 9 months old and beginning to show subtle differences in his development compared with other babies his age. Her son, Dustin, is now 10 years of age and received a diagnosis of autism at 2 1/2 years. We thank Denice for sharing her time, experience, knowledge and insights.

Denice knew at 9 months of age that her child was developing differently:

Dustin looked healthy and was healthy; he was quick to start walking. But he seemed focused in, stared into space, didn't interact or attend to baby games like 'touch your nose.' He didn't respond to certain noises but well to others— for example, he didn't respond to tones during hearing tests but did when I sat behind him shaking his bottle. Dustin didn't vocalize or coo, and would use a high-pitched screech. He waved his hands in front of his face, and, in retrospect, was ritualistic. He did not hug me but received hugs from me, and loved to be around me. He did not play, and crawled under the table to get away from other children—he even placed chairs as a block, which was pretty smart— he didn't want to be there.

“We shouldn't have to figure this out and should know that this (what we're seeing) is legitimate.”

Dustin also didn't like shopping malls; he would scream in there— looking back, we have realized that the shiny part of the floor was scary to him, such as in the kitchen and floors in stores and malls. But you could take him to the mall if you held him in your arms or stroller. He also couldn't manage stairs— Dustin wouldn't look and would feel with his foot. We shouldn't have to figure this out and should know that this is legitimate. A lot was his perception. Later, we had to desensitize him to this and other things such as certain food textures which he would not eat.

Denice took Dustin to pediatricians, psychologists, and others, who said no to autism. **“No one would say anything— they didn't want me to worry.”** Denice stated that **“Some parents know their child has some concerns but no one listens; and then a lot of parents go into denial and don't get help for their child.”** As a parent, Denice wanted to get help, and no one listened. So in the beginning, she did not qualify for services.

Looking back, what can we learn from this experience? What are Denice's recommendations to providers?

Be a good listener. Understand that concerns are legitimate most of the time. Listen to the concerns that we have— I was always told that I was comparing my child to other children too much. The main goal is to get help for the family— don't assume it's lack of nurturing or level of education; respect each parent who comes for help despite their education or appearance.

Denice stated that the turning point for her was when an autism specialist came to her home:

Janet took the time—she didn't just use a checklist. She talked with us, did an observation. This facilitated a diagnosis. It was so timely. I needed to do something now— I needed to get help.

Now, looking back at her experience, Denice concluded this interview with a final observation and recommendation for everyone— **“Providers work so hard. They are so overloaded, and so are the parents. But we are all battling the same thing. And if provided the resources, we could do even more together.”**

The Family Survey in SC-- Achieving Positive Family Outcomes through Family-Centered Care

by Lesly S. Wilson, PhD, OTR/L

THE FAMILY SURVEY:

Under Part C of the Individuals with Disability Education Act (IDEA), infants and toddlers with disabilities and their families are eligible for early intervention services. Several systematic reviews reveal significant benefits for children who receive early intervention services; however, the potential of early intervention services to help families is perceived to be even more substantial (Guralnick et.al, 1988). The 2004 re-authorization of IDEA determined the need for including additional measures for early intervention programs to use to specifically capture the child's functional progress and family involvement.

We know that families are key team members in the development of their child's Individual Family Service Plan (IFSP) to be carried out in the child and family's everyday environments. The IFSP process is designed to involve families in identifying their children's abilities and needs (Bailey et.al, 2005). It provides a road map for determining appropriate services, service providers, and goals for treatment. *The Office of Special Education Programs (OSEP) has determined that family involvement can best be captured by assessing "family outcomes." Specifically, from this data, the OSEP can also learn if families feel that early intervention services have helped them:*

1) know their rights, 2) effectively communicate their children's needs and 3) help their children develop and learn.

THE FAMILY SURVEY IN SOUTH CAROLINA:

As a result, a Family Survey, developed by the National Center for Special Education Accountability and Monitoring (NCSEAM) http://monitoringcenter.lsuhs.edu/parent_family_involvement.htm (with five added demographic questions), was implemented to assess the impact of South Carolina's early intervention services (BabyNet) on participating families. The NCSEAM Family Survey was chosen because of its proven levels of validity and reliability. The South Carolina Family Survey is disseminated 30 days prior to a child's scheduled transition from early intervention services and is available in hard copy, online and translated versions. The children and families, who have been in the system for less than six months prior to transitioning/exiting (due to factors such as relocation, voluntary exits, or deceased), are not surveyed.

The outcome measures process in South Carolina began in August 2006 and is ongoing. It is important that all service providers are aware of the family outcomes data collection process; however, it is equally important that service providers not assist with the completion of Family Surveys to aid against potential biasing of responses. It is acceptable for service providers to refer families with concerns or questions to TECS at 803-935-5227 (contact- Leah Perry).

RESULTS OF THE FAMILY SURVEY IN SOUTH CAROLINA:

The 2004 IDEA requires that South Carolina's Department of Health and Environmental Control (DHEC) publicly report how well the state performs relative to all Annual Program Report (APR) indicators, including the family outcomes. **The 2006 Family Survey** results revealed that 74% of surveyed families report that early intervention services helped them know their rights; 70% report that early intervention services helped them effectively communicate their child's needs; and 86% report that early intervention services helped them help their child develop and learn. **The 2007 Family Survey** results revealed that 76% of surveyed families report that early intervention services helped them know their rights; 69% report that early intervention services helped them effectively communicate their child's needs; and 85% report that early intervention services helped them help their child develop and learn.

Overall, the results from two years of surveying families reveal that South Carolina is aligned with national standards for family outcomes. *As providers it is important to continue interactions with children and families that support families knowing their rights, effectively communicating their children's needs and helping children develop and learn.*

REFERENCES

- Bailey, D. B. et al. (2005). Thirty-Six-Month Outcomes for Families of Children Who Have Disabilities and Participated in Early Intervention. *Pediatrics*, 116(6), 1346-1352.
- Guralnick, M. J. et al. (1988), Pediatricians' perceptions of the effectiveness of early intervention for at risk and handicapped children. *Journal of Developmental Behavior Pediatrics*, 9, 12-18.

More Information and Resources!

Planning Functional Intervention through Caregivers — the Routines-Based Assessment

from *Early Intervention in Natural Environments: A Five-Component Model* by Dr. Robin McWilliam
http://www.doh.state.fl.us/AlternateSites/CMS-Kids/ESproviders/ITDS/resource_bank/early_intervention.pdf

"Our best route to child outcomes...is through caregivers. Specifically related to home visits, it is the family-child interactions and other learning opportunities occurring between home visits that lead to child learning. This therefore forces us to consider seriously the purpose of the home visit." (R. McWilliam)

The routines-based assessment (RBA) is a way to ensure supportive and functional early intervention that is facilitated by providers through families and other caregivers; it was developed by R. McWilliam and has been adopted by several Part C systems.

The RBA includes a routines-based *interview* (RBI) as a primary focus. The main purpose of the RBA and RBI is to develop functional IFSP goals as well as treatment plan objectives for service delivery. The information below briefly describes the RBI process. Link to http://www.doh.state.fl.us/AlternateSites/CMS-Kids/ESproviders/ITDS/resource_bank/early_intervention.pdf to learn more about this assessment strategy, as adopted by Florida's First Steps Part C system.

The Routines-Based Interview Process:

1. **The family is prepared**—The family and other caregivers are asked to think about their daily activities and how well their child functions in each of those "routines."

2. **The interview is conducted**— For each routine, the interviewer *indirectly* asks six questions:

1. What does everyone else do, i.e., other family members?
2. What does the child do?
3. More specifically, what is his or her engagement like—how and how much does the child participate in the routine?
4. What is his or her independence like—how much can the child do by him- or herself?
5. What are his or her social relationships like—how does the child communicate and get along with others?
6. How satisfied is the caregiver with the routine? (The RBI Report Form— available through www.VanderbiltChildDevelopment.us<http://www.vanderbiltchildrens.com/interior.php?mid=3551>, click on Routines-based Interview (RBI) form— has a place to write a score from 1 to 5 if one is desired).



Throughout the interview, concerns, which are potential IFSP goals, are highlighted.



3. **Goals are selected and prioritized by the family**— At the end of the interview, the interviewer reads aloud the interview notes about "potential problem areas," and the family selects 6-10 goal areas; the family then orders these in priority order.* This is an alternative to basing goals on failed items from a test which might have little relevance to the child's and family's life.

4. **IFSP goals that are based on the family's input are developed by the team**— Goals developed from the interview are functional because they specify what the child or family is targeted to do, the context is identified, and the goal is important to the primary caregivers.

*McWilliam notes that as concerns are listed by the family, the provider should determine whether the problem is a *functional* concern. "Just because the child cannot do one skill on a test does not necessarily mean that it has any meaning in the child's life." The provider might be able to provide information or other learning opportunities related to that concern as an IFSP goal for the family. Finally, McWilliam states that "interventionists do have the ethical obligation to give families information; so, if they know a child is deficient in something and failing to work on it could hamper the child's progress, they should mention it" (this information should naturally be evidence-based, with the understanding that not all deficits need to be worked on).

Tell us what you think. Email
nalty.l@gmail.com

Mark your calendars!

May 22, 2008— the first annual SC Early Intervention Providers Conference, featuring Dr. Robin McWilliam, and other national and local presenters!



Information from Provider Relations For You!

BABYNET POLICY UPDATE

by Debra M. McCoy, Ph.D, LMSW, Provider Relations Coordinator

The following BabyNet reimbursement rate changes will go into effect on December 1, 2007:

-Increase in rates to match current Medicaid rates for Audiology, Physical Therapy, Occupational Therapy and Speech Therapy services. Only the procedure codes listed in this update are affected by the increase. All other procedure codes will continue to be reimbursed at the current rate. All claims submitted to Jasper with dates of service prior to December 3, 2007 will be reimbursed at the current rate.

-Elimination of \$20.00 travel reimbursement for services provided outside a clinic or hospital setting. Providers may bill travel for dates of service before December 3, 2007.

-Increase in rates to match current Medicaid rates for Orientation and Mobility (O&M) services. (South Carolina School for the Deaf and Blind is the only provider allowed to bill Jasper for reimbursement for BabyNet O & M services.)

Please note that while Medicaid has increased some rates for Audiology services, other rates for Audiology services have been decreased. BabyNet will increase its rates to match the Medicaid increases for Audiology services. However, we will not decrease reimbursement to match the Medicaid decrease. BabyNet will continue to pay those effected codes at the current reimbursement rate. For procedure codes where Medicaid pays less than BabyNet, Audiologists will be able to bill BabyNet for the difference between what Medicaid pays and the maximum amount allowed by BabyNet.

Procedure codes by service and rate schedule is available on the BabyNet website (www.scdhec.net/babynet) in the BabyNet Policy and Procedure Manual, Appendix 5. Please download a copy of the revised Appendix 5 for reference. In addition to the rate changes, other revisions have been made including policies related to interpreter services.

Should you have any questions or concerns about this update, please contact Debra M. McCoy at 803-898-0591 or Robin Morris at 803-898-0781. Thank you for the services you continuously provide to the children and families of South Carolina.

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*Mark your
calendars!*

**The 1st annual SC Early Intervention Providers Conference will
be held on
May 22, 2008 in Columbia, SC**

Mark your calendars!

Upcoming Workshops

January 30–February 2, 2008. ATIA (Assistive Technology) 2008 Conference, in Orlando, Florida. Contact: 877-687-2842 or visit www.atia.org for more information.

February 22-23, 2008, Family Connections Conference, in Columbia, SC. Call . Contact: 1-800-578-8750 for more information or visit <http://www.familyconnections.org/>

May 22, 2008, First Annual S.C. Early Intervention Providers Conference, in Columbia, SC, featuring Dr. Robin McWilliam, and other national and local presenters. More information will be announced. Contact: Leah Perry at (803) 935-5227.

Check out these resources...

To learn about resources at the Center for Disability Resources Library, contact Steven Wilson, wilsons@gw.med.sc.edu or 803-733-1501. The library contains books, videos, brochures, and audiotapes covering a variety of disability-related topics available for you; see the website at <http://uscm.med.sc.edu/CDR/index.htm> and materials available at <http://uscm.med.sc.edu/CDR/CDRsubjectlist.htm>

To learn more about autism and red flags, including video clips, visit <http://www.autismspeaks.org/>, sponsored by Autism Speaks and First Signs. Also see www.cdc.gov/actearly from the Centers for Disease Control and Prevention.

*Please send
in*

ideas for TECS products

See <http://uscm.med.sc.edu/tecs/>



Team for Early Childhood Solutions / The Center for Disability Resources / A University Center for Excellence

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TECS is contracted by the IDEA Part C lead agency (DHEC-BabyNet) to provide a comprehensive statewide system for personnel development and technical assistance.



If you need paper copies of the newsletter, have any questions about this newsletter, or would like to submit your ideas, please notify Leah Perry at 803-935-5227 or Lily Nalty at nalty.l@gmail.com

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