TECSNews— For the Allied eHealth Resource Network

Special points of interest:

- Providing services — what's our role?
- Important information about autism
- A SC family's perspective
- Resources for providers & families
- Important news & updates

How should we provide services that are meaningful & effective? — a continuing look

Information for this article was based on documents from the Colorado Department of Education Early Childhood Connections for Infants, Toddlers, & Families; Presentation on Enhancing Services in Natural Environments by Dr. Juliann Woods (2004), Nebraska Departments of Education & Health Human Services; multidisciplinary documents by the Workgroup on Principles & Practices in Natural Environments; APTA document on Maximizing Your Role in Early Intervention, downloaded 11/2008); & 2008 SC Early Intervention Conference. Specific references are available upon request.

We know that growth and development of children with special needs is best supported through underlined continuous learning opportunities. These opportunities are best facilitated in the context of every day experiences, events, and settings, with typical items, caregivers, and others in a child's life (i.e., the natural environments concept).

So how do we best do this? Before we look at expected implications for changes in service delivery, it is important to first take a closer brief look at the *intent of "natural environments."*

IDEA (preamble) requires that services promote *"...equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities"* by supporting children and their families within their every day situations. The IDEA vision is that all individuals— children and adults, with and without disabilities— actively participate in family, work, & community life, throughout the lifespan.

See a story from a family & provider, illustrating what it took to reach this goal, on pp. 8-10.

Providing supports in every day situations is a philosophy of inclusion...

It's a Philosophy of Inclusion:

Inclusive intervention benefits children with and without special needs— everyone uses modifications that help them participate (Odom 2000, http://www.nectac.org/inclusion/meetings/82000presentations.asp)

Natural environments (NE) in early intervention is comparable to the least restrictive environment (LRE) for school-age children. *For students, underlined LRE requires integration of services in typical classroom activities so that all children are supported, through the classroom teacher, to participate in the general education curriculum. Similarly for infants and toddlers in early intervention, underlined NE requires integration of services, through families/other caregivers, to help children participate in every day situations.*

Now, how do we best do this?

About this issue

This is the 9th issue of a quarterly newsletter for allied health professionals & other team members participating in Part C services with children 0-3 & their families! It is part of an overall effort to provide accurate & useable information & resources that support evidence-based early intervention in S.C.

This issue spotlights current recommended practices related to our *roles* in providing services in natural environments. It includes information from providers, researchers & specialists in early intervention, & professional associations. Articles feature ways to provide services that involve consultation in everyday situations, requirements for reporting of families' experience in Part C services (outcomes), and information about autism from MUSC researchers. *Be sure to read a story from a parent & provider from South Carolina on pp. 8-10.*

Finally, note new topics continued— professional association activities, & ideas for implementing assistive technology supports.

How should we provide services to help children learn & grow? *Continued from p.1*

It's about Helping Children Participate: In early intervention, it has been widely recognized that t**eam members should provide services and supports that have immediate relevance to participation in every day activities.** This involves providing <u>services with primary caregivers, to help them help their child actively engage in activities of home and community, independently or with others</u> (from Nebraska's Part C resources for practitioners, http://www.tacommunities.org/community/view/id/1029).

To do this, **services can look like this** (Woods 2004)...

A. Activities for objectives are "…the predictable and repetitive sequences of naturally occurring play, care giving, social and community activities and routines." **We can spend our time:**
- **interacting with families and others in the child's life by using a consultative model** "adapted for diverse **adult learners,**" *providing "resources, supports, information, modeling, joint planning and problem solving appropriate to learning style, [needs,] and preferences of caregivers and family members."*
- **working with families to integrate teaching ideas and practice** *within everyday routines and play, by using their materials, sequences, and strategies.*

B. Services center on a relationship with families and other care givers. **This involves:** *sharing educational resources, encouraging information exchange, following the family's lead, recognizing caregivers as decision-makers, and together selecting options for service delivery and support that best meets family needs.*

C. Supportive and respectful relationships foster teaching in every day interactions— **it can look like this:**

■ **Discuss "alternative" ways for caregivers and children to participate**, include "learning strategies for adults" (e.g., slowly layering in techniques, letting families choose methods, etc.), and help them "synthesize decisions, actions, and responsibilities" and develop plans. We provide information to support informed decision-making and explain roles and concepts such as natural environments & situated learning.

> Programs not children have to be ready for inclusion" (Odom 2000, http://www.nectac.org/inclusion/meetings/82000presentations.asp)

■ **Listen to each "family's story, accomplishments, concerns,"** explain why information is important to their every day lives, and "provide examples and developmental knowledge."

■ **"Watch what, how, & when family members interact; connect what is already happening to how the child learns**; and model side-by-side strategies or behaviors that support the interaction."

■ **Encourage families to select the natural learning opportunities** and embedded interventions they will use.

■ **Have families identify and prioritize activities they want to target.** Families select activities the child prefers, are motivating, are easiest for the family's schedule, and take place frequently, such as care giving activities, play routines, community interactions, or social and literacy activities.

■ **Individualize consultative or "triadic" intervention to the learning style of the caregiver**, using handouts, videotapes of others, side-by-side modeling, joint problem-solving and planning, and involvement with other parents and supports.

■ **Plan "what, who, how, when, where" of interventions together** with caregivers.

■ **Converse with caregivers to "continually gather and give information** on routines, activities, interests, concerns, child and family strengths, priorities for problem solving," and collaborate on next steps.

■ **Observe interactions** —
- **notice the routine**: does it have a predictable sequence, allow for repetition, involve everyday materials/toys, involve joint attention, is positive and brief, is motivating? *If not, we can layer these in.*
- **observe the child**: does s/he anticipate actions/objects, attend, initiate, respond to others or to cues, imitate actions/speech, independently participate? *If not, we can facilitate some of these in routines.*
- **observe the caregiver**: does s/he use a predictable sequence, expect participation (including partial participation), respond, expand, use objects, read the child's cues/communication, embed intervention or learning strategies, encourage? *If not, we can target some of these behaviors.*
- **observe the caregiver-child interaction**: does the position/proximity promote interaction, is there mutual attention, turn-taking, positive affect, cues, and repairs? *If not, modifications can be discussed to encourage these behaviors and outcomes.*

Read more about service approaches, models & training methods used across the country, at http://www.nectac.org/~calls/2004/partcsettings/partcsettings.asp

More on providing services that support the caregiver's role, *Continued from p.2*

To increase caregiver "competence" in inclusive/embedded or consultative services, <u>every one needs to learn about and agree to their role in the process</u>— *caregivers* will learn ways to facilitate their child's participation in preferred daily routines, and *providers* will "guide, inform, and encourage the caregiver and child in interactions," as they serve in the capacity of consultant, advisor, and coach.

How can we promote a family's/caregiver's role? Services usually begin with assessments, which should be used to gather pertinent information related to a child's current and future participation in natural learning opportunities in their home, community, and other settings. The following are some sample questions we can ask families and care-providers so that they become involved in the first steps of intervention, and so that they actively help develop IFSPs and treatment plans that lead to functional participation-based goals, activities, and outcomes.

Taken from the Nebraska Departments of Education and Health & Human Services 2008

Sample questions we can ask families and care-providers during initial visits:
- What are your concerns? What are your challenges in interacting with ____?
  - Tell me about the family and friends who help you with ____.
  - What activities would like to see ____ enjoying in the next year?
  - What communication have you had with ____'s parents about this concern?
  - Who at your center or in the agency do sometimes helps you with your concerns?

Sample questions that identify child/family "assets" and interests:
- What are you and your child especially good at doing?
- What are your child's favorite toys, people, and events?

Sample questions to gather more information (other than yes/no questions):
- Tell me how ____ plays with his friends.
- How does ____ communicate with you so you know what he wants?

Sample questions that gather information about the child's participation in terms of independence, engagement, communication and social interactions within activities/routines and about the family's expectations and priorities:
- At bath time, what does ____ do? (engagement)
- During bath time, tell me what ____ is doing all by herself? (independence)
- How does ____ communicate during bath time? (social communication)
- Are you satisfied with ____'s participation in bath time? (expectation)
- How would you like it to look different? (possible priority)

Sample questions to help the family and rest of the time together select priority goals and activities:
- Do some of these goals/activities need to happen before others can?
- Will this goal/activity create change for child/family in many activities?
- Will the learning opportunity for this goal/activity present itself frequently?
- Will this goal/activity make the child more independent?
- Will this goal/activity allow the family to do more things they would like to do?
- Will this goal/activity make life easier for the family?
- Does this goal/activity require "special" services/supports or simply increased learning opportunities?

After developing a mutual relationship and agreeing to roles, what might services look like? The following is a sample scenario of what a home visit might look like when our main focus is to increase caregiver competence using a consultative or "triadic" (provider-caregiver-child) approach. It should be noted that a consultative approach can be considered direct intervention because it involves the presence and participation of the child, with the child being the ultimate beneficiary of services.

Sample Scenario— increasing caregiver competence

Mom & provider have already agreed to their roles, mom has prioritized activities to target first, & they are meeting today to begin looking closer at the first daily routine for mom to "enhance." Mom & provider are discussing & developing a plan for mealtime, the activity mom wants to target first.

The provider brings in handouts that explain 1 or 2 strategies mom can include at mealtime; together they discuss the strategy or strategies, & watch a video of another parent using these during a meal. They talk about pros & cons of using the strategy(ies) with their child in their meal time situation, & mom chooses the strategy or modifications to try first.

They practice together during a lunch or dinner, with provider joining in the usual routine— the provider models, recognizes/reinforces, cues, expands on the caregiver's and child's behaviors, etc.; this mom uses the strategy best with written reminders and steps to check off; she modifies the steps so they are more easily followed and have a better outcome; the visual reminder is a quick check sheet that lets her check off steps she and her child use; this can later be used to describe and review how this worked for both of them.

After using the techniques for a week or two (depending on the schedule mom prefers, or on the schedule they together agree gives them the time and assistance needed), mom describes how it went for her and her child. Provider observes, joins in as needed, & together they plan next steps— change strategy, continue/ modify strategy, expand the same strategy, add a strategy...

There are several resources that describe what providers can do to facilitate a caregiver's role and competence. See previous newsletters for examples of these. **If you have ideas that you find helpful, please send them in to share!!**

INFORMATION FROM AROUND THE STATE

Autism Spectrum Disorders

By Walter Jenner, M.S., Education and Outreach Officer, SC Autism and Developmental Disabilities Monitoring Team, Developmental Pediatrics and Genetics, Medical University of South Carolina

The more we know…

Autism spectrum disorders (ASD) are a cluster of developmental disabilities characterized by pervasive deficits in socialization and communication, as well as unusual behaviors or interests. Impairment in social interaction may include behaviors such as poor use of eye contact or gestures, failure to share interests with others, difficulty making friends, or failure to respond to the emotions of others. Impairment in communication may include delays in the development of language, difficulty with conversation, echoing the speech of others, or using the same word or phrase over and over. Unusual behaviors or interests may include obsessions with specific objects or topics, rituals, repetitive movements, or preoccupation with parts of objects.

ASD includes autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger disorder. These defining traits may be expressed in mild through severe forms leading to the recognition that autism is a spectrum disorder. Frustratingly autism is a complex neurological disorder with no definitive medical tests. Diagnosis must be based on the child's behaviors.

The Centers for Disease Control and Prevention created cooperative agreements with sites across the nation to monitor the prevalence of autism spectrum disorders (ASD). Since 2000 the Medical University of South Carolina has been one of the Autism and Developmental Disabilities Monitoring sites (ADDM). South Carolina ADDM includes birth cohorts of almost 25,000 8 year olds in half of the state. Findings of the South Carolina ADDM program indicated that in the first two birth cohorts (reported in 2007), autism spectrum disorders, once thought to be rare, occurs in 1 in 161 children. All ADDM sites combined reached a prevalence of 1 in 150 children. Consistent with other surveillance reports, boys with an ASD outnumbered girls 3-4 to 1. Shortly SC ADDM will report on the completion of two more South Carolina birth cohorts with a fifth study currently underway. We will be able to report if ASD in SC is increasing, decreasing or remaining steady.

In our first two birth cohorts in South Carolina, developmental concerns were reported in 85% of cases before 3 years of age. However the median age of diagnosis of an ASD was 4 years 10 months. This indicates that, on average, children with an ASD were not receiving intervention services geared for children with an ASD until after the deadlines for participation in early intervention programs had passed. Yet increasingly, research reports are being published of the success of early intervention programs for children with an ASD. With the recognition of this serious public health concern what can early interventionist do to help children with ASD and their families?

Awareness and screening

The Commonwealth Fund report on Developmental Screening (2007) reported prevalence of developmental delays to be at least 10 percent, but early intervention programs aimed at addressing these concerns serve only 2.3 percent of children under age 3.

ASD is now the second most frequently occurring serious developmental disability in the United States after mental retardation. The American Academy of Pediatrics (AAP) in 2007 recommended that all pediatricians be cognizant of ASD at every well child exams and conduct formal ASD screening at 18 and 24 months, and encourage referral to early intervention programs.

Early intervention teams can help by conducting ASD screening as a routine part of an intake. One screening instrument, The M-CHAT, is available for free on line at http://www2.gsu.edu/~psydlr/Diana_L._Robins,_Ph.D..html. This instrument consists of 23 yes/no questions that parents can complete. It takes only minutes to determine whether a child is at risk for ASD.

Alerting vs. alarming Parents
In a study just completed at MUSC looking at 4 year old children with an ASD, 99 per cent of children had documented developmental concerns, reported by parents, before age three and almost 70 percent of parents report concerns before age 2. When a child is referred to an early intervention program, let parents know that it is important to rule out autism so that the best treatment approach can be chosen for their child.

Help for both parents and practitioners about ASD can be found at a number of "on line" locations. The Centers for Disease Control and Prevention website www.cdc.gov/actearly includes a new video "Baby Steps" providing information about typical development and ASD. Autism Speaks offers a video glossary comparing children with ASD to typical development at www.autismspeaks.org; click on "Be Informed" and then video glossary. South Carolina's DHEC BabyNet Service Guidelines for Autism Spectrum Disorders titled "Opening Doors for Treatment Guidelines" has recently been revised, with plenty of information for parents and practitioners and can be downloaded at www.scdhec.net/health/mch/cshcn/programs/babynet/docs/Autism%20Guidlines%20(posted%20Sept.%202008).pdf .
The South Carolina Department of Developmental Disabilities and Special Needs Autism Division offers a program guide for effective training to families and professionals to improve the lives of people with autism. A variety of programs are offered throughout the state during the year. Go to www.state.sc.us/ddsn for a copy of the 2008-2009 autism division training.

Referral for diagnosis can be made to each county's Department of Disabilities and Special Needs Board or to developmental pediatricians, licensed clinical or school psychologist, or a licensed psychiatrist.

Intervention

Early diagnosis will lead to earlier behavior based intervention which is associated with improvements in core areas. The active ingredients of effective programs for children with ASD include: a) earlier is better - intervention by 3 1/2 years is more effective than after 5 years ; b) goals need to be individualized and monitored regularly;

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Continued from page 4

c) intensity matters, meaning active engagement in meaningful activities for 25 hours per week and low student teacher ratio of no more than 2:1; d) family participation is essential; families are a critical component in effective programs (National Research Council, 2001: www.nap.edu).

In South Carolina the Department of Developmental Disabilities and Special Needs provides the Pervasive Developmental Disorder Program which includes service coordination and early intensive behavior intervention services utilizing applied behavior analysis (ABA). More information is available at the DDSN website, www.state.sc.us/ddsn; look for Pervasive Developmental Disorder Program.

The South Carolina Autism Society is expanding its role of service provision for children across the state. They can be contacted at www.scautism.org.

The Behavior Analysts Certification Board (www.bacb.com) is a non profit corporation whose mission is to promote an international certification program for behavior analyst practitioners. People meeting license criteria are considered specialist in conducting behavior assessments and therapy programs especially useful for children with ASD. In South Carolina 32 people are currently listed as BACB certified. The University of South Carolina has recently had course work approved for people interested in taking the BCBA examinations. At the South Carolina Autism Society conference in October, 2008 the first meeting to form a state chapter of behavior analysts was held.

South Carolina parents fought and won and autism insurance bill, initiating in July, 2008, now called Ryan's law, which requires insurance companies in South Carolina to provide medical coverage for persons who are diagnosed with autism spectrum disorder by age eight, with continuing coverage through sixteen years of age for treatments prescribed by a medical doctor. Included is coverage for behavioral therapy up to $50,000 a year.

Help is on the way...

Evidence based intervention means that educators are using procedures that have been studied carefully and these results have been reviewed and published.

The National Professional Development Center on Autism Spectrum Disorders, funded by the U.S. Department of Education, began in 2007 to promote evidence based practices for early identification, intervention and education and increase the number of highly qualified personnel serving ASD. States have been invited to participate in this professional opportunity.

This year Dr. Laura Carpenter at MUSC has been awarded a research grant investigating dietary supplements helpful for children with autism. If you know of a child between 5 and 12 years of age that has been diagnosed with an autistic disorder you might encourage the parents to call Suzanne at 843-876-1255 for more information.

April is Autism Awareness Month and April 2, 2009 is World Autism Awareness Day. Evidence is clear that early detection and early intervention leads to improved outcomes for children with autism spectrum disorders.

For more information about Autism Spectrum Disorders, contact Walter Jenner at jennerw@musc.edu.

INFORMATION FROM AROUND THE STATE

Workshop Spotlight: An Integrative Approach to Assessment and Therapeutic Intervention for Children with Special Needs, by Lesly S. Wilson, Ph.D., OTR/L

About the presenter: Sandee Dunbar, DPA, OTR/L, is a licensed occupational therapist with more than 25 years of clinical and consultative practice with children and families. She is a professor in the Occupational Therapy Program at Nova Southeastern University (NSU). Dr. Dunbar received AOTA Board Certification in Pediatrics, Neurodevelopmental Treatment Certification for Children with Cerebral Palsy, and certification in Sensory Integration. She is the author of the highly acclaimed book Occupational Therapy Models for Intervention with Children and Parents. This presentation was sponsored by Summit Professional Education (see http://www.summit-education.com/seminars.php for additional continuing education events).

Overview:

This workshop offered valuable information for <u>all</u> early intervention providers working with children at home, school, or other settings. It outlined not only the importance of family-centered care service delivery but also described numerous methods for implementing it when working with children and their families. Discussions focused on the importance of improving family satisfaction through services that involve core family-centered principles— Dignity and Respect, Communication, Strength Building, and Collaboration. The *Institute for Family-Centered Care* website was provided as an additional resource www.familycenteredcare.org to guide providers and families who practice family-centered care.
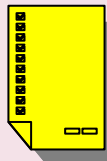
Attention was given to developing Family Protocols and S.M.A.R.T. team goals. Family Protocols offer a way to determine each family's core values, goals, and tasks during assessment that can be integrated into Individualized Family Service Plans (IFSPs) and Individualized Education Plans (IEPs). S.M.A.R.T. team goals offer a way to ensure that IFSP and IEP goals are S= Specific; M= Measurable; A= Attainable; R= Realistic; T= Timely. Such family-centered care strategies have been noted to increase family satisfaction ratings within six months time (Nelson & Polster, 2008).

Several models that support family-centered care service delivery were presented; the model that will be highlighted in this article is the *Person-Environment-Occupational (PEO) Model* (Law & et.al., 1996). This model provides a framework for individualized family-centered practice in which each component is thoroughly considered in initial assessment and re-assessment activities. The PEO model encourages an analysis of the person, environment and occupation influencing a child's functional performance as described below:

PEO MODEL
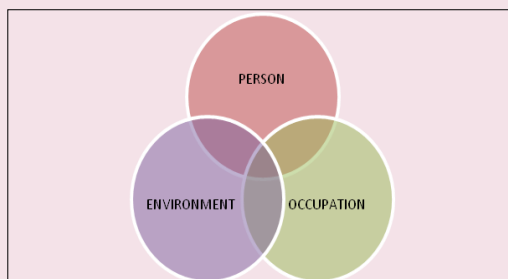
❍ The analysis of the child as a **person** involves looking at such factors as **age, diagnosis, likes, dislikes, cognitive abilities, physical abilities and medical diagnosis** to obtain a better picture of the "person" receiving services. *Critical analysis of the child as a person can help service providers gain clearer insights concerning the functional performance currently being observed during an assessment as well as guide future treatment interventions for the child and family.*

❍ The analysis of the child's **environment** involves looking at such factors as the **cultural, physical, emotional and socio-economic environments.** It is suggested that these factors be analyzed to determine the true "natural environment" for the child and its impact on the observed functional performance during an assessment. *Critical analysis of the child's environment can help service providers increase understanding of the support systems available for the child and can direct functional treatment interventions more appropriately for the child and family.*

❍ The analysis of the child's **occupation** involves looking at factors that are meaningful to the child and family such as **meal time, bathing, talking, listening, manipulating toys and playing with other children**. *Critical analysis of these factors can impact the goals developed for intervention during an assessment and can lead to future activities that enhance functional development in the most meaningful areas for the child and family.*

The PEO Model offers practical approaches to support family-centered care during the assessment process in order to enhance intervention and service delivery in early intervention by tapping into the three core factors related to the child and family. The PEO model supports success with child and family outcomes through a practice framework that helps providers capture necessary and practical information to develop comprehensive and effective IFSPs.

I highly recommend this workshop to other early intervention service providers.

References:
Law, M., et al.(1996). The Person-Environment-Occupational Model: a transactive approach to occupational performance. *Canadian Journ. of Occupational Therapy*, *63*(1) 9-23.
Nelson, D. & Polster, G.(2008). An interdisciplinary team approach to evidence-based improvement in family centered care. *Critical Care Nursing, 31*m 110-118.

More Assistive Technology Information and Resources!

What Do You Want to Say?
### Choosing Vocabulary for Communication Boards

The success of a child's first communication board involves <u>careful selection of vocabulary</u>. Children will be motivated to use their first communication board if the vocabulary is meaningful and helps them participate in daily routines and activities.

Including vocabulary that is motivating to the child is critical for a first communication board. Often, first communication boards are mainly comprised of biography vocabulary; however, most people in the child's life know the child's name, age, address and names of family members. Biography vocabulary is used rarely during daily activities and routines.

Research suggests *what* vocabulary is useful to include. Eighty percent of the vocabulary of most children consists of the same 300 words, also known as *general core vocabulary*. These words may be found in Dolch lists or at the AAC Institute (http://www.aacinstitute.org/Resources/ProductsandServices/PeRT/CoreVocabularyAndTheAACPerformanceReport.html). The biggest drawback to using general core vocabulary is that many of the words are difficult to represent using graphics or objects and these symbols will have to be taught. The other 20% of a child's vocabulary consists of vocabulary unique to the child and is known as *personal core vocabulary*.
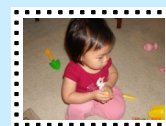
A child may use only single messages initially, but soon may be capable of combining single-word messages. It's important to consider the advantages of using single word messages over multiple word messages such as those listed below. *Eight single words can be used individually or in combination to create up to 30 different messages. In contrast, eight multiple word messages can only be used to communicate eight messages.* Combining two or more single-word messages is also beneficial to learning literacy skills. A child who can combine a noun and verb is demonstrating the ability to use syntax to create a sentence.

Single-Word
Vocabulary Messages

-go (go out, don't go, like go)

-more (more go, more eat, more drink)

-help (help go, help eat, help drink)

-eat (eat out, like eat, don't eat)

-drink (drink more, like drink)

-out (more out, like out)

-like (like more, like eat)

-don't (don't go, don't help, don't like)

Multiple-Word
Vocabulary Messages

-I want to go home

-I want more

-I need help

-I want to eat

-I want a drink

-I want to go outside

-I like that

-I don't like that

As children become proficient using the vocabulary on their first communication board, it's important to make revisions to it by removing vocabulary that is not useful and introducing additional vocabulary.

Look for next month's article for how to determine what symbols are best for each child's communication board.

References are available upon request. Carol Page O'Day is the staff speech-language pathologist with the SC Assistive Technology Program. She is available to help individuals with disabilities and their families and the professionals who serve them. Go to the brochure of the SC Assistive Technology Resource Room at http://www.sc.edu/scatp/resourcecenter.htm

A Parent's Perspective...so we can learn

It was an honor to meet and talk with Mary Ann, Valerie, and Susan. Valerie is Mary Ann's wonderful 23 year old daughter who has Down syndrome. Susan is my co-worker who told me that I had to tell this success story! Mary Ann graciously shared with us her early memories, adjustments, and dreams for her daughter, and then went on to articulate the wisdom that only comes from loving, living, and learning through life experiences. Valerie also generously shared with us her dreams and wishes and her suggestions for parents of young children with special needs.

We hope this story encourages, motivates, and in some cases helps and heals some of the challenges families face when wrestling with the news that your child has special concerns. To others, we hope it serves as a powerful reminder that when we work with any child, we are really investing in a family, who may be "wounded" or still struggling, but who very much wants us to think of their child like all other children - with all kinds of abilities who will make a contribution and become part of our community. Lily Nalty and Susan Davis

In their own words...

It's all about expectations. I remember wishing Valerie's special needs weren't obvious, because others saw her, thought of limitations and had different expectations. I saw Valerie as a child full of endless possibilities with the power to achieve beyond the world's expectations.

In the beginning… I had had limited exposure so I didn't think this would happen. For me, it was not only having a child for the first time, it was being thrown into a world I knew nothing about. It was like mourning or grieving. At first it's a shock—this is not my baby; you're in denial. This was the baby I'd waited for all my life—I had the highest hopes and dreams, such excitement about having her.

My biggest fear was that I, and the rest of my family, would be the only ones who loved her. When I was at school, children with special needs were segregated, and when they went out in the community, they went as a group. But I was so wrong—Valerie is the most loved person I know. People who meet her for the first time fall in love with her.

I *chose* to spend the first year learning all I could, talking to everyone I knew, to resolve in my mind that she had a different scenario than I had expected, that life was going to be different. What helped me the most is something another parent said to me—*"Treat her and raise her like any other child, with the same expectations."*

Now, looking back, Valerie was the one who taught me more than I could teach her. She's made me a better person. I'm more appreciative of things in my life—if I cook her supper, she says "You're such a good cook. You should cook for Outback," and other positive things like that. I am goal driven. Valerie taught me how to take one day at a time and to set goals that are flexible; she will reach milestones on her own time schedule, and if it doesn't happen, it's O:K.

I just kept thinking that this is a new generation, unlike the one I grew up in, that I wanted Valerie to be as independent, intelligent, and well behaved as possible. At a time when this was not popular, I put her in a regular church preschool, with a same aged group. Valerie loved school. She also went to segregated programs part of the time. I thought it would be more frustrating otherwise—I wanted her school experience to be successful, both for Valerie and her classmates, since this was at a time when inclusion was not the norm. I wanted people and children to think well of her and for her to be accepted.

I learned that it's O:K to use your intuition and do what you think is best. Valerie otherwise wouldn't have learned as much. The driving force was to go with what she chose or wanted to do, listening and honoring her dreams, including being as independent as possible and taking it a little bit at a time.

A Parent's Perspective continued...

In high school, Valerie was exposed to great work experiences. She began by wanting to be a nurse, then a teacher, and a "staff" at a daycare. You have to start early, be engaged, communicate your expectations regarding your child's future— prepare the school system! When our children graduate, they need to have been exposed to jobs of their interest, receive assistance in narrowing their interests, know where they can be successful, and by the last 6 months of school, they should have determined the type of job they want or secured the job they can continue in post graduation. Schools should talk to the employer, have it set and ready to go. Parents and professionals have to have unlimited or unbiased hopes and dreams. Parents need to be totally engaged in the process and clearly identify their expectations about life upon graduation regarding employment, living, or continuing education upon graduation.

Valerie wants to have a job "to pay for college." She wants to live in an apartment—"I like that." Our goal is to work toward Valerie living where there is a roommate and a supervisor. I'm her mom. I believe in more typical transitioning that most people experience, like moving from home to a college dorm, with meals cooked for you and supervision versus moving out of the family home into a home or apartment completely independent of supports. Listen to your kids. Encourage them to have dreams and goals and expectations to the extent they can be carried out.

The school may help you, maybe the church and other groups. Sign your child up for classes and activities she or he likes, whether it's cake decorating or joining a basketball league. We used to take Valerie to watch basketball games that my niece was in and she was really interested in doing that too. To fulfill this dream for Valerie, I approached our church. After a lot of effort the church, which was adding a gym at the time, began hosting a basketball team for children with skills like Valerie, for boys and girls with disabilities.

I wanted Valerie to have all the education she could, and didn't want to limit our dreams. My goal was NOT for her to be in a workshop. Valerie had dreams and aspirations and I knew there was something out there for her. Everyone has a talent, something they can do. Parents, follow your dreams, your intuition, and know that it's O:K to have expectations that seem contrary to what others are doing around you.

One of the things I learned from this meeting is that it's certainly not easy or straight forward when you embark on this type of journey. You also encounter people and events that help you along the way. One such turning point for Valerie and Mary Ann was when they met Susan Davis, who has helped set the stage now for the continuation of their dreams. L.N.

Susan writes…

I had the privilege of meeting Valerie and her mother through a mutual friend. My background in assisting individuals with employment made me particularly interested in meeting Valerie. Valerie, a recent graduate from high school, had not secured a position and was relentless in communicating to her Mom that she was ready to get a job! Like many parents, Mary Ann wanted to help Valarie, but due to some unexpected emergency situations, was not able to juggle doing one more thing! After meeting Mary Ann for coffee, she agreed that the three of us would meet to discuss the option of employment.

Valerie is a delight! An employer's dream - motivated, helpful, polite, dependable and willing to learn new things! We gathered resume information and discussed interests and skills. Transportation was a concern but we all agreed that we would cross that bridge when we came to it. Needless to say it was just weeks after Valerie's first interview with her "favorite store" before she was offered a position preparing stock for the floor. Mary Ann's schedule required that she pay a gal to get Valerie to work, and her family picked her up in the evening. Valerie will gladly tell you that she has been employed for over a year now and loves her discount card! Her employer can't say enough about her contribution and the joy she brings to the work place*. **See the end of this story with pictures of Valerie working at her favorite store, on p.10…***

A Parent's Perspective continued...

This is a success story because of a Mom who, since Valerie's birth, raised her daughter with real dreams and goals and started early to prepare her for life after high school. Today, Valerie is employed and continues to have dreams and aspirations. I hear she would like to attend college some day! S.D.

Valerie and her co-worker working in the stock room.

Thank you Valerie and Mary Ann for sharing your memories, dreams, and wisdom with us.

Valerie hard at work.

Information and Updates

Information to know, from Kristie Musick, Director, Team for Early Childhood Solutions (TECS)

Family Outcomes

In 2004, Congress mandated that states' early intervention and special education agencies begin annual measurement and reporting of the results families experience through receipt of Part B and Part C services under IDEA. For children birth to three served by BabyNet, these family outcomes consist of:

- knowing their rights,
- effectively communicating their children's needs, and
- helping their children develop and learn.

South Carolina began measurement and reporting of family outcomes in 2006, using a nationally validated and field-tested survey. The survey is sent to families at the time of exit from BabyNet, and results are reported to Congress every year. South Carolina uses Questions 25 – 51 of this survey, which may be viewed by clicking on the link below: http://www.monitoringcenter.lsuhsc.edu/New%20DATA%20FEB% 202006/2005_NCSEAM_PartC_Watermarked_%20(25196%20-%20Activ.pdf.

Service coordinators, service providers, and special instructors (providers with job titles of 'Early Interventionist' or 'Parent Advisor') have key responsibilities relative to the family outcomes:

- Inform families of the survey, and encourage them to complete and return the information.
- Become knowledgeable of and use evidence-based practices that support these results for families. A national, interdisciplinary workgroup has developed a set of Principles and Practices in Natural Environments (February 2008), *Agreed upon practices for providing services in natural environments*. OSEP TA Community of Practice- Part C Settings, http://www.nectac.org/topics/families/families.asp.

Recommended Practices

Recommended practices include the following:
Ensure the family understands relevant procedural safeguards and next steps.
• Review procedural safeguards related to providing consent for services and obtain written consent for IFSP services.
• Discuss the "timely" initiation of services.
• Make sure the family understands that changes can be made to the IFSP as needed.
• Give the family reports, records, and copies of the IFSP.
• Discuss confidentiality and family access to educational records.
• Agree upon next steps for all team members to begin services in a timely manner.

For on-going visits, use the IFSP as a guide to plan how to spend the time together.
• Begin each visit by asking-open ended questions to identify any significant family events or activities and how well the planned routines and activities have been going.
• Ask if there are any new issues and concerns the family wants to talk about. Explore if these concerns need to be addressed as new outcomes; if so, plan an IFSP review.
• Decide which outcomes and activities to focus on during the visit.

Participate with the family or other caregivers and the child in the activity and/or routine as the context for promoting new skills and behaviors.
• Offer a variety of options to families for receiving new information or refining their routines and activities, such as face-to-face demonstrations, video, conversations, written information, audios, CDs, diaries, etc.
• Gather any needed toys and materials and begin the selected activity or routine.
• Listen, observe, model, teach, coach, and/or join the ongoing interactions of the family and child.
• Encourage the family to observe and assess the child's skills, behaviors, and interests (a continual part of on-going functional assessment). For example, ask the family if behaviors are typical, if they've seen new behaviors (suggesting emerging skills), or how much the child seems to enjoy the activity.
• Use a variety of consulting or coaching strategies throughout the activity, including: observing, listening, attending, acknowledging, expanding, responding, probing, summarizing, etc.
• Reflect with the family on what went well, what they want to continue doing, and what they would like to do differently at the next visit.

Information and Updates, continued from p. 11

More Recommended Practices
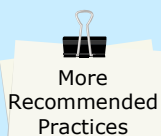
Outcomes continued

Jointly revise, expand, or create strategies, activities or routines to continue progress toward achieving outcomes and address any new family concerns or interests.

• Having listened throughout the visit, reflect on what you have heard that may suggest new outcomes or activities; explore with the family if this is something they want to address soon.

• Support and encourage family decisions.

• Focus recommendations on promoting the child's participation in everyday family and community life.

• Explain the "why" behind recommendations that you make so the family understands what to look for and do.

• Together, plan next steps and/or revise activities & strategies to build on child & family's interests, culture, enjoyment, strengths.

• Consider any adaptations and augmentations to toys, materials, or environments that are necessary for success.

• Try out new strategies or activities to be sure family members or caregivers can do them on their own.

• Determine if & what type of support from other team members is needed for next steps (consultation, information, co-visit, etc.)

Modify services and supports to reflect the changing strategies, activities, or routines.

• Identify community activities and informal supports that will assist the outcomes and activities to be achieved.

• Facilitate referrals and provide any needed assistance, adaptations, or support for the family and the child to participate in desired community activities.

• Plan what early intervention and other services and supports are needed to help the child succeed and make progress.

• Add to or modify the IFSP as appropriate. If changes are significant (adding outcomes, or changing services, frequency, or intensity), a team review of the IFSP is necessary.

A full version of the AGREED UPON PRACTICES FOR PROVIDING EARLY INTERVENTION SERVICES IN NATURAL ENVIRONMENTS can be found at: http://www.nectac.org/topics/families/families.asp**.**

References

Workgroup on Principles and Practices in Natural Environments (February 2008). *Agreed upon practices for providing services in natural environments*. OSEP TA Community of Practice- Part C Settings. http://www.nectac.org/topics/families/families.asp

The S.C. Assistive Technology Project through collaboration with Walton Options for Independent Living, has become part of the Southeastern Technology Access and Reuse Network (STAR), a regional initiative committed to finding alternatives to disposal of used durable medical equipment and assistive technology no longer used by original owners. The goal is to provide South Carolinians and S.C. organizations with opportunities to **access assistive technology and durable medical equipment through redistribution of used equipment that has been sanitized, checked for safety, and repaired for appropriate use.**

Walton Options will be collecting donated equipment from partner sites in selected cities throughout S.C. and then preparing it for redistribution to persons who need the equipment. Donated items such as wheelchairs, tub benches, hospital beds, hoyer lifts, cctv's, rolling walkers, lift chairs, cell phones, and specialized assistive technology such as communication boards and amplified hearing devices are all needed to build the equipment supply. Please call Anita Howard or James Sparks at 1-877-821-8400 or email equipmentdepot@waltonoptions.org to get information on where you may drop off donations. **More information about requests for the equipment and pickup routes will be coming in the future.**

Happy Holidays

We thank all our providers for their hard work and dedication during this holiday season, and wish you and your families a safe and happy holiday and best wishes for happiness and prosperity in the new year!
— from BabyNet Central Office

HAPPY HOLIDAYS

More News and Updates

Each newsletter will feature updates from state or national associations on activities related to early intervention (EI). Previously, a report about EI activities at the American Speech-Language-Hearing Association (ASHA) began this topic. Each issue will include reports from more disciplines.

AOTA Documents Regarding Early Intervention for Occupational Therapists
http://aota.org/Pubs/OTP/1997-2007/Features/2006/f-040306.aspx, by Tami Lawrence, M.S., OTR/L

"The article "*Side by side: Transdisciplinary Early Intervention for Occupational Therapists*" by K. Ovland Pilkington is a well-written guideline to assist therapists and other early interventionists in making the paradigm shift from clinic-based intervention to family-centered collaboration, with opportunities for more meaningful outcomes.

The author draws from Part C of the Individuals with Disabilities Education Improvement Act, to remind us that infants and toddlers should receive early intervention services "in settings where children without disabilities typically participate." The article encourages expansion of our concepts of "client" beyond that of a single child, to include the entire family unit. Empowering families and working in "natural environments" are recognized as critical in the shift toward the transdisciplinary team approach. Drawing from the fundamentals of occupational therapy, this article provides examples of novel techniques and settings for team building in early intervention, such as identifying and building capacities among parents, mentoring staff, and collaboration in community settings. Instead of introducing new equipment, the author suggests that we use the natural environment and "go in bare-handed, and see what happens!" Various other tools and approaches that are complementary to the transdisciplinary team in a natural environment are also described, including the DIR/Floortime model, and a role shift from the prescriptive to a participatory therapeutic approach.

Following this article, distinctions among Transdisciplinary, Multidisciplinary, and Interdisciplinary teams are defined, and a question & answer section has responses from Leslie Jackson, MEd, OT, AOTA's Federal Affairs representative and Practice associate, clarifying issues surrounding this practice shift in early intervention.

ASHA Document— Speech-Language Pathologists Serving Infants and Toddlers: Core Knowledge and Skills Required http://www.asha.org, by Danielle Varnedoe, M.A., CCC-SLP, SCSHA VP Clinical/Professional Affairs, USC COMD Clinic Director

The American Speech-Language-Hearing Association's official statement on the knowledge and skills needed by SLPs serving the infant/toddler populations was approved in February, 2008. The document details the specialized knowledge and skills outcomes that a certified and licensed SLP is expected to have in order to provide early intervention services in accordance with the ASHA Code of Ethics (ASHA, 2003). Eight (8) specific areas of service are covered in the knowledge and skill sets. These areas include:

Prevention and wellness

Screening, evaluation, and assessment

Planning, implementing, and monitoring intervention

Consultation/education for team members (other professionals and family members)

Coordination of services

Transition planning

Advancement of knowledge in early intervention

A speech-language pathologist is expected to not only be knowledgeable in family centered and culturally/linguistically appropriate services, but is expected to provide services based on current, high quality research evidence which supports the child's participation in his/her everyday environment. Thorough knowledge of federal and state laws/procedures regarding the Part C system and models for understanding family interactions/functioning is stressed throughout the document. Speech-language pathologists are strongly encouraged to advocate and advance the knowledge of early intervention through participation in research and consultation with other professionals.

Speech-language pathologists providing services to infants and toddlers have a specialized practice with unique challenges and needs. These guidelines are offered to assist speech-language pathologists in meeting these challenges in an ethically and responsible manner.

Mark your calendars!

Some Upcoming Workshops

January 12, 2009— Columbia, SC; January 13— Charlotte, NC. **Childhood Apraxia of Speech and functional Speech Sound Disorders: Differential Assessment and Effective Treatment**, Christina Gildersleeve-Neumann, Ph.D., CCC-SLP, www.meds-pdn.com or 803-799-7800 or 704-525-8350.

January 26, 2009— Spartanburg, SC; January 27, 2009— Columbia, SC; January 28, 2009— Charleston, SC; February 9, 2009— Savannah, GA; February 11, 2009— Augusta, GA. **Practical Strategies, Interventions and Treatments for Sensory Processing Disorder (SPD) in Children and Adolescents**, by Charlene Young, OTR/L, CEAS, www.summit-education.com or 800-433-9570.

February 19-21, 2009— Myrtle Beach, **2009 Speech Language Hearing Association Convention**, http://www.scsha.com/convention.htm or 888-729–3717.

January 30 and 31, 2009, **2009 Pediatric Conference**, sponsored by SC Occupational Therapy Association School System Special Interest Section and SC Department of Education, http://www.scota.net/26801.html or 888-64-SCOTA.

April 24, 2009— Charleston, SC, MUSC, **SCAPTA** (American Physical Therapy Association, South Carolina Chapter) **Spring Conference**, http://www.scapta.org/fllevts.cfm or 803-802-5450.

2009 workshops sponsored by the South Carolina Autism Society, http://www.scautism.org/2008workshops.html.

2009 workshops sponsored by the SC Assistive Technology Program, http://www.sc.edu/scatp/trainingschedule08.html.

Helpful resources and handouts for service with families and young children:

http://www.fisher-price.com/us/playstages/

http://letsplay.buffalo.edu/

http://www.magickeys.com/books/

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

BabyNet
South Carolina's Early Intervention System
SC DEPARTMENT OF HEALTH AND ENVIRONMENTAL CONTROL

IDEAs that Work

If you need paper copies of the newsletter, have any questions about this newsletter, or would like to submit comments or suggestions, please email Leah Perry at Leah.Perry@uscmed.sc.edu or Lily Nalty at Lily.Nalty@uscmed.sc.edu

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