

The *Up to 3* Times



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Evidence in Support of Support

by Suzan Albright, M.Ed

When Karen Sims' baby boy was born at Greenville Memorial NICU in August 2006, she already knew that her child had Tuberous Sclerosis. The ultrasound, conducted during Karen's 36th week of pregnancy had revealed 3 tumors in his heart. Postnatal testing identified other growths. Karen recalls, "Josh was found to have 5 cortical 'tubers' or calcified tumorous masses that look like small white potatoes throughout his brain. He also had two tumorous masses in each of the ventricles of his brain and a tumor on his left optical nerve. We were given a grim picture of what our future held with our precious son!"

Accessing services and support

The family's picture of their son's future began to improve after they received a referral to BabyNet. "Josh began EI services at 3 months. **Laura Long**, our [DHEC BabyNet](#) intake service coordinator, and **Amber Griffey** of [Anderson DDSN](#), who provides ongoing service coordination and special instruction, have been wonderful in working with Josh and

US! The therapies and genetic visits that were covered by BabyNet services have been a blessing!" Through [Family Connection](#) services, Karen received much appreciated parent- to-parent support from **Terry Hapstack**, whose son has Tuberous Sclerosis.

"We had tons of medical bills! Josh's care requirements meant I was unable to return to work as a teacher, so we were financially stressed." - Karen

Applying for financial support

"We had tons of medical bills! Josh's care requirements meant I was unable to return to work as a teacher, so we were financially stressed," Karen said. During a NICU follow-up visit, a nurse practitioner at Greenville Memorial Child Development Ser-

vices told Karen about the Katie Beckett waiver program. Karen mailed an application in October of 2006. On May 10, 2007, Karen received a letter informing her that the application had been denied.

Preparing the appeal

On May 29, Karen sent a letter of request for an appeal hearing. It was up to the early intervention team to support the Sims family effort to win the appeal. Karen was responsible for completing all the paperwork required by [Health and Human Services](#) and requesting in writing that the hearing be held near the family's home in Anderson. Terry helped inform Karen about the waiver process and advised her to maintain a detailed notebook of all Josh's medical records and billing statements. Josh's physical therapist, **Kim Shore**, played a key role in preparing for the hearing. Kim believes that, "Teamwork is imperative for *all* early intervention services." She had been providing PT services in Josh's natural environment, often visiting the home when Amber was also there. "We worked in conjunction with one another," says Amber.

Together these service providers coordinated their intervention efforts and gathered data on Josh's developmental levels. Developmental delays were indicated by the results of the HELP and AEPS that Amber administered. Kim's assessments, using the Peabody Motor Scales also showed delays, and she identified some early "red flags" such as increased muscle tone. (continued on page 2)

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The hearing convened on July 30, 2007. Both Amber and Kim were there to provide data-based evidence. “Each of us presented written documentation and verbal testimony based on our evaluations of Josh’s developmental status,” Kim recalls. As Amber views it, “The key was to ensure that Health and Human Services had accurate and appropriate information on which to base their decision.”

Evidence of support

In early August 2007, just a couple of weeks before Josh’s first birthday, the Sims family received the notice of eligibility they had been hoping for. It was a present for the entire family. Karen attributes the success of the appeal to the support of her team. “At the hearing, Amber and Kim were available to give their testimonies as well as the geneticist we were able to access through BabyNet. It was because of



Josh shares a favorite storybook with his BabyNet special instruction provider, Amber Griffey, during a recent home visit.

them we were awarded state assistance. We did not lose our house, and I could still stay at home with Josh!”

As his third birthday approaches, Josh is preparing to transition to preschool at Palmetto Elementary School, where he will receive PT and OT services. His mom says, “Josh’s great improvements are proof of this system at work! Early Intervention is the key!”



A TECS Tip of the Hat to BabyNet service coordinator **Amber Griffey** of Anderson County DDSN and physical therapist **Kim Shore** of Shore Therapy in Anderson, for donating their time to provide evidence to support the Sims family’s appeal for a Katie Beckett Waiver.

Tuberous Sclerosis Complex in Early Childhood

Tuberous Sclerosis Complex (TSC) is a genetic disorder characterized by a predisposition to form benign tumors in various body organs including the skin, brain/nervous system, kidneys, heart, and eyes. TSC is estimated to occur in 1 of every 6,000 individuals. As yet, there is no cure.

During infancy and early childhood, symptoms of TSC may include light col-

ored, leaf shaped patches on the skin, red-dome shaped papules on the face, and seizures. In general, the earlier the onset of seizures, especially infantile spasms, the greater the risk of cognitive impairment. Behavior disorders most often associated with TSC are autism, attention deficit, hyperactivity, and sleep problems. Family education and a multidisciplinary approach to treatment are

important aspects of early intervention programming. For more information:

- ◆ [Tuberous Sclerosis Complex: A Review. Journal of Pediatric Health Care \(2007\) 21, 108-114.](#)
- ◆ [Tuberous Sclerosis Fact Sheet: Intellectual and Behavioral Development Problems in Preschoolers with TSC](#)
- ◆ [The Tuberous Sclerosis Alliance](#)



The Power of the Story: How Katie (and 300,000 Other Children) Got Home

In 1981, the story of a 3- year-old named Katie Beckett changed federal Medicaid policy. She had lived in an Iowa hospital nearly all her life, with Medicaid paying the cost of her care. Katie’s parents wanted to care for her at home, but Medicaid would stop payment if she were to move back home—even though the cost of home care would be *lower* than the cost of institutional care.

Katie’s mother told her family’s story to President Ronald Reagan. In response to the President’s request, Congress passed legislation allowing states to waive family income

restrictions on Medicaid, so that Katie and 300,000 other institutionalized children with disabilities were able to go home to their families without losing their Medicaid benefits.

Not all states offer a “Katie Beckett Waiver,” as the program has come to be called; but South Carolina adopted the program in 1991. It is administered by the SC Department of Health and Human services. The application process and eligibility requirements are complex. For early intervention personnel, training in the Katie Beckett Waiver program is

available by contacting **Bobby George**, Director of Training and Development at 803-898-2594 or georgeb@scdhhs.gov. [Information and application materials](#) are available on the HHS website. [Family Connection of South Carolina](#) offers workshops for families and trains their family partners to provide information about the Katie Beckett waiver requirements and application process. For information about training events contact **Chrystal Ray** at 803-252-0914. ☀

The **TUBEROUS SCLEROSIS ALLIANCE** of the Carolinas

by Karen A. Sims, co-chair of *TS Alliance of the Carolinas*

The *TS Alliance of the Carolinas* is one of the many Community Alliances that provide support for individuals or families affected by Tuberous Sclerosis Complex. Like its national counterpart, the *TS Alliance of the Carolinas* was organized by mothers of young children with TSC: **Christi Davis, Amy Quintana**, and me, **Karen Sims**. We are all Moms who were affected by similar circumstances. We met on www.caringbridge.org a website for individuals or families wanting to communicate to their friends and families while serious events took place in their lives. Ultimately, we contacted the TS

Alliance and followed their protocol to organize the *TS Alliance of the Carolinas* into a branch that serves both South and North Carolina.

Since our first meeting in August 2008, the *TS Alliance of the Carolinas* has raised close to \$40,000 by hosting two fundraising events. Our major annual events include a walk-a-thon and golf tournament held in April & September. As co-chairwomen, Christi, Amy and I attend the annual "March on Capitol Hill for TSC" in DC. We meet with Senators and Representatives of states to raise awareness and gain support for funding of medical research to find a cure for tuberous sclerosis.

To learn more about Tuberous Sclerosis, volunteer, or participate in fundraisers, please call us at 1-800-225-6872 or visit our website:

<http://www.tsalliance.org/pages.aspx?content=376>

You can view a YouTube video of our Step Forward Walk-a-Thon at Lake Murray on April 25, 2009:

http://www.youtube.com/watch?v=Y_3ehmLcYWY

Our next event will be a golf tournament at Brookstone Meadows in Anderson, SC on Sept. 12, 2009. Hope to see you there!



What Is There to Say? A Look at Vocabulary Selection for Communication Systems

By Carol A. Page, PhD, CCC-SLP, ATP, South Carolina Assistive Technology Program

Children who cannot communicate with spoken words are introduced to augmentative communication systems. These systems may include a combination of symbols such as signs, pictures, photographs, text, and even objects. These symbols represent vocabulary words. All pictures, objects or photos in a communication system are symbols of real things in the environment and are not to be given to the child for play.

Careful selection of vocabulary for an augmentative communication system is vital for the communication success of the child. Choose words that will be motivating, reflect the child's interests, and are similar to what the child's peers are saying. Many communication systems begin with symbols that represent nouns such as ball, book, and bike. It's relatively easy to find pictures and objects to represent nouns. For example: a picture of a ball or miniature ball looks like a real ball.

Other pictures may be more abstract. For example a line with a dot above it may represent the word "on." Abstract picture symbols will need to be taught. It is difficult to find symbols for some words that are not nouns such as "an, the, and a." For these words, you may want to use only text for the child to recognize or "sight read" even if they can't phonetically read them.

Include other types of grammar or types of words for the communication system as quickly as possible. Choose from words that beginning verbal communicators use. These words include: a, and, away, big, can, come,

down, find, for, funny, go, help, here, in, is, it, jump, little, look, make, me, my, not, one, play, run, said, see, the, three, to, two, up, we, where, and you.

When choosing vocabulary words for communication systems:

1. Select highly motivating vocabulary.

It's important for children to realize how powerful communication systems can be.

2. Choose vocabulary that includes nouns (people, places and things), verbs (action words), adjectives (description words), pronouns, (I, my, mine) and other vocabulary. Here's a link to words pre-school children most frequently use: <http://www.vantatenhove.com/files/MarvinPreschool.pdf>

3. Use single words for each symbol to allow the child to combine symbols to make phrases and sentences. This promotes literacy, too!

Start with just a few vocabulary symbols at first and introduce more as the child demonstrates an understanding of using them to communicate. The easiest and most meaningful way to teach all symbols is during functional daily activities. It's so important for the child to see the parent, teacher, or sibling model how to use the communication system. Remember, most children say their first word after seeing and hearing the word modeled by a parent about a thousand times. It's the same for communication systems. If a child has a low-tech communi-

cation board, point to the child's vocabulary words as you name them out loud during everyday activities.

There are some resources for free communication symbols on the internet:

Pictures/Graphics:

www.imaginesymbols.com

http://www.prentrom.com/component/optio_n.com_docman/Itemid,108/task.doc_details/gid,112/

Photographs:

www.freedigitalphotos.net

pics.tech4learning.com/

Picture-Finding Search Engines:

www.picsearch.com (note: "kid safe")

Picture Sets:

<http://www.setbc.org/pictureset/>

References are available upon request.

Look for my next article on language stimulation. ☀

Carol Page is the staff speech-language pathologist with the SC Assistive Technology Program. She specializes in augmentative and alternative communication and literacy aids. She is available to help individuals with disabilities of all ages and their families and the professionals who serve them. To find out more information, see the SC Assistive Technology Resource Center brochure at <http://www.sc.edu/scatp/resourcecenter.htm>

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TEAM FOR EARLY CHILDHOOD SOLUTIONS (TECS)

As a program of the Center for Disability Resources, the Team for Early Childhood Solutions (TECS) is responsible for various activities related to South Carolina's statewide system of early intervention services for infants and toddlers with disabilities and their families. These include:

- ◆ Managing the Comprehensive System of Personnel Development (CSPD) for South Carolina's Part C early intervention system (BabyNet).
- ◆ Maintaining the database for the BabyNet System Personnel Credential, to assist the Part C lead agency in ensuring that providers of early intervention services meet the state's personnel standards.
- ◆ Researching and reporting information on Child and Family Outcomes that measure the efficacy of early intervention efforts in South Carolina, to assist the BabyNet system lead agency in meeting federal reporting requirements.

For further information and a copy of TECS' brochure, please visit the TECS website, which offers a variety of early intervention resources for families and service providers.

<http://uscm.med.sc.edu/tecs/index.htm>

Technical Support for Early Intervention Services in South Carolina

Speech-Language Pathologists Participate in CDC-Sponsored Research for Earlier Identification of Autism Spectrum Disorder (ASD) by Lily Nalty, M.A., CCC-SLP

The Center for Disease Control (CDC) and the Association of University Centers on Disabilities (AUCD) are sponsoring a mentored collaborative research study with Speech-Language Pathologists (SLPs) as part of the CDC "[Learn the Signs. Act Early](#)" campaign.

The objective of this collaborative research is to develop and inform SLPs on specific methods they can use to help families "Act Early" in navigating complex service systems to reach a diagnosis of ASD.

To accomplish this, the CDC has partnered with ASHA to disseminate an online survey to SLPs to help answer two questions:

- ◆ How do SLPs working with young children currently help families participate in the process towards ASD diagnosis?
- ◆ What additional ways can SLPs provide support and help families reach a diagnosis of ASD?

In July, SLPs will be able to take part in a voluntary national survey to address these

questions. Interviews will then be held with parents of children with autism and specialists in the field of early intervention and autism to answer similar questions.

Results will be disseminated through various forums to help therapists in their role of facilitating earlier diagnosis of young children with ASD. ☼

Child Outcomes Data Collection by Lesly Wilson, Ph.D., OTR/L

As our state approaches the upcoming July 1, 2009-June 30, 2010 data collection cycle, OSEP will be expecting us to clearly establish our state's baseline concerning child outcomes data, based on the reported data within our system. We all have worked hard as a system to develop our child outcomes process, refine the process and train personnel.

Now we are approaching the end of our preparation phase and there is still work to be done. We must improve the amount of child outcomes data inputs and the quality of the information inputted for accuracy at ENTRY and EXIT. At this time, it is even more important that BabyNet system personnel and Contracted Providers understand their roles and responsibilities related to child outcomes and actively participate in the team process to determine child outcomes ratings.

A **Child Outcomes Webinar & Teleconference** has been archived on TECS website to provide additional technical assistance/training regarding federal and state level expectations, resources, roles and process related to child outcomes. In addition, here is a listing of other available technical assistance/training resources :

- ***Child Outcomes Resource Webpage:** <http://uscm.med.sc.edu/tecs/childoutcomesinforevised.htm>
- ***TECSBOOK:** Child Outcomes Training Series <http://uscm.med.sc.edu/tecs/thecomprehensivepersonneldevelopment.htm>
- ***Email:** Lesly.wilson@uscm.edu
- ***Listserv:** subject heading "Child Outcomes" ☼