

The *Up to 3* Times

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First Steps Toward Lead Agency Change for BabyNet

Suzan Albright, M.Ed

Exercising authority granted by federal law to state governors, Governor Mark Sanford initiated a major change to BabyNet by signing [Executive Order 2009-12](#) on September 12. The order states that the goals of [South Carolina First Steps to School Readiness](#) align closely with the goals of the Part C of the Individuals with Disabilities Education Act, which provides federal funding for BabyNet. First Steps is the only state entity that is solely devoted to meeting the early educational needs of the state's young children.

The BabyNet lead agency is responsible for general supervision of the statewide system of early intervention services, and reports to the U.S. Department of Education, Office of Special Education Programs ([OSEP](#)). The Department of Health and Environmental Control (DHEC) will maintain and fulfill lead agency responsibilities for BabyNet until January 1, 2010 when First Steps will assume leadership.

Initial steps toward this transfer are being taken to ensure that early intervention services are uninterrupted. A Transi-

tion Advisory Team comprised of representatives from the state legislature, a variety of public service agencies, higher education, and parents of children with disabilities convened on September 11. The team was charged with examining all 16 components

of the early intervention system in light of federal requirements, research findings, and current recommend practices.

On November 4, the Team presented its findings and recommendations for improving BabyNet.

Team for Early Childhood Solutions ([TECS](#)) provided technical support to the workgroups during their deliberations. Representatives from OSEP, the National Early Childhood Technical Assistance Center ([NECTAC](#)), and MidSouth Regional Resource Center ([MSRRC](#)) gave technical assistance to state level decision-makers.

Under First Steps leadership, BabyNet will have a full-time Part C Coordinator to manage the program.

For more information on the transition process visit the [BabyNet](#) website at: <http://www.scfirststeps.org/> ☀

A TECS Connection to Family Connection

Leah Perry, B.A.



Taylor Perry (L), daughter of TECS Administrative Assistant, Leah Perry (R) celebrates her 9th birthday with a hug from Mom, a big cake, and a big smile. Leah is a Support Parent with Family Connection and serves on the Family Connection Annual Conference Committee. Read their story on page 2.

Inside this issue:

A TECS Connection cont.	2
CDR Library InfoAble	2-3
Family Satisfaction Survey	3
Child Outcomes	3
Prematurity Awareness Month	4

A TECS Connection to Family Connection (cont.)

Leah Perry, B.A.

Taylor Perry, was born October 19, 2000 in Columbia, SC at 34 weeks gestation. Just 14 inches long and weighing 4.8 lbs, my tiny baby spent several days in the isolette unit. She had a host of problems. She'd stop breathing if she became cold, had to be tube fed for 4 days, and then needed feedings every 3 hours for 10 weeks. She also had formula allergies and a dimple (hole) on her lower back that we were told "would close on its own." When it came time to bring her home I was very nervous because she was so tiny and I constantly watched her to make sure she was doing well.

As an infant, Taylor didn't sleep well and was always restless. She didn't like to be held, which to a mom is very hard because we want to cuddle our babies. As Taylor grew older she was always active and constantly in motion. At about age 3, she was diagnosed with attention deficit hyperactivity disorder (ADHD) and was prescribed medication to help her focus and "slow down." I had to learn quickly as much as I could about ADHD in order to help and understand her.

During a well child visit when Taylor was 6 years old, the doctor noticed something was not right. He asked "how long has she walked on her toes," to which I replied "basically since she began walking." He checked her arms, legs, and back and saw the dimple. He asked me what I'd been told about it, I replied, "that it would close on its

own." This set into motion a series of MRI's, ultra sounds, blood tests, and other tests which resulted in the following diagnoses: Spina Bifida Occulta, Tethered Spinal Cord Syndrome, Syrinx, Chari Malformation, Thickened Filum Terminale Syndrome, and Neurogenic Bladder. This was a very confusing and overwhelming time for me and my family. I had only taken Taylor to the pediatrician for a regular check-up, and the next thing I knew, I was in a variety of doctor's offices, trying to learn all kinds of medical terminology. Often I was on the computer researching everything I could in order to try to understand it all.

As TECS staff member, I knew of [Family Connection](#) and the many resources they have for parents of children with special needs. I contacted them, and within a day I was matched up with a wonderful Support Parent, **Becky Brown**, whose child has a similar diagnosis. Becky offered me help in a personal and caring way. She helped me find other resources that my daughter needed, sat with me during Taylor's surgeries, and visited us while Taylor was in the hospital. It is wonderful to know I have someone to talk to during the ups and downs. When Becky became ill and was out for a while, **Sheryl Connolly** became my Support Parent. Sheryl assisted me during an Individualized Education Plan (IEP) meeting at the school. With the support of my Support Parents, I was able to get Taylor some of the services she needs to help her in school.

I have benefitted so much from Family Connections that I have become a Support Parent my-

self, and I also enjoy serving on the Family Connections Annual Conference Committee.

Taylor is now an active, fun-loving, and beautiful 9 year-old girl with a great attitude. She has years of MRI's and ultra sounds in her future, but I know but she will handle it as always—like a TROOPER.

I want to emphasize that *early identification and referral are critical!* Looking back, I wish I had known about early intervention. There were many developmental red flags, and her conditions might not have gotten as bad, had we known about her diagnoses and eligibility for BabyNet. For example, had I known that the hole in her back was [Spina Bifida Occulta](#) and that [Tethered Spinal Cord Syndrome](#) is associated with it, maybe she would not have developed [neurogenic bladder](#) due to the cord hanging down for so long. Also, Taylor is currently in physical and occupational therapy and if I had known about [BabyNet](#), she would have been eligible, received services a long time ago, and might not need as much now. I am very grateful to my family, friends, and co-workers and also to Family Connections.

With the support of Family Connections, I am able to be a stronger person for Taylor and give her the support that she needs to continue to grow and be happy. ☺



A TECS Tip of the Hat to Family Connection Support Parents **Becky Brown** and **Sheryl Connolly** for helping our own "TECSan". Thanks, Partners!

InfoAble Portal Links Families to Web-based Resources

Steve Wilson, MLIS/MA, Center for Disability Resources Librarian

The InfoAble Portal (<http://uscm.med.sc.edu/infoable/>) is a free disability and health information resource developed by the University of South Carolina School of Medicine Library (<http://uscm.med.sc.edu>) for Family Connection of South Carolina. **Steve Wilson** and **Roz Anderson** at the University of South Carolina School of Medicine Library received an Express Outreach Award from the National Network of Libraries of Medicine Southeastern/Atlantic Region (<http://nlnm.gov/sea>) to fund this project. Steve Wilson is the Coordinator of the Center for Disability Resources (CDR) Library, an outreach project of the School of Medicine Library.

In addition to developing the InfoAble Portal, part of the funding was used to purchase two new computers and a projector for the Columbia Family Connection's new Family Wing.

The InfoAble Portal was designed to improve access to information for Family Connection and anyone seeking disability-related information online. The homepage includes the following options: *Explore health information*, *Books and Videos*, *Library Virtual Tour*, *Locate Clinical Trials*, *PubMed research articles*, *Disability Dashboards*, and *Ask A Librarian*.

The *Explore health information* link enables families to access authoritative information from MedlinePlus (<http://www.medlineplus.gov>). The *PubMed research articles* link allows parents to search the National Library of Medicine's MED-

LINE database of more than 18 million biomedical research article citations and abstracts. *Locate Clinical Trials* guides parents to ClinicalTrials.gov. *Ask A Librarian* is a web-based form to email the CDR Library Coordinator with information and material requests. There are also virtual tours of the CDR collection, which lends materials nationwide. In the virtual tour, you can click on certain books and videos that have hotlinks to the online catalog. The *Books and Videos* link searches the CDR Library online catalog.

The Disability Dashboards section provides a menu of topic-specific dashboards. These topics are derived from various Family Con-

(Continued on page 3)

2

nection support groups, including Asthma, ADD/ADHD, Autism, Down Syndrome, Fathers, Preemie, and Siblings. Although the layout is similar to the InfoAble Portal homepage, the dashboards narrow the searches to each of the topics.

Another goal of the project is to promote the freely available, quality information from the Center for Disability Resources Library and the National Library of Medicine (<http://uscm.med.sc.edu/CDR/index.htm>).

The InfoAble Portal project has been funded in part with federal funds from the National Library of Medicine, the National Institutes of Health, the Department of Health and Human Services, under Contract No. NO1-LM-6-3502 with the University of Maryland, Baltimore. ☀

TECS to Survey Family Satisfaction with BabyNet Services

Suzan Albright, M. Ed.

Families will have an opportunity to provide feedback about the BabyNet services they receive. The annual Parent Satisfaction Survey will be sent to all families of children ages birth to age three who are receiving BabyNet services. January 15, 2010 is the projected mail-out, and the deadline for return is February 19, 2010. The survey will also be posted on the TECS website for those who wish to respond online.

The survey instrument to be used is the Family-Centered Services Scale, a 25 item questionnaire developed by the National Center for Education Accountability Monitoring ([NCSEAM](#)).

It is designed to measure family satisfaction on various indicators of early intervention service quality.

TECS will report information from the survey to BabyNet administrators for their use in making data-driven decisions about improvements to service quality. The report will also be made available to the public. ☀



Child Outcomes: A New Level of Accountability for IDEA, Part C Programs

Lesly S. Wilson, Ph.D., OTR/L

The Law

The 2004 Reauthorization of the Individuals with Disabilities Education Act (IDEA), Part C required that states move toward a higher level of accountability for early intervention service systems. Such accountability came to early intervention (IDEA, Part C) as a result of an internal government review revealing that the Office of Special Education Programs (OSEP) did not have sufficient evidence to support the effectiveness of its early childhood programs (OMB, 2006; Greenwood, Walker,

CHILD OUTCOME AREAS

1. **(SOCIAL)** Positive social relationships
2. **(KNOWLEDGE & SKILLS)** Acquiring and using knowledge and skills
3. **(MEET NEEDS)** Taking appropriate action to meet their needs

Hornbeck, Hebbeler, & Spiker, 2007). As a result of the reauthorization of IDEA, the OSEP established additional child outcome measures to ensure the new level of accountability for states participating in the IDEA, Part C programming.

Child Outcomes

Child outcomes were established to determine a child's overall functional progress from the point of entry into an early intervention system, to the point of exit from an early intervention system. Data on the progress of children receiving at least 6 months of services is

required to be reported annually. Data are to be reported on the three outcomes for all children served, regardless of disability. Each of the 3 outcome areas require data capturing within five categories-- (a) Percent of infants and toddlers who did not improve functioning; (b) Percent of infants and toddlers who improved functioning but not sufficient to move nearer to functioning comparable to same-aged peers; (c) Percent of infants and toddlers who improved functioning to a level nearer to same-aged peers but did not reach; (d) Percent of infants and toddlers who improved functioning to reach a level comparable to same-aged peers; and (e) Percent of infants and toddlers who maintained functioning at a level comparable to same-aged peers.

IDEA, Part C specifies three general roles of all service providers: (1) consulting with parents, other service providers, and representatives of appropriate community agencies to ensure the effective provision of services in that area; (2) training parents and others regarding the provision of those services; and (3) participating in the multidisciplinary team's assessment of a child and the child's family, and in the development of integrated goals and outcomes for the Individualized Family Service Plan (IFSP). "Enhancing the capacity of families to meet the special needs of their infants and toddlers with disabilities" (IDEA 2004, PL 108-446) is the overall goal of Part C.

Child outcomes accountability measures were established to further support the concept of family centered care in order to achieve functional developmental progress. The IFSP team

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 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. Accountability concerning a child's functional progress between entry and exit of an early intervention system rest on all IFSP team members.

All IFSP team members should actively participate in the capturing child outcome measures and be knowledgeable of this process. It is important to be familiar with the Child Outcomes Summary Form (COSF) and the related tools for use with the form— the Decision Tree and the Early Child Outcome Center (ECO) Ratings in order to effectively provide input regarding your service area into the child outcomes process. The ECO (2005) defined an outcome as a benefit experienced as a result of services and supports received. It is important that the benefit of early intervention services are tracked during the child outcomes process.

Additional Resource:

TECS Child Outcomes Web Page: <http://uscm.med.sc.edu/tecs/childoutcomesinforevised.htm>

[References are available on request](#) ☀

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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

November Is Prematurity Awareness Month

Suzan Albright, M. Ed.

In a campaign to increase public awareness about the issues surrounding premature birth, the [March of Dimes](#) has designated the month of November as Prematurity Awareness Month.

According to information published by the March of Dimes, about 1 in 8 infants in the United States is born too soon—more than half a million babies each year. Furthermore, the rate of preterm births has been rising.

Premature birth is the number one killer of newborns in our nation. Children who are born prematurely are at increased risk for health and developmental problems. Compared with children born at full term, children born prematurely have higher rates of learning disabilities, cerebral palsy, sensory deficits, and respiratory illnesses.

South Carolina has one of the highest rates of premature births in the nation. During

the decade from 1996 to 2006 the rate increased over 25%. As of 2006, one in seven births was preterm. That is 15.4% of live births.

More information on prematurity is available from the following online resources:

- ◆ The March of Dimes Prematurity Awareness Month website
http://www.marchofdimes.com/prematurity/index_about.asp
- ◆ March of Dimes PeriStats website for perinatal statistics
<http://www.marchofdimes.com/peristats/whatsnew.aspx?id=37&dv=wn>
- ◆ High Risk Newborn: Prematurity is an online FAQ from the Medical University of South Carolina. Available 6Nov2009
http://www.musc-kids.com/health_library/hrnewborn/prematur.htm?print



- ◆ The Center for Disease Control and Prevention <http://www.cdc.gov/features/prematurebirth/>

