

early steps e-letter

Early Steps Medically Fragile Team



Nurse Denise Williams, left, chats with Latanya Jones during the picnic at Lakes Park, April 30.

Interview with Nurse Denise Williams

Bobby, 3 months old, is referred to Early Steps because he has trouble eating. His difficulty to swallow was evident immediately after the tubes used to feed him at the NICU were pulled out. He was born with a genetic condition that required him to stay at the NICU for an extended time and was on respirator for a while.

Bobby's parents had tried almost anything since he was discharged but

he's not gaining weight. They had been out of the State; they have sought all kinds of specialists.

The Early Steps team goes to Bobby's home to evaluate him. The evaluation not only establishes what areas of development might have been affected by his condition, the feeding problem and the prolonged stay at the NICU, but will also be a frame of reference to evaluate in the future the impact of the Early Childhood specialists' intervention.

"We have been supportive of the family," explains Nurse Denise Williams. "We provided informa-

tion about support groups made out of parents with similar concerns. We also found for them an Occupational Therapist (OT) with extensive knowledge on feeding."

According to Denise, this OT used a method that "turned everything around."

As the baby started to feed himself, "he gained weight, was more interested in engaging with its environment and improved motor skills," Denise said. "Parents were so relieved to have found something to help the baby."

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Medically... (cont.)

The positive results were not only evident in Bobby's physical development. As the baby started to feel stronger, his nutrition improved and the family could use their energy to focus on the positive, which in turn supported Bobby's social and emotional development.

This is not an unusual story. A good number of the cases that Early Steps is called to help are families with children with medical conditions that make them extremely vulnerable and place them in risk of developmental delays.

Denise is a team member of a group that she helped to create two and a half years ago.

"We put a *Medically Fragile* team together among other things because there were more and more 24-week babies saved in the hospitals," Denise said. "These preemies present a special set of challenges. We thought that creating a specialized team would help us to deliver more efficient services to children with special medical needs."

The initial team was made up of Physical Therapist (PT), Trina Puddefoot; an Infant Toddler Specialist (ITDS), an Occupational Therapist (OT) and Denise.

A little after the team was created Denise accepted a position at Healthy Start in Lee County. However,

she always missed Early Steps and decided to come back at the beginning of this year when a nurse position opened.

"Most of the staff that I used to work with are still here," Denise said. "I found that Early Steps has a very interesting and great group of professionals. This is very stimulating for me."



The current medically fragile team is made up of Speech Pathologist (SLP) Elli Grim, Clinical Social Worker (CSW) Sam Freck and ITDS Joan Foss.

Nurses at the NICU call Denise as soon as a child who could use Early Steps services is ready to be discharged. She picks up the files at the hospital and makes sure that there is a continuity of care for the baby.

"Some of the conditions which may determine that a child is med fragile would be major cardiac defects, respiratory issues such as chronic lung disease, bronchopulmonary

dysplasia, severe lack of oxygen at birth, tracheostomy, extensive brain bleeds, rethinopathy of prematurity grade 4, diabetes, strokes, HIV, genetic syndromes, Fetal Alcohol Syndrome (FAS), babies from mothers who abused drugs during pregnancy and shaken syndrome babies," Denise said.

YOUR CONTRIBUTIONS TO THE E-LETTER ARE WELCOME!!

We'd like to see all kinds of articles in these pages. These are the submission guidelines:

1. Articles submitted should be short and presented in narrative form. Articles may be edited for clarity and brevity. From one paragraph to half a page per submission. 2. Share success stories. Our mission is to educate, to inform and also to be uplifting. 3. Please submit documents as attachments to silviacasabianca@hpcswf.com. 4. You can also submit good quality pictures from trainings and team meetings. 5. Have your readers in mind (ES staff and outside providers).

Be innovative, thought provoking and positive.

"Keep away from people who belittle your ambitions. Small people always do that, but the really great make you feel that you, too, can become great."

Mark Twain

May was Better Hearing and Speech month



This annual event promoted by The American Speech Language Hearing Association (ASHA) provides opportunities to raise awareness about

communication disorders and to promote treatment that can improve the quality of life for those who experience problems with speaking, understanding, or hearing.

ASHA has many resources to promote this improvement. Visit: <http://www.asha.org>

- Between 6 and 8 million people in the United States have some form of language impairment.
- The prevalence of speech sound disorder in young children is 8 to 9 percent. By the first grade, roughly 5 percent of children have noticeable speech disorders; the majority of these speech disorders have no known cause.
- A cleft palate is the fourth most common birth defect, affecting approximately 1 of every 700 live births. Velocardiofacial syndrome (which can include a cleft palate, as well as heart defects, a characteristic facial appearance, minor learning problems, and speech and feeding problems) occurs in approximately 5 to 8 percent of children born with a cleft palate.

Source: <http://www.nidcd.nih.gov/health/statistics/vsl.asp#1>

- About 2 to 3 out of every 1,000 children in the United States are born deaf or hard-of-hearing
 - Nine out of every 10 children who are born deaf are born to parents who can hear.
- 3 out of 4 children experience ear infection (otitis media) by the time they are 3 years old.
 - In the US, 15,500 children have received cochlear implants.
- Approximately 3 to 6 percent of all deaf children and perhaps another 3 to 6 percent of hard-of-hearing children have Usher syndrome. In the United States, about 4 babies in every 100,000 births have Usher syndrome.

Source: <http://www.nidcd.nih.gov>.

Early Hearing Detection and Intervention

Each year, the EHDI conference brings together people who work in Early Hearing Detection and Intervention; assist in EHDI efforts on the federal level; provide screening, diagnostic and early intervention support to young children with hearing loss and their families; champion Medical Home activities within each state; are parents of children with hearing loss; or are deaf or hard-of-hearing adults who are helping to expand opportunities for young children with hearing loss. You can have access to videos and copies of presentations used at the 9th Annual National Early Hearing Detection and Intervention (EHDI) Conference held 1-2 March 2010 in Chicago, Illinois: <http://www.infanthearing.org/meeting/index.html>

Greenspan: Love, foundation for learning

Child psychiatrist Stanley I. Greenspan, who created “*floor time therapy*” as an intervention for children with developmental disorders, died in Bethesda on April 27, at 68.

He wrote several books pioneering the idea that loving relationships are the path towards socio-emotional health. Greenspan believed that a newborn had to



go through a great deal of work to transform overwhelming sensori-motor experiences and feelings into wishes and thoughts.

Greenspan postulated that emotional development was the foundation for cognitive development and learning. He explained that this emotional development happens along the following six developmental stages.

0-3 mo. – Child takes interest in the world

Basic internal regulation - Calm state, necessary for learning.

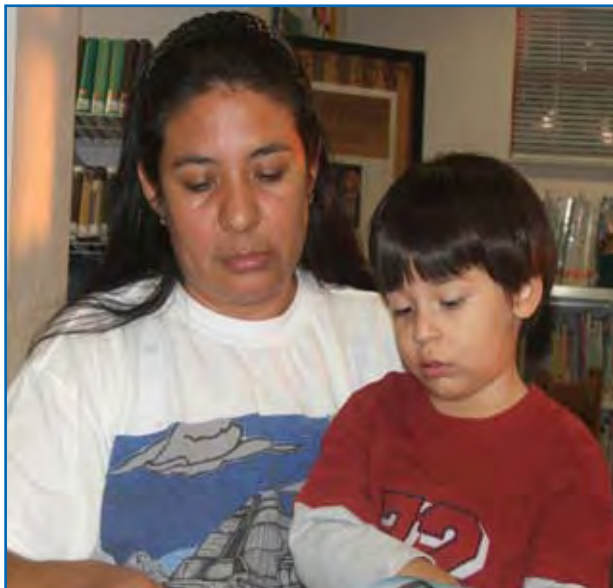
Danger signs: hyper-excitable, too easily overwhelmed or withdrawn, apathetic.

2-7 mo. – Multisensory relationship with caregiver

Danger signs: lack of emotional responsiveness to people, especially primary caregiver.

3-10 mo. – Somatic & psychological differentiation

Interact with caretakers, in back-and-forth manner, sending and receiving nonverbal messages.



9-24 mo. – Initiative and sense of self

Develops patterns of behavior

Danger signs: behavior easily disrupted; child goes from one extreme of behavior to another without logical transition.

18 mo.– 4 yrs. - Representational elaboration

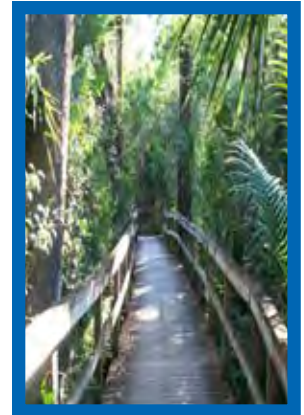
Uses symbols and words to communicate feelings, ideas, intentions.

Danger signs: child communicates only by acting out; child cannot distinguish fantasy and reality; lack of impulse control.

EVENTS YOU MIGHT WANT TO ATTEND

PATHS to the Future

SATURDAY JUNE 19 9:00 a.m.
 Student Union Bldg. Room 213
 Florida Gulf Coast University
 Call (239) 590-7771 or email cphilbro@fgcu.edu
 No charge



The Center for Autism and Related Disabilities at the University of South Florida (CARD-USF) will offer a three-hour training, "PATHS to the Future." The purpose of the session is to coach prospective facilitators to use PATH, Planning Alternative Tomorrows with Hope. PATH can be used as a short- and long-range planning process for individuals with autism and related disabilities as well a planning tool for non-profit organizations supporting individuals with developmental disabilities.

CARD-USF provides support and assistance with the goal of optimizing the potential of people with autism and related disabilities. For additional information about autism spectrum disorders, visit: <http://card-usf.fmhi.usf.edu>.



SPARC 2010
 STAND Pinellas Accessing Resources
 Conference
 Saturday, September 11, 2010
 8 - 5 p.m.
 Morgan Fitzgerald Middle School
 Largo, Florida
 Call (813) 258-5700 or email
stand@standadvocates.org
 Visit: <http://www.standadvocates.org>

This educational conference's goal is to provide parents, teachers, therapists and other professionals with resources that will help their children make achievements in all aspects of life. While focused on children with special needs, Sparc believe these resources are just as valuable to any child. Pre-registration price before 9-1-10: \$25.00 per person, \$40.00 per person thereafter.

Brain development

By Silvia Casabianca MHC

Are we born already wired? Is the human infant brain a tiny replica of the adult brain? Is it true that babies are not affected by events that take place in their lives? Is it true that infants don't have yet a mind? That newborns do not experience pain? That there is not such a thing as infant mental health?

Ideas on brain development and the mind have evolved throughout the centuries. Some answers about the functioning of the brain, about the anatomy and physiology of the nervous system have been found, but there is still much to learn, to research, and to know.

Science has evolved from holding that babies were just like little animals guided by instinct that needed very little care, to understanding that the first three years of life are essential for a healthy development. Now we know that neurons that fire together, wire together and that's how we learn.

One of the reasons that sustains the need for early intervention programs like Early Steps is precisely the knowledge we now have about the tremendous impact that all events happening during the first three years of life have on children's development.

Let's take a look at a few interesting breakthroughs in brain research.

EARLY BRAIN

Fetal magnetic resonance im-

aging has demonstrated that around the 18th day after conception the brain cells are already beginning to form.

NATURE & NURTURE

Explanations about what drives human development have evolved from maturationist theories holding that children learn and behave in certain way because there is a natural predisposition to do so, to ecological systems theory (Urie Bronfenbrenner) that emphasizes the influence of the many institutions and settings (family, community, school, political system) within children live.

Research has already demonstrated that we are the product of an interaction between one's genetic endowment (nature) and the environment (nurture). Science has proven that for example nutrition, hormones and chemicals influence the development of the fetus brain.

MIRROR NEURONS

Among the most interesting discoveries in the past few decades is the result of research on what has been called *mirror neurons*. These are nerve cells that fire not only when an animal performs an action but also -and this is the most interesting part - the same neurons fire when the animal observes the same action performed by another. Although most of the research on mirror neurons has been performed on primates, researchers have also found that in humans there is brain activity similar to that of mirror neurons.



The scientist V.S. Ramachandran believes that mirror neurons might have an important role in imitation and language acquisition.

STRESS AND DEVELOPMENT

Modern life has brought to our lives many different stressors: physical, chemical, biological, electromagnetic, emotional, mental and spiritual.

Medical science continues to demonstrate how in the process of adapting to stress, the body may suffer significant damage. Stressors elevate the production of adrenalin and cortisol and affects cognitive productivity. Chronic and cumulative stress leads to exhaustion.

Stress experienced by a woman during pregnancy affects the fetus and particularly its brain development. Intense anger, physical violence as well as any chemical stressor, floods the brain with stress hormones.

Various types of trauma or neglect activate neural pathways that may lead to child's increased muscle tone, sleep disturbances, increased startle response, and anxiety.

Damages caused by stress can be permanent, especially for the emotional brain.

7 Super Things Parents & Caregivers Can Do

1. Talk often with your children from the day they are born.
2. Hug them, hold them, and respond to their needs and interests
3. Listen carefully as your children communicate with you.
4. Read aloud to your children every day, even when they are babies. Plan and sing with them often.
5. Say "yes" and "I love you" as much as you say "no" and "don't."
6. Ensure a safe, orderly, and predictable environment, wherever they are.
7. Set limits on their behavior and discipline them calmly, not harshly.

Early Childhood- Head Start Task Force
U.S. Departments of Education and Health & Human Services

tips tips tips tips

By Silvia Casabianca



ITDS RESOURCES

www.babies-and-sign-language.com

This website was created to promote teaching all infants and toddlers sign language: "Sign language gives babies a way to communicate what they are truly thinking, feeling and/or needing. Because they learn to communicate early, Baby's mind develops a rapid interest in increasing communication ability." Rich in resources for both typically developing babies and babies with language and communication impairments.

As a complement, click below and watch this brief video of a baby communicating with sign language:

http://www.youtube.com/watch?v=7gSZfW4gVhI&feature=player_embedded#!

www.pathwaysawareness.org/tummytime

How much *tummy time* is necessary? When should babies start? What activities are best? The website provides answers to some of these questions.

The Early Steps Library

We have prepared a list of our available library resources, including brand new infant mental health books. The list is posted on the side of the shelf where the books are and will be posted on our website pages. You can do a library loan for up to four weeks! Just ask Katie about it.

