

BEACH CENTER STORIES

Against All Odds: Tianna, Early Intervention, and Family Support

Shortly after being deployed to Iraq, Katie, 22 years old and a private first class in the U.S. Army, became ill. The possibility of being pregnant never even crossed her mind. After all, she was on birth control. However, eight months later her miraculous baby girl was born. The doctors had predicted that her daughter wouldn't survive the birth. But Tianna beat the odds.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life



Tianna's Story

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Katie's Story: The Discovery

Katie and her boyfriend were both in the Army when Katie was deployed overseas. She left Kansas on May 1, 2005, and in a matter of weeks found herself in the hospital, half-way around the world.

"I just got really sick," Katie recalls. "I had been on birth control so was fully in denial." At first the military thought Katie was having appendicitis, so they sent her to Baghdad for tests. There the doctors there performed an ultrasound and discovered that Katie was pregnant – with twins! The Army shipped Katie home immediately. Four months into the pregnancy, Katie lost one of the twins. After that the doctors kept a watchful eye on Katie, performing ultrasounds once a week to see if the baby was still alive. The doctors said there was only a 40-50 percent chance that the baby would make it. Despite their fears, the pregnancy progressed normally ...until Katie was eight months along.

Based on a recommendation from a consulting fetal specialist, Katie was supposed to receive amniotic fluid index tests twice a week to ensure that the level was sufficient for the baby's development. Unfortunately, the military doctor didn't think the tests were necessary, and Katie ended up dehydrated and in the hospital once again.

Katie was then sent to *another* specialist in yet *another* city. While performing a routine ultrasound to measure amniotic fluid, the doctor noticed a blood clot on the baby's brain. Within one week, the clot was noticeably bigger. The doctor recommended amniocentesis to determine if the baby's lungs were developed enough to withstand premature delivery. They were and Katie was scheduled for Caesarian delivery the very next day.

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"He told me that the clot had enlarged a lot and that she was probably not going to live," Katie remembers. "The pressure in her head was so great he said she wouldn't make it." Amazingly, little Tianna was born on December 22, one month early. "She came out fine!" Katie says.

New Complications

"Like any mother, you think you are going to have a normal baby," Katie said. "Everybody does." While Tianna survived delivery, she was born with hydrocephalus, an abnormal accumulation of fluid inside the brain. Tianna also had the blood clot the doctor had detected *in utero*. "The hospital wasn't sure what to do because she wasn't even supposed to be born. They held off feeding her for three days and just observed her." After two CAT scans, Tianna was airlifted to a children's hospital in Kansas City.

The standard treatment for newborn hydrocephalus is to implant a shunt (a tube) in the baby's ventricular system to help the fluid drain into another part of the body where it can be absorbed. But Tianna's situation was complicated. The doctors feared the blood clot would clog the shunt so

they opted, instead, for inserting a more open device, a reservoir. That worked for a week and then Tianna developed meningitis. The reservoir was removed and the doctors once again predicted that Tianna wouldn't survive. But Tianna did. In fact, she stabilized.

In February 2006 the family was finally able to go home together for the first time since Tianna's birth. When Katie and her baby returned a week later for a check-up, "her head was huge again," Katie said. The doctors decided to go ahead and insert the shunt even though the blood clot was still there. Miraculously, within a month, Tianna was better and the blood clot was 90 percent dissolved. She had beat the odds.

Finding Essential Supports

Tianna's first few months in the world were medically precarious, to say the least. What helped her family stay on its feet emotionally was the work of several partners who supported not only Tianna but also the whole family.

During Tianna's stay at the hospital, a social worker stopped by daily to check with the family and determine what their needs were and how best to support them. The social worker arranged for family members to have a hotel room, free of charge. She also lined up meals and provided information on the medical issues facing Tianna.

Family members gathered around to offer their support, too. Lorenzo, Tianna's father, proved to be a source of positive thinking, strength, and support for both Katie and Tianna throughout the entire medical ordeal. Katie's mother flew in from her home in Vermont and stayed for six weeks to provide additional help. Between the three of them, they were able to support each other and ask the questions they needed to ask. As Katie recalls, "the first time we heard the word hydrocephalus we said, 'What is THAT?'" The family learned to keep asking questions.

Meet Peggy:

Family Support at Home

Upon Tianna's release from the hospital, Katie was referred to the early intervention program in her home county. Tianna wasn't eating enough and her left hand didn't open and close the way it should. The professional assigned to Tianna and her family as primary coach was Peggy, the early intervention program coordinator and an experienced special education teacher. Peggy called the family and then went to their home to meet with them, to listen to their story, and to hear about their needs and routines.

Initially, feeding was the primary concern of the family since Tianna was not eating enough and, as a result, had little energy. When other concerns arose regarding her overall development, Peggy and Katie consulted with additional early intervention team members to include a speech language pathologist, an occupational therapist, and a physical therapist. Each time Peggy brought a new support provider into the home, she took full responsibility for reviewing Tianna's history with them ahead of time. This one, small tactic took a major strain off Katie. "It's really hard to have to explain my case over and over to strangers," Katie said. "Peggy lets everyone know what the story is so I am just dealing with her and not repeating the information every time."

All supports and services were based on the priorities and needs of the entire family. Family input was essential to the success of both early intervention services for Tianna's development as well as for an ongoing successful parent-provider partnership.

Emotional Support Proves Critical

Important support for Katie, Lorenzo, and Tianna came in the form of information. Peggy gave the family a wealth of background on early intervention services, Tianna's diagnosis, and infant developmental milestones. According to Peggy, "Katie makes it easy because she knows *so* much about her daughter. She knows the areas that she is concerned about." For example, Katie wanted to know what "typical child development" was for Tianna's age. "She always wanted to be prepared for whatever was next."

Peggy made herself available not just to Katie but to extended family members as well. Katie's mother returned to town and had her own concerns and questions. Peggy met with her and shared her cell phone number so that she, too, could reach Peggy anytime she had questions.

Eventually Katie's mother started a support group for parents of children with hydrocephalus in her local Vermont community. Through this connection, she paired Katie with another family facing a similar situation. Katie and this family still maintain a long-distance friendship in which they share stories, information, and emotional support.

Motherhood and Advocacy

According to Peggy, Katie is "a great advocate for her daughter already!" The formal and informal supports provided to her helped to strengthen Katie in this role. In addition, Katie is always comfortable and willing to say ask for anything she needs, which Peggy sees as one of Katie's greatest strengths. Katie states it simply. "If you have a daughter with disabilities, you just have to do it. You need to learn as much as you can. I'm the only one that can do it for her. If I don't do it, nobody else is going to do it."

Today Tianna is doing well, meeting or exceeding her developmental milestones. The family had a scare in May when Tianna's head grew very large again. But after surgery to replace the shunt with a larger one, Katie says her daughter is "better than ever now. Her eyesight and ears are perfect. Now she is sitting up and crawling and eating all kinds of foods." Katie stays at home full-time to care for her daughter and she and Lorenzo are married. In fact, Lorenzo received a compassionate reassignment from the Army to be closer to a pediatric hospital and as this article was written, the family planned to move to Georgia within a few weeks.

Why the Relationship Works

When asked what she likes about her chosen field-- early intervention--Peggy says it's "the support of the families, more than anything else. Being able to listen to their stories, sit in that living room, and provide what is needed to help them to be happy, see hope in the future, and come together as a family."

Katie recognizes and values this outlook in Peggy, whom she sees as a friend. Any time Katie has a question or concern, she knows Peggy will really listen and respond with information and options in a non-judgmental fashion. "She lets **me** make the choice," Katie says.

The end result has been empowerment for a young mother who once found herself alone and ill in a Baghdad hospital. Katie jokes that she feels like she went to medical school herself "in about three months." Through early intervention services that benefited Tianna and all those who love her, Katie can now make educated decisions based on the needs and preferences of her whole family.

A Final Thought

“I wake up everyday and think about the words the doctor told me – that she is not going to be born, and she is not going to make it. Then I look at Tianna, and there she is smiling at me and laughing, and it just makes it all worthwhile.”

- Katie

RESOURCES RECOMMENDED BY KATIE, PEGGY, AND OTHERS

INTERNET

Infant Development:

<http://www.zerotothree.org>

Zero to Three is a great resource on the first few years of life. It covers everything from basic child development and childcare to issues of specific concern. It is a great resource for both parents and professionals.

Child Health Practices:

Bright Futures Website - <http://www.brightfutures.org/>

Bright Futures is a “national health promotion initiative dedicated to the principle that every child deserves to be healthy and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community as partners in health practice.”

Hydrocephalus:

Below is a list of various informational resources on hydrocephalus.

The Mayo Clinic

<http://www.mayoclinic.com/health/hydrocephalus/DS00393/DSECTION=1>

The Mayo Clinic provides a general overview of the medical aspects of hydrocephalus covering signs and symptoms, causes, risk factors, diagnosis, treatment, prevention, and much more.

The Hydrocephalus Association

<http://www.hydroassoc.org/>

The Hydrocephalus Association is geared toward providing “support, education, and advocacy for individuals, families, and professional.” The website provides information related to personal support, comprehensive educational materials, and ongoing quality health care.

The Hydrocephalus Foundation Inc.

<http://www.hydrocephalus.org/>

The Hydrocephalus Foundation Inc. is a “nonprofit organization dedicated to providing support, educational resources and networking opportunities to patients and families affected by hydrocephalus.”

The Children’s Hospital of Philadelphia

<http://www.chop.edu/consumer/jsp/division/generic.jsp?id=81168>

The Children’s Hospital of Philadelphia provides a webpage focusing on the fetal diagnosis of hydrocephalus that covers an overview, evaluation, and treatment options.

Madi’s Fund

<http://www.med.uvm.edu/madifund/>

Madi’s Fund is a nonprofit endowment fund for hydrocephalus research located at the University of Vermont College of Medicine in Burlington, Vermont. Katie’s mom helped put her in touch with the organizers of this website. It is a family with whom she has found support through sharing her story and concerns. The site is very informational regarding the facts of hydrocephalus and provides numerous resources to support families.

Military Support for Families:

Exceptional Family Member Program – direct link displayed below

http://www.myarmylifetoo.com/skins/malt/display.aspx?Action=display_page&mode=User&ModuleID=8cde2e88-3052-448c-893d-d0b4b14b31c4&ObjectID=e1217403-aa93-4158-8cf2-bf90de934a56

Ensures that the programs and medical services in the area in which the family is stationed will meet the exceptional family member’s needs.

You can also go to <http://www.myarmylifetoo.com/skins/malt/display.aspx> and click on “Home and Family Life” in the sidebar menu, and then you will find a link on that page.

Primary Coaching Model

Coaching in Early Childhood

<http://www.coachinginearlychildhood.org/>

This website is designed for early intervention therapists and service providers. It focuses on providing resources and information on evidence-based practices regarding supporting families within the contexts of their natural environments.

Katie, Lorenzo, and Tianna: Support Matrix and Tips

| Family Quality of Life Domains | For Parents | For Service Providers |
|--------------------------------|---|---|
| Family Interaction | <ul style="list-style-type: none"> • <i>Attend to family relationships</i> – Recognize that your primary concerns and priorities are for your family as a whole. • <i>Accept help from extended family members</i> – Be willing to accept the help and support of extended family members during times of crisis. Extended family members can be an immense source of support in a number of ways. | <ul style="list-style-type: none"> • <i>Keep in mind the importance of family needs and routines</i> – When identifying how best to support the family, ask them what their needs are and what are the important family routines. Let the family guide what type of services you provide to them. • <i>Put yourself in the perspective of the parent</i> – Try to understand and be empathetic to their concerns and priorities for their family. Do not be judgmental. Let them set the pace for intervention services. |
| Parenting | <ul style="list-style-type: none"> • <i>Get to know your child well</i> – Spend time with your child and get to know his/her needs and means of communication. | |
| Emotional Well-Being | <ul style="list-style-type: none"> • <i>Identify and address emotional needs</i> – Acknowledge your own emotional needs and ask for assistance in meeting those needs whether that be counseling, relationship, or communication support. Ask about sibling support, marital support, and emotional support. • <i>Celebrate and share good news with each other</i> – Share yours and your child’s accomplishments and successes with family, friends, and providers. | <ul style="list-style-type: none"> • <i>Be accessible</i> – Whether by cell phone or by email, make it easy and comfortable for the family to reach you. • <i>Provide support to the entire family’s circle of care</i> – When needed, be available to extended family as they provide informal supports. • <i>Be a friend – not just the expert</i> – Establish a relationship built on trust and mutual respect. Truly listen to the family and identify what is important to them. Share problem solving and decision-making. |
| Physical/Material Well-Being | <ul style="list-style-type: none"> • <i>Discuss not only your child’s needs but your own as well</i> – You can better support your child when you are not stressed about adult issues. Ask about financial support. Ask about life and stress management strategies. | <ul style="list-style-type: none"> • <i>Connect families to community resources</i> – Identifying community resources such as hospital family residence support, counseling, community support groups, social rehabilitative services, etc., can provide an immense source of relief for families experiencing sudden unpredictable needs and expenses. |
| Disability-Related Support | <ul style="list-style-type: none"> • <i>Get to know your doctors and nurses</i> – Be comfortable with them. Establish trust and form a relationship with them. • <i>Do not be afraid to ask for what your family needs</i> – Ask for what you need. You won’t lose services for not being compliant and complacent with the service provider’s recommendations. You are entitled to these services. | <ul style="list-style-type: none"> • <i>Share all the options, ideas, and information</i> – Empower the families you support by providing plenty of information regarding their questions or concerns. Give them the power to make an informed and educated decision based on their family’s preferences and priorities. |

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