

BEACH CENTER STORIES

Logan's Story: It takes a Village

From a doctor's office in Topeka, KS came a phone call from Monica, the young mother of then 18-month-old Logan to the TARC Infant and Toddler program. Logan's pediatric neurologist had concerns about his development and wanted to support the family in the best way he knew how, by referring him to the very capable infant and toddler program in his area. Logan's doctor suspected a possible diagnosis of Joubert Syndrome. Joubert Syndrome is a very rare genetic disorder that can affect muscle control, breathing, and tongue and eye movements. It can only be fully diagnosed by a brain scan that reveals a malformation resembling the shape of a molar.

Beach Center on Disability

Making a Sustainable Difference in Quality of Life



Logan's Story

It Takes a Village

No Diagnosis Needed

After spending months in doctors' offices and undergoing multiple tests and probes, Monica decided to opt out of the additional testing and screening required for an official diagnosis. Instead, she and her family decided to focus on Logan's development and growth. Monica explained, "As we kept going to the doctor and kept being sent here and sent there, I decided I really don't care what it is. I just wanted to make sure that he is getting some help and developing as much as he can." As Monica and her family worked diligently to support Logan and help him grow and develop, they saw he was not making the progress they'd hoped he would. Contacting the TARC Infant and Toddler program was the next step in providing Logan the additional support he needed.

Jo, an occupational therapist with the Infant and Toddler program, met with Logan, Monica, and the rest of their family, and she asked them one simple question, "What would you like for Logan?" At the time, no one knew what a defining moment that would be. When Jo first met Logan and Monica, his view of the world was mostly from his back, unless he was being held. Logan was rolling a little to reach things he desired, he was playing peek-a-boo, he could pick things up and drop them again, use gestures, and say "mama." However, Logan was not able to sit up on his own nor could he feed himself, and those were two skills Monica desperately desired for him.

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What Would You Like for Logan?

Jo asked one simple question, with no simple answers. Everyone had always been very accepting of Logan and his abilities, but when asked that one question, it was as if a new view Logan's life came over Monica and her family. As a matter of fact, Monica had a list of things she wanted to see Logan do. According to Jo, Logan was not only being loved and accepted as Logan, but he was seen as a "child developing with a lot of potential."

That one simple question led Monica to generate several goals for Logan: 1) hold his own bottle and feed himself, 2) become more mobile so he can follow Mom into another room, 3) sit independently without risk of falling, 4) be able to play with the other kids at day care and 5) give Mom a kiss on the cheek. Logan not only met those goals, but he surpassed them.

Logan's Village

Today Logan can do so many things. "I've never seen a baby do some of the things he does," Monica said. In the past four months, Logan has learned to stand while holding on to something, he can sit independently, and he can feed himself. At child care, he is sitting up 75 percent of the day, using an adapted chair with a tray in the front that assists with posture and eating. He now sits at the table with the other children and even helps to hand out the napkins at meal times.

Monica, her family, Logan's child care provider, and Jo have all worked closely to think of ways that they can help to support Logan's development. They are Logan's village. For this village, it is not the diagnosis that matters, it is Logan. With new-found ways to support Logan

and his development, every one in his village seems to be using their gifts to help. The family wanted to help Logan learn a new skill of opening a closing a door that was different from the kitchen cabinets. Because Logan loves doors, his grandfather, Tom, made him a wooden box with a handle that will allow him to practice that skill and to have a special place to put his toys. Jo had two special chairs made (one for home and the other for day care) to help Logan sit up, put pressure on his legs, and manipulate objects on a tray in front of him.

A Gradual Process

In addition to the various skills Logan has learned, a few more challenges still needed to be addressed. Logan had a pair of glasses that did not work for him. He was not tracking very well. Jo was able to bring in another of her colleagues, a vision specialist, who then began working on cognitively focused tracking activities with Logan. When Logan first began using the tracking activities, he was looking out of only one of his eyes. Now he focuses on things head-on and is learning to view his world with both eyes. Although he has had less significant gains in his speech, he is using some sign language and has become quite expressive using non-verbal cues. Monica said, "If I were to learn a second language, it would be sign language. I'd like to see Logan use it more."

This summer Logan has been spending time swimming at a local pool. According to his grandmother, Melissa, "he loves to swim and is learning new movements all of the time." In addition to his physical activities, TARC lent Logan's family a computer so he could practice some of the skills surrounding cause and effect. The computer program they are using is entitled Keywack. Not only is Logan able to practice on his very own computer, but now he is able to imitate his mom as she continues to work on her computer. One of Logan's favorite activities is listening to music. His favorite song is "Sweet Home Alabama." By listening to the song, he learned how to say the word "Bama." In an effort to build on his interest in music, Monica and Jo are trying to create a "Sweet Home Alabama" activity using the Hyperstudio program on Logan's computer.

Logan's Future

Logan continues to grow by leaps and bounds. Both his family and the rest of his village are amazed at how much he has developed since that initial IFSP meeting in January 2006. Everyone is excited to see what new and amazing things he will do in his future. Melissa shared a very important sentiment. "I have been a teacher for 22 years and I don't read the files of my students coming in. I don't see a need for that because it only tells me what other teachers thought the students were capable of doing, so it puts labels and restrictions. All I can say is challenge them the best you can and let them take off. You never know when they might bloom." Logan certainly is blooming.

What Makes This Village Successful?

When asked to describe what makes this partnership successful, characteristics such as determination, optimism, and working towards the same goal were used. Tom, Logan's grandfather, summed it all up by saying, "We don't quit. If there is challenge, we figure out how to work it out." Melissa, Logan's grandmother added, "We really try to focus on the 'cans.'"

Resources Recommended by Monica and Jo

Internet

Joubert Syndrome

Joubert Syndrome Foundation & Related Cerebellar Disorders

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

Sponsored by the Joubert Foundation, this website provides information about this rare genetic disorder and links to additional resources.

Technology

Keywack

<http://www.tucows.com/preview/207587>

Tucows is the publisher of the game designed to stimulate young learners by engaging in interactive play through touches on a keyboard.

Hyperstudio

<http://www.hyperstudio.com/>

Hyperstudio is a multimedia thinking tool for interactive learning. This link provides product information and details about ordering the software.

Monica and Logan: Support Matrix and Tips

FQOL Domains	For Parents	For Service providers
Family Interaction	<ul style="list-style-type: none"> • <i>Surround yourself with a strong support system</i> – It takes a village to raise a child. Share your and your child’s needs, accomplishments, and joys with family, friends, and service providers. Your strength comes in working towards the same goals. 	<ul style="list-style-type: none"> • <i>Encourage family involvement</i> – The family is part of a village. Share ways that everyone can be involved with supporting the child’s growth and development.
Parenting	<ul style="list-style-type: none"> • <i>Be optimistic</i> - When the vision you have for your child is positive and hopeful, he or she is more likely to reach the goals you set for them. • <i>Take ‘can’t’ out of your vocabulary</i> - It is a very limiting term. With an ‘I can’ attitude, you can face any challenge. 	<ul style="list-style-type: none"> • <i>Listen to the family</i> – Early intervention should be based on what a family wants for their child and what their interests are as a family. If you have your own agenda and your own ideas of what you want to do then that really interferes with supporting the family and their goals for their child.
Emotional Well-being	<ul style="list-style-type: none"> • <i>Ask questions</i> – Don’t be afraid to ask questions. If you don’t ask, you’ll never know. • <i>Be flexible</i> - Things don’t always go as planned. That’s ok. Be open to new directions and opportunities. 	<ul style="list-style-type: none"> • <i>Accentuate the positive</i> – Support the family in developing their strengths and building on their successes. • <i>You are part of the village, too</i> – The support you provide to a family ultimately helps the child.
Disability–related Support	<ul style="list-style-type: none"> • <i>Don’t get lost in the process of diagnosis</i> – Remember that what you do to support your child’s growth and development that often more important than a specific diagnosis. • <i>Speech is only one form of communication</i> - Be willing to learn sign language or other forms of communication if your child has a significant communication delay. • <i>Be open about what works and doesn’t work with your service provider</i> - Remember you learn from each other and share the same goal - to help your child develop and learn. 	<ul style="list-style-type: none"> • <i>Be aware of community-based resources</i> - Provide families with as many local resources as possible. When at all possible, facilitate the contacts between the necessary resources and the family.

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