



Complex Child E-Magazine

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The Perfect Child: On the Path to Acceptance

by Angela Sittler

All parents, upon discovering they are expecting, dream of having the perfect child. They want the standard ten fingers and ten toes healthy baby. They want the baby who crawls by six months and walks by one year...who says mama and dada when they walk in the room. The child who is the top of her kindergarten class and beyond. But what happens when the baby they get is not the "norm?" A baby who is not healthy, who has eleven fingers, who doesn't crawl until two years old, who hasn't taken that first step yet, and who doesn't say mama and dada. The child who is in special education, struggling to learn what his peers learned when they were two and three years old. What do these parents do? They either sink or swim. I chose to swim.

February 2, 2004 was an exciting time for me. I was going to have our second son, and couldn't wait to see him. I knew he might have a minor kidney issue, but then so did our first son. It was nothing I couldn't handle. After an extremely easy labor and delivery, Jacob Edward Sittler was born. And the moment I saw him, I could tell something was wrong.

After a few brief moments of holding him, he was whisked away to the Neonatal Intensive Care Unit (NICU). After what seemed like an eternity but in reality was only about 30 minutes, the NICU doctor came back in to explain that I didn't get the perfect child I had anticipated. Jacob had a dislocated hip, club foot, heart murmur, an extra finger, and low muscle tone, as well as hydronephrosis and other small abnormalities that pointed to some unknown genetic syndrome. I was in shock. This couldn't happen! I did everything right.

I went to the NICU to see my newest son, who was laying in an open bassinet hooked up to a heart monitor, oxygen, an IV, and a feeding tube in his nose. During the ten days Jake was in the NICU, a multitude of doctors came to look at him. He was poked and prodded, X-rayed, given ultrasounds and MRIs. He was never given an official diagnosis. I was sent home with multiple follow-up appointments scheduled and told to take care of Jake like any other child. I was sinking and didn't know where to find a life preserver.

The first three months were the worst. In public, I tried to pretend everything was alright, that I had two "normal" children. However, at home things were definitely not normal. Between all the doctor's appointments and the therapies, it was hard to be a "normal"

family. I also had a 2 ½-year-old son to worry about. He had started potty training, but every time Jake would go to the hospital he would take two steps backwards.

During this time I was angry. I turned away from church and God. I was mad at the world. Why would God give us a child like Jake when we did everything right? There were mothers that did drugs, had no prenatal care, and had perfect children. It wasn't fair, and I was angry. I cried myself to sleep many nights, trying to figure out why. What did I do, or not do, during my pregnancy that caused Jake's problems?

I avoided places where other mothers would go. I didn't want to have to see other babies the same age as Jake doing things he was supposed to be doing. I hated to attend family functions since my cousin had a baby two months younger than Jake who was perfect. All the things I enjoyed doing when my first son was little I didn't enjoy anymore. I had nothing in common with mothers of typical children. They would talk about when their children took their first steps or said their first words while I was wondering if my child would ever walk or talk. I basically became a recluse in my own house, feeling like I didn't really belong anywhere.

I turned to the internet and found some wonderful people who have been where I was now. They were there to listen to my rants and let me know I was not alone. They became my life preserver.

Slowly, I learned to become an advocate for my son. I realized that my mother's intuition still worked, even though my son was not the typical child. I learned to trust my intuition and push my point with the doctors and nurses who treated my son. Most wouldn't listen to me and treated me as if I was just an overly concerned mother. What did I know? But each time I argued with them, I ended up being right. This bolstered my confidence in my ability to care for my son, which in turn helped the doctors to learn that I did indeed know what I was talking about. In time, I learned that if I didn't advocate for my son, nobody would. I didn't feel like I was sinking anymore.

It took me seeing my son go through 13 surgeries and many more hospitalizations in the course of his four years to go from being angry at the world to accepting the hand we were dealt. It was a long and hard journey for me. I had to learn to deal with rude comments and stares from strangers and inappropriate comments from well-meaning family members who didn't understand what we were going through.

I don't hide the fact that Jake has special needs anymore. In fact, I embrace the fact that he is different. I have met some wonderful people I wouldn't have met otherwise, one of whom I consider a very dear friend. I also have seen some miracles. I have watched as my son has struggled to learn to sit and crawl, and appreciated it all the more when he did it. I have been witness to small milestones that I would have missed if Jake had been "typical." I still have moments when I cry myself to sleep, when I look at "typical" children and get a little jealous, and ask why. But then I see Jake do something new and smile, knowing he is my little miracle. I finally feel like an Olympic swimmer.

I still don't have a diagnosis for Jake and I don't know what the future holds for him. He is still in diapers, he still uses a wheelchair, and he is still non-verbal. But he is getting stronger everyday, and he is still teaching me new things.

Having a child like Jake has taught me many things. It has taught me to believe in myself, to fight for what I know is right for my son, and to have faith. I was asked the other day if I had the power to change the past and make Jake the perfect child, would I do it? I didn't even need to think about my answer, it was easy. My answer: No, Jake is already the perfect child.

