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to save a son

By *Sherri Zummo*



After her son attacked a police officer, Sherri Zummo huddled with him in the Emergency Department of their local hospital and refused to leave until the state guaranteed her the services she knew he needed.

I was so impressed—I had finally found a program for Robby, my son. The Positive Attitude Concerning Education and Socialization (PACES) program—a very structured, sign language-rich learning environment at the American School for the Deaf (ASD)—was perfect. Robby was deaf, had cognitive and behavioral delays, autism, and a growing tendency to hurt both himself and those around him. At ASD, he would be in classes with kids similar to himself and everyone around him—students, staff, and teachers—would use sign language. Further, he would be monitored one-to-one by staff 24 hours a day. He would be able to participate in sports. He would be able to participate in group activities, and he would be able to communicate with someone besides me.

However, a two-year fight with my school district led nowhere. They said that PACES was too expensive; they weren't going to pay. When I pointed out that they knew they could no longer provide an appropriate education for Robby and that his behaviors were becoming too severe to handle, I was told that in Connecticut where we live, parents can relinquish guardianship to the state; then the cost of my son's care would be split—the state would fund the residential piece and the school district would fund the educational piece. I couldn't believe this. I could never give my child over to anyone else. He is my child.

At the Department of Developmental Services, where I had also asked for help, the

Photos courtesy of Sherri Zummo



information was just as surreal. I was told that the waiting list to fund his education and care was too long to include us. Further, even if we could have an “emergency meeting” and the case was decided in our favor, I would have to accept the placement they chose. ASD would not be an option. The closest approved program was in Florida. The information was devastating. I had not originally considered residential care. In fact, when an ASD teacher first suggested it, I was offended. Like so many parents, all I wanted for my son was the very best and who could best provide this but me? Yet every door was slammed in my face.

The Hopes of Birth

I remember the morning that I drove to the hospital to be induced for my son’s birth. He was my second child. At home waited my four-year-old daughter. Like me, she was excited about the arrival of a beautiful baby boy. Life would be perfect—one girl and one boy, a daughter and a son. I had planned all sorts of amazing things for them. My son would play sports; he would be the high school football captain, the college baseball star, the president of the United States. After a complicated delivery that almost took his life and an eight-day stay in the neonatal intensive care unit, I was finally able to bring him home. We saw that the thumbs on both of his hands weren’t developed, and he had failed a newborn hearing

screening. Still, everyone assured me that this was normal, just fluid in his ears. I thought the worst was over.

Re-tested at six weeks, Robby was confirmed to be profoundly deaf in both ears. I was devastated—he would never be able to hear me say, “I love you.” I cried for 24 hours straight, then I composed myself. I knew I needed to find a way for Robby to function in this world.

I didn’t feel sign language was a good option as he only had four fingers on each of his hands, so I decided to go the oral route. Robby had hearing aids by the time he was eight weeks old, and we began intensive auditory and speech therapy. However, the high-powered hearing aids were useless; he didn’t have enough usable hearing. I then investigated cochlear implants, watching 36 children with cochlear implants during therapy sessions. They did fantastically, and we were urged to get Robby implanted as soon as possible. We went through the evaluation process and learned that my son had a monodini malformation, a malformed cochlea. Still the surgeon felt that he would benefit from the implant, and we proceeded.

Robby was implanted at one year of age. Immediately after surgery, chaos broke loose. Robby had a spinal fluid leak, and we spent seven days in the Intensive Care Unit with a shunt in his spine. Everything healed, and we still expected good results. However, when we went for the device activation,



home, he bit, kicked, and hit others; he would also ram his head into walls, punch himself repeatedly, flip tables, chairs, and other furniture and equipment. Besides hurting himself, he hurt other children; teachers and staff were sent to the hospital and I had internal bleeding, broken bones, and hair ripped out of my head. My health declined. A doctor told me that if I continued to live like this, I would die. The thought of that scared me immensely. If I died, who would take care of Robby? I was his lifeline. How would he live in a world without me? What would happen to him? Who would fight for his services now and as an adult?

I finally agreed to accept some help. The Department of Developmental Services labeled my son “level one,” the highest level of need. Money now went towards people

coming into my home to allow my family some respite. For the first time in years, I could take a shower or cook or spend one-on-one time with my daughter and husband. Unfortunately, the help was extremely limited. We couldn’t find people that could communicate with Robby or deal with his behaviors. My son wouldn’t detach from me. One of the people that had come into my home to help was a teacher at ASD. This was the woman who, after spending time with my son, asked me if I had ever thought about the PACES residential program at ASD.

The Turning Point

My son’s injurious behaviors continued to escalate. When

Robby was 10, he went into a three-hour tantrum, hurting himself and attacking my husband and me. He would calm for a minute, then jump up and attack someone or something. After hours of this and my daughter watching and crying, we called the police for the first time.

When they arrived, Robby attacked one of the officers.

They subdued my son, and watching this ripped my heart apart.

They said they had to take him by ambulance to the hospital for a psychiatric evaluation, so off to the hospital we went.



there was no response. That attempt turned into many more. After years of failed attempts at auditory response, we started to learn sign language. Robby was three years old. By the age of five, he was diagnosed as profoundly deaf, legally blind, on the autistic spectrum, and intellectually delayed; there were other medical and physical issues as well. Worst of all, he was starting to display aggressive and self-injurious behaviors.

The therapies multiplied, too. During the Birth to Three program, he had speech, auditory and physical therapy, occupational therapy, vision therapy, and sensory integration therapy. At three years old, he had started in our local preschool where the staff had basic sign language skills. One success: his brain adjusted to very strong glasses, and he was able to use his vision well.

When Robby was five years old, we had tried to send him to ASD for half days. ASD was an hour and a half away, and due to the autism and the long rides he became over-stimulated. So back to our local public school he came. He entered our local elementary school and his autism was addressed intensively.

The next years were filled with struggles. My son’s needs increased, his aggressive behaviors became worse, the fight for services became harder—and the educational gap between Robby and his peers became wider. Still, by third grade his communication reception had grown tremendously and he had a full-time teacher of the deaf. His other needs were addressed as well. Unfortunately, the kids in his class became less interested in playing with him as they got older. Robby could only communicate with one person in school and with us at home.

Meanwhile the injurious behaviors increased. In school and at

Once we arrived, I was told we could not leave before Robby was evaluated. Our local hospital was not equipped to evaluate children, so they called every hospital in the tri-state area. One after another, the hospitals in three states told us that they were either full or weren't equipped to deal with a child so complex. There was nothing to be done. We were told to take Robby home.

I hunkered down in thought, and I knew this was my moment. I reached down and found the strength to do what I needed to do for my son. I would do it no matter what it took.

I refused to leave. We would not go home, I said, until we got the services that my son needed.

That refusal sparked a 10-day stay in the emergency department of our local hospital. I called my senators. I called the Office of the State's Attorney. I called the news stations, and I called the newspapers. The response was overwhelming. We were on the news and in the newspapers, and the senators and representatives offered their support and made phone calls. The hospital stood behind us in our fight.

At the same time, the state agencies threatened me with arrest. They said that once I was arrested, Robby would be placed in foster care—and they reminded me that they didn't have appropriate foster care but that's where he would end up anyway. I was terrified, but I knew I had to hold strong for the life and future of my son. Finally, after 10 days during which my son and I didn't see the light of day, I signed a contract. I would maintain guardianship with full parental rights over my son, who was approved for funding in the PACES program at ASD.

A Decision Affirmed

Six weeks later, when the school van came and drove away with my son, I felt as though my heart had been ripped from my chest, as though someone had taken my soul. However, after waiting a week for him to adjust, I visited Robby for the first time—and my fears were dispelled. My son put his arm around another little boy as soon as I arrived and signed, "Mom, this is Robby's friend." That's when I knew with 100 percent certainty that I had made the right choice.

It has been four years since Robby joined ASD. He transitions between home and school beautifully. He is receiving an appropriate education and is making great strides. He has the ability to function in a world without mom. He plays sports. He has friends, and he is in a communication-rich environment 100 percent of his life. He is happy. My health has improved. I have more time to be a parent to my daughter, who left for college a few months ago and is enrolled in an accelerated five-year master's program in special education.

Every child is different and has unique needs. As parents, we know what is best for our kids. Don't ever let anyone tell you differently, and, most importantly, don't ever give up the fight. Together we can move mountains. We are our children's voice in the wider world—and they need to be heard.



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