

A Voice for Joshua by Vance Goforth

While this is extremely hard for me and my family to talk about, we realize that when we share Joshua's story, it's a way to help other families facing similar challenges by raising awareness of deficiencies in the current behavioral health care system.

Our amazing nephew Joshua was born December, 24, 2000, a healthy and beautiful baby boy. Twenty-nine days later we received the crushing and life-changing news that he had been the victim of child abuse and was in a fight for his



life. He coded while in ICU several times the first couple of days after the incident and the medical staff was able to revive him. Over the next few weeks with the swelling of the brain and hemorrhages behind his eyes, the outlook was not good. In fact, we were told more than once that the odds were that he would not pull through. Joshua did beat the odds and made it, but the Doctors were still telling us that he would most likely never walk, talk, see or hear.



After staying in the hospital for a little more than a month, he was released into foster care and we began to visit him. After Kristy discussed everything with me and I assured her that she had my full support, she decided to try for custody of Josh and start the adoption process. Kristy received custody of Joshua when he was three months old and soon realized that this was going to be a long and hard journey that would take the help and grace of God and the help of so many others.

The first six months Joshua had 30 to 50 seizures a day before they subsided when he was 9 months old. We enrolled him at Signal Center for his rehabilitation. and they did not focus on his condition or the odds of what he was facing, they just looked at what they could do to help him recover as much as possible. Today, through the grace and healing of God and the efforts of Signal Center, Josh is able to walk, see and hear. He continued to make progress over the next few years, but his neurologist warned us that he could possibly develop severe behavioral disorders as he grew older. We hoped that this would never happen but unfortunately it did, and severe aggression and self-injurious behaviors surfaced.

Joshua is now almost 21 years old. He has severe nonverbal autism, along with comorbid conditions like seizure disorder, cerebral palsy, bipolar and disruptive mood dysregulation disorder. The behaviors started in childhood. By 8 years old, issues at school got progressively worse and he was put on home bound after they became so severe the school system couldn't keep him safe anymore. We sought help through doctors and medications at first and then psychiatrists who recommended inpatient treatment ASAP. He was even accepted into a treatment facility only to be called the day before admission to be told that they couldn't treat Josh because we owned a wheelchair and their facility wasn't ADA compliant.

Everything started escalating during a trip to town a few years ago, Josh got upset and kicked out our van window and tried to crawl out at 55 miles per hour. I had to pull him back into our van and tried to keep him calm until we could get home. We decided to call a crisis number and see what they recommended. To our shock, they didn't know what to do, so they called the Department of Children's Services. DCS told us since this wasn't an abuse case, if we didn't see them in 48 hours then they weren't coming. So, there we were, making calls to agencies that couldn't help us, while facing crisis level behaviors on our own.

Josh's behaviors kept escalating and he was targeting our youngest daughter to the point that she was hiding daily from his outbursts. The nightmares really started as we began to call for help again. As we called crisis during these behaviors, we heard statements like, "We're not prepared for a child as low functioning as your son," or "If your son was suicidal then we could help." Yet again, crisis responders would leave and we were left to deal with these severe outbursts on our own.



We were advised many times to take Josh and "drop him off" at an ER department and let the state take custody. We were even told to get a divorce, because "it's easier to get help if the parents are separated." Needless to say, we didn't want to call crisis after some of these interactions. Finally, after much begging, the Tennessee Department of Intellectual and Developmental Disabilities came to our home and told us they would find us help. DIDD couldn't offer us anything until

Josh turned 22, so they called and set up an appointment with Children's Services. We were nervous about this because of the reaction we had before but we agreed to go to a meeting.

During this interview, we were asked why Josh was no longer welcome in our home. I explained that wasn't the case, we just needed help desperately. They requested documents from us and I provided them, but we never heard back. Joshua's behaviors had become daily at this point. After two weeks, I called DIDD and asked why they told DCS that Josh was no longer welcome in our home. They said, "You don't understand, if we didn't report it that way, they will never help your family." I was absolutely blown away after this. Not only did we not get help, they never followed up on the situation and he was getting worse by the day.

DIDD finally made a referral for Joshua to get into a new state program called ECF Choices in July 2016. He was accepted into this program and we were told he would get respite care, in-home services and other therapies and resources as needed. We thought yes! We're finally getting help! But days turned into weeks and weeks into months. My wife was sending emails to our coordinator begging for help but the reoccurring theme was "no providers available."

From 2016 to May 2017, the behaviors increased exponentially and had become very dangerous with severe aggression and self-injurious behaviors. In May of 2017, we still had not received the promised services and I was out of town for a conference when I received a call that Josh had a severe outburst and my wife had no choice but to call crisis again. This time crisis said that Josh needed help but couldn't find any facilities that had open beds. The crisis worker was extremely helpful but every path he tried was a dead end. Finally, he called DCS again This did not go well for the situation. They came out while crisis was still at our home, and began interviewing our other children on our back deck as they watched through the window as Kristy was hit, slapped and kicked just trying to keep Josh from hurting himself. The crisis worker ended up apologizing for calling them because he said "I've never had an experience like this before," and he couldn't understand why the situation was being handled the way it was. After all of this, my wife and family were left alone with no help after he got his meds and took a nap.

The next day our coordinator said to meet her at a Knoxville hospital and they would get Josh treatment. My wife and father had to self-transport Josh even though we had voiced concerns about severe outbursts he had while we were driving. When they arrived, we were yet again turned away and told that the hospital couldn't provide treatment. Even though they would not treat Josh, they didn't want Kristy to leave with him over safety concerns. They also advised taking him to an ER and relinquishing custody in order to get help.

Finally, they got Josh home and he was accepted to a hospital in Georgia the next day. Again, my family had to transport him because an ambulance service refused to take him due to his aggressive behaviors. We explained to the hospital administration that Josh has always been very quiet around people he doesn't know, and that he will eventually get used to his surroundings and then the behaviors will manifest again. He spent 12 days at this hospital and was sent home because "they witnessed no behaviors." Four days later he was tearing our house apart and hurting himself severely. I made the call to get him back into the hospital but was informed, "it doesn't work that way." I was told he had to go through the whole process of being turned down by every treatment facility in Tennessee once again. This would take months and Joshua was getting dangerously aggressive.



At this time, we were provided with ABA therapy. It didn't take long for the therapist to see that Josh needed residential treatment and that was what they recommended. Our therapist eventually resigned and we didn't get ABA after that. We finally received one-third of the in-home services that he was supposed to get in September 2017 and the behaviors kept increasing over the next few months. He had got so severe that he had broken several teeth and had done over \$17,000 worth of damage to our home and vehicles.

My wife and I had become increasingly isolated from everyone around us during this time and we struggled to keep anyone from seeing how severe our son's behaviors had become. We basically had confined ourselves in our home, taking turns trying to minimize the behaviors as much as we could all while being told that help is on the way.

I cannot even start to describe what life was like during December 2017 through February 12, 2018. The behaviors had reached a level that can only be described as the worst hellish nightmare you could ever have. To watch your child that you love so much inflict so much harm upon himself is too much to bear. The strain this brings is indescribable and even that isn't an accurate description. The stress was building day by day.

On February 2, 2018, the nightmares went into overdrive. We were coping the best we could and trying to keep life as semi-normal as we could for our other four children. On that day, Kristy had stayed with Josh while I took our youngest son Camden to workouts. I was on my way home when I received the phone call. At first the call was totally indistinguishable from all the screaming that was taking place. My heart sank as I tried desperately to find out what was happening, then I figured out it was one of my daughters that had called and finally I heard "It's Josh" through the screams.

It felt like a shock of electricity went through me before I went completely numb. I had no idea what was going on, but I was trying desperately to just get home. I was crying and praying as I drove as fast as I could. Camden was crying hysterically and begging God to help his brother. I actually arrived before the first responders, and as I ran in the house Josh had just stopped having the most severe seizure we had ever witnessed. Kristy had called 911 when the seizure kept going to the point that Josh quit breathing and turned blue. He gasped for air and started breathing again just seconds before I arrived home.

Whatever happened during this seizure changed Josh and the behaviors became even more amplified than before. Over the next ten days, I can't even say we were handling the outbursts because that would be a lie. The behaviors reached a fever pitch that ended with extensive injuries to myself and Josh.

Josh had bitten his wrist until it was almost down to bone and began breaking all of his teeth off by hitting his head on the floor and walls. I was bitten over 50 times during three different outbursts and received lacerations, bruises and a severe black eye that may have caused permanent damage. Josh had extensive injuries from the self-inflicted behaviors and was not calming down at all. We visited two different ER departments during these outbursts and mobile crisis was contacted twice. Mobile crisis never did the face-to-face evaluation that is required by state guidelines.

We took Josh back to his doctor the next morning after being in ER rooms all night. His doctor forced the issue and made crisis respond. Josh was eventually transferred after a three-day stay in another ER room but we had to get lawyers and judges involved just to get the treatment he needed. After a few weeks and multiple legal issues, he was transferred from Georgia, where they had said before he wasn't having issues, to Springbrook, an acute treatment facility in South Carolina that specializes in Autism and related disorders. They are trained for comorbid behavioral disorders such as Josh has, and they quickly recognized the severity of the behaviors. He was in treatment there for 15 months.



When Josh finally received the needed treatment, he started slowly making progress. Springbrook was amazing. They not only treated our son but also encouraged and gave advice to the whole family. After 15 months of treatment, Josh was transferred to residential care at Orange Grove.

Orange Grove is a complete campus for individuals with intellectual/developmental disabilities. It's an ICF and HCBS provider that provides school, medical services, dental services and residential services. The fact Orange Grove is an established ICF has been the key contributing factor to Josh's success there. They are staffed and prepared for behavioral issues; even though he is in a group home setting, the knowledge and resources are still there. Josh has been at Orange Grove since 2018. He will continue in the school program until he turns 22, then stay on in the residential program.

We were in pure survival mode for so long, we didn't realize how much all of this had affected our other children and family members. Joshua's siblings love him dearly and were quietly trying to deal with the situation as they watched things that no child should have to ever witness. After Josh was in treatment a few weeks, they began to open up to us about everything and it hit us like a ton of bricks. We were so consumed by managing the behaviors and keeping everyone safe, that we didn't realize how much the stress was affecting all of us. Slowly but surely, the kids began to heal from all of the trauma, and we started seeing improvement in school and other activities.

When Josh finally received the treatment he needed, we created a Facebook page, A Voice for Joshua (<https://www.facebook.com/changeforjosh>). I was determined that I would advocate for issues affecting individuals like Josh who have severe ASD and comorbid conditions. I'm not the most eloquent speaker and my posts are usually more solutions-oriented than other bloggers who can effectively pull on heartstrings, but I'm determined to keep advocating and sharing his story until needed changes take place.