

Justen, My Amazing Son
By Vana Stearns

As many parents, when my son Justen was born my husband and I couldn't wait for all those special moments when your children say mama and dada for the first time, come running to you with warm hugs and kisses, are so excited to go to the park to play or to have their faces light up seeing fireworks on the Fourth of July. For our son it took more than two years to get just some of those special moments, some of them we still have not experienced and may never. This is my son Justen's story.

When my daughter Ava was almost 2 our son Justen was born, he was such a blessing we couldn't believe how lucky we were to have a little girl and now a little boy, how our family was now complete. I always felt though like something was different or "wrong" when I was pregnant with Justen, I couldn't explain it, it was just a weird sense that something wasn't going to be "typical" about Justen, but my husband Steve would always say everything is fine, there is nothing to worry about and when he was born everything "seemed" perfect. As time went on I noticed some unusual things here and there he would never sleep, my husband and I were never really able to hold or cuddle with Justen, and he seemed sensitive to many different things such as sounds or the clothing he was wearing, but I would shrug most of them off or make excuses for Justen's behavior. Finally when Justen was about 18 months old (and the shrug offs and excuses had turned into real concerns) he went in for his check up and I didn't have just a list of a few things I was concerned about I had a book full of things that I was so unsure of with Justen. My husband took him in for that 18-month checkup (I think I was too scared to hear what they had to say and knew my husband would be stronger than I would). When my husband took him in as he started to tell the doctor all of the unusual things that were going on the doctor had handed my husband a piece of paper that had yes or no questions to fill out and on my husband's way home he called me and said, "they think Justen maybe autistic".

Tears, tears and more tears were really all I had. I knew it, it was that "feeling" I must have had when I was pregnant with him. There had been so many signs with Justen, but some of the signs he had, had nothing to do with autism, which confused me even more. Just some of the signs I had with Justen were how Justen rarely played with toys or the toys had to have specific textures to them for him to play with them, he did not talk (not one word), had no reaction to pain (like when he fell and hit our glass table he never even cried), would cover his ears, didn't answer to his name, didn't sleep well, had become a pickier eater, had trouble finding ways to self calm himself, would not allow anyone to touch or talk to him (including my husband and I), temper tantrums that never seemed to end and one of the things that bothered me over all was that he had no reaction to anything, like he was in a complete fog all the time.

When my husband got home I got all the paper work from him that was given to us on where to call, who to talk to and what they thought was going on with Justen. I immediately started to make phone calls and got in touch with Early Intervention. About a month or so later about 5 or so people came to my house to do an evaluation of Justen,

and there it was Justen was diagnosed with severe speech delay and Sensory Processing Disorder. At the time I really didn't understand what everything really meant or how everything was going to change for Justen, just kept my fingers crossed that his therapists would do everything that they could do for him and to also help me understand Justen's challenges. Justen started out having occupational therapy and speech therapy once a week. His poor occupational therapist, all Justen did was scream in her face for about the first 2 months, but when Justen finally came around and at least let her talk to him I could already see progress in him, little progress but it was something. I learned all that I could about SPD and was shocked to find out how many children and adults are affected. About 3 or 4 months into occupational therapy Justen was put on a sensory diet with his brush, that I brushed him 3 times a day with that started with me just brushing his hands, to me now brushing his hands, feet, arms, legs and back. I would have paid anything for that brush, that brush started to get Justen out of his fog, getting his senses to where they should be, I felt like it gave me my son back. About 4 or 5 months into Speech therapy Justen started to sign and say a few words, like more and ball. It was so amazing to hear his little voice really for the first time. I remember one night my husband was screaming my name to come upstairs and in the bathtub there was Justen picking up foam alphabet letters in the tub and saying them out loud I couldn't believe it. How was he doing this? Where did he learn this? Maybe he knew them all along but didn't know how to vocalize them. I was so proud of him, but one of my happiest moments was the first time he looked right at me and called me mommy, I had waited over two years to hear that, I had tears in my eyes looking at him and saying, "yes I am your mommy".

After about 7 months we started to see that Justen was at a stand still. Both therapists had tried some different techniques with him and it was like something was in the way, like we had another wall to climb over. My husband and I decided we wanted to get a medical diagnosis on Justen and so we started the process. On February 3 my father and I (my husband Steve needed to stay at home with our daughter) took Justen into his medical diagnosis. I thought that they may have told me he had ADHD or extreme OCD challenges, instead it went to me sitting in a room by myself being told, "yes your son is autistic". I cried, I don't think I heard anything else that medical pediatrician had told me after that. As I walked out of the doctor's office I thought I'm not going to cry when I tell my dad (he had been sitting in my car with Justen, that day had been like sensory overload for him) and as soon as I got up to my car and my dad stepped out I shouted to him, "Justen is autistic". I kept saying how mad/ angry I was and just kept crying. It never mattered to me that Justen had SPD or was autistic; I just didn't want my son to have any more challenges than he already had. I felt guilty, that this was somehow my entire fault all of Justen's challenges were because of me that I had done something to cause all of his challenges. That my strange feeling that something was "wrong" when I was pregnant was completely right, but I knew that I had to get over my anger, my guilt, this was the piece of the puzzle that we were missing for Justen, the piece to get him on the right track again and that no matter what I had an amazing son.

I remember waking up that next morning thinking this is a good thing, autism and SPD are just words it will never define who Justen is and who he will be. Really nothing was going to change for the worse only the better and that's exactly what happened. Justen

got a new kind of therapy, developmental therapy with a great therapist for once a week. He was working so much better with his speech therapist after she changed how she was doing therapy with him a bit and now speaks about 30+ words now some with and without signs (sign language). His occupational therapist started also changing how she was working with him and also started seeing him twice a week instead. His self-abuse has gotten so much better, his tantrums, he is now so alert and focused no longer in a foggy cloud. He loves to give hugs and kisses, we used to dread taking him anywhere, where now it's not so bad there are good and bad outings, not just bad like before. He now knows how to play with most toys (and has gotten better with what textures the toys have) and although he does stim (self-stimulatory behavior) at times with his toys its ok and we just try to redirect him. We are also working on a food therapy at home with help of our occupational therapist, and we are seeing some progress (even as little as it is).

I have always tried to make sure I understand Justen's disabilities as much as I can. I feel it is very important to be as educated as much as possible so that I can continue to educate others and especially my daughter. My beautiful amazing daughter Ava is a god sent; she works so well with Justen and helps me beyond belief, I couldn't ask for a better daughter. She is always there to tell Justen "it's ok" and "don't worry buddy", I feel sometimes that Ava and Justen have a secret language that I will never understand. She is able to help him in so many ways, which is so amazing to watch. Justen will be starting Special Education school in October and I'm excited to see how much more he is going to flourish, but it pulls at my heart knowing how much of a change this will be for Justen and how it may be very overwhelming for him for awhile. It is going to be a huge transition for Justen, but one that will be well worth it.

I also have a great support system that was very hard to find at first being that I never knew anyone else that had a child with SPD or autism. My husband and I have a great support system now with many family and friends that understand what we are going through and try to help us as much as possible, and although I appreciate our family and friends beyond words it wasn't until I joined my SPD support group (SPD Parent Zone) that I really felt I was understood and could talk about my fears and joys of having a special needs child. People that truly, truly understand what I am going through, what my family is going through day in and day out, and for all of them I am so grateful.

Although Justen has made so much progress I know that there will be bad days that I may want to pull my hair out, days where Justen may regress, but that's ok I know I have the tools to recognize what is going on and how to help him with what may come our way. I never expected my life to be like this, never would have thought I would have been able to handle all of this, but I look at Justen and think of how much he has taught me, taught everyone. My son is an inspiration to me, in a little over a year he went from a little boy that was in such a black fog to a little boy that is now flourishing before my eyes and I'm so thankful for all that I have. As I have always said I would never change my son for the world, but I would change the world for my son.