

Kelly's Story

I am a mom of three children (ages 5 years, 4 years, and 2 years). My middle son was diagnosed with Sensory Processing Disorder (SPD) at 28 months. That diagnosis has been the best thing that has ever happened to our whole family. Before that he wasn't sleeping, eating, and talking. He continuously was having major meltdowns which at the time seemed like the most unreasonable things. We were constantly battling with him and our life was so crazy. After that diagnosis I have been on the mission to learn as much about the SPD as possible. My goal is to understand my son and make his life and ours better. It has been a year and a half now and our lives are extraordinarily different. Thanks to all the hard work with his therapists, teachers, our 2 other children, and my husband and I, he is a totally different child. Here is my story from the beginning:

Riley was born two weeks early and thank God because he was already 9 pounds 10 ounces. He was our first son and second child. Our first child, Addison, was 14 months at the time. Riley was healthy and we brought him home from the hospital two days later. We were so excited he was so healthy. Addison was born 2 months premature due to my severe preeclampsia. She had to stay at the hospital for 2 weeks until she gained a few pounds. Thankfully that was her only obstacle. Right off the bat, Riley was great and things seemed to be really easy because all he did was sleep, eat, and poop. Then when he turned two weeks old everything changed. He wouldn't stop crying and he wouldn't sleep. It was awful. I was going crazy because I had Addison to take care of, and she was running around and seeking attention but I was never able to put Riley down. All he would do was cry. Our pediatrician said that he had colic and there wasn't anything we could do for it. "You just have to wait it out" he said. Wait it out...every second felt like an eternity with a baby that doesn't do anything but cry. We tried the swing, it didn't work. He hated to be pushed in a stroller. The only thing that would calm him down was my husband or I walking around holding him or bouncing him while holding him on an exercise ball. We were so burned out that many nights in the middle of the night we had to drive 45 minutes to my parent's house. They would walk around with him so we could get a little sleep. We continued with this constant struggle until he turned 4 months. That is when he started to crawl. He really started to blossom and started to become a happy baby. My dad even gave him the nickname Smiley Riley.

At 7 months he took his first steps and by 8 months he was running. That is all such early development, that I couldn't help but to be so proud and amazed. One night I was in the kitchen cooking and I heard Addison and Riley laughing hysterically in the other room. I came out of the kitchen and I found Addison running and 8 month old Riley chasing after her. They ran back and forth from the living room to the dining room for 20 minutes chasing each other laughing. Finally, I thought, this is what parenthood is all about. My children are happy and having the best time playing with each other. It was a wonderful moment and I felt truly happy. We were always so amazed at how solid and strong he was at such an early age. Instead of using his arms and legs to climb, he would just use them to steady himself and lift his entire body with his ab muscles. He developed a noticeable six pack before he turned one. Everyone used to call him Brain Urlacher or the beast. He was always rough housing. He would jump off of really high heights, he would always climb up everything, he would spin for hours without getting dizzy, he would crash into everything, and there were never any tears. From the moment he woke up to the moment he feel asleep he was constantly moving.

I am a stay at home mom and had enrolled Addison and Riley in all the baby classes; music classes, art classes, gymnastics, baby dance classes. Every day we were going to a different baby class. The classes were for children Addison's age, but Riley was allowed to come along because he was physically capable of doing all the activities. Addison would follow along with the classes, while I chased Riley around.

When Riley was 14 months we were in one of the baby dance classes. Addison was dancing with all the other children and Riley was running around and hopping everywhere. One lady was watching him as he was hopping and said to me "I think he is counting", and he was. He would hop all the time and count his hops. He was able to count to 10 and knew the entire alphabet by the time he was 14 months. I was so proud of these early accomplishments.

Things changed quite dramatically at about the 19 month mark. His tendencies to do his own thing in the baby classes caught up to all of us very quick. He got kicked out of gymnastics because he would not follow directions. He couldn't sit in a circle and warm up with the other kids. The directions and structure that all the other kids, including Addison, were so easily able to follow just wasn't possible for Riley. He just wanted to do what he wanted to do. If I tried to get him to stay in line and do what all the other kids were doing he would have a major meltdown. We had to stop going to all the classes for the same exact reasons. He started to have major meltdowns at even the simplest daily activities. He started to have a real problem when we could cut his nails, wash his hair, brush his teeth, clean his face and wash his hands. All of those things would make his scream so bad it was like we were torturing him. He was fully potty trained at this time because he hated the feeling of a wet or dirty diaper. He became very scared of noises. He would run away, hide and scream at the most mundane noises. He started to always wear a beanie (tight winter hat) to make the noises more manageable. Up until this point he was an amazing eater. Then all of a sudden he hated to eat food and would only eat a select amount of food and it always had to be the same brand. If it wasn't a food he liked he would scream and run away. It really made holidays and family gatherings very difficult, especially since we really didn't have a good explanation. He also still wasn't sleeping through the night, and our method to get him to go to sleep was to take him for a car ride. I had about a 40 minute route I would always drive. If we didn't drive him in the car it was a long hard struggle to get him to bed. Most nights staying up until 12am until he finally passed out. You would think that since he wasn't sleeping he would be tired all the time during the day. But that wasn't the case, he wouldn't stop moving. I, on the other hand, was exhausted to my core.

I was starting to question if there was something going on with Riley. I kept thinking, what is wrong with my child? Why can't he just calm down and be normal? Am I just a bad parent? Why is he freaking out about all these silly things? Everything seemed to be such a struggle now. Before, he was this very active little boy who was always happy and willing to do anything. I was always so proud of my tough little football player. All of a sudden he was becoming introverted. Everything freaked him out. I was 5 months pregnant with my third child. I had two children to take care of and one of them was freaking out about everything. I had no idea what to do. My doctor kept telling me how amazing he was, and was even telling me I should sign him up for the Chicago Bears football team. Everyone else kept telling me that he is the second child and a boy...they develop later than girls. I didn't have any friends that had kids and my brothers or sister didn't have kids, so I didn't have anything to base it off of. I was a young mother, and I had the word of my doctor, so I trusted that. My mom, sister, and husband started to say they think something is wrong with Riley too. The word "autistic" was brought up a couple times by them. I thought autism was like the movie Rain Man. But I said that the doctor said nothing was wrong. So I trusted that.

At his second birthday party we were all sitting at the table eating birthday cake and my brother said Riley doesn't talk. I got extremely defensive, and started yelling "He talks...he talks a lot! He just doesn't talk when he is eating!" The truth was he wasn't really talking. I thought he was talking because he would use a lot phrases that my husband and I would use. He would always repeat stuff he heard. We couldn't believe his love for letters. He knew all his letters and loved to sing songs. If he saw a movie, he would be able to recite the words and actions of the movie after watching it once. He loved to watch the

same movies and TV show over and over again. His memory was so amazing. It came as a huge shock later when I learned that his love for these things comes from their “constant”. They never change, and always stay the same, and Riley could count on that to be true, which is why he was so into them.

That fall he started school. The very first day at school he bit a teacher because she took away his ball because play time was over and they were going back to their classroom. The Director of the school (who also happened to be my neighbor) told me he has some sensory issues and he wasn’t talking like all the other children his age. She was the first person to tell me she thinks he should start “Early Intervention”. What was “Early Intervention”? What are sensory issues? I had never heard of them. At the same time I was so excited that there could be an explanation to all this chaos.

I called the Early Intervention office that day to make an appointment, but had to wait a month to get the evaluation. The evaluation consisted of 4 therapists(Speech therapist, Occupational Therapist, Social Worker, and Developmental Therapist) coming to my house asking me a million questions about him and each of them took turns playing with different toys with him. I was so amazed that they could figure out what was wrong with him just by the way he interacted with them and how he played with the toys. At the end of the evaluation they said that he needed Speech Therapy twice a month, Occupational Therapy once a week, Developmental Therapy once a week, and Behavior Therapy twice a month. I couldn’t believe all the services that they said he needed to get. It was eye opening for me. I thought he was this amazing, intelligent boy, who was going to become the best NFL player ever. My dreams of screaming for him on the side lines as he scored the winning touchdown were instantly shattered after this evaluation. All these things I loved about him, and thought were so amazing turned out to be all the signs of Sensory Processing Disorder.

One week later he got kicked out of school. I felt hopeless. Riley was getting kicked out of everything. He is very tall for his age and he towered over the other kids. He would get really excited and would run up to the other kids and squeeze them. He would also run really fast and crash into them. The teachers told me that the other kids were becoming scared of him. It broke my heart because I know Riley, and he is so loving. He is the sweetest kid. He doesn’t have an ill bone in his body. I learned later that because he couldn’t feel pain, he didn’t realize how much pressure he was giving when he squeezed someone. He wasn’t trying to hurt anyone. He just got excited and wanted to play with them. He was biting the teacher because he was upset that she was taking away his toys and he didn’t have the language to tell them that he wanted to keep playing with the toy and not go back to the class. When he got kicked out of school, it turned out to be a blessing in disguise. My daughter was attending the same school, and we decided to pull her out at the same time. I started her at a Montessori School in November and she was in school from 8am-3pm everyday instead of 9am-11:30am 3 times a week. This gave me the time for all of Riley’s therapies as well as taking care of my new baby Carter, while Addison was at her new school. It was getting so difficult to juggle Riley, Addison, and Carter. They all demanded so much, especially Riley and I was glad that Addison was in a place that she would be learning and getting lots of attention. Now I could focus on getting Riley the help he needed as well as Carter.

Due to insurance paperwork and lack of therapists we had to wait another month to start therapy. Then the end of the year holidays came and we had to wait longer. I was so frustrated. I just wanted to start these therapies and get my son better. I had started to become very good friends with another mother who had two boys. She had told me about this program that supposedly taught young children how to read by watching videos. It was called “Your Baby Can Read”. I thought this would be perfect for Riley because of his amazing memory and his love for watching the same videos over and over again. I could start this program while we were waiting to start therapy. We started the program and all of a sudden

he started to spontaneously talk. One day we were getting ready to pick up Addison from school. Riley looked over at Carter sitting in his car seat and pointed at him and said "Car Seat". I started to scream. I was so excited!! That was one of the words in the videos. This program was teaching him how to talk. He had memorized about 20 of the words in the first week and started to talk. The video taught body parts, animals, colors, mostly all of your children first words. I couldn't believe it!! I was so excited. He flew through the whole series in 2 months. It was typically supposed to take children 2 months to start to recognize a word or two. He had learned how to read and speak all 200+ words in two months. To this day, I still use reading to teach him new words.

In January we finally started therapy. Once a week we had a development therapist, speech therapist, an occupational therapist and a behavioral therapist come to our house to "play" with him. It was a lot of work, but we started to see some major changes in his behavior. He started to eat better, to speak more, he began to feel pain, he began to sleep better at night, and started to play with his sister and brother. The therapist had given me knowledge to help my son come out of his own world and into our world. I checked out every book I could from the library about SPD and bought as many sensory products as possible. We built our basement into a sensory room with a trampoline, slides, swing, ball pit, and many other sensory toys. We totally changed our lives and how we did things to help my son.

About a month into therapy my husband brought up Autism again. Earlier that day Riley had made this amazing creation out of Lego's. I was so proud and saved it to show to my husband when he came home from work. He said that was a characteristic of autism. He said, "come here" and brought me over to the computer to show me an internet site that had a bunch of signs for Autism. I almost crapped my pants. I couldn't believe it. He had 98% of all the symptoms. I remembered seeing Jenny McCarthy on Oprah a month or two earlier and she was talking about her new book and how she cured her son of autism. I went to the library right after I read that article on the internet to get her book. I told my husband I was going to read the book and find out that Riley wasn't anything like her son. But the exact opposite happened. I stayed up that night and read her whole book. After the first couple chapters of her book I put the book down and started crying hysterically. Her son sounded exactly like Riley, minus the seizures. I couldn't believe it. I really thought that my son had autism now. My husband, sister, and mother were right. Her book was really inspiring and I thought that I too could "cure" my son. I was going to do whatever it took to make that happen. That book started my mission to "cure" my son.

I took Riley to our pediatrician the next day to see what he thought. He said "Riley, autistic....NO WAY!" But I asked him to just take a second and REALLY look at him. I called Riley's name and he didn't respond. I called him a couple more times and he didn't respond. He was off in the corner lining up his Lego's by color. The doctor immediately became concerned and gave me the number for Children's Hospital in Wisconsin's Child Development Center.

After a couple of attempted tries at Children's we finally finished our evaluations in April. I had to cancel a few appointments because I had to be rushed to the hospital. I thought I was having a heart attack, because I was so nervous about finding out what the doctors were going to tell me about my son. I think those missed appointments were a blessing because it gave Riley a few more months of therapy and he dropped more of the autistic characteristics. We had to have 3 different evaluations at Children's. A 2 hour Speech and Language Evaluation, a 2 hour medical doctor's evaluation, and a 2 hour evaluation with a psychiatrist. Then the three specialists came together to evaluate all there finding and concluded that Riley is not autistic. Yeah! He has major ADHD, anxiety, a little OCD, and a speech delay. But they told me not to try any of the diets, don't do any of the supplements, don't do the therapies, they don't

work. They gave us medicine for his ADHD and sent us on our way. But the therapies were working and I continued to do them.

After I started going through all this with Riley, my friend Dawn (the same friend who told me about Your Baby Can Read) found out that her son has speech delay and sensory issues too. Finally I had someone that I could talk to about all the struggles I was going through other than a therapist or teacher. She has become my very best friend. We have recently started an SPD Parent Support Group in our area because of how much our friendship has helped us. My husband has been there 110% of the way learning everything he can about SPD and working so hard with Riley. It is one thing to have your husband to talk with about it, but it's different to have a friend. She has been so helpful and is always there to celebrate a great success, or be supportive through a failure. It's so great to have a friend that totally understands what you are going through. Now through our Parent group I have a bunch of friends that understand what I am going through too.

It's hard for people that don't have children with SPD to understand what is going on, even family members don't get it. My son looks normal, but he doesn't act normal. So people think it's a behavioral issues and the result of bad parenting. I am anything but a bad parent. I love my children more than anything. I will move mountains to try and make them the best they can be.

As my son Carter got older I also noticed that he had some sensory issues too. Through all the things I had gone through with Riley, I was able to notice what was going on with Carter and I knew how to get help. I got help early, because I know how important it is to catch SPD early. The earlier, the better.

My daughter Addison just turned 5. We had her 5 year check up with our pediatrician this week. When we went to her doctor's appointment Riley and Carter came with me. Riley, Carter and Addison all stood by the fish tank and were talking about how cool the fish are. Riley and Addison were interactively talking about how they were going to be scuba divers when they grow up and all the cool fish they are going to see in the ocean. They were not running around, they were all standing there talking to each other. When we were called back into the room, we all got up and walked back to the room with the nurse. They all sat in the room coloring and we were all talking to each other. When the doctor came in he was shocked. He said he couldn't believe Riley. He said, "Who is this boy? This is not the same boy. He isn't running around and trying to get out of the room. He is sitting still and coloring and talking. Whatever you are doing with him keep it up." I started to cry. I was so happy to hear that.

Riley is now about to finish his second year at a special needs preschool. He gets OT and Speech at school. He gets food therapy, Speech therapy, and Behavioral therapy weekly from our private therapy group outside of school. We have surrounded ourselves with people that understand him and help him get better daily. We still have struggles, but he is thriving now because of all the wonderful people in our lives. I am so grateful of all the knowledge I have learned through other parents with SPD kids, his teachers, therapists, books, Google, Dawn, and Jenny McCarthy. My son will always have sensory issues. He is just learning how to cope better with them. I continue to educate myself to help my son get better. I am so proud of him and everything he has accomplished. I am so grateful for everyone who has helped us along the way, especially my husband and children. I never thought that my life would be like this, but I am so glad that it has been. I am a better person for it, and it has brought our family closer than ever.

