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A NEW NORMAL

ONE MOM'S EXPERIENCE WITH SENSORY INTEGRATION DYSFUNCTION



By Jennifer Shaw

Sensory Integration Dysfunction is closely associated with autism in that many autistic children have some form of SID. To date, the medical community is unclear of the exact connection. SID is also often misdiagnosed as ADD or ADHD.

I was the mother of two beautiful girls and was thrilled to add a son to our family. After a difficult and dangerous pregnancy, we were especially thankful that our baby boy, who we named Toby, was born healthy. He seemed to be a very unhappy baby compared to our girls, but we hoped he would grow out of it.

"He wouldn't touch anything or play, he did not want to be touched, and he was terrified of being messy or being anywhere near things like grass or sand. A drop of water on his clothing would make him scream. It became really frightening and we did not know how to help him."

The first indication that something was out of the ordinary was when we could not get him to eat any food. I nursed him without a problem, but when we introduced baby foods, it was a daily struggle that we lost. We also

noticed that he never babbled or made any sounds and he rarely smiled. Eventually, it was clear that he was very speech-delayed, but because he had suffered from repeat ear infections which caused clinical deafness during his first year, we attributed a lot of his mood to pain and hoped that when his hearing improved, his speech would come along. After surgery on his ears, his hearing did get better and his infections went away, but he still did not make any sounds.

During Toby's second year, my father was dying of ALS (Amyotrophic Lateral Sclerosis, often referred to as "Lou Gehrig's Disease") and that took much of our emotional energy. But Toby's behavior was becoming more and more extreme. He wouldn't touch anything or play, he did not want to be touched, and he was terrified of being messy or being anywhere near things like grass or sand. A drop of water on his clothing would make him scream. It became really frightening and we did

not know how to help him.

When Toby turned two, we started him at a therapy school for speech delay. There was an occupational therapist on staff and she was the first to diagnose Toby with Sensory Integration Dysfunction (also known as Sensory Processing Disorder). Toby's brain was not interpreting sensory input correctly. People with this disorder can suffer in a variety of ways, but in Toby's case, he was extremely hyper-sensitive to touch of any kind. Food in his mouth, clothes on his skin, crumbs on his hands were all completely intolerable to him - he thought they were actually hurting him.

Toby began play-based occupational therapy, speech therapy, some physical therapy (because he didn't touch things or play and had poor balance, his muscles were very weak), and food therapy. Within two months, my son who had previously uttered no sounds said, "I love you, Mom." Within a year,

Toby's progress was nothing short of miraculous. He is now five and was discharged from all private therapies a year ago. He never had to have any medications or drug therapies. Although he still has some minor sensory issues, he has learned to cope with those challenges and he is now considered a typical child.

I am a songwriter and recording artist, not a doctor or therapist, but we learned a lot of things in our journey with SID that I share with people who suspect this condition in their own children. There is so much hope if you know where to look, and although Toby's outcome is not typical, there is help for every child with this diagnosis. So here's my advice:

"Treatment is so much more effective before the age of three that you cannot afford to waste time. If you suspect something, trust your instincts and get your child tested by an occupational therapist."

Do not ignore the signs even if you don't know what they mean. This is by no means a comprehensive list, but some of the symptoms of SID are speech delay, poor coordination, poor balance, avoiding touch or seeking touch in extreme ways (running into walls or falling down on purpose, running into people), extremely picky eating or extremely messy eating, irritability or a "difficult" personality. SID is often misdiagnosed, especially in older children, as ADD or ADHD.

Do not wait, even when your pediatrician tells you to. After everything we went through with Toby, my pediatrician (whom I love and respect) told me that she gave me the wrong advice by advising me to wait for Toby to catch up. This is what most doctors are taught, and while it is probably true for many problems, SID is not one of them. Treatment is so much more effective before the age of three that you cannot afford to waste time. If you suspect something, trust your instincts and get your child tested by an occupational therapist. If they say there's nothing to worry about, fine, but if not, you have not wasted valuable time that your child needs for therapy.

Get educated. Find out all you can and do everything in your power to help your child on a daily basis at home. We used to laugh about "our life as therapy" as we tried to integrate all Toby's therapies into everything we did. An excellent book on this topic is "The Out of Sync Child" by Carol Stock Kranowitz.

Get help. There is a federal program for developmentally-delayed children from age 0-3 available in every state. It goes by many different names - ours was called "Help Me Grow". They will do testing and help get your child into therapy programs, most of which are free if you qualify. Toby's therapy program literally changed his life and ours. You can call the special needs department at

your local school district and they should be able to tell you who operates the program in your area. After the age of three, help is available through your local school district. Take advantage of any therapy coverage on your insurance plan. Talk to your therapists about what you can do at home, watch the therapy whenever possible, and ask a lot of questions. We were able to overcome a lot of Toby's food issues only because we learned techniques from our therapists.

Re-define baby steps. This is not a quick fix. For example, Toby was literally afraid of food. We were not usually able to get him to stay in the same room with us while we ate. And sitting down and eating a meal was out of the question. So first, we worked on getting him to be with us in the room at meal times, eventually coaxed him to sit at the table, then got him to allow us to put food on the plate, then he learned to touch the food with a fork, then he touched it to his tongue but didn't eat it, etc. It was a long, frustrating process, but my son eats a healthy diet now and the simplicity of a family meal has become a true blessing in our lives.

Get support. SID can be very lonely and frightening. Our church was an amazing support to us and truly held us together at times. I met so many parents of special needs children at the school and it helped us realize we weren't alone. They were also a wonderful resource of ideas as we all talked about what was working or not working for our children.

Don't give up. SID can be overwhelming and confusing. It can be hard to navigate the system. Every therapy will not work for every child and you will need to be careful and wise about your choices. Take comfort in knowing that there is help and things can improve. You are your child's best advocate.

SID makes family life difficult, and it can be very hard to watch your child struggle. But there is hope and help, making positive results very possible. With persistence, we can help our children cope with their world and enjoy their lives, as we enjoy the blessing that they are in ours.

Online Resources:

www.spdfoundation.net
www.sensory-processing-disorder.com
www.sensorynation.com

Jennifer Shaw is a skilled musician, a devoted mother, and a passionate minister. She has a Master's degree in vocal performance, a wonderful husband, three beautiful children, and a heart's desire to share her love story with Christ with audiences everywhere. For more information about Jennifer, visit online at www.jennifershaw.com