

# Sensory Integration

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## From the Editor

This issue of the *Sensory Integration Special Interest Section Quarterly* presents personal narratives about growing up with a sensory processing disorder and parenting a child with sensory processing difficulties. Although this issue is a break from our normal evidence-based articles, the Standing Committee believes that these accounts are important reminders of why occupational therapy practitioners do what we do in clinical practice, teaching, and research. Both contributors to this issue wrote as a way to help others. We encourage you to share this issue with students, clients, families, and coworkers.

<SISIS Quarterly Editor>

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### Growing Up With Sensory Processing Challenges

■ Judy A. McCarter, OTR/L

My earliest memories of my childhood are of how itchy my clothes were, how odors made me feel nauseated, and how riding in a car would make me vomit. My parents responded by making my clothing out of fabrics that I could tolerate, having my hair cut in a barber shop (fewer odors than a beauty salon), and keeping a coffee can in the car for me when I became carsick.

I continued to wet the bed until age 6, and could not ride a bike until I turned 7. My fear of movement and clumsiness was interpreted as being stubborn; admittedly, I often could be controlling and defiant. My dislike of recess made me sick because I knew that I would always be the last one picked for a team. I often would not get work done during class so that I could stay inside during recess. Free play during recess was not much better. We were required to play on the jungle gym. For me, it was a fearful place that became a confusing maze with no way out. I would spend my whole recess trying to get out of the jungle gym! Learning other new skills, especially ones that involved numbers, letters, and spatial organization, was very difficult for me. In those days, self-gripping fastening materials did not exist, so I had to wear shoes with laces. I remember being afraid that I would have to take my shoes off during the day because I knew that I could not tie them again myself.

Reading presented its own challenges, with words running together and some letters appearing backward on the page. In

elementary school, I was placed in a special reading program held in the boiler room of the school. I knew that I had to get out of that program for several reasons. First, walking down the steep stairs to the reading area was frightening; I was afraid that I might fall and die or have to be taken to the hospital. Second, the boiler made horrible, scary groaning sounds, and the room felt so hot that my heart would race, and I was afraid that it might suddenly stop. Finally, the primary reason I wanted to get out of the reading program was because it was known as a place for the kids who were not smart, and thus, the reading program was yet another invitation for teasing.

As I got older, I developed stronger verbal and social skills that helped me to survive some of my challenging situations, but I always worked very hard to make sure that I did not make mistakes that would cause people to notice that I was a little different. I had made friends who helped me through tasks like sewing in home economics class, and the boys in my auto mechanics class were always more than willing to show off their skills, relieving me of having to touch greasy parts or use my visual-perceptual skills to put complex pieces back together. When I played basketball, I had a difficult time remembering which basket to shoot for, so a friend wore a red shirt and sat in the stands directly behind the correct basket so that I would not score for the wrong team. No one ever knew that she was doing that to help me!

By my teen years, my compensatory skills had improved, but my mistakes came at a higher social price. There were times such as walking into the boy's locker room or going to the wrong building and walking into the wrong classroom that felt devastating. Although in some ways things got better as I got older, by the end of high school, I still believed that there was something different about me.

It was not until college that I found a sense of relief. I remember going to a class about new research in the biological sciences where I heard a discussion about the sensory integration work of Dr. Jean Ayres.

That day changed my life. I began to see myself as one of the persons described in Ayres's work and research. That day helped me to know that the way I interpreted sensations did not make me stupid, clumsy, or lazy. That one 15-minute lecture changed my life forever as well as my perception of my abilities and possibilities. From then on, I believed that I could achieve whatever I wanted and that I would just need to work harder to overcome new learning situations. That lecture helped me to understand why I did not feel comfortable in my own skin and, more importantly, that it was fine because there were others out there just like

me! For me, it was a moment of ultimate validation and forever life changing.

From that point on, I never stopped learning about sensory processing disorder (SPD), not only for myself, but also for my own children’s sensory processing challenges. I have learned that dealing with SPD is an ongoing process. Last year, I started a distance postprofessional doctorate program at Creighton University. Using the technology and the related visual-spatial skills is very challenging for me. Like others with SPD, it sometimes takes me longer to learn new skills, and sometimes I have to relearn things that I thought I had already mastered. Having an understanding of how I learn and how I process sensory information, however, has allowed me to approach situations differently and to be more patient with myself when I do not “get it” the first time.

Additionally, I have recently completed the Sensory Integration and Praxis Tests certification, and I am so thankful for the qualified instructors from the University of Southern California and the certification offered by Western Psychological Services. I would encourage every occupational therapist who wants a better understanding of SPD to pursue the certification. The training information provided is invaluable when working with the persons with SPD and provides a good knowledge base to explain the theory to physicians and other health care professionals.

Parents need to understand that the value of SPD treatment goes beyond sensorimotor skill improvement and can lead to improvements in their children’s self-confidence and self-esteem. These improvements are forever life changing for some individuals. For me, learning about sensory processing showed me that it is okay to be sensitive and have a unique perspective of the world. It has helped me to understand my children and my clients, and in the process, made me a better mother and clinician.

I wrote this article for three reasons: to encourage parents of children with SPD to seek treatment for their children by qualified professionals, to express my appreciation for all the occupational therapists who have invested both time and interest in developing their skills to treat children and adults who have this hidden disorder, and to express my gratitude to the researchers who work tirelessly to research all aspects of sensory processing and provide an evidence base for treatment. ■

**Judy A. McCarter**, OTR/L, is President, *Functional Therapy Inc.*, 2305 West Waco Street, Broken Arrow, Oklahoma 74011; [judymccarter@cox.net](mailto:judymccarter@cox.net).

## Parenting a Child With Sensory Integration Challenges

■ Michelle O’Neil, RN, BSN

**H**aving a child with sensory processing issues is very challenging for a parent. It is also an opportunity to see the world differently and to grow. Nothing has stretched me farther than being my daughter’s mother. It has drawn from me a depth and strength of purpose I never knew I had. It also has shined a light on unhealed parts of myself, parts that would have remained hidden had I not been a parent to this particular child.

My daughter has Asperger syndrome. In many situations, she is not able to conform, and her sensory issues are a big part of it. She has never been a child you could scold into better behavior. It just doesn’t work. She is not trying to be defiant; she is experiencing fight or flight in her body. Coming down hard on someone who is already scared only escalates the problem. I know this from experience.

For instance, a family member tried to hush her at church one time with a little pinch to the arm. That type of thing worked on other children in the family. It sent them a clear message and put them in their place. But when tried on my daughter, the tactic had the opposite effect. She wailed and became even more disruptive. You learn quickly when you have a child with sensory issues that what works for other children often will not work for your child.

The first few years of her life, I would try to take my daughter to various activities that were supposedly fun for children, such as Kindermusik ([www.kindermusik.com](http://www.kindermusik.com)), gymnastics, and an afternoon at the kiddy pool. My daughter inevitably would have a meltdown. Strangers would glare at us, deeming me an ineffective parent or her a brat. I would look around at all the other mothers chatting casually with one another, their happy children playing nearby, and wonder what I was doing wrong. Sometimes when I could not figure it out, the helplessness would turn to anger. I have lost my temper with my daughter on more occasions than I care to mention. The feelings of shame around that stay with you.

When my daughter was little, I had been to three different pediatricians who discounted my concerns. In a quiet pediatrician’s office, my articulate daughter comes across merely as precocious. When I asked one pediatrician who specializes in developmental issues, motor delays, and depth perception issues, he suggested that I was disappointed because she was a bit clumsy and would never be an athlete. (I myself am not an athlete and do not have the slightest interest in sports.) When asked about the horrific tantrums that were happening several times a day, another young pediatrician suggested breezily, “Tell her she’s making a big deal out of nothing.”

I thought, “Thanks for nothing,” as I left.

Finally, when my daughter was 3 years of age, we made an appointment with an occupational therapist, who introduced us to sensory integration dysfunction. She helped me to understand that my daughter was living in a world that was overwhelming to her. It was a real condition. Her behavior was not bratty, and I was not a lousy parent. That confirmation and validation felt good as was having something tangible to tell other people and to explain her behavior.

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So what is it like to live with a child with sensory integration issues? Frankly, it can be maddening.

For a long time, my daughter would not tolerate short sleeves. She would wear tank tops, or long sleeves, but short sleeves did not feel right. If I did not have a clean tank top for her, she would wear a long sleeve shirt in 90-degree weather. Most parents do not realize how truly controlling they are. Parents of kids with sensory issues encounter control issues constantly and have to step back and decide what is important and what needs to be let go. It is a challenging process. We become experts at picking our battles and feel constantly judged for the ones that we let slide for the moment.

Having a child with sensory integration issues also can be embarrassing. My daughter has amazing visual acuity. She went through a phase where facial moles grossed her out. We'll never know why for sure, but we imagine that she sees moles as if under a magnifying glass, with every crack and crevice highlighted. If she got seated across from a relative at a family dinner, and that person had a mole on his or her face, my daughter would first begin to gag and then run from the room ready to vomit, all the while screaming about the offending mole.

The hardest part of having a child with sensory issues has been the screaming. The sound of my child screaming rattles me to my core. I suppose nature intended it that way, perhaps to promote survival, but you never get used to it. When someone is so sensitive to the world, everyday experiences feel like scream-worthy insults. When anything can set off your child, you begin to walk on eggshells. My daughter has very sensitive ears and as a result became phobic of sudden loud noises. One of the worst offenders was sneezes. If someone sneezed, the pain she experienced was unbearable. She would drop to the floor shrieking, covering her ears, as if someone had taken an ice pick to her eardrum. I began to hate people who had the audacity to sneeze in public. If they did it repeatedly, I would fantasize about hurting them as I held my wailing child. The obtuse sneezer would very often look at me like I was the problem. Further, every children's television show features sneezing at some point. My capacity to despise the writers of these television shows for their utter lack of creativity has taken me by surprise.

Public bathrooms are still a nightmare, especially those with hand dryers and automatic flushers. Before we started homeschooling, my daughter would "hold it" from 7 a.m. to 3:30 p.m. in order to avoid the bathroom at school. She finds it almost impossible to go to the bathroom in a stall when other people are coming in and going out of surrounding stalls because she is so busy covering her ears and worried about when the next flush is going to happen. She also has motor delays and worries about how long it will take her to wipe. The cheap toilet paper breaks off too easily, and she can never get enough. Obsessive-compulsive tendencies also cause her to worry about germs. My daughter just cannot handle all the stress. At 9 years of age, she does not want me in the bathroom stall with her, which leaves me standing on the outside, while she cries and screams as if she's being tortured (which in her mind she is). As a parent, you often feel helpless.

Being at the mercy of the world every day, which can and does send my child into screaming fits, sometimes makes me feel like an abused spouse anticipating the next intrusion into my fleeting peace. I know that she cannot help it, and I feel awful for feeling so victimized. At an autism conference I once attended, a researcher said that the mothers of kids with autism show brain

activity on magnetic resonance imaging scans that is similar to those of war veterans with posttraumatic stress disorder. I believe it. I still react to things that used to make my daughter scream. Sneezes no longer bother her, but they still make me jump.

When you are dealing with parents of children with sensory integration issues, my hope is that you, as practitioners, will give them compassion. You have no idea about the Herculean effort it might have taken to get the child out the door and to your appointment. You have 1 hour with that child during a session. The parents have a lifetime.

If the same parents appear spacey, keep in mind that they are not unintelligent. It is just that you and the services you might provide are not their only concern. The parents likely have many other irons in the fire. Keep in mind that each therapist, physician, speech pathologist, chiropractor, or specialist might think that he or she is the main show. None of them are. They are just pieces of the child's puzzle, and the parents are doing the best they can to juggle them all under very trying circumstances. Often, there are siblings to consider, marriages stretched to the brink, school issues, and financial concerns weighing heavily on their minds. You have no idea how many meltdowns they may already have navigated through that day.

As a professional, you have a lot of power. A parent will not remember whether his or her child complied that day and did all the tasks the therapist put on the visual chart, but parents will remember whether you judged them for not practicing at home. They also will remember whether you gave them a smile and acknowledged that they have a lot to deal with. One of the most validating things a professional ever said to me was, "I acknowledge I'm asking you to do more in a given day than I could ever do myself." I was hanging on by a thread that day, but her validation made me feel as though I could go on.

No one sets out to be a bad parent. Having a child with sensory integration issues often causes me to feel like one. It can be humbling. The child's needs are so high, and I can only do so much. Sometimes I am just plain tired. Sometimes it feels like I'm treading water with a sack of bricks on my back. But when I slow down and meet my child where she is, I realize many of the things she cannot tolerate were no fun for me either. I had just been living too automatically to notice. As it turns out, I cannot stand shopping malls either. I feel frazzled in loud places too. No, we will not go on that frenetic family vacation to Disney with the grandparents, aunts, uncles, and cousins. My child has autism, and Disney sounds like hell to her. As I've learned to say no to so many things society expects of me, those bricks have started to come out of the sack. My child, with all that she is, is actually freeing me. Her sensory issues have given me permission to be very discerning about who I associate with, both personally and professionally.

I have a child who experiences the world at a heightened level. The thing is she experiences joy this way too. When she is happy, joy ripples through her body to the point of coming out in an arm tic. Her body cannot contain the happiness. I doubt many people feel joy the way she does. When I stop trying to change her and remember to accept her for all that she is, I get to experience that kind of joy too. ■

**Michelle O'Neil, RN, BSN**, is a mother and writer, [www.FullSoulAhead.com](http://www.FullSoulAhead.com), Cleveland Heights, Ohio; [liferileyo@gmail.com](mailto:liferileyo@gmail.com).

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