

# SENSORY FOCUS

UNDERSTANDING THE ISSUES BEHIND THE BEHAVIOR

WINTER 2014

## OCCUPATIONAL THERAPY:

### Supporting the Parents' Perspectives

by Paula Aquilla, OT, DOMP

*Please Don't Let Me  
Be Misunderstood*

by Marla Roth-Fisch

*Can Medicine Help Treat  
Sensory Issues?*

by Edward Aull, MD



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THIS ISSUE:

*The Most Basic Sense Is Invisible*  
Jennifer McIlwee Myers

*PlaySense: The Importance of  
Changing a Game Midstream*  
Barbara Sher, MA, OTR

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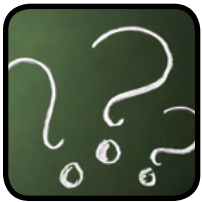
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# SENSORY FOCUS

UNDERSTANDING THE ISSUES BEHIND THE BEHAVIOR

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**B**rrrr! Is everyone keeping warm out there? For our subscribers here in the U.S. and the Northern hemispheres, winter has been a bit of a challenge lately. Will this polar vortex stop coming to visit soon?

Well, we have big news to warm you up—and it is exciting news, at that! *Sensory Focus* will again be available in print form, starting now. *SI Focus* (our original name) went completely digital in 2011, and some of our readers have missed having a magazine in hand. You've spoken, and we've heard you! As of this issue, Winter 2014, you can receive your copy of *Sensory Focus* in good, old-fashioned print format.

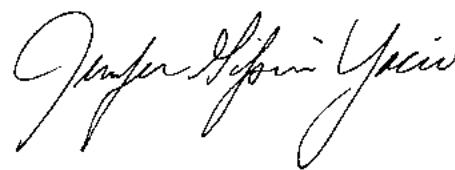
So, what do we have lined up for you in this issue?

One of our favorite OTs, Paula Aquilla, shares ideas on how parents and OTs can best work together to help the child. Dr Edward Aull discusses the possibilities when using medication to help ease

sensory issues in kids with autism. Also, Marla Roth-Fisch relates how most kids with SPD are misunderstood. She also relates some groundbreaking research about SPD and the brain. Jump to page 18 to read about it—I know you want to!

Rounding out the magazine are articles from our two wonderful columnists. In Focus on Autism, Jennifer McIlwee Myers lets us in on her own introduction to the importance of interoception. Then, in PlaySense, Barbara Sher outlines how to teach kids to change a game in mid-stream—no easy feat!

So sit back, get yourself a mug of something warm, and immerse yourself in the *Sensory Focus* experience. Enjoy!



**Jennifer Gilpin Yacio**  
*Vice President of Future Horizons, Inc.*  
*Editor in Chief of Sensory Focus*

A smiling man and woman are sitting on a light-colored couch. The man, in the foreground, is wearing a light blue button-down shirt and jeans, holding a striped mug. The woman, behind him, is wearing a pink shirt and jeans, also holding a striped mug. They are surrounded by children's toys, including a yellow stuffed animal, a blue and orange toy, and a teddy bear on the floor. The background is a bright, modern interior with a white wall and a wicker vase.

# OCCUPATIONAL THERAPY:

## Supporting the Parents' Perspectives

**Paula Aquilla,  
OT, DOMP**



**O**ccupational therapists (OTs) are sensory detectives, always trying to figure out the underlying reasons for a child's behaviors. The holistic framework of occupational therapy enables the OT to view the whole child, as well as the child within the family, the classroom, and the community. As OTs, we are most successful in our intervention when we pair up with parents. We need to take the time to learn the goals and hopes parents have for their child. We need to learn about the home and classroom environments and learn what activities are already happening, so we can customize our strategies and suggestions. Learning about the goals and strategies of the other professionals who are supporting the child's development enable us, as OTs, to streamline goals for parents.

Children with Sensory Processing Disorder (SPD) experience difficulty reacting to sensory input, and this can result in a mismatch with task demands and the expectations of the activity or the environment.<sup>1</sup>

The process of early identification, diagnosis, and engagement in therapies can

often be a maze for parents. Critical decisions must be made early, even during the early stages of learning. Parents often describe feeling intense pressure to get early intervention, even as they are coping with the shock of a diagnosis, grief over the life they had hoped for, isolation, and the overwhelming need to make choices and decisions.

**It is imperative for OTs to listen, support, and problem-solve with parents and children to empower families and support the best quality of life possible.**

Occupational therapy can be very helpful to parents in supporting their child in the early stages of intervention. Many of us in health care look at the pathologic condition, and, by doing so, our intervention can be negative and bleak. When we look at the whole child, however, we can see all the strengths and interests the child has, and we can

see the effects of the delay or disorder on function. We can enable parents to understand their child better by seeing the whole child and providing education. We can shine a positive light on challenging behaviors by offering possible reasons for the behaviors, suggesting strategies, and referring patients to other professionals who can also help.

Maternal mental health, family routines, and well-being can be affected by raising a child with disabilities.<sup>2</sup> It is imperative for OTs to listen, support, and problem-solve with parents and children to empower families and support the best quality of life possible.

The relationship between the OT and the child and the OT and the parent begins at first contact. The initial conversation can provide parents with the opportunity to be heard and to communicate their concerns to a person who understands. By providing a family-centered practice, parents can feel that they are a part of the process. Parents are given education and choices about their child's care. The positive outcomes can include parental self-advocacy, positive parent and child behaviors, and a sense of well-being in the family.<sup>3</sup> Empowering parents means inviting them to



participate in and “own” each step of their child’s care. In the past, therapists often assumed the role of the director of therapy, and, now, the director’s chair is shared!<sup>4</sup>

The everyday skills of dressing, sleeping, eating, using the toilet, brushing teeth, and so on, are skills that can be affected by sensory-processing difficulties. These tasks of daily life are on the OT’s radar. Having strategies for facilitating these activities can make everyday life easier for parents and children and go a long way toward increasing the quality of life in the family.

There are many excellent occupational therapy clinics that specialize in children with SPD. Following are some characteristics of clinics that use a family-centered model to guide their intervention. The benefits of the focus on the child and family are many!

### Preassessment Parent Meeting:

The initial contact with a child’s parents is a positive exchange of information. The parents feel like they have been heard and feel hopeful that the OT is familiar with the challenges they and their child are experiencing. Parents learn

that they are not alone; there are many children who experience similar challenges. Parents also learn that there are many things that can be done to help!

### Assessment:

This process begins with a parent meeting, where the OT learns about the child, what has already been done, and what the parents hope to gain from the assessment. The parents learn more about SPD and learn that there are many things that can be done to maximize their child’s development, behaviors, successes, and quality of life. Speaking about the child happens without the child present, so the child feels respected.

The assessments chosen reflect the parents’ goals for the assessment. Parents are encouraged to observe the assessment. This is not always possible, but every effort is made to include parents. Paper and pens are provided, so parents can write down questions or concerns that can be addressed later.

The assessment process should be comfortable for the child. Correct chair and desk heights, breaks, water, and snacks are made available to

ensure physical comfort. Positive feedback, high-fives, and parent hugs ensure emotional comfort. The assessment is conducted in a comfortable place, where the best functioning of the nervous system can be seen. Challenging activities are presented, and, if the child has difficulty organizing a response, the activity can be

**Goals are specific to each family. Values, goals, resources, and priorities are specific to every family and are taken into consideration when planning intervention.**

reintroduced in another way. The approach to the task and the way the child completes the task provide more information to the OT about his or her ability to complete the task. Parents learn about their child through observing the process. There may be other information that comes up during the assessment that needs to be

shared during the postassessment parent meeting.

## Postassessment Parent Meeting:

Assessment findings are discussed within the context of the child and his family. Connecting parent concerns to the assessment findings enables parents to understand behaviors they see at home, at school, and in the community. Parents learn that there are many things that drive behavior. Many parents report that they have more patience with their child as they better understand the reasons for a behavior. Parents also report that they are more creative during play and interaction, when they understand their child better. Being able to problem-solve during challenging times can also be a positive outcome of having increased knowledge about the child.

Goals can be created at this meeting, as well. Parents often have many goals that are similar to the goals any parent would have: happy children, good relationships with family and friends, success in school, feelings of competence, independence in self-care skills, and confidence in meeting life's challenges. Parents gain

an understanding of how to support their child and how to work with him or her instead of modifying their child's life in anticipation of a potential outburst.

*Julia is a 7-year-old girl who loves to go to McDonald's for a treat. She gets so excited that she often lies down on the floor of the restaurant, which poses a safety risk to her and the other customers. Her mom is embarrassed by this behavior and wishes Julia would just stop it!*

*Julia's mom learned that providing proprioceptive input (deep-pressure touch) helps Julia's nervous system to feel organized. In the postassessment parent meeting, she and the OT problem-solved around this behavior and surmised that lying on the floor may be providing proprioceptive input to Julia's ribs and sternum, which helps her cope with her excitement over being at McDonald's. Deep-pressure hugs, push me/pull me exercises (with her own hands), and pulling on a piece of Theraband were tested to help Julia combat the disorganization of her excitement. Julia no longer lies on the floor at McDonald's!*

Goals are specific to each family. Values, goals, resources, and priorities are specific to every family and are taken into consideration when planning intervention. Checking in with families on a regular basis to ensure that therapy is meeting their goals ensures that the family-centered approach is engaged and working.<sup>5</sup>

*Julia's mom e-mailed me to say that having an understanding of why Julia laid on the floor enabled her to have patience, creativity, and acceptance. It empowered her to advocate for and be compassionate to Julia and other children who express their needs through their behaviors. "Having this information contributed to my feelings of competence as a parent," she wrote.*

## Intervention:

The OT works with parents, teachers, and caregivers to design the best possible sensory environment to enable comfort and success for the child. Approach tips are shared, as are strategies for success with activities. The best therapy consists of a combination of good therapy at the clinic, where

parents participate, and a series of home activities that fit into the family's natural routines (mealtime, bath time, story time) and favorite activities.<sup>5</sup>

Many, many parents have become strong advocates for sensory therapy. They have tried the strategies and activities and have found them to be effective. The family's quality of life has improved in many of the families that have come through our clinic and have used a sensory-integration treatment approach.

The outcomes of occupational therapy with a sensory-integration treatment approach that were cited in a study by Cohn, Miller, and Tickle-Degnen<sup>6</sup> were divided into child-focused and parent-focused outcomes. The child-focused outcomes included:

- Social participation—the ability to participate in family, school, and community activities and the ability to maintain relationships with siblings, peers, and others.
- Self-regulation skills—the ability to recognize the state of the nervous system and how one feels and to develop and use strategies to regulate and manage behavior.
- Perceived competence—

The ability to feel confident that one can regulate behavior and meet challenges.

- The parent-focused outcomes included:
- Learning strategies to support the child's regulation, soothe the child, and support the child's success.
- Personal validation—being able to express the difficulties experienced when raising a child with SPD and feeling competent as a parent.

A family's success depends on the success of each family member. A sensory-integration model enables families to learn about their child and understand behavior through this lens. Participation in the therapy process empowers parents with knowledge, strategies, and confidence to support their child's development. Success with the strategies within the therapy setting and at home helps parents to feel competent. Competent parents are better advocates for their children.

A parent-centered approach is a win-win situation! OTs can share knowledge with and learn from parents, and parents can learn and gain competency in parenting skills, thus helping children with SPD to thrive! Where do I sign up?

Special thanks to Dr Lucy Miller and the STAR Center for sharing wonderful ideas used at the center to engage and empower parents. ♦

## References

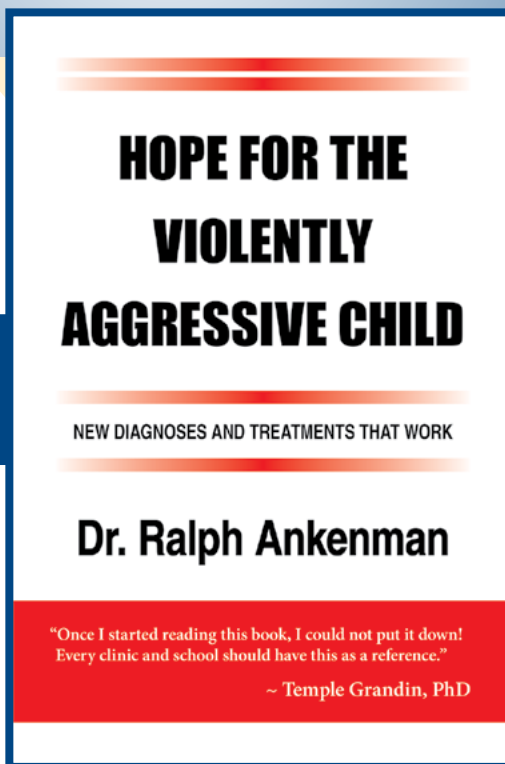
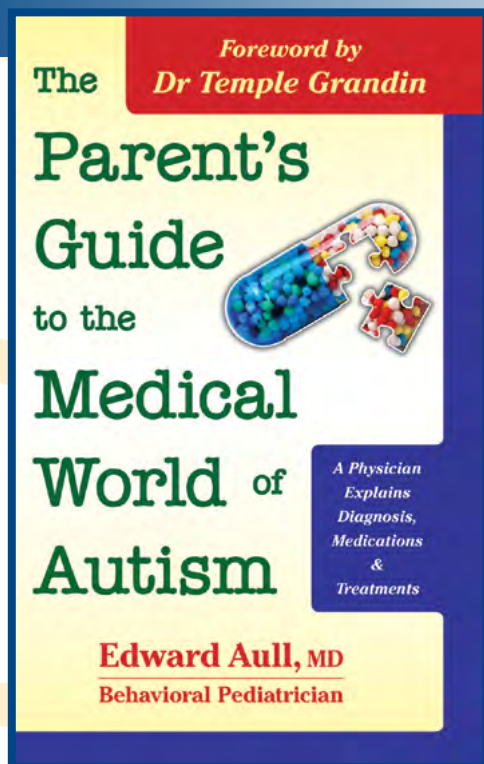
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*Paula Aquilla is a pediatric occupational therapist in Toronto, Ontario, Canada. She co-authored Building Bridges through Sensory Integration, now in a new edition.*



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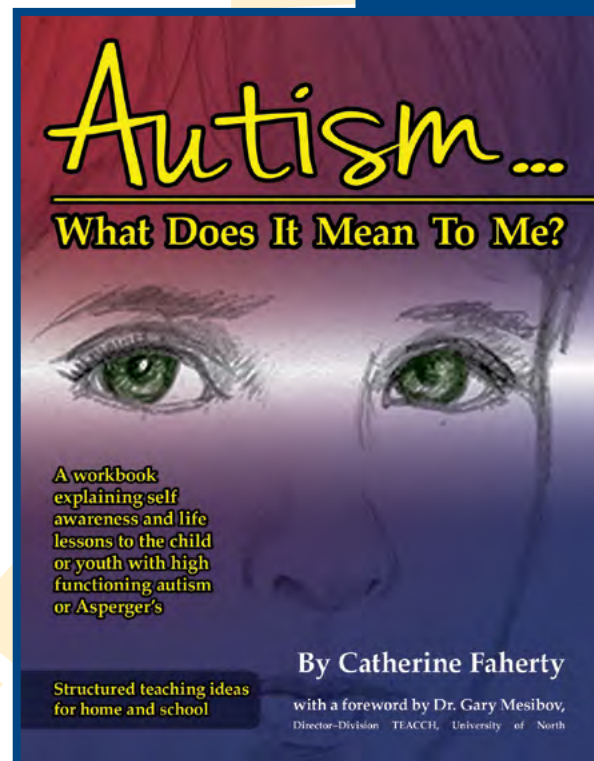
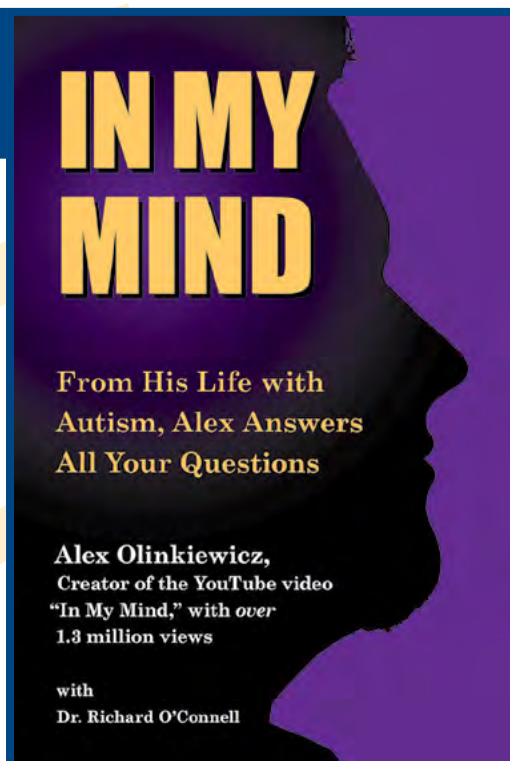
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# The Most Basic Sense Is **INVISIBLE**

*Growing Up with Sensory Issues* by Jennifer McIlwee Myers, Aspie At Large



One day my husband and I were at Universal Studios, and I was seriously overwhelmed by the huge amount of intense sensory input. It was a major case of sensory overload, and we started heading toward the parking structure to get me into a better space.

While we were walking, I suddenly had to sit down. I wasn't consciously aware of being dizzy or light-headed, but I just couldn't keep going. Once I sat down, I was planted. Standing up, communicating clearly, and even just interacting with other people were not options. It was a total melt-down and a total loss of functioning that neither my husband nor I was prepared for.

Universal is a theme park, so wandering characters are the norm, and one of the characters noticed I didn't look so hot. The next thing I knew, I was in a wheelchair being rushed to first aid, where the nurse immediately put me in a secluded corner bed and coaxed me into drinking Gatorade—a LOT of Gatorade.

It was very simple, really. I was overheated and dehydrated to the extent that I couldn't function. It could happen to anyone in a busy theme park on a hot day. But, it was much more likely to happen to

**It's so basic,  
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goes wrong.**

me—or to anyone with Sensory Processing Disorder (SPD).

The sense of how hot or cold we are, when we need to eat or drink, when we are tired, when we have a stomachache, or when we otherwise need to attend to our own bodies pretty darn urgently is one of the most important senses humans (and other animals) have. It's officially called “interoception.” Since that sounds like the title of a big-budget sci-fi movie that didn't do as well at the box office as the producers had hoped, I have my own personal terms for it.

I call it the “basic body sense” or (sometimes) the “inner body sense.” And, basic it is. It's so basic, in fact, that we never think of it or guess that it exists unless it goes wrong.

And it is more likely to go wrong if you have SPD.

So how does SPD affect the basic body sense? Well, there are quite a few possible effects.

Some kids don't get hungry. The brain just doesn't send the signal that tells them that an uncomfortable feeling in their gut means they should eat something. When you think about it, it's pretty weird that sensations that happen in the mid-torso are actually closely related to the mouth. It can be hard for a kid to figure that one out if his body isn't sending the right signals.

The opposite extreme happens, as well. To my great frustration, it happens to me often. When my body wants me to do something for it, a lot of the time, it comes out as “hungry.” If I'm tired, I feel hungry. Sometimes if I'm dehydrated, I feel hungry, but not thirsty. Mild stomach distress feels like hunger. That last one is a real pain.

If the problem gets worse, it can trigger a generalized feeling of panic or rage. The body is telling the brain that something is very wrong, but with no clear signal as to what it is, any kind of hostile or negative feeling may pop up.

If your inner body sense is on the jumbled side, then this feeling of panic, frustration,



sadness, exhaustion, or anger can seem like it comes from the outside world. The brain becomes so focused on finding what is wrong and fixing it that every little thing around you becomes incredibly important, and any little thing out of place or unexpected becomes absolutely HUGE.

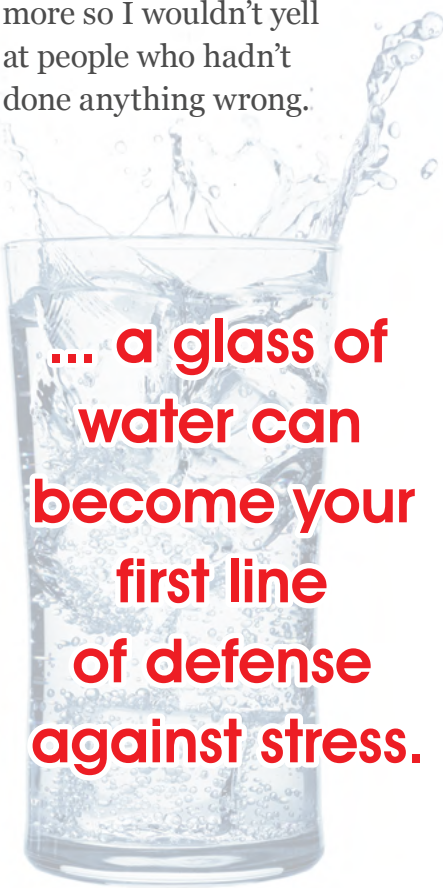
If a child is experiencing that sensation, the feeling can create an intense feeling of tension. It's sort of like the physiological and chemical state of someone in a 1930s B movie, who has been trekking through a dangerous wilderness. Each sound or movement, each crack of a twig, may presage some horrible doom, and possibly the appearance of a large monster that eats humans. It could happen at any moment.

Growing up, if I was dehydrated, I was in that state of tension, and the second anyone did anything that seemed out of place or unexpected to me, I blew up. It was a full-on terrified and furious fight-or-flight reaction, and, worse, it was self-sustaining.

Since yelling and fighting to “fix” the situation didn't improve how I felt, I could continue to lose it for some time—sometimes to the point of exhaustion. It never occurred to me that if I sat down and drank a glass of water and/

or ate a piece of fruit (as there's lots of water in fruits and veggies), I'd feel a lot better.

Just learning enough about SPD to realize that it was possible for me to feel lousy because I was thirsty made a huge difference. I don't particularly like the taste of water (especially bottled water), but I could condition myself to drink more so I wouldn't yell at people who hadn't done anything wrong.



**... a glass of water can become your first line of defense against stress.**

Logically, if paying conscious attention to my body's needs can save me and a lot of other people time and pain, then clearly, it is worth it to try to avoid that. Since getting a drink is sometimes all I need to do to pull it together, I do so.

Paying conscious attention to the real physical needs that most folks take for granted is a great Step One for people with SPD. Parents, teachers, and OTs can help kids with SPD by introducing them to basic facts about their bodies and how to keep those bodies happy. After all, if you know that you sometimes need water to get yourself on an even keel, then a glass of water can become your first line of defense against stress.

Feeling good takes either a good solid basic body sense or some supplemental information about what your body needs. Here, knowledge is power, just like “Schoolhouse Rock” taught us.

As for the Universal character who made sure I got medical help for my dehydration—I considered it well worth the time lost to have been diagnosed by Dr Frankenstein. ♦

*A woman with Asperger's Syndrome, Jennifer provides countless tips to improve the lives of those with sensory difficulties. She is the author of How to Teach Life Skills to Kids with Autism or Asperger's (Future Horizons, 2010).*



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# Can Medicine Help Treat Sensory Issues in Autism Spectrum Disorders?



*Edward Aull, MD*



**S**ensory issues are very common in patients with autism spectrum disorders, although they are not part of the Diagnostic and Statistical Manual of Mental Disorders criteria for a diagnosis. They are often more severe in patients with significant autism than in patients with mild issues, but they often require attention, such as medication, therapy, or avoidance. Patients may have more than one sensory issue, and the issue may affect any of the senses. Trouble tolerating loud or unexpected noises or a certain pitch of sound is common, but this may ease with age. Issues with smells are common and may prohibit eating certain foods or entering the cafeteria; however, avoidance of the cafeteria is more commonly related to the noise level. Visual sensitivity seems to cause less impairment than the other senses; however, the inability to make eye contact with another person is renowned in individuals with autism spectrum disorders.

The sense of touch often causes difficulty. It is common to see patients who have difficulty making physical contact with other people, maybe even refusing hugs from family members. Touch also creates

difficulty with food textures. One of the more common issues is with clothing sensitivity. There are clothes the patient won't wear, owing to the feel on the patient's skin. This may relate to tags, belts, button thread, embroidery, turtle-necks, and stiff cloth. One of the most common touch sensitivities I see is difficulty with the seam in the toe of the socks. I had a family who bought 50 pairs of socks for their son, in an effort to find seven pairs that he would wear. I have had patients who feel that there are right and left socks in a pair of tube socks. I believe that the symptom of having trouble with the seam in the toe of a sock is highly suggestive of an autism spectrum disorder diagnosis.

Medications can be helpful with sensory issues, although in an indirect manner. Selective serotonin reuptake inhibitors (SSRIs) are the medications I use the most to treat sensory issues. Typical SSRIs are Prozac, Zoloft, Paxil, and Lexapro. The SSRIs do not numb the sensory issue but lower the resultant anxiety. They let difficulties "roll off one's back" easier and lower the anxiety about an upcoming anxiety-provoking event. Having anxiety about incurring anxiety is common and causes impairment.

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I tend to use Prozac and Zoloft the most, but Celexa and Lexapro work well in some patients. I tend not to use Paxil, because of the weight gain and the variable length of effectiveness. It does work well, and although it is not approved by the U.S. Food and Drug Administration (FDA) for use in children, there is a good deal of literature on its use in children, with good outcomes. Selective norepinephrine reuptake inhibitors are also used. This group includes Cymbalta, Wellbutrin, and Effexor. When prescribing these medications in patients with autism spectrum disorders, it is important to start at a low dose and alter the dosage at a slow pace. How often a change in dose is appropriate will vary with the medication

## FOCUS ON MEDICATION

*“... I can take her to the park with her sister, and I couldn’t do that before.”*

used; however, it will generally be no more often than every 2 to 3 weeks. Although dosage is started low and moved up slowly, it is important to understand that the final dosage may be typical of adult dosages, even in young children. Children metabolize medication much more quickly than adults; however, they may also be more susceptible to side effects, which must be monitored.

Medication treatments for sensory issues will usually result in fairly major changes. Patients will try new foods. They will wear clothing that was never tolerated before. They may be able to go outside and not have to worry about buzzing insects. I had one parent who said, “I know they may discover in thirty years that my

child may have certain issues because she took Prozac as a child, but right now, I can take her to the park with her sister, and I couldn’t do that before.” This statement was made more than 25 years ago, and there are no known lasting effects of Prozac at this time. Prozac, Zoloft, and Lexapro are FDA approved for use in children. These treatment strategies are also effective in adults.

In summary, medications may be helpful with sensory issues in an indirect manner, but with good, clinically significant improvements. Results are likely to be better if the physician is used to treating patients with autism spectrum disorders. It is not that one medication is stronger than another as much that some patients do better with one medication versus another. The medications are not curative and likely will have to be continued over a long period of time. ♦

*Dr Aull has a private practice in Carmel, Indiana, for the medication treatment of patients with attention-deficit/hyperactivity disorder, autism spectrum disorders, and associated comorbidities. He is the author of a new book, The Parent’s Guide to the Medical World of Autism.*



Tami's daughter, Heather, was diagnosed with Asperger's Syndrome just before her 13<sup>th</sup> birthday. Heather spiraled out of control medically and educationally until an occupational therapist helped lead her to a functioning recovery. This included the use of a sensory diet and Craniosacral therapy, and biomedical supports. Tami shares her recommendations for other parents as she tells Heather's story of coming through the fog.

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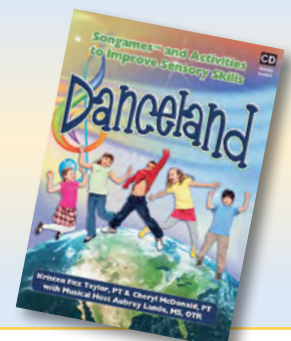
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# Please Don't Let Me Be Misunderstood



**Marla S.  
Roth-Fisch**



*with* **Gina  
St. Aubin**

**T**he classic song, “Don’t Let Me Be Misunderstood,” written by Bennie Benjamin, Gloria Caldwell, and Sol Marcus, keeps playing over and again in my head when I’m asked the question, “What are the misunderstood aspects of Sensory Processing Disorder (SPD)?”

According to updated research, SPD affects 5% to 16% of children in the general population.<sup>1</sup> To put that into a perspective we can grasp, it affects more than one child per classroom.

Most of us don’t have the capacity to see what goes on inside a child with SPD, or any child, for that matter. We depend on our eyes to observe and our minds to question what we see externally—the behaviors of our children. We must tune in to the reactions our children have to their surroundings, some of which can be confusing, frustrating, and downright unforgiving.

In the song “Don’t Let Me Be Misunderstood,” the words “When things go wrong I seem to be bad” speak to me about what can happen with children who have SPD. If a child is overwhelmed, his reaction may include a meltdown, drawn-out temper tantrums, “bad” behavior, or simply

withdrawal. “Typically, these children are misdiagnosed as having attention-deficit/hyperactivity disorder or autism, or they do not receive a diagnosis at all. Instead, an assumption is made that the child has ‘bad’ behavior,” says Dr Lucy Jane Miller, founder of the first comprehensive SPD research program nationwide. She is also the author of *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder (SPD)* and co-author of *No Longer A SECRET*.

### Gina’s Story

*A colleague and friend of mine, Gina St Aubin, author and founder of SpecialHappens.com, has three children, two of which have sensory-related challenges. I asked if she would share one of her experiences of her children being misunderstood, and she wrote the following:*

A child could potentially be mistreated not only by a misunderstanding individual, but also by a person that is unaware of what SPD is and what it could potentially look like. A person who is not aware of SPD can recoil and change the way he or she interacts with

the child, thus causing the potential for future isolation.

Take, for instance, my oldest son, who has a diagnosis of SPD, among other things. My son has trouble with his sense of touch, in terms of having a sense of stability and an awareness of his body in space. Many times, he has acquired this information from hitting or biting or banging into someone else. With time and work, he has been able to transform his need to make this connection for “body placement” in a gentler form—he kisses.

One time, we went into a pet store. A female associate welcomed us, and as she talked about the kittens they had, my son began rocking back and forth. Finally, his rocking moved him within striking distance. He planted a kiss on the woman’s shoulder (thankfully, this time it was a shoulder). With the next rock, he placed a hand on her arm.

It all happened so quickly—causing the unsuspecting sales associate to look shocked. I spoke to my son and physically prompted him to make distance and “ask before kissing.” The woman was understandably thrown off. She politely and blankly replied that it was okay, but we were experienced enough to know that this kind of “okay” meant that it really

wasn't okay. She didn't understand what had happened, and she most certainly would be talking about it after we left. She kept her distance from us after that.

Similarly, pickup time for my son at school can come with a mix of chaos and release. After school, he likes to play his favorite game, "Zombie Tag." Playing tag seems to help him get the pressure he's seeking. One day, out of nowhere, he came from behind me toward a family friend I was talking with. In a flash, he "tagged" her, hard, on her breast, and ran away, laughing and yelling "TAG!" To say she was surprised is putting it mildly. Luckily, she was familiar with us, and at least she "got" it. Even if she felt a little uncomfortable about it, at least we could laugh about it.

We work hard to spread awareness about my son's SPD, so he won't be misunderstood. We can't reach everyone, but we continue to try. When more people have an idea of what SPD is, the easier it will be for my son to not be misunderstood, and, hopefully, others won't recoil from him so often.

~Gina St Aubin

When reactions are misunderstood, it can result in misdiagnosis. Then, the effect is mistreat-

ment, and an unfortunate result is a miserable child and family!

Let's not be misinformed and have your child be misunderstood. If you see the signs and symptoms of SPD in your child, check out the SPDFoundation.net red flags. Schedule your child for extensive and accurate testing, preferably by an occupational therapist who is familiar with SPD. Talk with your doctor, and invest in knowledge and a treatment strategy, especially if you are:

- The parent or caregiver who sees your child doing out-of-the-ordinary types of things and notices that he is not on track with developmental milestones.
- The educator who observes behaviors that disrupt the entire classroom in an ongoing manner, where it becomes hard to maintain focus so learning can happen.
- The pediatrician or primary care physician who has great knowledge on many different health issues, except for SPD.

**Dr Mukherjee and Dr Marco's research provides the first biologic evidence that SPD is indeed a valid disorder, answering the claim of some that SPD is not "real."**

- The child who has no idea why you act the way you do, but you'd like to start looking for answers.

## Groundbreaking News

Recently, there has been some groundbreaking news on SPD and the brain. According to a new study from the University of California, San Francisco (UCSF), published in the online journal *NeuroImage: Clinical*, researchers found that children with SPD have quantifiable differences in brain structure, which confirms a biological basis for the disorder. These differences set SPD apart from other neurodevelopmental disorders, such as attention-deficit/hyperactivity disorder and autism.<sup>1</sup>

Researchers at the SPD Foundation have been studying SPD for more than 30 years, and the Foundation supports continued research of SPD. They organized a multidisciplinary team of experts, called



the SPD Scientific Workgroup, that includes 50 physicians and scientists from research institutions such as Harvard, the Massachusetts Institute of Technology, Duke, and many other universities. These researchers have provided physiological, neurological, psychological, etiological, familial, and other data about SPD.

The UCSF study was led by two members of the SPD Scientific Workgroup, senior author Pratik Mukherjee, MD, PhD, a professor of radiology, biomedical imaging, and bio-engineering at UCSF; and Elisa Marco, MD, who led the study; along with postdoctoral fellow Julia Owen, PhD. Marco is a cognitive and behavioral child neurologist at UCSF Benioff Children's Hospital.

Dr Mukherjee and Dr Marco's research provides the first biologic evidence that SPD is indeed a valid disorder, answering the claim of some that SPD is not "real." In the recent release of the 5<sup>th</sup> edition of the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, the application of the SPD Scientific Workgroup to include SPD as a valid diagnosis was turned down. This new study may suggest that the decision should be reconsidered.

The continued chorus from the song, "I'm just a soul whose intentions are good oh Lord, please don't let me be misunderstood," rings true for many with SPD.

Don't let your child be misunderstood. ♦

### Reference

1. University of California, San Francisco, Web site. Breakthrough study reveals biological basis for sensory processing disorders in kids. [www.ucsf.edu/news/2013/07/107316/breakthrough-study-reveals-biological-basis-sensory-processing-disorders-kids](http://www.ucsf.edu/news/2013/07/107316/breakthrough-study-reveals-biological-basis-sensory-processing-disorders-kids). Accessed December 18, 2013.

*Marla Roth-Fisch is the award-winning author/illustrator of the children's book Sensitive Sam. She is also VP External Board of Directors for the SPD Foundation. Her second children's book, Sensitive Sam Visits the Dentist, will be released in Fall 2014.*

*Gina St. Aubin is a member of the Board of Directors for the SPD Foundation. She also founded and is the contributing editor for Special Happens, a site dedicated to helping families with special needs. You can visit her website at <http://specialhappens.com>.*

### Beyond echolalia...

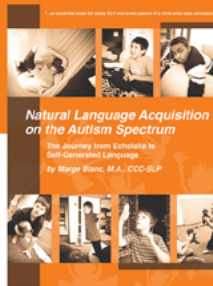
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# PlaySense

## The Importance of Changing a Game Midstream



by Barbara Sher, MA, OTR,  
The Gameslady

I laid the mat down on the carpet to begin the game. The mat had eight dots of different colors painted on it. The players were preschoolers. It was the second week of school and they were about to play, for the first time, the jump-to-color game that I've played a gazillion times before, because kids love it. It's easy. They get to jump forward, backward, and sideways—in small jumps and huge jumps. Little kids like any excuse to jump, and it's a good activity for practicing motor skills and identifying colors.

The children were sitting on the carpet, waiting to begin.

I started off by “casually” deciding who would go first. “The person who goes first,” I said, looking around for the child who would most likely be a good demonstrator, “is wearing a black shirt and blue pants.” I use this method to get the kids to really notice each other and pay attention to details. It's good for developing social skills.

Normally, the kid with the black shirt and blue pants on

gets all smiley and steps up for his turn, or another child or two will excitedly point the child out.

Today, it didn't turn out that way. “The person who goes first is wearing a black shirt and blue pants,” I said. No one moved—not even the child

**... but that elated sense of succeeding without an adult's help was missing.**

dressed in black. I elaborated.

“It's a black shirt, with a gray hoodie.”

Nothing.

“He has yellow on his shoes.”

Still nothing.

I then pointed to the child. He seemed surprised, but he happily got up to take his turn.

It didn't take long for me to see that he didn't know his colors. Asking him to “jump to the red dot” had no meaning for him or, as it turned out, for most of the others. I discovered I would have to point to the colored dots I named.

The kids were still having fun jumping, but that elated sense of succeeding without an adult's help was missing.

And then it hit me—this was the beginning of the year! Except for a few returning students to this very rural Head Start center, almost every child in the room was having his or her very first school experience. I needed to come up with another way for them to succeed.

That's when I noticed the pile of vinyl shapes stacked nearby. Each one had a photo of a child taped on it. This was the teacher's method for setting up the morning circle. Each child would come in, take the mat with his or her photo on it, and sit down on it.

I picked up my large mat and, with the teacher's permission, put down eight of their small mats. I changed my instructions to, “Jump forward to Emily ... and sideways to Karako ... and backward to Caitlin.”

This time, everyone could do it, or at least some version of it, and everyone was having fun trying.



It wasn't long before some of the kids were given a turn to be "teacher" and tell a classmate whom to jump to and which way to do it.

At the end of the game, the kids were given a moment of free play, where they could jump on the mats any way they wanted. Some kids went on to other things, while others jumped and jumped until it was time for me to say "adieu," to return another day with a new game.

Another color-based game could have involved pictures of fruit and vegetables placed on top of the colored dots: a cucumber on the green dot, grapes on the purple one, and so on. It's better to start with what they know when learning colors, and build on that.

But today, for this jumping game, our goals were accomplished:

Motor skills practiced—check.

Social skills developed—check.

Confidence expanded—check.

Joy factor increased—check, and double check. ♦

*Barbara Sher is an occupational therapist and the author of ten books on children's games. Barbara's books are in any online bookstore and her Web site, [www.gameslady.com](http://www.gameslady.com).*

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Date	City, State	Presentations by
January 24	Monterey, CA	Dr Temple Grandin, Eustacia Cutler & Beth Aune, OTR/L
February 14	Denver, CO	Dr Temple Grandin, Sean Barron & Raun Melmed, MD
March 7	Indianapolis, IN	Dr Temple Grandin, Eustacia Cutler & Dr Jed Baker
April 11	Raleigh, NC	Dr Jim Ball & Maria Wheeler, MEd
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-- Judy

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-- Nancy

Most importantly, she's never, **\*\*never\*\*** been able successfully to socialize with people her own age before. In the past people were always either very kind and patronizing or ignored her completely. This weekend, people often sought her out just to spend time talking with her.

-- Linda

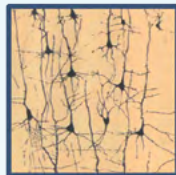
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