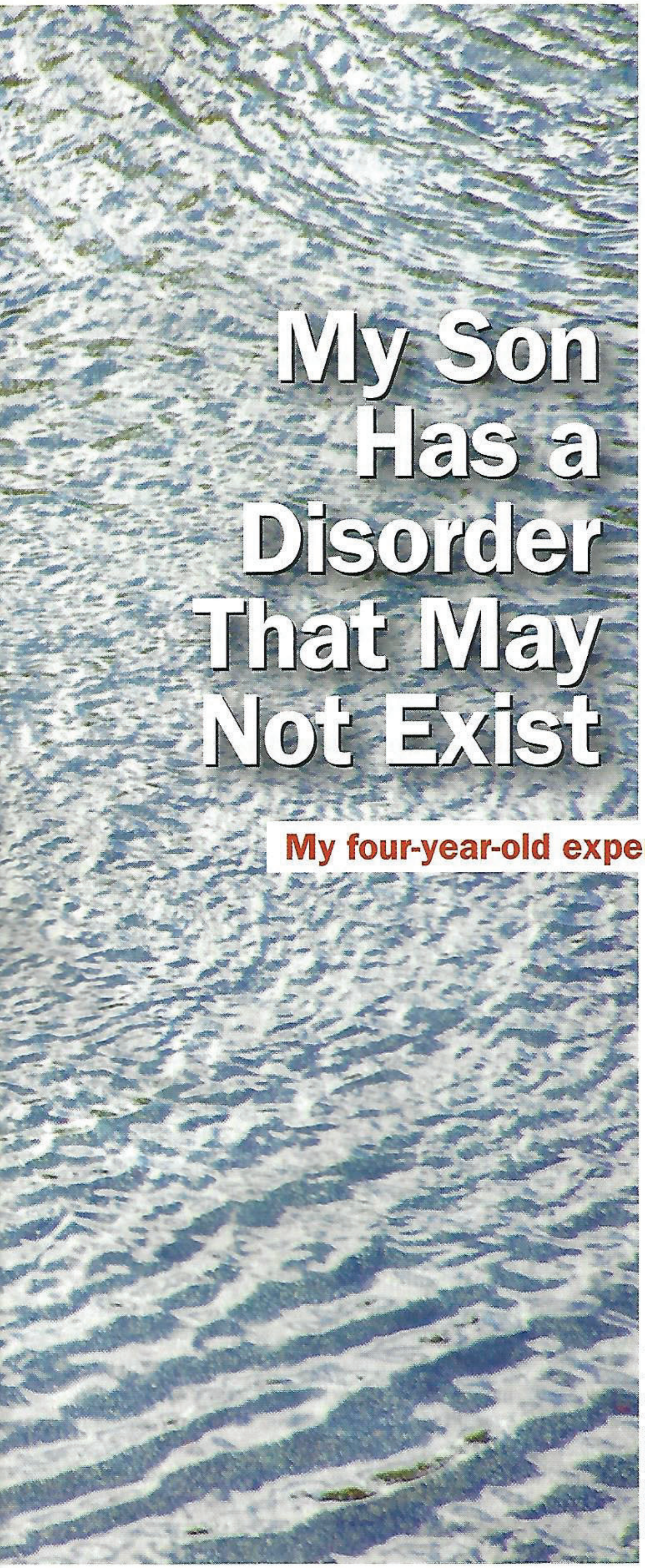

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My Son Has a Disorder That May Not Exist

The symptoms are undeniable, but the research is limited, and so a debate rages over whether to recognize sensory processing disorder

By Melinda Wenner Moyer

My four-year-old experiences a different world than I do. He can smell a freshly peeled banana from across a room. The hum of a running blender hurts his ears. He abhors the feeling of moisturizing lotion on his skin and washes his hands only in ice-cold water. He loves the taste of lemon juice.

According to his occupational therapist, my son has sensory processing disorder. This means that he has difficulty perceiving, responding to and integrating sensations in ways that can affect his social relationships, daily activities and quality of life. Occupational therapists say that the disorder can manifest itself in diverse ways, depending on which senses are affected and how; there are dozens of possible sensory permutations. My son seems to be overly sensitive to smell and touch and sound; he is underresponsive to taste. He also has trouble discriminating the qualities of certain sensations, including where his body is positioned in space, which affects his coordination and motor skills. He meets with his occupational therapist once a week for sensory integration therapy in what is called a "sensory gym"—a space where he plays with swings, jumping balls, shaving cream and climbing walls in ways designed to teach his nervous system more appropriate perceptions and responses to sensations and to build his confidence and coordination. According to a 2009 study, as many as one in every six kids suffers from sensory problems that are serious enough to disrupt their daily lives.

Everything I have written about my son's disorder, however, is hotly contested. In some circles, sensory processing disorder, or SPD, simply doesn't exist. Although a cadre of occupational therapists fought for 12 years to have the disorder listed in the current iteration of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), the American Psychiatric Association (APA) opted not to include it—which means, basically, that the group does not recognize it as a legitimate condition. In 2012 the American Academy of Pediatrics (AAP) published a policy statement recommending against the use of the SPD diagnosis, too. It argued that sensory problems are likely to be symptoms of other recognized developmental disorders, such as autism, attention-deficit/hyperactivity disorder and anxiety disorder. It also concluded that "the amount of research regarding the effectiveness of sensory integration therapy is limited and inconclusive."

This is, in fact, the crux of the problem—the field desperately needs more research to elucidate and support its theories, but it is caught in a catch-22 bind. Who wants to fund research on an unrecognized condition? "There is this incredible negative reaction when we go for funding," explains Lucy Jane Miller, an occupational therapist and early childhood education specialist who founded the Sensory Processing Disorder Foundation, a nonprofit organization that seeks to increase awareness, funding and research for the disorder, as well as the STAR Center, a nonprofit organization in Colorado that assesses and treats children with SPD. "People are emotional about this as if it's a religion or a belief system and not a science."

In 2014 the SPD Foundation's funding for research—most of which came from the Wallace Foundation, an independent philanthropy—totaled approximately $600,000. By comparison, in its fiscal year 2014 the National Institutes of Health's funding for autism research alone totaled $188 million, according to a search I conducted of its records. Since SPD was first described in the 1960s, questions have far outnumbered answers, but the field has never been given an adequate opportunity to address them. "I've been doing research for 40 years, and it's been very frustrating," Miller says. "I don't know how we're going to break through."

The State of the Evidence

The senses can be thought of as the lenses the body uses to understand itself and its relationship to the outside world. It's not crazy, then, to think that they would mediate the development of everyday skills. One of the first researchers to develop this idea was the late educational psychologist and occupational therapist A. Jean Ayres. In the 1960s, while working at the University of California, Los Angeles, Brain Research Institute, Ayres devised a theory of sensory integration that hypothesized that sensory systems do not develop independently of one another and that sensations are also not processed independently but are instead integrated in the brain. She likened problems with this system to neurological traffic jams that prevent parts of the brain from receiving the information they need to accurately interpret and respond to various types of sensory information. (In addition to the senses that everyone knows—sight, sound, touch, taste and smell—there is also proprioception, the sense of the position of the parts of the body in relation to one another; the vestibular sense, which notes the orientation of the body in space and how it is moving; and interoception, which detects internal regulation processes such as hunger, thirst, heart rate and the need to use the bathroom.)

FAST FACTS

SENSORY STANDOFF

❶ As many as one in six children has difficulty processing sensory inputs—a condition often called sensory processing disorder (SPD).

❷ Occupational therapists commonly treat SPD, but the condition is not formally recognized by psychiatrists or pediatricians.

❷ Research suggests a biological basis for SPD, but more studies are needed to build a consensus about the disorder and its treatment.

> **"People are emotional about this as if it's a religion or a belief system and not a science," says Lucy Jane Miller, an occupational therapist who conducts research on SPD.**

Ayres's theory, and its terminology, has evolved over the decades, and the belief today is that some individuals have problems *modulating* sensory information, in that their nervous system is either oversensitive or undersensitive to sensory stimuli—essentially they have problems interpreting and responding appropriately to the intensity of sensory information. Some individuals may also (or instead) have problems *discriminating* sensory information, which means that they have trouble identifying the spatial and temporal qualities of sensations they experience. Someone who has problems with auditory discrimination may not be able to distinguish between different types of sounds or know where they are coming from, whereas a person with vestibular discrimination problems, such as my son, may not always know where his body is in space and may be clumsy. Individuals with discrimination problems may also have sensory-based motor disorders, which are characterized by poor stability and body control (known as postural disorder) or problems with motor coordination (dyspraxia).

Over the past 15 years research has suggested that sensory variations are "real" in that they are rooted in subtle brain differences. In 1999 scientists at the University of Colorado Denver and the University of Denver exposed 19 children with sensory modulation problems and 19 healthy children to a barrage of sensory stimuli in a short amount of time: they smelled

In addition to issues with the five familiar senses, affected children may have difficulty with proprioception (knowing the relative position of one's own body parts) and the vestibular sense (orienting one's motions in space).

wintergreen oil, heard a siren, saw a flashing light, felt a feather move across their face and had their chair tilted back 30 degrees. These stimuli were provided quickly, 10 times in a row. While this went on, the researchers applied electrodes to the children's index and middle fingers to measure their electrodermal activity—the electrical characteristics of their skin, which, among other things, can change with the activity of the sweat glands. (Electrodermal measurements are used in polygraph tests.) With the exception of four children with sensory modulation problems who did not respond to the stimuli at all (all the control subjects did), they found that the kids with sensory modulation problems had larger electrodermal responses than the control group and that their responses did not decrease as much as they did for the controls when the stimuli were repeated. The results suggested that although most individuals might, for instance, hear an air conditioner turn on and then stop noticing the hum a few minutes later (a normal response called habituation), those with sensory modulation problems will continue to hear and be bothered by the sound for longer. But electrodermal tests are controversial—their measurements can be affected by various external factors, such as room humidity, so it is hard to know for sure that the observed differences were meaningful.

Studies using electroencephalography, which measures voltage changes in the scalp related to the activity of cortical neurons, have also found differences in brain activity between individuals with and without symptoms of SPD—but EEG has limitations, too, such as the fact that it only measures activity close to the brain's surface. In a 2011 study, researchers at Colorado State University found EEG differences between children with and without SPD when they were exposed to auditory beeps. The children with SPD who had the most abnormal EEG recordings performed the worst on tests of sensory and motor performance, too. This finding suggests that my son's shrieks in response to being smeared with lotion may be directly related to his brain's abnormal response to the sensation—in other words, he is not "overreacting," as some might say, because his perceptions really are more intense. "These kids truly are more responsive, and they don't tend to inhibit that input. They never really habituate to the information the way that they should," says Teresa May-Benson, executive director of the SPIRAL Foundation, a nonprofit Massachusetts organization dedicated to research and education about SPD.

In recent years researchers have begun using more cutting-edge technologies to understand what underlies these potential brain differences. In 2013 researchers at the University of California, San Francisco, and the University of Denver used diffusion tensor imaging, a form of magnetic resonance imaging that reveals how white matter is organized in the brain, to compare the white matter tracts in children diagnosed with SPD with the tracts in those without the condition. They, too, found significant differences between the groups: the affected children had less white matter microstructure integrity in the pathways connecting regions involved in multisensory integration. And the more serious the children's sensory symptoms were, as reported by their parents, the less integrity they had. But the study was small and limited, involving 40 boys and no girls, so again, it is hard to conclude a lot from it.

THE AUTHOR

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These studies suggest that sensory differences have clear biological roots and that serious sensory problems might be signs of a disorder, but they haven't been enough to convince some scientists, who tend to see sensory problems as symptoms of other, more recognized conditions. Research suggests, for instance, that up to 88 percent of children with autism spectrum disorders have sensory processing problems. A study published online in June showed, using MRI, that the brains of these children do react more strongly to sensory stimuli than do the brains of children with autism who do not have sensory issues. In addition, a 2011 study found that children with ADHD are more likely than unaffected children to have sensory symptoms.

Some neurologists think that sensory issues are simply a sign of neurological immaturity: few adults seem to suffer from sensory processing problems, they say, so most kids probably grow out of it. (Many occupational therapists, however, disagree. They say that adults often remain sensitive to sensory stimuli or have motor coordination problems but have learned to avoid the situations that make them uncomfortable.)

An imaging study found that the brains of children with SPD had weaker white matter structure in pathways involved in sensory integration, compared with the brains of unaffected children.

To add to the problem, there is no "gold standard" for diagnosing sensory processing disorder. Occupational therapists typically use standardized tests, parent reports and clinical observations to make the diagnosis, but different diagnostic approaches may be used depending on the child and the therapist. And sensory differences can, of course, be normal. "A child may be in a specific place on a bell curve, but that doesn't mean he has a disorder," says Winnie Dunn, an occupational therapist and neuroscientist at the University of Kansas Medical Center who developed a series of widely used assessments for identifying sensory processing patterns in children and adults. Some sensory differences can even be useful: an individual with a particularly sensitive nose, for instance, might become an excellent sommelier.

Ultimately few skeptics outright reject the idea that SPD could exist—they just argue for more supporting research. For instance, in response to letters reacting to the 2012 policy statement by the AAP, the two lead authors wrote that they were both "'believers in the existence of sensory-based neurobehavioral problems but feel that more research is definitely needed before a clearer understanding is reached that may lead to a consensus on what characteristics make up the 'disorder.'"

Miller, who spent years campaigning to have SPD included in the *DSM-5*, argues that organizations such as the AAP and the APA seem to have a higher standard of evidence for SPD than they do for other conditions: "We have a lot of studies—more than most of the diagnoses in the *DSM*—but still, there is this incredible negative reaction." The standoff has taken a toll: one researcher I talked with told me she didn't want to speak on the record, because she had "reached the stage of battle fatigue on this topic."

Sensational Treatments

There is little question today that various sensations are processed together and that they play an important role in coordinating movement. "Sensory input from the different senses converges in a region located in the upper back portion of the brain called the posterior parietal cortex," explains Dan Marigold, director of the Sensorimotor Neuroscience Lab at Simon Fraser University in British Columbia. "The sensory information is integrated to provide an estimate of the state of the limbs, body and environment," which helps to facilitate planning and execution of goal-directed movements, he says. When people have problems integrating sensory inputs, then, it makes sense that they could have trouble with everyday tasks and complex movements.

But the idea that therapists can improve motor skills and coordination with sensory integration therapy is highly controversial. In a nutshell, the therapy is designed to present individuals who have sensory processing problems with opportunities to experience challenging, multisensory experiences in a safe, play-based environment. These experiences help to organize the person's nervous system so that it responds more appropriately to sensation. Yet to some pediatricians and psychologists, the approach reeks of pseudoscience. A pediatric neurologist writing for the myth-busting Web site Quackwatch has described sensory integration therapy as "unproven and irrational."

One problem is that many early studies on the therapy had design flaws, making it difficult to make solid conclusions about its efficacy. Some studies, for instance, reported that the symptoms of children who underwent sensory integration therapy did improve compared with children who received no treatment—but such studies do not account for the fact that children might improve with one-on-one attention from empathetic adults no matter what kind of therapy they receive. It is also possible that some sensory symptoms simply improve with time, as children learn to cope.

Other studies have failed to assess true sensory integration approaches. In 2007 researchers analyzed 34 studies that had supposedly tested the efficacy of sensory integration therapies and found that only 38 percent of the interventions had been designed to be challenging and only 15 percent were provided in a play-based context—both of which are crucial attributes of the therapy. "Sensory integration therapy is very intricate, and there are a lot of subtleties to it," May-Benson explains. Beth Pfeiffer, an occupational therapist at Temple University,

A four-year-old works out in a sensory gym in Washington, D.C. Guided by occupational therapists, this kind of sensory integration therapy is designed to expose children to sensations that they find challenging in a safe, playful environment. Some small studies have demonstrated its benefits, but many questions remain.

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puts things more bluntly: "There are a lot of people who publish on sensory integration who don't even really understand what the intervention is." In addition to the fact that the therapy itself is complicated, results can be a challenge to measure. "If you think about what the intervention is targeting, it's really targeting neurological change—the way the brain processes information," Pfeiffer says. "So the outcomes could be so varied." Individuals with SPD often have very different symptoms, too. "It's not, 'Okay, we're going to give you this drug and expect this change,'" May-Benson explains. "It's, 'We're going to do these 10 things, and it's the combination of these 10 things that result in this final outcome.' And the final outcome is also influenced by your personality, your drive, your environment and all these other things that we don't have a lot of control over—so it becomes very challenging in a large group study to get results that are statistically significant."

Nevertheless, in 2007 Miller and her colleagues did get statistically significant results from a pilot clinical trial. They split 24 children with sensory modulation problems into three groups. One group received the therapy twice a week for 10 weeks. A second group spent the same amount of time each week doing fun activities with an adult who had a background in education or psychology. The third group was not given an intervention. The researchers found that, compared with the two other groups, those who received sensory integration therapy made more gains toward achieving the goals their families had set, such as being able to try new foods at dinner without gagging or tolerate wearing socks, and they improved more on the attention, cognitive and memory subtests of an IQ test.

In a 2011 study, Pfeiffer and her colleagues separated children who had autism in addition to sensory processing problems into two groups. One group received sensory integration therapy, and the other received fine-motor-skill-based occupational therapy for six weeks. This study, too, found that the children receiving sensory integration therapy achieved more of their family's goals. The therapy was also better at reducing the frequency of autism-related mannerisms, such as hand flapping.

But these studies were small and limited, and not everyone is convinced by their findings. Funding for more substantial research continues to be sparse, and those in the field often feel downright ostracized. "I think there's a group that has an inherent bias against it. It's almost like they shut the door," Pfeiffer says. That may reflect the fact that occupational therapy as a field lacks the status of medicine. Some wonder, too, if sexism plays a role—Ayres was a woman, and most occupational therapists today are female, yet many vocal critics of SPD and sensory integration therapy are men.

Even when researchers *do* get funding, it is rarely enough to support the types of studies the field desperately needs. "We have a critical mass of researchers who are doing really good work, but I'll tell you what: treatment studies are expensive," explains Roseann C. Schaaf, an occupational therapist and neuroscientist at Thomas Jefferson University. The $500,000 grant she recently received from Autism Speaks did not fully cover the cost of a 32-subject trial designed to test the efficacy of sensory integration therapies in children with autism.

While it might seem reasonable for funding organizations to be wary of supporting research on an unproved approach for a condition that is not universally recognized, the only way to shed meaningful light on SPD is, in fact, to conduct more and better studies. Parents with kids like mine know, beyond a doubt, that our children are struggling and need help. Is it asking too much to look beyond old biases and divisions to get some answers? **M**

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