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PHOTOS BY TODD SUMLIN - tsumlin@charlotteobserver.com

Antonio Turrisi lies in a hammock as he works with Courtney Enos at Pathways for Learning in south Charlotte. Antonio's mother, Jennifer, says he has benefited from therapy for his sensory processing disorder, helping him to overcome clumsiness.

They just can't stand it

The smallest things bother kids with sensory processing disorder, but skeptics scoff at the diagnosis

BY AMANDA CHAN
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It's unbearable to wear clothing with tags. It's impossible to use scissors, no matter how many times you try. All mushy or soft foods are unbearable — not because of the flavor, but the consistency.

Depending on whom you ask, it's either common childhood behavior, a neurological disorder that requires intervention or something in between. Its name is sensory processing disorder, and it occurs, advocates say, when the brain cannot properly process incoming signals for an appropriate response.

Sensory research is still young; prominent California occupational therapist and psychologist A. Jean Ayres began studying sensory integration problems only in the 1960s. Many skeptics scoff at

the notion of such a disorder and say the root of the problem has more to do with bad behavior or neurological immaturity.

But families who live with it and the occupational therapists who treat children with the issue say there's no doubt it exists.

To have sensory processing disorder, experts say there must be a significant effect on daily routine. The disorder is usually found in children, though adults can have it, too.

"Everything's coming in and getting messed up for them," said Heidi Tringali, a Charlotte occupational therapist who sees a lot of children with sensory issues. "It tastes too strong, smells too strong,



Antonio gets a high-five from Enos after his session.

They're just disrupted... and their existence is so much more difficult than just a typical developing child."

There have been few published studies on the prevalence of SPD. But one study done in association with the Sensory Processing Disorder Foundation estimates that one in six children is affected by sensory issues, which can range from mild to severe. However, SPD has not yet been officially recognized by the American Psy-

SEE SENSORY, 3D

Sensory processing disorder at a glance

Sensory processing disorder is divided into three categories.

- The first comprises sensory over- and under-responders and sensory seekers — people who may overreact or underreact to pain or noise, and people who may seek out bear hugs and crave lots of motion.
- The second includes people with sensory motor disorders, who may seem clumsy and uncoordinated.
- The third encompasses people who have trouble discriminating between the different senses.

WHAT THERAPY INVOLVES

Therapy is typically used to treat people with sensory processing disorder. Experts say it's important to seek out an occupational therapist who has extensive training and experience with SPD, or who is certified to administer the Sensory Integration and Praxis Test, the official diagnostic test.

A symptom checklist, parent questionnaires and interviews may also be done for diagnosis.

Recommended therapy includes weekly (if not more frequent) sessions and daily sensory "diets" that involve brushing the limbs with a surgical brush, putting tension on joints, doing exercises and doing heavy work to stimulate muscles and joints.

Not all insurance companies cover therapy, and a session can cost \$90 to \$160.

— SOURCES: LUCY J. MILLER, SENSORY PROCESSING DISORDER FOUNDATION; NICOLE CYPHERT, INTEGRATION STATION; TONI SCHULKEN, PATHWAYS FOR LEARNING.

SENSORY

■ from 1D

chiatric Association.

A touch feels like a shove

It's important to note the differences between a child with sensory processing disorder and a child who's just picky or problematic, experts say. For example, a typical child who steps from an air-conditioned room outside into the heat may whine and complain for a bit. But for a child with sensory problems, it can be almost unbearable.

A typical child who complains that a poke feels like a shove may just be trying to get attention or pick a fight. But to a child with sensory problems, that poke really does feel like a shove.

Kids can be clumsy, but children with sensory problems may struggle in vain to write with a pencil because the motor skills are just so off. Academic and social problems often ensue.

Children's lives aren't segmented, so "if something is going awry, then other things are going to be affected," said Toni Schulken, director of the Charlotte occupational therapy practice Pathways for Learning.

Sensory processing problems occur when the brain's neurons can't correctly interpret incoming signals, said Lucy Jane Miller, executive director of the Sensory Processing Disorder Foundation in Colorado.

When the signals are mixed up, that affects the senses of touch, movement and balance, and space, she said. In the sensory processing world, these are known as the tactile, vestibular and proprioceptive systems.

But there's no cure for sensory processing disorder. Rather, occupational therapists help patients learn to cope.

The SPD Foundation is trying to get the disorder recognized in the "Diagnostic and Statistical Manual of Mental Disorders," the official catalog of mental disorders. The next edition, known as the DSM-5, comes out in 2013.

To put things in perspective, autism wasn't included in the DSM until 1980. Before then, it was seen as a form of childhood schizophrenia. And even when it was recognized, it was limited to just one type and six



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Antonio Turrisi's therapy includes inchworm walks around a big mat, which requires the ability to implement "praxis," or motor planning, to do the multistep crawl. He also rides on a giant swing, with his therapist pushing him in wide circles to right his sense of balance.

symptoms until 1987, according to the nonprofit Autism Speaks.

But Eric Taylor, who is in the work group for childhood disorders for the DSM-5, said sensory processing disorder isn't included in the current draft because there isn't yet a clearly defined description or set of symptoms.

For a disorder to be added to the manual, it must fulfill a list of requirements that includes scientific validation and distinction from other disorders, said Taylor, a professor at the Institute of Psychiatry at King's College in London.

"We're not ruling it out for all time and not saying it's a definite 'no,' it just hasn't yet passed the mark," Taylor said.

Will they grow out of it?

Research is still being done to find a cause - what makes those neurons incorrectly interpret multiple signals, said Miller, of the SPD Foundation.

Brain wave research done by the foundation suggests that children with sensory issues have a jumpy response to sensory stimuli, no matter how many times they're exposed to it. Typical children would have jumpy responses only the first or second time, Miller said.

Some doctors acknowledge that sensory issues are real, but that these issues don't indicate a disorder so much as an immaturity of neurological development. In other words, kids eventually grow out of it.

Other disorders

Sensory processing disorder is commonly coupled with other learning or developmental disorders. It is sometimes mistaken for attention deficit disorder, because in both cases there is a perceived inattentiveness and need for movement. Autistic people also have sensory problems, but certainly not all people with sensory problems are autistic.

For more information on sensory processing disorder and to find a qualified occupational therapist near you, visit www.spdfoundation.net.

"Children who appear to be hypersensitive to certain stimuli - that is a real phenomenon," said Dr. DuBose Ravenel, a High Point pediatrician who focuses on behavior. "But the question is whether it represents a pathology, or just some combination of factors," like the child's temperament and parents' reaction to behavior.

Ravenel co-wrote a book that speaks out against the labeling and diagnosis of atten-

tion deficit hyperactivity disorder with family psychologist John Rosemond, who writes a parenting column that appears in The Observer. Rosemond argues that the symptoms exhibited by children with sensory processing issues are really just behavioral problems that can be handled with discipline.

If a girl exhibited symptoms and was diagnosed with SPD but a behavioral approach cured her, that "impeaches the theory behind it," Rosemond said.

Parents see the effects

Some families beg to differ. They've seen the problems with their children, and they've seen the effects of therapy.

For Noah Kellar, a 9-year-old who lives in Charlotte, affection and physical contact from doting family friends used to put him in a constant panic mode.

"It was irritating, and I'd get mad," Noah said. "There was just too much going on."

It became embarrassing for the family because people thought Noah was being rude or disrespectful. He couldn't play well with other kids. They tried discipline and incentive, but nothing fully

worked.

Danetta Kellar, a licensed speech pathologist, knew something was different about her son since he was 18 months old.

"As a professional and a parent, I knew something was up," she said. She took him to an occupational therapist, and after a long examination, he was diagnosed with SPD.

Three years of therapy later, Noah is a typically functioning rising fourth-grader. He knows that if he starts to get anxious about something, he needs to move around to calm down. In fact, when his SPD was at its worst, his mother made a tip sheet for his teachers so they'd know how to deal with different behaviors.

At Pathways for Learning in Charlotte, therapists work with kids in rooms filled with gym mats, swings, trampolines and crafts.

Seven-year-old Antonio Turrisi's session on a recent afternoon started with a ride on a giant swing. His therapist, Courtney Enos, pushed him in wide circles to right his sense of balance.

Then, she had him do inchworm walks around a big blue mat, which requires the ability to implement "praxis," or motor planning, to do the multistep crawl. Next

was a strategy game conducted while lying in a suspended hammock, then a clay-and-beads exercise followed by a word search.

Before therapy, Antonio's mom, Jennifer, said he was always unusually clumsy and could barely write his name across a piece of paper. She took him to a number of other therapists, but he made little progress - until now.

After about eight months of therapy, Antonio can sit still in a chair and write all the uppercase and lowercase letters of the alphabet.

"I thought this was something he was going to have to outgrow or that he was just being extremely fussy," she said. "But I knew we had to do something, and I was willing to try anything to help him."



J. Turrisi

THEY JUST CAN'T STAND IT by Amanda Chan

I enjoyed writing and reporting this article the most out of all the work I did this summer. It involved balancing my own personal views with those of the people I was interviewing. It all came to be when my editor told me about a parenting column by a family psychologist that had run a couple weeks prior. He basically said sensory processing disorder did not exist, but rather it was a behavioral problem that parents should try to resolve using discipline. This contention struck a severe cord with many parents in the Charlotte area who had children with the supposed disorder. Considering the disorder is not recognized by the American Psychiatric Association (APA), nor the Diagnostic and Statistical Manual of Mental Disorders (DSM), I knew I couldn't just talk about it as if it was something as recognized as, say, autism or bipolar disorder. I knew I couldn't just take people's words for it. I talked to at least six different occupational therapists, to make sure I completely understood this complex disorder. I talked to at least 10 different families, all sharing their experiences with the disorder and the effect that therapy had. I talked to doctors who didn't necessarily believe it. I talked to people from the APA to see why they didn't want to include it in the DSM. I talked to the head honcho of sensory research in Colorado, who told me her side of things. And, to see things for myself, I read all the studies that came out to use as support for the article – but didn't just take the studies at face value. The resulting article, I thought, was fair. My editor helped me to pepper in words like “advocates say” and to keep my biases in check throughout, too. In the end, a story ran in the paper that I felt comfortable backing up if someone were to question any of my reporting.

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