

The Next Attention Deficit Disorder?

By [Claudia Wallis](#)

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With a teacher for a mom and a physician's assistant for a dad, Matthew North had two experts on the case from birth, but his problems baffled them both. "Everything was hard for Matthew," says Theresa North, of Highland Ranch, Colo. He didn't speak until he was 3. In school, he'd hide under a desk to escape noise and activity. He couldn't coordinate his limbs well enough to catch a big beach ball.

Matthew, now 10, was evaluated for autism and attention deficit hyper-activity disorder, but the labels didn't fit. "We filled out those ADHD questionnaires a million times, and he always came out negative," Theresa recalls. "When we found this place, I cried. It was the first time someone said they could help."

This place is the Sensory Therapies and Research [STAR] Center, just south of Denver, which treats about 50 children a week for a curious mix of problems. Some can't seem to get their motors in gear: they have low muscle tone and a tendency to respond only minimally to conversation and invitations to play. Others are revved too high: they annoy other children by crashing into them or hugging too hard. Many can't handle common noises or the feel of clothing on their skin. A number just seem clumsy. Adults can remember kids like these from their own childhood. They were the ones called losers, loners, klutzes and troublemakers. At STAR Center they wear a more benign label: children with sensory processing disorder (SPD).

Never heard of it? You're in good company. Neither have many pediatricians, neurologists, psychologists and teachers. But in the parallel universe of occupational therapy, which focuses on the more primal "occupations" of life--dressing, eating, working, playing--SPD is commonly treated. Last month, at a conference on SPD in New York City, 350 occupational therapists (OTs) and others gathered to hear about the latest research and therapies.

OTs have been treating SPD, also known as sensory integration dysfunction, since 1972, when A. Jean Ayres, a University of Southern California (USC) psychologist and occupational therapist, published the first book on the condition. As defined by Ayres and others, SPD is a mixed bag of syndromes, but all involve difficulty handling information that comes in through the senses--not merely hearing, sight, smell, taste and touch, but also the proprioceptive and vestibular senses, which tell us where our arms and legs are in relation to the rest of us and how our body is oriented toward gravity. Some kids treated for SPD can't maintain an upright position at a desk; some are so sensitive to touch that they shriek when their fingernails are trimmed or if they get oatmeal on their face.

Sounds and smells can be overwhelming. When lawn mowers roar outside the home of Lizzie Cave, 4, a STAR child, she's been known to vomit.

Families that find their way to the STAR Center and other groups that treat SPD typically have traveled a long road to get there. Their common refrains: My doctor doesn't believe in SPD; teachers can't handle it; insurance won't pay for therapy. There's good reason for that. SPD is not listed in medical texts or in the Diagnostic Statistical Manual (DSM), the bible of psychiatric disorders. Doctors acknowledge sensory issues as a common feature of autism and a frequent feature of ADHD but not as a stand-alone disorder. Lucy Jane Miller, a former protégé of Ayres and head of the STAR Center, is spearheading a campaign to change that. She has organized a national effort to have SPD added to the next edition of the DSM, the fifth, due out in 2012. Earning a spot in the DSM V would make it easier for researchers to win grants, kids to get accommodations at school and families to be reimbursed for a course of treatment, which, at the STAR Center, often costs \$4,000.

To receive recognition, advocates must provide persuasive evidence that "this is not just part of autism or ADHD, that it's a better definition of what these kids are experiencing," says Dr. Darrel Regier, director of research for the American Psychiatric Association and vice chair of the DSM V task force. What's needed, says Regier, is a body of peer-reviewed studies that defines "a core set of symptoms, a typical clinical course" and, if possible, good treatment data.

SPD research so far is provocative but limited. "It's hard to get grants for a disorder that doesn't exist," laments Miller, whose recent book, *Sensational Kids*, offers a guide to both research and treatment. Many studies are flawed by vague criteria for identifying the condition, samples that include kids with other disorders, and an utter lack of standardized treatment.

But Miller and others have been slowly building a research base. Studies at her SPD Research Institute, adjacent to the STAR clinic, have identified neurological differences between children with sensory-processing problems and typical kids. In one set of experiments, electrodes are attached to children's hands to measure nervous-system activity in response to a series of stimuli that include a siren, a powerful wintergreen scent, the brush of a feather against the cheek--each repeated eight times. A healthy child will show a strong electrodermal response--basically a measure of sweating or stress--to the first exposure but will quickly habituate, showing little response to the final repetitions. Kids with one brand of SPD jump through the roof with every repetition. "It's as if they are stuck in fight-or-flight mode," says researcher Sarah Schoen.

Other experiments at the University of Colorado have found that kids with sensory problems have atypical brain activity when simultaneously exposed to sound and touch. And a 2006 study of twins at the University of Wisconsin gave evidence that hypersensitivity to noise and touch have a strong genetic component.

No one can say with certainty how many kids are severely affected by sensory problems, though preliminary work by Miller suggests it may be 1 in 20. A critical question is where to draw the line between what's normal and what's pathological (see sidebar). Studies conducted by Alice Carter, professor of psychology at the University of Massachusetts, Boston, suggest that 40% of children ages 7 to 10 are so sensitive to touch that tags in clothing annoy them, and 11% overreact to sirens. But no one would claim that all these kids have a sensory disorder. Carter thinks SPD is too vaguely defined for prime time in the DSM. Instead, she favors adding it to a section at the back of the manual on disorders that warrant further study. Granting it such provisional status would open the door to more research funds. Then, if validated, SPD could have a shot at being included in the DSM VI--due out somewhere around 2025.

But parents of children who are struggling today are not inclined to wait 18 years, so they spring for therapy that has only anecdotal validation. Treatment is highly individualized, but much of it involves guiding the kids to do more of the things they don't do easily and respond less to the things they can't abide. Lizzie Cave works on noise sensitivity by listening to a calibrated series of audiotapes. Jacob Turner, 3, improves his tolerance for food textures by playing with gooey concoctions and allowing a therapist to put them ever nearer his mouth.

Families get instructions on how to adjust their children's "sensory diets" to help them function better at home and in school. Christopher Medema, 7, now puts a weighted blanket on his lap when he's doing seatwork at school. The steady pressure meets some of his need for tactile input and helps him focus. His family has learned to accommodate his craving for motion. "He likes doing math flash cards standing on his head," says his dad, Steven.

As for Matthew North? He still looks a little limp while dangling from gym equipment, and the blue eyes peering above a sprinkling of freckles gaze warily at people he doesn't know. But the boy who couldn't catch a beach ball last summer is now learning Tae Kwon Do and even soccer. "I saved a couple of goals," he admits, with a little prompting from Mom. That sounds an awful lot like recovery--from whatever it is that ails him.

The original version of this article misidentified occupational therapist A. Jean Ayres as having been on the faculty of UCLA. In fact, Ayres taught and did her groundbreaking research on Sensory Processing Disorder at the University of Southern California (USC).