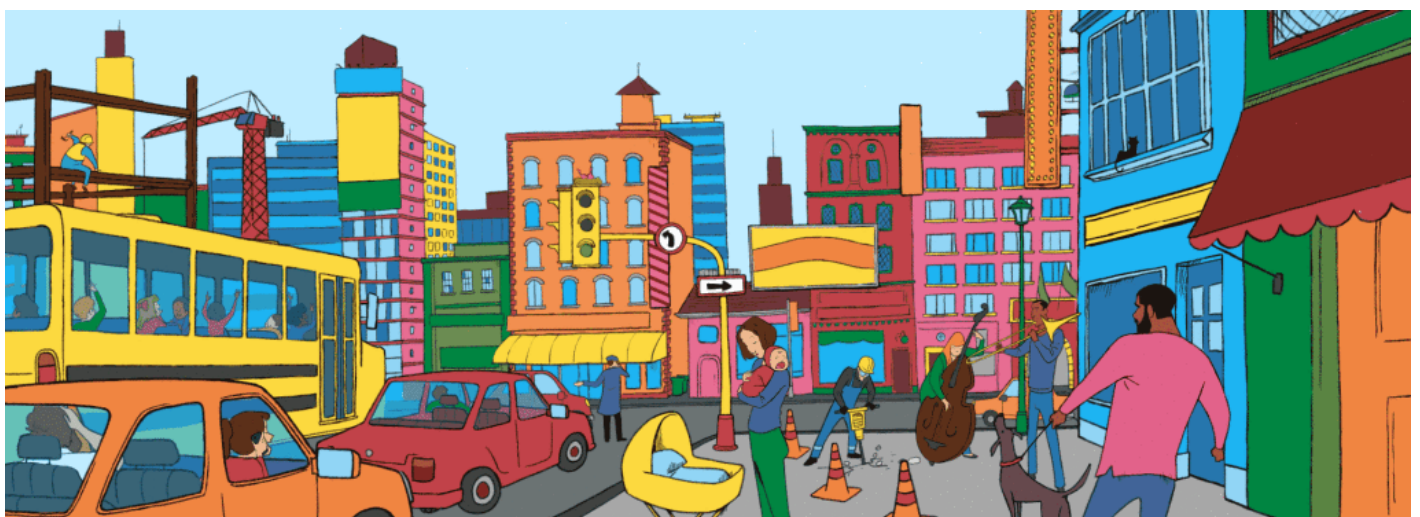


DEEP DIVE

Talking sense: What sensory processing disorder says about autism

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*Illustrations by Alois di Leo*

Jack Craven has superpowers. When his mother, Lori, misplaces an item in the house, she asks the 12-year-old to “look in your head,” through the rich catalog of visual information he seems to assemble without effort. Jack always finds the lost object. His astonishing memory for faces enables him to pick out someone he’s seen only once or twice before from a sea of strangers in a crowded school gymnasium. His sharp hearing makes him an excellent vocal mimic. Request that he sing a Beatles tune and he’ll ask if you want it sung in the style of Lennon or McCartney.

But great powers, as any superhero narrative goes, come with great challenges. He endures, rather than enjoys, the arcade birthday parties popular among tween boys in suburban Atlanta where he lives. They’re just too noisy, too busy, too overstimulating. Jack’s hearing is so sensitive that he can’t always eat at the table with his family, because the sound and sight of them chewing might make him throw up. As an infant, he never slept for more than four hours at a stretch, and had to be held upright the whole time, his stomach pressed against his mother’s chest and her palm pressed atop his head.

Jack has sensory processing disorder (SPD), a condition that includes people who are overly sensitive to what they feel and see and hear, but also those who are undersensitive, and still others who have trouble integrating information from multiple senses at once. SPD is not an official diagnosis. It isn't included in the newest edition of the "**Diagnostic and Statistical Manual of Mental Disorders**" (DSM-5). Still, it is widely used as a catch-all by clinicians, and some studies suggest that it may affect **between 5 and 15 percent** of **school-age children**. Children with the clinical label SPD also have a lot in common with children diagnosed with autism, up to 90 percent of whom also **have sensory difficulties**.

Jack doesn't have autism, but Ari Young, who lives a few hundred miles away in North Carolina, has both SPD and autism. And Ari, too, has certain impressive abilities, thanks to his super-sensitive senses. His acute visual memory allows him to recite articles from Wikipedia nearly verbatim — although, unless the article is on a history- or science-related topic he's particularly interested in, he may be able to recall the information only in the order in which he learned it. Ari's mother, Heather McDanel, says his sensory peculiarities and his autism are all bound up together. With many of his idiosyncrasies, "I don't know if that's the autism or if that's sensory, or a combination of the two," she says.

Like Jack, Ari also had sleep-related quirks as an infant: He could drift off only while rocking in a baby swing to a recording of birds chirping, and his bleary parents had to restart it every 15 minutes throughout the night. A speech therapist first mentioned SPD when Ari was not yet 2 years old; the autism diagnosis came later, when he was 2 and a half.

Even today, at age 9, Ari tends to hum to himself either when it's too quiet or to drown out noise. He attends third grade in a mainstream classroom, but his sensitivities sometimes make school a struggle. A few months ago, when an unexpected announcement that class would be dismissed early caused his fellow students to erupt into happy chaos, the hubbub sent Ari running, sobbing with confusion and surprise, to the front office.

Sensory problems can not only disrupt a child's ability to learn in school and form friendships, but upend the lives of whole families. "These are really challenging kinds of problems for children, whether they're diagnosed with something or not," says **Grace Baranek**, professor of occupational science and occupational therapy at the University of North Carolina at Chapel Hill. And for families, it can be difficult to get help.

Yet SPD also offers an opportunity: Studying people who have sensory problems with or without an autism diagnosis could help these children and provide insight into the relationship between sensory problems and the core social and communication problems seen in autism. It's easy to imagine that a young child who hardly registers the sights and sounds of the surrounding world may not tune in to her father's games of peekaboo, and may miss out on these formative moments of communication. Meanwhile, a child for whom those sights and sounds are unusually intense may be too overwhelmed to focus on his mother's attempts to catch his attention and never learn

some of the subtleties of the social world.

In the past several years, the advent of more precise, objective ways to measure sensory responses and behavior, coupled with imaging techniques that pinpoint how the brain processes sensations, are providing a window into how this process goes awry — and perhaps, ultimately, how to get it back on track.

“She’s not afraid of bears or afraid of dying,” Linda told the pediatrician. “She’s afraid of socks.”

Forgotten history:

Sensory differences were part of the first descriptions of autism, but were ignored for many years. Leo Kanner’s 1943 paper **first introducing the concept of autism** opens with an account of one boy’s precocious singing skills, remarkable memory for faces, and aversion to ordinary childhood pleasures such as riding a tricycle or sliding down a slide. Kanner and other researchers also noticed that many children with autism were hypersensitive to loud noises or seemed indifferent to pain.

But in the early decades, research on these aspects of autism was mostly descriptive and speculative. Few researchers were gathering empirical evidence about how children with the condition experienced the world. By the 1980s, interest in this area had fizzled.

Meanwhile, outside the context of autism research, an occupational therapist and neuroscientist named A. Jean Ayres was developing the theory that processing and integrating basic sensory information underlies many daily living skills. “It’s hard to imagine now, but people didn’t understand that when a child was having some difficulty moving their hands to button their coat, or to do some kind of school activity, that this could be related to brain function,” says **Roseann Schaaf**, professor of occupational therapy and neuroscience at Thomas Jefferson University in Philadelphia, Pennsylvania.

In the early 1970s, Ayres first described ‘sensory integration dysfunction,’ in reference to these difficulties with everyday activities. As researchers learned more about the brain mechanisms involved, the term ‘processing’ replaced ‘integration’ and the condition became known as SPD. Ayres developed tests for identifying these troubles, such as asking a person to identify which finger has been touched without looking. She also created sensory integration therapy, which involves activities that engage multiple senses simultaneously, such as finding objects hidden in sand or a bin of beans, or sitting on a swing while batting at a suspended ball.

Ayres' work became enormously influential among occupational therapists — healthcare professionals who help people with everyday life skills. These days, occupational therapists are primed to consider sensory explanations for a child's difficulties with, say, handwriting or teeth-brushing. And many occupational therapists still use Ayres' therapy or something similar to help with these problems.

By the early 2000s, autism researchers began to rediscover sensory processing, thanks to new tools in brain imaging and psychophysics, the precise measurement of the brain's electrical responses to stimuli. There has also been a growing appreciation that **sensory difficulties** are a big part of **what makes autism so difficult** to cope with. Today, they're such a widely recognized aspect of autism that they are included in the diagnostic criteria for the condition.

Still, many child psychiatrists do not see SPD as a distinct diagnostic label. They say the symptoms are too diverse and there's too much uncertainty about what SPD is and how to distinguish it from other conditions such as autism, attention deficit hyperactivity disorder (ADHD) or anxiety. "We know that sensory issues are important in a variety of kids with a variety of different diagnostic labels," says **Carissa Cascio**, assistant professor of psychiatry at Vanderbilt University in Nashville, Tennessee. Those who have sensory problems without any of the other conditions are rare, she says.

But some parents say this doesn't jibe with their experience, and that their children's problems are fundamentally perceptual in nature. Linda, the mother of a child with SPD, recalls that her daughter had always been very particular, almost obsessive, about what clothes she would wear. But these quirks morphed into a full-blown terror of going to school once she entered first grade; she worried about having to go to an assembly, or having to use the bathroom with its loud, unpredictably flushing toilets. (Linda asked that we withhold her last name to protect her daughter's privacy.) A pediatrician gave an anxiety screening questionnaire to see if Linda's daughter might qualify for that diagnosis, but initially the label just didn't seem to fit, Linda says. "She's not afraid of bears or afraid of dying," Linda told the pediatrician. "She's afraid of socks; she's afraid of hats."

In fact, a 2012 twin study found that just over **half of children** with sensory sensitivities do not qualify for diagnoses such as anxiety, depression or ADHD (the study did not consider autism).

Meanwhile, the million-dollar question remains: What's the difference between children who have autism and the perceptual processing problems that usually accompany it, and those who have the problems alone? Why does Ari have an accepted condition — autism — that includes being easily overwhelmed by noise, whereas Jack has similar struggles but no such diagnosis? Looking carefully at the differences between children like them may help answer these questions. "An approach like that is incredibly useful because it can give us a compare-and-contrast view of what's specific to autism and what's more general to sensory differences in a broader sense," Cascio says.

How it feels:

The controversy over SPD has created a conundrum in pursuing that research, however. “It’s very hard to get funding for research on something that doesn’t exist,” says **Lucy Miller**, an occupational therapist and founder of the **SPD Foundation**, a nonprofit research and advocacy organization. And, of course, it’s difficult to establish whether SPD should be considered a stand-alone condition without studying people who have it. “These are kids that aren’t necessarily being referred to studies because they don’t have a disorder” as defined by diagnostic manuals, says **Elysa Marco**, director of the Sensory Neurodevelopment and Autism Program at the University of California, San Francisco. “It’s sort of a round robin.” Her group is running a **crowdfunding campaign** to support their SPD research.



A handful of researchers have been able to investigate SPD as a separate entity, and their findings are advancing the argument that it deserves its own diagnosis. Some children who don’t fit any

recognized condition nonetheless have atypical sensory systems, these studies find. Researchers in one study used electrodes placed on the skin to show that children who have this informal clinical label **react more strongly to everyday stimuli**, such as the sound of a siren or the stroke of a feather across the face, than do either controls or children with ADHD. Another study showed that the parasympathetic nervous system, which slows the heart rate and breathing, is **less active in people with sensory processing** problems than it is in controls.

The most compelling evidence that SPD has a distinct neurological basis comes from a 2013 study that found that boys with SPD have **atypical white matter** (long nerve fibers) connecting regions related to sensory processing. “They have real, measurable brain connectivity differences,” says Marco, who worked on the study. A follow-up study published earlier this year adds to the picture: Brain connections are altered in girls with SPD as well, and the more severe a child’s difficulties with processing sound, the more **pronounced his or her white-matter alterations**.

These studies also show some intriguing parallels between children with autism and those with sensory difficulties but no formal diagnosis. For example, children with autism show **dampened parasympathetic nervous system activity** similar to that seen in children who’ve been described as having SPD. And children with autism, just like those with SPD, have abnormalities in **white-matter pathways involved in processing sensations**.

“It’s a possibility that these groups started out very similarly and there’s some sort of protective factor that keeps people with sensory processing differences from becoming kids with autism,” Cascio says. But so far, that’s just speculation.

There are also differences between sensory problems in autism, SPD and other conditions, and these are only beginning to be mapped out. Children with autism have **disruptions in brain connectivity** along social and emotional pathways, whereas those pathways are intact in children with SPD alone. Children with SPD tend to **have more problems with touch than do those with autism**, whereas children with autism **struggle more with sound processing**. This may explain why language and communication problems are characteristic of autism.

Whether a child is oversensitive or undersensitive may also play some role in what diagnosis she winds up with. Dampened responses to a new sight, sound or touch are **more common in autism** than they are in children with SPD or **other conditions**, whereas a sensory system that is dialed all the way up is seen across autism, **ADHD** and anxiety alike. As toddlers, children with autism also tend to have **more profound sensory abnormalities** than do those with developmental delays.

The notion that sensory problems underlie autism symptoms makes sense, but has yet to be tested, says **Sophie Molholm**, associate professor of pediatrics and neuroscience at Albert Einstein College of Medicine in New York. “I wouldn’t even want to say that the sensory processing issues are causal,” she says. “We don’t know that at all. We just know that these are symptoms that we frequently see in these disorders.”

It could also be that how perceptual problems relate to autism depends on the child. “I think this is part of the conundrum of autism,” Marco says. “Are kids simply not showing [social] awareness and interest ... because they are so sensitive that they have shut it out completely? Or are they really, truly at their base just not interested?”

“These are really challenging kinds of problems for children, whether they’re diagnosed with something or not.” Grace Baranek

Sense and sensitivity:

These questions matter because children who are chronically flooded with sensations, or are distant from the world around them, need help — whether they have autism or not.

Many of the day-to-day struggles of people with autism have to do with perceptions gone haywire, such as being overcome by sounds, or feeling a revulsion toward certain foods. This home truth may often go unnoticed and unaddressed by clinicians, but it has a powerful impact on family life.

Some parents of children with autism are big fans of sensory integration and similar therapies. They say the interventions help soothe the most disruptive problems of everyday life. Jennifer, the mother of a teenage boy with autism and **fragile X syndrome**, a related condition, says the occupational therapy her son began around age 3 was transformative. He was nonverbal at the time, and thanks to this therapy, she finally understood that her son’s senses were wired in a way to make some things soothing and others bothersome to him. “We realized that’s why he likes his hands rubbed so much, and his arms squeezed,” says Jennifer. (She asked that her last name be withheld to protect her son’s privacy.) It helped her grasp why her son demanded tight pajamas, and would only wear one particular pair of shoes. “It started making sense to us,” she says — and made it easier for her to meet his needs.

Until a few years ago, the evidence supporting sensory integration therapy for children with autism or other conditions was relatively thin. And some practices of therapies that focus on sensation, such as working with playdough, hanging upside-down, or brushing a child’s skin to desensitize him to touch, can seem unscientific or even downright bizarre. The approach is also difficult to study because it tends to be ad-hoc. Clinicians “come up with treatment plans that are highly individualized, and that’s another challenge for really rigorous scientific study,” says Cascio. “It becomes really difficult figuring out what the relevant outcomes are, how are you going to measure them, how you measure improvement.” And in the past, the field was generally more focused on therapeutic practice than on creating standardized interventions.

Some families of children who lack an official diagnostic label struggle to get any help at all. “There

are a lot of people who suffer from this kind of difficulty, and they're not able to access services or get the kinds of accommodations they need in schools, or early intervention, without the diagnostic label," says Baranek.

Lori Craven is homeschooling her son Jack because she says it was too difficult to get the public school system to accommodate him. Because Jack doesn't have hearing loss, he wasn't eligible for an assistive technology that amplifies his teacher's voice to help him focus. Because he doesn't have vision impairments, the school balked at providing enlarged, simple-looking versions of worksheets, or even allowing Lori to prepare them. "I just realized I was spending so much time fighting the school — I was trying to do it for them, and it was too much to ask," Lori says.

Savvy parents of children with SPD often seek out an additional diagnosis such as anxiety or ADHD — or embrace one when it is offered. Linda says that in the end, it was her daughter's anxiety label that helped the family arrange an individualized education plan for her daughter. The anxiety diagnosis "seemed to be the language that the school understood best," she says.



This fancy footwork around labels and diagnoses may become a thing of the past as researchers

pursue the ultimate goal: figuring out which treatments for sensory problems are effective. They hypothesize that the right treatments will work whether a child has autism, anxiety, ADHD or no diagnosis at all, as long as the underlying problem, such as being too sensitive to touch, is the same. “You’re trying to establish what the commonalities are,” Baranek says. “And looking to see if those interventions actually help in similar ways despite the different diagnoses.”

That means tailoring the treatment to the child rather than to the diagnosis. “I think [occupational] therapists do this on the fly,” says **Alison Lane**, associate professor of occupational therapy at the University of Newcastle in Australia. “But we don’t have a systematic way of saying, ‘This child with this particular pattern of behavior and sensory features will respond best to this type of approach.’”

Lane and others have begun **defining sensory subtypes** within the autism spectrum, in an effort to more systematically **match symptoms to treatment**. She plans to use this framework to guide therapy in a pilot study later this year.

A **precisely defined procedure** for choosing sensory therapies in autism will also help make studies in this area more rigorous, says Schaaf, the Philadelphia-based occupational therapist and neuroscientist who led the development of such an approach. She is using it to test whether sensory therapy or a more standard autism treatment is better at boosting the ability of people with autism to integrate auditory and visual information.

A small pilot study of this approach found that sensory therapy in children with autism improves not only their perceptual difficulties but **also their social skills**. “That was unexpected,” says Schaaf. “We didn’t hypothesize that at all.” In their follow-up, the researchers are collaborating with Molholm’s team to track the children’s sensory integration abilities through electroencephalography to observe brain activity, as well as monitoring how they are doing in daily life. The study, slated to run for five years and involve 200 children, began enrolling participants in February.

Researchers are also applying neurobiology findings to treatment studies of SPD. Marco is collaborating with the SPD Foundation on a pilot study to scan the brains of children with SPD before and after occupational therapy, in order to determine whether the intervention improves brain connectivity.

In the meantime, Ari Young has come up with his own way of managing his highly attuned brain, on top of the therapies he gets for autism. He often wears headphones at school to block out distracting or distressing noises, but he has noticed that most other kids don’t wear them. “I used to feel like wearing headphones would just kind of pin me out of the rest of the group, make me look like I was not paying attention,” he says. They also make it more difficult for him to hear what his teacher is saying.

So Ari has been conducting a sort of informal sensory therapy, challenging himself to briefly take his headphones off during events such as school assemblies and performances. “Sometimes there are quiet moments at loud concerts, when ... I decide to peek open the headphones a little bit,” he says. “And then when the next loud part comes, I snap them back on as fast as I can.”