

Lost in Translation

By Kathy Summers

In *Leaves of Grass* Walt Whitman wrote, "I sing the body electric," and he was right about one thing: The body's electrical messages to the brain—not the brain itself—color our world. But what if your body's messages misfire, as they do in children with Sensory Processing Disorder? Then Mozart might sound monstrous, and a barefoot walk in the grass could feel like a walk over worms.

Kelsey Ganes got kicked out of preschool at age 2 1/2 because she wouldn't finger paint with chocolate pudding. Now 15 and already taking college classes, she says flunking preschool was a big relief.

"I knew I was never going to finger paint; it just wasn't going to happen," she explains. But the problem wasn't just the pudding, it was the whole school experience. The smelly markers, slimy paste, and noisy children all sent Kelsey into sensory overload. Running through sprinklers made her goose bumps hurt and walking through wet grass made her skin crawl. Until age 4, she couldn't even enter a grocery store without having a meltdown. "Between the lights and the noise and the smells of everything cooking over in the deli—I just couldn't do it," she recalls. "I'd have a tantrum in the middle of the store, which isn't such a good thing."

When Kelsey was a baby, her mother Kristine would cry as she watched other infants molded to their mothers' shoulders, cooing. "Kelsey had to be facing straight out," she recalls. Later Kristine saw other children playing at birthday parties, sometimes breaking down in exhaustion afterwards, but with Kelsey it was different. She'd freeze up in complete overwhelm right in the middle of the party.

Kristine learned to look for signs that her daughter was about to melt down and would quickly remove her from the situation. Well-meaning friends told her she was spoiling Kelsey, that she was overprotective and hovering. Finally, when Kelsey was seven, Kristine's feeling that something was wrong was finally confirmed. Her daughter was diagnosed with sensory processing disorder (SPD), a complex brain condition that affects about one in 20 children (and probably more).

Children with SPD often behave in ways that make them seem like bad kids, even though they're not—they're just wired differently, says Lucy Jane Miller, PhD, OTR, an occupational therapist, lead SPD researcher, and author of *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder* (Penguin, 2006). "The information comes in, a response goes out, but the response isn't lined up with the information." Other than this sensory disconnect, these children are normal and just as intelligent as other children. Like Kelsey, many are intellectually gifted. No one knows what causes SPD, but experts suspect birth-related injuries or other early life traumas.

Making sense of sensory issues

Everyone experiences some sensory overload, Miller explains. When you drive home from a hectic day at work in heavy traffic and then walk in the door to hear your kid's radio blasting, it's normal to want to yell, "Turn that off."

But for children with SPD, the brain decodes sensory information differently, so they don't respond appropriately. They may overreact to the smell of perfume, the sound of background noise, or the feel of water with temper tantrums, withdrawals, or anxieties that interfere with their normal life.

For example, as a baby Danny Shaw cried so hard his whole body turned red whenever his parents tried to bathe him. When his mother Mia so much as pressed her cheek against his, the skin turned bright red. Sudden sounds startled him, and he wanted to nurse continually for comfort whenever people came to visit.

Some children with SPD under-react, not crying when seriously hurt or even noticing when someone touches or calls them. They seek out intense sensory experiences, some of them disruptive or dangerous. They often get misdiagnosed with attention deficit hyperactivity disorder (ADHD), although they may actually have both conditions along with other developmental or learning difficulties.

Still others get lost easily, fall off playground equipment, overshoot a chair, or have trouble sorting words from background noise. Some have trouble with everyday movements like opening a car door and getting in the seat. They appear clumsy and have trouble learning to crawl, walk, run, or ride a bike.

This may seem like an odd assortment of behaviors, but they all stem from a single nervous system process, says Brock Eide, MD, who runs the Eide Neurolearning Clinic in Edmonds, Washington, with his wife, Fennette Eide, MD. Not every child with these symptoms has SPD. But if you see a pattern of behaviors that interferes with your child's social life and skill development, the sooner you seek an evaluation the better.

"These children know they're different," says Kristine. "When they see other kids having fun licking the frosting off cupcakes, and it gives them a gag reflex, they want to know what's wrong with them and why they can't be like everybody else."

The dangers of misdiagnoses

If any of this sounds familiar, find a neurologist or qualified occupational therapist (OT) to either rule out or medically pinpoint specific problems. OTs can help your child function better in his daily routines and roles—"occupations" like eating, sleeping, getting dressed, playing with others, and school work.

Trust your own instincts and, if necessary, seek other opinions. Because many SPD behaviors overlap with better known disorders like ADHD, oppositional defiant disorder (ODD), Asperger syndrome, and others, a great number of children who actually have SPD get misdiagnosed.

The real danger? Children who get misdiagnosed also get the wrong treatments. "We've seen kids on three or four medications at a time," says Fennette Eide. "For years they've been given, unsuccessfully, different types and combinations of medications."

Adding to the confusion, the name of the disorder has changed. When occupational therapist A. Jean Ayers pioneered the study of sensory integration theory in the mid-1900s, she called the disorder sensory integration dysfunction (SID). Others called it dysfunction in sensory integration (DSI). By any name, researchers find the study of the disorder extremely challenging, which

may explain why it isn't yet listed in the Diagnostic and Statistical Manual (DSM), the standard for diagnosing most childhood disorders. One study does show that sensory-motor conflicts cause long-term sensory symptoms and pain. But many pediatricians remain skeptical, possibly because the individualized treatments are difficult to validate and no pharmaceutical solutions exist.

While researchers seek funding for more studies, parents are just happy to find treatments that work. Mia, for example, has seen clear progress with therapy since Danny's neurological evaluation a year ago at the Eide Neurolearning Clinic. The Eides quickly ruled out the previously suspected Asperger syndrome and diagnosed SPD. "Within two or three sessions, we noticed a huge difference in his interactions with other children," says Mia.

Danny's therapy at the clinic consists of simple activities, such as working with different textures, throwing bean bags at a target, and climbing around in a big hammock. At home, Mia learned to redirect Danny's destructive energy by asking him to vacuum or carry heavy bags of groceries. When he has trouble processing sensory stimulation, Mia holds up her hands and has Danny push against them with the palms of his hands.

"It's hard to describe and explain the connection between the physical activities and Danny's social and emotional development, but we can see that it works," says Mia. Now five years old, Danny is learning to tone down his overreactions to sounds. Although he's still wary of water splashing his face, he's much more relaxed at bath time.

Different treatments for different troubles

Neurological rehabilitation for SPD involves therapies personalized to how each child processes information. For example, Kelsey's occupational therapist used her love of swinging as a tool for teaching her to respond normally to creamy textures, something many children with SPD find unbearable. While swinging on her belly, Kelsey had to slide her hands and feet across shaving cream placed on a mirror on the floor. With the swing to comfort her, the once icky substance began to feel okay. At that moment, the therapist explained, "This is what cream normally feels like."

Children whose problems include auditory processing do well with a combination of occupational therapy and listening therapy. The inner ear acts as a relay station for sensory input to the brain, so listening therapy helps the child perceive information from all the senses.

Others need vision therapy. In the nervous system, all the senses balance each other out, and sometimes one sense is at the heart of a problem that affects the others, says Fernet Eide.

For other children, getting to the root of the problem might call for speech or physical therapy, but the ultimate goal is the same. A family-centered team approach works best, says Miller.

Coping strategies

Children also need to play and participate in outside activities that help develop their nervous system. But children with SPD rarely feel at home in any environment or even in their own skins, say the Eides, authors of *The Mislabeled Child: How Understanding Your Child's Unique Learning Style Can Open the Door to Success* (Hyperion, 2006). The Eides recommend six key steps for helping children with SPD become more comfortable and functional in their environment.

1. Make the world more sensory-friendly.

Create safe zones at home and at school where your child can go when he feels like he's heading for a meltdown. At home, identify and remove triggers that overwhelm your child, such as noise, glare, obstacles, and unnecessary motion. Eliminate irritating shirt tags and shoes that pinch. To encourage better sleep, provide sunlight and exercise during the day and establish a regular bedtime routine. Give advanced warnings before changing activities and allow time for transitions.

2. Manage sensory-seeking behaviors.

If your child bounces off the walls seeking more sensory input, provide appropriate bouncing activities such as jumping on a mini-trampoline or pogo stick. Provide appropriate squeezing activities like playing with therapy putty and chewing double sticks of gum. Encourage athletic activities that integrate bouncing and squeezing movements, such as soccer, gymnastics, martial arts, and swimming. The rhythmic nature of these activities allows the sensory-seeking child to anticipate the movements she makes and receives, so she can prepare and plan better.

3. Manage sensory-avoidant behaviors.

If your child overacts to sensory input, provide a daily plan of controlled sensation called a "sensory diet." The plan, which should be monitored by a trained therapist, may include desensitizing the skin by firmly brushing it with a soft plastic brush. Gentle rocking in a hammock, swing, or rocking chair can help calm the child and improve her sense of body position. The sensory systems are highly linked, so improving sensitivities to touch often improves other sensitivities.

4. Improve whole-body balance and movement.

If your child has trouble processing feedback from his muscles, provide activities that improve body tone, posture, and balance, such as standing on a balance board; playing move-and-freeze games; and doing reverse sit-ups (arching head and feet up while lying on the stomach). Skills gained from activities like these help protect your child when he plays hard or falls.

5. Improve fine-motor function.

If your child has poor fine motor coordination (called dyspraxia), provide activities that strengthen fingers and allow deep finger pressure, such as tearing folded paper, stretching rubber bands over a pegboard, and playing with building sets.

6. Improve emotional regulation.

If your child has trouble adjusting to different environments and sensory stimuli, provide activities that help her prepare more effectively for transitions and new activities. Suggest basic self-calming activities, such as yoga breathing and meditation. Watch carefully for signs of overloading.

In Sync

Any child with significant SPD has a long, long way to go, says Brock Eide. Single digit years are the worst. In adolescence and adulthood, challenges come and go in cycles worsening around growth spurts, illnesses, and stressful events. You can also expect good times and unexpected benefits. For one thing, families that share the challenges of SPD often form stronger bonds.

"I've met some really amazing people throughout all of this," says Kelsey. "And I'm really close to my friends. When you can explain something like this to your friends and they'll back you up, it's just great." Kelsey also jokes that her mom is really her best friend. "It sounds horribly lame and completely dorky to say my mom is my best friend, but from the time I was a tiny child she understood me when nobody else did. And that's really cool."

A sense of play

Most children are out of sync some of the time, so they know how it feels to be out of tune, out of place, out of control, or out of it altogether, says Carol Stock Kranowitz, author of *The Out-of-Sync Child Has Fun: Activities for Kids with Sensory Processing Disorder* (Perigee 2006). But children with SPD are out of sync most of the time. Keeping SPD children safe is critical, she says, but so is getting them away from the TV to play. Depending on your child's particular sensory issues, the following SAFE (sensory-motor, appropriate, fun, and easy) activities may help.

Pretzel People

Together with your child, prepare pretzel dough using your favorite recipe or a gluten-free, casein-free mix. When the dough is ready, have fun forming pretzel people. "When our boys were small and out-of-sorts, making pretzel people was a sure way to get them back in sync," says Kranowitz. It doesn't matter which recipe you use, she explains, what matters is the sensory pleasures of kneading and forming the dough, inhaling the aroma, and breaking bread together.

- **Benefits:** Promotes fine motor skills, tactile discrimination, and awareness of body position.

Flashlight Tag

Ask your child to lie face up on the floor or bed. As you move the flashlight slowly across the wall, ask her to follow the light with her eyes and then her finger, elbow, knee, foot, tongue, or nose. Shine it on the floor so she can jump on it with both feet. Have her hold her own flashlight in both hands and make patterns or play follow the leader with your light. Add more challenges when your child is ready.

- **Benefits:** Strengthens visual-motor integration, eye-hand coordination, directionality, grading of movement, communication, and relatedness.

Musical Hoops

Arrange hula hoops on the floor in a circle, one hoop per person. When the music plays, have four or more children go from hoop to hoop around the circle. When the music stops, every child finds a hoop to stand in. To increase the challenge, have children jump from hoop to hoop, forward or backward.

- **Benefits:** Improves auditory discrimination, balance, motor planning, directionality, grading of movement, and visual-spatial discrimination.

Smash and Smell

Together with your child, pick flowers or herbs from your garden and arrange them on white paper. Place another piece of paper on top. Help your child gently but firmly hit the top paper with a mallet or press it with a rolling pin so the juices stain the papers.

Your child can remove the top paper, pick out the petals, and smell the floral scent of the crushed blossoms on her fingers.

- **Benefits:** Stimulates the olfactory sense, tactile discrimination, fine motor skills, eye-hand coordination, and grading of movement.

Getting kids to eat

Children with SPD are typically picky eaters who eat nothing but junk food. There are chemical reasons for this that have to do with a stressed out sensory system, explains Kelly Dorfman, MS, a nutritionist in North Potomac, Maryland. Our sensory systems also tell us when to eat, but their systems are malfunctioning, so no amount of advice to "only offer healthy food until they eat it" will work. They'd starve, she says, because their brains just aren't getting the message. She offers the following structured plan for better nutrition, with the added benefit of helping children respond better to therapy.

Rule out potential physical problems. Eating involves every sense, so you have no way of really knowing why your child is picky about certain foods. He may refuse a banana because of the texture, or simply because it's yellow. Before trying to change his eating habits, make sure his sensory issues don't include an oral-motor problem that affects his ability to chew.

Close the nutrient gaps. Topping the list of nervous system essentials is a multiple vitamin that contains adequate B vitamins, vitamin E, and the minerals zinc and magnesium. Essential fatty acids are equally important for brain health. And digestive enzymes may help because children with SPD often have undiagnosed stomach problems. Talk with a qualified health practitioner for specific requirements.

Create a structured plan. Choose one nutritious food to introduce that has similar qualities to a food your child already enjoys. If he only eats crackers, for example, he's probably low on protein, so try chicken taquitos.

Make a chart. Give the plan a two-week time limit and break it down into little skills your child can accomplish. The goal might be to eat one bite or four bites or just to offer the food on the plate for 14 days. Start where your child is and offer a reward for the tiniest accomplishment.

STAY CALM. If you can stay calm when your child melts down, you are almost guaranteed to make progress.