Special points of interest:

Also In this issue:

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Autism Agenda

Linn Benton Lincoln ESD-Cascade Regional Autism Program

Taking a Deeper Look at Whole Body Listening: It's a Tool Not a Rule

Elizabeth Sautter, MA, CCC-SLP https://www.socialthinking.com/Articles?name=Whole%20Body%20Listening

Phrases like "pay attention" and "listen carefully" ring out in classrooms across the country. Moms, dads, and other caregivers can be heard saying some version of these same words to children everywhere. Paying attention and listening to others are not only considered essential for social communication, but also for learning to be part of a group and for academic success. In fact, these skills are clearly outlined in the Common Core Learning Standards that teachers use to grade their students.

Although we can easily agree that the ability to listen is important, listening involves more than "hearing" with our ears. So how is this multi-layered skill best taught? To make listening more concrete and teachable, speech pathologist Susanne Poulette Truesdale (1990) came up with a powerful, and now very popular, concept known as "whole body listening." This innovative tool breaks down the abstract concept of listening by explaining how each body part other than the ears is involved: the brain thinking about what is being said; the eyes looking at or toward the speaker; the mouth quiet; the body facing toward the speaker; and the hands and feet quiet and kept to oneself. In a more recent article (2013) Truesdale stresses that the most critical part of whole body listening takes place in the brain. She states that "when we are asking someone to think about what we are saying, we are in essence asking for the listener's brain to be connected and tuned-in."

Over time, other professionals have expanded the initial whole body listening concept to include the heart as a way to encourage empathy and perspective taking. This later addition is helpful when working on social interactions and relationships in which the purpose of listening is not just to "hear" and interpret what is being said, but also to demonstrate shared involvement to make a positive impression. This expanded concept of whole body listening is woven into parts of Michelle Garcia Winner's larger Social Thinking® methodology to teach the fundamentals of how and *why* we listen to figure out the "expected" behavior when around others. Similar to other Social Thinking Vocabulary that breaks down the social code, whole body listening has become a foundational concept to help make this and other abstract concepts more concrete and easier to understand, teach, and practice.

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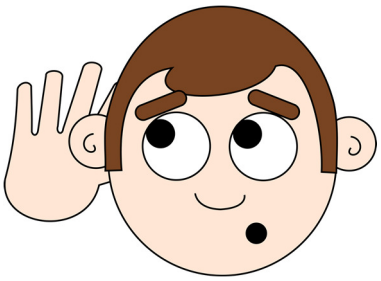
WHOLE BODY LISTENING CONTINUED.....

Truesdale emphasizes that whole body listening is "a tool, not a rule," meaning that adults need to think flexibly about how best to use it. There is no "one way" to teach the whole body listening concept. The goal is to create effective approaches for those with a variety of learning styles. And most importantly, to do this in ways that respect each person's particular needs and abilities.

Kids Do Well If They Can

When children struggle to meet classroom standards related to listening and following directions, they may be misunderstood or possibly labeled as "behavioral problems." According to their age/stage of development we expect children to learn how to focus, listen, and follow directions intuitively, using the "built-in" social regulation sense we assume all children possess. However, some children don't intuitively acquire the social skills and self-regulation that we typically associate with listening. To support these children, parents and teachers need to take a step back and view the situation through a different lens.

Dr. Ross Greene, a psychologist and expert in working with kids who have challenging behaviors, suggests that we ask ourselves, "Does the child *have* the skills needed to perform the task?" He states it perfectly: "Kids do well if they **can**." Greene believes that it is our job to figure out in which areas our children need support, understanding and/or accommodations so that they **can** do well. To explain listening in a way that makes sense, a host of social cognitive and sensory processing skills may first need to be concretely taught. And in some cases, children with social learning, sensory processing, attention, or other regulation challenges may not be able to perform tasks generally associated with listening, such as keeping one's body still, making eye contact, or staying quiet.



What's So Hard About Listening?

When we prompt children to "get out your math book," do you get an image in your mind of what that looks like? How about "sit down"? These requests are concrete and simple to define and picture. But words like "listen" or "pay attention" are more abstract and challenging to define. What does this request really mean? How does it look in various situations and contexts? And why even care about listening? They are open for interpretation based on the person asking and the context or situation. For instance: listening during story time is different than listening on the playground or during a conversation. When a request leaves room for interpretation, the person being asked needs to be aware of and consider both the person making the request and the social rules within that context. This requires strong social attention, social awareness, and social perspective taking.

In addition, when met with a request to "listen" some adults expect children to not only listen with their ears, but to stop whatever they are doing and *demonstrate* that they are listening with their entire body. This adult-defined expectation may include standing completely still, similar to a soldier at attention. This is not only difficult for most children, but impossible for some. Listening with your whole body involves integrating all of the body senses (sensory processing), and combining that with executive functioning (self-control of brain and body), and perspective taking (thinking of others and what they are saying). This is not an easy task and it's extremely important to be aware of the processing complexity involved. Many children do not fully understand what is expected of them or may not be able to meet the expected demands when it comes to listening.

Tips From Whole Body Listening Larry

Many parents, teachers, and other professionals supporting children appreciate the way that these guiding professionals have helped break down the abstract concept of listening into more manageable, concrete actions. Kristen Wilson, a former therapist at my center, Communication Works (CW) in the San Francisco Bay Area, created a story and lessons on whole body listening using a character named Whole Body Listening Larry and examples of how he struggled with paying attention. After Larry learned what was expected of him and each part of his body, he found listening much easier. He wanted to help others by sharing what he had learned.

The clients at our center could relate to Larry's struggles. They appreciated how the story helped them learn and remember how to show that they were listening. Larry's story also reminded kids to advocate for themselves when they were unable to focus or attend with their whole body. Kristen Wilson and I saw that Larry was an effective teaching tool and together co-authored the books *Whole Body Listening Larry at Home* and *Whole Body Listening Larry at School* (2011), which were published by Social Thinking Publishing. The books have given children a deeper understanding of what to do in various situations in which they have to self-regulate and listen, and teachers and parents have appreciated a way to talk about this concept and teach it.

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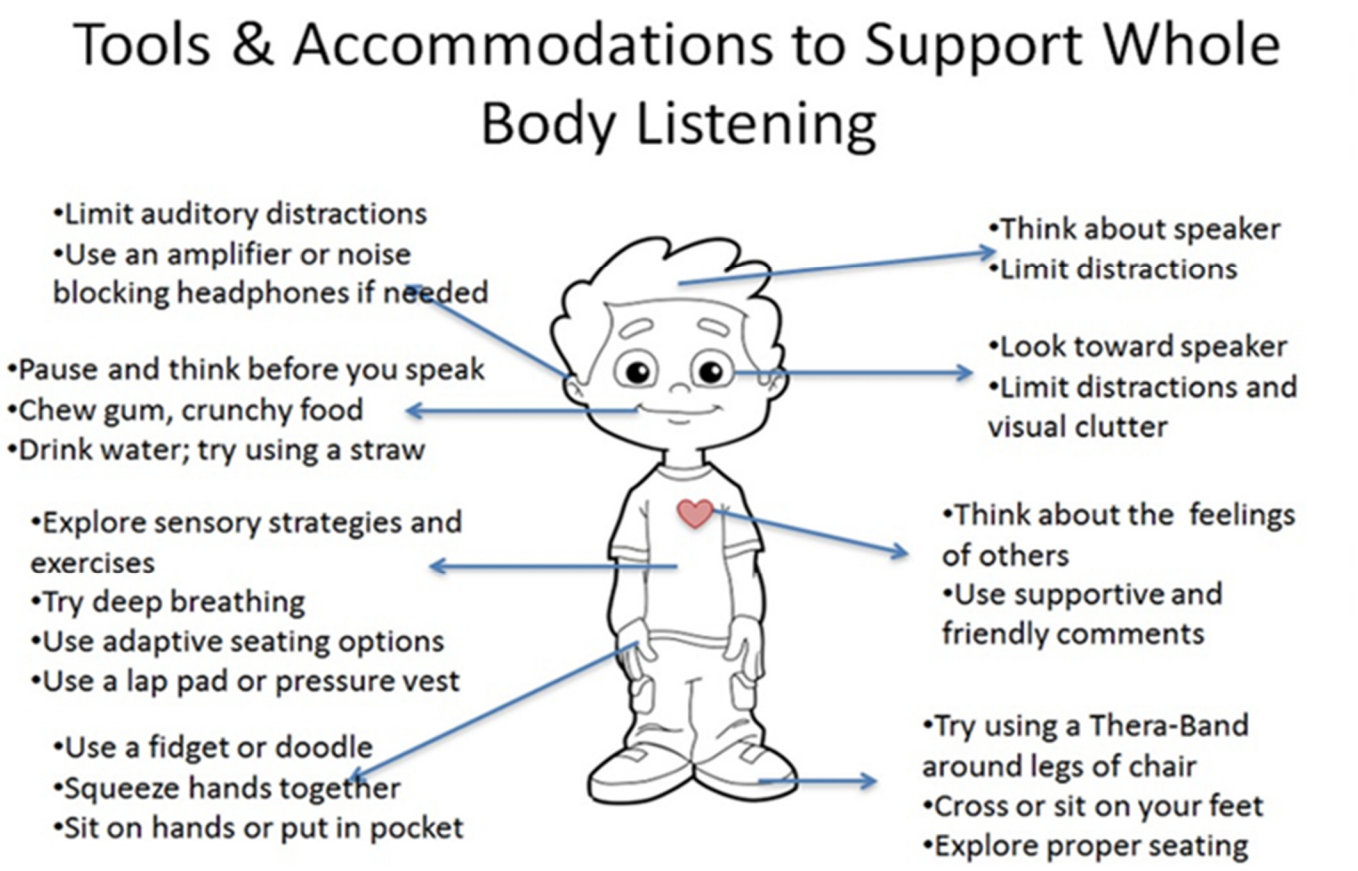
A Tool, Not A Rule!

As with other tools and curricula, the abilities and developmental level of each individual must be considered before implementing whole body listening. Some of the skills used in whole body listening, such as maintaining eye contact, staying still, or remaining quiet are extremely difficult and may cause stress or simply not be possible for certain people. When this is the case it's important that adults demonstrate awareness and understanding. Parents, teachers, therapists, and employers should make modifications and help individuals advocate for themselves in a variety of social, educational, and work-related situations.

Given the popularity of the Larry books, posters, and lessons, it is important for adults to be sure that the material is appropriate for anyone to whom it is presented. Teachers, parents, or other adults should not "enforce" this concept or any other on someone if it will cause anxiety, distress, or shame. When a child or adult is interested and capable of learning how to listen with his/her whole body it can be helpful to explore strategies and accommodations with the support team.

To aid in teaching whole body listening, some general strategies and accommodations follow, developed by myself and Leah Kuypers OT/R, another former therapist from CW and author of the popular curriculum, *The Zones of Regulation*®. Each person is different and should be assessed for individual needs and support. Also included is information to build awareness for differences that may occur, especially for those with sensory processing challenges. In these incidences modification and differential teaching should be implemented. The following visual provides a quick reference:



Ears: Limit auditory distractions. Explore the use of an amplifier (e.g., frequency modulation (FM) system) or noise blocking headphones if the child is easily distracted by background noise.
Be mindful: People who are hard of hearing or deaf can listen through ASL interpretation, lip reading, gestures, and written words or images.

Eyes: Look toward the speaker, maybe not directly but checking in for facial expressions to "read" emotions and others' intentions. Limit distractions and visual clutter.
Be mindful: Direct eye contact can be overwhelming, intimidating, or difficult (even painful) for some. Persons can hear what is being said even if they are not looking directly at the speaker.

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WHOLE BODY LISTENING CONTINUED....

Mouth: Practice impulse control by pausing and thinking before speaking (brain filter). Chewing gum or crunchy food can provide sensory input that helps regulate one's system. Drinking water, especially through a straw, can be helpful.
Be mindful: Some people need to make verbal sounds to help them process what is being said and stay calm.

Hands: Use a fidget or doodle. Squeeze hands together. Sit on hands or put them in pockets.
Be mindful: Some people move/ flap their hands as a way to regulate themselves and can still listen/hear while moving their hands.

Feet: Tie a Thera-Band or deflated bicycle tubes around legs of a chair as a place to rest the feet and/or use as a fidget for restless feet. Explore proper seating for posture and comfort. Cross or sit on feet to help keep them still.
Be mindful: Some people need to move their body to stay regulated, attend, and feel comfortable. If they are moving, they can still listen and may be able to learn better.

Body: Explore sensory strategies and exercises (e.g., chair push-ups, deep breathing, etc). Consult an occupational therapist to explore adaptive seating options and use of a weighted lap pad.
Be mindful: Some people need to move their body to stay regulated, attend, and feel comfortable. If they are moving, they can still listen and may be able to learn better.

Heart: When children are developmentally and cognitively ready, help them think about *why* we listen to others. This includes creating rapport, a shared experience, and considering the feelings of the speaker and others and how their listening behavior might affect the thoughts of others. Practice building perspective taking and thinking about others versus themselves and their own interests during social interactions and conversation when wanting to remain part of a group and/or make a good impression. Practice using supportive and friendly comments and using the Social Fake (a Social Thinking strategy of acting interested even if you're not) when needed. Also, help children understand that when we are around others it is socially expected that we care (pay attention to them) enough so that others feel comfortable with our presence in the group.
Be mindful: Caring about others and how our own behavior affects others in a social situation can be shown in many different ways. Don't assume someone doesn't care just because that person has difficulty with whole body listening. Also, it's crucial to acknowledge and teach that some people make us feel uncomfortable. We don't have to personally care about everyone we talk to and adults should not force caring where it doesn't exist or if the person does not seem friendly or safe.

Brain: Teach kids about the brain and how it works. Teach short and sustained attention strategies. Practice controlling impulses. Introduce The Social Fake (Social Thinking concept) and limit distractions. Lastly, one of my most favorite tools is mindfulness, which has been proven to be a powerful tool for the brain and all other body parts. Teaching how to be aware of the present moment, on purpose, can really help with knowing when to pause and reflect before acting, and knowing how and when to use whole body listening.
Be mindful: It's important to do a check-in before assuming that someone is not thinking about what is being said—they might show it in a way you don't expect.

Be An Advocate

If the expectations of whole body listening prove difficult or impossible, it's important to advocate for your child or for yourself. For example, if you or your child/student find it hard or painful to maintain eye contact, discuss this with the relevant people involved in the situation. Stating what's real and true at the onset helps to create reasonable expectations and prevents a situation in which expectations go unmet. By modeling and teaching advocacy skills, adults help others develop the ability to speak up for themselves.
Adults can also create an environment that's conducive to good listening by keeping expectations reasonable for the developmental and cognitive level of students. Keep these ideas in mind:

- Sitting still for long periods of time is hard for *everyone*, and not possible for some.
- The goal is not to create student "drones" who are taught to demonstrate whole body listening in only one specific way.
- Whole body listening should not be used to discipline children. Don't forget that it is a teaching tool—not a rule.
- Create an environment that is conducive for listening with your whole body. Limit distractions, think about calming techniques, and be sure to support transitions and awareness for when listening with the whole body is expected.
- Help create situational awareness by talking about the hidden rules and the level of whole body listening that is expected at a given time.

Whole body listening is a useful tool that breaks down the tasks involved in listening. It has not only aided in making a complex concept clearer, but it increases awareness of expected behavior and can facilitate the teaching of self-advocacy skills. If taught, practiced and supported in a mindful manner, it can become a habit and more automatic response. However, to use this concept correctly, we must be sensitive to the unique abilities of each person. Parents, teachers, therapists, and even employers should consider the challenges that whole body listening may cause and, when needed, should adapt listening strategies to suit a person's particular needs. When appropriate modifications are made and abilities are taken into account, whole body listening can be a powerful tool that benefits a broad and diverse range of people.

10 'Autism Interventions' for Families Embracing the Neurodiversity Paradigm

November 4, 2015/by Briannon Lee

In most places, as soon as a child is identified as autistic, they are funneled straight in to early intervention therapies. Based on a medical model of disability, these therapies see autistic children as disordered, and aim to change autistic children so that they will play, communicate and move more like their 'typically developing' peers.

In contrast, the neurodiversity paradigm* views autism and other neurodivergence as a natural and valuable part of human diversity. There is not an 'ideal' brain or correct style of neurocognitive functioning; all are valued. *There is not an ideal or correct way for children to play, communicate and move; all are valued.*

If families, caregivers and health professionals accept the neurodiversity paradigm, 'autism early intervention' looks very different. *The target of intervention is not autistic children, but their social and physical environments.* Autistic children are supported in families and communities to develop as unique and valued human beings, without conforming to the developmental trajectory of their neurotypical peers.

1. Learn from autistic people

Learn as a family about autistic ways of being and autistic culture, neurodiversity, and disability. *Autistic people are the only experts on autism*; find us and our work. Don't ask us to educate you, but listen and learn.

2. Tell your child they are autistic

Tell them now, tell them early. Talk about autism matter-of-factly. *Explore what being autistic means for them*. Teach your child about disability and how they are disabled by society. Build pride and an understanding of human rights from a young age.

3. Say NO to all things stressful & harmful

Say no – to quackery, to intensive normalizing therapy, to excessive socializing, and to inappropriate school environments. Say no to anything that causes stress or harms their bodies. Say no to anything that will interfere with their ability to say No themselves in the future. *Model self advocacy early.*

4. Slow down your life

Autistic children need time and space to develop in their own way at their own pace. Ideas about happy 'productive' childhoods are based on neurotypical norms. Cut out all of the extra activities and socializing, and busyness of life. *Discover the pace that works for your children.* You might find that lots of downtime at home is vital for their healthy development.

5. Support & accommodate sensory needs

Observe your child closely, talk with them, and tune in to their sensory needs. *Meet their sensory needs creatively* (you don't need to spend lots of money). *Defend and protect your child from sensory assaults.* Frame this as an accommodation they require as a child with disability, in the same way other children require ramps or interpreters.

6. Value your child's interests

There is no right way to play. *Special interests are good for autistic brains, and a natural way that autistic children learn and develop*. Don't use them as a 'way in' for other learning, therapy or change. Don't attempt to broaden their interests, or restrict access to special interests. Join in, learn about and share their interests; but also respect your child's wishes for time alone with their favorite things.

7. Respect stimming

Stimming (self-stimulatory behavior) is like breathing for autistic children and adults. It feels good, helps us feel connected and focused. *It is harmful to interfere with children developing and enjoying their own stims*. Unless children are hurting themselves or others, respect their need to stim; never shame them or stop them. Stimming is beautiful!

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SUPPORTING AUTISM FAMILIES CONTINUED….

8. Honor & support all communication

Don't overly focus on the development of verbal speech. Human communication is much more than speech, and many autistic people are non-speaking. *Honor and respond respectfully to all communication from your children.* Support your child to access communication supports such as symbol-based AAC, sign language, typing, or RPM so that they have access to alternative ways to communicate with family, friends and others.

9. Minimize therapy, increase accommodations & supports

Intervene with therapy only for issues impacting health and wellbeing. A good question to ask: "Would my non-autistic children access this therapy?" *Focus your energy and advocacy efforts on accessing accommodations and support for your child to participate in family and community as they choose.* Autistic children may require 1:1 support more often or at different times than other children. They also have a right to accommodations to enable inclusion in school and community.

10. Explore your own neurocognitive differences

Explore similarities between you and your child's sensory, cognitive, and social needs. *Accepting and valuing your own unique brain, goes a long way towards respecting and accommodating your children's needs.* Many autistic children have neurodivergent parents; exploring your differences might help you identify something really important about yourself!

-Briannon Lee

http://respectfullyconnected.com/2015/11/10-neurodiversity-friendly/

SUMMER CAMP OPTION

This summer camp has been highly recommended by parents.
"This camp is really good and worth the travel and money. There are scholarships available as well."

Camp Yakety Yak (June 29-July 31: 5 weekly sessions)

Teaching Children the Language of Friendship

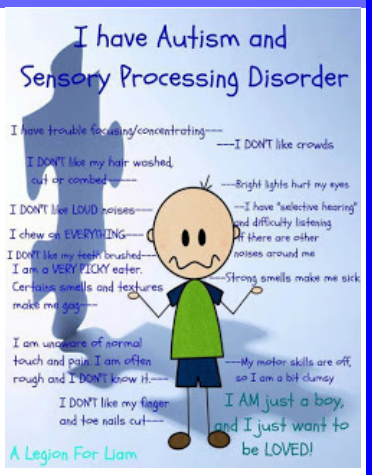
Camp Yakety Yak is a social skills day camp supporting friendship development in children with special needs, AGES 5-15. Siblings and peer models welcome!

Every day, the weekly theme makes up the curriculum of one or two 30-minute classes per day. Every week, campers participate in CYY's specialized social skills curriculum, cooking activities, outdoor play, PE/playground/sports games, art & music, sibling snack group, and whole group activities such as recess and assemblies with the weekly theme incorporated. Camp Yakety Yak is still a therapeutic-based summer camp! We thought weekly themes might engage the imagination and excitement of our campers, and will be used as an engaging platform to teach social, emotional, behavioral and communication skills.

CAMP LOCATION: Mountain Park Church, 40 McNary Parkway, Lake Oswego, Oregon

http://www.campyaketyyak.org/

Talking sense: What sensory processing disorder says about autism



Some children are highly sensitive to sound, sight or touch, whereas others seem almost numb. Exploring the differences may offer insights into autism.

by Sarah DeWeerdt 1 June 2016

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 under sensitive, 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.

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TALKING SENSE CONTINUED...

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.

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).

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TALKING SENSE CONTINUED...

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 under sensitive 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."

Continued on page 10.

TALKING SENSE CONTINUED...

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?"

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.

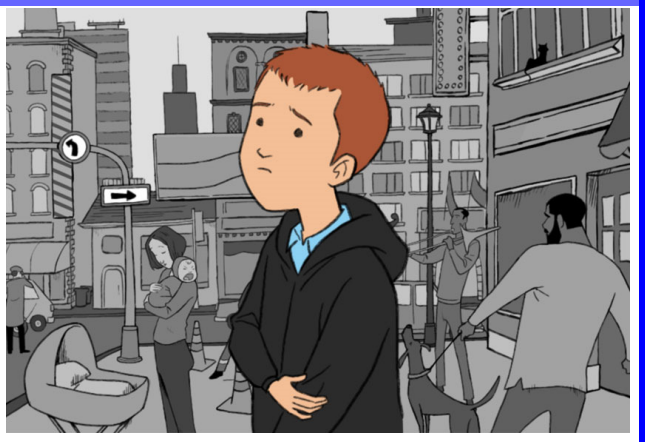
Lori Craven is homeschooling her son Jack because she says it was too difficult to get the public school system to accommodate him. Because Jack doesn't have hearing loss, he wasn't eligible for an assistive technology that amplifies his teacher's voice to help him focus. Because he doesn't have vision 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."

Continued on page 11.

TALKING SENSE CONTINUED…



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."

https://spectrumnews.org/features/talking-sense-what-sensory-processing-disorder-says-about-autism/

SENSORY WEBSITE SUGGESTION

"A Sensory Life" http://asensorylife.com/index.html

We are so happy you have found us! Perhaps you have found us through social media or an online search, or Angie's books. Either way, you will find this website to be packed full of free sensory resources and tools! This website is intended and designed to work hand in hand with the books written by Angie Voss, OTR, yet can stand alone as a resource for you. There is a very large amount of content on this site, so to help you navigate and to quickly access the topics of interest, utilize the search bar below to find any of the terms you would like more information on or for further instruction and details from the "Ideas to Help" sections in Understanding Your Child's Sensory Signals or Understanding Your BABY's Sensory Signals. (for example...enter key-word **bubble mountain** and it will link you to that page on this website).
All of the information on this website is original content written by the author and occupational therapist, Angie Voss, OTR otherwise noted.

CALM DOWN TOOLS FOR OLDER KIDS

www.andnextcomesL.com

Items that give kids a brain break

- Puzzles
- Chapter books to read
- Blank notebook/journal and writing utensils
- Coloring books
- Scratch art doodle pad
- Activity books
- Brain Quest cards
- Doodle books
- Mad Libs
- One player travel sized games

Items for auditory sensory support

- Noise cancelling headphones
- MP3 player with music, nature sounds, audiobooks, etc.
- Sound machine

Items for oral motor sensory support

- Chewing gum, hard candies, or lolli-pops
- Snacks with a variety of textures
- Chew necklace

Items to support breathing & relaxation

- Book of yoga poses or yoga activity cards
- Rescue Remedy Spray

Items that provide proprioceptive support

- Punching bag or bop bag
- Mini massager
- Weighted lap cushion
- Hand weights
- Resistance/exercise bands
- Compression clothing
- Heated blanket
- Weighted blanket
- Skipping rope

Items to squeeze, fidget with, or keep hands busy

- LEGO kits
- Stress balls
- Rubik's Cube
- Wooden or metal logic puzzles
- Craft kits
- Cat's cradle

Items to visually calm

- Kaleidoscope
- Eye mask
- Look & find books
- Lava lamp

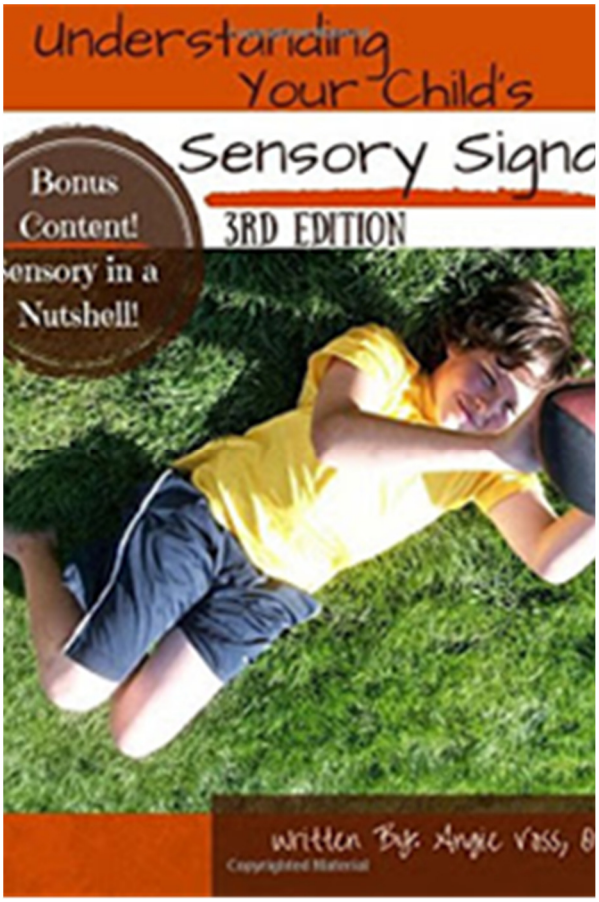
Items for olfactory sensory support

- Calming essential oil spray
- Scented lotion

The Ultimate Guide to Brain Breaks

by Heather Haupt

This well-researched, easy-to-read book breaks down how and why movement matters for learning and optimal focus. It not only equips you to incorporate brain breaks into your family or classroom's day, but also how to reap the life-long benefits by helping your children (or yourself) recognize the signals your body sends that you need a movement break! The book includes 60 amazing brain break exercises, with detailed instructions, pictures and printables/cards. Available in print or e-book at http://ultimatebrainbreaks.com/the-book/



Understanding Your Child's Sensory Signals

by Angie Voss

This practical handbook includes over 210 of the most common sensory signals and cues a child may be giving you. You can simply look up an issue such as "messy hands must be wiped off frequently during meals," and this resource provides the reasons behind the behavior and ways to help with that specific sensory behavior. This resource is geared for daily use and designed to work hand in hand with ASensoryLife.com, where you can find printable handouts, links, sensory how-to videos, sensory tools and equipment ideas, as well as ways to address sensory issues on a budget.

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CALM DOWN VISUALS