

SENSORY FOCUS

UNDERSTANDING THE ISSUES BEHIND THE BEHAVIOR

SUMMER 2014

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Everyone Has Sensory Issues

Easy Coping Strategies

Temple Grandin, PhD

When the Lights Go Out

Carol Kranowitz, MA

Thinking About Stimming

Catherine Faherty

Protecting Your Children's Futures

Betty Lehman

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SENSORY FOCUS

UNDERSTANDING THE ISSUES BEHIND THE BEHAVIOR

Summer 2014

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Wasn't it just yesterday we were complaining about the snow and frigid temperatures? What a difference a few months makes! Here in the Northern hemisphere, we are enjoying the heat of summer. And many of us have the kids home from school for the summer holiday. We hope you are enjoying your time together, and maybe even a vacation or two!

As you may remember, I am the mom of a 20-month-old little girl. It is so much fun watching her grow and change. Obviously, I have sensory issues on the brain and have kept a keen lookout. She does show some minor tactile issues, but forewarned is forearmed. I'm so glad to be aware, and able to help, or at least able to understand and react accordingly. Wouldn't it be wonderful if all parents could be this sensory aware? I know I couldn't have been, before I learned about SPD.

Speaking of which—you are about to encounter some wonderful teachers in this summer issue.

We welcome Dr Temple Grandin's unique sensory insight as she shares an excerpt from her upcoming third edition of *The Way I See It*. If that's not enough star power for one magazine, we are thrilled to have the input of the illustrious Carol Kranowitz. The author of the groundbreaking *The Out-of-Sync Child* shares some great ideas on how to get kids involved with sensing the world around them in healthy, fun, and delicious ways.

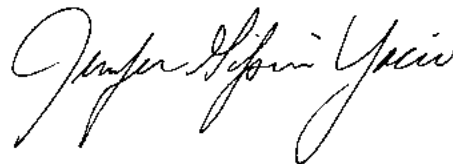
We are also blessed with the insight of the wonderful Catherine Faherty, author of *Autism: What Does It Mean to Me?* She gives some great

advice for anyone dealing with stimming. And, for the first time, we have advice from a CPA! Betty Lehman tells us how we can best plan for our children's futures by creating a Life Care Plan. It's important stuff to prepare for.

As always, we are so proud to have our uber-talented columnists, Jennifer McIlwee Myers and Barbara Sher. Jennifer talks about the effect of sensory issues on behavior, while Barbara continues her three-part series on how to handle situations like Mary Poppins. I think you will gain from everything we are offering here.

Do you gain from it? Seriously. Is there something you are loving about our magazine, or something you'd like to see more of? Please let me know! I want to hear your input and ideas. And, your letter may be featured when we start out Letters to the Editor page next month. We love what we've heard so far, but maybe we haven't heard from YOU yet. Yes, YOU. Tell us what you think. You can even write me directly at Jennifer@sensoryworld.com. I am looking forward to hearing all you have to offer.

But for now, it's time to sit back, relax, and enjoy this issue of *Sensory Focus*.



Jennifer Gilpin Yacio

*Vice President of Future Horizons, Inc.
Editor in Chief of Sensory Focus*

A group of people are shown from the waist down, holding hands in a circle. They are positioned against a background of a bright blue sky with scattered white clouds. The people are wearing various casual clothing, including jeans, a red pair of pants, and a yellow cardigan. The overall mood is positive and inclusive.

FOCUS EVERYONE

Everyone Has Sensory Issues

Easy Coping Strategies

Temple Grandin, PhD

From The Way I See It

One of the problems in understanding sensory issues is that sensory sensitivities are very variable, among individuals and within the same individual.

I have been talking and writing about sensory problems for over 20 years and I am still perplexed by many people who do not acknowledge sensory issues and the pain and discomfort they can cause. A person doesn't have to be on the autism spectrum to be affected by sensory issues.

Most people feel an aversion to nails being drawn across a chalkboard. That's a negative sensory experience. Many times I have heard of people who get almost instant headaches when exposed to certain scents, like strong perfumes or the smell of gasoline. That's a sensory experience. A woman I know tells me her hearing is very sensitive when she first wakes up in the morning, and even normal sounds are sometimes offensive for the first 30 minutes or so. That's a sensory challenge.

Think about going to the mall and shopping on a busy Saturday afternoon. For some it's energizing, but for others, it leaves them exhausted.

These people are having trouble with the sensory bombardments that are typical of the mall environment: the constantly changing sights, smells, voices, and music, being bumped into by others, and so on.

Sensory issues are very real, and I think they are more a matter of degree than being either present or absent in people. I also believe that as our world in general gets louder and busier with more people, more cars, more urbanization, and a heavier reliance on technology, sensory issues will become more pervasive as our sensory systems become increasingly overloaded.

A person doesn't have to be on the autism spectrum to be affected by sensory issues.

For me and other people on the autism spectrum, sensory experiences that have little or no effect on neurotypical people can be severe life stressors for us. Loud noises hurt my ears like a dentist's drill hitting a nerve. For some individuals, the seams in a pair of socks or the rough texture of materials like wool on their skin can feel like being constantly burned. This explains why a child's reaction is to take them off—he's not being defiant; the socks are physically hurting him. For others, even the light touch of another's hand on their arm can be painful. They shrink away from people not because they are antisocial, but because even brushing up against another person can feel like razors being drawn across their skin.

I think so many professionals and nonprofessionals have ignored sensory issues because they just can't imagine that an alternate sensory reality exists if they have not experienced it personally. They simply cannot imagine it, so it does not register in their minds. That type of narrow perception, however, does nothing to help individuals who do have these very real issues in their lives.

Even if they don't understand it on a personal level, it's time they put aside their

personal ideas. Scientific research has now documented that sensory problems are real. Higher-functioning adults with autism and Asperger's syndrome are writing about their sensory issues in great detail. Many of these individuals agree that sensory issues are the primary challenge of autism in their daily lives. There is a great need for more scientific research on the brain abnormalities that are associated with different sensory problems and the methods to treat them.

Sensory Problems Are Variable

One of the problems in understanding sensory issues is that sensory sensitivities are very variable among individuals and within the same individual. A person can be hyper-sensitive in one area (like hearing) and hypo-sensitive in another (like touch). One person can have a marked olfactory sensitivity, and another might not be affected at all in that sense.

Complicating matters even further, on a day-to-day basis, in the same individual, sensory sensitivities can change, especially when a person is tired or stressed. These many and constantly shifting variables

There are two ways a child can respond to sensory overload: withdraw and shut off the world or scream and yell.

make it difficult to design research studies to test therapies to treat sensory sensitivities.

So professionals will loudly make assertions such as, "There is no research to support sensory integration therapy with individuals with autism"—tacitly suggesting the therapy is ineffective. The absence of clinical research does not mean sensory therapies are not viable for children or adults. It simply means research has not been done to date.

Furthermore, with the variable nature of sensory issues in autism, we must look at research with a slightly different slant. If 20 children are put in a study and four benefit

from the therapy, while sixteen don't, is it ethical to deem the therapy ineffective? It worked in four children. Four children's lives are now markedly different; their world is no longer so uncomfortable to live in.

A better approach in situations like this is to delve deeper into why it works for some, and not for others, to continue to explore what is going on in their brains by doing follow-up research between the responders and non-responders, rather than arbitrarily dismissing the therapy altogether.

There are two ways a child can respond to sensory overload: withdraw and shut off the world or scream and yell. Some children who appear to be non-responsive are actually in sensory shutdown due to sensory overload.

Parents and teachers often ask, "How can I tell if my child has sensory problems?" My simple answer is this: Watch your child closely—the signs are there. Do you see him putting his hands over his ears to block out noise? Does he become agitated every time you're in a bustling, noisy, or chaotic environment? Are there certain textures of food he just will not tolerate? Do you find your child pulling at or taking off clothes that have rough textures or

tugging at necklines where tags are rubbing?

Children and adults who have tantrums and cannot tolerate being in a large supermarket, such as Walmart, are almost certain to have sensory problems. Also note: Tolerance levels quickly diminish when the individual is tired or hungry. For example, a child may tolerate a large grocery store in the morning but not during the afternoon.

Desensitization to Sensory Stimuli

Some children can learn to tolerate loud noises that they previously could not tolerate, if they initiate the sound and have control of it. Let the child turn on the smoke alarm or other feared sound. Start with the volume low and gradually increase it. With the smoke alarm, you could start with it wrapped in heavy towels to muffle the sound and then gradually take the towels off. There must NEVER be a sudden surprise. The child must have control.

Easy Strategies

There are some simple things parents, educators, and service

providers can do to help prevent sensory problems from hindering your child's education and life. Avoid multi-tasking, especially when working with the child. Have a quiet place that is free from outside distractions to do teaching, discrete trials, or other therapies. I have difficulty hearing if there is too much background noise—I can't discern my communication partner's voice from all the other sounds going on around me.

Make sure the child gets lots of exercise every day. A significant number of research studies support the benefits of regular daily exercise. Exercise is really good for the brain and can help children with hyper-sensitivities calm down and children with hypo-sensitivities rev up their systems for optimal learning states.

Sometimes very simple interventions can have amazing effects. One little girl could not tolerate a large supermarket for more than 5 minutes. After her mother bought her a pair of children's pink-tinted sunglasses, she was able to get through an hour of shopping.

Other children learn better when they are shielded from the distracting flicker of fluorescent lights. Some of the energy-saver fluorescent light

bulbs have such a high degree of flicker that I cannot read with them. Some fluorescent lamps have electronic circuits to reduce flicker, but others make some people on the autism spectrum feel as though they are standing in the middle of a disco nightclub. (Try concentrating on a math test in that type of environment!) If fluorescent lights can't be avoided, a lamp with an old-fashioned incandescent light bulb should be placed next to the child's desk to help eliminate flickering, or kids can wear baseball caps with longer brims to shield their eyes from some of the flicker.

Auditory Problems

Auditory challenges are often cited as the number one sensory challenge among individuals with autism and Asperger's syndrome. There are two kinds of auditory problems: (a) sensitivity to loud noise in general and (b) not being able to hear auditory detail, such as discerning one voice among other sounds, or hearing the hard consonant sounds of words. An auditory sensitivity to noises, where sounds hurt the ears, can be extremely debilitating.

Sound sensitivity can make it impossible for some people

on the spectrum to tolerate normal places such as restaurants, offices, and sports events. These extreme auditory problems can occur in both nonverbal individuals and those who are very high functioning and have marked intelligence and language capabilities, such as college-educated people with Asperger's syndrome.

Auditory training therapy is useful for some people. In auditory training, a person listens to electronically distorted music during a couple of sessions a day for 10 days. The music sounds like an old-fashioned record player that is speeding up and slowing down. Auditory training therapy helps some children and adults, yet it has no effect on others. The main improvements seen in those it helps include reducing sound sensitivity and increasing discernment of auditory detail. For many children, getting their auditory input under control results in improved concentration and fewer behavioral issues and provides an opportunity for other therapies and learning situations to take hold.

Some people with more minor auditory challenges use earplugs or music headphones to block out distracting or painful sounds—things such as chairs scraping on the floor in the cafeteria, the constant

ringing of telephones in a busy office, or maneuvering through a crowded airport. Earplugs must never be worn all the time; this can cause the individual to become even more sensitive to sound. Earplugs need to be taken out for at least half of the day, but they can be used in noisy places, such as shopping malls or the gym.

An Integrated Approach to Treatment

Severe sensory sensitivity can be a MAJOR barrier to learning in children and can affect employment and socialization as the child grows and becomes an adult. My own sensory problems are minor nuisances, but for others, they can literally wreck a person's life. There are many highly intelligent adults with autism or Asperger's who are brilliant minds in their field, but they have such severe sensory issues that they cannot tolerate a normal job environment. They must either find ways to work independently from home, where they can control sensory input, or remain largely unemployed. Employers are beginning to understand sensory issues and some will even make accommodations

when the needs of the person are explained. On the whole, however, we as a society have far to go in appreciating the challenge of living with sensory issues that most people on the autism spectrum face daily.

Teachers and parents should look closely for sensory issues in a child or young adult. Recurring behavioral problems often have a sensory issue as the root cause of the behavior. If a sensory issue is suspected, a consultation with a good occupational therapist should be the next step. These individuals are trained to recognize sensory issues and then develop a customized program for the child. Interventions such as application of deep pressure, slow swinging, and games that involve balancing work best when they are done every day.

Sensory issues are daily issues. If the services of an occupational therapist are available for only half an hour each week, parents and teachers should visit the session and ask the therapist to show them what to do the rest of the week. For children, a combination of sensory therapies such as sensory integration administered by an occupational therapist, auditory training, and visual interventions, coupled with other treatments, works best. Special diets help some children with

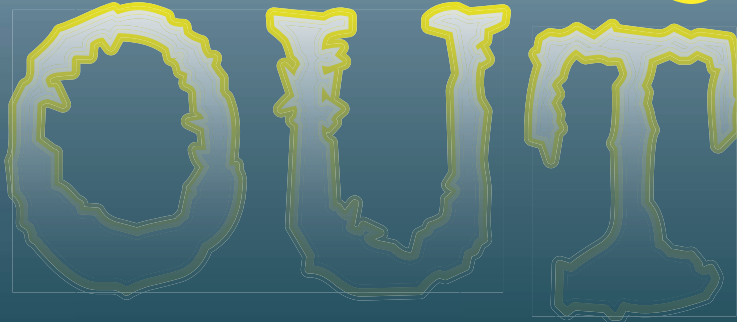
their sensory issues; improvements are seen not just in tolerating different textures and types of food but also in other sensory areas, as well. With older children and adults, a low dose of a conventional medication may reduce sound sensitivity if less invasive methods have proven unsuccessful. ♦

Temple Grandin, PhD, is an internationally respected specialist in the design of livestock handling systems. She is also the most famous person with autism in the world today. She was recently named one of Time magazine's 100 most influential people and is the subject of the award-winning 2010 HBO biopic. Temple has authored several books on autism and is a worldwide speaker on autism topics. Her Web site is www.templegrandin.com.

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When the Lights Go



An

advertisement from an electric power company was dropped through my mail slot today, which shouted, *BLACKOUT:*

Could It Happen Again?

It got me thinking about survival skills. When an outage occurs and we can't switch on the electric power, we must switch to our own power to get



Carol Kranowitz, MA

from place to place, prepare meals, communicate with others, and entertain ourselves.

Will we be prepared, especially those among us with Sensory Processing Disorder (SPD) and other physical challenges?

Alas, so much is done for us these days that we are all becoming “do-ees” instead of “do-ers.” Learned helplessness is everybody’s problem.

Consider automatic doors, electric can openers, battery-operated pencil sharpeners, Velcro fasteners, electronic keyboards, TV remotes, pre-sliced vegetables, and sensor faucets in public restrooms. (Who’s the sensor? Not us!) These “smart” things are designed to make life easier and cleaner today but they deny children opportunities to develop skills they will need tomorrow. Kids need steady practice using their sensory systems and engaging their bodies to push, pull, squeeze, rotate, twist, tie, zip, write, slice, chop, and perform other everyday actions. How smart is a device that renders us senseless?

Let’s not allow devices to extinguish our senses! We need our senses!

We need them, first, for survival. We must be at the ready to satisfy physical demands like hunger and protect ourselves from potential

threats. When we feel safe and feel that we will survive, we can relax and use our senses for a second vital purpose—that of discriminating what is happening around us.

Sensory discrimination helps us do and master important skills. The more important an activity is for survival, the more senses are involved. Because eating and making love are essential for life, they

Kids need steady practice using their sensory systems and engaging their bodies to push, pull, squeeze, rotate, twist, tie, zip, write, slice, chop, and perform other everyday actions.

are the two human activities that engage all eight senses simultaneously. (Can you think of a third? Let me know.) In contrast, watching TV while lying on the couch uses only two senses—visual and auditory—and passively, at that.

Effective learning takes attention, time, and practice. We learn to write after learning to scribble, to obey traffic rules

on the road after riding bikes at the playground, and to pitch a baseball after tossing a beach ball. Many hands-on moments with regular faucets lead the way to turning an unfamiliar faucet handle with appropriate force, in the correct direction, and to the right extent ... and then turning the handle to “off” before walking away. (Can a sensor faucet teach all that?)

To develop and enhance our kids’ survival skills, let’s provide real, three-dimensional, fun, and functional experiences to get their bodies and brains in sync. Think of heavy-work activities that use kid power, not electric or battery power. Think of action verbs, like *push, pull, lift, carry, slice, chop, jump, climb, throw, catch*, and so forth. The more kids do, the more they can do, and the more likely they will be to survive, superbly, when the lights go out. ♦

Carol Kranowitz, MA, is the author of The Out-of-Sync Child and co-author with Joye Newman of Growing an In-Sync Child and In-Sync Activity Cards. She is working on a new book, The Out-of-Sync Child Grows Up. Carol is a board member of the SPD Foundation. Her Web site is www.out-of-sync-child.com.

HEAVY-DUTY ACTIVITIES TO DEVELOP KID POWER

HEAVE heavy, indestructible grocery items into the cart, such as bags of beans and potatoes, plastic bottles of water, cans of soup and iced tea, and so forth. The heavier, the better.

HOIST grocery bags into the car, into the kitchen, and onto the counter.

LIFT the items out of the bags and stow them in the refrigerator and pantry.

SLICE vegetables for a circle salad (the recipe follows).

CHOP vegetables for a chopped salad.

TWIST a mill to grind pepper.

GRATE a large, firm wedge of cheese by using a box grater.

PEEL carrots, cucumbers, and potatoes.

TUG the string or **ROTATE** the handle of a salad spinner to dry lettuce.

TEAR lettuce leaves into bite-sized pieces.

HUSK corn on the cob.

VACUUM, SWEEP, SHOVEL, and RAKE.

DRAG the hose to water the grass or wash the car.

TUG the puppy around the block.

CARRY the laundry basket upstairs.

STAND UP without using hands.

DO PUSH-UPS.

CLIMB STAIRS without leaning on the banister.



HARD WORK IS FUN

A preschool student of mine loved playing in the Housekeeping Corner. At home, this privileged boy had a nanny, housekeeper, and cook to serve him. At school, donning an apron, he served others. He swept, ironed, dressed the baby dolls, prepared imaginary meals like "Magic Soup," and tidied up his own messes. One day, I said, "At our school, you are one of the hardest workers!" Laughing, this resourceful child said, "At my house, people who work hard have all the fun!"

CIRCLE SALAD

For ages 7 and up (Note: Some children younger than 7 can handle a kitchen knife well, and some children—regardless of age—cannot. You know your child best, so please use your own judgment!)

What You Need

- **Sharp, round-tip kitchen knife**
- **Large cutting board**
- **Vegetables:** Yellow squash, zucchini, and peeled cucumbers (easy to slice for children with poor muscle tone, low stamina, or poor motor coordination). Carrots, celery, unpeeled cucumbers, onions, scallions, radishes, grape tomatoes, and olives (these require more motor planning, strength, or dexterity)

What You Do

1. Slice vegetables into circles.
2. Mingle all the pretty circles in a bowl and serve with your favorite dressing.

Helps Your Child Develop and Enhance:

- Motor planning (for using kitchen tools)
- Bilateral coordination (for using two hands in different ways to accomplish a task)
- Social relationships (for being

part of a team and helping to feed a group)

- Can-do spirit (for trying new activities and perhaps new foods)
- Nutrition (for nourishing the body as well as the central nervous system)
- All eight sensory systems (even picky eaters who don't engage their gustatory sense still use seven senses!)

Tactile: Hands manipulate the vegetables, developing touch discrimination and fine-motor skills

Proprioceptive: Hands, arms and upper body get into correct position to push the knife through the vegetables, developing appropriate force

Vestibular: Body is upright and stable, improving balance; muscles needed to handle the food and tool are engaged, improving muscle tone and stamina

Visual: Eyes see the vegetables, hands, and knife, improving visual discrimination and visual-motor coordination

Auditory: Ears hear the knife touching the board, improving auditory discrimination

Olfactory: Nose smells the vegetables, improving what

the nose knows and stimulating the appetite

Gustatory: Mouth tastes the circle salad (let's hope), increasing the number of foods the child will eat

Interoceptive: Internal organs digest the food, improving general health

Ways to Make It More Challenging

- Slant the knife to slice ovals for an ellipse salad
- Cube the vegetables to make a block salad
- Use a melon-baller to scoop little orbs of watermelon, cantaloupe, and honeydew to make a sphere salad
- Celebrate holidays with color-coordinated vegetables (green peppers, parsnips, and carrots for St Patrick's Day; and broccoli, mushrooms, and tomatoes for Columbus Day)

What to Look for

- The child holds the vegetables firmly and has good control of the knife
- The child slices the vegetables in somewhat regular circles
- The work stays on the cutting board
- The child is engaged and having fun

Thinking About Stimming

Catherine Faherty

Flapping, spinning, jumping, rocking, pacing, flicking ... self-stimulatory behavior, or stimulating, takes many forms. This is a topic that calls for deeper understanding and respect on the part of typically developing family members, friends, teachers, and therapists, along with the nurturing of self-knowledge and compassionate self-acceptance by the person who stims. For the longest time, stimulating was (and often still is) deemed inappropriate and has been targeted for extinction by some autism treatment and educational programs. The prevailing theory early on was that if stimulating is allowed to occur even a little bit, it will increase in frequency. Actually, in my classroom in the early 1980s, and in my later work

with children, adults, families, and professionals with the TEACCH Program at the University of North Carolina, I discovered just the opposite. In the classroom, by letting my students engage in self-stimulatory behavior on a regular basis, usually at specific times and places, the total amount of stimulating actually decreased. Even back in the 1980s it felt right to me to remain positive about a person's natural body movements. I tried to avoid negative connotations to these behaviors, as long as the movements were not harmful to the one stimulating or to others in the vicinity.

I still remember being joyful and playful while engaged alongside my students in spontaneous jumping and

flapping, with my contribution of air guitar, dancing, and singing to the Jackson Five blaring on the record player. I also remember the good-natured amusement on the face of our principal during his periodic unscheduled visits to my classroom when he found us jubilant in the play area! I discovered through trial and error that my students became calmer when I not only increased the level of structure throughout the day but scheduled time for movement—even sanctioning stimulating! In fact, I watched the children closely and modeled some of our activities during P.E. on their spontaneous stims. Not battling my students' flapping, rocking, and other movements and not focusing on forced

stimming elimination unless the stims were physically harmful to the person helped promote an all-around positive and up-beat school experience for my students.

That was almost 30 years ago. I am still thinking about stimming, and there is even more to think about.

Imagine what it may feel like to be a child whose natural body movements are labeled inappropriate, wrong, bad, and so deviant that they must be stopped immediately. In some cases, punishment is an accepted part of the treatment. The unquestioned mandate given so widely and freely of “Quiet Hands!” teaches the child that her hands—and their natural movements—are wrong. Repeatedly prompting a child to stop stimming (either through implication, announcement, or demand) often results in the child concluding that enjoying the moment or helping herself cope in the moment or purely moving in her natural way is so bad—so wrong, that it must be noted and addressed in a negative manner. A large amount of time, attention, and energy is devoted to the elimination of stimming by the people responsible for her educational program. Individualized Education Program, or IEP, goals

are dedicated to its eradication. For some autistic children and adults in certain treatment and educational programs, “Quiet Hands” and its accompanying strategies may actually be experienced as an act of aggression on the part of the person who moves her hands, leaving her feeling vulnerable, attacked, and unprotected. This vivid inner experience typically remains unknown to the teacher, therapist, or parent. Read the book *Loud Hands: Autistic People Speaking*, published in 2012 by the Autistic Self Advocacy Network, to better understand a perspective that may be very different from those who are privileged to have typical development.

It is true that stimming often results in the person appearing different than what is expected. Okay. It could serve as an effective reminder for us to educate peers, siblings, school staff, and the community at large about diversity and respect and to free us all to come up with novel and truly inclusive ways to interact and have fun, equally. Stimming is a natural behavior that is often enjoyable and/or otherwise beneficial to the person who is stimming. There is an overabundance of information for autistic children and adults on how to be social, and even

though much of it unquestionably claims to come from an inclusive philosophy, almost all “social skills strategies” emerge exclusively from a neurotypical perspective, with its focus on how to help the autistic person

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interact better socially. The assumption that to “interact better socially” means to “interact in a socially accepted, mainstream, nonautistic manner” is usually left undisputed.

What if all students—both autistic and nonautistic—learn about stimming and about how,

why, what it is? That everyone stims in their own ways? And that sometimes stimming is associated with enjoyment, pleasure, and happiness? Or that it's a way to take care of oneself and maybe get calm and centered? Or, it can be a reaction to the need for something to change? What if the teacher, therapist, parent, or friend announced aloud, "It's time for a stim break, everyone!" And then the whole class or whole family or maybe just two people jump up and flap, spin, or otherwise stim together? What might this communicate to the

one who naturally stims ... and to the ones who notice, watch, wonder, and learn?

There are many ways to be. And many ways to enjoy. And many ways to be together. Social learning.

For practical information for your students or family members, I refer you to pages 41-65 in the second edition of my book, *Autism ... What Does It Mean To Me?* These pages directly support self-knowledge and mutual understanding about stimming and other related, noticeable body movements. ♦

Catherine Faherty created a model classroom for elementary school students with autism in the 1980s, before becoming a TEACCH autism specialist. She has written manuals and co-developed many training models. Catherine speaks at international conferences, trains teachers, and mentors professionals in autism-related curricula. Her popular workbook was recently published with the revised title Autism ... What Does It Mean To Me? (Future Horizons, 2014). Her site is www.catherinefaherty.com.

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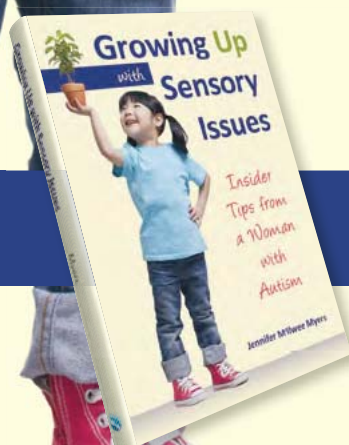
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When Is a Behavioral Problem Not a Behavioral Problem?



*Growing Up with
Sensory Issues*

*by Jennifer McIlwee Myers,
Aspie At Large*

HUMAN behavior is actually fairly simple: We tend to do the things that help us get more of what we want and less of what we don't want. It's so simple.

The problem is that we, as individuals, are often terrible at focusing on what we really want and don't want—and we are generally working with out-of-date brains. We'd love to be healthier, but we eat junk food because after roughly a kabazillion years of evolution our brains are well tuned to seek out the sweet, salty, and fatty foods that are found in nature or easily derived from it. We'd love to be more fit, but the same kabazillion years of evolution tell our brains that it is vital to conserve energy and find easier ways to do things.

So if a heckuva lot of the human race is dealing with instincts that urge them to seek things they don't need, why are we surprised when kids who have Sensory Processing Disorder (SPD) behave in seemingly unpredictable ways? Teachers and parents find themselves repeatedly trying to reward good behaviors and tie punishments to bad behaviors and are then bewildered when that child with SPD does exactly what he theoretically shouldn't do.

That's because kids with SPD are also tied to brains that aren't optimized for the situations they find themselves in. A child who is hypersensitive may be calmer and way more able to cope after vigorous activity, but that doesn't mean he'll seek active play on the playground.

In fact, that overly sensitive child may frequently repeat behaviors that lead to him being kept in from recess. Why? Because recess is overwhelming, and while physical activity may be soothing, it is on the other side of serious pain.

It's back to the brain. If something is painful, you avoid it. If a child associates the playground with chaos and bullying, and something he does gets him the chance to stay in, he might just keep doing that behavior. Even if he doesn't feel much like it—there are parts of the brain that “protect” us whether we think about it or not. The same kind of brain that tells you that exercise is bad and a deep-fried Twinkie is good will lead kids to exhibit behaviors that solve their immediate problem without helping them out overall.

My second-grade teacher didn't realize this and was bewildered by me, and then,

4 years later, by my sister. She tried very hard to motivate us with rewards and by making learning as fun as possible, and the whole thing backfired on her like crazy.

I should mention that Miss X was one of the nicest people I have ever met. She was intelligent, she loved children, and she loved teaching. I adored her.

The same kind of brain that tells you that exercise is bad and a deep-fried Twinkie is good will lead kids to exhibit behaviors that solve their immediate problem without helping them out overall.

But while Miss X absolutely liked and encouraged us with all of her heart, she didn't know how to “motivate” me or my sister Catherine. In fact, at one parent-teacher conference, she told my mother that trying to motivate either of the McIlwee girls was like trying to push a rope!

Miss X was looking at a behavioral problem. She had first one then another girl who

could not be convinced to participate in many important and educational classroom activities. She didn't realize we were both being protected by our own brains.

This was second grade, so we had a variety of educational "stations" located in the classroom to enable us to play games and do activities that would help us learn math, geography, and whatever the heck else second graders are supposed to learn. We were all encouraged to use our "free learning time" at any of these stations so that we could learn in a fun environment and learn through play.

These two girls had one thing in common: hypersensitivity. We could barely stand to be in a classroom in which many children were working independently or in small groups at these little stations. It was a chaotic whirl of children talking, laughing, arguing, and moving about. It was also socially stressful: We couldn't figure out the correct (non-bully-triggering) social behaviors when so many kids were doing so many different things; just filtering out any one voice was impossible, never mind trying to function in a group.

When I had Miss X as my teacher, I would race through my worksheets in the morning so I would be sure to be able to choose the "quiet reading" station. It was just a bookcase and some pillows to sit on behind a couple of room dividers, but it was a pretty decent sensory oasis in a classroom full of chaos. Nothing mattered to me as

she found her own solution: She slowed down.

By deliberately doing her worksheets as slowly as possible, she could avoid the learning station problem entirely. The part of the classroom where our desks were located was separate from the stations, and as more and more kids finished and moved to various stations, she found herself more and more alone in the quietest part of the room. All

she had to do was go as slow as possible, and she could protect herself from the noise and social chaos.

And Miss X did not know what to do with either of us. When she had me, she would try to talk me into trying some of the other stations. Then, 4 years later, she tried to motivate Catherine to get her worksheets done sooner. Miss X was smart enough to tell that Catherine was very bright and capable, but she could not figure out how to get her to do the work.

Miss X was worried about motivation. She saw two girls whose behavior prevented them from learning as much as they could, and she tried to find ways to get us to change our behaviors. And she didn't have any awareness at all of the fact that those learning stations

I wonder if learning about SPD and about how intensely our brains can work against us by trying to protect us might help other people understand that our behavioral problems are often not actually behavioral problems.

much as getting that worksheet done so I could hide from the rest of the classroom for as long as I possibly could!

My sister had it a little rougher. She's smart as a whip, but when she first started grade school, she wasn't really much into reading, and she really wasn't all that comfortable in that slightly claustrophobic reading area. So,

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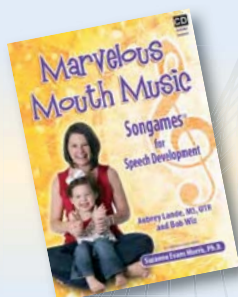
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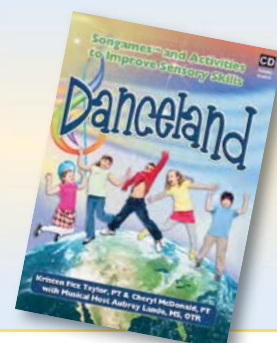
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were so painful to us that neither of us could be motivated to join our classmates there. It simply wasn't possible.

What is important here is that Miss X looked at this as a behavioral problem: What can I do to encourage or motivate this child to do an important learning activity?

The real problem was not behavioral; it was academic. The real question was not "How do I get this child to do X learning activities?" but "How do I find ways for this child to learn what she needs to?"

Miss X was so focused on altering our behaviors that she put all of her efforts into getting us to do what the other children did. Despite her genuinely outstanding intelligence and compassion, she didn't understand that the real problem was that she had unknowingly tied vital learning activities to very difficult sensory challenges.

She worked very hard on that behavioral problem, and there was no chance that someone might have suggested SPD as a possibility all those years ago. Given her genuine love of teaching, I would be surprised if she could not have found ways to make the classroom work for us if she had more information.

I wonder if learning about SPD and about how intensely our brains can work against us by trying to protect us might help other people understand that our behavioral problems are often not actually behavioral problems. After all, many of us (me included) work very hard at motivating ourselves to eat better and exercise but ignore the very intense self-protective mechanisms of the brain.

Think about it: What if instead of joining a gym and vowing to go there every single day, we spent a little time each day trying out different kinds of exercise? What if instead of trying to go on extreme diets, we tried adding in a small amount of healthier food? Instead of ruling out all junk food, add in one "healthy eating" day per week, to try out new stuff.

What if instead of expecting ourselves and/or our children to transform and somehow start doing all of the things our brains object to so strenuously, we tried figuring out what the end goal was?

The reason I would not go and play with the other children at learning stations was that it was an overwhelmingly negative sensory experience to me. What if Miss X had that information and told me

that she needed me to get out library books about the stuff the learning stations were supposed to teach? What if she had rewarded my sister with time alone instead of trying to push her into the most chaotic part of the classroom?

What if we stopped trying to push that rope, and instead started trying to understand ourselves and our children? It might not change the world, but it seems like it might be worth a try. ♦

A woman with Asperger's syndrome, Jennifer provides countless tips to improve the lives of those with sensory difficulties. She is the author of How to Teach Life Skills to Kids with Autism or Asperger's (Future Horizons, 2010) and the recently released Growing Up with Sensory Issues (Sensory World, 2014).

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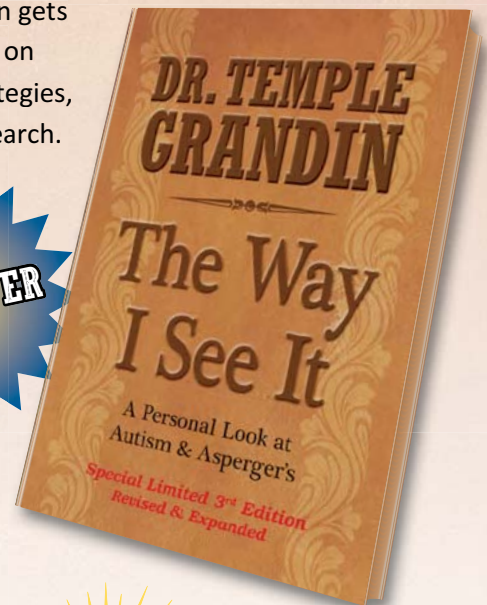
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PlaySense

by Barbara Sher, MA, OTR,
The Games Lady

The Mary Poppins Cure

In my continual quest to be more like Mary Poppins and use a little bit of fun to get the chores done, I have also come up with games to include a little bit more joy on the emotional level when needed!

Mum's Gone Crazy

I'm always amazed by how quickly my daughters can break into an argument. It's just squabbling, but it can get on my nerves. This game is a showstopper way to distract fighting children and help them regain their sense of humor. It's a guaranteed bickering-buster.

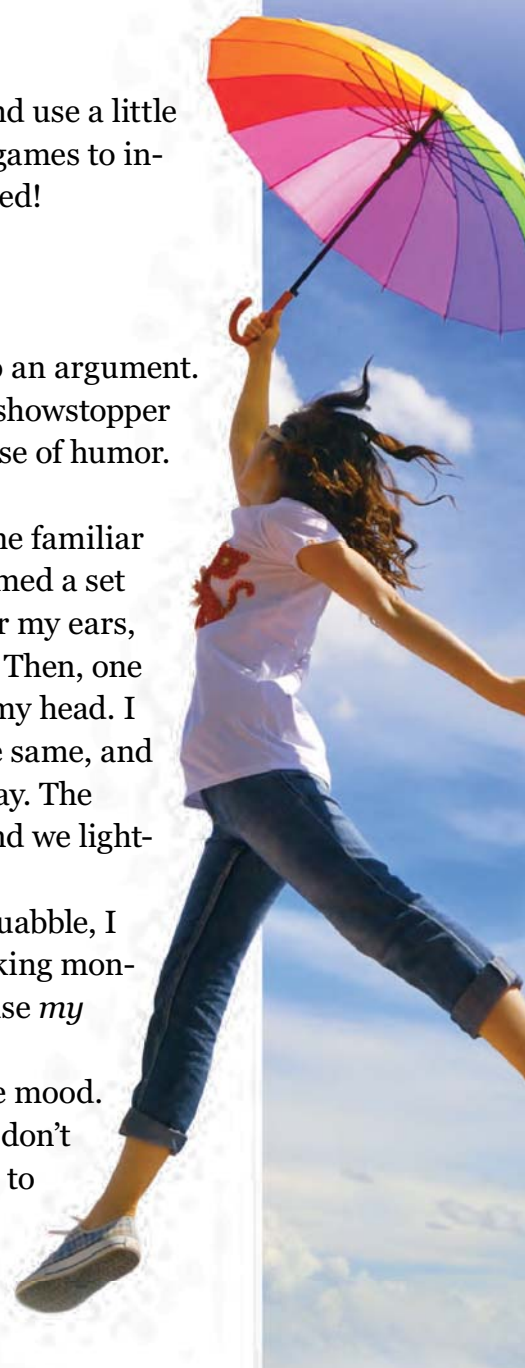
One day, while sorting laundry in the living room, I heard the familiar call and response of "Did not!" "Did too!" On an impulse, I jammed a set of my husband's clean underwear on my head, probably to cover my ears, and kept on sorting. From my daughters came stunned silence. Then, one of them pointed out that I was wearing Daddy's underwear on my head. I acted nonplussed, as if to say, "Who doesn't?" They then did the same, and soon we were parading around as if we were on a fashion runway. The show didn't last long, but it broke their argumentative mood, and we light-heartedly went on with our day.

Another day, inspired by the growing tensions of another squabble, I began to act like a gorilla, jumping around, scratching, and making monkey sounds—"EEEE!" At first, it probably helped only to release *my* tension, but soon all of us were monkeying around.

It was so silly that we couldn't help but laugh and lighten the mood.

All children can enjoy being monkeys in their own way. You don't need to be verbal or even be able to jump around. You just need to be able to scratch your trunk or pound your chest!

Mothers and kids can also turn into "tickle monsters" at a moment's notice, which is just when that moment is needed.



In Search of the Grumpy Bug

This game can lighten the moment and help jolly a child out of a bad mood. When a little one is grumpy, I sometimes act surprised:

“You’re grumpy? That doesn’t seem right—you’re usually in such a good mood. Ah, I know what’s happened—you’ve got a grumpy bug hiding on you. I’ll get rid of that for you.” I then proceed to search for the bug. I check ears and armpits, look down shirts and inside pockets and between toes, all the time acting exasperated and determined. “It’s *got* to be here somewhere. I just *know* it!” By the time I “find” the bug, the small one is giggling and often helping me look. Together, we toss the grumpy bug away.

But if we’re not careful where we toss it, the bug gets on someone else—and then we have to search him, too. Often, in a classroom, soon everyone is claiming to have the grumpy bug, and there’s a lot of searching and a lot of giggling.

I end the game quietly by looking for the “love bug.” We have to look in a lot of places: Maybe it’s in the flower pot. Maybe it’s in the soft blanket. When we “find” it, I ask the child to handle it gently and put it somewhere on her body,

in a pocket or right next to her heart.

“When ya got the love bug, everything’s gonna be all right.”

Wash That Mood Right Out of the Room

This game can get rid of a bad mood that is infecting kids and get the floor cleaned at the same time. You have to be in the mood for a bit of chaos, but it’s worth it—as my friend Jane, who home-schools her four kids, would tell you. I like the game because it involves water and spending time on the floor, and that means everyone, regardless of motor or sensory skills, can find something fun about Jane’s method.

On days when crankiness has been contagious—someone woke up on the wrong side of the bed and yelled at someone, who then snapped at someone else, who then passed the mood on, until everyone is grouchy—Jane fills a bucket with warm, sudsy water and starts spreading it across the floor. Nothing entices a kid more than water and bubbles—Jane’s kids grab the sponges (already conveniently laid out) and start spreading the water around, along with slipping and sliding and spinning in circles on their bottoms. Jane

knows, as I do, that all that erratic movement is good for developing coordination in young bodies. The vestibular system of the inner ear, which controls balance, is stimulated, reinforcing the children’s internal sense of which way is up—even if they take a few tumbles.

If it all gets too nutty, Jane brings in Step Two, the water for rinsing—and then Step Three, the towels. Everyone gets a big towel to dry the floor in whatever way they want, which might include riding the towel like a magic carpet across the floor. When, like any game, the toweling game gets old, Jane dries the parts of the floor that were missed, tosses the towels in the washing machine, and goes on with her day with a cleaner floor and a lighter heart. ♦

Barbara Sher, MA, OTR, is a pediatric occupational therapist who has published seven books on children’s games. You can find her titles and workshops in any online bookstore or on her site, www.gameslady.com. Comments and requests for presentations can be e-mailed to her at barbara.sher@gmail.com.

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Betty Lehman

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is intentional planning that focuses on the care needs, financial needs, and legal needs of the whole family. Like an Individualized Plan, a Life Care Plan is created by a team of professionals who understand how to design your plan to support the needs of your entire family throughout their lifetimes. This means making sure that there is enough money and that the money is controlled in such a way that every family member has the opportunity to have the best quality of life possible, given their unique circumstances. The Life Care Plan is usually centered on funding

sources, such as private assets, insurance, and public benefit programs.

One way to envision what is required from a thorough Life Care Plan is to ask the following questions: “If my spouse and I perished in a common accident last night, would everything be OK?” “Would my family know what to do?” “Would my family know how much I loved them?” “Would my family know Johnny’s routine or how best to comfort Becky?” “Would my family have enough money?” “How much money does my family need?” and “Would my family be legally protected?”

These questions are answered by having a Life Care Plan in place. Start with writing down your Family Mission Statement to discover and express your family’s values. Your values as a family are the heart and soul of a fully considered Life Care Plan, as they are the guiding force of daily decisions. By writing out the Family Mission Statement, the professionals you work with will be better equipped to help you create a Life Care Plan tailor-made to embrace your values and create the best quality of life for every family member, when you are no longer able to guide their lives.

Another important tool for your family's Life Care Plan is the Letter of Intent (LOI) document. Think of the LOI as a family instruction manual in which the outside world is given all the information needed to step into "your shoes." Your LOI expresses what you know historically and what you desire in the future for your children, in areas such as:

- Education
- Daily activities

Although the LOI is not a legally binding document, it is an often underused planning "tool." The LOI:

- Gives future support personnel insight and advice about your child's needs
- Provides directions for lawyers, trustees and guardians about your wishes
- Saves time when others know your child's likes, dislikes, self-management techniques, talents, and

Your values as a family are the heart and soul of a fully considered Life Care Plan, as they are the guiding force of daily decisions.

- Residence
- Employment
- Medical history and care
- Environment management: What is needed to feel safe?
- Social activities and recreation
- Religion
- Trustee(s): Who will help manage taxes and money concerns?
- Advocate/Guardian: Who will look after, fight for, and be a friend to your child? Whom do I trust?

strengths

- Protects your child from unnecessary confusion when he must depend upon someone other than your family for care and support
- Paves transition by giving future support personnel vital information they will need, like your child's medical history

After you have completed your Family Mission Statement and LOI, you will have a clearer idea of why you would like to

protect and grow your assets. This knowledge will help you when having conversations with a financial advisor, disability advisor, and attorney.

Melissa Edelman, CLU, ChSNC, believes that no chances can be taken with the financial future of your family, so she recommends that when selecting your financial advisor, it is best to choose a Chartered Special Needs Consultant (ChSNC) who has the additional training to provide proper planning for families with loved ones who have special needs. A ChSNC understands what is required to plan for the financial needs necessary to maintain the quality of life for a person who may not be able to fully support himself financially, the education needs of typically developing children, and retirement for the parents.

Laura A. Mathews, a board member of the Sensory Processing Disorder Foundation and an attorney who helps families with Life Care Plans, believes in creating a design with the help of financial and disability advisors that has flexibility and longevity and can address such needs as, "We do not know what happens next, so we need to plan to have documents and money in place that meets the family where they are at any given

time, even if it is 75 years from now." Laura also believes that a "one size fits all" planning approach for "atypical families" should be avoided at all costs.

Planning for the future requires time, thought, and professional support. As change is constant, a Life Care Plan should be updated when needed. Your plan may change with changes in:

- Market performance
- Tax law
- Government benefits and services

- Eligibilities
- Family: New baby, divorce, death, marriage, inheritance
- People: Developments and progress
- Changes in family values or goals

Although the efforts to create a fully considered Life Care Plan are rigorous, when your planning is in place, you will be able to say, "If something were to happen to me, my family would grieve, but they would be OK." To be able to know in your heart and in reality that

you have created the supports others will need in your absence will bring great peace of mind to you and to the people you love. ♦

Betty is a CPA and the mother of a grown son with autism. She served as the executive director of the Autism Society of Colorado and spearheaded 14 Colorado statutes to improve the quality of life for people with disabilities and their families. Her Web site is www.lehmandp.com.



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-- Verona

Both boys started to have increased eye contact, awareness, joint attention, and both were trying to talk more during the 2nd week.

-- Judy

In addition to words coming more readily to him and reading skills markedly improving, Cade has been calmer and more focused, and he has exhibited new behaviors.

-- Nancy

Most importantly, she's never, ****never**** been able successfully to socialize with people her own age before. In the past people were always either very kind and patronizing or ignored her completely. This weekend, people often sought her out just to spend time talking with her.

-- Linda

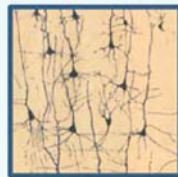
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