

Autism is...?

—The Magazine—



**IT'S OFFICIAL!
—NOW WHAT?**

After the diagnosis

**The Importance of
Early Intervention**

Do It Yourself!

The best therapist?—You!

Issue 1

Resources for parents, educators, and anyone caring for those on the autism spectrum.

Autism is...? The Magazine—Issue 1

Autism is...? The Magazine has the needs of parents, grandparents, and caregivers of children with autism at heart. It provides helpful information, motivation, inspiration, and a way to connect with others who face similar challenges.

To learn more, visit www.autism-is.com — www.facebook.com/Autism.Is

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For more information, please visit www.autism-is.com.

Credits:

**Editor-in-Chief
Contributing Editors**

Ymkje Wideman-van der Laan
Anita Florijn, Kerri Stocks

**Design
Website**

awex
www.autism-is.com

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“Autism is...?”

That is the question my 5-year old grandson asked me one day when he overheard me talking with a friend about his high-functioning autism. I told him I would explain it to him, and then searched for a book, or anything, that would address the subject in a clear and age-appropriate manner.

After looking on many websites and making calls to numerous bookstores, I still did not find anything to explain autism to this bright and inquisitive youngster in a fun and positive way. That night I wrote the book, “Autism Is...?”

My grandson loved it, and so did a number of my friends—professionals who work with or for children with autism. “You must publish this,” and “I will be the first to order your book,” were some of their comments.

One book led to other books, and eventually to the idea of starting my website, and putting together a magazine with basic information on a number of pertinent autism topics. I hope this magazine will fill the vacuum for information for you that I myself experienced when my grandson was first diagnosed, and which many parents of newly diagnosed children experience as well.

This first issue includes basic information about autism, initial reactions to receiving the diagnosis, the importance of early detection and intervention, information about sensory processing disorder, do-it-yourself tips, and a short list of resources to get you started.

I hope *Autism is...? The Magazine* will provide the kind of real-world, practical, and helpful information that you may be looking for and need, and that it will make your autism journey a little easier.

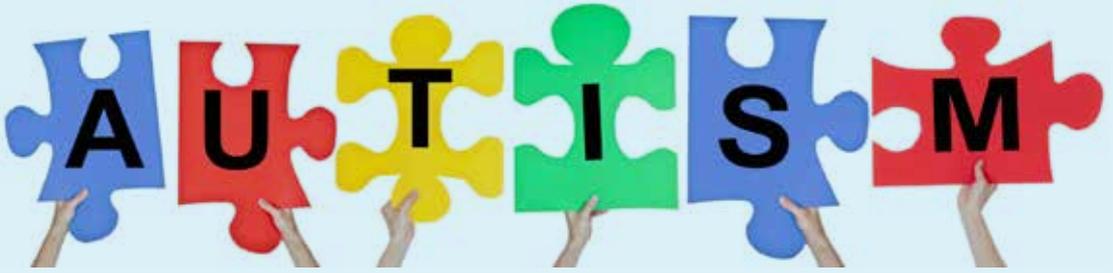
A handwritten signature in black ink that reads "Ymkje".

Ymkje Wideman-van der Laan

Editor-in-Chief

Order Ymkje's book, *Autism Is...?* at <http://autism-is.com/autism-is-books/autism-is> or on Amazon.





Autism Is...?

The basics

Autism is a brain disorder that affects communication, social interaction, and behavior. Individuals with autism typically have difficulty understanding verbal and/or nonverbal communication, and learning appropriate ways of relating to other people, objects, and events.

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities—including classic autism, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger’s Syndrome (AS)—that affect a person’s ability to understand what they see, hear, and otherwise sense.

No two people with ASD are the same. As its name implies, ASD is a “spectrum” disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities, such as Sensory Processing Disorder (SPD), Attention Deficit Disorder (ADD), and Attention Deficit Hyperactivity Disorder (ADHD).

How common is autism?

Autism is more common than childhood cancer, cystic fibrosis, and multiple sclerosis combined. It is estimated that in the US alone, one out of every 68 children born today has some form of ASD. Roughly translated, this means as many as 2 million Americans are believed to have some form of autism—and this number is on the rise not only in the US, but worldwide. Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a startling rate of 10-17 percent per year. Autism knows no boundaries of race, ethnicity, social status, family income, lifestyle, or educational levels, and can affect any family and any child. Although the overall incidence of autism is consistent around the globe, it is estimated to be on average 4 to 5 times more likely to occur in boys than in girls. ■

Persons with autism may show signs of the following characteristics:

- Be non-verbal or have limited verbal abilities.
- Resist change.
- Use gestures to express needs rather than words.
- Laugh or giggle inappropriately.
- Cry for no apparent reason.
- Repeat words and/or phrases as a response.
- Prefer to be alone.
- Have difficulty mixing with others.
- Throw tantrums—display extreme distress for no apparent reason.
- Make little or no eye contact.
- Be sensitive to touch, and not like hugging/cuddling.
- Do not respond to regular teaching methods.
- Attach passionately to objects.
- Show no real fear or sense of danger.
- Be over or under-sensitive to pain.
- Have awkward gross/fine motor skills.
- Do not respond to verbal cues (as if deaf).
- Be sensitive to sound, or bright lights.
- Exhibit self-stimulating behavior, such as hand flapping, finger flicking, body rocking.
- Become anxious in new situations.
- Do not understand consequences of actions.
- Have difficulty remembering facts or details of circumstances.

Some Basic Helpful Hints for Interactions with Individuals with ASD

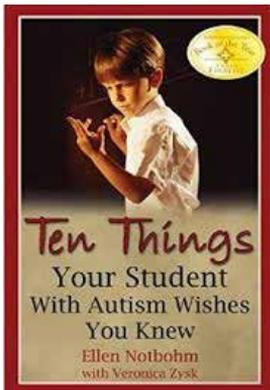
- Focus their attention by, for example, gently touching their shoulder.
- Use simple (but normal) language; speak calmly, clearly, and in a normal tone of voice.
- Use concrete, not abstract, terms and ideas when giving instructions.
- Repeat simple questions, allowing time (10-15 seconds) for a response.
- Proceed slowly and give praise and encouragement.
- Do not attempt to stop self-stimulating behavior physically.

Remember: Each **individual** with **autism** is **unique** and may **act** or react **differently!**

Autism can be explained to younger children, siblings, family members, and others you interact with like this:

People with autism are born with brains that work differently than others' brains, so they learn differently. Many times a person with autism will have a hard time talking with people, and understanding what they are saying. Some people with autism cannot talk, while others talk a lot. Certain things may not feel, sound, smell, or taste the same to a person with autism, and sometimes this difference is upsetting. Sometimes people with autism rock back and forth or wave their arms and hands. They may not know they are doing this, or how it looks to others. It is important to remember that each person is different whether he or she has autism or not. We all have unique qualities that make us special. ■

Taken from the *Autism Society of North Carolina* and *Autism Speaks* websites <http://www.autismsociety-nc.org/> and www.autismspeaks.org, and other sources.



In her book, *Ten Things Your Student with Autism Wishes You Knew*, Ellen Notbohm compares a person with autism to a Mac computer in a PC-dominated environment. She writes, "He is hard-wired differently. Not incorrectly—just differently." The brain with autism thinks differently than a brain without autism, and the basic operating systems of the two brains will not be compatible until we learn each other's way of thinking, and adapt the way we communicate.

It's Official!—Now what?

After the diagnosis

By Jennifer Lingle, M.Ed.

Everyone experiences the news, “Your child has autism,” differently, and everyone reacts differently. The reactions range from “I knew it! I have been telling the doctors this for the last 12 months,” and “I don’t think it’s autism,” to “Really? I think he is just getting a slow start.”

When I was 15 years old, my older brother passed away. He was just 19 years old. It was an extremely rough time for me. I remember sitting in the school psychologist’s office feeling angry, scared, disappointed, and lonely. I felt like nobody understood what I was going through. Even though I knew in my mind that other people had experienced loss, I felt like my feelings were unique, and that the world just didn’t get it.

The psychologist gave me a piece of paper that listed five steps. She told me, “This is what you will go through. This is the grieving process.” I thought to myself, *Oh, so not only does she not have a clue how I am feeling, but now she presumes that she knows what my future will hold.* I was angry and convinced that I was the only one feeling this way, and that nobody could possibly understand what it was like, especially someone who had never lost a brother.

You may wonder why I am telling you this. Well, I speak with many parents about their feelings, and about what they went through when they first heard the words, “Your child has autism.” Then I talk with them about what they are going

through 3 months, 6 months, 1 year, 5 years, and 10 years later.

Watching my mother go through the stages of grieving, showed me how the process was different for her than it was for me, just like each of your experiences are very much different from the experiences of other parents. Still, when I listen to your stories, I hear many similarities between what you have been through with your child’s diagnosis, and what my mother went through when she lost her son. Of course, your experiences are different from those of someone who lost a child to death. Your child is thankfully still very much present in your lives, but many of you have gone through, or are going through a process very similar to the grieving process.

Perhaps your process involves mourning the loss of the hopes and dreams you had for your child, while others may be going through a completely different process. Whatever the case may be, you might relate and benefit from the five steps involved in grieving that were passed on to me when I lost my brother.

Of course, not everyone goes through these five steps, and some may not go through these stages in order. In my case, once I got over my initial anger that someone would even assume what I was feeling, I found comfort in knowing that wherever I was in this process, there was an actual name for it, and that I was not alone.

Whatever your coping mechanism is, it is yours to experience. Your feelings are unique to you. Nobody knows what you go through, except for you. However, I felt an amazing peace when I opened my heart to the idea that there really is a process. Even when I felt like I was going to fall apart, I found sanctuary in knowing that at the end of this so-called grieving process, I was going to be able to accept my reality, and I was going to be okay.

It can take a long time to come out of the denial stage, and that is okay. Try not to blame yourself or anyone else for where you are in your journey. Give yourself time to feel the exact way that you are feeling. Only when you are ready can you move on to the next step.

Perhaps you will waver between two or three stages. Maybe you are already at the acceptance stage, but you still experience anger and depression. Life is a process and a journey.

I also want to note here that for parents of children with autism, I

would list number 3 as hope. We read everywhere about the importance of early intervention, therapies, and intensive instruction, so many of you enroll your child in various classes to where their day is filled to the max with therapy. Many of these therapies work and can make a huge difference for your child. When parents fill the schedules of their child with autism with every possible therapy and program imaginable, it is because they are full of hope that something is going to help their child come out of their autism.

The most important thing to remember in all of this is that children with autism are a gift to our world. Even though it is tough when you first get the news, your child with autism will teach you many things. He will test your strength, and you may question your courage. However, one thing is certain, your child accepts you and loves you for who you are; a parent who is doing the best they can on their journey for the love of their child. ■

The Five Stages of Grief

1. Denial—“This isn’t happening to me. I can’t believe this is happening.”
2. Anger—“This is so horrible. This is so unfair. I am so hurt and angry.”
3. Bargaining—“If I do this, it will make him better.”
4. Depression—“I cannot take it. I don’t want to get out of bed. I am so heartbroken.”
5. Acceptance—“I am ready to take the next steps. What do I need to do to help my child? I am going to be okay. He is going to be okay.”

(Adapted excerpts from the book, *Death and Dying*, by Elizabeth Kubler-Ross)

Jennifer Lingle, M.Ed. is the founder and director of Autism Educates (<http://www.autismeducates.com>). She wrote this article in memory of her brother, who passed away on January 29, 1992. It is with love in her heart that she says to the world, “While the thought of not having my brother can be challenging, I am a stronger, more confident person because of it.”



What to Do After the Autism Diagnosis

By Lisa Jo Rudy, former *About.com* Guide

Don't panic!

For most parents, a diagnosis of autism is like a kidney punch. You feel breathless and overwhelmed. Your world has been turned upside down. But remember that autism, despite its many challenges, is not a dangerous condition. There's no need to panic! You and your entire family will benefit if you can think clearly and calmly.

Remember that your child has not changed.

Yesterday, your child was not labeled autistic. Today, he or she has been handed that label by a professional. But the label doesn't change your child or your love for him or her. All the good things you saw in your child yesterday are still there today—and will be there forever. Part of

your job will be to help him or her build on those strengths to compensate for the challenges of autism.

Don't rush into action.

The research says that early intervention is important. By the same token, however, autistic children grow and develop over time just like everyone else. It's tempting to leap into as many therapeutic treatments as you can. But until you know what's best for your child, it's a good idea to take it slow.

Read and ask questions.

A huge number of websites, books and resources are available about autism. Select a few and dig in. Find a local support group and get involved. Learn how other parents have managed situations similar to yours.

Determine your child's needs.

What exactly are your child's needs and deficits? Autism is a spectrum disorder, which means that your child may have many needs or just a few. Does your child have speech delays? Sensory issues? Social deficits? By asking all of these questions of your medical practitioner, your family, and local support groups, you can start to create a picture of the services your child might need.

Research your autism resources.

Now that you know what your child needs, you need to determine whether those therapies are immediately available to you—and if they are, how to put them in place. If you are in a rural area, you may have fewer options available than if you're in a city. Your medical insurance may cover only a fraction of the therapies you've discovered. Your school district may have specific options available. Once you know what's immediately available, you can set up a program that suits at least some of your needs.

Start with the basics.

Literally dozens of treatments are available for autism. Start with the basics—the treatments that are easily

available, funded, and appropriate. For most families, the basics include speech, occupational, and physical therapy. For younger children, home-based therapeutic programs are often available; preschoolers and school-aged children may be offered therapies through the school system.

Add therapies slowly.

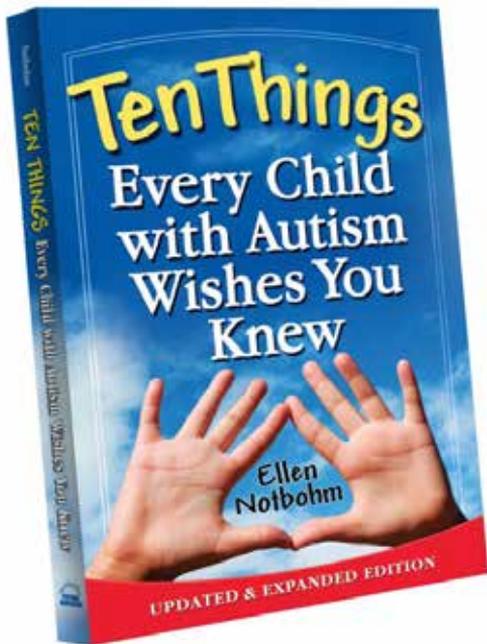
If you decide your child is not getting all he or she needs, you may be tempted to jump into many different interventions at the same time. Of course, there are interventions that have an immediate impact for the better or worse, including some pharmaceuticals. Most treatments, however, require days, weeks, or even months to really make a difference. By making changes slowly and observing your child's reactions, you can see what works and what doesn't.

Remember to breathe.

Your child's diagnosis is important, but so is your own life, your other children, your health, and your finances. It's ok to take a break from time to time, and to just be. Only when you're at your best can you hope to give your child all he or she needs to grow, develop, and enjoy life! ■



Lisa Jo Rudy is the mother of Tommy, age 14, diagnosed with PDD-NOS—an autism spectrum disorder. She is also a professional writer, researcher, and consultant. Lisa and her videographer/photographer husband, Peter, live in Massachusetts. Their son, Tom, is homeschooled, and their daughter, Sara, attends public school. Lisa is the author of the book, *Get Out, Explore and Have Fun: How Families of Children With Autism or Asperger Syndrome Can Get the Most Out of Community Activities*, published in May, 2010 from Jessica Kingsley Press.



Ten Things

Every Child with Autism Wishes You Knew

By Ellen Notbohm

From the book *Ten Things Every Child with Autism Wishes You Knew*, 2nd edition, Bronze Medal in Psychology, ForeWord Book of the Year Awards. Reprinted in its entirety with permission of author

Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute—the inconsistency. Autism can be baffling, even to those who spend their lives around it. The child who lives with autism may look “normal,” but his behavior can be perplexing and downright difficult.

Autism was once labeled an “incurable disorder,” but that notion has crumbled in the face of knowledge and understanding that increase even as you read this. Every day, individuals with autism show us that they can overcome, compensate for, and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s basic elements has a tremendous impact on their ability to journey towards productive,

independent adulthood.

Autism is a complex disorder, but for purposes of this article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills, and whole child/self-esteem issues. Although these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly, every parent, teacher, and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. I am a child.

My autism is part of who I am, not all of who I am. Are you just one thing, or are you a person with thoughts, feelings, preferences, ideas, talents, and dreams? Are you fat (overweight), myopic (wear glasses), or klutzy (uncoordinated)? Those may be things that I see first when I meet you, but you're more than just that, aren't you?

As an adult, you have control over how you define yourself. If you want to single out one characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. If you think of me as just one thing, you run the danger of setting up an expectation that may be too low. And if I get a sense that you don't think I "can do it," my natural response will be, why try?

2. My senses are out of sync.

This means that ordinary sights, sounds, smells, tastes, and touches that you may not even notice can be downright painful for me. My environment often feels hostile. I may appear withdrawn or belligerent or mean to you, but I'm just trying to defend myself. Here's why a simple trip to the grocery store may be agonizing for me.

My hearing may be hyper-acute. Dozens of people jabber at once. The loudspeaker booms today's special. Music blares from the sound system. Registers beep and cough, a coffee grinder chugs. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can't filter all the input and I'm in overload!

My sense of smell may be highly

sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle three with ammonia. I feel like throwing up.

And there's so much hitting my eyes! The fluorescent light is not only too bright, it flickers. The space seems to be moving; the pulsating light bounces off everything and distorts what I am seeing. There are too many items for me to be able to focus (my brain may compensate with tunnel vision), swirling fans on the ceiling, so many bodies in constant motion. All this affects how I feel just standing there, and now I can't even tell where my body is in space.

3. Distinguish between won't (I choose not to) and can't (I am not able to).

It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, I hear "*&^%\$#@, Jordan. \$%^*&^%\$&*." Instead, come over to me, get my attention, and speak in plain words: "Jordan, put your book in your desk. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it's much easier for me to comply.

4. I'm a concrete thinker. I interpret language literally.

You confuse me by saying, "Hold your horses, cowboy!" when what you mean is, "Stop running." Don't tell me something is "a piece of cake" when there's no dessert in sight, and what you mean is, "This will be easy for you to

do.” When you say, “It’s pouring cats and dogs,” I see pets coming out of a pitcher. Tell me, “It’s raining hard.”

Idioms, puns, nuances, inferences, metaphors, allusions, and sarcasm are lost on me.

5. Listen to all the ways I’m trying to communicate.

It’s hard for me to tell you what I need when I don’t have a way to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now, I can’t find those words. Be alert for body language, withdrawal, agitation, or other signs that tell you something is wrong. They’re there.

Or, you may hear me compensate for not having all the words I need by sounding like a little professor or movie star, rattling off words or whole scripts well beyond my developmental age. I’ve memorized these messages from the world around me because I know I am expected to speak when spoken to. They may come from books, television, or the speech of other people. Grown-ups call it echolalia. I may not understand the context or the terminology I’m using. I just know that it gets me off the hook for coming up with a reply.

6. Picture this! I’m visually oriented.

Show me how to do something rather than just telling me.—And be prepared to show me many times. Lots of patient practice helps me learn.

Visual supports help me move through my day. They relieve me of the stress of having to remember what comes next, make for smooth transition between activities, and help me manage my time

and meet your expectations.

I need to see something to learn it, because spoken words are like steam to me; they evaporate in an instant, before I have a chance to make sense of them. I don’t have instant-processing skills. Instructions and information presented to me visually can stay in front of me for as long as I need, and will be just the same when I come back to them later. Without this, I live the constant frustration of knowing that I’m missing big blocks of information and expectations, and am helpless to do anything about it.

7. Focus and build on what I can do rather than what I can’t do.

Like any person, I can’t learn in an environment where I’m constantly made to feel that I’m not good enough and that I need fixing. I avoid trying anything new when I’m sure all I’ll get is criticism, no matter how “constructive” you think you’re being. Look for my strengths and you will find them. There is more than one right way to do most things.

8. Help me with social interactions.

It may look like I don’t want to play with the other kids on the playground, but it may be that I simply do not know how to start a conversation or join their play. Teach me how to play with others. Encourage other children to invite me to play along. I might be delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don’t know how to read facial expressions, body language, or the emotions of others. Coach me. If I laugh when Emily falls off the slide, it’s not that I think it’s funny.

It's that I don't know what to say. Talk to me about Emily's feelings and teach me to ask, "Are you okay?"

9. Identify what triggers my meltdowns.

Meltdowns and blow-ups are more horrid for me than they are for you. They occur because one or more of my senses has gone into overload, or because I've been pushed past the limit of my social abilities. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, and activities. A pattern may emerge.

Remember that everything I do is a form of communication. It tells you, when my words cannot, how I'm reacting to what is happening around me.

My behavior may have a physical cause. Food allergies and sensitivities, sleep problems, and gastrointestinal problems can all affect my behavior. Look for signs, because I may not be able to tell you about these things.

10. Love me unconditionally.

Throw away thoughts like, "If you would just—" and "Why can't you—?" You didn't fulfill every expectation your

parents had for you and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of growing up to be successful and independent are slim. With your support and guidance, the possibilities are broader than you might think.

Three words we both need to live by: Patience. Patience. Patience.

View my autism as a different ability rather than a disability. Look past what you may see as limitations and see my strengths. I may not be good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, or pass judgment on other people?

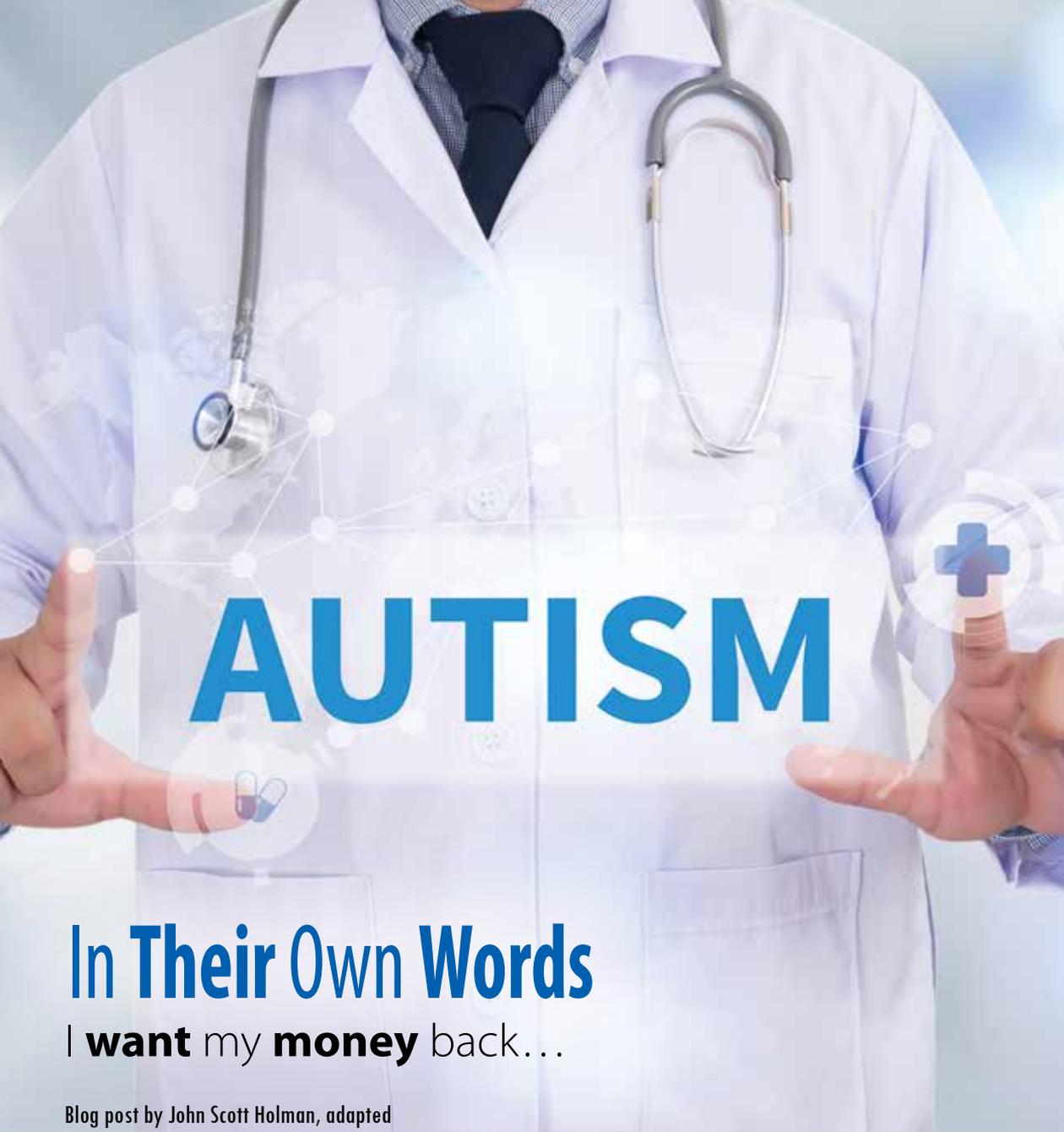
I rely on you. All that I might become won't happen without you as my foundation. Be my advocate, be my guide, love me for who I am, and we'll see how far I can go. ■

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Award-winning author and mother of sons with ADHD and autism, Ellen Notbohm's books and articles have informed and delighted millions in more than twenty languages. Her work has won a Silver Medal in the Independent Publishers Book Awards, a ForeWord Book of Year Bronze medal, Honorable Mention and two finalist designations, two Mom's Choice Gold Awards, Learning magazine's Teacher's Choice Award, two iParenting Media awards, and an Eric Hoffer Book Award finalist designation. She is a contributor to numerous publications, classrooms, conferences, and websites worldwide. To contact Ellen or explore her work, please visit www.ellennotbohm.com.



AUTISM

In Their Own Words

I **want** my **money** back...

Blog post by John Scott Holman, adapted

At the tender age of fifteen, I saw my first psychologist, a stern, elderly man who smelled like a second-hand bookstore. His full, wiry beard was speckled with white and gray, as if it had caught the contents of an overturned ashtray. It fell past his chest, disappearing beneath the edge of his massive, oak

desk. I wondered if it reached his toes, and I leaned forward awkwardly, hoping for a revealing glimpse.

“Young man,” he said, startling me. “Tell me why you’re here.”

“Do you shampoo that beard?” I asked.

“Excuse me...?”

“You look like Charles Darwin.”

He leaned back and stared at me, mildly annoyed, as if I was a fly he had noticed swimming in his coffee. “Your family is concerned by your behavior. I believe...”

“I commend you, sir!” I interrupted. “The world is experiencing a shortage of truly magnificent facial hair; you’ve got the best beard I’ve seen all year! You know who else had a good beard? Sigmund Freud. Are you a Freudian psychologist?”

“Young man, let’s try to stay on topic.”

“Right, beards... Nobody could beat Tolstoy’s beard. Now that dude had a beard!”

“Young man!” he bellowed, startling me again.

“Humph... Young man,” I muttered. “Just ‘cause I can’t grow a big fancy beard...”

The psychologist lifted a notepad from his desk and began scribbling absentmindedly. “I’m afraid,” he said, “that you have a very serious case of Bipolar Disorder.”

“Huh? How do you know? I’ve only been here for five minutes!”

“Trust me; I’ve been around a long time.”

“But... I’ve never had a manic episode, and the DSM-IV clearly states...”

“You, my dear boy, are an upstart!” the psychologist fumed, a fat, blue vein trembling in his forehead.

“Ok, chill dude... I’m bipolar. Whatever you say... Beethoven was bipolar. I don’t think he had a beard though...”

For as long as I can remember, people

have been trying to figure me out. Other parents told my mother and father that I was clearly lacking discipline. Teachers refused me an education unless I was prescribed enough Ritalin to keep the Rolling Stones touring for another century.

Hyperactive, precocious, and more than a little odd, I was truly a handful. Snakes, snails, and puppy dog tails? If only my mother was so lucky. Someone must have littered my gene pool with pixie sticks, happy meals, mountain dew, and an Encyclopedia Britannica.

“There’s something wrong with him,” my mother would sob. “He’s allergic to people! He won’t sit still, he won’t listen, he’s always hurting himself, and he’s smarter than my whole graduating class put together!”

I treated other children like overgrown action figures, ordering them about, an infantile Cecil B. DeMille directing a playground epic. “C’mon Tina, say that line again, and this time, say it with feeling! Put down the Polly Pocket and explain your character’s motivation!” Eventually, my peers developed their own interests, and I was left to wander the playground alone, thinking of Ghostbusters, Power Rangers, and... existential motifs in Russian literature.

“Scotty’s latest obsession,” was a phrase used regularly to describe the most current of my all-encompassing interests. At twelve years-old, I had forgotten more randomly collected information than most people will learn in college. My obsessions gradually became less and less age appropriate as my focus narrowed; retired barbiturate and amphetamine combinations used as

antidepressants in the 50s and 60s; and the impact of synesthesia on the literature of Vladimir Nabokov, to name a select few.

I wasn't interested in girls, or boys, for that matter. My parents bought me a Mustang for my sixteenth birthday—I drove it all of three times. I wore the same few outfits day after day. I was diagnosed with ADHD, Generalized Anxiety Disorder, Borderline Personality Disorder, Major Depressive Disorder, and, of course, Bipolar Disorder. I spent time in hospitals and treatment centers.

At 24 years-old, my girlfriend suggested that I might have Asperger's Syndrome.

"Huh?"

"Scott," she said, "you can recite every line of the movie Cabaret, yet you haven't seen it since you were thirteen. You just listed every currently marketed benzodiazepine in alphabetical order, apparently for my entertainment.

"So...?"

"You're a walking dictionary, but you can't remember your own address. Not only can you not drive, you can't figure out which of the three cars parked in your driveway is mine. I think you should see a doctor."

"I've seen them all."

"Scott..."

"Ok... ok... Wait, I'm autistic? I want my money back..."

How did I manage to live a quarter

of a century without being properly diagnosed. I'm autistic—duh!

Discovering my autism has been my saving grace. I will never forget the overwhelming emotions that poured over me when I first read about Asperger's Syndrome in the DSM-IV. I'm not broken. I'm not bad. I'm just autistic, and that is alright! Since being formally diagnosed, I've come to understand and embrace myself for the remarkable person I am. In a few short months, I've become a prolific autistic writer, with a column appearing this week on www.wrongplanet.net, a potential contract with a publishing company, public speaking engagements, and an opportunity to travel to San Francisco to help Alex Plank and crew film a documentary on Hacking Autism.

Somebody pinch me!

Even when I had given up on myself, God had a plan for my life. I now have the opportunity to use my gifts to spread awareness of Autism Spectrum Disorders. If sharing my experiences spares other autistics from going through the pain of living undiagnosed, my struggles will not have been in vain.

My diagnosis has been my vindication and my inspiration. I want to shout it from the rooftops: "I'm autistic!"

Well, better late than never.

Seriously though, I want my money back... ■

"I've learned that every human being, with or without disabilities, needs to strive to do their best, and by striving for happiness you will arrive at happiness. For us, you see, having autism is normal—so we can't know for sure what your 'normal' is even like.

But so long as we can learn to love ourselves, I'm not sure how much it matters whether we're normal or autistic." —Naoki Higashida, author of *The Reason I Jump*

From a Grandmother's Journal

By Ymkje Wideman-van der Laan



From early on, it was clear that my grandson was extremely active and had boundless energy. When a family member saw him bounce across the living room floor in a “stationary” ExerSaucer at one year of age, she commented that he reminded her of her son at that age, who has Asperger’s Syndrome. I had never heard the term before, and brushed it off, as surely, my grandson was just a typically active and healthy baby.

As he grew, we started noticing some other behaviors that seemed a bit different from “normal.” He would excitedly hop up and down in front of the TV while flapping his hands, for example, and walk across the floor on his tiptoes. He was also very slow with starting to speak. On the other hand, he proved to be very bright. He could identify word-flashcards by pointing after showing him a word only once or twice.

When he started attending a private pre-school at two years of age for several mornings a week, I soon received reports that he was crying a lot, and not behaving as the other two-year olds in his group. They encouraged us to have him evaluated, which we did shortly before his third birthday.

We were relieved to hear that even though there were some developmental delays, he did not need or qualify for

special services. However, problems in pre-school persisted, and a short time later, after several meltdown incidents, the school staff called a meeting. The head of the preschool handed me a tuition refund check, and told me Logan would not be able to attend further. I left the meeting in tears—upset and sad—and determined to get to the root of these problems.

We moved shortly afterwards. While enrolling my grandson for preschool in our new location, I requested a class with an experienced teacher, who would be patient and understanding of him. I passed on his previous evaluation to the school counselor, and explained what had happened in the private preschool. This wonderful woman could not have been more sympathetic and assured me they were going to do their very best for my grandson—and so they did!

She contacted me not long after this, and told me that in our new location, my grandson did qualify for services. She also suggested retesting right away, as she suspected he had autism. Once diagnosed, I felt relieved to have a “name” for the challenging behavior we had been faced with, and I started reading everything I could find on the subject.—And thus our autism journey began. ■

The Importance of Early Intervention

By Ben Rimland, Autism Science Foundation (www.autismsciencefoundation.org, July 20, 2011)

A treatment method or an education method that will work for one child may not work for another child. The one common denominator for all of the young children is that early intervention does work, and it seems to improve the prognosis.—Temple Grandin

Certainly, we are all too familiar with the unfortunate reality that there is no tailor-made treatment for all forms of autism. Different combinations of drugs that may work well in some individuals may be ineffective in others, and the same rule seems to apply to therapy and other forms of care. However, there is one form of treatment that proves effective in every single application—early intervention. With incredible improvements in diagnostic techniques, specialists are now able to diagnose autism spectrum disorders in infants as young as six months.

A study, published in the journal *Pediatrics* and conducted by researchers at the University of Washington (UW), provides solid, empirical evidence as to the positive effects of early intervention. Autistic infants and toddlers as young as 18 months were placed into specially designed groups administered by UW specialists. The children placed into the specialized groups received approximately 20 hours of therapy a week from the UW team, and five hours a week of parent-led therapy. Five years after the beginning of the study, researchers noted an 18-point increase in IQ among the children involved in the study, compared to the four-

point improvement of children in the control group (a standard community intervention group). Moreover, children in the specialized group also improved receptive language skills (listening to and understanding speech) by 18 points, compared to 10 points in the control group. (<http://www.sciencedaily.com/releases/2009/11/091130084720.htm>)

Clearly, the application of intensive, early, and specialized intervention in children with autism can prove to be quite effective. But what does this all mean? Plainly, it allows autistic individuals access to care at a younger age, when the brain and cognitive systems are in their nascent stages of development. The earlier an autistic child receives care, the better his or her prospects for living a fruitful and productive life become. The American Academy of Pediatrics recommends screening for autism at 18-month and 24-month check-ups, simply to reinforce the idea that autism, when caught early, can be treated even more effectively.

For all of the advancements we have made in the past few decades, for all of the science that has helped revolutionize treatment, nothing can replace early intervention as the most effective weapon for combating autism. ■

Do It Yourself



The best therapist?—You!

Adapted from a blog post by Dave Angel, <http://parentingaspergers.com>

I recently interviewed Karen Hannon, who is a certified autism coach from New Hampshire, USA. Karen specializes in working with parents, and with young people who have Autism Spectrum Disorder (ASD).

Karen's own story is an interesting one: She herself has a child on the autism spectrum. She told me that, over time, she

has learned more and more about ASD. Karen then took that knowledge and applied it to her own son. Through her persistence and application of what she learned, she achieved some great results with her son, including taking him from being completely non-verbal to speak fluently in just 6 weeks! However, she still relied on the doctor who diagnosed

her son for ongoing help and support, until one day, the doctor turned around and said, “I can’t help you anymore; now you’re the expert!”

The doctor was referring to the fact that she was obviously the number one expert about her son (as all parents are), but also that she had the best possible knowledge of the day-to-day needs of her child with ASD.

The doctor could help with the diagnosis, medical issues, and some ongoing hints and tips, but as the mom, Kareen had made it her role to read and apply all kinds of material on ASD to her son. Also, her learning on a daily basis as the parent of a child with ASD far surpassed that of the Doctor’s knowledge in this area.

I have to say that this is an essential learning point for all parents—that in so much of your child’s life you are the expert. Not the doctor, therapist, teacher, or other professional.

You are there every day with your child doing the best you can, and learning invaluable lessons just through that experience.

Of course, I am not saying that professionals are not needed, because they most certainly are and bring their own expertise—be it in the field of education, medicine, speech therapy, or otherwise—but they are not THE EXPERT on your child—YOU are.

For many parents this is just a reminder of what you already know, but for others this may (I hope) make you sit up and think.

It is a natural tendency for many of us to think the doctor knows best. I was raised with this as a fairly central belief, and that’s what my parents’ generation believed. However, while from the medical training viewpoint the doctor does know best, they don’t know everything about your child.

As a parent you need to know when and how to ask the right questions such as:

- What are the side effects of this medication?
- What is the effectiveness of this approach you advocate?
- How does this approach actually work, can you explain it in simple non-medical terms?
- Can you explain the particular behaviors that my child displays?

Through asking the doctor questions, you will become an active part of the process, and will not just be passively TOLD about everything. This also goes for schools, therapists, and everyone involved in your child’s care.

To be clear—I do not advocate disrespect or distrust of professionals; far from it. There are amazing doctors, psychologists, teachers, and therapists out there, but you cannot afford to take everything that they tell you as best for you child without question.

I hope this empowers you and encourages you that you, as parents, have the knowledge about your child to ask the right questions and work with the professionals to get the positive results for your child that everyone wants. ■



Autism and Sensory Processing Disorder

How to deal with sensory issues

By Kerri Stocks

Dr. Tony Attwood, world-renowned Asperger’s Syndrome and Autism Spectrum Disorder (ASD) expert said, “Children and adults with ASD can have extreme sensitivity to textures.” (Attwood, 2006, p. 3.) Sensory issues can be a huge cause for discomfort for individuals on the Autism Spectrum.

A number of things can cause sensory issues:

Taste. Specific food and drink textures can be very uncomfortable for an individual with autism. It can cause such discomfort that their throat can actually close up and not allow the food to move down. Many ASD individuals enjoy plain and bland foods—especially when younger. As they get older, they may be open to attempting various flavors, but up until that time, to force the child to eat something that tastes uncomfortable or has an uncomfortable texture will most likely lead to a big battle.

Clothing. Individuals with ASD can find seams very uncomfortable, scratchy, and so incessant that they can have an actual meltdown because they do not know how to stop

the uncomfortable experience. Certain materials are not productive because of the irritant to their skin. Having the child try on their clothes and have them sit down, go for a walk, stretch, etc. before you purchase new clothing may save you time in having to return the clothes.

Environmental experiences. A home that is full of tension can undo a child on the Autism Spectrum. They can feel everything through their skin and so they can take on others' moods. Not having the ability to understand the dynamics of others' body language, facial expressions, and personal experiences can also cause them great discomfort, and so they can unintentionally react to the negative environment. If they are put in a situation that is busy, constantly moving and loud, the individual with ASD feels very uncomfortable, and they are unable to process what is bombarding their minds and their brains. It will all be coming in very loud, and unable to make any sense of their surroundings, the individual on the Autism Spectrum may fall apart. To avoid this, allow the child to process one thing at a time. For example, you are taking your child to a party. Turning up extra early so your child can sit and observe everyone arrive, what is on the table to eat, and all the celebratory extras—balloons, streamers, etc.—will help the child to not be caught off guard and lose their self-dignity in front of their peers.

Auditory/Sound. Tones of voices, car horns, endless chatting, music, etc., can

What is Sensory Processing Disorder (SPD)?

SENSORY Processing Disorder (SPD), formerly known as Sensory Integration Dysfunction, is a neurological disorder causing difficulties with taking in, processing, and responding to sensory information about the environment and from within an individual's own body. The senses include visual, auditory, tactile, olfaction (smell), gustatory (taste), vestibular (balance and spatial orientation), and kinesthetic (the sense of one's own limbs in space).

While SPD is a condition separate from autism, 80% of individuals with autism also have SPD. Those who have SPD alone are sometimes mistaken for having autism, so when their sensory issues are addressed, their "autism" is resolved.

A child with SPD is either going to act out or withdraw in order to manage the overwhelming stimuli of their environment. Lindsey Biel, author of "Raising a Sensory Smart Child", recommends first and foremost ruling out a physical reason for a given behavior (i.e. if the child is hitting their ear, check for infection). From that point, take the behavior as a clue to what is bothering the child. Once that is addressed on a personal level, try to make the child's environment more sensory friendly.

Numerous strategies and products exist to help you in this quest. If you have unanswered questions about your child's specific problems, Ms. Biel's book has a reference section to identify immediate solutions to any given sensory issue.

—Excerpt from a post on
<http://www.autismkey.com>
September 8, 2011 by Susan Moffitt

enter the head of an individual with autism in such an overpowering way that they may feel the need to put their hands over their ears, or even hit their head, so they can get the invasive sounds out of their heads. The auditory ability individuals with ASD have is very good. They can in fact be known to hear things that others are not able to hear. For example, a woman on the Autism Spectrum could hear a “hum” in her computer monitor. Since the computer was under warranty, she had it sent away to be fixed. It came back three times with the same statement: “No sound or any other defect detected.” Eventually, a few months later, the noise she had heard became so loud that others finally heard it! Unfortunately, the warranty was over and she was stuck with the bill. This example shows that just because you may not feel or hear something that your ASD child does, it does not mean they are making it up.

Feelings/emotional experiences—An overload of emotions that are brought on by daily experiences can bring a person on the Autism Spectrum into a total meltdown. You may experience the emotion “embarrassment” and feel a bit hot, but an individual with ASD can feel like they are burning, so their sensory overload brings on more emotions, and soon the individual is in a whirlpool of feelings. Helping a child make sense of what they are experiencing can help them file the information away for when they are on their own.

Visual—Lights, sun brightness, specific images, etc. can be extremely sensitive for a child with ASD to handle. Supplying your child with sunglasses or a hat with a brim will help dim the brightness of the light so the child does not feel the pain that intense brightness can cause. A jumper, jacket, or long-sleeved cotton shirt can be helpful to keep the sun off the skin, or perhaps your child may choose to go out when the sun is at the coolest and stay inside when it is the hottest.

Individuals on the Autism Spectrum feel their sensory experiences 100% stronger than an average person does. For example, a mosquito bite that causes a human’s skin to itch will most likely not lead to the average individual falling apart. An individual with ASD may feel the itch equivalent to 100 mosquito bites, so this discomfort will become all that the individual can focus on until the incessant annoyance stops. This means that what may be okay to handle for the average individual, will cause great pain and discomfort to an ASD individual.

The only way to develop a plan to minimize sensory issues is to observe your child and watch what elements may cause them discomfort and what doesn’t. Documenting these sensory issues is very helpful, not only for yourself, but especially for those teaching or caring for your child outside the home. ■

Kerri Stocks is a Behavior Restructuring Therapist who has autism herself, and has a son with autism.

Resources

1. **100 Day Kit**

<http://www.autismspeaks.org/family-services/tool-kits/100-day-kit>
The Autism Speaks 100-Day Kit, and the Asperger's Syndrome and High Functioning Autism Tool Kit, were created specifically for newly diagnosed families to make the best possible use of the 100 days following their child's diagnosis of autism or AS/HFA.

Anyone can download the 100-Day Kit free! You can also view a web-version of each section by clicking on the links. PDF files are available on each site.

2. **Book: Early Start Denver Model for Young Children with Autism, Promoting Language, Learning, and Engagement**, by Sally J. Rogers, PhD and Geraldine Dawson, PhD

http://www.autismspeaks.org/docs/d_200911_ESDM.pdf

“This book marks a very significant milestone in the development of appropriate interventions for young children with Autism Spectrum Disorders. The integration of goals and teaching strategies from developmental, behavioral, and context-oriented approaches is unique. The chapters on theory will press even experienced interventionists to think about what they are attempting and why, and the detailed descriptions of activities show exactly how theory meets practice. With multisite research underway to test the encouraging results of early studies, this manual will enable interventionists to think more broadly; choose concrete, measurable, and useful goals for each child; and collaborate across disciplines within a comprehensive intervention framework.” – Catherine Lord, PhD

3. **Book: Raising a Sensory Smart Child.** By Lindsey Biel, M.A., OTR/L and Nancy Peske, with a foreword by Temple Grandin; 399 pages. Subtitle: *The Definitive Handbook for Helping Your Child With Sensory Integration Issues*

Reading this book is like being in the best support group ever—led by an occupational therapist who has all kinds of time to sit with you and strategize all those sticky sensory situations, and populated by parents who've been there, done that, and are happy to share. –Terri Mauro, *About.com Guide*



Autism is...?

Autism: Where the “randomness of life” collides and clashes with an individual’s need for sameness.

—**Eileen Miller**, *The Girl Who Spoke with Pictures: Autism Through Art*

What would happen if the autism gene was eliminated from the gene pool? You would have a bunch of people standing around in a cave, chatting and socializing, and not getting anything done.

—**Temple Grandin**, *The Way I See It: A Personal Look at Autism & Asperger’s*

Autistics are the ultimate square pegs. The problem with pounding a square peg into a round hole is not that the hammering is hard work; it’s that you’re destroying the peg.—**Paul Collins**

Autism is part of my child; it’s not everything he is. My child is so much more than a diagnosis.

—**S.L. Coelho**, *The World According to August - One Good Friend*

If they can’t learn the way we teach, we teach the way they learn. —**O. Ivar Lovaas**

Autistic beings develop and bloom if their spirits, talents, and self-esteem are not destroyed by bullies, prejudice...and being forced to be “normal”.—**Trisha Van Berkel**

“If I could snap my fingers and be non-autistic, I would not. Autism is part of what I am.”

—**Temple Grandin**