Autism Parenting Magazine

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SENSORY PROCESSING DISORDER

WHOLENESS AND COMPLETION ISSUES

If your child or a student that you teach seems defiant or like they "just won't listen," then you need to read this article.

HOW TO GET AN OFFICIAL DIAGNOSIS

It wasn't until 1994 that Asperger's could officially be diagnosed. But now an official diagnosis is necessary for any formal government support. This article will help you understand the issues surrounding getting an official diagnosis

HOW DID I KNOW MY DAUGHTER WAS AUTISTIC?

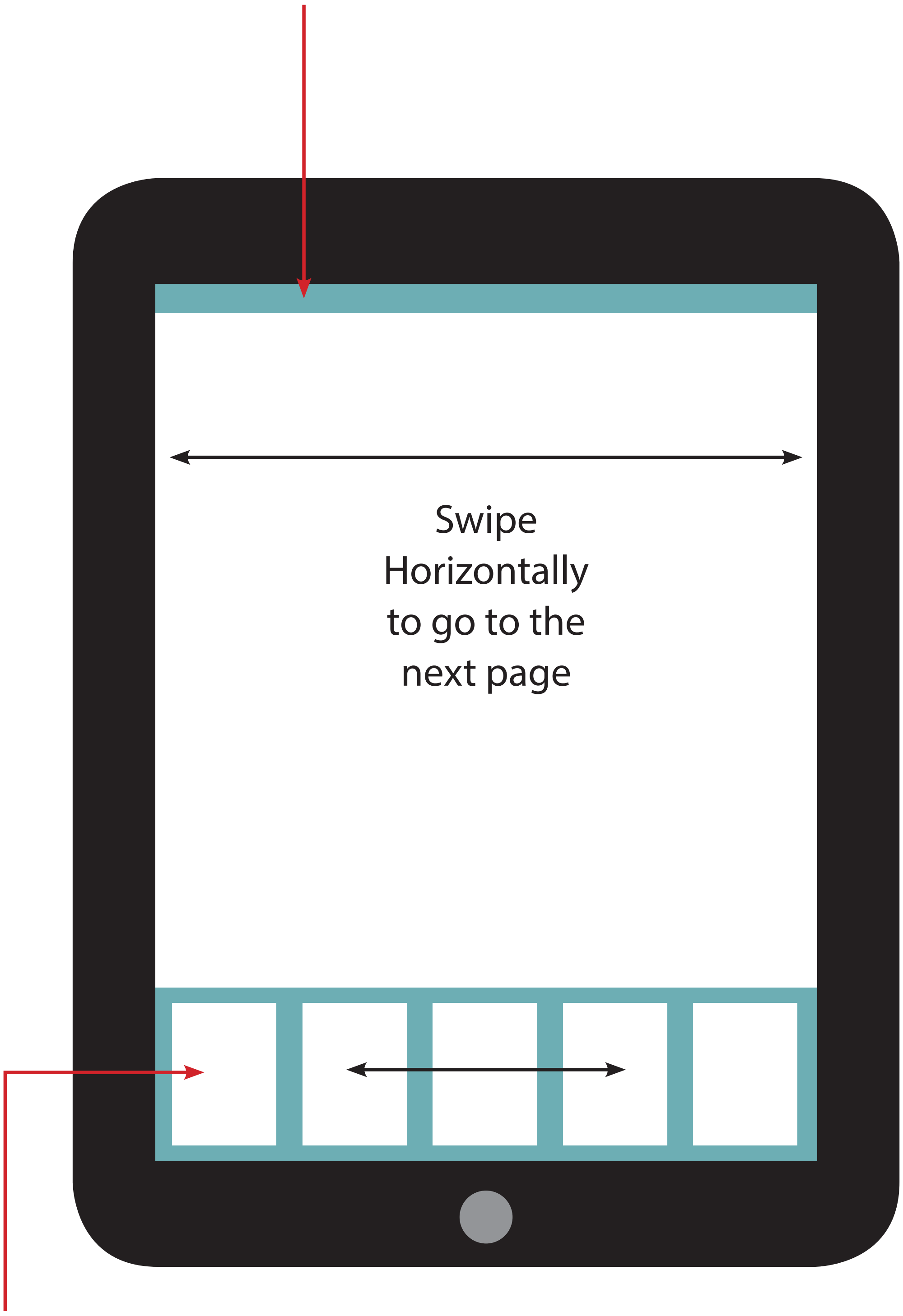
My first child was a beautiful, healthy, bright eyed little girl. As an educator, I had such high hopes. I hung black and white pictures next to her changing table and read to her every day. Then one day, my experience in education told me something was wrong with my beautiful baby

Table of contents

How to use this app?

Tap & Hold the screen to show the top bar

HOME Tap to return to the app home page



Tap & Hold the screen to show the bottom bar

Swipe Horizontally to quickly navigate pages
Tap selected page to View

Sensory Processing Disorder

Every person needs to integrate the signals that we receive through our senses to do daily activities. However, for people with Asperger's Syndrome this is difficult because of Sensory Processing Disorder (SPD).

For those of you that are unfamiliar with SPD, here is an explanation from the SPD Foundation:

"*Sensory Processing Disorder* (SPD, formerly known as "sensory integration dysfunction") is a condition that exists when sensory signals don't get organized into appropriate responses. Pioneering occupational therapist and neuroscientist A. Jean Ayres, PhD, likened SPD to a neurological "traffic jam" that prevents certain parts of the brain from receiving the information needed to interpret sensory information correctly. A person with SPD finds it difficult to process and act upon information received through the senses, which creates challenges in performing

> **“You are not alone! Most medical professionals were not trained to recognize sensory dysfunction.”**

countless everyday tasks. Motor clumsiness, behavioral problems, anxiety, depression, school failure, and other impacts may result if the disorder is not treated effectively.”

Many adults have gone undiagnosed all their lives wondering why they have such a problem with the everyday tasks that neurotypical people seem to handle with ease. You are not alone! Most medical professionals were not trained to recognize sensory dysfunction. As a result, many people struggle with this hidden handicap and end up being ridiculed, which in turn can lead to secondary problems like social anxiety.

Each person with SPD is affected differently. Some people are hyposensitive meaning that the person is under-sensitive, which usually leads them to seek out sensory input. Whereas, other people are hypersensitive meaning that they are over-sensitive to certain stimuli. Some people have a combination of hypo- and hyper-sensitivity. For instance, a person can have a hyposensitive auditory system seeking out loud noise but be orally hypersensitive leaving them to be labeled as extremely picky eaters. People with a hypersensitive olfaction often struggle to justify why they should concern themselves with hygiene because strong smells of deodorant and hair products can be truly upsetting. There is one quote from an unknown author that has stayed with me since high school, which reads, “You only have one chance to make a first impression.” This statement is painfully true. If you meet someone smelling of body odor with your hair disheveled – this will leave a lasting impression on the person that you don’t take pride in your appearance, which usually then leads them to believe that you don’t value chabut I racteristics such as organization, cleanliness, etc.

How do you overcome this?

Due to the fact that every person is differently affected by SPD, it is important to receive occupational therapy with a sensory approach to tailor the session to your individual needs. The occupational therapist can work with you to find different calming techniques that can be used when over-stimulated or stimulating activities when your brain is craving sensation. They may even develop a “sensory diet,” which is when you schedule certain sensory activities throughout the day to help regulate your central nervous system.

Some other good suggestions to alleviate sensory triggers are:

- Use non-scented deodorant
- If the sensation of showers is bothersome, then take a bath. In order to eliminate the drastic change in temperature when exiting the tub, use a small space heater to warm the bathroom.
- Use an electric toothbrush instead of a manual.
- Try cutting or smashing small fruits (like blueberries or grapes) if you don’t like the bursting sensation in your mouth
- Buy clothes without tags.
- Try seamless socks.
- Try different kinds of sheets. Many people like the feel of the jersey sheets compared to cotton.
- In order to make brushing your hair less painful, consider wetting your hair before your brush it. Fill a spray bottle with water and a small squirt of conditioner. Shake then spray to help break up knots in your hair.
- Wear noise reduction headphones or ear plugs when sounds become overwhelming.
- Consider wearing sunglasses inside if florescent lighting is too bright for your eyes
- Compressions can be very relaxing to some people. If you have someone that you trust and know well – ask for a hug. Other people find massages helpful. Or you can try Temple Grandin’s “squeeze machine.”

Wholeness and Completion

If your child or a student that you teach, seems defiant or like they "just won't listen," then you need to read this article.

When my daughter, (who has Asperger's Syndrome), was a toddler I had concerns that she was deaf at times because of the way she would ignore me when her name was called.

Me: "Mary."
Me: "Mary."
Me: "MARY."
Me: "MARYYY."
Me: "MARRRRRRYYYYYYYYY!"
Mary: "What." {Expressionless, without even looking up}

So I did what any concerned parent would do, I talked to her pediatrician who scheduled a hearing test at CCMC (CT Children's Medical Center). Her hearing was perfect.

Completion Issues and Routines

I have learned very much from my daughter. Even after years of being an educator, it amazes me the information that I have yet to learn.

As soon as Mary was able to walk, (which in her case wasn't until 2 and half or a little later), I noticed that she would shut every door that was open. It drove me crazy because I was worried that she would smash her little fingers. I was unaware that what she saw was something "incomplete." In her eyes, that door HAD to be shut. This was perhaps the first completion issue that Mary presented. Doors can be an easy trigger for autistics.

Mary has the ability to envision entire scenarios before they happen. Also, until she plays out the entire scenario, she has the innate ability to focus so intently that she can tune everything else out. This is sometimes not just an envisioned scenario but can also be an action that she is accustomed to doing. In either case, you cannot interrupt! Saying or screaming her name will not stop her, and if you physically try to stop her from completing the action or scenario then a major melt down will occur. This is normal for children with sensory issues and autistics. It is commonly referred to as a "completion issue." To many people

with autism, things have a distinct shape. A ball is a circle (to a child) or a sphere (to an adult). When this shape is altered it creates a certain amount of anxiety and/or discomfort because the image that they are used to is dissimilar. Any change, albeit change of plans or a change in imagery is unsettling to a child with autism. Just like a change in scientific materials will undoubtedly bring about a different concluding result in an experiment, so will a change in plans or imagery bring about a different emotional response in an autistic person.

Routines are extremely important to a person with Asperger's Syndrome. For Mary, part of her weekday routine is walking down the sidewalk to her bus stop. Day after day, I would try to stop her before the end of the sidewalk to keep her away from the road as a safety precaution. Her defiance continued to grow. Instead of walking out with me, she would bolt out the front door in hopes of completing her path to the school bus before I could prevent her from finishing. However, I was unaware that what she was doing wasn't defiance. It was her "completion issue."

To Mary, she had a path and a routine that must be completed before her bus got there. If she didn't *complete* her path then who knew what would happen next. Autistics need a routine for comfort, safety and security. With all of their sensory issues, they often feel like they don't have much control over their daily lives, which is quite aggravating.

So try to become creatures of habit. I'm not saying set a schedule every day and stick to it, because life changes. However, you can give your kid a great sense of security by creating some routines throughout the day. Trust me; it relieves a lot of anxiety and behavioral outbursts. I will admit that when someone told me to make a picture schedule for Mary at home, I didn't want to even consider it. I admit that schedules are imperative to achieve peace and tranquility, but I also encourage "wiggle room." For instance, have "open play time" (kids can play anything alone or with someone) or "out-of-the-house time," (which can be going to the grocery store or going to the park). At first, I thought I had to plan every second of everyday, which to me is just not practical. Life changes and I want my daughter to know that.

So what I have done, that works for us is to have a "wake up routine," and a "bedtime routine."

Our WAKE-UP ROUTINE

For my family, the kids wake me up at 5:30 almost every day. I tell the girls to go use the bathroom and get dressed. While they get dressed, I change the baby's diaper and get him dressed for the day. When I am done changing the baby, I go into the girls' room and check to make sure that their clothes match and that the clothes they chose are appropriate for the weather. Then I remind them to brush their teeth. Once teeth are brushed and clothes are approved they are let downstairs. (I have gated the top of my stairs.)

When we get downstairs, Mary has a cup of warm chocolate milk and watches one kid-approved show from our Netflix Instant Queue. Meanwhile, I set up the coffee maker and feed the baby. After the baby is fed, mommy has her coffee and watches the news while the girls eat breakfast. Then we have what Mary has come to call "open play time." The girls can play what they want. Around, ten in the morning I pull out the crafts and do something crafty with them. It can be something as simple as folding a piece of construc-

> **"To many people with autism, things have a distinct shape."**

> **“In no way, am I suggesting that you stop cutting your child’s food.”**

tion paper and letting them use my stamps to make a card for someone; playing with play dough or floam; or something more constructive and planned like the cookie monster foam crafts that we made this morning. At eleven my cell phone alarm goes off to remind us to clean up our craft and make room for lunch. I make lunch. We eat. Get shoes on and begin the battle to brush hair. So we can make it outside by 12:20 to stand at the edge of the road to wait for the bus.

After school, she has a snack and has “open play.” At 4:30 my cell phone alarm goes off again to remind me to start making dinner if I haven’t started yet. So if the girls are playing outside they know that they have to come inside, while mommy cooks. We eat dinner between 5:30 and 6. Then, bath time, a Backyardigans episode, brush teeth, use potty, read one story, tuck in the girls, lights out then say prayers, and then I sing a certain order of lullabies until they are both asleep.

I highly recommend timers. There is no arguing with the timer. It is concrete. It has helped in so many ways. We even use the microwave timer if one of the girls wants a turn with what the other sibling has. If you don’t have a timer on your, stove, your microwave or your cell phone - buy one. You’ll thank me later. I have become used to my cell phone since it is always on me if I’m at home, at work, at the park, etc. It is my built in timer.

Whole and Half

Most, if not all autistics, have aversions to food. In other words, they are extremely picky eaters usually because of their sensory issues. However, you can help alleviate some of the food tantrums by understanding this next issue.

One of the worldwide habits that parents do for their young children is cut their food. Why? To avoid choking. It is just a natural occurrence at any dinner table to see a parent cutting a kid’s dinner up for them.

However, cutting up food to some kids with autism creates a problem. For example, cutting a strawberry in half can be disturbing because the fruit is incomplete. So now the child is not only struggling with the temperature of the strawberry (was it refrigerated or room temperature) and the texture (all those tiny little seeds), but now they have to deal with the food not being whole. This of course leads back to completion issues. They have an image of what a strawberry should look like and you have altered that image. This provokes anxiety and frustration.

In no way, am I suggesting that you stop cutting your child’s food. However, if they are old enough and have a full set of teeth, you might want to consider it.

In conclusion, there is light at the end of the tunnel. This completion issue has many benefits. For instance, Mary knows that she cannot step into the street until the bus door is open. Once I learned about completion issues, I was amazed to learn that Mary could run full speed up the sidewalk but she would stop dead in her tracks when she got to the edge of the road. Why? Because the path was complete and she couldn’t move until the next task, which is waiting for the bus driver to open her door. My neighbor asked my one day, “Aren’t you scared that she’ll run into the road?” I confidently smiled and said, “I know she won’t.” She said, “How can you be so certain?” I said, “Because that would break the routine. She has programmed herself to know that she takes 6 steps out the front door, twelve to the left and fifteen straight and she can’t move until the bus door is open.” Mary has never once, stepped into the road until that bus door is open. (This does not mean that you should let your child run toward the road!) In case I haven’t mentioned it - every autistic person is differently affected. I am just trying to shed some light on the issues that I have seen and lived first hand so that other parents and educators might be able to understand why an outburst or meltdown occurred and possibly prevent one next time. To gain a better understanding of triggers, check out this list at http://www.fabstrategies.com/documents/fab_trigger_calmers.pdf.

How to get an official diagnosis

In this post we will discuss the issues and techniques surrounding diagnosis of Asperger's Syndrome. The issue has become a bit of a minefield with many general practitioners refusing to allow people the opportunity for an official diagnosis.

Many people have already taken the free online AQ Test, which will give people the opportunity to get an initial insight into the degree of their autistic traits without the hassle or expense of going for a medical consultation. While it gives a good general indication where one is on the autism spectrum, it is not a substitute for an official diagnosis.

We have written this post to try and represent diagnosis perspectives from a UK and US angle however we are aware that the advice we give may differ between countries (and states) so you will need to do your own research in your place of living to determine the best course of action.

Why get an official diagnosis

There are many benefits to getting an official diagnosis, which many people don't realize.

With adults, an official diagnosis is essential if you intend to claim benefits. Supplemental social security income or disability insurance both require an official diagnosis. Here are some tips for people in the UK on how to go about claiming disability allowance

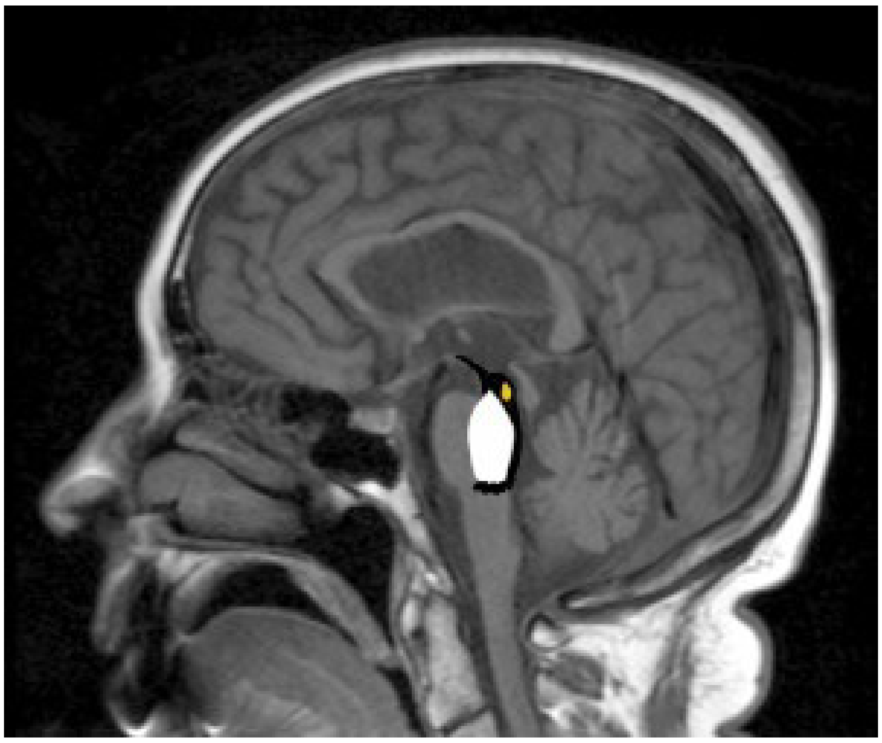
As well as benefits, adults with Autism are also entitled to disability rights. This enable them the right to disclose and request accommodations at their place of work.

For toddlers and children, the earlier they are diagnosed the sooner services can be provided. Occupational Therapy and Applied Behavioral Analysis are just some of the many useful resources out there for kids that can help them.

How to get officially diagnosed with Aspergers

It wasn't until 1994 that Asperger's could officially be diagnosed. Usually the best starting point in the process of diagnosis will be your GP (Doctor). Depending on your country of residence, they will then refer you to one of the following:

1. Neuropsychologist (PhD)
2. Psychiatrist (MD)
3. Social worker with AS experience and a MSW degree
4. Psychologist with AS experience and a Masters degree
5. Scientific Study being done at a university



If your GP is not willing to refer you directly you may also want to consider going direct to the specialist.

In The US

For help in your state click this link http://grasp.org/page/statebystate-help.

Or try http://www.healthgrades.com/neuropsychology-directory

Also, you can call your insurance provider under behavioral health needs.

In the UK

You can check out this link to find a Neuropsychologist or psychiatrist in your area - http://www.bps.org.uk/psychology-public/find-psychologist/find-psychologist

Getting a free diagnosis

We have observed from feedback from people who taken the AQ Test that GP's are not always willing to provide a free diagnosis. We wanted to offer a few alternatives that you may find helpful.

There are many scientific studies being done at various colleges or medical centers about Asperger's. Many of the studies will even pay you for your time and you get free MRI and PET scans. You have the right to request the findings once the study is done. There is a list at the Global and Regional Asperger Syndrome Partnership (GRASP) site www.GRASP.org, which is in the US. Click the "Help &Resources" tab and then scroll down to the Diagnostics sources link. There are a few going on in the state of New York.

If you have already taken the AQ test on our website, you may want to check out a number of similar free online tests:

Broad Autism Phenotype Test – This test will measure the mild autistic traits that are present in the person taking the test

Aspie Quiz - This is a slight variation of the AQ Test which will compare the Autistic traits against Neuro Typical (non autistic) traits.

Mind in the Eyes Test – People with ASD often do not interpret facial expressions easily, this test is designed to evaluate your capacity to read facial expressions.

Before the appointment with your GP

Unfortunately, many doctors are still not knowledgeable or up-to-date with Asperger's Syndrome. So do the homework for them. When you go to speak to your doctor, bring a list of your concerns with you. This will help the doctor and save everyone time. You can also print out a list of Asperger's characteristics in order for the doctor to compare your traits to the characteristics list. This way if your GP is not well-informed, you can be helping educate him, which may help him refer other patients in the future.

(If the child is a resident of the USA and is under the age of three then call or email www.birth23.org. Evaluations done before the child's third birthday are FREE. Do not delay! Trust your gut instinct and get services for your child as soon as possible. It really does help.)

The testing process

Most processes use the DSM IV criteria for diagnosing Autism and Aspergers Syndrome

Children are usually tested using the M-CHAT (Modified Checklist for Autism in Toddlers). It consists of interviewing parents and evaluating the child. Parents should be prepared for paperwork and checklists. They will ask when your child achieved milestones (ie. How old was your child when they started walking?)

For adults, questions of your childhood behaviors and your current behavior will be taken into account. You will be asked questions and might need to consult your parents or siblings about your childhood.

Dealing with the diagnosis

Everybody is different when it comes to responding to the diagnosis that they have Aspergers or Autism.

For some, it is a relief because it helps you understand why you are the way you are. You have a reference point and you can understand that there are many people around the world with the same condition.

But for many people, accepting the diagnosis is not easy; it can bring memories from the past about occasions when the symptoms were most present. Perhaps from social events, childhood or school.

It's easy to think of ourselves as different and inferior. We don't feel good enough and sometimes we suffer from low self esteem.

One of the most important things to remember during the period following diagnosis, is that Aspergers can be a gift as well as a curse. Yes its true, sometimes we struggle with life and social skills that are easy for many Neurotypical (NT) individuals. However people with Aspergers Syndrome have many different abilities and qualities. The ability to see and understand the world in different ways with a different perception can add so many gifts to the world.

If you haven't seen the movie about Temple Grandins' struggle with autism and her subsequent achievements in life, we recommend you do. Not only did Temple find a way to overcome the Emotional distress, but she also gained a PHD in animal science and became an internationally recognized speaker in the Autistic community. Temple is truly an example to us all.

> Without the qualities of Asperger's Syndrome, we wouldn't have the pioneering theory of relativity that was developed by Albert Einstein, or the widespread adoption of the Windows operating system when Bill Gates created Microsoft. It's important to find your contribution to the world, however big or small.

How did I know my daughter was autistic?

By Leslie Burby

To be completely honest, I thought I was well educated on special education. I mean after all, I have worked with several different students with a wide range of learning disabilities, physical disabilities, etc. However, reality didn't set in until I had my own child. Let's face it - there is a huge difference between reading something in a book and living it.

My first child was a beautiful, healthy, bright eyed little girl. As an educator, I had such high hopes. I hung black and white pictures next to her changing table and read to her every day. Then one day, my experience in education told me something was wrong with my beautiful baby. Since her birth I struggled to get her to eat. She was very thin and the insurance company even sent someone to weigh her weekly. All she did was sleep and then as she got older, it was impossible to get her to go to sleep. Eventually, I learned that my daughter is autistic. To be more specific my oldest daughter, Mary, has Asperger's Syndrome. To me it seemed like a very long time to get her properly diagnosed and treated. Today, when I tell people that I have a daughter on the autism spectrum they always ask 2 things:

1. "When did you know?" (Or what symptoms did you notice first?)

I always say, to be honest I knew almost immediately. I was sure by the time she was six months and had no doubt by the time she was one, that something was wrong. At first I thought she had S.P.D. (Sensory Processing Disorder). **All autistics have sensory processing issues but NOT all people with sensory issues are autistic.** And

2. "How did you know?"

In my daughter's situation, it was her sensory sensitivities that were very apparent from the beginning. Sensory sensitivity or sensory processing disorder (S.P.D.) is a neurological disorder that has trouble taking in, processing and responding to sensory information from not just the five senses (sight, smell, taste, touch, hearing) but with the proprioceptive and vestibular senses, too. I had never heard of the latter two so let me explain. Proprioceptive dysfunction is when your body doesn't know where it is in space so your body has trouble positioning your limbs in relation to each other, which makes people with a dysfunctional proprioceptive sense appear clumsy. The vestibular sense is the sensation of body rotation, movement and gravitation that are controlled by the inner ear, which becomes apparent when you have a child that enjoys spinning for 20 minutes and can still walk a straight line. I didn't know what was wrong, but I knew that something was awry. So I started to make a list, which was very helpful to medical professionals. I recommend that everyone does the same with their child. Click here to view a checklist of SPD related symptoms. http://spdsupport.org/resources/symptoms.shtml

Below is the list of some of the sensory related symptoms that I noticed and when my daughter (Mary) reached her developmental milestones.

Hyposensitivity Vestibular Dysfunction

- Craves fast, spinning, and/or intense movement experiences
- Loves being tossed in the air
- Could spin for hours and never appear to be dizzy
- Always spinning in a swivel chair/getting upside down positions
- Loves to swing as high as possible and for long periods of time
- Is a "thrill-seeker"; dangerous at times
- Rocks body, shakes leg/s, or head while sitting
- Likes sudden or quick movements

Proprioceptive Dysfunction

- Seeks out jumping, bumping, and crashing activities
- Kicks his/her feet in chair while sitting at table
- Sucks on fingers
- Loved to be swaddled but is satisfied to just be covered when sleeping
- Prefers clothes (and belts, hoods, shoelaces) to be tight
- Loves/seeks out "squishing" activities
- Enjoys bear hugs
- Excessive banging on/with toys and objects
- Loves "roughhousing" and tackling/wrestling games
- Frequently falls on floor intentionally
- Loves pushing/pulling/dragging objects

Auditory Hyposensitivity –

- Loves to make noise
- Loves loud music
- Needs directions repeated over and over

Hypersensitivity to Oral Input –

Extremely picky eater

Drinks must be a certain temp

Extremely picky about cups and feel of nipples

As an infant…

Never mouthed objects even when teething

Never put feet down to bounce on legs of a person; or in the "jolly jumper" or exersaucer

Never put pressure on her legs

Would raise legs into a seated position and hold them there when asked to stand up

Showed poor motor skills – (most of these were met with the dedication and hard work of the PTs and OTs)

Rolled over (Nov. 10th 2007 – 4 months old),

Disliked being on belly as an infant,

Delayed in crawling (day before 1st bday),

Pull to stand (Oct 2008-15months old),

Cruising (Nov 2008-16 mo. old),

Stand up by herself in middle of floor (March 2009 – 20 months), take her first steps (mid January 2009 -18 months old),

Will take a few steps with assistance (Feb 2009)

Will toddle on own (April 2009 – 21 months)

When she finally did roll over she wouldn't roll back to her original position

She doesn't kick one leg at a time – instead she thrusts

> **"All autistics have sensory processing issues but NOT all people with sensory issues are autistic."**

> **Today, Mary is doing great. Most people don't even realize that she has a behavioral disability.**

her legs from her hips bilaterally (stimming) Click here for a definition of stimming - http://en.wikipedia.org/wiki/Stimming

Took awhile to adjust to the feel of water, grass and sand (for months she had to be sponge bathed) (wouldn't venture off outside blanket for fear of touching the grass) (took several days to be acclimated to the sand box)

As a toddler Mary…

Is constantly seeking thrill

Loves to rock

Loves to be upside-down

Loves to bounce

Loves to spin

Loves to climb

Loves to swing as high and fast as possible

Becomes distressed about having nails clipped or things in her hair

Likes to wear hats/hoods

Must have a hat/hood on to keep her hair from flapping against her head when jumping or swinging

Hates the wind or anything that causes her hair to move

Has frequent temper tantrums that can last 45 minutes

Leslie and her daughter Mary

Has many mood swings

Becomes violent at times with herself (for no apparent reason will start hitting herself on the head or head-butting things)

Needs to be wrestled down to have her diaper changed

Likes to wear sunglasses

Does not stay asleep – very easily awaken

Is nearly impossible to get to sleep

Is *extremely* affectionate with people –loves hugs...although they usually have to be requested or initiated by her

Likes to sit on different objects – will sit on books, boxes, cans, toys, etc.

Sucks two fingers upside-down to soothe self

Randomly throws herself onto the floor

Is extremely difficult to feed (she is a very picky)

In constant motion – when sitting or excited her legs and arms are constantly flailing

Bangs or hits her head –not just when frustrated

Purposefully sticks her fingers in the back of her throat to initiate her gag-reflex

Seems very lazy –if anything is too heavy or too much work she gives up

Today, Mary is doing great. Most people don't even realize that she has a behavioral disability. If it wasn't for the early intervention that I sought after, I wouldn't be able to sit here today and type this. Don't get me wrong, there are days or places that she still cannot tolerate. For instance, Stop & Shop has lighting that still sets her off today. However, things have gotten a little easier and I am fortunate to have an autistic child with the ability of speech. After she is calm, we can sit down and try to figure out what set her off. My husband and I have also learned to watch for cues that signal us that she has had too much and needs to be removed from an environment. This kind of learning, you can't learn in a book. Some things, must be lived.

Aspergers Violence and the Adam Lanza Shootings in CT

In the wake of the recent shootings by Adam Lanza at Sandy Hook Elementary School in Newtown, CT there has been a lot of speculation that the cause may have stemmed from the fact that Adam Lanza has Asperger's Syndrome.

Because of this there is a lot of fear that people are going to think that all Aspie's are gun-slinging killers and many parents are concerned that their children may face discrimination because of the issue.

We thought we would write a short post as we had a few requests from people on our mailing list to comment on this issue.

First, we would like to say that when something like this happens, there is a tendency for the press to sensationalize events. People look for something or someone to blame. The conclusions that are often made in this time don't necessarily stand up. In this blog by John Elder Robinson, he raises the point that correlation does not imply causation. In the same way that most of the gun related violence is performed by Caucasian males it's difficult to say that all Caucasian males are killers.

Second, while there is research to suggest that people on the Autism spectrum have a slightly higher rate of aggressive behavior and outbursts, it is a kind of behavior that is not characterized by premeditated attempts of Mass Murder. Examining crime statistics also we can see that the violent crime rates for adults with Asperger's are 1.3% compared to 1.25% of the population as a whole. If we examine deeper into the statistics also we can see that the majority of this kind of offenses are actually related to property offenses.

Thirdly, it's unclear whether Adam had actually been formally diagnosed with Asperger's. Psychologist Dr. Beth Weiner recently commented that having studied the behavior of Adam seemed to indicate that it's more likely he had an antisocial personality disorder than Asperger's. According to Dr Weiner, "If you bump into someone with Asperger's in the hallway, they might not process it correctly and they might lash out, but they don't plan out something in a premeditated way."

One thing that is very clear about the whole event is that both Adam and his mother clearly had a few issues that were also unrelated to Asperger's. We hope that the media eventually sees sense in the wake of this incident. It's not fair to discriminate on an entire group of people just because of the actions of one individual.

How Lego made the day of a young boy with Asperger's

Can you remember the feeling when you were a child and you really wanted something? Even to the point of saving all of your pocket money.

But how disappointed would you be if you saved all of your pocket money, Christmas and birthday money for two whole years for something you really wanted, only to find that you couldn't buy it anymore. Well that's what happened to James, a 10-year-old boy with Asperger's Syndrome.

He wrote this letter to Lego:

LEGO Systems, Inc.
555 Taylor Road
P.O. Box 1600
Enfield, CT 06083-1600
USA

LEGO Group Headquarters
East Europe, SNG countries, the Baltic States and the Balkans
LEGO Trading A/S
DK-7190 Billund
Denmark

Dear Sirs,

My name is James Groccia and I am 10 years old. I have been playing with many Lego sets and products since I was about 4 years old. I have brick sets, Hero Factory, Creationary, Lunar Limo and more. I participate in a Lego Playgroup to help with my Social Skills (I have Asperger's Syndrome) and I love playing with Legos at home (I play with them every day).

A couple of years ago, I saw The Emerald Night Train set (K10194) and fell in love with it. I wanted it right away, but my parents said I had to save the money to get it. For two years I kept all the money I got for birthday and holiday gifts, some of my allowance and some money I got for participating in a research project. At last, a couple of months ago I had my $100 and was ready to buy the Lego set of my dreams!

My mom started looking for it on line and could not find any. We checked the Lego store in our area and they didn't have it either. I was completely crushed. You've stopped making it! It seems the only way to get one now is to pay $250 on Amazon or ebay, since now it is considered collectible.

I got another Lego set, thinking I could forget about the Emerald Night, but every time I see it anywhere on line I get very sad and disappointed. I still want the Emerald Night so badly, but there are none to be found.

Do you have any at your corporate headquarters? Perhaps I could get one that way? If you have any other ideas, I would be happy to hear them. I have never wanted a Lego set so badly ever in my life!

Your most loyal Lego fan,

James G. Groccia

And received this reply

September 13, 2012

Dear James,

Thanks for your interest in our products.

James, I'm afraid that we no longer made the Emerald Night. I understand how upsetting this news can be. I realize that you saved up your money to purchase it, I do apologize for any disappointment this news may have caused you.

The toy store shelves aren't big enough to hold everything, so sometimes we have to stop making a few of the older sets. Meanwhile, we have a team of experts in Denmark whose job it is to invent LEGO® toys every year. They spend their time trying to create new and fun toys for children of all ages.

You never know though, some of the old favorites sometimes make a comeback, so keep a look out!

The best way to track down discontinued LEGO sets or individual pieces is to check the following secondary market websites:

http://www.bricklink.com/ and http://www.peequestion surbron.com

Please note that these websites are not affiliated with the LEGO Group.

I hope one of our many new LEGO toys will inspire the LEGO fans in your home. To take a look through the hundreds of sets and toys go to www.LEGOshop.com and remember to keep an eye on the 'Exclusives and Hard to Find' section, which includes classic and collectible sets!

Thanks again for contacting us. We are always pleased to receive feedback from LEGO fans! If you could take a moment to complete a four question survey, it will help us make sure we are providing the best customer service to you.

Sincerely,

Thomas

LEGO Direct Consumer Services

Then a box arrived with this letter:

Dear James,

We are always thrilled to hear from our LEGO fans! You truly have a passion and joy for LEGO. I am amazed at how many sets you have at

only ten years old! I am a very big LEGO fan myself and enjoy some of the same sets you do. We received your letter here in Consumer Services and were very touched by your determination.

The Emerald Night Train is a wonderful set, so we can understand why it is your dream to own it. I commend your willpower and patience to save money for over two years just to purchase this set. It is very evident that no other set could make you happier. We can understand how disappointing it must have been to find it had been discontinued. Due to your passion for LEGO and your heart-warming letter, we knew we had to go above and beyond to help make this a reality.

We have located an Emerald Night Train for you, James, and included it in this package! I am sure you will enjoy building it and cherish your time playing with the train. We are excited to know that we could help make this dream come true for you! Now there will be no more sadness or disappointment when you think about it ...just happiness!

We hope you will continue to love to build and create with LEGO. Fans like you are why we are so lucky as a company. Who knows, maybe you will be working for The LEGO Group one day! You certainly have the heart and passion for our bricks to do so! Happy building, James!

Sincerely,

Megan

Consumer Services Advisor

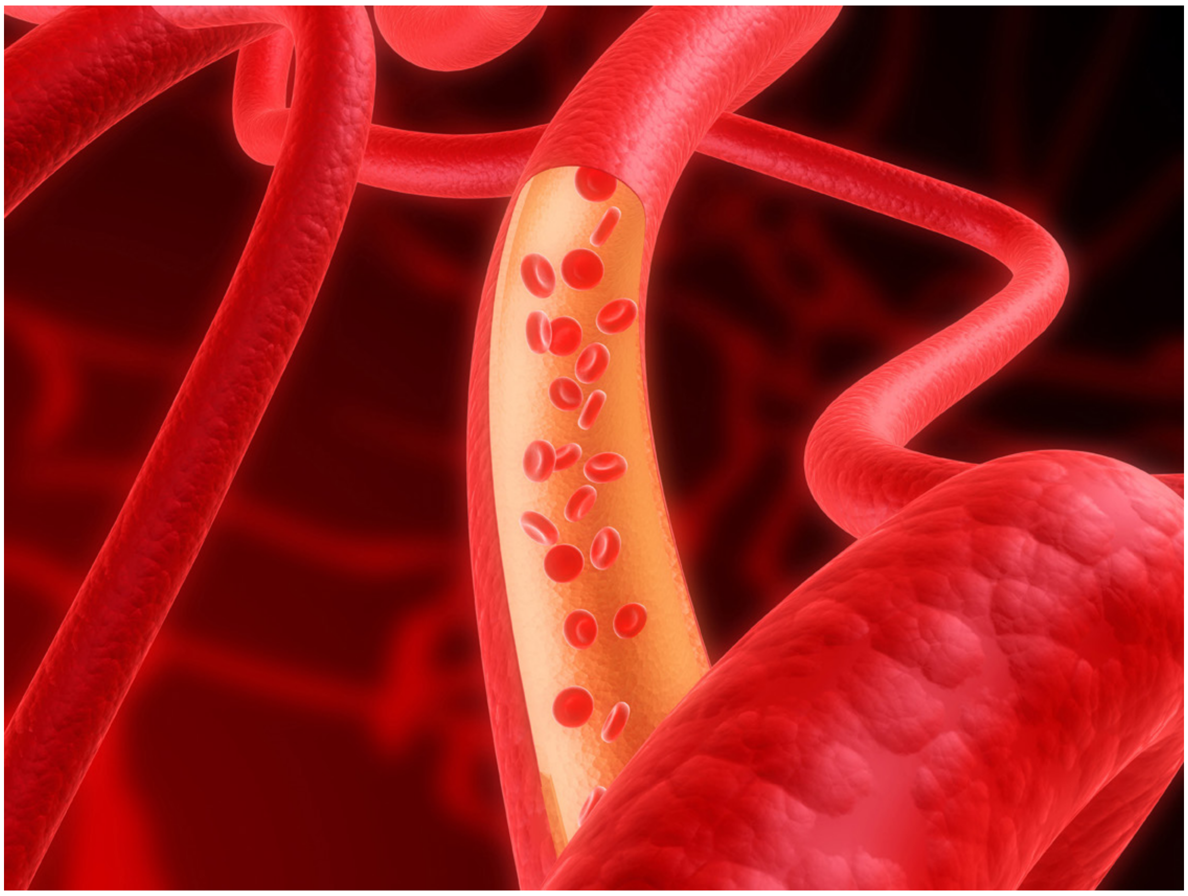
James was tragically disappointed, that was until he received a package in the post. Check out the video…..

Autism in the blood?

By Leslie Burby

Recently in the news, autism and blood tests have been a common thread. The two main companies that seem to have caught my attention the most for autism research are Lineagen Incorporated with its FirststepDX genetics program and SynapDx Corporation on its quest to find a blood test to diagnosis autism.

Both companies are attempting to get children with autism the earliest diagnosis possible since early intervention has proven to be the most effective. Right now, parents can have their child screened using the M-CHAT checklist for ASD (Autism Spectrum Disorder) at their 18 month and 24 month check up if there are any developmental delays or concerns. However, most children don't receive an official diagnosis until they are at least four and half years old, which means for three years the child is not receiving specialized services. So by the time they enter kindergarten they are socially delayed and overrun with sensory issues that make it extremely difficult for kids with ASD to function. With the help of identification through a blood test, children can obtain a faster diagnosis which in turn means that they don't have to wait to receive services until kindergarten or first grade when a teacher raises concerns to the parents. The effort to diagnose younger has been ongoing for years but scientists have revved up the research in the past year across the world. Lineagen started their mission for finding an autism gene after Hakon Hakonarson, MD, Ph.D of his team at Children's Hospital of Philadelphia discovered genetic variants and granted Lineagen exclusive commercial rights. On May 17, 2012 Lineagen announced that they had completed their 9,000 – person study confirming the duplicated genes associated with ASD.



My daughter was one of these subjects. Her pediatrician asked if I wanted free genetic testing done on my daughter's blood work. At first, I said no because I didn't want my daughter be poked and prodded like a "lab rat" or some sort of "medical guinea pig." However after discussing it with my husband and further explanation from the pediatrician and calls to Lineagen – we realized that she could be part of a major breakthrough. We learned that Lineagen is a diagnostic healthcare company conducting free genetic testing in an effort to find an "autism gene." We opted to have it done in hopes that it will be of help to future generations. After a few weeks our pediatrician presented us with a binder containing the findings, an explanation and an offer for genetic counseling. The results were met with mixed feelings. Lineagen had found that my daughter has duplications of five entire genes. The results went on to state,

> "At this time it is unknown whether having an extra copy of any one of these five genes results in any clinical features. The duplicated region also contains a breakpoint in the FHIT gene. Both deletions and duplications of the 3p14.2 region (including the FHIT gene) have been reported in patients with autism spectrum disorder. However, the Database of Genomic Variants contains numerous reports of both deletions and duplications in intronic regions of FHIT suggesting that this duplication may be present in the general population. In addition, one genome-wide association study showed that variants in an intron of FHIT (3p14.2 region) are associated with Asperger Syndrome…"

My daughter has been clinically diagnosed with Asperger Syndrome from various tests such as the M-CHAT. So it was shocking to me to read that just one year later Australian scientists had come far enough to predict ASD in children.

In September of 2012, it was released that "Australian Scientists had developed a genetic test to predict autism spectrum disorders in children," with more than a "70% accuracy rate in people with European decent." "The researchers used U.S. data from more than 3,000 individuals with autism in their study, published in the journal Molecular Psychiatry, to identify 237 genetic markers in 146 genes and related cellular pathways."

On December 6th, 2012, *Time* posted an article stating that the "Boston Children's Hospital researchers describe a new experimental test to detect the developmental disorder, based on the differences in gene expression between kids with autism spectrum disorder (ASD) and those without the condition. The blood-based test appears to predict autism relatively accurately, at least among boys, and has already been licensed to a company, SynapDx, for commercial development." According to http://www.synapdx.com, "SynapDx's approach measures RNA gene expression differences, which current research suggests can distinguish between people with ASDs and those without. SynapDx is in the process of conducting additional studies to validate this approach."

So clearly scientists are making great strides in pinpointing genetic markers for autism which instills hope that we will someday be able to diagnose autism in toddlers to get them help starting at 18 months so they will be much closer in relation to their peers by the time they enter school. Any help to increase social and language skills seems ok by me.

Understanding Autism

Frank L. Ludwig

> 'Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.' – Albert Einstein

Being autistic means being different – not only different from those off the autistic spectrum but also from those on it. It might be said that autism is ultimate individuality.

This, of course, leads to problems in society because everybody is expected to conform. When as children we are pressed to do things we don't want to do and to perform routines and rituals without seeing the reason behind them, we start to revolt against a world that doesn't make sense to us and which tries to force us into submission.

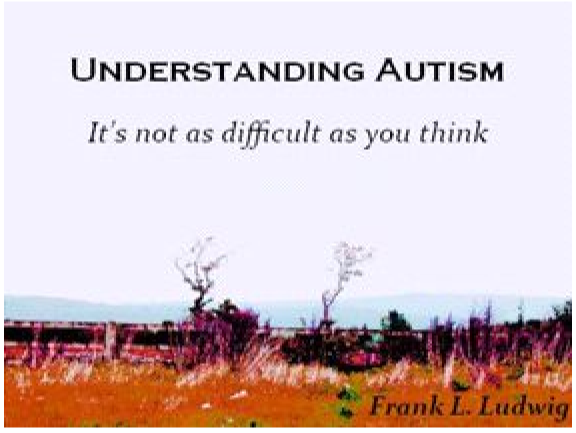
When this happens, we withdraw from the world as much as possible in order to protect our feelings and our identity. And if you want to get through to us, the most important thing is understanding our position – empathy, respect, reassurance and patience will get you a lot further than you imagine.

While non-autistic children learn by copying adults and following instructions, we learn by experimenting and logical thinking. Therefore it's not sufficient to tell us what to do and what not to do, you will have to convince us of the reasons behind it; this is also why we are far more likely to question anything without (or with flawed) proof or things that are handed down as facts.

It is also important to give us the feeling that we have a say in our lives. Giving us plenty of choices will make life a lot easier, both for you and for ourselves.

We tend to have a very strong and inflexible sense of morality and justice which others often consider stubborn. As in all areas, we develop our sense of right and wrong by rational thinking, i.e. 'I don't want to be hurt, therefore it is wrong for anybody to hurt anybody else' (you could call it logical empathy). This makes our opinions more rigid and allows for less exceptions; it also makes us more likely to disobey orders that go against our conscience and speak up against any form of injustice that is accepted by society, regardless of the consequences.

Many of us have problems articulating ourselves, and some of us never talk at all. This doesn't mean that we don't want to communicate; many of us have learned to express ourselves through writing or typing on computers or stencil letter boards and thus were able to finally get in contact with our caregivers and the world. It also gave us the opportunity to prove that we are not as stupid as many believe – on the contrary, most of us turn out to be highly intelligent.


UNDERSTANDING AUTISM

It's not as difficult as you think

Frank L. Ludwig

A lot of us find it difficult to talk about the weather because we don't see the point, and communication for the sake of communication is an alien concept to us. We also find it difficult if not impossible to say niceties that we don't mean; if we did, not only would our compliments be entirely worthless, but we would put our credibility at stake.

Most of us have one or more areas of expertise from a very young age which we may rant on about, either because we assume that you're interested or because we can't think of a more appropriate conversation topic.

We say what we mean with no intention of offending anyone, but our honesty and bluntness are often misinterpreted. We have a hard time noticing and deciphering non-verbal communication, such as body language, facial expressions and undertones. So if you have to say something, say it – literally.

Many of us have problems making eye contact because it feels intimidating and prevents us from focusing on the conversation.

Most of us have some sort of a stim (which is short for self-stimulation) such as rocking, hand flapping or face picking. There can be plenty of different reasons for this since it helps with self-reassurance, focusing and dealing with anxiety, to name but a few.

We can only do one thing at a time, but we are a lot more focused on and absorbed in matters that are of interest to us. We have great potential, provided we are given the opportunity to develop it.

We are easily discouraged. One 'He won't ever learn to spell' can be the death knell of a brilliant literary career.

Researcher Bill Jenson observed that 'if you drop your expectation level for a child with autism, they will drop to that level.'

THIS FACT CAN'T POSSIBLY BE OVERESTIMATED!

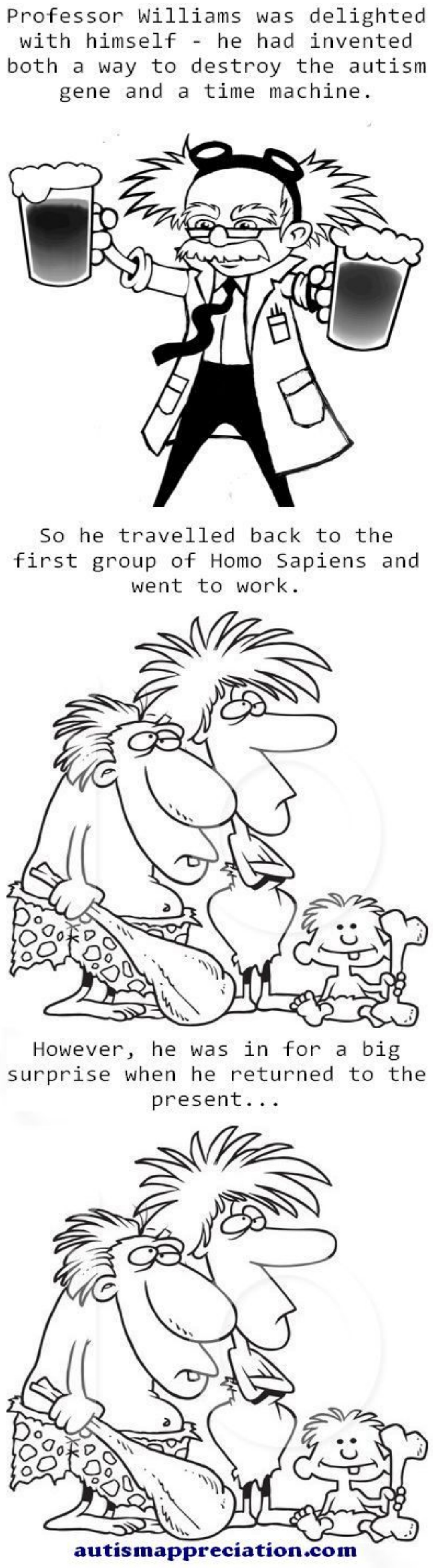
For us, all sensations are perceived unfiltered, which means the buzzing sound of the fridge and the sizzling of the frying pan are just as intense for us as your voice when you're talking to us. In some cases the intensity of these sensations can become too much for us to deal with and lead to a meltdown which may look like, but should not be confused with, a tantrum.

Being ourselves is more important to us than fitting in. Being ourselves is more important to us than being accepted. Being ourselves is more important to us than being successful. Being ourselves is more important to us than being appreciated. Being ourselves is more important to us than anything else.

We enjoy having friends. We enjoy being accepted. We enjoy being successful. We enjoy being appreciated. But not for a single moment would we compromise one inch of our identity to achieve these things.

Some of us, like myself, embrace their condition and see it as a natural and indispensable part of human diversity while others would prefer to get rid of it, like the man who posted on Facebook that he'd 'gladly sacrifice 30 IQ points to be like everybody else.' But in either case, understanding and respecting our individuality and uniqueness will make it a lot easier for us to function in a world that doesn't make a lot of sense to us.

There are leaders, and there are followers, and there's nothing wrong with that. But there are also those who don't want to be led or followed, and there's nothing wrong with that, either.



Biography:
Frank L. Ludwig was born in Hamburg in 1964 and has lived in Sligo (Ireland) since 1996. In 2007, after 11 years of trying, he became the first male childcare worker in his county. He is an accomplished poet and writer and was diagnosed with Asperger's syndrome in 2014.

Ludwig has his own domain at http://frankludwig.com, and his autism-related works can be found at http://frankludwig.com/autismappreciation.html.

Feel free to connect with him on Facebook at https://www.facebook.com/profile.php?id=100000001240567&ref=tn

Hand Over the Control:

Improving Concentration and Conduct

by Lora Brothers

There are days when we, as parents and teachers of children diagnosed with ASD, feel powerless, like the chaos has taken over and nothing we do seems to help. An uncomfortable, annoyed child is already on the edge of emotional overload…

When she is using all that energy just to cope with the cold room and the noisy fan, being asked to pick up her dishes or answer her grammar questions can send her into a screaming, crying tantrum! There are so many seemingly small things that encroach on our sanity---all of Lucy's shirts are too itchy or Braden's eggs were too salty this morning—things that torment little ones with ASD and give them such a hard time. Give them back some of the control and watch it help your child get more comfortable in her environment.

There is such a lot of sensory stimulus, much of it unwanted, that autistic children (as well as those with Pervasive Developmental Disorder and sensory integration problems) have to deal with and attempt to overcome all the time. Instead of gritting your teeth when Lucy complains that the dog is breathing too loudly or her chair is poking her in the back, let her adjust her setting to be more comfortable. Instead of trying to police her comfort for her, put the locus of control on her. Ask her which chair would be better, or would she like to sit in another room to do her homework or let the dog outdoors. This incites functional communication and encourages her to think about her physical and emotional well-being and frame it verbally to problem-solve instead of suffering, complaining and then screaming in misery. Empower her to articulate and take charge of her sensory issues. Talk about three primary external sensory irritants and how to manage them.

You likely have all the items you need for a sensory control kit around the house. Here are the tools you'll need to help your child:

- lamp
- sunglasses
- earbuds/headphones
- towel
- plastic bag of ice

LIGHT

"I CAN'T do this!" He shouted, shoving the paper and pencil off his desk and beginning a keening, banshee wail of rage. After retreating beneath his desk and taking three big breaths and squeezing his silly putty, Caleb was able to put into words what was bothering him. It wasn't the math workbook page or his pencil being too dull or anyone near him humming—it was the overhead light.

In the classroom, it was as simple as telling Caleb he could turn off one strip of fluorescent lights so the infuriating hum of the tubes and the flickering glare didn't hurt his eyes and make it impossible to concentrate. Knowing he could choose to do that at any time made him immediately calmer and more able to focus on his work—if the brightness or hum got too much, he could fix that himself without having to get upset! At home, it's as easy as getting a sturdy pull-chain lamp for your child to switch on and off for softer ambient light in lieu of the brighter overhead fixtures. A shaded task lamp can help your ASD child look at a book or draw a picture or do a puzzle more comfortably and with less distraction.

If you have smaller kids who would be in danger of pulling a lamp down on themselves or a classroom teacher who is less understanding about sensory needs than one would prefer, sunglasses are an easy fix. Your child can call it her rock star costume and wear a pair of sunglasses inside too-bright shops or the classroom to help reduce the sensory irritant of uncomfortable levels of light.

TEMPERATURE

While neurotypical individuals can concentrate in a room that is uncomfortably cold or warm within reason, children on the spectrum cannot tolerate being in a place like that. Lucy is either freezing to death or burning up…she is a walking misery of hyperbole. That's when you pop a bath towel in the laundry dryer for a few minutes to warm it and let her roll it up and lay it along the back of her neck and shoulders if she's too cool, or pull a plastic baggie of ice from the refrigerator (the freezer will keep it too hard and cold) to wrap in a dishcloth and press to the back of her neck. She can adjust her ambient temperature quickly that way, as well as eating an ice pop or drinking a cup of warm tea with honey will soothe her inner temperature.

If you're out of the house and the weather or interior temperature is making your little one fractious and uncooperative, know that she is trying to tell you that this hurts her. And give her the control to fix it. Ask if she wants to go with you to stand in the shade if it is hot outdoors and get her a cool drink. If it is too cold inside the church, take her outdoors for a few minutes to get her jacket from the car or simply to warm up. Let there be freedom of movement so she knows that she can move to a more comfortable place or take off her socks if she is too hot. Teach her to adapt her environment to her comfort, instead of teaching her to pretend it is all right.

NOISE

Plenty of behavioral meltdowns can be traced back to the irritation of ambient noise. The fan on the counter is too loud. The dishwasher makes a scary noise so she can't eat her dinner. Someone in the classroom is whistling or tapping his pencil and it is intolerable. Put a stop to the tantrum that can follow by acknowledging the hateful sound and giving your child an easy way to stop it.

Noises can be infuriating at times, and this effect is magnified by the sensory challenges faced by autistic youths. Realistically, your child can't 'just ignore it' as many tell her to do. The overwhelming presence and repetition of a distressing sound--whether it is the annoying music playing over the speaker at the store or neighbor's dog barking at night—is like an ice pick to the ear for a little one on the spectrum. So give her the power to turn it off.

Environmental sounds are unavoidable at times, but you can empower your child with a set of ear buds or headphones. If there is a bothersome noise, she can pop in her ear buds and it will muffle the irritant. She can plug them into a phone or MP3 player and listen to music she likes or even a sound file of a vacuum cleaner, crickets or other soothing white noise she enjoys. Even without an electronic source of more pleasant sounds, the ear buds or headphones will dull the annoying noises and help her to concentrate and be more comfortable.

Help teach your child to take control of the sensory irritants in her environment and you are giving her a tool to master her behaviors as well. Your child will feel more capable, a more effective manager of her needs and challenges. Identify her sensory triggers and find strategies and tools to bring those triggers under her control for a more comfortable, calmer child.

BIO:

Lora Brothers lives in rural Illinois where she teaches second grade in a high-poverty school. Lora has a BS in Elementary Education and MS in Education Administration. She enjoys using her classroom experience working with special needs children to inform her freelance writing. She lives in an adorable red house with her husband, daughter and two tyrannical miniature poodles.