

AUTISM AND SENSORY PROCESSING

**An Overview from Lived
Experience**

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Important Definitions

A couple of important definitions when discussing autism:

“allistic”: not autistic

“neurotypical”: having a brain that has the same neurology as the majority of the population (aka not autistic, ADHD, schizophrenia, bipolar, sensory processing disorder, etc.)

“neurodivergent”/“neurodiverse”: not neurotypical

Eight Sensory Systems

- Sight
- Sound
- Touch
- Smell
- Taste
- Vestibular
- Proprioceptive
- Interoceptive

Vestibular

- Sense of balance
- Sense of forces/gravity
- Inner ear fluid

Proprioceptive

- Sense of where the parts of your body are in relation to each other
- Sense of where your body is in space
- Soft tissue/ligaments/connective tissue/muscles

Interoceptive

- Sense of status of internal organs/muscles/temperature
- Sense of hunger/thirst
- Sense of pain/breathlessness
- Sense of nausea
- Sense of needing to use toilet
- Sense of itching
- Sense of sensual touch

Four Sensory Modes

- “The Norm”
- Hyper-sensitive
- Hypo-sensitive
- Sensory Seeking

Hypo-sensitive and sensory-seeking can sometimes accompany each other, but not always

Some aspects of a sense can be one mode, and other aspects of the same sense can be a different mode

Regarding one sense having more than one mode: I read about someone who is hypersensitive to minty tastes, and hyposensitive to fruity tastes, for example.

Hypersensitivity

What does that look like, and
what does that mean for autistics?

Sight

- sensitivity to light (causes pain)
- ability to notice details/attention to visual details that may escape others
- distinguishing more shades than others
- sensitivity to flashing lights (causes pain)
- sensitivity to lights at night
- would quite likely prefer visually “quiet”/ uncluttered scenes

Lights at night = claws on a chalkboard (vs. sunlight, which is often like human nails on a chalkboard).

Sound

- sensitivity to certain tones/pitches
- sensitivity to loud volumes
- possibly something resembling relative or perfect pitch
- difficulty distinguishing important sounds from “white noise” sounds
- difficulty setting a sound as “white noise” (i.e. getting the brain to ignore it)

I react badly to the high pitch that both children 5 and under and female opera singers can attain. Opera (songs rather than instrumental music) makes me actually physically nauseous. And I've had to cover my ears against a niece's squeals of excitement.

Touch

- reactions to being touched by certain liquids and/or solids (ex. certain fabrics, water, wood, leaves, etc.)
- “delicate” skin
- reactions to being touched by certain chemicals (ex. alpha-hydroxy acid, aka AHA)
- inability to tolerate the feel of things like clothing seams, tags, etc.

AHA is a common component of hand creams. I can't use any cream with AHA in it, because I react badly.

Touch cont'd

- inability to tolerate certain textures (this can affect what we choose to eat, in an example of sensory overlap)

Smell

- sensitivity to certain scents (ex. cigarette smoke, cleaning products, scented cleaners, air fresheners, etc.)

(I have some examples on the next slide)

- ability to distinguish subtle scents

I react quite badly to cigarette smoke and most scented cleaning products. I don't mind citrusy scents, as long as they're not completely artificial. On the other hand, I can't tolerate Earl Grey tea, because the smell of the bergamot makes me think of the aforementioned cleaning products.

Smell cont'd

Bath & Body Works,
Avalon Mall



Saje, Avalon Mall



Welcome to the sensory nightmare of the Avalon Mall. On the first floor, going up the hall from where the entrance to Sears used to be (or going into the main part of the mall inside from the Starbucks), you have Bath & Body Works. I have to walk on the opposite side of the hall and cover my nose from two stores before until two stores after it – and that's on a good day, when my senses aren't acting up too much. On the second floor, going along the direct hall from the Cineplex to Lawton's, you have Saje. I've stopped going along that hall – instead, I take the long way around – because even on a good day, the smell from Saje permeates almost that *entire* hall, the full length of it. On a bad day... well, I have to cover my nose when I get off the escalator beside Fog City.

Taste

- sensitivity to certain tastes (ex. mint, fruity tastes, spicy hot – which is a mix of taste and interoception)
- ability to distinguish subtle tastes
- preference for eating different foods separately (rather than mixing them on the plate)
- ability to taste things others cannot (ex. alcohol, differences in taste of food colouring, annatto)
(I have an example in the next slide)

Both my best friend and I tend to keep foods separate on our plates (with the exception of sheppard's pie for me); it's something I never really paid much attention to until my father pointed it out last year, and then when she was reviewing this presentation for suggestions and editing, my friend pointed that out as well. Annatto is a colouring agent, orange-red, used for cheeses among other things. (Some types of cheddar have annatto in them.)

Taste cont'd

My sister's wedding cake



My sister got married on August 31st, and this was her wedding cake. After tasting it, I promptly declared that I liked how each layer had different flavours. My sister's reaction: No, Trudy, they're all the same, they just have different food colouring. But I definitely tasted different flavours. Also, I and most autistics I know personally (pretty much every autistic I've mentioned it to) can definitely taste alcohol. It doesn't matter what type of drink (or medication) it is, it all tastes the same to me (except for champagne, which has a slight variation due to the carbonation, and two or three variations of wine coolers I tried in my early twenties).

Vestibular

- very strong awareness of movement and of forces acting on the body
- constant dizziness
- illness when moving in elevators, on escalators, moving fast, etc.

Proprioceptive

- strongly aware of where your body parts are in comparison to each other
- sometimes *overawareness* of that, to the point of interfering with thought and other sensory systems

Interoceptive

- acute awareness of bodily states (hunger, thirst, state of bladder, etc.)
- very low pain threshold/high sensitivity to pain
- high sensitivity to spicy hot tastes (this is actually a pain response)
- high sensitivity to “gentle touch” (issue with “C-afferent” nerves)
- regularly sensing one’s own heartbeat

Interoceptive cont'd

- acute awareness of sensual touch

A Note re the Intense World Theory

- proposed by Henry and Kamila Markram
- hypothesizes that autistics experience the world in very intense ways, which can in turn overshadow other aspects (like the subtleties of body language)
- has not been accepted as “scientific fact”, but does explain certain aspects in a more positive light

Intense World Theory cont'd

- suggests that sensory processing in such a priority that the brain “demotes”/de-prioritizes other tasks
- suggests the intensity experienced is part of what overwhelms us
- does not account for hyposensitivities

Hyposensitivity

What does that look like, and
what does that mean for autistics?

Sight

- needs very bright light to see
- has difficulty making out details but is not near- or far-sighted
- ability to tolerate lights at night better than most
- ability to tolerate flashing lights better than most (if not epileptic)
- would quite likely prefer visually “busy”/ cluttered scenes

Sound

- has issues hearing things
- certain types/categories of sounds don't register well
- difficulty differentiating important sounds from "white noise" in opposite direction from hypersensitivity (brain considers most sound to be "white noise")
- can be linked to Central Auditory Processing Disorder (CAPD)

Central Auditory Processing Disorder often involves difficulty distinguishing human voices and words. I know of at least a few autistics who have this issue. Recent research suggests that while neurotypical brains "reward" the sound of human voices with dopamine, autistic brains don't.

Sound cont'd

- sometimes have trouble absorbing information from sound – can need to shut down other sensory systems (aka close eyes, for example) to help concentrate

Touch

- difficulty feeling anything touching skin
- difficulty distinguishing between different materials/patterns/textures (ex. different weaves of fabric, brushed vs non-brushed metal, etc.)
- has to push hard to feel patterns/textures
- responds well to deep pressure

Smell

- difficulty smelling anything but strong scents (or anything at all)
- difficulty distinguishing different smells
- difficulty distinguishing different tastes (because smell plays even more into taste than tastebuds do)

Taste

- difficulty distinguishing between different tastes
- everything seems “bland”

Vestibular

- difficulty sensing movement
- difficulty balancing (ex. tripping or stumbling on thin air, issues balancing on one foot or balancing in general)

Proprioceptive

- difficulty moving limbs to where expected/
sensing where limbs/appendages are in
relationship to each other (ex. tripping over air,
bad hand-eye coordination, difficulty catching
things, difficulty aiming kicks and throws,
clumsiness in general, etc.)
- sometimes feeling a sense of disconnection from
your body
- responds well to deep pressure

Those examples under “difficulty moving limbs to where expected”? That’s me. Tripping on thin air can be either vestibular (see previous slide) or proprioceptive, or sometimes both.

There are times when I feel like electricity is running through my nerves – almost like a nerve conduction test, except I’m not hooked up to electrodes. That’s usually a sign that my proprioceptive system is acting up, and I need deep pressure semi-urgently, or I’ll start to get that “disconnection from my body” sensation kicking in.

Interoceptive

- very high pain threshold/low pain sensitivity (ex. thinking broken ankle is a minor sprain)
- difficulty determining whether hungry or thirsty
- difficulty knowing when need to use the toilet (story behind this!)
- difficulty identifying internal temperatures (ex. fever)
- difficulty identifying sensual touch

So, back in April there was a tweet going around mentioning how anyone who wasn't "toilet trained" by adolescence obviously had a low IQ. In response to this, I wrote a post on my blog (see end slide) about how if someone had hypo-sensitive interoception when it came to their bladder, it would be *physically impossible* for them to realize when they needed to use the toilet. A few days after I posted that, a parent responded saying that this is exactly the issue her daughter had, but at least her daughter was able to articulate it to them so they were aware of this.

Sensory Seeking

What does that look like, and
what does that mean for autistics?

Sight

- seeks out situations with flashing/bright lights
- seeks out lights at night
- seeks out visually “busy”/cluttered situations

Sound

- seeks out loud noises
- seeks out certain tones of/pitches of noise
- seeks out certain forms of music

One of my best friends (who I asked for opinions on this presentation, as she has different sensory issues/needs than I do) likes power metal in particular because it has very clear vocals; she has issues with sound in that it's hard for her to distinguish between human voices and other types of sounds.

Touch

- seeks out new patterns/textures to feel
- seeks out things with different textures
- seeks out certain textures that are enjoyed (ex. kitten fur, etc.)

(see/feel examples provided)

I brought in certain preferred touch-sensory objects as examples

Smell

- seeks out strong scents
- seeks out subtle scents

Taste

- seeks out strong tastes
- seeks out selections of different tastes within one meal
- seeks out certain types of tastes (ex. a friend seeks out acidic tastes)

Vestibular

- seeks out movement involving forces – centrifugal or G-forces, usually (ex. flying, driving on highway, spinning around, swinging on swings, hanging upside-down, rocking)
- seeks out opportunities to practice/use balance (gymnastics, ice skating, walking along curbsides, etc.)

The list of movement involving forces – that’s directly from my preferences. It’s also where some of the “stereotypical” movement patterns of autistics (the spinning in circles, some elements of the rocking back and forth) come from.

Proprioceptive

- seeks out ways to experience relationship in space between parts of the body (ex. deep pressure, hugging oneself, rocking back and forth, rubbing hair between fingers, flapping etc.)
- presses parts of the body against other objects (ex. tapping fingers or feet, pushing knees against desks, chewing on things, etc.)

Interoceptive

- seeks out sensations that would produce pain
- seeks out sensual experiences

Alexithymia

What is alexithymia, and how does it relate to sensory issues?

This will be a very quick section.

Alexithymia Is....

- a difficulty identifying and describing emotions, and
- a difficulty distinguishing between emotional and physical sensations
- approx. 10% of the population have alexithymia; however:
- approx. 50% of autistics are severely alexithymic, and nearly all of us experience some degree of it

Definition of alexithymia taken from the blog of Musings of an Aspie: <https://musingsofanaspie.com/2013/02/05/taking-the-alexithymia-questionnaire/> – also check out: <https://musingsofanaspie.com/2013/01/31/emotional-dysfunction-alexithymia-and-asd/>

Alexithymia Is... cont'd

- more common among the parents of autistic children than the parents of allistic children
- there is some research that suggests some of the autistic deficit in social communication/ impaired affective empathy is related more to alexithymia than to autism itself
- not a formal diagnosis, but a way of explaining and conceptualizing a common set of experiences

Studies in question (mentioned on Musings of an Aspie's blog, link in previous slide's comments): Bird et al, 2010 and Silani et al, 2008

...Related to Sensory Issues Through...

- the element of the difficulty in differentiating between emotional and physical sensations
- extreme example: panic attacks – for years, I didn't know that what I called “nerve attacks” (because of what was going on the first time I remember having one) were actually caused by anxiety; I had no idea I was anxious
- one person I know of only recently realized that feeling cold = being upset

Related to Sensory Issues cont'd

- psychosomatic issues: this is a major/the major one. Examples:
 - headaches/nausea = stress/anxiety
 - problems walking = fear of failure

Stimming

Last, but hardly least... the matter of
stimming. How does it connect
to sensory issues and modes?

Stimming is Used For...

- calming down when stressed/nervous/overwhelmed/approaching meltdown/shutdown (emotional regulation)
- expressing emotion (sometimes positive, sometimes negative)
- assisting in focusing/concentrating
- dealing with sensory overload or underload
- communicating with other autistics

Stimming is Linked to Sensory Systems Because...

- most of the time, stimming involves the physical world in some way or another, and of course, our sensory systems are our links to that physical world
- stimming can help deal with sensory issues, depending on the stim and systems involved
- note that quite frequently, stimming will hit more than one sensory system (examples follow)

Sensory Stimming Examples

- rocking back and forth (vestibular, proprioceptive, sometimes touch)
- spinning in circles (vestibular, proprioceptive, sometimes touch)
- chewing things (touch, proprioceptive, sometimes interoceptive and/or taste)
- tapping fingers (proprioceptive, sound, touch)
- eating (taste, smell, proprioceptive, touch, interoceptive)

Chewing things: Including straws, pens, pencils, coffee stirrers (ref *Neurotribes*, Shannon de Rosa's son, who chews the green Starbucks stirrers), fingers, etc....

Eating: spicy foods, fruity foods, foods with textures you enjoy, dealing with hunger

Sensory Stimming Examples cont'd

- listening to music (sound) (can activate/help creativity)
- reading (sight) (can activate/help creativity)
- flapping (proprioceptive, touch)
- rubbing things (touch, proprioceptive, sometimes sound)
- squeezing things (touch, proprioceptive, sometimes sound and/or sight)

Rubbing things: fabric, various textures, skin, etc.

Squeezing things: clay, rubber, stress balls, silly putty, skin, etc.

Sensory Stimming Examples cont'd

- driving (vestibular, sight, sometimes proprioceptive and/or sound)
- hanging from a tree or climbing equipment (vestibular, proprioceptive, touch, sometimes sight)
- petting animals (touch, sometimes proprioceptive and/or sound – especially if cat)
- playing with hair (touch, proprioceptive)

Sensory Stimming Examples cont'd

- pacing/walking/stalking (vestibular, proprioceptive, touch, sometimes sight)
- singing (sound, proprioceptive, sometimes touch and/or interoceptive) (sometimes creativity)
- fiddling with things (touch, proprioceptive, sometimes sight and/or sound and/or smell)
- even using the toilet (interoceptive)
- watching flames (sight, sound, smell)

Fiddling with things: pens, paperclips, pencils, snow globes, etc.

Harmful Stimming

- chewing body parts (touch, interoceptive, proprioceptive)
- banging body parts against walls/objects/people (touch, interoceptive, proprioceptive, sometimes vestibular)
- cutting oneself (interoceptive, touch, proprioceptive)
- burning oneself (interoceptive, touch, proprioceptive, sometimes smell and/or sight)

Chewing body parts includes: cheeks, tongue, lips, fingers, webs of hands, hands, arms.

Banging body parts includes: head, arms, hands/fists, legs, feet, elbows, torso, knees

Harmful Stimming cont'd

- scratching oneself (interoceptive, touch, sometimes proprioceptive, possibly sometimes visual)
- popping pimples (interoceptive, touch, sometimes visual)

There are no doubt a number of others.

How to Deal With Harmful Stims – One Way

1. You cannot remove stims without replacing them with another one – that just leads to huge problems down the road (see slide “Stimming is Used For...”). So step one is to accept that you need to *replace* the harmful stim.
2. *Explain* to the person in question what you are trying to do and why. Presume that they are competent enough to know that it’s a problem, and just haven’t come up with a solution themselves.

Important Note: As it says in the title of this slide, this is *one way* that one can try to deal with harmful stims. This is currently theoretical, based on my own experiences and knowledge of stimming and stims. There are some cases (as was brought up in the talk) that the harmful stim has a direct cause (case of headbanging due to child having lice and being unable to communicate it); in those cases, treating the cause would likely treat the harmful aspect of the stim.

Also, presuming competence is always a wise idea.

Let’s use chewing on the forefinger/index finger’s knuckle as an example for a stim that we want to replace, because it’s causing a lot of harm – the skin is getting broken and infected and causing a great deal of pain, and it’s damaging the teeth.

(This, by the way, is an example from my childhood that I still resort to sometimes.)

Visual provided.

Replacing Harmful Stims cont'd

3. You need to identify which sensory systems the stim uses, and hopefully both *how* and *why*, because you need a replacement that will use the same systems and have the same overall effect.
4. Start by trying to replace *one* thing about the stim, preferably the most harmful, but keep *all other actions* the same (see example). Note that this is an *intermediate* step; it won't solve the whole problem.

3. Sensory systems: A) Proprioceptive. The finger is pressing against the lips, tongue, and teeth, and the thumb is touching the chin. The teeth/jaw are moving to touch each other in the chewing motion. The teeth are pressing against and rubbing/squeezing the finger. —> “Here is where the part of your body that is touching/pressing against another part ends, and where this other part begins.” B) Touch. See proprioceptive, but rather than movement, look at the actual touch. Also the texture of your finger against your tongue and other skin. C) Interoceptive. The chewing motion creates a pain in the finger. D) Taste. When the teeth break the skin, blood appears, and tastes salty/coppery. Even before they break the skin, you can still taste the skin itself.

4. The main problem with this stim is the teeth breaking the skin of the finger. Try pulling the finger back so that the knuckle is just brushing against the front of the teeth, and pull the inside of the cheeks in. The chewing motion is kept the same; the teeth, lips, possibly tongue, and finger are all still touching each other/pressing against each other. There is still pain (from the cheeks) and resistance to the chewing motion (again, from the cheeks), but the skin of the finger is no longer being broken. The taste of blood has been removed from the situation, and a few other sensory aspects (the texture of the inside of the cheeks) has been added.

Replacing Harmful Stims cont'd

5. If that works, go on to the next step; replace another aspect of the stim, hopefully the next most harmful (perhaps even the replacement action from Step 4 – see example).
6. You may need to try many different variations in order to get a replacement/few replacements that work(s). Ignore Yoda; try and try again.

5. Next step: Stop the chewing on the inside of the cheeks. Keep the finger where it is, and remove the cheek biting. Hold a chew toy or chew jewellery piece with your thumb and forefinger, and chew on *it*. The finger is still touching/pressing against the (front of the) teeth, the (top) lip, and possibly the tongue; it's also holding a chew toy, or a stick attached to a chew toy (or stir stick, or tongue depressor, or other thing that's better for chewing on than a body part). The teeth/jaw are still making a chewing motion and meeting resistance, and pressing against the chew toy. The thumb is not just touching the chin, it's also now pressing against the chew toy as well. You've removed the pain.

6. Say the change in Step #5 doesn't work – there *needs* to be an interoceptive component to the stim in order to get the full effect. Or there needs to be a taste component. Try substituting a salt toffee for the chew toy. That would give a salty taste; it might even click with interoception because you're eating something.

Replacing Harmful Stims cont'd

7. Accept that if this works, it will be slow. Change is difficult, especially if that change is dealing with something that has helped someone cope with the world as it is.
8. If this method doesn't work... talk to other autistics. Use Twitter's #AskingAutistics hashtag. Check out the blogs of autistic adults. Ask for suggestions. And point out that you are trying to *replace* rather than *remove*.

The #AskingAutistics hashtag was specifically created for these kinds of situations, where someone needs help regarding an autistic, whether helping, understanding, or supporting, and the people who respond are usually delighted to help, and welcome honest inquiries and requests for assistance. Mentioning that you are trying to replace a harmful stim – saying something like that will usually gain you respect, because you're proving that you respect that autistics stim for *reasons*. 😊

? Any Questions ?

So, does anyone have questions about sensory issues, alexithymia, stimming, or anything that might be related to one or more of those topics?

Contact Information

Please feel free to contact me with questions, requests, etc. about autism, autism advocacy, or presenting about autism-related topics. If I don't know the information, I probably have contacts of my own who do! ☺

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