

How I
learned to
stop
normalling
and love
being autistic

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I'm just a fortysomething white lady, talking to a group of esteemed colleagues, asking them to laugh along with me as I unpack my personal trauma.

I CAN TELL YOU ABOUT:

- my nerdy research
- current discussions in the Autistic Self-Advocacy community
- the books that have gotten me through these trying times
- my experiences as a white, well-educated, middle-class-adjacent, speaking, cisgender feminine person with “stealth autism” (aka “masked autism”)

I CAN'T TELL YOU ABOUT:

- the experiences of non-speaking autistics or those with higher support needs*
- the experiences of autistics who face multiple marginalizations (e.g. ableism plus racism, transphobia, queerphobia, classism, etc)*
- local services and supports

*please see the video and Instagram links at the end of these slides for suggested viewing/following!

You're probably wondering how I got here.

Smart kid, shy, bookish, clumsy, very high anxiety, talked early but *not to anyone*, couldn't tie my shoes by the time Kindergarten started and nobody noticed for over a year because I was very, very quiet. Spent summers reading beyond my age level and making dioramas of old-timey dry goods stores in shoeboxes while other kids rode bikes and played sports.

Early adulthood of crushing self-doubt and highly questionable decision-making, which I somehow survived. Diagnosed with depression, anxiety, more depression, more anxiety, and eventually with ADHD and also... anxiety.

Fast-forward to a conversation with an autistic friend. I've been telling her about my difficulties getting an ASD assessment for my eldest daughter. The friend looks at me and says, "You know... there is a strong heritability factor... and you do have an awful lot of traits..." Prior to that, we'd been chatting excitedly about the sound qualities of the walls in some of our favourite rooms, so, fair enough.

And so it begins...



Interestingly, nobody in my life has been remotely surprised by these inquiries and revelations. Apparently, I've never really passed as "normal."

(Image link: https://www.instagram.com/p/CZcmR3yFr_D/)

Particular and peculiar...

- My doctoral research asks how autistic readers experience poetry. I argue that if autism influences a person's communication style, language comprehension, sensory experiences, and cognitive processing, then autism *can't not* result in a relationship to poetry that is unlike that of neurotypical readers. I refer to this “particular and peculiar” mode as “autistic close reading.”
- I also study the disability memoir as a genre, with a focus on literary memoir by autistic writers.
- I am planning a future research project which will use creative methodologies to investigate the influence of autistic modes of communication on my own poetic process.

Critical Autism Studies

- is a subdiscipline of Critical Disability Studies; term has been in use since 2016.
- is an interdisciplinary field that privileges the expertise and lived experiences of autistic individuals over the findings and opinions of non-autistic researchers, parents, etc.
- rejects the notion that autism is something to be cured or prevented, focusing instead on the way the rhetoric of “cure” impacts autistic community/ies and culture/s.

(Some key texts listed under “References” at the end of this presentation)

Phenomenology of autism

- is a philosophical understanding of autism gleaned from the first-person experiences of autistic people.
- seeks to understand *unmediated* autistic experience. What does autism look/feel/think like when it is not constrained by non-autistic expectations, standards, and demands?
- is radical! Postdisciplinary! Disruptive! Emergent! Crucial!

Ableism: discrimination against disabled people; the notion that disabled people are of less value than non-disabled people, and that disability is fundamentally burdensome, tragic, and undesirable (and, by extension, so are disabled people).

Even if autistic people reject the medical paradigm, we are still subject to ableism. Under the social model of disability, anything is a disability of society deems it so.

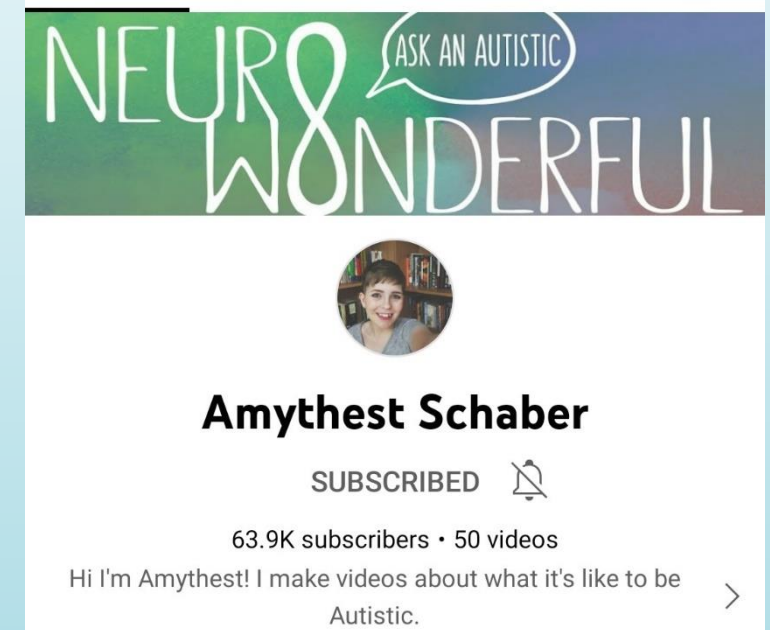
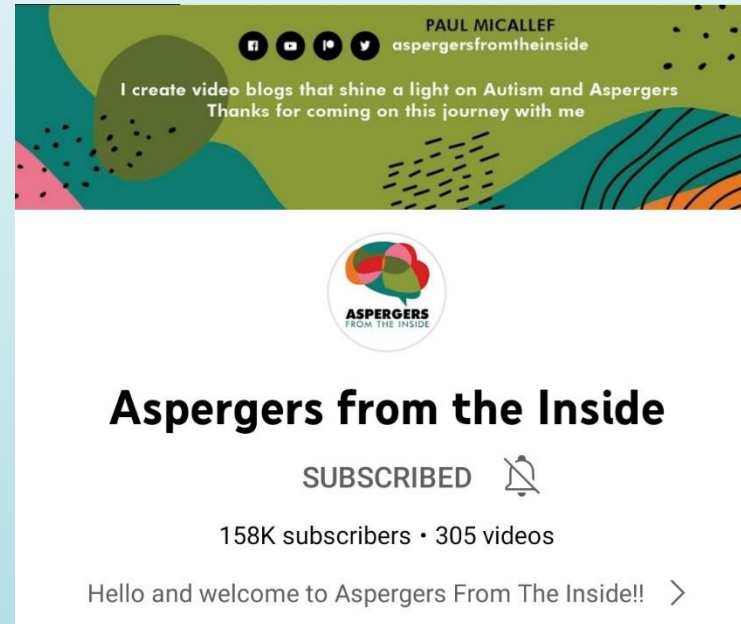
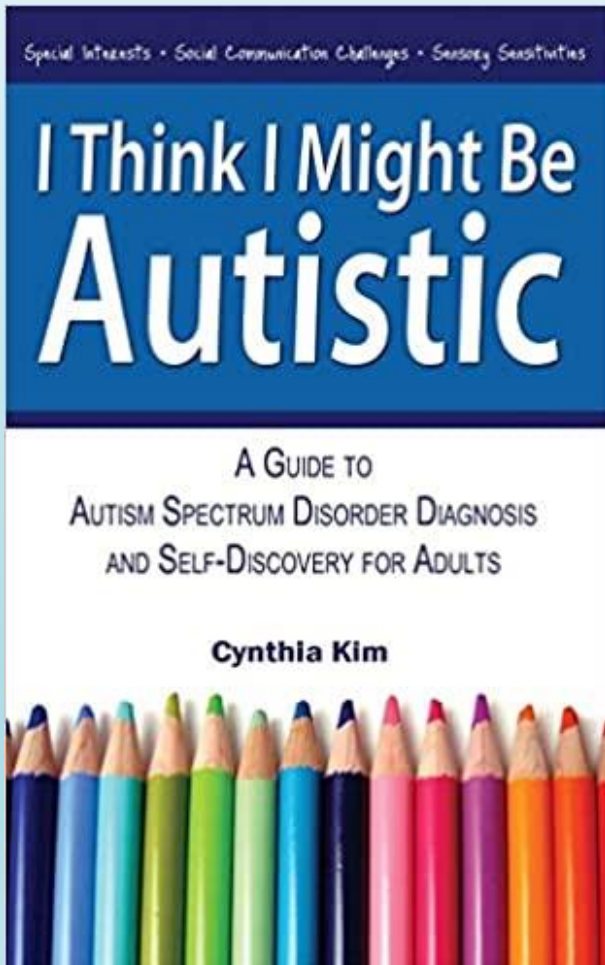
Autistiphobia: fear of autism and of autistic people; fear of a child or loved one being/becoming autistic. Uses language of “risk,” “awareness,” and “intervention” in discussing autism. Suspicion and distrust of autistic people, as manifest in the requirement for autistics to have a (presumably) non-autistic professional “vouch for” them via diagnosis.

The dominant paradigm... isn't great for autistic people.

Neuronormativity: the notion that there is a neurologically “normal” and “natural” way for a person to be. People who deviate from this norm are only accepted by the mainstream if they can demonstrate that they aspire to meet the norm and are working hard to emulate it (e.g. “quiet hands,” being trained to make/fake eye contact, suppressing interests and passions that other people might find “cringe”).

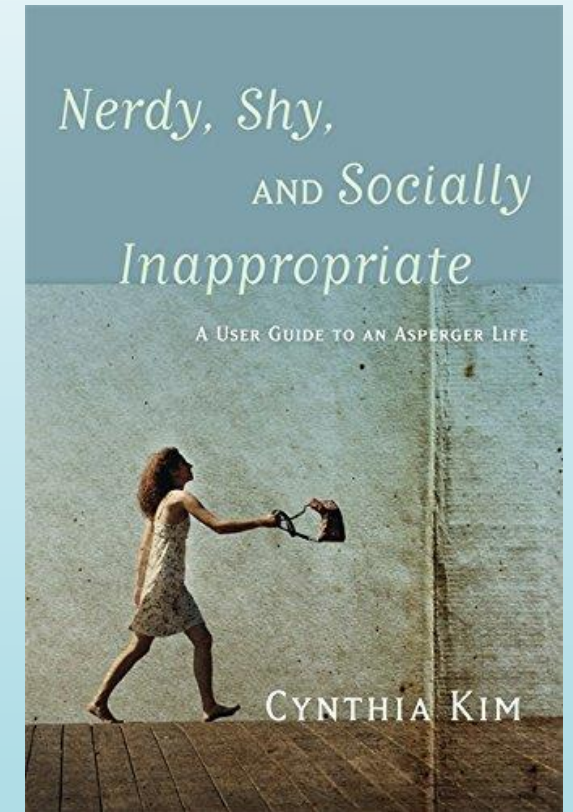
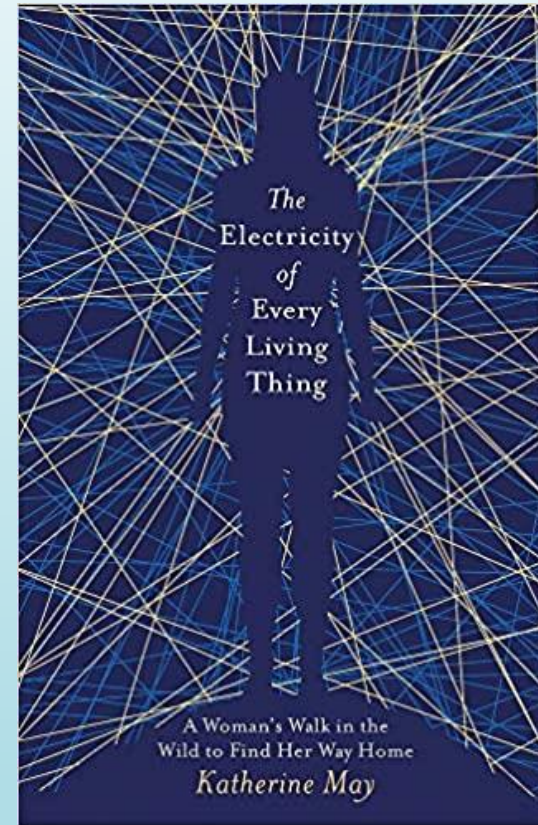
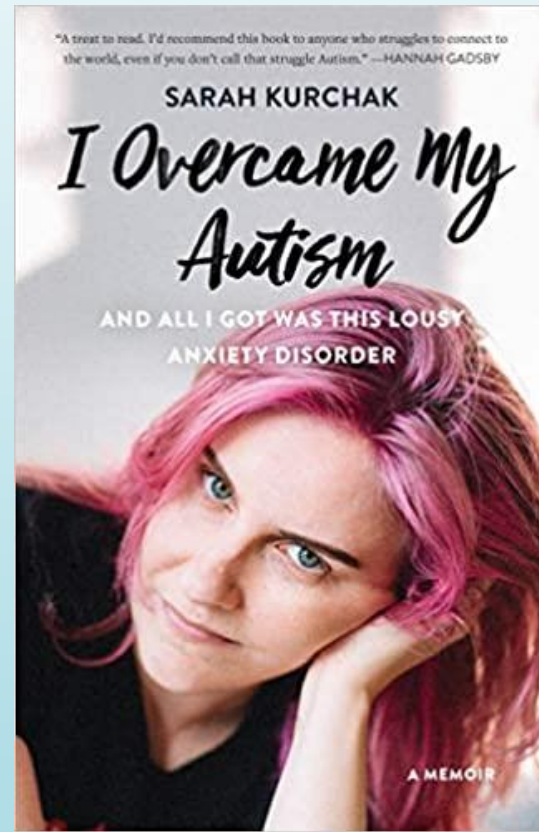
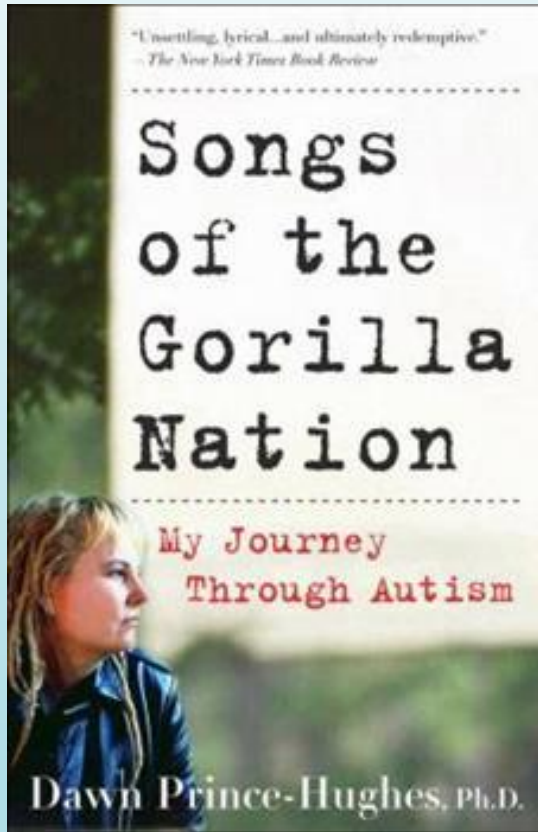
Our successes and failures are evaluated against non-autistic expectations, standards, and values. Inevitably, we fall short.

A few handy resources that helped me out:



Paul Micallef on YouTube: www.youtube.com/c/AspergersfromtheInside/
Amythest Schaber on YouTube: www.youtube.com/c/neurowonderful
Cynthia Kim's website: musingsofanaspie.com/about

And a few more:



These are the books I refer to, lovingly, as my “unauthorized biographies.”

“So, when you say *autism*, what do you mean, exactly?”

“Autism” and “Autism Spectrum Disorder” are *not* interchangeable terms

ASD

- A diagnostic category outlined in the DSM-5
- Diagnosis requires rigorous assessment by trained, authorized clinical professionals
- Considered a permanent disability; diagnosis can allow you to request accommodations, claim tax credits, etc.

AUTISM

- Is consistent with the DSM’s description, but traits are interpreted more positively and less as “abnormalities”
- A “mode of being” some people share, whether they have a clinical ASD diagnosis or not
- Might be considered an impairment, a disability, or simply a collection of personality traits

Why would people not be clinically diagnosed?

- Lack of resources; lack of finances; poor/no insurance coverage; no authorized clinicians in area; resources are available but inaccessible;
- Underwent assessment but didn't meet the thresholds of impairment; available clinician not up-to-date with autism research; deemed too "well-adjusted" or "high-functioning" to need support;
- Med/psych trauma due to sensory overwhelm in clinical environments, experience of medical gaslighting, harm from prior misdiagnoses/inappropriate treatments, or racism/gender bias/transphobia/classism in medicine;



wanderingpatient
Prague, Czech Republic



wandering patient 
@tarlovcystpati1

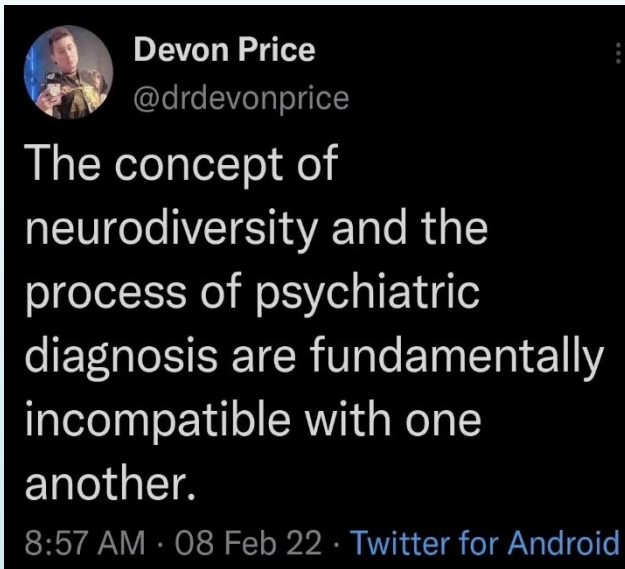


Autistic people still can't get drivers licenses and drive cars in our country. This is one of the reasons for many people to not to seek an official diagnosis when they suspect that they could be autistic.

Why would people not be clinically diagnosed?
(cont'd)

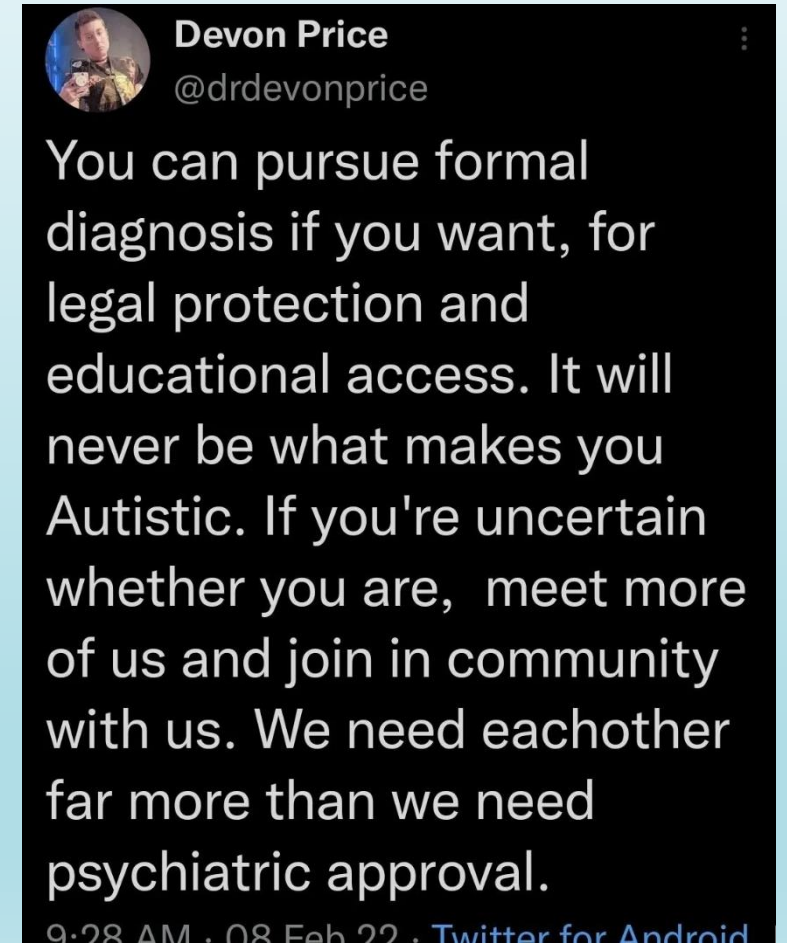
- Fear of potential repercussions (immigration/free movement, employment, custody of children, regional laws e.g. ability to hold a drivers license);

(Link to post:
www.instagram.com/p/CT5MsSPsaSi/)



(Link to post:

www.instagram.com/p/CZuK79jrFsz/)



Why would people not be clinically diagnosed? (cont'd)

- Political/philosophical objection to medical paradigm; rejection of med/psych fields as gatekeepers of autistic identity

What if we looked at
autism another way?

“To me, the *state of being autistic*...

... is indistinguishable from what I've always thought of as *living in a state of poetry*: a state in which nothing around me is unworthy of notice, where the connections between seemingly disparate items and sensations are as clear to me as if they were strung together with ribbon, where everything is overlaid with patterns of sound and vibration, where sensations are turned up to 11, where inanimate objects can have personalities and voices that are more 'real' than those belonging to people I've known for years.”

(Me, from my journal, June 2020)

“The thing I study...

... is more like color than like color-blindness – it’s a thing that happens between sensing bodies and sensuous worlds, in the particularity of each. I have come to think of the thing I seek out as a *mode of engagement with the stuff of the world* – a way of *being with* one’s surroundings. In particular, it is a form of permeability, of deep existential vulnerability, to the order of things around us: structured systems, elements in their robust relations, arrangements both deliberate and disavowed.”

Elizabeth Fein, “Autism as a Mode of Engagement”

“One way to think about autism...

... is as a particular relationship with attention. To be autistic is to yearn to sink your attention into things that give you pleasure. That might be a complex system of information, or a specific song on repeat, or the way that light dances on the water.

All the while, your attention is drawn painfully away by the ragged discomfort of the world, the wrong noise, the wrong light, the wrong kind of information. Until you can take control of your own time and space, everything feels like an exhausting, enervating yearning for home. Home is where your attention can rest happily, absorbed in what you love.”

[Katherine May](#), author of *Wintering* and *The Electricity of Every Living Thing*

“Although ‘autism’...

... is an abstraction, it is tightly connected to a reality, to autistic individuals who are real, out there, and who are much more than their representations. Questioning our practice in the way that we theorize and represent autistic people... is a necessary response to our encounters with difference ... [S]uch an approach calls us to humility and attentive engagement in an ongoing struggle to bear witness to those who cannot readily represent themselves in terms we can comprehend.”

Kristina Chew, “Autism and the Task of the Translator”

“Honestly, the day I was formally diagnosed with autism ...

... was a very good day. Because it felt like I'd been handed the keys to the city of me. Because I was able to make sense of so many things that had only ever been confusing to me. Like why I could be so intelligent but struggle to leave any proof. Why I can't fill in forms. [...]

What this [stand-up comedy] show is is a metaphorical preposition that explains the relationship between what you think you think you see me think... and what I'm genuinely able to think. Because I like the way that I think. If the world is right and I'm right in it, I can find my funny zip and my thinking expands. There is beauty in the way that I think.”

Hannah Gadsby, *Douglas*



Image link: <https://www.instagram.com/p/CZejjMcsSxs/>

What if we started to appreciate autism as a generative praxis?

generative (adj.): capable of producing something

praxis (n.): the practical use of knowledge

At its freest, autism allows us the possibility of observing the world in a way that is unmediated by neurotypical Groupthink.

Autistic people tend to employ “bottom-up thinking,” which “is said to take place through a process of taking in details and building up from there. The fragmented bits and pieces are structured and categorized, and then an induction is made—a process that brings rise to something. This thinking style involves formulating connections with other examples to make sense of what is occurring, and then capturing the commonalities between the connections into something concrete. In total, the bits and pieces are being reassembled into something that makes sense and leads to a resulting conclusion.”

Samantha Craft, “Bottoms-Up: The Innovative Thinking Style of the Asperger’s Mind”

Researchers in the humanities are asking how autistic modes of interpretation can open non-autistic people to deeper, more enriching experience of the world:

- Philosopher Erin Manning aligns her concept of “the artful” with what she calls “autistic perception,” a moment of experience where there is “as yet no hierarchical differentiation, for instance, between color, sound, light, between human and nonhuman, between what connects to the body and what connects to the world.” She writes that when artists are “subsumed by process, we often seek this kind of perception, and it is available to us all: autistic perception does not belong exclusively to autistics.”
- Music theorist Joseph Nathan Straus writes that “autistic hearing provides an alternative to normal hearing, which is undertaken in silence and oriented toward global coherence, the synthesis of wholes from parts, the creation of relationships among discrete events, the subsuming context, and the creation of conceptual hierarchies, particularly in the domain of pitch . . . I am not suggesting that all people with autism hear autistically, or that you have to be autistic to hear autistically.”
- Literary theorist Ralph James Savarese has written extensively on the relationship between autism and poetry, drawing on research in disparate areas including audiology; he writes, “whereas autistics excel at processing the perceptual aspects of speech sounds, neurotypicals excel at processing the semantic ones. While scientists interpret the former exclusively in a negative light—as a sign of underconnectivity in autistic brains—I emphasize its poetic value.”

But how does this help autistic people in crisis?

- Thinking, living, and *being* as our authentic autistic selves can't happen when we're in survival mode.
- Autistic people who are living under overlapping pressures of autistiphobia, racism, misogyny, transphobia, queerphobia, poverty, and other forms of violence are not afforded the space for autistic joy.
- We don't even know what an autistic life free of trauma looks like. We don't know which "classic" autistic traits are truly innate to autism and which are trauma responses. There is no control group of untraumatized autistics to observe!
- Many of us are trying to live our best lives without any idea what that means. The process of unmasking is slow, messy, painful, and exhausting.
- We need support at all levels, but we need it on our terms, and some of us are still learning what those terms are. This is not a quick fix!

But if you want to join us, here are a few suggestions:

AGITATE FOR BETTER HOUSING, BETTER HEALTHCARE, AND UNIVERSAL BASIC INCOME :: INVITE AUTISTIC STUDY PARTICIPANTS TO BE LISTED AS CO-AUTHORS :: READ AUTISTIC WRITERS ONLINE AND IN PRINT :: SUBSCRIBE TO AUTISTIC-CREATED PODCASTS AND VLOGS :: FOLLOW BIPOC AUTISTICS AND SUPPORT THEIR WORK :: SUPPORT AUTISTIC-RUN ORGANIZATIONS AND INITIATIVES :: BELIEVE AUTISTICS WHEN THEY SAY THERAPIES HAVE HARMED THEM :: IMPLEMENT UNIVERSAL DESIGN WHEREVER YOU CAN :: VALUE AAC, SIGN LANGUAGE, AND OTHER FORMS OF COMMUNICATION AS HIGHLY AS YOU VALUE SPEECH :: REMEMBER THAT ETHICS STANDARDS ARE ONLY A BASELINE :: IF YOUR LOCAL AUTISM SUPPORT ORGANIZATIONS HAVE NO AUTISTIC EXECUTIVE-LEVEL STAFF, ASK WHY :: PRESUME COMPETENCE :: PRACTICE HUMILITY AND VULNERABILITY :: QUESTION “NORMAL” :: IF YOU’RE WRITING ABOUT US, KNOW THAT WE’RE GOING TO READ IT :: BE PATIENT WHILE WE LEARN WHAT WE NEED :: LIGHTEN UP! IT’S JUST AUTISM!



For your
viewing and
listening (and
following)
pleasure:

@mrchazz in conversation with Tiffany ([@fidgets.and.fries](https://www.instagram.com/fidgets.and.fries)) and TJ ([@nigh.functioning.autism](https://www.instagram.com/nigh.functioning.autism)) on the intersection of race and autism (Instagram: www.instagram.com/p/CYR1aN_BiYG/)

[@sefscatterbrain](https://www.instagram.com/sefscatterbrain) talking to @mrchazz about lived experience of ABA as a transgender autistic person (Instagram: www.instagram.com/p/CYcKVBfBatn/)

Autistic authors Katherine May and Kate Fox discuss “attention, joy and really good vacuum cleaners” (Instagram: www.instagram.com/p/CYCPUDvDMhB/)

Understanding Social Cognition in Autism: Diverse Intelligences (YouTube: www.youtube.com/watch?v=xZcLW64hNCs)
EXCELLENT research on autistic peer-to-peer communication!

to be pro
**NEURO
DIVERSITY**

 is to be
**ANTI
RACIST**



[@jtknoxroxs](#)

More folks to
follow:

[@nd.narratives](#) (Sandra, writer and podcaster, discusses intersections of race and neurodiversity)

[@speechologist](#) (Vivian Tisi, autistic SLP, discusses intersection of race and neurodiversity)

[@the.autisticats](#) (collective of four young gender-diverse autistic folks who often post and discuss academic autism research)

[@drdevonprice](#) (Devon Price, autistic social psychologist, author of *Laziness Does Not Exist* and the forthcoming *Unmasking Autism*)

[@jtknoxroxs](#) (Jen White Johnson, disabled and neurodivergent Afro-Latina artist)

[@divergent_design_studios](#) (Marta Rose, queer ND youtuber, artist, and interior designer)

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Thanks for listening!

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P.S. My poetry collection, THE DEBT (Biblioasis, 2021), is available at a fine bookseller near you.

