

Divergent Presentation: Autistic Views on Neurodiversity in Research

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Author Note

Warning: the content of this paper addresses sensitive topics. *The author has included discussion of ableism, abuse of power, behaviorism, child abuse, eugenics, filicide, harm to self and others, hate speech, homicide, homophobia, neglect, racism, and suicide demanded by a full and honest exploration of the subject matter.*

Presentation slides for facilitated discussion of this paper are made available via direct communication with the author. Thank you for hearing, contemplating, and meditating on these topics of grave concern to marginalized people all over the world, and in your communities.

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When considering authentic representation in research design, one need look no further than crip, deaf, and queer discourse to see that marginalized communities who endeavor to define their own rhetorics face uphill battles. The failure of established paradigms to address the reality, much less the needs, of neurodivergent people is resounding. Herein we will consider shared language on related topics before reporting on the history of research regarding autism and the violence of the clinical gaze. We will then explore current directions in autistic academia while describing the pathology paradigm in more detail. And finally, possible futures shaped through autistic work within the neurodiversity paradigm will be illustrated. All of this will be accomplished through heavy quotation of sources despite recommendations to the contrary (American Psychological Association, 2020, pp. 269-278), in the way of an autistic rhetoric insofar as it is largely echoic in composition. The voices quoted here share atypical qualities, and reverberations, across other cultural divides. This is a feature, not a bug.

Terminology

To be clear, diversity is not something any single person may possess or imbue. Each person may be accurately labeled neurodivergent or neurotypical, while we are all collectively a neurodiverse group of people (Walker, 2021, pp. 42-46). Neurodiversity represents a plurality, the ever unfolding set of variety in epigenetic and behavioral expression. Therefore, such a thing as a “neurodiverse person” does not exist.

While awareness of the language of neurodiversity spreads, its users risk running afoul of other more subtle linguistic pitfalls in much the same way that very few who embraced the new

hotness around the turn of the century actually knew how to accurately apply terminology surrounding “cloud computing” when it first landed within public discourse. In this case, they also risk alienating those who view such semantic violations as reason to raise an exception.

Walker, in *Person-First Language Is the Language of Autistiphobic Bigots*, explains how words used to talk about other people should neither be underestimated nor go unquestioned:

Person-first language is rooted in autistiphobia and anti-autistic bigotry, and its use is widely recognized by most of the autistic community as being a reliable indicator of autistiphobic attitudes. ... The autistiphobic bigotry inherent in person-first language doesn’t become obvious until you listen to how it sounds when you use that same sort of language to talk about members of other historically oppressed and marginalized groups. Here, give it a try: *People with homosexuality? Children who have Jewishness? Adults experiencing femaleness? Ooh, how about individuals living with Blackness?* ... There are only two kinds of people who use person-first language when talking about autistics:

1. Autistiphobic bigots
2. People who don’t know any better

... Given the sheer pervasiveness of autistiphobic attitudes and autistiphobic language in the world today, and given that person-first language is even taught in college classrooms and professional training programs, you can hardly be blamed for having accepted and adopted such language without realizing it’s autistiphobic and disrespectful of autistic people. You’re not a bad person for not having known any better than what you were taught. And now that you do know better, you can *do* better. (2021, pp. 91-103)

Wherever we consider what it means for a person to diverge from neurotypical standards we must be certain to make room for a wide variety of possibilities. And while the concepts were originally developed on autistic listserv discussions, neurodivergent does not equate to autistic. The neurodivergent umbrella covers everything that would be said to lie outside of conformance with more typical bodyminds, including epigenetic influences such as ADHD,

cerebral palsy, or synesthesia, as well as life experiences resulting in brain injuries or PTSD. I happen to have my own personal collection of such diagnoses, both native and acquired, but owing to the wealth of published work regarding my primary identification as autistic, our discussion will be focused within that frequently non-speaking, rocking, echoing, pacing, awkward, hated space.

The overall framing of this discussion, as well as the language used in and developed by autistic community, resides in queer spaces, queer behaviors, and queerly presenting people.

There is nonsense in autistic being and doing, nonsense meant multiply: the excess of sense and sensation, the absence of sense and sensation, the monotropic perception of field as partially whole or wholly partial. Autistic rhetorics can and do hold meaning, but so too are they symbolic for their nonsymbolism, for their simplicity and their pedantry and their nothingness. (Yergeau, 2018, p. 144)

Yergeau explains that common (autistic) behaviors called stimming “might take shape as finger flicking, full-body rocking, knitting, nose picking, vocalizations, ritualistic sniffing, hand waving, rapid eyeblinking, or banging one’s head against an object or surface” (2018, p. 201). These self-stimulatory behaviors, or stereotypy, serve many roles but are generally pathologized as masturbatory and overwritten by behaviorists. They are routinely expressed, with or without attached meaning, as communication, echophenomena, self regulation, ecstatic release, or distractions from embodied turmoil by those who stim.

Savannah Logsdon-Breakstone, in *Plural of Medium*, also speaks to the ways autistic people communicate:

Sometimes our method and our medium is ignored or not understood, but that doesn’t make it less our medium. ... I can use this medium, the medium of digitized writing by the hitting of keys, in times when I can’t even verbally speak at all, in times where my

messages as a kid might have been lost in other people's reactions to my screaming wordlessly because I didn't have the right words to speak anymore. (Bascom et al, 2012, pp. 289-292)

Bascom addresses a specific set of common, though again, not exclusively autistic, behaviors categorized as echophenomena in *An Ethnography of Robotics*:

Echolalia is a metalanguage. ... Echolalia is what you use when language is too much. It's just also what you use when it's not enough. These things are not opposites. ... Echolalia, from Echo, of Greek mythos, cursed to speak only through the words of others. ... When I'm echoing, referencing, patterning, quoting, punning, swinging from hyperlexic memory to sysesthetic connection, words are my tangible playground. ... The bestworst part is no one ever knowing. (2012, pp. 298-302)

In terms of generalized experience, failure to access a much needed pressure relief valve, a stim, could result in escalation of dysregulation to the point of a meltdown. "Meltdowns and self-injury ... serve as prime exemplars of the pain and frustration that might accompany autism.... If meltdowns transpire because one's body cannot otherwise express, then capturing that expression via language or some other modality can surmount an impossible task" (Yergeau, 2018, p. 204). No two meltdowns are alike, and even one singular meltdown experience often defies encapsulation (Yergeau, 2018, p. 176).

"Able-bodied identity escapes being an identity, because able-bodiedness is default and classic and planar" (Yergeau, 2018, p. 152). "Allistic, generally speaking, means nonautistic; in like kind allism refers to the state of nonautism" (Yergeau, 2018, pp. 168-171). "Allism's derivation mimics that of autism, where the Greek *autos* is meant to signal self, and the Greek *allos* is meant to signal other."

It is easy, tidy, and convenient to dismiss the diagnostic gaze as an example of disabled passivity. ... clinical wills and clinical practices bend toward, around, and in opposition to those of us who are neurologically queer. We practice demi-rhetorics, queerly relational and queerly nonrelational spaces, spaces in which our disclosed bodyminds continually (re)invent the contours of rhetorical being. (Yergeau, 2018, p. 206)

Yergeau asserts that the violence in diagnosis means that “To claim autism is to claim rudeness, silence, tactlessness, nonpersonhood; it is to invite doubting others to lay diagnose or question one’s rhetorical competence” (2018, p. 154). Amanda Forest Vivian described an all too common experience in *They Hate You. Yes, You:*

Because, of course, if I told anyone I was autistic, they said I was lying, or I had a different kind of autism that made me smart and talented, so I wasn’t like Those Kids, the kids who needed to be cured. And that I should think about their parents, about the money and time to care for a person like that, about the dreams that are shattered when your kid is really autistic, not smart autistic, the real kind. (Bascom et al, 2012, pp. 184-188)

“Claiming rhetoricity, claiming self-definition, claiming empathy or understanding – all of these claims, in some way, defy autism’s clinical categorization” (Yergeau, 2018, p. 167).

“Part of the autism experience is not being believed.” This disbelief is present within atypical reports of perception and experience, within oddly embodied movement. Phil Schwartz asks, “What is so intrinsically wrong about hand flapping, about narrow and unusual interests, about an aesthetic sensibility attuned to repetition or detail rather than holistic gestalt, or objects rather than people?” (Yergeau, 2018, p. 199).

We quiet our hands, and our echoes, we stop stimming, and look near enough eyes to appear as though we’re making contact, regardless of our mounting discomfort. This effort,

often the unconscious result of bigoted conditioning, might also be accurately labeled as autistic masking. It helps us to avoid running afoul of the hidden curriculum, or unspoken social rules, during attempts to pass through neurotypically conforming society. Take note in Yergeau's description of the imbalance wherein one might say it is socially acceptable for allistics to call out autistics for hidden curriculum violations, while the opposite case is decidedly NOT true (2018, pp. 172-173). Asserting boundary violations as an autistic person is frequently met with acts of neurotypical aggression.

Yergeau also addresses "autistic perception, which Erin Manning has described as 'a complex dance of attention,' and an 'attunement to life as an incipient ecology of practices, an ecology that does not privilege the human but attends to the more than human'" (2018, p. 144). So when we speak of autistic listening we are speaking of a deep, whole bodied listening, a listening attuned to self as resonant within one's environment. With that in mind, consider Bev Harp's question in *Are You Listening*:

The most important thing to keep in mind is that speech is not the same thing as language, and that communication is a much larger concept still. Listening is at least half of the work. When I am not speaking, I am still communicating; most of the time, I am using some form of language. *If you do not try to see what I am already offering, why would you expect me to try harder to give more?* (Bascom et al, 2012, pp. 305-308)

"To developmentally disabled individuals, developmentalist discourses (such as Piaget's) reek of ableism" (Yergeau, 2018, p. 202). In my own observations, those diagnosed with autism are often found because they are expressing symptoms, not of their neurology, but of frequently co-occurring conditions. How many times has a child been brow beaten over failing to parrot the correct reply in a discreet trial before they were ever analyzed for apraxia (difficulty with skilled

movements, gestures, or speech)? If they *were* evaluated for apraxia, was it *before* littering their personal records with notes about non-compliance? When one faces dynamic disability, with performance measures greatly affected by environmental stressors, fine motor skills could also present with varying reliability. Couldn't they? (Yes, they could).

In this vein, non-speaking autistics have long argued for what Ralph Savarese calls a “sensorimotor perspective on autism. Sensorimotor approaches regard atypical sensoria, mind-body disconnects, disjunctures between volition and embodied response, and impairments in motor planning and coordination as core components – at times even the underlying essence – of autism” (Yergeau, 2018, p. 195). Jim Sinclair describes the pervasive nature of autism as something that “colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence” (Yergeau, 2018, p. 192). Yergeau, after exploring Savarese’s view of autism’s essence being its considered lack of essence, writes that “autistic people have long been claiming that they have theories of mind, much like they’ve long been claiming that autism is a fully embodied experiential, much like they’ve been claiming that autism is a motoric culture of flaps and echoes and bodily disobedience. ... autism is embodied semiosis” (2018, p. 200), a continual and personally scoped symbolic creation where intent and meaning are both ephemeral and essential.

One cannot authentically participate in a discussion of autistic experiences as fully representative without taking a tour through historic influences of eugenics, also known as the striving to alter the human gene pool via attempts to exclude those judged inferior while promoting an idealized superior class. The violence of selective breeding and scientific racism has been enacted via varied policies through the years, including marriage prohibitions, forced

sterilization, and filicide targeting mental and physical disability, low IQ, deviant behavior, and minority membership. In total, these were acts of political and clinical aggression inseparable from white privilege and ableism which left open questions about the negative impacts of such programs on genetic ecology, immunity, and resilience brought to bear by the risks inherent to inbreeding depression (Wikipedia Contributors, 2019).

Amanda Baggs beautifully defines and defends a non-speaking position in *The Meaning of Self-Advocacy*:

Self-advocacy doesn't mean staff get to pat us on the head, use the right buzzwords, tell us what wonderful little self-advocates we are, and then chastise us or put us on a behavior program when we get angry at them about *their* controlling behavior. ... real self-advocacy will always upset the status quo in some way. ... They will not be able to pretend away the power inequalities between us and live in fairyland where everyone's the same and that's what counts.

Self-advocacy has been and is still often labeled intransigence, non-compliance, treatment resistance, *lack* of motivation, behavior issues, violence, manipulation, game-playing, attention-seeking, bad attitude, bad influence, babbling nonsense, self-injurious behavior, inappropriate behavior, disrespect, disruption of the milieu, catatonic behavior, social withdrawal, delusions, septal rage syndrome, and even seizures or reflex activity.

To say that the parent-advocacy movement or any other group of people *created* our voices is arrogant and shows *real* disrespect for the price many of us have paid for using our voices. We have always had these voices, in many forms. It is others who have shut us out, shut us up, and refused to listen. (Bascom et al, 2012, pp. 315-319)

While I will continue to introduce topics and expand definitions throughout this work, let us wrap up our initial discovery of language relevant to the topic at hand with a comparison between the terms impairment and disability, taking special care to regard each concept

individually and in relationship. Cal Montgomery wrote, “Disability is injustice, not tragedy; unequal treatment, not inherent inequality” (Bascom et al, 2012, p. 76). This is to suggest that disability equates to dis-enablement as opposed to in-ability. We must maintain a separation in our consideration of impairment (the ways our bodyminds differ from each other) and disability (the ways impaired people are excluded by society). The ways that people are disabled is due to choices made, like the lack of planning for accessibility needs in support of a given impairment at the beginning of a project as opposed to bolting a post-hoc add-on module onto work already considered complete. Disability does not pertain to any inherent ability of a given bodymind.

History

Racial Hygiene in the United States was the translated title of a 1913 textbook used as “the seminal guide to applied eugenics” for German students of the time, as well as being a fully representative statement of how we arrived here. In the 1930s, American law became the de facto eugenic blueprint for the Nazi defense of Nordic *Blut und Rasse* (e.g. Aryan blood and race) from dysgenic influences. Silberman reported that more than 400,000 people were forcibly sterilized by the Nazi regime (2015, p. 118).

One of the favored sons of that regime participated in practicum with leading eugenicists of the day, and his name would for a time be shared by a privileged class of autistic presentation. With Hans Asperger maintaining a focus on so-called little professors in his definition of *Autistic Psychopathy in Childhood*, and their capacity for highly creative insight and expression, he may have tried to spare them from immediate certain death by focusing on skills which could serve the state, but his clinic and all the records were a mere pile of debris and ash after the war.

Written contemporaneously, but published a year prior, Leo Kanner became a public figure with *Autistic Disturbances of Affective Contact*. In public, he never spoke about Asperger, so all over the world autism became known as *Kanner's syndrome* (Silberman, 2015, p. 140). These men stirred up decades of confusion about the ways in which autism manifests (hint: they were only interested in writing about young white male specimens).

A colleague of Asperger, Erwin Jekelius, went a step beyond sympathizing and directly aided Nazi officials in drafting a secret plan to rid the world of melancholic, coarse, and clumsy boys which would evolve into Hitler's Final Solution (for enacting the Holocaust). They started with the murder of a single child, declared an idiot by doctors (Silberman, 2015, p. 109).

The roots of modern day filicide, or what has unfortunately become the celebrated act of murdering one's own burdensome offspring, were documented in the late 1930s by Werner Catel (chief neurologist at the University of Leipzig) when labeling such unfortunates as monsters, or *missa carnis* (heaps of insensible flesh lacking souls, per Martin Luther's definition). They were seen as absent any value when considering the ways they might contribute to society at large through such a biased lens. A personal physician of Hitler, Karl Brandt, was dispatched with the intent of ensuring no fault lie at the feet of the parents begging for euthanasia, and indeed offered the protection of the Führer's direct intervention on their behalf (Silberman, 2015, p. 131). With Brandt's guidance, they were careful to welcome parents onto the killing floor while soothing their troubled minds with talk of the greater good.

Fast forwarding through a few unremarkable and oppressive decades, owing to their continuance of themes already explored, we land at UCLA in the 1970s. Here, a tenacious Ole Ivar Løvaas, already featured on the cover of Time magazine for his work literally beating the

divergence out of children, lorded over the Young Autism Project (designed to make them indistinguishable from peers) and, with George Reker's aid, the Feminine Boy Project (the largest federally funded project of its kind, designed to intervene similarly in the lives of "sissy boys"). His basic approach to either type of queer behavior is reflected in this quote:

You see, you start pretty much from scratch when you work with an autistic child. You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense. ... You have the raw materials, but you have to build the person. (Yergeau, 2018, p. 116)

Both of these research studies aimed to prove the value of aversive techniques and operant conditioning core to the thriving modern day industry of Applied Behavior Analysis. Both of the projects were grounded in these bigoted theories, which continue to rule over the lives of autistic people even now, despite global resistance to conversion therapies and a purported societal acceptance of neurodivergence.

Yergeau (2018, p. 120) asserts that "Neuroqueerness abides, resides – and behavioral interventions work only to instill behaviors that appear neurotypical while obfuscating or shelving those behaviors that signal queerness." Most of the autistic children were described as regressing to their pre-ABA behaviors soon after their program concluded. The star of television interviews and Richard Green's book *Sissy Boy Syndrome* came out as gay when grown, and committed suicide by hanging at age 38. Walker describes the work in a more general way, providing this comparison, "The professional ABA perpetrator and the homophobic schoolyard bully are ultimately in the same line of work, enforcing the same compulsory normativity from different angles" (2021, p. 185).

Before social media took over the world, autistic discourse moved at the speed of pen-pal letter writing campaigns. These campaigns grew into yearly retreats for discussion of how autistic people, as a community, wanted to shape the rhetoric that bounded their existence. Jim Sinclair wrote “I had sometimes been able to establish meaningful communication with people before, but it always involved my having to learn the other person’s language and do constant laborious translating” (Bascom et al, 2012, p. 25). He contrasted that experience with the ease participants found in directly communicating in uniquely autistic ways when they were able to share space together.

More recently, despite efforts by autistic creators working tirelessly on behalf of community established priorities, the inertia (and corporate money) behind opposition to self-advocacy, according to Sinclair, has been winning out:

Any attempt by a group of disempowered people to challenge the status quo – to dispute the presumption of their incompetence, to redefine themselves as equals of the empowered class, to assert independence and self-determination – has been met by remarkably similar efforts to discredit them. (Bascom et al, 2012, p. 34)

Yergeau writes, “Diplomacy is trickery dressed as morality” (2018, p. 151). Diplomatic action is, a frequently demanded tool leveraged in ongoing oppression of marginalized groups, a way to police the tone of arguments raised against privileged classes, a useless paradigm when punching up is the only resource left for an abused group. “Autistic people are called unempathetic, rigid, black-and-white thinkers in a society in which most political discourse is inhuman, inflexible, and polarized”. Nick Walker includes bold arguments in urging us to throw away the master’s tools: “The concept of a ‘normal brain’ or a ‘normal person’ has no more

objective scientific validity – and serves no better purpose – than the concept of a ‘master race’” (Bascom et al, 2012, p. 231).

While on the subject of race, let us note that non-white children in the United States “are diagnosed far older, and in much smaller proportions, when compared with white children” (Yergeau, 2018, p. 157). Nirmala Erevelles argues this is due to a legacy, and the modern day practice, of “eugenic criminology”:

Kayleb Moon-Robinson, an autistic and black child who, at the age of eleven, was charged with disorderly conduct for kicking a trash can at school. ... arrested for felonious assault when he resisted going to the principal’s office after the school resource officer attempted to forcibly drag him there. ... This 6th grade child has to face life as a convicted felon before he’s even old enough to drive. (Yergeau, 2018, p. 157)

Yergeau reports on the relevant, and disappointing, makeup of Autism Speaks leadership in the year 2013: “Of the thirty-three board members, twenty-five were white men and only one board member was a person of color. All board members, of course, were nonautistic” (2018, p. 158).

Status Quo

Autism Speaks “has for years compared childhood autism prevalence to a number of fatal situations, such as car crashes and hypothermia.” Promotional materials from the group have routinely exclaimed that “more children will be diagnosed with autism spectrum disorder than AIDS, diabetes, and cancer combined” (Yergeau, 2018, p. 156). Amanda Forest Vivian incisively declares: “Unfortunately, it’s exactly the powerful momentum of how things are done which keeps people from thinking much about the things they are doing”. She offers this challenge:

Every person in power who unthinkingly chooses or supports indistinguishability is adding to its mass. It's an army of laziness, an army (usually) of feeling safe in your body. Of being able to talk about how much you love *The Office* in between sessions of training [an autistic kid] not to make jokes that don't have an obvious punchline. (Bascom et al, 2012, p. 282)

Similarly, Walker calls out shoddy work by therapists, educators, and other professionals in *Guiding Principles for a Course on Autism*:

The present state of autism related discourse, theory, and praxis in the academic and professional spheres is deplorable. The discourse and theory reflect a level of ignorance and bigotry that would be regarded as scandalous in most academic circles today if it involved any other historically oppressed group. (2021, pp. 144-156)

Shain Neumeier, J.D., a survivor of coercive medical and mental health treatment, wrote the following in reference to the Judge Rotenburg Center (JRC):

For over [fifty] years, JRC has used painful methods of controlling the behavior of Autistic people, people with intellectual disabilities, and people with mental illnesses. This includes long-term mechanical restraint to a four point board, food and sensory deprivation, social isolation, and most infamously, electric shock.

For a couple of years, it used a relatively weak device ... with a shock lasting a tenth of a second that reportedly felt like snapping a rubber band against one's skin. ... Brandon Sanchez was shocked 5,000 times in a single day.

... the program designed and began to manufacture its own device, which it called the Graduated Electronic Decelerator (GED). ... three times as powerful, in fact, with shocks lasting for a full two seconds. ... GED regularly caused burns, which were bad enough that it became medically necessary to stop shocking students for a number of weeks.

... [with] the GED-4, which was three times as powerful as the original GED, ... electric shock became the primary aversive used at JRC, replacing the use of techniques such as spatula spansks, pinches, muscle squeezes and ammonia pellets....

Meanwhile, the United Nations declared that its use of electric shock and long-term restraint on children and adults with disabilities violated international human rights protections against torture. Still, the Massachusetts legislature failed to pass any state laws banning or regulating the shocks, and JRC continued to enjoy the support of its students' families, with Brandon Sanchez's father saying that he would rather put a bullet in his son's brain than have him go off the GED, claiming that it would be more humane.

[In 2012] the United Nations condemned JRC for its torture of people with disabilities a second time and demanded that the U.S. government investigate and take action to stop it. Still, as of writing this, JRC is still open, and continues to shock, restrain, starve, and otherwise abuse.... They assume that doctors, parents and other caretakers who deal with people with disabilities know best, and thus what they do to, or agree to on behalf of, people with disabilities must be necessary. ... must be managed rather than understood. (Bascom et al, 2012, pp. 204-217)

Bev Harp, in *Connecting Dots*, takes the argument even further:

Somebody calls autism a tragedy. Somebody kills an autistic person. Somebody doesn't see how these two events are connected. ... This one is not like the others. This one is out of our range of understanding and compassion. ... Nobody asks autistic people what this might mean for their futures. ... The voices are crying for understanding, not for the murdered but for their killers. (Bascom et al, 2012, p. 256)

Communication comes in many forms, most of which are ignored in ableist public discourse. One's lack of effective use of mouth words has nothing to do with whether or not they have anything to say. Situational Mutism is a thing (and any reader currently discovering this is encouraged to behave as an ally in looking it up before coming back to the topic with trauma

informed questions of those with lived experience – autistethnographies are richly detailed, varied, and often freely available (Yergeau, 2018, pp. 24-28)). “Embodied communication forms – including the echo, the tic, the stim, the rocking body, the twirl – represent linguistic and cultural motions that pose possibility for autistics” (Yergeau, 2018, p. 181). Bascom tells us:

My hands are an automatic feedback loop, touching and feeling simultaneously. I think I understand the whole world when I run my fingertips together.... I need to have quiet hands, because until I move 97% of the way in your direction you can't even see that there's a 3% for you to move toward me. (2012, pp. 180-181)

In her article *Autistic Community and Culture: Silent Hands No More*, Elizabeth Grace ponders the question of whether Autistic Community is itself an oxymoron. In one fell swoop she not only shatters that take, she also takes down the notion of functioning labels: “Even if an Autistic does not use oral language at all, there is no differentiation with that in terms of typing, in the way it looks online. This puts all of the Autistics together on the same page” (Bascom et al, 2012, p. 145). She goes on to report that she “noticed that in Autistic culture, re-explaining is considered polite and thoughtful.” It is not taken as immediate cause for confrontation, a surprisingly pleasant discovery I made during my own late in life arrival within autistic digital spaces.

Lacking access to the human right of communication translates all too often into neurodivergent people being perceived as less than. “If we are not seen as fully human, then we can be treated however others wish. ... we can be freely bullied and abused, rejected and excluded. ... it doesn't matter if others jeer, ridicule or poke fun at us” (Bascom et al, 2012, p. 119). And we are, ... and they do.

Walker explores the importance of language, and the ways words affect experience:

The shift from the pathology paradigm to the neurodiversity paradigm calls for a radical shift in language. ... we speak of autistics in the same way we would speak of any other social minority group.... In the long run, the sort of language that's used to talk about autistics has enormous influence on how society treats us, and on the messages we internalize about ourselves. (2021, p. 21-22)

To this end, I frequently and proudly declare that "I am not a person with autism. I am an autistic person" (Bascom et al, 2012, p. 223). I make this declaration despite the fact that "every time I tell anyone I [am autistic] they seem determined to interrogate and confound the reality of my disabled life" (Bascom et al, 2012, p. 253). I need them to confront the their own bigotry, and our shared experience, if I am ever to achieve a durable and authentic public existence. I need them to do this so I can avoid disclosing documentation of my personal health history by way of seeking basic access to public resources. I need them to do this so that my level of burnout does not depend on their epistemically advantaged whim in evaluation of whether my requests are based in truly needing accommodations vs. some search for advantage through special treatment. Yergeau writes that "disclosure – and with it the presumed invitation – can do real violence to neuroqueer bodies" (2018, p. 192). Walker also notes observing that "the pathology paradigm serves to exacerbate rather than mitigate autistic disablement" (2021, p. 67). I am living proof.

I was born autistic. I was born disabled.... My complaints when something was too loud, or if I heard a troubling sound, or my clothes were irritating, were just me acting out and calling attention to myself. After all, it wasn't like I was disabled. I would have to learn to quiet my hands and body; to ignore the strange sensations. I would have to struggle to make myself indistinguishable. (Bascom et al, 2012, p. 153)

“One of the cruelest tricks our culture plays on autistic people is that it makes us strangers to ourselves” (Bascom et al, 2012, p. 8). Across the globe, in every region, we find autistic people living as foreigners within their own societies. Many of them express the tragedy that their world holds no place for them. They are not thought of during planning, or included early, or often, (if at all) to allow for accommodating their needs to move and make noise and show up differently. Instead they are forced into compliant behavior patterns before *earning* the right to basic access (that is, if they are *allowed* the right to life beyond infancy). Likewise, in *Grabbers*, Bascom describes conflict she has both experienced and witnessed: “It’s a grabbers vs. flappers warzone. ... they grab our hands, ‘*don’t do that, people will think you’re retarded.*’ ... The most basic human thing is just *existing in space*, and you quickly realize that you do even *this* wrong” (2012, pp. 202-203).

Zoe Gross provides an illuminated list of pathogenic comparisons to autism in *Metaphor Stole My Autism: The Social Construction of Autism as Separable from Personhood, and its Effect on Policy, Funding, and Perception*. She calls out researchers and charities for the ways they define autism; using military metaphors – battling the condition, a monstrous force, warrior moms; using kidnapping metaphors – autism as entity, autism as body-snatcher, children stolen away; using barrier metaphors – empty fortresses, living behind a wall, waiting to be set free; and using death metaphors – comparison to AIDS or cancer, a fate worse than death, mourning a living death, etc., etc., etc. She concludes:

As a result, our society’s first priority with regard to autism is finding a cure or means of prevention, as opposed to creating an inclusive environment.... ... in 2009, 32% of autism-related research dollars went to research which focused on determining the cause and prevention of autism. In contrast, only 3% went to research geared toward improving

services for [autistic people], and less than 1% went to studying the needs of autistic people across the lifespan. ... Many [autistic people] would prefer to see initiatives funded which would foster the inclusion of autistic people in society – for instance, job coaching, de-institutionalization, personal assistance for those who require it, and greater access to methods of Alternative and Augmentative Communication (AAC). ... These metaphorical constructions of autism do not encourage non-disabled people to take Autistic opinions seriously, they only increase the stigma associated with autism in our society. (Bascom et al, 2012, pp. 258-269)

It is important to highlight the other major slices of that funding pie which were left out of the discussion; 20% slices of the budget went to each of the inquiries, “How can I understand what is happening?” and “Which treatments and preventions will help?” (Bascom et al, 2012, p. 272). Neither of these priorities were established by autistic people (many of whom are parents) who have been freely offering help to (warrior) parents of autistic children only to be unironically rejected as not autistic enough to have a voice in the conversation. For those tracking the math, that’s less than 4% of all related research spending devoted to subjects addressing concerns actually supported by the autistic adult community. Even the Department of Defense seemed dubious of their results published showing year over year data with 76% of ABA cases resulting in no change, with an additional 9% with worse results at one year (Stewart, 2019, p. 10).

Amanda Baggs addresses the assumption and projection that often leads toward communication breakdown in *Autism, Speech, and Assistive Technology*:

“Maybe we can help you reduce any anxiety so you won’t have to rely on your keyboard.” That’s when any remaining ideas in my mind that this person was a real expert on autism fell apart. ... to me, my keyboard means freedom. I don’t “rely” on it – I use it so I don’t have to rely on my limited speaking abilities. ... And here, again, was someone trying to take this freedom away from me, under the assumption that if I could

... speak sometimes that I must always be able to speak, and that the only thing that could prevent me from speaking would be anxiety.

Autistics who can speak sometimes but not others are urged to speak all the time, and if they have difficulty when they do speak, that is ignored. ... I have a right to communicate in whatever means is possible for me to communicate.... And not only do I have that right, but I have the right to *choose* what means of communication is appropriate for me. ... I have rarely, if ever, been unhappy directly because of trouble speaking. I have quite often been unhappy because of not having those other options for communication.... And I am still unhappy to see that the first order of business for “helping” an autistic is so often to attempt to take those options away. (Bascom et al, 2012, pp. 320-323)

We would do well to remember these words from rhetorician and professor Melanie

Yergeau, regarding a population whose needs are largely ignored:

... most autistics are adults, despite what autism charities might have us believe. ... Many insurance companies will not cover adult assessment, as most states’ autism parity laws (if they even have them) only structure diagnostic coverage up to ages eighteen or twenty-one. ... county and state developmental disability agencies often require that one receive an official diagnosis prior to age twenty-one or twenty-two in order to receive vital services. (2018, pp. 163-165)

Ariane Zurcher, a parent to non-speaking activist Emma, had read that her daughter’s autism diagnosis was a fate worse than death. They were sold on a program with promises that she would be mainstreamed by kindergarten. When 40-hour weeks of ABA failed to break the 4 year old girl, the clinicians blamed Emma’s parents for the failure. When so-called recovery demands a complete restructuring of the autistic child’s environment, maybe we should be asking more questions like the one Ariane arrived at: “Why do we not use ABA for the neurotypical

population?” (Yergeau, 2018, p. 120). “... despite rampant objection on the part of autistic activists. The discourse surrounding ABA, however, is primarily controlled by researchers, therapists, and parents of autistic children” who stand in vehement opposition to the position of autistic allies adopted by the Zurchers (Yergeau, 2018, p. 147).

There’s a growing body of published work, including both personal accounts and scholarly research, on how the suppression of non-normative embodiments for the sake of compliance with standards of neuronormative performance ... does profound psychological harm to neurodivergent people and is strongly correlated with depression and suicidality. (Walker, 2021, p. 186)

Julia Bascom explains the requisite level of introspection that needs to be honored in service of this community quite passionately:

People with no voice of their own and no belief that a lifeskills kid could ever have anything to say are the gatekeepers of who gets listened to.... So you see, I’m supposed to teach writing, which is less a matter of direct instruction about commas and more a matter of facilitating practice in having a voice. Drawing is just looking, and singing is just hearing, and writing is just listening to your own voice. These kids need to be told, explicitly, repeatedly, *by at least one fucking person*, that they **have** voices, and they are valuable voices, and they deserve to be heard, and the first person they should want to listen to them is themselves. It takes practice. (2012, p. 297)

The alternative is accepting more of the silencing of young voices as well as what follows in an observation of one of the teachers in the school where Amanda Forest Vivian was an intern:

“James,” she said, “I know you’re upset. But what you’re doing with your hands looks silly.” This boy, all the tension in him being channeled into something harmless, something she had to look under the table to see. His tension was silly. His discomfort was an inconvenience. He was 8 or 9 years old. (Bascom et al, 2012, pp. 184-188)

Possibilities

Zoe Gross, in *Pedagogy of the Confused* (Bascom et al, 2012, pp. 313-314), offers relatable experience: “Learning about disability rights has empowered me to be in control of my education, to ask questions without shame, to sometimes try to change my environment instead of always trying to change myself.” It wasn’t until I had repeatedly read eerily familiar patterns in expression from various autistic people that I wielded any ability to use community wisdom to my own advantage. I had intuited the truth of it years ago, but to deeply understand the words “We don’t function very well in groups, let alone as groups. Autistic connections seem to be made on a person-to-person basis, one person at a time” was truly revealing (Bascom et al, 2012, p. 29). Imagine the effort wasted, and the stress endured, through decades of compliance with a social order demanding normative group participation which is directly at odds with one’s very existence.... I have leveraged this knowledge in building people networks since, and have noted much more resilient connections as a result.

With that success, and all the work leading up to it, I was able to let go of deep seated anger and process bound up grief. The fire in my belly still gets stoked by injustice, also resident is deep mourning of opportunity lost to closed minds or hearts through the years, and repeatedly triggered traumas frequently activate my sympathetic nervous system. Reasons for this experience, deeply layered and nuanced, despite my own effort to adhere to a sensory diet in avoidance of overload, continue to arrive as part of the forever unfolding that is my autistic life.

Walker, in *Autism and the Pathology Paradigm*, discusses the ways in which theories related to autism are enacted:

... autism-related professional and institutional praxis is overwhelmingly dominated by a focus on ‘fixing’ autistic persons ... at the expense of any significant focus on societal

acceptance of autism, accommodation of autistic needs, removal of systemic barriers to access and inclusion, or supporting autistic persons in thriving *as* autistic persons. ... Only a fundamental shift in the discourse – a shift from the pathology paradigm to the neurodiversity paradigm – is likely to create any substantial improvement in the realm of autism-related praxis. (2021, pp. 125-128)

I have come to believe that moving beyond the violence of normal is a minimum first step toward the liberation of neurodivergent bodyminds. Radical acceptance of atypical presence and discarding old tooling are required next steps, or we'll continue building the same destructive experiences (Walker, 2021, pp. 16-28). We must stop recognizing normal as a valid human diversity concept. Ari Ne'eman's words also remind us that we must plan for inclusion:

As the national conversation about autism has increased in tone and fervor, we who are the targets of this discussion have not been consulted. To those who believe in the motto of the disability rights movement – “Nothing About Us, Without Us!” – this situation has to change. (Bascom et al, 2012, pp. 88)

Connection with people previously thought to hold zero capacity for conversation becomes effortless in a well fit context. If we pair native neurodivergent speakers with those who struggle to adapt to neurotypical communication we see networks form and information flow. The father of a non-speaking autistic adult (in 1996) had this to say about his observations of the first Autreat (e.g. autistic retreat) a quarter century ago:

Here people who could paint and draw equally shared experiences with those who can't hold a pencil or a brush. People who are very articulate equally shared experiences and understood those who could only jump or clap their hands or point to letters on a letter board or a picture board to respond to a question. (Bascom et al, 2012, pp. 60-61)

I'd like to acknowledge that "ABA doesn't aim to offer neuroqueer children new repertoires of meaning. To smile isn't to signify one's contentment; it's to comply with a behavioral and prosocial demand" (Yergeau, 2018, p. 125). Conversion therapy has always been driven by manipulation on behalf of the comfort of those wielding power; there has been very little interest shown in the needs or undiscovered disabilities behind undesirable behavior. To honestly address discomfort surrounding neurodivergence we need to focus on the perils of passing:

... which include overwhelming stress, self-hatred, and loss of autistic identity and community. ... Judy Endow argues that nondisabled people wrongly assume theirs to be the natural sociality, effectively othering and quashing disabled means of communicating and knowing. ... Rachel Cohen-Rottenburg asserts that passing is an imitation borne of compliance, wherein "burnout [is] inevitable." (Yergeau, 2018, p. 194)

"Dependent can mean controlled by others. It can also mean requiring the support of others. None of us, of course, is independent in either sense" (Bascom et al, 2012, p. 81). I want to see the elimination of techniques condemned as torture by the United Nations on minor children, techniques like forcing them to carry backpacks containing electroshock equipment remotely triggered for infractions as minor as failing to touch one's nose on demand (Yergeau, 2018, p. 97). I want to ensure that people know disabled children have died from frequently used restraint and seclusion practices in public schools within the United States. I want everyone to know that "autism is a culture unto itself, a culture that is not only socially created as a disability but is a countersocial way of being, communing, and communicating" which is every bit as valid and varied as neurotypical culture (Yergeau, 2018, p. 108).

Conclusion

“Why is it important that people with disabilities talk for ourselves, and that we fight against that which is about us without us?” This question was asked by Ari Ne’eman while celebrating the 5th anniversary of creating the Autistic Self Advocacy Network. Perhaps it was in response to contemporary testimony citing autism as worse than cancer “because the person with autism has a normal life span” (Bascom et al, 2012, p. 98). Or perhaps a public service announcement comparing the odds of having an autistic child with one’s chances of being in a fatal car collision had something to do with that decision. Ari also provided an answer:

Even love, in the absence of empathy, can be harmful. When people that you talk about, or set policy on, or conduct research regarding, are not in the same room, even good people feel licensed to say horrible things. You cannot help people through pity and fear. (Bascom et al, 2012, p. 100)

Penni Winter wrote, “Autistic rights are disability rights, which are human rights” (Bascom et al, 2012, p. 122). I write from a personal perspective, as an autistic survivor of decades of abuse from self-described well-meaning individuals before ever realizing that I was a part of a culture constantly subjected to willful ignorance and hate crime. Forty years after my earliest memories I finally started confirming answers to the questions that had plagued me for the duration. I gained the ability to tell myself “maybe you function exactly as you ought to function, and that you just just live in a society that isn’t yet sufficiently enlightened to effectively accommodate and integrate people who function like you” (Walker, 2021, p. 28).

The pathology paradigm is nothing more than institutionalized bigotry masquerading as science. ... When we hear someone refer to autism as a “disorder” or “condition,” it

should instantly set off the same sort of alarm bells in our minds as hearing someone refer to homosexuality as a “disorder” or refer to a member of some specific ethnic group as “inferior.” (Walker, 2021, pp. 129-131)

Nobody in my life knew about neurodiversity. I had to learn these concepts on my own, which I accomplish(ed) through engaging in neurodivergent community despite possessing supposedly broken sociality. For this reason, the notion that the pursuit of “normalization instead of quality of life forces us into a struggle against ourselves” resonates deeply within my supposedly broken bodymind (Bascom et al, 2012, p. 91). In the essay *Loud Hands & Loud Voices*, Penni Winter uses words that might have spilled from my own pen. “This is not theoretical. I have spent decades of my own life straining to make myself over into that elusive ‘normal,’ and hating myself for not succeeding” (Bascom et al, 2012, p. 117).

Winter also wrote, “Many autists are busy to the point of stress simply surviving their own lives” (Bascom et al, 2012, p. 125). In considering challenges accessing support that acknowledged her own contributions, Amy Sequenzia shared that “Most of them never thought about asking us what could make our lives more productive, less anxious; or trying to understand a non-speaking autistic who has not yet found a way to communicate” (Bascom et al, 2012, p. 160). Her message is very similar to those from most of the publicly non-speaking participants I’ve encountered in community forums in their expression of lacking curiosity and compassionate outreach.

Autism is a genetically based human neurological variant. ... the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable. ... Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. ... autism has been frequently misconstrued as being essentially a set of ‘social and communication deficits,’ by those

who are unaware that the social challenges faced by autistic individuals are just by-products of the intense and chaotic nature of autistic sensory and cognitive experience. ... to describe autism as a disorder represents a value judgment rather than a scientific fact. (Walker, 2021, pp. 85-87)

Meg Evans notes that “as we work to create more opportunities in society for ourselves and our children, we are storytellers above all else” (Bascom et al, 2012, p. 166). Some of our most important stories touch into tragedy and heartache. Intersecting marginalizations deepen and complicate these emotions, and the stories attached to them. Every year in March there is an international day long vigil to mourn for those lost to filicide. I light and tend to a candle. I read aloud the names of those lost since the last time I held vigil. I have held that space by myself, knowing deep down that I am part of a global community whose voice is rising up.

Autism Speaks co-founder Suzanne Wright spoke before her death about a public health crisis: “We’re now playing catch-up as we try to stem the tide and ultimately eradicate autism for the sake of future generations” (Yergeau, 2018, p. 147). Sequenzia beautifully sums up a contrasting, much less eugenic, less hate crime inspiring, view:

If organizations like Autism Speaks were really thinking about us, they would stop spreading fear of autism and they would start talking to us, the only true experts on autism. ... They waste their energy trying to fix what is not broken, what is simply different. And the autistic individuals are silenced.... They don’t have the insight, the expertise and ultimately, the right to direct the conversation about autism. This right belongs to us and we are the only ones who can decide who our allies are, who can speak on our behalf. (Bascom et al, 2012, pp. 275-278)

As one with an incredible affinity for pattern recognition, one who frequently engages in the ecstatic expression of embodied rhetorics, one who is perpetually unlearning internalized

ableism, and one who still on occasion gets called things like moron, it brings me great joy to recognize the progression of thought over time in the final three echoes chosen for this missive. I see the awesome possibility in making this knowledge commonplace, the possibility resident within leaving normal behind, in embracing perpetual angst on a learning edge where unique therapeutic relationships are built and thrive with each individual seeking help.

These voices may not be my voice, but they are most certainly our voice, the neuroqueer, the neurodivergent, the autistic. I implore you, take time to sit with these ideas, and sit with any discomfort that unfolds, and engage respectfully and thoughtfully with neurodivergent wisdom. Many futures depend on your own repetition of these echoes....

“Recognize that nearly everything written or taught about neurodivergence by neurotypical ‘experts’ is just plain wrong, and is harmful to your autistic clients” (Walker, 2021, p. 140). “In disclosing autism, we are both too autistic and not autistic enough, variously called fakers, whiners, retards, and mindblind” (Yergeau, 2018, p. 139). “We are no longer asking for charity. We are demanding our rights” (Bascom et al, 2012, p. 103). *Nihil de nobis sine nobis.*

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