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The Autism Sonnets: Explaining Myself to Myself

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Abstract

In this paper, I explore my autistic identity through poetry. I briefly explain the medical model of autism, diagnosed as a disorder through the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, highlighting the amygdala as a brain structure that is particularly affected by autism. I outline my writing process for this project and offer suggestions for practitioners or other autistic writers. I then present a collection of sonnets where I problematize the deficit-based pathologizing of autism in the *DSM-5*, contrasting it with the social model of disability. I conclude with my ambivalence toward getting a medical diagnosis.

Keywords: autistic, autism spectrum disorder, neurodiversity, social model of disability, therapeutic writing

Introduction

Over the past 15 years, I have slowly come to understand myself as autistic.[1] The more I work as a special education teacher and the more I socialize with autistic people, the more comfortable I am with this conclusion. This project explores my autistic identity, my rejection of the medical pathologizing of autism, and my ambivalence toward pursuing a medical diagnosis.

Autism is considered a pervasive developmental disability, causing 'significant social, communication and behavioural challenges' (CDC, 2020a). It is perhaps most seen to impact the ability to develop

relationships with other people because of a perceived lack of social skills, antisocial or aggressive behaviours, and fixated interests. Once thought to be relatively rare, autism is now diagnosed in roughly one in 54 people (CDC, 2020b), although this varies by jurisdiction. The primary vehicle for diagnosis of autism is the American Psychiatric Association (APA) 2013 publication, the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. The criteria for autism spectrum disorder in the *DSM-5* were revised from its predecessor to encompass 'classic' autism, as well as other related developmental disorders, such as Asperger's syndrome. This revision has not been without criticism, particularly in that its criteria may lead to under- or overdiagnosis (Wing et al., 2011; Singer, 2012; Sweet & Decoteau, 2018).

Autism is a complex condition, affecting all domains, and it would take a lifetime to discuss all relevant aspects. I want to highlight, however, one particular brain area: the amygdala. This organ, which functions as a site of 'translation' among the sensorimotor, affective, and cognitive domains, consistently shows unusual patterns of activity in autistic people (Berger, 2012, p. 3). We often have difficulty making sense of emotions or sensations, conflating the two, and showing a heightened rate of synaesthesia (van Leeuwen et al., 2020, p. 10), a condition in which sensory information is processed with a sense other than the one typically engaged (e.g., tasting colours).

Allman et al. (2005) posit a difficulty with intuition in autistic people, particularly in social situations (p. 372). Although I know I am unaware of much of the subtle nonverbal communication around me, I realize that as I retune in to my body and my writing, if I write about my body sensations, my 'Spidey senses' are activated: I can feel my stomach start to knot, my sternum begin to tighten, the soles of my feet tingle as though they were on a roller coaster, or my heartbeat begin to elevate. Probing the connection between these sensations and the life circumstances I am writing about, I can understand when a situation is or is not good for me—a relationship, a job, a plan. Making these specific connections in my daily writing has allowed me to understand my sensations as intuition, another function for which the amygdala seems to be at least partly responsible (Lieberman et al., 2004, p. 424).

My daily writing practice has allowed me to be more fully aware of the sensations of my body, to disentangle sensation from emotion, and emotion from cognition, and to process the three domains in a more coherent manner. In this way, writing has taken over the job that my

amygdala is not capable of doing. To untangle the domains, I use Metcalf's (2008) proprioceptive writing technique. Using her proprioceptive question (What do I mean by….?), I interrogate my thoughts, labelling them as accurately as possible and thereby differentiate between my sensations, emotions, and thoughts, simultaneously differentiating my memories from my current situation. After this analysis work is done, writing poetry allows me to reintegrate the domains again, but without the chaos of the original thought patterns.

I often begin with K. Jane Watt's contemplative practice of writing, a method that includes a timed portion of making meaningless doodles on the page, engaging the brain with the sensorimotor act of writing before beginning to write. When my initial draft is complete, I examine what I've written to see where I am (Fox, 1997, p. 134) and how I can revise it to express myself more completely, and, importantly, within an organizing schema that allows my thought pattens to be calm and truthful. I begin with form: If, for example, there a change worthy of a volta, I may turn the free verse into a sonnet. If there is a line that repeats or is worthy of repetition, I might instead choose a villanelle. I then look at devices: The delineation between an emotion and a sensation often brings out a metaphor. If it does, I will use it, refine it, extend it. If I can hear a rhythm in the words that expresses an emotion, that will become my meter.

Ethical and Practical Considerations for Practitioners

It is important to note that autistic people are not a monolith—autism is a cluster of behavioural descriptors, each of which can be present in varying degrees. This is an important consideration for practitioners: It is common to assume that nearly everyone is neurotypical and to accommodate autistic people on a case-by-case basis. This is not truly inclusive practice; in any group, there is a high likelihood that there will be at least one autistic person (diagnosed or not), and with such varying needs, universal access points are necessary. These can be beneficial to all participants, not only those with autism. As our understanding of autism evolves, practitioners should keep current with new strategies for inclusion.

Many autistic people find it comforting to know what to expect. An agenda of a course or seminar is very helpful for us, even if the agenda is not precise. I do not necessarily need to know what time everything will happen, but it is great to know what the order will be. The agenda can be

changed if necessary, but a little warning in order to get used to the idea is appreciated. Having a clear idea of the expectations of either the process or the product is equally helpful.

This also applies to the structure of writing. I've been reading sonnets for thirty years, and it was partially for that reason—familiarity and structure—that I chose to write sonnets for this project. I am familiar with other poetic forms, but using them would feel more risky. In a therapeutic writing setting, a universal access point might be to remind participants of some more common forms and allow them free choice. For me, and for many autistic people, having the structure of a sonnet to rely on is much less scary than the vagueness of free verse.

Something to note during the writing itself is that it can be difficult for autistic people to label emotions. This can also be true for people who've experienced trauma, people with ADHD or reactive attachment disorder, or people with intellectual disabilities, among others. They may need help to analyse what feeling words actually refer to. I am sometimes surprised to find in my own writing that when I write 'I'm sad,' for example, I may mean that I am actually happy but tired, or that I am happy but believe the happiness won't last. The proprioceptive question (Metcalf, 2008), What do I mean by …? is a powerful tool for understanding my own emotions and can be a tool for practitioners to use with clients, as long as they first clearly explain the question's use—unexplained, it may seem too much like an interrogation or critique.

And finally, the therapeutic environment should be considered. Sensitivity to quick or unexpected movement, harsh lighting, or chaotic or loud noise is quite common for both autistic and neurotypical people, and can be accommodated quite easily in most settings. A variety of seating options can help with sensory processing difficulties, and the option to write using different media (pencils, crayons, computers) can be helpful as well. In a group setting, it is also very important for autistic people to have social demands lowered. Many people still insist on eye contact as a demonstration of manners; this can be a very unnerving formality for autistic people. Many seminars have unstructured time to get to know other participants, which can cause real panic in autistic people. A structured ice-breaker activity is much better and allows anyone to make connections.

The Autism Sonnets

I wrote the original version of this paper, and these sonnets, over two months as my final project in an Athabasca University course, *MAIS 621 Narrative Possibilities: The Transformative Power of Writing, Story, and Poetry in Personal and Professional Development* (Lengelle, 2018), which featured topics such as the therapeutic potential of poetry and writing in health care settings. In this project, for each criterion of autism spectrum disorder listed in the *DSM-5*, I have written a poem and a reflection. I have chosen to use blank verse sonnets as a compromise between autistic and artistic sensibilities: the sonnet format gives me structure and routine, but the blank verse affords me flexibility.

Criterion A: Persistent Deficits in Social Communication and Social Interaction Across Multiple Contexts (APA, 2013)

In this poem, I describe having realized that I broke an unwritten rule earlier in the day, too late to change my behaviour or apologize. I use repetition to demonstrate my rumination. I break the rhythm twice: in line nine, to emphasize the imperative and express frustration, and line fourteen, to draw attention to the missing repetition as I break out of the rumination.

Playing School

I wake up in the night with stomach cramps.
With stomach cramps and sweat and kicking legs.
I finally understand there was a rule.
A rule I didn't know about that day.
Unspoken rules for them to build a wall;
A wall that traps me outside and away.
Belonging is a role I try to play;
I play but don't succeed when I'm with them.

Tell me the rules, at least let me decide!
Let me decide to close my eyes or not.
But don't make me the one who doesn't know
Who doesn't know the punchline of the joke.
When we played school in my old neighbourhood,
I was the principal; the rules were mine.

Autistic people want relationships. We feel empathy. We are able to love and be loved (Muller et al., 2008, p.188; Crompton et al., 2020, p. 1438). The difficulty is that social rules neurotypical people take in

stride are unspoken and context dependent, causing anxiety in many autistic people: 'If I know what the rules are, I can belong, instead of just pretending to belong. Not knowing the rules is like when everyone knows a secret except for you—it's terrible' (Moores, 2020).

This criterion is clearly written through the lens of the medical model of disability: a deficit-based model, where disability is centred within an individual who needs to be cured in order to function in the social world without impairment (Goering, 2015). For autistic people, the cure is to change our behaviour.

The social model of disability posits that the differences in communication and interaction are deficits *only because barriers exist in the environment* (Inclusion London, 2021). A social model understanding of autism might address behavioural change in the person, but also looks at adapting the social environment. Muller et al. (2008) note that although the autistic participants in their study 'described deliberate efforts to improve personal relationships' (p. 181), they also advocated for social supports, such as structured social activities, explicit communication, instruction in the use of social cues, and opportunities for coping with social stress (pp. 181–184).

As more autistic people become involved in autism research (Kapp, 2019) and become active in the disability rights movement (Krcek, 2013, pp. 11–13), the tension between these two models continues to grow. The power, however, remains with neurotypical researchers and the historic inertia behind the medical model of disability that has pervaded our understanding of autism—and of disability in general (Areheart, 2008, pp. 180–181).

Criterion A1: Deficits in social–emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions (APA, 2013)

In this poem, I describe a typical school staff room, complete with cliques, territories and bullies. I disrupt the meter, adding a 'damn' when I find I am out of sync with the group, and doubling the unstressed syllables 'if you' as I rush to catch up with the conversation.

The Staff Room

If you sneak up on them from the side, you might –
Damn. They're crowded chair to chair already close.

Renee's tight smile and Paula's pale blue eyes
There's nowhere you can sneak, you'll have to hover.
If you hover quietly waiting for your turn –
Damn. They're speaking over, rushing for attention.
Andrea's laugh and Martin's raving tales.
There's no turn-taking here, they don't need it.

If you signal with a look, a smile, a nod –
Damn. They've all already chosen smiling partners
They look toward the loudest or the funniest
There are no looks left for you, I'm afraid.
If you write an email, they will reply all.
But they won't email you, or speak, or call.

As a special education teacher, I have written dozens of education plans for kids with autism, most involving conversation skills. The number of moving parts in a conversation is unbelievable: words, body language and tone of voice, relationship and relative status of the speakers, the environment they're in, the recent and non-recent pasts of each speaker, their individual levels of alertness. Each one influences the interaction (Muller et al., 2008, p. 179). It is true for a conversation between strangers at a checkout and between partners at the kitchen table.

The real problem is communication style. Dekker (n. d.) points out that autistic people tend to converse with a different rhythm, less nonverbal communication, and more direct and literal messaging than neurotypical people. Unfortunately, although the cross-communication is mutual, the consequences of the different communication styles are lopsided: autistic people are often seen as more egocentric, and neurotypical people believe themselves to be more helpful than they actually are in social interactions (Crompton et al., 2020, p. 1445).

> ***Criterion A2: Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication (APA, 2013)***

This poem is based on a memory I have without context. I remember the physiological and emotional experience, but I have no idea where I was, or who looked me in the eyes. I use enjambment to demonstrate the racing thoughts that accompany the shock of unexpected eye contact. In the

sestet, I move on to end-stopped lines, more clipped and matter-of-fact, and more confined to the rules I have taught myself.

The Best Defence

At times, when you are happy sitting at
Your desk, and working, you don't notice
The eyes heading your way, to catch you with
Two laser beams, two sheets of lighting that
Will burn the fingers of your brain. The pain
Is as ethereal as the blank spot
Beneath a fire, as complex as the cruelty
Of people you had thought that you could trust.

I wish my left could look into your right,
My right into your left at the same time.
The laser beams should go straight eye to eye,
Into our brains for perfect understanding.
It's better if you start it before them;
The trick is look them right between the eyes.

Eye contact is a peculiar phenomenon. It activates mirror neurons (neurons responding to another person's actions or emotions), facilitating social behaviour (Iacoboni, 2008, p. 654). However, eye contact can also be a threat signal (Harrod et al., 2020; Ellsworth & Carlsmith, 1973, p. 280). Avoidance of eye contact is common in hypervigilant states (Schneier et al., 2011, p. 85). Interestingly, autistic people who are experiencing eye contact show hyperarousal of the amygdala (Dalton et al., 2005, p. 519), the same process by which traumatic memories are created (MacCurdy, 2000, p. 163). Trevisan et al. (2017) did a qualitative study on the effect of eye contact on people with autism and found themes of fear, physical pain, violation, intimacy, and strategies to manufacture appropriate eye contact or response to eye contact from others.

I remember so clearly the process of teaching myself how to make eye contact in grade two. It was a puzzle, but I had to do it; according to TV, it was the only way people could know when I was telling the truth. I became so conscious of eye contact that it is still in my thoughts when I am having important conversations.

Criterion A3: Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing

imaginative play or in making friends; to absence of interest in peers (APA, 2013)

I wrote this poem about mistaking reciprocal relationships as being transactional. It is a sequence of situations causing the least to the most anxiety.

What Everyone Else Knows

I love the clarity of Christmas giving –
Not buying—buying has its traps because
If you don't know them, then your gift will fail
And gift cards are just handing someone cash.
At work, we have a Sunshine Club, with rules:
No contribution, you won't get a gift
And big things happen by surprise, so it's
A bit less orderly than one-for-one.

But love—is love a present? I don't know –
You don't know when you'll need to take it back.
It hurts to give too much, to give too little,
And where's the line between the different types?
And when do you bring flowers to a dinner?
And when do you buy drinks for the whole group?

I have never met an autistic person who does not like people. We just have difficulty showing it. Sensory processing issues are a major component of autism; it is hard to converse if you have a lot of interesting things bombarding your senses (Kojovic et al., 2019, p. 10). Combined with the difficulty with social thinking and gaze avoidance, it can appear as though we are not interested in peers, but it just is not true.

I can, with difficulty, understand my feelings. Perspective-taking makes understanding relationships much harder. If I do, generally the terms of my understanding are simplistic and transactional—although recently, in my daily writing practice, I was able to say 'I am worthy of love. I mean that even if I go on to nothing "more" in my life, I have done enough, accomplished enough, have intrinsic value' (Moores, 2020). I proudly made this revelation to a person who is not autistic. His response was, 'Yes, and?'

Criterion B: Restricted, Repetitive Patterns of Behaviour, Interests, or Activities, as Manifested by at Least Two of the Following, Currently or by History (APA, 2013)

In this poem, I use the octave to describe the experience of learning about the bricklayer's quotidian passion, and the world of his passion being opened to me. In the sestet, I use many quicker, sharper images of worlds I have not been invited into, but which I know are socially acceptable (if only on the fringes). I finish by inviting the reader into my world.

Beauty in Brick

When you and I, in love, hitchhiked to Dover
The bricklayer picked us up (he called us sweet),
He pointed at a perfect herringbone –
Proud and shy at once that it was his.
Since then, I've looked at bricks to spot the pattern
(The blandest secret beauty there could be)
I imagine no one knows that it exists
In plain sight, just bricklayers, and you and I.

Craft beer, fedoras, adult colouring books,
Slanty sharp hair, cartoon clothing, furries,
Tattoos and unicycles, moustache wax,
Are hipsters of us, or just mocking us?
I have a special interest, a bland beauty:
If I'm in charge, the schedule will be perfect.

Elite performers practice the same sport or instrument for hours each day. A chef creates and recreates the perfect dish fifty times in an evening. It would be dishonest to pretend that I do not understand that there is a difference between my special interest and theirs. Like most autistic people who navigate more or less successfully through society, I know what things I need to hide from the neurotypical people around me (Parish-Morris, 2019). If I were to talk about all the schedules and timetables I have made for work and pleasure, they would not praise the attention I put into my craft. They would call me weird. The definition eludes me.

Criterion B1: Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases) (APA, 2013)

In this poem, I describe two aspects of my childhood experiences of writing: the creative and the technical. In the octave, I use enjambment and

run-ons to simulate the sensory excitement I felt at the time. The special attention to hands and feet, with their enormous number of nerve endings, gives precedence to the sensory aspect of autism.

Hands and Feet

Miss May sees through my weird into my gold;
She takes me to the library to write
A book! To celebrate, I scream and make
The special feeling when I claw my hands
My heart jumps and there's pleasure in my veins
The big kids see the weird but it's so good
So painful and so tiring I can't do it
As often as I want to any more.

My feet are different, tingly on the bottom
When I'm up high and nothing down below
Like sitting on a cliff with a strong wind
It climbs up to my stomach, small but big.
And sometimes my feet move, and I will find
My toes are tracing out

my name –

or

'help.'

Stereotypy is the classic autistic behaviour: lining toys up, playing with a fidget spinner, flapping arms (McConkey et al., 2009). I've done all those things, especially as a child, and most especially lining things up.

Baron-Cohen (2006) posits the idea of hyper-systemising: Autistic people seek to understand the world through fitting components into a system. According to Baron-Cohen, different systems have different degrees of predictability, which he characterized as percentages on the 'lawful' continuum. He uses the example of a light switch as being 100% lawful: when you flip it, the light turns on every time. Lining up toys is a systemizing behaviour. Social systems are much less lawful, and therefore less predictable.

My favourite toys as a child were Garfield figurines. I would line them up, trying to put them in order of most to least favourite. Most to least favourite of inanimate objects—and even concepts—was and remains a big deal for me. This type of anthropomorphism is more common in autistic people than neurotypicals (White & Remington, 2018, p. 2), and while it is generally a calming and pleasant experience (p. 7), it can cause stress

(Negri et al., 2019, p. 293), as it does when I feel guilty for not liking every object the same amount.

As I am right-handed, the right side was my favourite for a while after I understood the difference between right and left. One day, though, I started to feel guilty, as though I were hurting the left side's feelings, so I changed favourites. I then felt guilty again, and also a bit resentful—the right side, after all, was my real favourite. I decided that the fairest way to handle it was to switch favourite sides every few months. One day Mom explained to me that Uncle Ron was her half-brother. When I asked what that meant, she joked, 'It means this side (pointing at Uncle Ron's left) is my brother and this side (pointing at his right) isn't.' I said, relieved, 'Good, that's the side that's my favourite right now.'

An anthropomorphised system becomes more social (therefore less lawful), and deciphering my own feelings is hard. In my line-ups, the toys in the middle of the line were trickier to place. I had to line them up over and over to get it right. I also felt guilty about not being fair to the ones that were not my favourites. I still collect and order things, but now I use Marie Kondo's (2014) question (Does it spark joy?) with everything I own and categorize by more objective criteria—my books are all my favourites and are organized by colour, for example.

Stereotypy helped me to understand unusual occurrences in my life. One day, my grade one teacher changed all of our desks around. From that day on, I would make desks out of paper and arrange the Garfield toys at them. Then I would say, 'We have to switch classrooms,' move to a different spot, and arrange everything again. As a teacher, I still love arranging desks, although planning it on paper is the fun part—carrying it out is not the point. The point is the ritual, its endless permutations, and the flow state it inspires (Milton, 2017).

Physical stereotypy is less about the ritual and more about the sensory experience. The claw hands are a way I figured out as a child to release (I think) adrenaline into my bloodstream. It feels like a jolt of intense pleasure and slight anxiety at the same time, and I can feel it course through my body. I eventually learned to do it without clawing my hands, just by internally making a little release. This way, I can control whether it starts in my arms or in my torso. It leaves me feeling wiped out.

I used to lie on my bed making schedules and find my feet writing words on the wall. It was unconscious, just writing my name over and over. I wonder now if it was an unconscious use of language to integrate my

identity with my body. One day when I was a teenager, I realized it was not my name I was writing, but *help*. Soon after, I moved away from the turbulent life of my mother and stepfather to live with my father and stepmother. I stopped writing *help* after that.

> ***Criterion B2: Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat the same food every day) (APA, 2013)***

Many of my early childhood memories are of terrible novel experiences: too many forks in a fancy restaurant, not knowing how to eat a lobster, freezing on the bus because I was not used to ringing a bell to signal that I wanted to get off; even now trying to figure out a new public transportation system is awful for me—not the subway maps and bus schedules (those are lovely), but figuring out how to pay my fare. In this poem, I write about these horrifying situations.

In the fourth line of the sestet, I break out from the blank verse to show the escalating anxiety of having to face something scary in order to avoid something scarier before returning to the comforting rhythm in the end.

I Don't Pretend that Travelling Alone Is Fun Anymore

I've learned that if there are too many forks
To stop myself from crying, and to stay.
The restaurant will often post a menu
Outside, and if they don't, I'll look online.
But it is hard and sometimes I'll just find
The Keg, although the food is just all right.
It's worth it for the rest of knowing what
Is coming. Dinner should be comforting.

I've learned to watch the people on the platform
To see the rules of paying fares and lines
And if I have to, I can be so brave

If that's the only way to see you in New Jersey on New Year's Eve, even if the bus is empty and I am so afraid and empty and lost and you seem to be so far away so far away

What will I do when you're not there to show me
How to eat and how to take the bus?

There is a particular binary in our culture that I find troubling. On one hand, adulthood is presented as achieving financial and housing independence (Hoolachan et al., 2017, p. 65); on the other hand, our media celebrates mavericks and dreamers who prioritize emotional success. Prioritizing a stable job and home is portrayed as a failure of self, leading to midlife crisis (Freund & Ritter, 2009; Hermans & Oles, 1999); maturity is presented as a function of disappointment and lack of energy to have adventures into the unknown every day.

Daily adventures in the unknown sound horrible to me. There is nothing better than knowing what I am going to be doing today. I pre-game restaurant menus, I mentally rehearse conversations, and I live in a beautiful rut. Not that I cannot break out of the rut with enjoyment; I just need a bit of mental rehearsal and a lot of warning.

Criterion B3: Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest) (APA, 2013)

If You Asked One Hundred Autistic People

'What is your special interest?', you would see
One hundred soft and crooked secret smiles,
Two hundred warm and sparkling wrinkled eyes,
Some flapping arms, some jumping legs, some still.
With sensitive equipment, you would find
No more than six thousand peaceful happy beats
Of hearts, in bodies soft with relaxed joy;
Relaxed excitement cannot be contained.

You couldn't see the billions of lives made
Utopian, poor neurotypical!
Increasing boundless universes jumping
The everything and nothing of perfection
The joyful permutations of our search
And easy grasp of wonder in our minds.

Perseverative interests and self-stimulatory activities often appear on autistic children's education plans as something to be extinguished. When I was entering the field of special education, there was a belief that if we could get rid of the behaviours, we could get rid of the autism—always taken for granted as the underlying goal. This belief persists, despite criticism from autistic and neurotypical researchers (Rosenblatt, 2018;

Lacruz-Perez et al., 2021). In other circles, however, perseverative interests are now known as 'special interests' (Koenig & Williams, 2017, p. 2), and perspective on their functionality has shifted (p. 8).

We have recently become aware of girls being underdiagnosed for autism, in part because they 'often have more age-appropriate interests, such as dolls, horses or princesses' (Volkers, 2018). More normative special interest topics unintentionally assist in what is known as social camouflage, the masking of autistic traits in neurotypical environments (Milner et al., 2019). Camouflage can also be intentional, as in the case of teaching oneself to make eye contact. This 'appropriateness' of interests is not only a factor for identifying autistic girls and women: How many birdwatchers or train spotters may be exhibiting autistic special interests (Swift, 2013)?

> ***Criterion B4: Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement) (APA, 2013)***

In this poem, I contrast two anxiety responses, mine and my ex-husband's, as well as two of my sensory responses. I use short, lurching phrases in the octave, demonstrating the sensation of airplane turbulence, to which I respond with pleasure and excitement. At the same time, my ex has anxiety from lack of control over the environment. In the sestet, he asserts his control over his social environment, causing an anxiety reaction in the same part of my body where I felt elation earlier.

Turbulence

Without a warning, while they serve the meals –
I have my water, wine, tomato juice;
You have your diet coke, your magazines –
A roller coaster bump, my eyes light up.
I see your fear; my stomach feels such joy –
Another roller coaster bump, I laugh –
I try to hold on to three things at once.
Unfortunately, it's the wine that spills.

Without a warning, when you're feeling bored –
You turn on your approval until we need it –
You make my stomach scared, and then you soothe;
It magnifies my gratitude for peace.

I like my turbulence better, but I have learned
To live with yours, a stranger kind of joy

I find it fascinating that sensory processing differences were excluded from the *DSM* until the fifth edition. For me, the sensorimotor aspects are fundamental to my autism.

Sensory behaviours are classified as *seeking* and *avoiding*, both of which can interfere with social interactions. Hilton et al. (2007, p. 170) note that autistic people often avoid interactions that are too overwhelming (too noisy, too much light), or are distracted from interactions by seeking sensory input (staring at a patterned shirt, smelling perfume). These seeking/avoiding behaviours also impact executive functioning skills, such as inhibition control and decision making (Pastor-Cerezuela et al., 2020, p. 20).

Autistic people tend to go into a state of physiological arousal easily, are diagnosed with anxiety disorders at a higher rate than the general population, and are more likely to have extreme reactions to anxiety, all connected with the amygdala (Theoharides et al., 2019, p. 1). One way that autistic people manage anxiety is by managing sensory input, through self-isolation or sensory breaks (Fricker, 2020, p. 19).

Criterion C: Symptoms Must Be Present in the Early Developmental Period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life) (APA, 2013)

In this poem, I use a third-person description of my younger self, creating distance between me and my past, and a closeness between my current self and the reader.

My Living Room

That little boy is staring at the carpet
Not touching it, the weave is just too rough
But staring, at the shapes made by the pattern
The shapes are countries, continents, a world.
He doesn't understand that different countries
Have different ways of doing things from his.
Imagining is hard, so he can't see
Scenes in his mind, just reruns of his life.

Picturing that carpet in my mind
Is the nearest to heaven I think I can get
I feel at one with everything I've known
I feel no need to know anything else.
Love, when I leave the world for good, I hope
The room has ugly carpeting and you.

In my childhood, Barry Levinson's 1988 film *Rain Man* was really the only popular culture reference to autism. My father, a special education teacher, had some experience with autism, but not much—his specialty was intellectual disabilities. Both of my parents had suffered intense trauma, had had adverse interactions with the health and education systems, were of lower socioeconomic status—they lacked all factors more likely to result in a younger diagnosis of autism (Daniels & Mandell, 2014).

Many autistic children with comparatively good communication and adaptive skills are diagnosed either late or not at all (Cane, 2015 p. 22–23). Parents are able to coach children into camouflaging: I can remember (with knots in my stomach) the awful instances of my mother sitting me down and explaining 'the rules of our society' to me.

Criterion D: Symptoms Cause Clinically Significant Impairment in Social, Occupational, or Other Important Areas of Current Functioning (APA, 2013)

After twelve years together, I discovered that my husband had been having affairs and siphoning off money since the very beginning. Unfortunately, this is not uncommon. In a 2020 qualitative analysis, Pearson et al. point out several themes that make this type of abuse more likely to occur in relationships with autistic people (p. 17): compliance, expectation of non-reciprocal relationships, gaslighting, being overly trusting, and missing out on social cues that might indicate manipulation, among others (pp. 14–15). The breakup of this relationship, described in this poem, was a sad turning point, when I began to be more sensitive to cognitive dissonance.

Burnout

It took me longer, in the end, as usual –
I'm smart, but dumb, as Jordan used to say –
But on the day that I found my first lie,
And ran away from you, into the dirt,
My chest a box of fire being crushed with panic,
Something changed within me, finally.

I'll never live with lies that make me sick;
Not about love, and not about anything.

So, thanks, I guess, for this two-sided gift,
It wasn't on my list, but now it is.
I'd rather be alone in my apartment,
My stomach warm and calm with honesty,
Than out there where the world is living lies
And angry at me for my silent truth.

There is a dark side to camouflage: autistic burnout, the depression-like syndrome that comes from expending an inordinate amount of emotional energy on camouflage (Mandy, 2019), minority stress (Botha & Frost, 2018) and life stressors (Raymaker et al., 2020).

For me, autistic burnout comes directly from the cognitive dissonance that is present when rules and behaviour do not make sense, and camouflaging becomes impossible. I understand rules like 'Don't shout fire in a crowded theatre,' and complying with them is completely reasonable to me (I did have to be explicitly taught, though—through a bizarre set of life circumstances, I once did shout fire in a crowded theatre, and I literally laugh now when remembering the stage manager's gentle reminder that this was probably an unwise practice).

Then there are the rules like 'Don't wear hats in school.' It is this kind of rule that keeps me awake at night ruminating. It is illogical, unfair, tramples on freedoms of expression and religion, and I am expected to enforce it with my students. It is stressful. Kapp (2016) points out that an enhanced sense of fairness and a difficulty in perspective-taking create difficulty in moral reasoning for autistic people (p. ii).

Finally, there are rules such as the current ones of the COVID-19 crisis: Social distancing and mask wearing will make us safer. I am happy to follow these rules, both for my own safety and as a pro-social gesture toward more vulnerable people. They are the perfect rules to me: logical, low-cost, high-reward. It infuriates me that they are not followed, are not enforced, and are actively fought against. Fear of COVID-19 is not what gives me anxiety; it is the illogic of not following the rules (Senland & Higgins-D'Alessandro, 2016, p. 3097).

Criterion E: These Disturbances Are Not Better Explained by Intellectual Disability (intellectual developmental disorder) or Global Developmental Delay (APA, 2013)

I structure this poem as a dialogue between me and my mother. In the final line, I break the rhythm to something less forced, as I find myself feeling at home with my autistic friend.

They're Jealous

'I don't think they like me too much, mom.'
'Remember you're alone because you're smart.
You'll be a writer or a scientist.'
'I don't feel alone, mom, I feel fine.
Why do they talk about things that don't matter?'
'Remember you're alone because you're smart.
You don't need sports, you'll get an A in math.'
'I don't feel alone, mom, I feel fine.'

'Why is it hard to find someone to love?'
'Remember you're alone because you're gay.
You'll find someone, you just have smaller chances.'
'It's not that I feel sad, I'm just alone.
Except when I'm at Bettie's house for coffee,
Watching TV, laughing in the soft light.'

I tested as gifted in grade three. It was not surprising; my mother was incredibly gifted, and my father moderately so. My brothers and I landed right about in the middle of them IQ-wise.

There is a prevailing myth that gifted people, especially gifted children, have poor social skills (Galloway & Porath, 1997, p. 118). It certainly relieved my parents—finally an explanation. Mom told me that the other kids would be jealous, thus satisfactorily explaining my friendlessness (though not my brothers' popularity), and that was that. I skipped grade five and assumed that my lack of friends was a combination of peer jealousy and being a year younger.

I lived under that assumption until my first educational psychology course, when the professor astonished me by explaining that gifted kids actually tend to have better social skills than typical kids (see Pontes de Franca Freitas et al., 2014; Galloway & Porath, 1997, for example). I was further astonished to discover that acceleration is nearly uniformly a socially positive experience for gifted kids (Assouline et al., 2015, p. 59).

As a lot of the bullying had been about my gender presentation and sexual orientation, after I came out, I shifted the explanation to my being gay; but I never really fit into the queer community, and I had similarly terrible social skills at clubs, when dating, when married…. And frankly, most of the gay people I know, intelligent or not, also find me peculiar.

Severity Level:
Level 3: Requiring Very Substantial Support
Level 2: Requiring Substantial Support
Level 1: Requiring Support (APA, 2013)

Choir

This song is sung so strangely, in the dark.
The singers are divided into rooms.
How can we sing together without hearing
The other voices making up the choir?
I guess they find it easier recording
Separately, then putting it together
Unwanted noise is edited away
It's just the voices they want to put in.

It's pale, this sound, it's not what it could be,
Conducted by a person we don't know
Our voiceless voices straining in our rooms
More like an echo than a melody
If the echo's the only song we're allowed,
I don't want it; I don't want to sing.

If I had to narrow down my opposition to the medical model of autism diagnosis to one thing, it would be this chart. When we describe levels of severity, there is a judgement being made. Even when we talk about something not being severe, we are viewing it with a negative lens. No one talks about severe giftedness or says that someone is not severely gifted; giftedness is something that we want. To be a person with autism is to be diagnosed with a mental disorder. Following the diagnosis, the disordered are split into levels of disorder. Autism is something that we hate, fear, are disgusted by, pity.

In my research for this paper, it was always the articles written by autistic people, with research that included autistic voices, that resonated for me. Neurotypical researchers divide us by levels of functioning,

interpret our behaviour in terms of obtaining goals, describe us as having no empathy nor need for love. In this poem, I use the metaphor of a divided and silent choir, being conducted by someone from the outside. The conductor chooses whose voices matter and whose can be silenced for the good of the song. I call into question the validity of the song itself.

And there is my diagnosis dilemma. I believe my way of being and thinking and behaving and interacting in my world are described well by autism. It explains myself to myself in a way that makes me feel comfortable and satisfied. It brings me joy. Maybe an assessment would confirm it; maybe not. I want a diagnosis because I want an expert to confirm my feelings. I do not want a diagnosis because I do not want to have to rely on an expert to confirm my self-knowledge.

But mainly I do not want a diagnosis because I am not ill.

Notes

1. Autism is what I would consider a core identity schema; it is not an aspect of the self that can be separated from the self and leave the identity intact. In this way, it is similar to gender identity, sexual orientation, cultural or racial identity. For that reason, I avoid using 'person first' terminology (i.e., person with autism) unless in direct quotation.

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