

Queering Autism: Heteronormative Barriers to Autism Identification

by

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Abstract

Autistic people are everywhere and not limited by any intersection including race, religion, country or culture. Many of us experience social oppression and disadvantage. In this autoethnography, I explore some of my experiences navigating being “different”, even in today’s culture. This analysis highlights key areas where culture can have a negative impact on autistic people. From a transfeminist disability studies framework, utilizing queer theory and the neurodiversity paradigm, I explore the positive impacts of queering autism within my own life. Through personal accounts of queering, I highlight how some heteronormative barriers can be reduced in one’s personal life, with the potential also to be applied more broadly within culture. Implications of queering autism broadly include an application within the medical and psychological fields and government autism program changes. Utilizing autoethnographic accounts and stories from within my community, I discuss the barriers to autism identification among those with numerous identities that do not align with stereotypical white cis male-centred autism concepts within culture that have also had impacted me throughout my lifespan. The stories told advocate for inclusive research and increased funding to share the stories of marginalized voices, policy changes and community education initiatives. I conclude with the importance of queering autism to increase access to autism self-identity, particularly among autistic people who are not cisgender males.

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Chapter One: Introduction

Overview

Just over four years ago, I stumbled onto a video of storytelling that ultimately would lead to an entire and enlightening identity shift in myself. Sarai Pahla's (2015) TEDx talk was full of vulnerable stories from throughout her lifespan about how she views and interacts with the world as a person on the autism spectrum. Though the language used in her talk to describe autism has changed, the stories she told resonated so profoundly with my own. The next video featured interviews with autistic adult women (Iris, 2018). Their stories resonated with me deeply, but I still sought external validation for this discovery. I contacted my psychology professor to see if she thought I should be assessed. She was a very successful psychologist with multiple autism intervention clinics and studied under famous interventionist Ole Ivar Lovaas at UCLA. Knowing her strong background in autism, I thought she would be a good authority on whether she saw me as potentially autistic. She confirmed my suspicions that I was likely on the spectrum and I was nervous and relieved. I knew I was different and now I had a direction to look into with greater detail. I had recently completed my undergrad in psychology, and I never fit into the conceptions of autism I had been taught. Only through listening to stories from autistic adults themselves was I able to discover my own identity as an autistic person and connect with my community of autistic peers.

Fast-forwarding to a few years later, while sitting on my patio with an iced tea in hand, I was yet again surprised with a life-altering story. This time, it was from a library book that I stumbled across called *Spectrums: Autistic Transgender People in Their Own Words* (Sparrow, 2020). For the first time in my mid-twenties, other people's stories mirror my understanding of identity, gender, sexuality, and place in the world. Their words explained experiences I had left

unexamined and unexpressed. Intersectional autistic storytelling is a powerful representation, adding validity to the plethora of autistic experiences in the world. It enables many more autists to feel connected to others in their community through stories of shared experience. I hope to become part of that representation and share some personal stories of the frustrations in this life being autistic without knowing or understanding it. I will be carving out a space to examine a small sampling of my autistic experiences that were difficult to navigate within a cisnormative neurotypical world, hoping this will help others that can resonate to explore their own unexamined experiences. Through these reflections in this project, I aim to broaden others understanding, striving towards a queer and neuroinclusive future.

Qualitative research into the experiences of autistic adults often describes how many feel isolated, like an alien, and struggle to find their place in the world (Lewis et al., 2020; Stagg & Belcher, 2019). Lewis et al. (2020) found that the multiple marginalized identities of their participants contributed to increased feelings of isolation due to a lack of shared experience of the world, stigma and lack of understanding. Qualitative research methods can restrict the full sharing of experiences by using topic parameters and structured interviews. Even though I thrive when given structure like many other autistic people, there is a personally impactful difference in works not restricted to a specific structure, that is creatively made by autistic people for autistic people. Examples of this currently in the literature are often very open-ended books generally grouped by intersection or topic, which creates space for many meanings and takeaways. This allows a showcase of the many ways autistic people experience and express themselves within the world. For example, *All the weight of our dreams: On living racialized autism* focuses on sharing the stories of autistic people who are Black, Indigenous, and People of Colour while also creating space for other intersections such as gender divergence, age, intellectual ability, and

immigration status (Brown et al., 2017). Autistic anthology *Stim* shares the creative and queer ways in which autistic people are embracing self-expression through stimming (Huxley-Jones, 2020). In *Typed words, loud voices*, autistic people who use text to speak share personal stories and advocacy for non-speaking autistic people navigating a hostile and ableist speaking world (Sequenzia & Grace, 2015). These books boldly represent what many autistic people haven't yet seen represented in mainstream media or literature. The creation of space for self-directed stories not centred around a research agenda or problem to solve about autism has created more meaning and personal impact on my own life than any autism research or educational program.

Looking through the unabridged windows of autistic lived experiences into the fullness of their realities made me realize that my own experiences are not unusual or unique but rather common autistic experiences. Autistic stories sharing their perspectives of the world was my first time seeing my whole self in another group of people. As a disabled autistic, trans, queer, asexual-spectrum person from a religious and broken family, the presentations of love, gender, family, community and workplace in mass media didn't reflect my lived experiences. All the widely published representations of life I was raised on focused on neurotypical ways of interacting and experiencing the world which was not relatable to me. For example, when watching neurotypical trans experiences online, I decided that wasn't my personal truth until I saw how some autistic people described their own transness. This is just one example of how the many parts of how my own identity as an autistic person took longer to discover due to the simple lack of representation of stories within my neurotype to connect to.

Halfway through reading an anthology of transgender autistic people's stories, I started a chapter by Baden Gaeke Franz organized by years in their life, with specific stories, commentary, and reflection (2020). I was reading about their life, but it was as though I was

reading about my experiences, with similar realizations across our lives almost down to the same year. We both didn't fit the stereotypical trans or autistic stereotypes enough due to how the world often perceives transness through a neurotypical lens and autism through a straight, cisgender lens. Once I was entirely transported into Baden's story about their gender and autism journey, I was shocked by a brief paragraph about looking into grad school and writing a thesis on the topic of autistic trans people. It felt validating to see myself and my life experiences reflected in those pages. It was the push I needed to try to find another way to succeed in grad school. I didn't realize until reading that book, identifying with other trans autistic people, and reading their amazing work in the community that I could do the same.

During my undergrad, I pursued the goal of a Ph.D. or PsyD with the intent to make a career for myself in research. But all the preparatory work I did throughout my undergrad to get into grad school could not get me over the insurmountable social barrier of networking well enough to find an advisor who would take me on as their student. After many failed networking events and cold calls/emails, I gave up on my dream of grad school and switched career goals to human resources instead. Six years later, empowered by stories of success from my newly found autistic community, I was accepted into a grad program that removed those social barriers at the University of Manitoba. The power of storytelling, such as the ones found in *Spectrums*, can create spaces of empowerment, change, and enlightenment to create the most authentic version of ourselves (Sparrow, 2020). Stories contain experiences that can change lives and bring people together across time and space through shared experiences. This autoethnography seeks to share stories that further validate queer autistic ways of being for other autistic people, while educating the broader community toward a more inclusive and queered perspective of autism.

My own experiences of delayed autistic identity development are also well supported in the literature. Access to self-knowledge and minority identities such as sexual orientation and gender divergence have been found for some to not be discovered until adulthood due to heteronormative social norms, race, religion, and other intersectional ties (Campbell et al., 2022; Hall et al., 2021; Haltom & Ratcliff, 2020). I hypothesize and explore in my thesis that heteronormativity within society also contributes to delayed autism identity through an autoethnographic method. The autism literature has started to record the role that gender norms and culture have played in autistic people diagnosed as adults (Bargiela et al., 2016; Huang et al., 2021; Kanfischer et al., 2017; Lewis, 2021; Singh & Bunyak, 2019). The majority of the research surrounding late-diagnosed autistic people centers on the experiences of white women (Lupindo et al., 2022), with significant underrepresentation of Black, Indigenous or People of Colour (BIPOC) autistic participants (Jones et al., 2020) and Trans/Gender Diverse (T/GD) autistic people (Mallipeddi & VanDaalen, 2021). This research seeks to further discuss the mechanisms underlying many of these social barriers to autistic identification via the concept of heteronormativity.

This autoethnography highlights the mechanisms of cisnormative heteronormativity that contributed to the social, cultural, and institutional barriers of my journey towards autism identification. Significant emphasis placed on how heteronormativity from society and internalized heteronormativity contributed to my autistic camouflaging and delayed identity development milestones. The value of my autoethnographic accounts of these barriers intends to educate a broad audience. This includes educators since they are just as likely to believe false narratives and myths about neurodivergence as the general population (Gini et al., 2021; Howes et al., 2021).

Terminology and Definitions

To ensure readers are aware of emerging and current terminology used throughout autism, queer, and disability studies discourse, I have included a section on words central to understanding this paper. Autistic self-advocates have challenged the use of some words, reclaimed others, and made entirely new ones. Changes to language around autism have been one of the many steps taken by the autistic community to shift control away from medical professionals who have spoken for us, about us, and without us over the past decades.

Terms to Describe Autism

Pathology-first language. Historically used to describe a person's pathology, resulting in increased dehumanization and stigma (Dwyer, 2022). Examples include severely autistic, autistic disorder, and "autistic psychopathy" (Asperger, 1944/1991, p. 39).

Person-first language. Arose as a response to correct the harm done by pathology-first language. Emphasis was placed on a person's humanity as separate from their diagnosis or affliction. Examples include a person with autism, a person affected by autism, and a person diagnosed with autism spectrum disorder.

Identity-first language. Arose as a response to person-first language, which is believed by many to perpetuate the pervasive beliefs of inferiority surrounding disability, contributing to the stigmatization of disability (Dwyer, 2022). Identity-first language purports that a person's disability can be a positive or neutral part of a person's identity, difference, or predicament. This disability identity does not need to be separated from their personhood because it is not seen as inferior or negative. Examples include autistic person, autist, and autistic.

The words chosen to discuss autism within the literature are essential to how it is interpreted and enacted by autistic people within society (Botha et al., 2021). Choice of language

in both everyday interactions and published works can contribute to the historical and present epistemic injustices of autistic populations. The use of language surrounding autism that equates it to a disease, something that a person is afflicted with, or can be separated from contributes to epistemic injustice and stigmatization of autistic people. Examples of offensive and stigmatizing language in current social norms include persons with severe/mild autism, persons with autism and persons with autism spectrum disorder (Bury et al., 2020). Historically, pathological language first (e.g. autistic disorder, severely autistic) was used in deeply harmful ways, and person-first language was used to counteract the pervasive discussions around autism as a pathology (Dwyer, 2022). The shift from pathology-first to person-first language did not address the underlying belief structure that autistic people were pathologized or disordered.

As direct resistance to person-first language, most autistic adults now prefer what is broadly called identity-first language, placing autism within a person's identity, rather than as a distinct affliction separate from their personhood (Bury et al., 2020; Kenny et al., 2016). Self-advocates have reclaimed many but not all the terms used in pathology-first language, such as using autistic both as a trait and as a noun. Differences between pathology-first and identity-first language may not be readily seen, as a person may still use autistic as a pathology rather than as an identifier.

The public pushback from non-autistic people against how autistic people self-identify is the result of their viewing autism through an ableist lens (Shakes & Cashin, 2020). An example of this enacted in the public realm includes how an autism support worker said she respects those who identify as autistic but will only use person-first language because she works with higher support needs autistic people (Shakes & Cashin, 2020). An example of this ableism within the autism literature is Vivanti's (2019) column that suggested that identity-first language should be

used more often. Still, person-first language can't be removed from the literature for those with more support needs and co-occurring intellectual disabilities. This belief that those with higher support needs should be separated from their autism while others with lower support needs can use it as an identity label is rooted in ableist notions of functioning being tied to personhood. In disagreement with the allistic person-first discourse, an autistic person argued on Twitter that other marginalized identities are no longer seen as pathologies, such as being queer or Black. This includes how it is not acceptable to say that these communities "ha[ve] gayness" or that they "ha[ve] [B]lackness" while autistic people are still pathologized, and their personhood is separated from what makes them different (Shakes & Cashin, 2020, p. 223). Despite the debate over the importance of labels within society, those with marginalized experiences of the world have historically been further marginalized and "kept as second class citizens" via language that perpetuates systemic ableism (Shakes & Cashin, 2020, p. 223).

Self-advocates criticize the underlying beliefs of person-first language, that a disability dehumanizes a person or makes them inferior, so their personhood must then be separated from their disability to reconcile the dissonance between persons and their supposedly dehumanizing disabilities (Botha et al., 2021; Dwyer, 2022; Shakes & Cashin, 2020). They are changing the language around autism shifts the paradigms associated with it. The paradigm associated with identity-first language is liberation from the pervasive ableist belief that being disabled or impaired makes a person stigmatized, dehumanized, and lacking agency (Bottema-Beutel et al., 2021).

The use of person-first when referring to higher support needs but identity-first for lower support needs is at the core of the argument that disability is still viewed through an ableist lens, especially around the level of impairment. Within a Dutch sample, autistic people and parents of

autistic children were more likely to use person-first language with higher self-reported autism traits and lower IQ (Buijsman et al., 2022). The authors noted that the preference for person-first language could be due to social stigma and self-stigma due to being more disabled, which results in further health, socioeconomic and social disparities. This view also aligns with Han's systematic review of autistic populations with higher support needs and disablement linked to negative self-concept and increased stigmatization (Han et al., 2022).

To follow the advocacy of the wider autistic community and self-advocacy networks, I use identity-first language when discussing autism and other neurodivergence throughout this project (Botha et al., 2021; Shakes & Cashin, 2020; Walker, 2021). Aligned with other autistic authorship practices, to respect individual differences, people on the autism spectrum who prefer person-first over identity-first when referring to themselves will be discussed in their chosen language (Adams & Liang, 2020; Walker, 2021). However, to be aligned with advocacy efforts to change perceptions of autism within society, sources from non-autistic researchers using person-first language without asking autistic participants for their preferred language have been rewritten into identity-first language.

Definitions

Meanings of words readily change throughout time, with some words having once been a slur being reclaimed by those groups, while other words have changed their meanings entirely over just a few years (Adams & Liang, 2020). A list of terms as they are currently understood to be used most generally by those who use them is below. These definitions are ever-changing by the groups who own them, so this is a general representation of commonly accepted terms within the current literature and communities as it stands today.

Applied Behavioural Therapy (ABA). This therapy seeks to normalize autistic behaviours into normal ones through behaviourist interventions (McGill & Emerson, 1992). Behavioural therapy aims to teach autistic people to behave in ways that would make them indistinguishable from non-autistic peers. The methods that focus on behaviours only, and goals of normalization are widely contested by autistic people who report adverse effects, trauma, and abuse by behavioural therapists. Emerging research on this topic due to community advocacy suggests that the treatment may be traumatizing for many autistics who have received it (Kirkham, 2017).

Heteronormativity. Heteronormativity is generally described as the social policing of how a person's gender and sexuality are interpreted and presented within a society (Marchia & Sommer, 2019). This comprehensive definition can be further specified using prefixes:

Heterosexist-heteronormativity. The inherent bias and privilege of politically and socially enforced norms around heterosexual behaviour, especially against or superior over other orientations (Marchia & Sommer, 2019).

Gendered-heteronormativity. Focused on the relationships between a person's experience of gender as they were assigned at birth and expressions of femininity or masculinity outside of expected social norms. This includes a person's experience of gender roles within romantic relationships and how they enact their gender to people of the same or other genders.

Hegemonic-heteronormativity. The systemic shaping and changing of people within society under patriarchal goals toward a cisgender and heterosexual presentation of life as the normative and, therefore, only correct stance. This pervasive belief system hinges on the reinforcement that femininity in females and masculinity in males are only valid expressions of gender within society. Also noted is the hegemonic whiteness associated with these expressions

of gender and how racialized communities are often never considered to be meeting the gendered norms of society since they are also entrenched in whiteness (Allen & Mendez, 2018).

Cisnormative-heteronormativity also called cisheteronormativity. The policing of both cisgender and heterosexual ideals as inseparable parts of the same system. This places individuals on a hierarchy of privilege based on their adherence to normative gender and sex. For example, a heterosexual binary (male-to-female or female-to-male) trans person would have a lower social location than a cisgender heterosexual person due to their divergence from cisnormativity. Even though a person may be a heterosexual man or woman, their trans identity will still be policed for gender divergence.

Disability. With multiple models of disability in the literature, the model to be used as a reference point within this project is the social model of disability. This model defines disability as the disabling barriers faced in society, not a person's impairments (Oliver, 2013). Following the social model of disability, there is a greater focus on political and social action that can lessen and eliminate some experiences of disability (Barnes & Mercer, 2004). Disability exists because there is a social devaluation of different embodied experiences of the world (Titchkosky, 2011). Unevaluated ontologies toward impairment and non-normalcy are significant contributors to what created perceptions of disability within society, and what sustains disability in the present (Pfeiffer, 2002). Challenging ableist and normative ontologies can reorient perspectives of impairment to value-neutral, and facilitate the social change required to remove the social barriers of disability.

The intersectionality of autistic people is important to consider, as it can impact how they are disabled within society. To avoid stigmatization, some autistic people may present themselves as subtly different or not different at all through impression management strategies

often called masking (Mandy, 2019; Schneid & Raz, 2020). These strategies make others more comfortable and often result in increased safety due to beliefs associated with divergence being dangerous, especially among Black autistic people (Davenport et al., 2021; Pearson & Rose, 2021). Ventour-Griffiths, a Black autistic advocate describes the double pressure that he faces to conform to both neurotypical and Black cultural norms (2022).

In the intersections of language and ability, nonspeaking autistic people experience significant social barriers. Nonspeaking lived experiences include others assuming that they are nonthinking, nonfeeling, and without intellect (Guerra, 2022). Nonspeaking autists have also experienced educational barriers from teachers (Kripke-Ludwig, 2020), lack of personal agency, and significant privacy violations (Barry, 2022). Autistic nonspeaker Elizabeth Bonker shared in her valedictorian speech at Rollins College that despite prejudices and numerous social barriers, she dreams of helping bring communication to the 31 million autistic nonspeakers across the globe (2022). She discussed how due to global prejudices against nonspeaking autists, millions of autistic people are denied their right to access communication. She ended her commencement speech by calling for everyone to see that each person in this world has value, with the capability to change society.

Gender is another important factor in the lived experience of autistic people. Autistic women face barriers due to cultural gender norms and gender-restrictive autism discourse (Moore et al., 2022). These barriers have been so significant that researchers have found their autism presentations to be clinically significant enough to change current practices in autism diagnostic testing (Bargiela et al., 2016; Hull et al., 2020; Suckle, 2020). Dr. Price (2021), argued that female autism phenotype theories ignore the similar lived experiences and autism presentations of other marginalized groups. Instead of female autism, Price (2021) suggests that

sexism and socialization of gender stereotypes cause females and other non-cis males to mask their autism. Likewise, racism, homophobia, transphobia, and other forms of oppression cause masked autism too. Since autism assessments and research were based on young, white, autistic cisgender males who are also disruptive so anyone outside of any of those intersections will face barriers based on those varying intersections (Price, 2019).

Autism is diagnosed in the current literature as neurodevelopmental deficits in behaviour and communication (American Psychological Association, 2022). This dominant approach to autism as a disorder has been critiqued to exclude the social context and lived experiences of autistic people to consider the social context of autism and differences instead of deficits (Mac Carthaigh, 2020). A recent systematic review of language use in the autism literature found that this view of autism as a deficit or disorder is still very prevalent (Bottini et al., 2024). Despite this prevailing deficit-based model, the communication deficits associated with autism in those without an Intellectual Disability (ID) are non-existent when speaking to other autistic people but clinically observable in cases of autistic-to-allistic communication (Crompton et al., 2020). Implications of this research suggest that the deficits associated with autism are a different but highly effective form of communication. This further indicates that autism without ID may not be a neurodevelopmental disorder marked by deficits but a socially created disability through differences in how autistics interact with allistics. Implications of this work for future research include how different ways of interacting and existing are not deficits within autistic-autistic interactions (Davis & Crompton, 2021). Throughout this paper, aligned with autistic advocates, I do not refer to autism as a disorder. Autism in the advocacy community is not defined as a clinical diagnosis. Instead, it is simply an identity or word that describes one of the many neurocognitive variants within our neurodiverse world.

Neurodiversity and Neurodivergence. Neurodivergence is a different way of perceiving, sensing, and thinking compared to predominant (or neurotypical) norms within society (Rosqvist et al., 2020). This neurotypical society does not cater to or act appropriately for those with differences outside this norm, which is called neurodivergent. The term neurotypical may not perfectly describe every person, but it represents the norms and expectations for how people should think and act within society. Those considered neurotypical or neurodivergent do not have a specific type of brain or embodiment. Some people can be born neurodivergent, but others can be made neurodivergent through life experiences such as traumatic brain injury, the use of psychedelics, traumatic experiences, and more. No person is also born neurotypical; they become neurotypical through typical social participation. Neurotypicality is legitimated through the value of typicality and the devaluing of divergence. Neurodivergence isn't inherently a disability, however it often becomes one through the systematic oppression of this group (Straus, 2013).

Neurotypical privilege is when a person is comfortable navigating within society and is not judged for their mind being different. The current structures do not discriminate against their neurocognitive functioning, and compliance within society is rewarded accordingly with being perceived as normal. A person may be neurodivergent but have neurotypical privilege due to their divergences not causing barriers for them within society. Some neurodivergent people can also pass as typical at some times but not others due to compensatory efforts to be perceived as typical. These false neurotypical personas are not limited to autistic people but any kind of neurodivergent person seeking to avoid harm, abuse, or further trauma for previous divergent expressions of self (Ai et al., 2022). This ability to hide divergent traits within neurotypical society by some neurodivergent people has been widely debated as to whether it benefits them

due to significant negative mental health consequences (Bril-Barniv et al., 2017; Cassidy et al., 2019; Hull et al., 2021).

Queer. Queer is a term with many meanings. At its core, all meanings stem from anti-normative expression, identity, or behaviours. To queer something is to transgress, subvert, defy, and oppose normativity. Queering is more than just a catch-all term for 2SLGBTQ+ people; it is a term that anyone can use when seeking to break through normativity toward a creative and liberated future. Once used as a slur, advocates and members of the 2SLGBTQ+ community have reclaimed this term as an ongoing protest against those who use it as a slur and claim it as an identity with pride (Rand, 2014).

Positionality

The lengthy history of autism research is shrouded in the belief that autism is unknowable and must be interpreted through allistic perspectives. By centring my autistic perspectives as valid and accurate depictions of autistic experiences, I challenge these prevalent practices in the field. I am a white settler to Canada from European origins, which requires reflections on my own power and privilege throughout this work. Though I am trans and non-binary, I often pass as a cisgender woman, albeit a queer one. Many of my stories and perspectives are located within my upbringing as a middle-class girl, entrenched within a Christian culture and family environment. Though the primary goal of my work is to argue for the queering of autism within the broader culture, my own identity as a queer-non-binary person who does not find comfort or identity within traditional cultural concepts of gender and social life may also impact my perspectives presented here. Further, much of the present literature on autism is written and constructed by other white autistic authors who were also assigned female at birth and may also often pass for neurotypical cis women.

The frameworks and methodologies utilized in this project are reflections of the importance of intersectionality, neurodivergence- and queer-affirming values. There is no debate as to the legitimacy of the diverse ways in which a person can be autistic within this project. Rather than calling for a specific type of queered autism, I instead strive to communicate the queering of autism at an individual level, which has different ends and meanings for each autistic person who engages in the queering of their autistic self. I situate myself as a member of the autistic community who writes about their own experiences for others to resonate with and consider its meaning for themselves. Rather than articulating what queered autism *is*, I argue current cultural understanding of autism I have been exposed to *is not* accurate or helpful and requires queering.

Purpose, Objectives, and Rationale

This autoethnographic thesis utilized critical autism studies and queer studies literature to inform my exploration into the relationships between heteronormativity and autism identity development. I reflected on my personal experiences and development, related them to wider cultural experiences, and discussed how many heteronormative cultural norms created barriers to my own autistic identity development. I explored how shedding internalized heteronormativity within my own life, and queering my autism created greater access to self-knowledge, community building, and improved mental health in my own life. I sought to explore how the broadening of autism definitions and expressions led to my own autism discovery. The prevalence of how current cultural perspectives of autism continue to be largely entrenched within heteronormativity perpetuates barrier for many undiscovered autistic people.

The opportunity to discover one's own autism can positively alter self-concept and identity. This is also called biographical illumination (Tan, 2018). This thesis seeks to highlight

cultural barriers to this illumination throughout my lifespan to highlight areas for future change. The stories of coming to learn about my autism later in life, the adverse effects of this delayed understanding, and the harmful effects of diagnosis gatekeeping across various aspects were explored. The goal was to challenge current paradigms of autism as a set of cisgender male presenting deficits and refocus it. These heteronormative structures are facilitators of disabling environments, limiting opportunities for autistic identity formation and access to services. This study also sought to uplift and add to the emerging voices of trans, queer, and disabled autistic people calling for the queering of autism. The queering of autism decenters young white cis male experiences, exposing the deficit and pathological paradigm's harm, and moves toward an inclusive and neurodiversity-affirming paradigm.

This autoethnography held a different perspective than what much of the present autism research purports. The predominant medicalized and interventionist paradigms surrounding autism research frequently dehumanizes, pathologizes and perpetuates the social disablement of autistic people by upholding non-autistic perceptions of autism as more objective or valid than autistic lived experience (Botha, 2021; Catala et al., 2021; Walker, 2021). Even at the most basic level, autistic people have been denied the epistemic authority to lead discussions on their group experiences (Botha, 2021). This pervasive paradigm surrounding autism perpetuates the social oppression, further marginalization, and denial of the epistemic agency of autistic people. This thesis rejects these notions of non-autistic ownership over autism epistemology. Instead, it contributes to the queering of the autism literature by embodying the autistic community's fight to assert the authority of autistic voices within autism discourse.

Project Significance

Awareness of autism in its authentic and diverse forms has yet to take shape within the general population. This project is the first of its kind in the literature to explore autoethnographic autistic experiences with a focus on heteronormativity. Intersectional research in late autism discovery/diagnosis is significantly lacking, and I seek to fill some of that gap with my own experiences. This autoethnography seeks to provide representation to professionals and the broader community about the adverse effects that cisheteronormativity has had through the sharing of personal experiences specific to autism and marginalized identities. I intend to utilize the findings of this autoethnography to better inform future research directions that can be applied more broadly to the experiences of other late-identified autistic people. Many more autistic people will go through life without awareness of their autism until self-advocates and allies can proliferate autistic perspectives that queer autism and challenge the heteronormative barriers to these conceptions. My stories within this autoethnography are much-needed autistic representation, education, and challenges to the present issues facing non-identified and late-identified autistic people.

Statement of Problem

Historical underrepresentation of diverse autistic perspectives has created barriers to accessing autism identity, diagnosis, and support services for marginalized communities. There continues to be a lack of space created in research and media for the diverse presentations of autism outside of young white cisheteronormative male presentations (Grove et al., 2024; Jones et al., 2023). Queering autism includes those who inhabit marginalized, older, non-conforming bodies and genders. The subversion of heteronormativity within autism creates opportunities for change within culture and professional environments. By queering autism, unidentified autistic

people may finally have access to more accurate information about autism, be able to join a community of autistics with similar lived experiences and begin the critical process of self-awareness and acceptance. The differing autistic expressions of women and Trans/Gender Diverse (T/GD) autistic people is a significant knowledge gap that needs to be addressed within culture and research to begin breaking down these barriers.

Males are four times more likely than females to be diagnosed in Canada (Public Health Agency of Canada, 2022). Actual prevalence rates of autism are expected to be much more balanced across gender and other identity factors due to numerous social, cultural, attitudinal and institutional barriers (see Adams & Young, 2020; Bargiela et al., 2016; Cumin et al., 2021; Howes et al., 2021; Lewis, 2017; Milner et al., 2019; Sritharan & Koola, 2019). Researchers that require a diagnosis to include autistic voices in research further marginalizes autistic people who are unable to attain a diagnosis (D'Mello et al., 2022). Emerging research also suggests that queer and trans identities are more prevalent in the autistic population than in the general population (see George & Stokes, 2018; Qualls et al., 2018; Thrower et al., 2019; Warriar et al., 2020). In a study of just over 640,000 participants, people diagnosed with autism were 3 to 6 times more likely to be trans or gender-diverse (T/GD) than the general population (Warriar et al., 2020). And T/GD adults were also more likely to suspect they were autistic (without access to assessment) than the general population. Those who were not diagnosed with autism were excluded from these prevalence rates. If the researchers were to have asked autistic self-identity rather than autism diagnostic status, these rates could have been higher.

In America, Black autistic children with intellectual disabilities are significantly more likely to be diagnosed than Black children without intellectual disabilities (Maenner et al., 2020). These gaps in identification are multiply caused; the general public does not know, and the

medical and institutional autism programs do have some evidence to support these gaps. Many professionals do not share these gaps or implement the difficult and costly measures required to address them due to neurominority privilege and discomfort challenging norms (Onaiwu, 2020). These measures include additional education on the lived experiences of racialized autistic people, strategic partnerships with minority-serving organizations, and mentorship to promote diversity.

Research Questions

The guiding question of my autoethnographic thesis is: What experiences and influences led to my late identification of autism? As part of the review, I will answer the following questions:

1. What cultural beliefs and stereotypes created barriers to autism identification?
 - a. How did heteronormativity delay my identity development?
 - b. How did queerness break down barriers towards my autism identity development?
 - c. What would the impact of queering autism be within society for autistic people?

Autoethnography

Historically, though they may not be directly labelled as such, researchers have been conducting autoethnographic research throughout the centuries (Jones et al., 2016). Traditionally from anthropological research, ethnography was conducted when a researcher entered into communities to study them from their outsider perspective (A. P. Bochner & C. Ellis, 2016). In the 1970s, autoethnography was described to be merely an ethnography written by an insider within the society. It did not fully develop into the critical and reflexive method it is more known to be today until the 1980s with the emergence of post-modern, phenomenological, and critical attitudes which challenged positivist notions of “truth through method” (Ellis & Bochner, 2006,

p. 209). Autoethnographic research locates “the particular experiences of individuals in tension with dominant expressions of discursive power” (Neumann, 1996, p. 189). Such methods are valuable when contrasted against normative western research, which often places its highest value on positivist research with distance and neutrality towards their studied subject. Only slow and small changes can result from examining the master’s house using the master’s tools (Lorde, 1984). More transformative tools developed outside of the parameters of mainstream academic research such as autoethnography can act as a greater catalyst of change.

For the last 50 years or so, researchers in the social sciences have been discrediting personal experience and subjectivity in research practices (Jones et al., 2016). Despite efforts to better research society through objective methods, the outcome included many gaps that did not align with lived experience. The need for autoethnography was especially required in disciplines that studied marginalized populations where research was at times grossly misaligned with lived experience. Autoethnographies in the 1990’s and 2000’s around the topics of disability, mental and physical health, gender, sexuality, race, and ethnicity began to gain recognition within the social sciences. These autoethnographic accounts arose as an “antidote” to “balance or reposition” prevalent discourses on these topics (Jones et al., 2016, p. 89).

Autoethnography in recent years has been described as a queer research method (see Adams & Holman Jones, 2011; Browne & Nash, 2016; Holman Jones & Harris, 2019). Queer methods do not adhere to disciplinary traditions and focus on areas that have been excluded from research in the past. Critical autoethnographers have focused their research on the experience of power relations and intersectionality through questioning culture and practices within society (Holman Jones & Harris, 2019). Through autoethnography, Bochner and Ellis (2016) described the nature of autoethnography is to queer the spaces in which they critically discuss. The results

of autoethnography are not just changing the conversation about marginalized or oppressed groups, but the disruption of practices that contribute to their oppression.

Autoethnographic research approaches have been described by Anderson (2006) to include 5 important parts. First, is full membership in what is being researched. Second, is the analytical use of reflexivity. Third, is the requirement of storytelling in written form. Fourth is the research goal of bettering the social or theoretical conceptions of the topic researched. Spry (2001) adds that it is “a self-narrative that critiques the situatedness of self and others in social context” (p. 710). Jones (2005) goes even further to state that “the point of creating autoethnographic texts is to change the world” (p. 765). Situated within queer and critical approaches, autoethnographic methods are aligned with my goals of queering autism through critical analysis of culture and personal experiences.

Research Design

Autoethnography was selected as the research design of this project to deeply explore cultural experiences of autism through personal experience. Autoethnographies conducted by autistic people have coined the term ‘autieethnography’ or ‘autistethnography’ to describe the different but equally valid experiences of the world through an autistic perspective (Grace, 2018; Hacking, 2009; Yergeau, 2018). Autieethnographies are limited in the literature, with none focusing on the role of heteronormativity within society, so this study seeks to fill that gap (see Barkved, 2021; Lloyd-Barlow, 2021; Mitra, 2022; Walker, 2019).

One of the core features of autoethnography and feminist standpoint theory is the notion of reflexivity, that is to look at one’s own experiences and analyze them within their context and social positioning (Hekman, 1997; Pensoneau-Conway et al., 2017). In the literature, autistic people have been described as lacking reflexivity, theory of mind, and rhetorical capabilities

(Baron-Cohen, 2000; Heilker & Yergeau, 2011). These notions of disabled people being unable to speak to their own experiences and reflect upon their position within society have contributed to their further marginalization (Simplican, 2017). Autoethnographic research through disability studies and feminist lenses that challenge these notions are essential to the survival and political action of disabled people (Simplican, 2017).

Autistic people are likely to be viewed as deceptive, lacking credibility, and their voices are valued less than non-autistic experts in autism (Botha, 2021; De Hooge, 2019; Lim et al., 2021). Further, autistic people are still faced with the reality that they are not seen as key stakeholders or experts in the autistic experience (Gillespie-Lynch et al., 2017). Online discourse under the hashtag #autism centers on non-autistic perspectives to the detriment of the autistic community to the point that autistic people have created their own spaces separate from these so-called experts, as seen under the hashtag #actuallyautistic (De Hooge, 2019). This autoethnography is an act of resistance against that devalued space I have been placed into as an autistic person, showing how autistic people have expertise on autism, and that autistic autoethnographies are valid forms of autism research. This methodology challenges prevalent epistemologies of autism towards autistic-led explorations of autistic embodiment and experience.

Research questions will be answered thematically according to the harmful archetypes found within present Western society. Thematic presentation of ideas was chosen over a timeline approach to maintain the coherence of thoughts and consistency of these barriers throughout the lifespan within a given theme. Themes will focus on prevailing beliefs/myths within culture, such as gender bias, ageism, behavioural stereotypy, communication deficits, and exceptionalism.

Method

My method followed an adapted version of narrative analysis for autoethnography, as discussed by Cooper and Lilyea (2022). This method was chosen due to the emphasis on the value of stories and storytelling over seeing experiences as data points to be coded, aggregated, and examined apart from their contexts. I first began by writing about relevant life experiences across my lifespan, narrowed down these experiences into a handful of vignettes that illustrated my key areas of concern, then conducted a thematic analysis of them. Part one of the autoethnography is a categorized collection of stories. The categories follow three major periods over my autism journey: (1) Before I discovered I was autistic, (2) when I discovered I was autistic, and (3) the process of reshaping my identity and sense of self as an autistic person. Part two of the autoethnography reviewed these experiences through the previously mentioned frameworks, identifying themes, key takeaways, and then critically examining how cultural and attitudinal barriers delayed my autistic identity development. I also added additional details surrounding the vignettes relevant to these themes, as well as stories and experiences from peers, the autistic community, and academic literature. In the final part, I discussed the benefits of undoing these barriers for autistic people in the present, as well as future next steps on queering autism.

Early reflections on this topic and the review of potential stories to use in vignettes were used to build the foundation of the research questions and proposal. I found a common theme of heteronormativity ran across many of the stories I wanted to write about and as a result made it a central focus. A balance of topics which focus on both individual barriers as well as systemic or institutional barriers was chosen to highlight the broad scope of this issue and its many parts that need to be addressed holistically. Other barriers and topics in my story of autistic identity

development included many other factors that were also explored alongside the experiences of my peers.

The names used in the vignettes are pseudonyms used to ensure the anonymity of all parties involved. I chose to exclude the use of a pseudonym in my *Malingering or Autistic?* vignette and reference to a friend's similar psychologist story because I did not want to risk someone reading those stories out of context and believing an actual psychologist with that last name had conducted such biased assessments. To prevent the risk of the pseudonym I chose being truly believed to be the person I am referring to, I wrote the story to exclude that language entirely. While I could have disclosed the names of the psychologists, I chose not to because the goal of sharing these stories is to highlight how our experiences may be seen currently as individual problems, but they are all too common and part of a larger problem which requires systemic change.

Chapter Two: Theoretical Frameworks

Disability Studies Framework

Disability studies is rooted in disability rights activism, which refutes current medicalized notions of disability as being caused by individual's deficit or pathology. The perspective of disability as an individual affliction was socially created by capitalism and medicalization and continues to this day (Barnes & Mercer, 2004). Just as how current conceptions of disability as requiring cure, treatment, and prevention are socially constructed, social change can shift those constructions toward more affirming, liberatory, and emancipatory futures. The social model of disability speaks to how environments disable individuals, not focusing on their impairments. Essential to this model is that impairment does not cause disability, environmental barriers do. The social model does not attempt to be an exhaustive framework however, it has limitations in its application to impairment, which often overlaps with disability but does not necessarily cause disability (Oliver, 2013). This model has been critiqued by Kafer (2013) to not be relevant to or exclude certain disabled people's experiences, such as those who seek treatment or cure for their disabilities or those who see their disabilities as individual impairments alone that they do not identify with. Despite it not being a perfect model to describe the experience of every person with a disability, I believe it plays a vital role in shifting the general perspective found in culture toward people with disabilities from pathologizing to more nuanced. Kafer (2013) adds that the only way where crip (meaning disabled) futures will be attained is through seeing disability as primarily political and relational action.

Intersections between disability and other oppressions often have similar experiences between them that adds depth to these ideas. For example, Finkelstein (1991) discussed how disabled people's place in society is explained in part by the social death model. This is

described as when a person is alive but cannot meaningfully engage with society due to being devalued and having to face too many barriers to full participation. When society dehumanizes a marginalized group, they are not in a position to make change for themselves due to the low social standing that they have been pushed into by others. Similarly, Tourmaline et al. (2017) discuss how Black queer and Black trans culture experiences social death via similar methods of oppression. They challenge notions that Black queer and trans culture will always be driven to social death, and that these issues are rooted in individuals perpetuating white man mimicry. They also suggest these ideas are based on larger systems of anti-Black thinking and practices that can be changed socially. They suggest reflections on “how racial capitalist logics reproduce themselves within oppositional political-intellectual formations precisely through the frameworks of gender and sexual conformity” (p. 17). These reflections locate the issue within the broader social context, while also focusing on these issues within compulsory cisheteronormativity.

Queer Theory

Queering in practice is the disruption of normativity to counter-cultural norms toward a more relational and non-hetero compulsory way of life (Ahmed, 2006). Queering is the disruption of norms while seeking new paths, forging queer futures of belonging and new meaning. The philosophical side of queer theory largely rejects bioessentialist and identity politics, singular notions of what queerness is, opting for queerness being rooted in action, and challenging the value of normativity (Walker, 2021). Queer theories reject essentialism, naturalism, and binarity, instead focusing on how identities are socially constructed through participation in society (Butler, 2006). Queer theory challenges heteronormative social structures in both society and research toward more liberatory and self-determining ends (Minton, 1997). This includes

advocacy from community groups to not only depathologize queerness but also to change who gets to speak as an authority on queer issues. Minton (1997) argues that queer theory is rooted in displacing the power that scientific professionals have, giving that power instead to queer people themselves to speak on this subject and create their own knowledge. To queer research is to focus on research that has “been deliberately or accidentally excluded from traditional studies” of the subject, often utilizing methodologies that are not traditionally seen in that discipline (Halberstam, 1998). Queer theory is an incredibly important framework for this research due to overlapping themes of challenging many forms of hegemonic normativity, resistance to medicalization, and valuing the agency of people in marginalized positions.

Further linking queer theory to autism research, having a typical mind is required to meet the heteronormative standards of society (Walker, 2021). Neuronormativity is the societal belief that there is one typical mind (neurotypical), with neurodivergent people (such as autists) not meeting this requirement. This mismatch results in viewing neurodivergent people’s gender or sexuality as non-existent or limited to how they believe a child would experience them. For many neurodivergent and transgender people, neurodivergence is significantly related to gender divergence and departure from cisheteronormativity (Bornstein, 2022). Addressing neuroessentialism is within the scope of queer theory because of its foundations in rejections of essentialism and heteronormativity, which are inseparably tied to the performance of a typical neurotype. The queering of neurotype, gender, and sexuality can be summed up in one term, neuroqueer. Neuroqueering is primarily used as a verb to challenge the constructs of heteronormativity and neurotypicality simultaneously. It is anticipated that significant emphasis on queer theory and neuroqueering will be placed on my identity development throughout my autoethnography.

The Neurodiversity Paradigm

In 1998, Sociologist Judy Singer first coined the term neurodiversity to argue for neurotype to be seen as a variation of human neurology rather than as a disorder (2017). She embedded her neurodiversity paradigm within disability studies but critiqued the social-constructionist model underlying much of this discipline. She argued that the equalization of minds and bodies within social constructionist disability studies was contrary to what many autism advocates were arguing for. They have argued that autistic minds are not equal or comparable to allistic ones, with causes of disability coming from both biological determinism and social constructionism. Despite these differences in conceptualization, their goals are aligned. They are both a “social justice movement that seeks civil rights, equality, respect, and full societal inclusion” (Walker, 2021, p. 27). Activists seek to facilitate a change in fundamental cognitions around what it means to be a person within this world. This includes re-evaluating what is seen as disordered or pathologized and accepting wider variations of human experience. This movement is not synonymous with autistic rights, though there is a significant overlap of activists between the Neurodiversity Movement and the Autism Rights Movement.

Not all neurodivergent people are disabled due to their neurodivergence. Examples of neurodivergence in non-disabled people who have changed their neurocognitive functioning include those who take psychedelics or dedicate their lives to meditation. Neurominority describes people who are neurodivergent and disabled within society because of their traits being incompatible with the environment. There is continued discussion about the boundaries of neurodivergence about episodic or temporary disabilities being part of this group. Yergeau discusses neurodivergence as not a simple “yes/no formulation” (Yergeau, 2018, p. 85), but instead is both a verb and adjective, a way in which people queer their lives beyond leaning into

their unique physical movements or inclinations, it also includes many different ways of being, with special recognition of the many intersections a person holds, including a “plurality of identities, orientations, affective stances, and lived experiences, modes ranging from autism to deafness to trauma to asexuality” (Yergeau, 2018, p. 86). This also includes their concept of demi-rhetoricity and cultural biases against some neurodivergent people who may not be fully rhetorical. In this context, Yergeau (2018) described demi-rhetoricity as not being able to easily reflect, speak or act with intentionality at all times. For example, there are times when our hands may flap for no apparent reason, we may struggle to comprehend and empathize with experiences outside of our own understanding. The demi in demi-rhetorical means that there may be instances throughout time and place where we appear arhetorical or rhetorical, and both are completely acceptable human forms of being and operating within the world.

The Neurodiversity Movement likens the pathologization of homosexuality in the past and subsequent depathologization of it because of advocacy for the goals within its movement. One divergence from early gay rights activism is the emphasis placed on how “normal” and “part of society” homosexual people can be. Instead, the Neurodiversity Movement seeks to change societal beliefs and norms, significantly widening them and, at times, turning them on their head. Rather than just accepting more types of people into a deeply oppressive society, the goal is to change it so that further oppression of neurodivergent people is no longer a reality. The goal of this movement does not seek to eliminate all of disability within society, but rather to break down the social and attitudinal barriers that neurodivergent people experience.

Chapter Three: Literature Review

Autism Research

Autism research, since its beginnings, has centred around the so-called scientific study of men and boys (Tierney et al., 2016). Autism was conceptualized around the unexpected divergences of usually white, privileged boys, which differed from underprivileged groups where they used terms such as “feeblemindedness” (Gibson & Douglas, 2018, p. 7). Looking back, Hans Asperger noted autistic gender and sexuality divergence in his observations, but ultimately saw autism as heritable and not changeable like later behaviourists (Asperger, 1944/1991; Czech, 2018). Hegemonic-heteronormativity and autism have been tied together ever since conversion therapy and behavioural therapy was pioneered by Ole Ivar Lorvaas and other researchers at the University of California with the same end goal of normalizing children in the 1960’s and 1970’s (Gibson & Douglas, 2018; Rekers et al., 1977; Rekers et al., 1978). Expert interventions that devalued diverse expressions of childhood interests, instead utilizing capitalist, gendered, and coercive behaviourist methods of so-called development fundamentally shifted how autism was treated and conceived of within society.

Entrenched within autism discourse even in the present is the goal of changing autistic behaviours to allistic ones. The very nature of allistic social behaviour continues to be entrenched in heteronormativity, and thus the treatment of autism frequently reinforces gendered roles, interests, and behaviours. “Autism Conversion Therapy” has been used to describe the parallels between autism’s Applied Behavior Analysis (ABA) and gay conversion therapy (Gibson & Douglas, 2018, p. 2). While conversion therapy for minors is now banned in Canada (“An Act to amend the Criminal Code (conversion therapy),” 2021), public funds still continue to support the conversion of young autistic minds into neurotypical ones (Pyne, 2020). It has been

an incredible milestone for sexual and gender minorities to receive protection from conversion therapy. Meanwhile, in Ontario, ABA is a requirement for autistic students, with all special education teachers requiring ABA training (Ministry of Education, 2007). Autistic people continue to fight a similar battle against their own right of freedom of expression and liberty against the conversion of their autistic traits to allistic ones. There continue to be many social barriers to prevent autistic people from being seen as whole persons, deserving of self-determination and respect to live their authentically autistic lives (Pyne, 2020). Currently, there is growing discourse on autistic culture to be recognized as a protected group to support these aims (Davidson, 2008; Emily, 2017; J, 2013). Similarly to how the social model of disability focuses on how disability is perpetuated within society, rather than on individual deficits or impairments, so too is there a growing movement to shift the focus of autism from deficits-based to traits-based thinking. Straus invited readers to “imagine that it is a social construction rather than a medical pathology, and that people labeled as autistic comprise a definable minority group.” (p. 466). When making this shift towards exploring how we prefer to communicate and connect with one another, what is left behind are common traits which uphold the group apart from deficits. Straus (2013) described the culture of autism, created by autistic people, not by professionals with a few key tenets, local coherence, fixity of focus, private meanings, writing, art, and music. Cognitive styles prevalent in the autism community include being attentive to details (local coherence), and preferring repetition (fixity of focus). Further, having a rich inner life, with deep personal meanings and inner connections, autistic people are more likely to instead think in chains of associations metonymically, contextually, and to the outside observer, may seem entirely arbitrary. Rather than simply trying to defy neurotypical ways of thinking and being in the world, we instead focus on the creation of our own rich inner worlds which often

can connect to other autistic rich inner worlds. Unfortunately, autistic behaviours and communication methods which are not harmful to the self or others are frequently targets of therapeutic interventions, which perpetuates the marginalization of autistic people, and limits autistic expression. Advocacy efforts to have autistic expressions recognized as cultural rather than as disordered are important steps toward legitimizing autistic ways of being within society. If autistic self-expression becomes a respected difference within society, then trying to make autistic people fit into society through interventions such as ABA would no longer be relevant.

Presently, autistic people are more likely to experience interpersonal, structural, and attitudinal barriers, compounded by gender and race, across all aspects of life, including employment, healthcare, mental health supports, and relationships (Adams & Young, 2020; Hayward et al., 2018; Lehmann & Leavey, 2017; Roman-Urrestarazu et al., 2021). Presenting a unique challenge for autistic adults is the pervasive myth that autism is restricted to childhood (King et al., 2020; Malik-Soni et al., 2021). An example of this played out in Ontario's Ministry of Children, Community and Social Services autism program, whereby funding is halved by the time a child reaches middle school, with the program ending further funding on the child's 18th birthday with no additional funding (2022). Similarly, all other Canadian provinces only allow funding up until a child turns 18 (Autism Canada, 2017). After then, Autistic adults must apply for general adult disability income support or employment services.

Camouflaging and Masking

Autistic camouflaging is the use of cognitive and behavioural strategies to blend into a neurotypical social environment, hiding autistic differences (Cook et al., 2021). These strategies are often forced and unconsciously employed, creating a "neurotypical façade" often referred to as a mask or masking (Price, 2022, p. 18). Price (2022) compares the process of autistic masking

in the neurotypical world is related to a gay person being presumed straight in the heteronormative world. Experiencing the world differently and needing to move through the world in non-normative ways often result in either being othered or conforming. Those who camouflage or mask their autistic differences do so as their only means of achieving physical or psychological safety. People with marginalized identities are more likely to employ masking since their non-autism-related differences increase their likelihood of social oppression. It is also important to emphasize that masking is not exclusive to autistic people. Throughout this paper, the terms masking and camouflaging is used when specifically autistic masking is being discussed. Masking is one of the impression management strategies utilized by marginalized people. The literature has more extensive research on these strategies among 2SLGBTQ+ and BIPOC groups but also includes people with disabilities, especially invisible disabilities and mental illness (Ai et al., 2022).

Masking has been linked to stigma at both the individual and group level (Pearson & Rose, 2021). At the individual level, this can be observed through comments about odd or quirky behaviours or ways of speaking. At the group level, this includes cultural notions of what autism looks like, biases against autistic people, and stereotypes. Key to this is that whether a person is aware of their own autistic identity, their behaviours and experiences can be influenced by these stigmas, unknowingly creating a mask. Further, once an autistic person takes on their autistic identity, whether they disclose it to others or not, masking to avoid these stigmas frequently impacts well-being negatively. This experience is related to Du Bois' discussion of double consciousness, the experience of needing to be aware of how you are being always perceived by others due to the lack of safety around being Black in America (Lento, 2021). The resulting stress from the awareness of the discrepancy between the presented self and the actual self has

been described in the autism literature to be closely related to autistic burnout and increased likelihood of suicidality (Pearson & Rose, 2021). Further, it was found that the higher the autistic individual's perceived stigma of autism and their autistic traits, the more likely they were to camouflage these traits and experience negative impacts on their well-being (Perry et al., 2022).

The autistic camouflaging literature largely centers on the experiences of white, university-educated women (Cook et al., 2021). While it is true that females are more likely than males to mask, gender is not the primary predictor of masking (Price, 2022). Masking often results from the broader experience of social exclusion, rather than gender or sex assigned at birth. Much of the literature on female presentations of autism similarly also applies to the experiences of 2SLGBTQ+ and BIPOC autistic people due to the shared effects of white cisheteronormativity. Further, the camouflaging literature frequently failed to report race/ethnicity, gender identity, sexual orientation, and socioeconomic status (Cook et al., 2021). In the cases where they were reported, they were often homogenous groups lacking diversity. Future research in this area should focus on more representative samples of the general autistic population, especially those with multiple marginalized identities.

Autism Diagnosis and Self-Identification

The autism literature does not frequently distinguish between autism self-identification and autism diagnosis. My approach to autism distinguishes between two moments, (1) when or if an autistic person is diagnosed with autism, and (2) when or if an autistic person accepts their autism as part of their life or identity. I distinguish between these two concepts because there have been shared stories of autistic people being diagnosed early in life, but parents and professionals hiding this diagnosis from them (u/Commercial-Scholar59, 2021). This meant that these autistic people grew up being denied access to knowledge of their own identities that others

already knew. Similarly, people who grew up with undiagnosed autism, only to receive a diagnosis later in life, may reject the diagnosis, the autistic community, and choose not to form any part of their identity with this label. As a job coach, I have worked with some clients who have an autism diagnosis but choose to not identify as autistic. They distance themselves from the autistic community and instead choose to situate themselves within the neurotypical world, striving to reduce any autism-related differences. This illustrates how some people may have a formal autism diagnosis, but these diagnoses do not dictate linear paths towards autistic identity formation, nor self-discovery or self-acceptance.

While a formal diagnosis may be necessary to access certain supports and accommodations, the primary focus of this work is on the positive impact of self-identification rather than diagnosis. This is a shift from viewing an autism diagnosis as the end of identity discovery. Instead, I operate from autism identification as the beginning of self-discovery and life-building. This approach centres autistic culture and the power to self-identify with autistic others beyond the medical model or disorder-based view of autism.

Additionally, many marginalized autistic people may not have access to qualified diagnostic services, which could prevent many diverse autistic people from participating in autism research. Institutional barriers to accessing diagnostic services, within the assessments themselves, and cultural barriers that prevent autism from even being considered as a possibility are compounded for marginalized autistic people. Demographic variables associated with the age of autism diagnosis in an Australian sample found that later diagnoses were found in populations that were female, not intellectually disabled, and were non-native English speakers (Huang et al., 2021). They also found that people with autism diagnoses in their family and higher autistic traits were more likely to be diagnosed late, contrary to previous research examining factors in late

diagnosis. They also found a significant relationship between non-binary gender and late diagnosis, though their sample of those with this gender was small, warranting further research. Further, a history of other psychiatric concerns or diagnoses was a predictor of later diagnosis, perhaps due to the overshadowing of autism by other concerns. They also suggested that in the case of depression and anxiety, autistic individuals may not be able to seek out an autism diagnosis due to how these diagnoses may limit their abilities for self-advocacy and seeking support.

Interviews with autistic people diagnosed over the age of 50 found that they all knew there was something different or wrong about themselves that they had to make efforts to hide or camouflage from others (Hickey et al., 2018). Their diagnosis provided comfort due to the externalization of problems from their past not as a personal flaw but as a result of being autistic in a non-autistic built world. Similar late diagnosis experiences have been recorded in larger samples, most emphasizing empowerment from self-identifying as autistic (Lilley et al., 2023; Lilley et al., 2022; Stagg & Belcher, 2019). In a sample of males who were diagnosed as adults, they also found that lack of diagnosis until adulthood had a negative impact on mental health, and prevented self-acceptance until after diagnosis (Lupindo et al., 2022).

Intersectionality

Focusing on intersectional perspectives of autism is central to this work's values and goals. To queer autism within culture requires centring marginalized autistic voices as essential knowledge holders. I argue that those with the largest stake in how autism is known in culture are autistic people, especially autistic people with marginalized identities.

The axis of gender, especially women and autism, is increasingly present in the literature. Research has examined the experiences of autistic women, and their resistance to hegemonic

autism conceptions, stereotypes, and claims on autistic identity (Seers & Hogg, 2021). A qualitative exploration of women's experiences highlighted how they experienced being othered both by allistic culture, but also othered by the medical community which failed to accept autistic differences by gender (Seers & Hogg, 2021). They found a theme of struggling with gender expression and performances of femininity due to their desire for social inclusion to the consequence of their own comfort and identity development. Participants described their own process of self-acceptance of gender, creating their own version of what it meant to be women as different than what culture says it should be. Seers and Hogg (2021) also noted that with social change allowing for broader expressions of gender, these concerns may lessen with time for autistic people and their own experiences of autism at the intersection of gender and gender expression. In a literature review, it was found that language used around autistic people's gender was highly restricted, perhaps due to biases around autism research's deep roots of cisnormativity and bioessentialism (Moore et al., 2022). Research utilizing theories of the extreme male brain, female phenotype, and empathizing-systematizing limited how an autistic person could self-identify. Descriptions of gender and identity among autistic participants were reported to differ from the non-autistic literature on gender identity due to their neurotype. Research exploring how the identities of autism and gender interact is still in its infancy, with varying reports of causal and non-causal relationships differing depending on the sample (Adams & Liang, 2020).

At the intersection of 2SLGBTQ+ identity and autism, significant barriers and disparities are faced by this group. In an American sample, it was reported that 20% of autistic people who were straight, white, and cisgender were refused services by a medical practitioner (Hall et al., 2020). By comparison, 35.7% of 2SLGBTQ+ autistic people were refused medical services,

almost double the refusal rate of their non- 2SLGBTQ+ identifying autistic peers. In these cases where medical services were refused, the authors confirmed that they did have coverage for them and were eligible, so the participants had to seek additional doctors or facilities beyond what was required for access to care. Significant barriers around gender-affirming care were noted, especially around medical practitioners not believing that autistic people could understand themselves enough to know that they were trans.

Autistic people are significantly more likely than the general population to identify as 2SLGBTQ+ (see George & Stokes, 2018; Qualls et al., 2018; Thrower et al., 2019; Warriar et al., 2020). Despite the documented increased prevalence of these identities, there is still a significant literature gap in the self-reported experiences of autistic people's gender and sexual orientation (Sala et al., 2020). Prevalent mindsets around autism and asexuality persist, perhaps limiting funding and exploration into the intersection of autism and sexuality. These explorations and knowledge transfer to the broader culture create a significant knowledge gap in 2SLGBTQ+ people getting access to accurate knowledge about autism and the potential for their own self-discovery of their autistic identity. Similarly, despite rates of gender dysphoria and trans identity being more than double the rate of the general population, the literature has yet to document the experiences of dysphoria, and its potential different descriptions or conceptions in trans autistic people.

Autism is frequently represented in the media by white males (Matthews, 2019). Sheldon Cooper, though said not to be diagnosed with autism by producers of the show, is nevertheless portraying common and stereotyped autistic traits. The impact of autistic portrayals on television, regardless of the formal diagnosis given, impacts the community's understanding of autism. His autistic behaviours are viewed through the lens of his status as a white male within society. His

privilege allows him to be “immun[e] from political movements, social complexities, sexual expectations, and cultural conventions” (p. 57). Further, he wrote,

While there are overlapping rhetorical reasons for why Sheldon is not Asian, Hispanic, a woman, physically disabled, obese, or a member of any other historically marginalized or disenfranchised group, Sheldon as white rather than as black may articulate an entrenched historical Western “us versus them” racial schism (p. 57).

Especially due to the prevalence of autistic people with savant-like traits or exceptional memory dominating the media, Matthews (2019) argues that the ties within culture of whiteness and intellectual superiority can be seen in how autistic savant representations in media are almost entirely white men. Additional autistic historical and fictional characters in Western media include “Raymond Babbitt (Rain Man), Gary Bell (Alphas), Alan Turing (The Imitation Game), Christopher Boone (Curious incident of the Dog in the Night-time) and Sheldon Cooper (the Big Bang Theory). Many of these representations of autism follow the same tropes of other white male leads in media, that is they are a “lone, misunderstood underdog, the besieged white man versus the world” (p. 63).

Aligned with Matthew (2019), this work argues “that autism, whether lived or as portrayed, cannot be properly understood as a cultural artifact without reference to race” (p. 59). The missed identification of non-white autistic people can be attributed to the cycle of historical autism research focusing on white males, media portrayals of autism perpetuating this, and these portrayals perpetuating autism as a white male condition. These portrayals then signal to autistic people with presentations that differ from white males that they are not actually autistic, leaving them out of both the media and the research. Further, in Western media, men tend to be overrepresented in more intellectual roles, while Black characters are more likely to be placed in

physical roles, focused on sports, humour, labour, or sexuality. How race is represented within media widens the distance between the ubiquitous savant-like autistic white man and the realities of being Black and autistic.

The literature is significantly lacking in the area of race and autism, perhaps because researchers don't know better, it doesn't seem evident, or because they simply do not care to prioritize it (Onaiwu, 2020). The impact of this is that the lack of non-white autism representation contributes to the barriers that autistic people face daily. For example, autistic behaviours continue to be perceived as suspicious or aggressive when done by BIPOC. Black people are more likely to experience the use of force and mistreatment by law enforcement due to their race, and autistic Black people are at higher risk due to their disability (Autistic Self-Advocacy Network, 2017; Hutson et al., 2022). Suggestions for improvement include better law-enforcement training and greater connections between Black autistic people and researchers to conduct more research in this area (Hutson et al., 2022).

Chapter Four: Autism Discovery and Identity Development

Being Autistic Without Knowing it

This section is a collection of stories from before I understood my autistic identity. The stories chosen highlight experiences that I have not frequently seen described in the literature but deserve space for discussion and identification of similar experiences for other late-identified autistic people. All the stories below were part of my own revelations in re-processing my past once I recognized my autistic identity. These stories illuminated many parts of my past that I previously just thought were personal flaws, deficiencies, or odd difficulties when they were instead common experiences within the broader autistic community. This section is not an exhaustive list of stories highlighting all the ways in which I was autistic as a child. There were other stories that I set out to write in this section which had much stronger arguments in this way, making for a better explanation of why it was missed. Some stories were too difficult to even reflect on at any great length, and a few people from my personal life who were apart of those events would have access to this document. I had to exclude my strongest stories because I am uncomfortable to share them knowing that some of the parties involved might recognize themselves and be deeply saddened to know how it negatively impacted my life.

Nail Polish is Only for Girls

I can still vividly remember this one sunny Saturday on my quiet crescent in my sleepy suburban town. Every weekend that Chris stayed at his father's house he would run down the hill and around the corner and ring our doorbell, hoping I was home and he would be invited in. We were the same age and shared many of the same interests as kids. He and I did countless activities together, from colouring, crafting, playing dress up, baking or building things. Other times we played independently but we still felt connected in the same space just spending time

together. He was the youngest of 2 boys and I was the only child. We didn't have a strong concept of gendered activities. We were more drawn to do what was interesting to us than the gender norms associated with that type of activity. This particular Saturday while we were both spending time together at my house, I pulled out my colourful bin of nail polish. Chris watched me as I was trying to decide which colour I was going to pick. When I started to paint my nails, he was still watching and with so much curiosity and excitement he asked me to paint his nails too. It was like I had asked him what flavour of ice cream he wanted. Once he picked out the colour he wanted from the bin I happily painted them a sparkling deep purple colour. We both felt happy about our updated looks and how good his first experience and choice of colour looked on him. As usual, Chris would either forget the scheduled time or we would lose track of time and his brother would come by to collect him for supper. Like always, I was planning our next day's activities oblivious at that time as to how our fun activity would change me and our friendship. We were around eight years old, and this happened in the early 2000's. We didn't ever call each other, and we didn't have cell phones to text one another on so like usual, I waited for him to ring our doorbell to play together. Sunday came and went, and so did the next Saturday. I knew he was there, but he wasn't coming over, so my mom suggested that I go check on him.

He normally came to my place, but I wanted to play, so I timidly walked over to his house and rang his doorbell. His parents answered the door, and his stepmother quickly addressed me about how inappropriate it is to paint a boy's fingernails. As she was scolding me, I could see behind her Chris and his older brother listening in the distance. I was speechless and shocked. Apparently, what I had done to Chris not knowing it, was an inappropriate gender-specific beauty enhancement. I was raised with the encouragement to pursue any hobby or

interest. This was an eye-opener that other parents believed in gender-specific activities. After Chris's very tall, masculine, and intimidating father left the doorway, I asked her if we could still play today but she said that he wasn't allowed to. Finally, the day came when Chris came back to play. I felt so bad, and I asked Chris about what happened that day when he went home with painted nails. He too was stunned by the experience and went on about how much his fingers hurt after his stepmom finished scrubbing off the nail polish as soon as she saw it. He still wanted to let me know he loved his nails that day and that he would do it again too if he could.

This story outlines how both myself and a childhood friend didn't hold strong concepts of gender roles until they were forced onto us at a young and impressionable age. I am grateful that I was encouraged with gender-free exploration of interests. For a short while this shielded me from gender policing until I started engaging more with our broader community. I believe that one of the main reasons that my autistic nature was missed during my young years was due to how one primary parent saw themselves in me and accepted my personhood as I was, free from comparison with my peers, gender norms, and cultural/religious norms.

This vignette describes how I was first confronted with the concept of gendered-heteronormativity. I did not experience the policing of cisgender or heterosexual ideals at home, and instead developed a largely agender understanding of the world instead. Due to my concept of traditionally gendered items not being gendered, it was a rude awakening once I spent more time engaging with people outside of the home. Even though this gender policing didn't have to do directly with me, it did significantly impact how I saw the world and peer relationships thereafter. While authentically playing with a friend, I was caught unaware that a part of my self-expression and way of existing as myself in the world could be considered definitively wrong by someone else. The unexpected realization was that something I had done without meaning any ill

will had caused problems for that friend. After that, I began the state of being hyperaware of how I was behaving and how others would perceive it. I will be more careful now about how I behave with others. Even though I hadn't done any harm or disrespect to him or anyone I took this gender-specific reprimand quite personally. It significantly contributed to my hypervigilance and thoughts of being constantly self-monitoring for social compliance as I progressed through my elementary school years.

Autistic people, myself included, often feel a strong need to abide by rules, personal morals, and values. Due to my internalization of doing something incredibly wrong by breaking gender norms, I began to be aware of and work towards being the best version of my feminine self so I would not further break the gender norms of my environment. There was relative safety found in abiding by these norms, which was made easier when Chris moved away. When behaving and appearing as best I could as a feminine girl, especially while engaging with other girls, I felt more positively perceived by others avoided conflict and felt like less of an outsider. The more I was able to blend in with my assigned gender expression, the less likely I was to feel like I was doing something wrong.

Playground Analyst

In discussing childhood times when I acted oddly, my mother told me about a story from before I can remember. Most autoethnographies recall stories from the writer's own memory of their personal experiences. Despite this, I believe this story is important to include because it is a story from a time before I started masking, to compensate for my differences, and was truly acting as my authentic, autistic self. The child that my stay-at-home mom knew and spent all her time with before I entered school was a little person full of creativity and curiousness but did show signs in many unexpected ways of being different. I was early with many milestones

including walking but showed difficulty in some skills and abilities including reading and articulating what I was thinking or feeling. I needed more time, instructions, details, and attention to complete some milestones or tasks. I was still eager to do and learn whatever I could that interested me along the way. I am working to find that carefree person again in adulthood.

In the 90's, I lived in an older area of town and next door to fraternal twins who were less than six months older than me. We spent almost every day together since before we could walk. Starting at around the age of two our moms took us three on many excursions as well as daily trips down the block to play at a local playground while they sat on a bench to chat. My mom vividly remembers how I always sat on the bench with them, or alone somewhere close by, for about ten to twenty minutes, watching my friends intensely before engaging. She said,

I had no clue what you were thinking about even though I did ask. You just sat quietly, watching, looking at the playground, and around at whatever else you could see. My best guess is that you were studying everything and planning in your head what you wanted to do or not do, or if you even wanted to play with them. But I really had no clue. You wouldn't budge until you were ready, no matter if others encouraged you to go play or if you were going to miss out on something. You only played if and when you were ready, not a second before (Personal Communication, 2023).

My mom heard from other leaders in various groups how she should be pushing me more to play and interact with the other kids, and other moms did try to help at times with no luck. But as my first advocate, she sensed that their efforts were causing me tremendous stress and let me play however I wanted. She recognized how important it was for me to have this observation time before engaging. She also shared that I was much happier overall when I made the choice on whether I wanted to play alone or with others in the playground without challenging it. She said

“Some days you had no interest in playing what the others were playing, and you were content to do your own thing. Why would I force you to play something you didn’t want to just because the were and they wanted you to join? And other days, you’d play with the kids until you no longer wanted to, telling them you were done and out and then went on to do your own thing.” She would tell them “[Erin] will play when [they’re] ready to play, and [they] can play however [they’d] like.” Any form of play was acceptable, regardless of whether it was what the others were doing. This perspective tremendously shaped how I was able to eventually engage with others and my environment in my days before starting school.

When the playground was busy, she recalled how other parents would sometimes talk to her about how I wasn’t playing in the same way as the other kids. They would even make comments about her own parenting, saying that she should be doing better as a mom to socialize me. Even with comments from other mothers about my divergent behaviour, she always disregarded their feedback. She didn’t intervene during my bench-sitting time and even advocated for me with other pushy parents. She recalled saying to others a few times, “No, just let [them] be!”

Though this story may not be a textbook case of autistic behaviour, which is often rooted in us being unaccommodated, misunderstood, and pushed to our limits, it is a story of an autistic person’s natural tendencies not being pushed into neurotypical expectations of play. I believe that this story could be an example of textbook autistic behaviours if we are given the space to be ourselves. If I was regularly pushed to play before I was ready, or in ways that I didn’t feel comfortable with by my parent or others, then more distressing behaviours characteristic of unaccommodated autistic children would have arisen earlier on. Even growing up with twins next door who had more normative play styles, I was not compared or judged against them,

despite our different developmental milestones and ways of interacting with the world around us. This example of my differences being accepted and accommodated from such a young age meant that my early years of development didn't constantly struggle within an incompatible environment. Had my home not been so affirming and understanding of my needs and differences, I would have likely had more frequent meltdowns, behavioural concerns, and cognitive rigidities earlier on. Rather than experiencing difficulties with the way the world operates while young and under the close protection of my mom, I discovered them in my elementary school years and on, once the pressure from outside the home to conform was much stronger.

The often-understated influences of normative play and social interactions were present from before I was even capable of being aware of differences from neurotypical peers. In this vignette, my non-normative approach to watching the playground before engaging was met with pressure from parents of other children to engage normally. Their intention may not have been to dismiss my need to observe before engaging in play, but the result of their pushing was the attempted policing of neuronormativity through a socially acceptable way to play.

Being raised by neurodivergent parents who were raised to fit and blend in, they were unaware of their neurodivergence which resulted in my own divergent behaviours being protected at times and seen as normal within the smaller context of our family. Also, unknowingly they passed along many ways to think, cope and thrive, which they learned the hard way. Even though there are many stories of how my behaviours weren't normal within our broader community, they were accepted and protected by my mom because she had felt and experienced similar frustrations with more damaging consequences as an autistic person who just assumed she was different and damaged without understanding why. Her coping mechanisms,

compensatory skills, and advocacy for me allowed me to operate as my most authentic autistic self during my younger years. Once I began spending more time away from this protection and safety, especially at school, I began to experience the greater weight and expectations of neuronormativity within culture.

Where Did You Go?

I found it too challenging to connect with peers organically. I instead exploited the weaknesses of others and mostly neurodivergent peers to gain favour with classmates higher on the social ladder. Rather than spending my elementary school years focusing on learning and exploring the world, my primary concern was my psychological and social safety. In hindsight, this is when I started camouflaging and autistic masking.

Through my peer study, I tried to emulate their mannerisms and to become more like the people they liked. For example, in grade one I noticed my classmates really liked people who made jokes. Since I struggled to understand and make jokes, I tried to find other ways to make people laugh. Since I couldn't make jokes with words, I found ways to make people laugh by doing things physically. For example, another kid made others laugh by subtly cutting his hair when the teacher wasn't looking. Knowing I could also cut my hair and make kids laugh, I copied this behaviour with great success until a teacher noticed what I was doing and confiscated my scissors. Moving on I joined in with others that made us all laugh while centering out and annoying another person. For instance, I had a folding ruler which made a clicking noise each time it folded. I repeatedly clicked it until a nearby classmate grew angry and disrupted the class. Looking back, it's clear that the classmate I targeted was likely neurodivergent too.

In second grade, I noticed for the first time how a small collection of kids could control a whole group. Our school and class sizes were small, and the selection of friends was limited. As I watched from a safe distance, I witnessed them terrorize and ridicule others who shared similar ways of expression and interests as I had. In hindsight, they are common autistic traits that the group recognized as different, and they somehow felt that it justified their behaviour. The onset of my hypervigilance at school marked my perpetual self-scrutiny, as I perceived myself under constant surveillance by peers, trying to not do anything that seemed "weird." I was constantly aware of my gait as I walked between classes, where to put my left hand while my right hand was writing. Even how I raised my hand to ask a question of the teacher, how my face looked while I intensely focused on the lesson, and every other small movement that others might be watching me do throughout the school day. I would constantly listen in on the conversations of my peers and was always scanning for a judgmental look or any mention of me. It was also important to pay attention just in case they were mocking others behaviours that might be similar to anything I would do or say. I would watch them carefully to see who they would mime out, taking note of whatever they made jokes about, and paid careful attention to watch who they would pick on the most. All this was done to avoid being, the center of their toxic attention, believing that I would lose the few friends and sense of safety I had if I became their next target. The class bullies targeted the same few kids, yet it was their observations of Sabrina in particular who ignited my hypervigilance. She endured the brunt of their focus, and I saw myself and my own traits in her.

Sabrina was new to our class in grade two and freely displayed what I now know to be stereotypical and overt autistic behaviours. The only difference between her and I was that she openly displayed her individuality at school, being more carefree and truer to herself, whereas I

was more secretive and quieter, often hiding those traits. I worked hard to never expose those things to maintain my friendships and to prevent being the next target. One day in the classroom, our teacher announced the opportunity for us to win prizes in a special science competition. Excitement buzzed among the class as we discussed the criteria and guidelines. When the teacher revealed the prizes for the winning team, Sabrina literally leaped from her seat, enthusiastically flapping her arms, and letting out a high-pitched squeal. Her display mirrored how I felt, and I wanted to join in showing my excitement however, I stopped myself just in time when hearing the horrifying murmurs and laughs. Their mockery spread like wildfire throughout the class, with almost everyone, including myself, laughing at her. The teacher intervened and ordered us to stop, pointing out that this mockery is inappropriate. What remained more palpable in my mind was how the class teased and laughed at her genuine excitement in such a cruel way. I told myself to never show such excitement or reveal my true self at school.

The enthusiasm Sabrina showed that day was mimicked time and time again, adding to the negative image we were all to embrace. The fear of bullying loomed over me. I dreaded the prospect of being ridiculed, scorned, or mocked behind my back. I will never exhibit the wrong emotion, intensity, or physical behaviours at the wrong time. I wasn't safe to express my true self around my peers. This realization marked how isolated I needed to be from what I felt leading to excessive monitoring of others' perceptions and constant scrutiny of my body's actions and my mind's directives. While many perceived me as only shy, reserved, and anxious during that time, I was also becoming conscious of my differences and recognized the need to camouflage for my well-being.

These are the earliest moments I can pinpoint on why I started to mask autistic behaviours. Though these may seem trivial or standard behaviour made by peers when compared

to stories of intense bullying, the annotations of my peers were enough for me to recognize my differences and the potential harm I would experience if they were to turn toward me next. To varying degrees, people may alter themselves in some way when in public, or at school compared to home. The main difference between what I would say is a normal amount of change and what I did was because I truly believed that some parts of myself were so flawed that I had to create new mannerisms and ways of interacting with others. I needed to veer from my natural self to keep in the background and not be seen as the peculiar person. As a result of often not knowing how to behave, suitably, I withdrew and chose not to interact. I found that being perceived as shy was more socially acceptable than saying or doing the wrong thing. My shyness turned into a personality that followed me throughout elementary and into high school.

I had found a safe way to avoid being criticized for not socializing well was to hardly socialize at all. The development of my shy girl mask hid my autistic ways of communicating and being in the world. After moving away and attending two more elementary and three high schools in two different provinces, I was like a turtle who was slowly coming out from behind my shell of a mask, only to retreat into my shell at any signs of pushback from those around me. During that time if I had felt confident to embrace various forms of self-expression and interests and if others knew where I needed to be encouraged to explore regardless of competency or expression, I believe my corrective process of unmasking could have happened at a much earlier age than my twenties.

Feelings of distress and shame shaped my realization that differences in behaviour were viewed negatively by my peers. Having very little exposure to the concept that being different was bad before entering school, my harsh realization was that others had different perceptions about divergent behaviour than I did. Though I didn't identify or share this internal conflict of

feelings at the time, in hindsight being autistic and hiding it has taken me years to unravel the damage that followed me through into adulthood.

Poor Little Introvert

In the eleventh grade, which was the second of three private high schools, I qualified for the opportunity to participate in a working mission's trip spending eight weeks in the Dominican Republic. During this first time away from home, I experienced many problems that in hindsight had to do with my neurodivergence within an unaccommodating environment. My concerns were not understood and created many insecurities which had a lasting impact on my personal development. Of the many stories I could share about my teenage years as an unidentified autistic person, I will share this dreadful experience from my semester abroad.

I found myself in a complex social situation which despite my best effort, I could not bridge the gap of differences between myself and my peers. The program's structure and demands posed significant challenges for me. Each day, we were instructed minutes before we had to head out, if we were going to teach in a school or do manual labour on a job site. Without any control over my schedule and not being able to know about details in advance, I struggled to go with the flow and found it limited my ability to be present and do the work required of me. Another issue for me was that our lunches were packed for us, and we had no say over how much food we were given, or what it was. One of the worst meals we were served multiple times was sardine sandwich lunches. On those days, I would warily remove the sardines from the bread, reluctantly eating fishy-tasting bread as my only available sustenance while working under the hot Dominican sun. Meal options were non-negotiable, and our daily tasks were determined by a morning draw, leaving me unable to mentally prepare for teaching English or manual labour. One-on-one peer interactions, regardless of gender were prohibited. Further,

safety rules also stated that if we want to leave the facility, girls must always leave in groups with a male present. Also, during our scheduled free time, we had to either engage in group activities, or specific solo activities. I was far more comfortable with one-on-one conversations, which were prohibited, so I struggled to form connections. I frequently engaged in reading for my independent activity because I struggled to engage in a large group setting. I also had to share a room with six or more peers which negatively affected my sleep and didn't provide a reprieve from the amount of social interaction I had to participate in leaving me utterly exhausted.

Midway through the trip we were granted a Skype call. I had reached my limit, and I offloaded all my frustrations to my mom, stating that I couldn't endure the constantly changing environment any longer and needed her support. I was completely exhausted by being away from my routine, familiar surroundings, and was unable to self-regulate any longer. Following my meltdown, she reached out to my teacher who was on the trip with me, which led to a meeting involving the principal back home, my teacher, and other school leaders to discuss how to handle my well-being. Instead of providing some accommodations for me, the only solution they gave was for me to leave the program and fly home. Despite our efforts to explain how serious this was for me, it seemed that they interpreted my outburst as a privileged only child and hormonal teenager, wanting special treatment. I became apprehensive about choosing my preferred option due to the long-term social repercussions once back in school. The thought about how everyone in my small high school would know I failed to complete the program and transitioning into new classes halfway through the semester seemed even harder to endure. Rather than accommodating my needs which mostly evolved around communication, time to comprehend these new experiences and come to terms with them, I made the difficult decision to remain on the trip with no further accommodations. From my perspective at the time, the negative social consequences

of returning home mid-trip would have been greater and lasted beyond my time on the trip. A few weeks later, I heard another student's homesickness was accommodated by allowing them additional time on the phone to back home during our free time. I felt intense anger, hurt, and betrayal that my needs were unmet while this other student was. I felt deeply misunderstood and even more like an outsider. This sense of difference between myself and my peers only grew more distant throughout the trip. From that experience, I learned that sharing my concerns with even educated adults in authority for my well-being didn't help me. In fact, I only experienced more difficulties after expressing my needs, so this meant that I did my best to keep my needs inside after that.

Towards the end of our trip, we had a free day to either explore the town or remain in the facility for games or coursework. During that free time, I felt a sense of rejuvenating peace as I spent most of the day alone in my mosquito net-cloaked bunk bed catching up on a reading assignment, but I was unaware of how most of the day had passed by. My roommates spontaneously went out to the store and returned with ice cream, snacks, machetes, and other items, which I regretted missing out on. Now with renewed energy I asked if they wanted to go out again, but they declined. "We just came back, why would we want to go out again?" This was completely rational, but I realized that this was the last chance that we would have to go to the store before we left this town and went on to another location. I turned away and started crying to myself when I realized that I missed this opportunity. One of my roommates noticed and inquired about why I was crying. Reluctantly, I admitted feeling upset about missing out on the outing and souvenirs. This led to accusations of attention-seeking by others in the room, intensifying my emotional instability, word of my distress spread, prompting a small group of classmates to go out again for me. During the outing, a compassionate classmate asked if there

was anything else troubling me. I confessed my disappointment about not having many photos of my time on this trip because my point-and-shoot camera broke during our first few days of the trip. I also shared how difficult it was for me to join euchre games because everyone had a euchre partner except me. From that day onward, she made sure to take at least one photo of me at each new location. She also made sure that I had the opportunity to participate in future games by saying we should rotate euchre partners. Her advocacy and efforts to include me improved my social integration during the trip's final days.

Our debrief in the hours before our flight back to Canada, everyone in the class voiced their reluctance to leave, expressing feelings of sadness and anxiety about returning home. I distinctly recall most people crying or being near tears at the thought of returning home, while I was also near the point of tears out of excitement that the trip was finally ending. As part of the post-trip tradition, we were tasked with writing a note to each classmate on the trip. These notes were meant to foster a sense of continued connection among us, particularly for those who had developed strong bonds during our time together and were expecting feelings of separation upon their return. When the notes were distributed, I noticed that my envelope was notably thinner compared to the thick and bulging envelopes of the more sociable members of our group. This observation further highlighted the disconnect I felt between my peers and myself.

When back home, I read the letters from my peers and felt even more disconnected from them. They truly did not understand me or value my differences, even after spending two months together. One of the letters from a peer said that she didn't realize how much I was struggling on the trip until that day I cried in our communal bedroom. Another person wrote that she felt bad for me being such a "poor little introvert," wishing she could have helped me talk more so that we could have been better friends. This was the theme among many other classmate's letters,

them stating regret around not getting to know me very well and mentioning my shyness or quietness as the cause for our lack of connection. I remember feeling particularly broken. I seemed incapable of connecting with others and this collection of statements about my inadequacies during the trip solidified it. I took their observations to the internet after, wondering if I may have a personality disorder affecting my ability to empathize and socialize with others. After that deep dive, I wondered if I might have antisocial personality disorder. I came to this conclusion in part because I failed to bond with others in the group, but also because when we saw such devastating poverty, starvation, and visited an orphanage for children with disabilities, I did not cry like the others. Believing that I did not have sufficient empathy on top of failing to connect with my peers on this trip fueled my fifteen-year-old mind to believe the worst about myself. Seeing the challenges I faced within the group, my mom made concerted efforts to engage with me in ways that brought me happiness and a sense of connection upon my return. She encouraged me to re-engage with my few friends and my hobbies, particularly reading. Even though our family was facing significant financial constraints, she treated me to choose a stack of books from the bookstore to take home, knowing how passionate I was about reading. Once again, my mom acted as my intercessor, both directly with me and with the school. Through her efforts, she reintroduced me to the niches and interests that replaced feelings of isolation and disconnection with excitement and joy.

While my introverted and anxious self provided me much relief in the social and identity struggles I had as a teen, it also created a barrier to my autistic identity. I used my identification with the word introvert to describe how I socialized while in high school. Finding this word to describe myself was one way that I displaced the negative view I had towards myself for not fitting in or being able to participate in a social group very well like my peers. After reading

Susan Cain's (2012) book *Quiet: The Power Of Introverts In A World That Can't Stop Talking*, I found myself feeling more at ease in my own skin. My revelation from the book was since our culture's environment is designed by and for extroverts, this was why I felt so disconnected and incapable of operating like a normal person in society. Reconsidering some of my internal struggles and placing them where they belong on to the external environment, I was able to feel more confident in who I was despite struggling tremendously with the environment I was in. Cain's (2012) chapters discussed how friendships and relationships can be more harmonious or have more tension based on each person's level of introversion or extroversion. This provided me with a framework for how to seek out others that I may be more likely to have successful connections with. I found that close friendships with other introverts provided me with a greater sense of community rather than trying to become an extrovert with extroverted peers. Though the label of introvert was helpful at the time, it didn't get to the root cause of my feelings of disconnection and differences from my peers.

The next label I found to describe myself was anxious. To be more specific, I used to describe myself as socially anxious, environmentally anxious, sensitive to the environment, easily overwhelmed and needing predictability to reduce anxiety. Due to the significant increase in discussions of mental health during the 2010's, I found myself among them using anxiety to describe many experiences which were both anxiety and other causes that I now have the language from autism to describe more accurately.

Like many other autistic people, I explored the internet and found some words that might describe me: Highly Sensitive Person (HSP), antisocial personality, and autism. Based on what I was reading at that time, none of my experiences seemed to clearly fit the descriptions, but I did fit a few of each. I read that highly sensitive persons tend to experience the emotions of others

strongly, but I had memories of responding with low empathy in some situations. Like my trip to the Dominican, I remembered being questioned by family about why I was not crying or appearing sad when we had to put down our family dog who had been my playmate since before I was born. Everyone had lost their appetite that day our dog's one way-trip to the vet's office that morning, but I was more concerned about how it was past lunchtime. I was baffled by my irregular heightened or muted reactions to situations from being so overwhelmed riding on a school bus and being almost numb to my dog's passing away. We knew that something was different but couldn't figure out why that was the case. The textbook descriptions of autism often mentioned the lack of desire for social connection, which could not have been further from the truth for me. I constantly desired feelings of social connection but was unable to achieve them. I didn't identify that my hyperfocused fixations and obsessions with a toy or television show were comparable to the textbook examples of trains and dinosaurs. Instead of recognizing myself as autistic even with access to the internet and having looked at articles on autism, I didn't generalize these online descriptions. I most strongly found myself agreeing with the experiences of introverts and people with social anxiety instead. In hindsight, I wonder how many of those folks who identified as a socially anxious introvert have since found autism to better describe themselves now that more diverse autism representation is being presented online.

It's A Sign

For my eighteenth birthday, my celebratory restaurant of choice was Canada's only all-Deaf staffed restaurant called Signs. It was the only restaurant of its kind where patrons communicated with the staff using sign language. I rehearsed for this special night out by practicing ASL with my Deaf friend. I was excited and ready to order for our table at the restaurant with my prepared script. My parents, boyfriend, and I rode together to downtown

Toronto, parked on the busy main street, and were seated in a comfy booth in the middle of the restaurant. Looking around, there was ASL hand-gesture signs plastering the walls, more wait staff than patrons, with their hands moving and mouths moving, and comforting aromas filling the space. The light bulb above our heads had a glass cover that didn't diffuse any light onto our table below. These compounding experiences became overwhelming, and I began to lose my ability to form thoughts or words.

Before we could order our meal, intense waves of heat rushed over my body, building in intensity. As I stared at the menu's many options, I couldn't pick one to order. My heart began racing, my body sweating, and I couldn't even focus my eyes on the menu anymore. I was being rushed to decide, adding to my building struggle. After a few minutes of this intense discomfort, I felt an unexplainable impulse to get up and leave and run away to anywhere but there. The hunger and excitement I once felt for the opportunity to use the sign language I had been hyperfixating on learning fell far behind my increasing need to leave this situation. I was unable to use the ASL I prepared, unable to communicate what I was feeling with everyone at my table, and I needed to leave. The best option I could think of to escape was to go to the washroom. It took every ounce of my energy to form the words "I need to go to the washroom." Still needing my order, I was pushed to decide before I got up from the table. Since my menu was open, I picked what was on that page; a BBQ chicken Caesar salad and rushed off. I probably would not have chosen that any other day, but it was done. Once in the washroom, I hardly felt better. After a few minutes and feeling like I had spent too long away from the table trying to find the words to explain whatever I was unable to express verbally, I returned to my seat. By the time I had returned, the orders were already taken. I had missed my chance of ordering for all of us in ASL which was the very reason I had picked this place that I looked forward to for months. As soon

as I returned to the booth, overwhelming pangs of heat, tension, and the urge to run away continued to build up in my body. I could only stare at the table, unable to carry a conversation. I soon said “Sorry, I have to go, I’ll come back when the food arrives” and with that, went outside. I overheard my mom suggesting that my boyfriend follow me outside, but I refused the company. Once I walked outside the restaurant’s front doors, I walked up Yonge Street to the corner of Yonge and Wellesley Street. I sat on the steps of a convenience store with my head in my trembling hands, trying to take deep breaths while occasionally letting out groans of tension from my chest. Quickly losing my ability to think coherently again, I focused my energy on keeping my hands planted in my face and elbows touching my knees, trying to stay seated on that street corner, fighting the urge to lose myself in my indescribable anguish. As my birthday meal progressed in my absence, each guest took turns trying to coax me back inside. No comfort or coercion could ease the overwhelming feeling that I could physically catch fire and explode simultaneously at any moment. Sitting on that busy street corner, I only felt pain and overwhelmed, simply trying my best to just tolerate my own existence. I didn’t go back inside the restaurant, and my meal was put into a takeout container. It was time to go home, in the uncomfortably quiet car ride back home to the suburbs. Even though I felt utterly drained I felt a comforting sense of relief to be strapped in the car as we headed back home. During my recovery, I felt embarrassed about my conduct and the impact I had on the evening. I was very disappointed in myself for spoiling the experience for us all that I was eagerly anticipating. This feeling persisted at school, where I felt guilty for misleading my peers that I enjoyed the restaurant experience.

I now speculated that maybe some of the anxiety and panic is from being overstimulated or sensory overwhelm. I worked with a therapist to overcome my displays of panic and anxiety

around these environmental triggers with little success. If I had access to more comparable knowledge and language to describe how these environments impacted me, I could have made more informed choices about how I wanted to spend my time. I often instead felt frustrated by why, despite my best efforts, I couldn't overcome what I now know to be called overstimulation. I should have had access to accommodations or adaptations for my sensory sensitivities such as headphones and stim tools. I believe that this would have helped alleviate years of thinking that I was failing to solve a problem about myself. With the label of autism, I would have started to accept these parts of myself, avoiding what could be avoided and accommodating what couldn't.

I believe a large reason why I pursued an undergraduate degree in psychology was to find explanations for my own struggles around understanding both myself and the world around me. I pursued the study of the human mind to understand my own and better interpret how I could feel complete. The more time I spent studying psychology, the greater the gap I felt between myself and the disorders I was reading about. The pathologizing of the symptoms and experiences of people with the diagnoses mentioned made me feel as though those people were a completely different species with such serious problems that I couldn't relate with. When I later learned that many of my peers had the very diagnoses that I'd learned about, I was at times shocked due to how normative they appeared to behave. For example, I remember the first time a close friend told me she had major depressive disorder in my 3rd year of my psychology program. I was stunned by this because of the amount of time I spent with her and that she didn't seem to align with the descriptions of severity we were taught required for that diagnosis. There were persons I knew who attended school with me with other diagnoses including depression, bipolar, ADHD and anxiety all of which displayed differently from what I was taught in class. At the time, I still didn't have autism on my radar as a potential area I needed to re-evaluate. Perhaps this was

largely due to not knowing of any peers who were autistic or publicly identified as autistic at the time. If I'd known even one openly autistic person who shared a few autistic traits with me, I believe that I would have been able to discover for myself that I was autistic earlier. If that person were in a mentoring, teaching, or supervisory capacity, I believe that this would have been ideal for exposing me to the idea that autistic people can be in all areas of life, not just at the ABA camps for young boys held in the basement of our university.

Connecting my experiences with the literature, since I struggled to feel truly understood, part of a community, and understand myself with the language I had, I experienced hermeneutical injustice. Hermeneutical injustice is defined as “undue intelligibility deficit: because of biases in either conceptual or expressive resources, the speaker’s contribution or experience is not adequately understood, whether by the speaker or by others.” (Catala et al., 2021, p. 9018). This injustice led to years of feeling alien, wrong, and knowing something was different but unable to access the knowledge or language to describe what it was. This ultimately negatively impacted my self-concept and identity.

Discovering Autism

There’s a Word for That

After work on a warm summer’s day, I sat outside with a library book called *Spectrums: Autistic Transgender People in Their Own Words* for the first time (Sparrow, 2020). Little did I know that the stories enclosed in this book would fundamentally alter my self-concept, identity, and life course. For the first time in my mid-twenties, other people's stories reflected my understanding of identity, gender, sexuality, and place in the world. They had words to explain experiences that I was unable to articulate. Many stories that I read and saw online about trans

identity did not resonate with me until I read stories of autistic trans folks. I discovered then that the way I see, interact with, and move through the world was so tied to my autism that these differences would also impact my experience of gender. In hindsight, I didn't fully understand my gender until I had the words given to me to accurately explain them. Having new vocabulary and concepts from trans autistic authors offered me a completely different way of looking at and understanding myself and the world. Finally, the words on the page matched with my reality.

For the first time, I could identify fully with the stories written in the anthology and by extension, found community and belonging. I am an autistic, trans, queer, asexual-spectrum from a religious and a broken family with multiple health conditions. The mainstream presentations of friendship, relationships, gender, family, community, and employment in mass media didn't reflect my lived experiences. All the widely published representations of living I saw up until that point focused on neurotypical ways of interacting and experiencing the world were not a reflection of me. For example, when watching neurotypical trans experiences online, I concluded that wasn't my truth until I saw how trans autistic people described their own feelings and experiences. This is just one example of how the many parts of my identity took longer to discover and understand due to the lack of representation of stories within my intersections and lived experiences.

Halfway through *Spectrums*, I started a chapter by Baden Gaeke-Franz organized by years in their life, with specific stories, commentary, and reflection (2020). I was reading about their life, but it felt like I was reading about my own experiences, with similar developments across our lives almost down to the same year. We both felt not trans, nor autistic enough due to how the world often perceives transness through a neurotypical lens and autism through a straight, cisgender lens. Once I was entirely transported into Baden's story about their gender

and autism journey, I was astonished by a brief paragraph looking into grad school and writing a thesis on the topic of autistic trans people. Seeing myself and my life experiences reflected in those pages sparked the desire within me to explore how I could also find another way to get into grad school. I didn't realize until reading that book, identifying with other trans-autistic people, and reading their amazing work in the community that I could do the same.

Development of Autistic Identity

The COVID-19 Catalyst

My environment played an essential role in my journey towards accepting myself for who I am. I didn't feel comfortable to actively explore and try out different self-concepts until a series of major life changes took place within a matter of months. Being in a long-term same-sex relationship mirroring neuronormative and heteronormative dynamics, I had minimal room to experiment with queering my self-expression or contemplating if my identity is a good fit. The COVID-19 pandemic and ensuing lockdown was the catalyst for taking in the identity of autistic and making changes towards living a more authentic and sustainable life.

In March 2020, my partner and I, both in corporate work, transitioned to remote work, and were subjected to strict limitations on activities outside our home, much like everyone else in the world. This enforced solitude compelled me to reassess my chosen lifestyle, long-term partnership, and career trajectory. This may not seem to directly relate to my autistic identity development, but it collectively laid the groundwork for the facade I constructed to maintain a semblance of security in my lifestyle, and it was rapidly headed toward burnout. The first cracks in the neurotypical presenting mask that I had worked years to create started to form when my long-term partner and I separated soon after lockdown in the Summer of 2020.

Internalized heteronormativity is another important factor present here. Similarly to internalized ableism being part of my journey of undoing when accepting my autistic identity, so too is internalized heteronormativity. Though I discovered my queer identity years before my autistic one, my own internalized heteronormativity was still seeped into my queer identity. While in a stable, long-term relationship and identifying as a cis lesbian at the time, I did not deconstruct my heteronormative concepts of relationships. Instead of queering all aspects of romantic relationships, I had internalized heteronormativity so much that I only changed one variable, which was the gender of the person, but kept nearly all other aspects of the relationship the same. By perpetuating the very systems of oppression which I was trying to break free of without even realizing it at the time, I was limiting myself of discovering my full identity and ways of living which would better align with my values and true self.

In the summer of 2020, I left a vibrant downtown city life to move into a suburban basement apartment with a backyard for my dog. This major change in environment created new routines, with new opportunities for self-discovery and exploration. A month and a half after moving to the suburbs, I bought my first car. This was a life-changing purchase which allowed me to experience a new level of self-reliance and independence that created a passion for exploring and enabled me to gain a connection to nature I had never experienced before. Driving throughout the seasons, weather conditions, and across long distances allowed me to tune into my environment and self in ways I hadn't realized could be possible.

I also started a more queered relationship with a non-binary person. During this time, we co-created a supportive space to explore ourselves more authentically. We found social media content created by autistic creators which ignited further self-exploration into this area of active autistic identity exploration. In this creative environment, I explored what an autistic identity

meant for me practically and how to be my authentic self. First, I started to pay more attention to my body's cues and less time forcing myself to act, think, or feel in ways that were not natural for me. As I found posts written by autistic people for autistic people, I found myself becoming more comfortable in my body, better able to cope with stressors, and navigate the world around me.

For example, in a post called "Tips for newly diagnosed/discovered autistics," @neurodivergent_lou described how experimenting with self-stimulatory behaviours and how it can be helpful to explore, especially since many autistics have been trained out of using helpful stimming behaviours (2021). They listed behavioural movements, fidget items, apps, and other materials to use to support exploratory stimming. Posts like this on social media were critical in exploring and developing new ways of understanding myself and moving throughout the world. I actively explored common autistic stimming, facilitated by fidget toys, and purchased my first pair of noise-cancelling headphones.

Grocery shopping has been a deeply uncomfortable sensory experience for me which I struggled with even pre-autism identification. The informal assistance I had while living with a previous partner included me waiting outside of the grocery store with our grocery trolley while she went inside and did the grocery shopping. The first time I chose to explore how to find the best way for me to navigate difficult spaces took place when we separated. At that time, curbside pickup was newly available due to lockdown restrictions, and this made the transition to solo grocery shopping much easier. It was a very imperfect process, where frequent returns were required due to broken eggs, expired products or the wrong items were selected by the grocery picker. I began going into grocery stores as a result. Once I discovered the methods that autistic folks use to accommodate themselves in sensorily overwhelming environments, I tried it for

myself. The first few times I went into public with my noise-cancelling headphones, sunglasses, and sometimes hat on with my mask, I felt incredibly self-conscious and anxious about standing out from others around me. However, the relief I found from making those adaptations ended up outweighing the anxiety and stress I felt about how I appeared to others. Once headphones and sunglasses became a habitual practice for me, the anxiety I once felt about it melted away, leaving only a more comfortable shopping experience in its place. If people have ever made comments about my appearance, I haven't heard them. Another unexpected benefit of such practices while shopping included me feeling less inclined to force smiles and eye contact since they couldn't see it behind my mask and dark mirrored sunglasses, anyway. This new period of trial and error in self-exploration was intentionally queered and authentically me. I explored changes in my gender expression and identity, and new ways of engaging relationally outside of the confines of heteronormativity and neuronormativity. This allowed me to also explore autistic expression at the same time, which I pushed away by my internalized heteronormativity.

The Intersection of Gender and Autism Identity

As I became more comfortable exploring new autistic forms of self-expression and identity, I found my desire to change how I was living intensified exponentially. I found myself increasingly dissatisfied with areas of my life that I had given much credence to, including how my voice sounded, my name, and how others saw me. Rather than seeking to constantly avoid conflict or being seen as weird, I was instead seeking to feel more comfortable in my own skin. One of those steps I took while exploring my own autistic identity was my gender identity as well. I found while assessing my autistic mask that much of it was related to presentations of gender that didn't fit me, or at least didn't fit me all the time. While I was living downtown and working in a corporate media company, I explored my fashion choices toward a more masculine

presentation, wearing button-down shirts with a blazer almost every day, but I never strayed from stereotypical lesbian attire. Instead of keeping myself in the box of lesbian and exploring from there, I operated from the position of a human first and rejected the gendered cultural associations that surround clothes, hair, and other various forms of self-expression.

While pursuing my new genderless self-expression, I cut off fourteen inches of my hair, thrifted an entirely new (sensory-friendly) wardrobe, changed my name, pronouns, and started testosterone to lower my voice. To the outside world, it may have appeared that I swung the pendulum towards an entirely masculine appearance, however, I still found joy in many traditionally feminine items including floral prints, jewelry, and some dresses. While a single word to describe my own gender still does not exist for me, I would say the word that comes closest is agender. To me, this means that I do not have any gender. I am not a man or a woman, and my gender expression should not be seen as expressing, masculinity, femininity, or anything within that binary. Rather, it is based on how I feel as a human apart from societal conceptions of gender. At times I may choose to engage in specific attire that matches how I want others to see me, but it is different from my own self-concept of my own gender. For example, to be recognized by others as more of a queer person, I may emphasize dressing masculinely. When travelling through the United States, due to anti-trans legislation and high incidences of hate crimes, I chose to dress very feminine to avoid hostility. I don't inherently find masculine or feminine presentations dysphoric. Instead, both are integral to me, and I enjoy swiftly transitioning between or blending them. I used to struggle with persons who weren't sure what to interpret from my non-binary identity. Only in recent years have I started to acknowledge and actively pursue the positive effects of others perceiving and understanding me as non-binary. My dysphoria in many aspects of my life led me to believe I was cisgender until I realized I could

freely express myself without the singular expression I once thought was essential for being transgender. Despite experiencing only mild dysphoria then and now, the harmony I feel from expressing myself differently than in the past is applicable to embrace my identity as a transgender, agender person.

Why share this gender identity development story when it doesn't seem to relate to autism? Because for me and many others, my gender and autism are inextricably linked. My gender is the way it is because I am autistic. Take away one, and the other might cease to be as it is. The variables of gender and autistic identity in my own life are dependent on one another. Though this may not be the case for all trans autistic folks, I believe that my own conceptions of community, and culture, and the ways I interact and perceive the world around me have a large impact on my own gender and gender expression. This sentiment was similarly described, "gender is a flimsy social construct that can often seem nonsensical to people on the autism spectrum" (Adams & Liang, 2020, p. 146). I also agree with this sentiment because, although I grasp the gender constructs of society, they no longer influence or define my own self-concept.

In its simplest form, many of the clothes I wear are made of materials and shapes that are most sensorily tolerable for me. My priority in clothes is not how masculine or feminine a piece is, but rather how comfortable it is and whether the design is something I can tolerate that day. Most busy days, I prioritize wearing plain clothes without designs or bright colours. Opting for loose-fitting black and dark blue garments allows me to feel the least stimulated by what I am wearing. These comfortable outfits also happen to be more androgynous or masculine presenting. On days when I am working from home and not planning to see anyone, I tend to gravitate towards wearing an oversized pink t-shirt and pink sweatpants for optimal comfort and the enjoyment that comes from wearing a colour that I find calming from head to toe. Other days

when it's hot outside, I often want to wear a cotton dress because of the way the breeze flows through the garment, not because they are typically perceived to be feminine and worn by women. On other hot days, I opt for shorts if I will be active because a flowing garment would be hindering. I tend to avoid tight-fitting clothes due to the increased likelihood of experiencing agitation from wearing them. My perceptions and experiences of clothing are aligned with the reported experiences of other autistic adults (Kyriacou et al., 2023). This included others reporting that they preferred clothes that they couldn't feel, that weren't tight, breathed well, and didn't have patterns. They also reported cutting off the tags from their garments, as do I, along with struggling with the sensory experiences of seams. This is another aspect of my clothing choices that I prioritize. How I value my sensory needs and devalue how others perceive the garments is one of the ways I see my autistic identity and gender identity being inseparable. I prioritize my sensory needs over fashion or how others may perceive the gendering of my clothing choices. Though I could not find any literature focusing on the intersection of clothing choices, gender, and autism, there is research which found that 75% of a small sample reported hypersensitivity to clothing materials, tags, and the tightness of the materials (MacLennan et al., 2022).

External Validation and Self-Doubt

I didn't publicly come out as queer until I was in a stable long-term relationship in undergrad, and I didn't come out as autistic until I was formally diagnosed. I felt a strong need to have my identity validated by others before making those bold statements which went against neuronormative and heteronormative society on my own. Not believing I had the authority to assert such claims about myself, I relied on others to help prove these things to be true. Before I had been formally diagnosed, the only people I disclosed this to was my partner, mother, and one

friend who directly asked me. A conversation with this friend took place on Instagram (personal communication, February 11, 2021). She said, “Girl are you autistic? Because same” and I responded “OMG Staaahp really?? That's so cool. Maybe that’s part of why we get along so well 🤔”. And she responded stating “Ahah there was a connection we never even knew about.”

Upon conversing with her during the writing of this vignette, she could not recall what prompted her to ask this question. Somehow, we connected deeply without knowing each other’s neurodivergence, and had commonalities in our ways of thinking which weren’t explicitly stated yet. After confirming with her our shared neurotype, we were able to explore our experiences of being neurodivergent in a neurotypical world together. She wasn’t diagnosed as autistic, but I was. We shared many stories about our autistic traits and experiences which solidified in my mind the importance of self-identification without the need for a formal diagnosis. We connected so deeply on our shared experiences, and in those stories, my diagnosis did not change how we both experienced the same barriers, concerns and prejudices by society. With her being my first autistic friend, I also developed for the first time a strong sense of connection with autism as something outside of myself, something that others could have without a formal diagnosis and still be valid.

Through that connection, I continued my process of coming out as autistic with more people that I interacted with, which further reduced the self-doubt that I had through positive interactions. For example, while getting a haircut, I disclosed to my stylist that I was autistic and they paused the haircut momentarily to exclaim how they thought that they, too were neurodivergent (personal communication, June 22, 2021). They thought it was cool that I had a diagnosis but there was no way they would be able to get a diagnosis with their intersections as a queer and non-binary person of Indo-Guyanese descent. With immigrant parents who have

limited English and differences in perspective about child development, paired with their unwillingness to speak to a psychologist, they said it would be pointless to get assessed for autism since they had to submit a parental report of their childhood issues. My fifteen-minute haircut appointment turned into two and a half hours of talking about the validity of self-identification and self-diagnosis of autism as an alternative for them due to the barriers they faced to formal diagnosis. They continued to doubt their own ability to make that determination for themselves, expressing similar concerns to the ones that I had in being able to make such a strong claim about oneself. A couple of months later I had another hair appointment. I enquired how they were feeling about their own neurodivergence journey of discovery. They responded that they are starting to verbalize that they are an ADHD and autistic person, hesitantly and cautiously (personal communication, August 25, 2022). They said that it was a very difficult concept to accept, and that they had the authority to make such a statement about themselves. Nevertheless, they were starting to believe it about themselves the more they interacted with other neurodivergent people and felt part of a larger group of people with similar shared experiences. They noted a caveat however, that they believed that they wouldn't feel comfortable making those claims publicly due to issues with family beliefs and prejudices.

About a year later, they came out as neurodivergent publicly, shedding the self-doubt they once had, which was from the medicalized notions of deficits and diagnosis (personal communication, August 28, 2023). The validity of their autism and ADHD was developed internally through connecting with other neurodivergent people and identifying as part of a larger community. The validation of their neurodivergence from a psychologist was not required when they had the neurodivergent community providing all of the validation they needed to feel connected and affirmed. Similar sentiments were found among non-diagnosed autistic adults,

including (1) self-identification before seeking a diagnosis, (2) identifying despite the diagnosis, and (3) seeking self-identification as an alternative to diagnosis (Routledge, 2024). For my friend and many others who experience barriers to formal diagnosis, there is no other option but to self-identify.

Malingering or Autistic?

“It doesn’t seem like you have autism, you communicate well,” said a psychologist during her administration of my psychoeducational assessment in the Fall of 2022. My experiences described here of the invalidation I felt by a medical professional is not uncommon among my autistic friends and community. My discussion of this invalidating assessment led me to realize that even though I may not always be recognized as autistic, the real-life negative experiences of being autistic in this world still often apply to me. I felt distressed by the opinionated view of this professional when I was seeking a thorough assessment of my strengths and weaknesses in my psychoeducational assessment. I am certain that I did not receive a thorough assessment report due to clinician bias.

For this assessment I brought copies of my autism, ADHD, and adaptive functioning reports and diagnosis letters. I was stunned with disbelief when she had verbally dismissed and rejected parts of my identity and formal diagnoses within a few hours into the assessment. Despite these diagnoses, classified as developmental disabilities, she stated in the report, “Erin does not have a developmental disability.” Hearing dismissive comments is not uncommon for me when I disclose my autism, especially to medical professionals. That same psychologist then later wrote in my report, “Their verbal responses frequently included elaborations that were not responsive to the question, but that reiterated problems that they have experienced.” The psychologist failed to account for elaborations and veering off-topic being common traits of how

autistic people convey their thoughts. She also stated, “Erin asked some questions about the questions, which would have solicited the answer to the question, had a response been permitted.” She also failed to acknowledge a common trait among autistic folks is that we often need greater specificity to understand a task more fully before delivery. Though this assessment report did not include the word malingering to describe my results and behaviour, I will share how the psychologist stated this indirectly and the negative impact it had on my growth of self.

Even though she wrote, “Erin participated easily in the videoconference...” it was a well-performed facade. I was heavily suppressing anxiety, anger, and disappointment towards her uncensored comments and about the added stress I was subjecting myself to. Years of watching others effortless performances were my training for camouflaging and self-taught survival method of hiding my true emotions. It led me to develop strong competencies to appear calm, cool, collected, and convincingly neurotypical in difficult situations. My testimony of struggle and difficulty was interpreted as incongruent with how I communicated and presented myself to her. It was incredibly difficult to receive her inferences that my self-report was untruthful and that my previous diagnoses couldn't be plausible. She stated in her final report,

On measures of symptom validity, Erin's responses indicated exaggeration symptoms, with an improbable pattern that does not fit within any diagnostic pattern or with their existing diagnoses. Current results also rule out dementia. Their symptom reports must therefore be taken to be non-credible.

In addition to the non-credibility of my own self-report to questions asked, my previous test results were also deemed invalid by her. She wrote, “Their pattern of failing very easy tests while passing more difficult tests signals that the results of this assessment must be taken as minimal indications of Erin's functioning. She later wrote,

It is difficult to ascertain whether Erin's low scores in math computations are an accurate reflection of their actual abilities, due to issues with validity raised during the assessment, at least Average problem-solving skills. Nevertheless, Erin may wish to use a calculator when completing math operations (which is typically provided as a universal accommodation to all students).

There are two parts of her report that I think are important to the interpretation of it. First, is her disbelief that I struggled to do simple math despite having problem-solving abilities. These problem solving skills were the primary focus of the more difficult word-based math questions, as though a sheet full of multiplication questions versus word questions requiring non-math based logic are the same. Having a "spiky profile" where there is a strong contrast of functioning being very high in some areas, and very low in others, has been described in the literature to be experienced by neurodivergent people (Doyle, 2020, p. 109). The Weschler Adult Intelligence Scale was one of the tests utilized in my assessment. My scores were average in most areas, with some parts having slightly above-average scores, and a couple parts scoring very low, at the bottom percentile. Doyle (2020) utilized the same scale I was assessed with to illustrate the negative impact of spiky profiles on neurodivergent people. What this spiky profile means, is that while the average person's scores may remain fairly consistent across different parts of the test, the spiky profile may have different areas significantly higher than average, lower than average, and average, all within the same test. Due to this psychologist's lack of recognition of spiky cognitive profiles, the results of my non-average scores led to the interpretation that it was due to my own "minimal effort".

One of the areas in which I had incredibly low scores was in some of the mathematics questions. I have always struggled with executing basic mathematics. For example, I never fully

grasped parts of math including the order of operations, double- or triple-digit subtraction and multiplication, and the multiplication table. In the case of the mathematics testing used during this assessment, I believe that purely number questions such as fraction multiplication or speed subtraction of multiple-digit numbers require different knowledge and cognitive processes than using the logical reasoning required of the “harder” math questions. Many of the more difficult mathematical questions required more logical reasoning than actual mathematics abilities. I explained to her in the assessment report meeting that it did make sense why I was unable to do the “easy” questions and did better on the “difficult” ones, because for me basic math is difficult, but using logic, language, and reasoning to solve problems is easier. She dismissed my self-report and explanations, saying that the test results were the results (referring to the scores being invalid), which was incredibly difficult for me to trust. Even when disputing her claims directly at the time of the assessment report and after in email form, she did change her interpretation of my results.

It's possible that one of the major contributors to the psychologist not believing my self-report of symptoms was due to gender bias. Even though I am non-binary, I look and sound like a queer woman in the eyes of society. Because of this, I am usually perceived by others to be a woman and experience many of the same gender-based issues that women face. This is not limited to just social interactions. Even in the final report that the psychologist sent to me, despite my stating that I only use they/them pronouns, she used both she and they pronouns in the report when referring to me.

After receiving her final report, which did not include any test scores, percentiles, or ranges, I requested them for my own records. When she emailed only one of the many reports she conducted, she replied with the report and stated, “...it is not in your best interest to invite

unqualified persons to interpret your scores.” Even though I am not trained on how to interpret these test scores and am unable to afford another psychologist to review it, I downloaded all the guides and interpretation materials that I could to reevaluate and discern the truth. After spending hours learning how to interpret these tests, I found that my test results varied drastically by the measure being taken. For example, I found that my calculation and math facts fluency percentile rank across multiple tests were 1-10 (RPI 0/90-17/90), meanwhile my sentence writing fluency and other written factors had a percentile rank of 79-82 (RPI 96/90-99/90). Believing my results to be valid indicators of my abilities, I found my own analysis of the scores alone to be valuable to see which areas of my cognitive abilities were lower than others.

I shared with the psychologist during my intake that I was struggling with completion and comprehension of readings throughout my time at college and university. I described how I had to take a part-time course load, tutoring and extra semesters. I took much longer than my peers to complete assignments and readings when studying together. I was aware of these differences between myself and my peers throughout all my schooling and wanted to pinpoint exactly what that difference was to better utilize my time and probability for success. I also stated that I was using assistive software but was still struggling and I hoped the tests conducted would provide potential answers for how to bridge the gap. When I provided this “elaborate” and “off-topic” response to her question, she responded by declaring that university is inherently difficult, every student struggles to read academic work and complete assignments. When I re-stated that I noticed differences between my peers and I when working together in the length of time it took me to read and comprehend the same readings, she dismissed it, saying something like “most people in university are above average, so your average abilities may appear below average.” She continued, “you are average, but the people you are surrounded by are above average”

Hearing her say that before the testing was even halfway completed, I was foreseeing that my normative appearance was going to mean that my concerns would be dismissed.

In the recommendations section of her report, she suggested as an accommodation that I “may wish” to use a calculator, which is a universal accommodation for all students. She also conveyed that “Many students find the use of test-to-speech software helpful when completing longer reading tasks. As such the student may wish to use software...” indicating that again, I can “wish” to use accommodations rather than understanding my necessity for them. Further, she wrote “Erin will need to be candid about their functioning, including both strengths and any problems being experienced.” I had shared my experiences openly and candidly with her, and they were taken to be non-credible. She continued, “It is not possible to establish what factors might have interfered with Erin’s optimal engagement during testing and when reporting on their difficulties.” When asked about my efforts during testing, I said that I was fully engaged and trying my absolute best throughout the entire assessment. Further, she wrote about her observation of my behaviours in that, “They generally persisted with difficult tasks, could indicate when they reached the limit of their knowledge” and to the contrary that “They were attentive to tasks, with no lapses evident.” I was in disbelief that she reported suboptimal engagement despite also claiming my attentiveness when seemingly aiming to dismiss my ADHD diagnosis.

It is a common theme throughout my life that teachers and others have persistently believed I should be able to do something that I was repeatedly unable to do despite my best effort. In contrast to how many non-speaking autistic people have the problem of presumed incompetence (Sequenzia & Grace, 2015), I have experienced presumed competence. Due to my invisible disabilities, when I am subpar at something, or unable to do something expected of me,

this often leads to the interpretation that I don't care or try hard enough, or at worst, assumed as display spiteful intent. While presuming competence is notably important among people with visible disabilities, there will be times when all disabled people exhibit incompetence. In these moments, perceptions need to be carefully reasoned to ensure it doesn't end up negatively impacting how we are seen or understood. These experiences of persons with invisible disabilities are not unique to me. The psychologist who interpreted my actions within the assessment, illustrates a conceivable cultural belief and fear that many people with disabilities are faking it for special treatment (Dorfman, 2019). Perhaps the psychologist unjustly concluded that I was trying to fake my symptoms and gain access to special treatment as a result.

How does this apply to my identity development? I know some validation may come from a professional or literature, but my assessment of identity must be my own. This one psychologist failed to see and understand me for who I am, discrediting my honest and open self-description and functioning. I am confident to stand firm and not allow her skewered assessment to alter my observations and understanding of myself. Letting go of the hope of knowing more about myself and my varied areas of cognitive functioning through her assessment was a challenging process. When sharing these test results with numerous friends, family, ADHD coach, and therapist, they all agreed that this interpretation of my results indicated strong clinician bias and outdated understandings of ADHD and autism. Professionals that I shared this story with have said that this is unfortunately a common experience that neurodivergent people's genuine behaviours and self-disclosures are discredited and disbelieved (See Garcia-Molina, 2024; Hampton et al., 2023; Han et al., 2023; Leven, 2020).

Being disbelieved and discredited is of particular concern around the intersection of gender and autism. In a sample of women in the UK who have sought and were seeking autism

assessments, the majority of them reported “being disbelieved and dismissed by healthcare professionals” (Harmens et al., 2022, p. 8). Further, they found that those who were not validated in their autistic identities by these important professionals were more likely to report decreased well-being and increased identity concerns. Trans and autistic people have also reported being disbelieved and discredited due to their intersecting identities (Strang et al., 2018). For people who had previously been known as only autistic before their coming out as gender diverse, they described how it was reported by others in their lives to be “probably some autistic thing,” rather than as a valid identity (Strang et al., 2018, p. 4049). Due to the often-poor perspectives on autistic people’s agency and ability to self-determine our own identities, we face additional barriers to identifying as gender diverse. We can also experience difficulties balancing individual needs and sensory needs with being correctly perceived by others as our gender.

I received an autism diagnosis from one clinical psychologist, and then a couple of years later, another clinical psychologist told me in a psychoeducational assessment that I was “normal” with no disabilities. While there are numerous differences between these two professionals, the most significant difference I remember is the first psychologist's approach of actively listening to me and considering my performance in the assessment as a true reflection of my abilities. I shared the same stories of struggle during the background interview part of the assessments. But one report led to understanding and affirming my experiences, and the other led to the assumption that I was exaggerating and non-credible.

I have pondered what it would take to alter perceptions of autism within both our culture and the psychological field. This includes individuals who are autistic but do not clearly exhibit stereotypical traits to be accepted and not subjected to bias or prejudice by the very professionals tasked with understanding and supporting us.

Chapter Five: Queering Autism

Research and Epistemology

Taking place almost exclusively online, the neuroqueer project advocates for “the deconstruction of oppressive able-bodied/able-minded discourses through disidentification” (Egner, 2019, p. 131). Those who use the word neuroqueer to describe themselves or engage in neuroqueering actively resist the binaries of identification and counter-identification to pursue a third path of identity outside of social norms entirely. This movement combines activism across the intersections of disability, sexuality, and gender. Being a relatively new term, there is very little published on what differentiates neuroqueering from queer theory and crip (disability) theory. Egner (2019) highlights how while crip theory deconstructs the normativity of able-bodiedness, it does not do so to the same degree as able-mindedness. Though normativity of being able-bodied and able-minded are both part of society, advocacy tends to focus on challenging norms around the body more than the body-mind. Neuroqueering is not focused on labels or categorizing identities, but rather on the shared experiences of oppression, and beliefs around rejecting assimilationism, social hierarchies, heteronormativity, and cure/treatment narratives.

The neuroqueer movement is important to my arguments towards queering autism because it is from these foundations that I argue it is essential for researchers to question and reconceptualize their work. Epistemological understandings of autism need to be rebuilt upon the self-expressed experiences of autistic people themselves, not through the lens of non-autistic people and their focus on autistic functioning within an allistic environment. I believe that since I was raised by neurodivergent parents, my world that was both allistic and autistic at the same time. Many of my autistic traits were accommodated and accepted enough to prevent me from

being recognized as autistic earlier on in my life. Since my mom could see and sense many of my autistic behaviours in herself, many meltdowns were prevented, and many needs were simply accommodated growing up. My outward autistic traits themselves were not negatively impacting myself and others enough. The current need for overt destructive or problematic behaviours tends to necessitate an autism assessment. In a scoping review, it was found that clinical assessments for autism were not sufficient for women and people who camouflage their autistic traits. I also argue that people who have built informal accommodations and supports into their lives to prevent disablement and difficulties would further be excluded. These diagnostic assessments and conceptions of autism are often defined by the extreme struggle and incapacity of autistic people to perform aspects of daily living that can be accommodated unknowingly. Because of the many measures taken in my own life to make myself able to live and work independently, this prevented me from being able to see my own autistic traits and difficulties. Similarly, when autistic people experience periods of burnout, when their usual strategies for daily living can continue no longer, that is often when they discover their own autistic identity (Raymaker et al., 2020).

It has been found that people diagnosed with autism after the age of twenty-one were more likely than people diagnosed before to be women and have mental health diagnoses (Jadav & Bal, 2022). Researchers hypothesized that a reason why those with adult diagnoses were more likely to have mental health concerns was due to living with unsupported autism and lack of understanding about themselves for so much of their lives. Those who are diagnosed earlier tend to have access to self-understanding and may see autistic differences as something that can be accommodated and supported. Without having the label of autism to use as a tool for creating changes to my environment until adulthood, my parents and I saw my struggles as a problem I

had to solve, often fighting for small accommodations which would have been more easily understood and accepted by others if I had the label of autism to give it more weight.

In a sample of autistic people diagnosed over the age of 50, they all lived typical lives in the eyes of society, being able to be fully employed, marry, and have children (Stagg & Belcher, 2019). The triggers for many of them receiving a diagnosis in adulthood included a child getting a diagnosis and a peer having recognized their neurodivergence and suggesting an assessment. As some autistic people have the privilege of creating lives that are accommodating enough for them to operate within society well enough that it doesn't cause too many problems for others or themselves, a shift in autism understandings must continue towards recognition of traits and needs rather than problem behaviours and lack of functioning.

Another major concern among the autistic community around whether to get a diagnosis or instead to self-diagnose or self-identify are concerns around medical practitioners minimizing their concerns, or not believing them. It was found in a sample of 665 autistic adults that 94.4% of participants believed that medical professionals wouldn't believe them (Lewis, 2017). In my vignette *Malingering or Autistic?* I shared my experiences of being told by a psychologist that I did not appear to have autism, ADHD, and that I was trying to fake my results during my psychoeducational assessment as well. This vignette helps to illustrate how these concerns expressed by other autistic people are valid and something to be concerned about when discussing neurodivergence with medical professionals.

A close friend of mine has also experienced significant barriers to autism diagnosis due to a clinician's biases of autism. She was assessed for autism using the Autism Diagnostic Observation Schedule (ADOS-2) at a publicly funded adult neurodevelopmental centre in 2022. After completing the test, the clinician reviewed the answers with her, and stated that the scores

were within the range for clinical significance, indicating she should receive an autism diagnosis. The clinician said that she didn't seem to be autistic, so the clinician went back through the test questions to lower her scores below the threshold for diagnosis. In a follow up meeting to discuss her final report, the clinician stated "If we were in Europe I would have diagnosed you with Aspergers. But since they took it out of the DSM, I can't diagnose you here." The clinician's statement is not true. Even within my own autism assessment report, it stated that my "behaviours and reported concerns were consistent with the DSM-5 criteria of Autism Spectrum Disorder (formerly known as Asperger Syndrome)." Misinformation and misidentification shown among the psychologists who conducted my friend's autism assessment and my psychoeducational assessment is not only a one-off individual clinician problem. Formal reports have been submitted by others on my behalf and my friend's behalf with The College of Psychologists of Ontario (CPO), and the Regional Assessment & Resource Centre (RARC) at a major public University in Ontario. In my friend's case, further inquiry or action was made by the CPO. In my case with the RARC, their reply to concerns about clinician bias and request for being re-tested with a different psychologist were dismissed and instead stated they could connect me with other community psychologists for further testing. In my friend's and I's cases, there was no action taken by either institution to educate, change practices, or prevent these experiences from being repeated with others. Upon further checking, both psychologists have no discipline or other proceeding records on the CPO public registry as of December 2023. Without systemic change, the increased understanding of autism in individuals and culture does little to effect meaningful change. Access to a formal diagnosis will continue to be a barrier, keeping supports and services away from people who present their autism differently.

The lack of intersectionality and diverse representation of autistic participants and researchers within autism research is a major contributor to why autism should be queered. The act of queering research means changing how research is collected to be more inclusive. This includes centring autistic voices within the research, ensuring at a minimum, autistic consultation and review of the research and whenever possible, including at least one autistic person on the research team. The sampling of autistic people in research should also include efforts to ensure a diverse range of autistic people, across various intersections including gender, race/ethnic background, and socioeconomic status. Further, the methods used should be designed to be inclusive for both speaking and nonspeaking autistic participants. Another best practice in the peer-reviewed journal *Autism in Adulthood* includes the evaluation of all articles by an autistic community member who reviews each article, as well as including autistic people at every level of the journal's operation and governance (Nicolaidis, 2019). This journal's standards of practice and language guidelines are an example of what queered autism needs to include in practice today. Other autism journals adapting many of the values and practices that *Autism in Adulthood* has, needs to address many of the concerns found in today's literature by filtering out the still heavily prevalent ableist and anti-autistic sentiments found among present autism research and researchers (Botha & Cage, 2022).

Moving from the participation of autistic people within research towards a more emancipatory approach is another important next step. This means actively challenging the epistemology that surrounds current autism research with a neuroinclusive approach, seeking to increase the benefits of the research by, with and for autistic people. Emancipatory autism research includes autistic people forming the research, being directly involved in its direction and being able to shape the impact it will have on the autistic community (Bertilsdotter Rosqvist et

al., 2019). These efforts may be hindered by structural barriers within academia around the ownership of work, theories, and concepts. Even when full emancipatory approaches cannot be taken due to these barriers, researchers can reflexively examine their own positionality, develop research methods that increase diverse representation, and ensure that their research is disseminated in an accessible manner.

Education

In discussions about how to queer autism within the education system, I believe an important first step is first changing perceptions of autism within society. This includes becoming aware that “you could have an autistic colleague” so that autism doesn’t only exist within special education classrooms (Coward, 2022, p. 165). Attitudinal changes towards autism by educators towards the broadening or queering of what autism looks like in addition to what kinds of lives and professions an autistic person can have, are essential to changing perceptions of autism within society.

Educators, such as Miller (2022) described how their training on autism generally presents autism as a disorder, having significant emphasis on leading people to see autism as something broken or wrong about a person. This mentality is picked up by students who are aware that they are on the spectrum, and students who are undiagnosed/unrealized autistic. By excluding the neurodiversity movement from teacher education, the perpetuation of these negative attitudes towards autism continues to be embedded within the ethos of the classroom and school. Miller (2022) suggests instead, switching to the use of positive language around differences to ensure that being autistic isn’t framed as an entirely bad thing, both with teachers, and with students. Autism training that mentions the social and environmental struggles of neurotypical peers also helps highlight how teachers facilitate the development of all students,

creating an understanding among all that everyone has struggles and areas to grow in. Miller (2022) further emphasized how connecting autistic people with other autistic people (both students and staff) allowed the students in their program to feel “less isolated and were happier about themselves and school life in general” (p. 152). These experiences can be transformative and major contributors to academic success, development, and happiness of students.

In a collection of works written by autistic educators, Ponnudurai (2022) described how she created a space within the schools she worked at to be a “safe and reliable person” for them to help them navigate the school system (p. 89). Being a mixed-race autistic woman in the educational system, she has become a role model for other students, showing them that “being mixed-race and having a disability are not barriers to progressing through life and achieving goals” (p. 89). Ponnudurai’s presence was a much needed representation in the school system, both in mainstream programs and supported learning. The increased presence of autistic educators at all levels of the educational system are an important representation for both the educators and students they teach (Miller, 2022). There are numerous barriers autistic people face within the education system, many ‘are not intrinsic but contextual’ (Coward, 2022, p. 158). Teachers may have a hard time staying in the profession due to the constant social interactions, loud environments with large amounts of students, noises, and smells that come with these spaces.

Recommendations mentioned by autistic teachers for change in the education sector include increasing accessibility of classrooms themselves which benefit both the autistic teacher and students with whom they work. Firstly, adaptations for autistic students are often helpful for all students and staff alike. Loosening the requirements for all students to socialize and learn in the same way is liberatory for everyone, not just those who require it. An example of this

includes being able to take work from one area of the classroom to another to complete the work more successfully (Miller, 2022). These mindset shifts within the school and classroom environment can be teacher-led and management-supported. Kammer (2022) concluded that “[u]nusual teachers, like unusual children, should be viewed as an asset for their unique contribution to education and ultimately to society.” (p. 120). By changing the perspective on unusual and different, from bad to neutral, to then valuable, our differences have the chance to blossom into contributions to society.

Further support for this de-emphasis on normativity comes from Moyses (2022) who found in her doctoral research that the primary factor among autistic girls who dropped out of mainstream secondary schools were issues related to social conformity and uniformity. Their priority in an ideal school environment emphasized the role of adults in their educational satisfaction. This includes them being able to better understand and respond to their individual needs. Further, supportive attitudes and greater understanding among staff would have made a significant difference in their educational experiences. In other research, it has been found that parents are often better able to describe the needs and experiences that their children are experiencing in the educational system than educational authorities on autism who are operating from impersonal and outdated theories of autism.

Social Action

Queering autism within the literature is brought out of the autistic community’s advocacy to change conceptions of autism from an individual deficit problem to a social justice problem. Botha (2022) describes how shared experiences as a minority group bring autistic people together and define the autistic community. This is directly contrasted with the current “culture of autism”, which defines autistic people based on a set of symptoms, problematic behaviours,

and deficits that are perpetuated by medical practitioners, institutions, and many community members (p. 105). Advocacy by the autistic community and autistic researchers to emancipate autistic people from the culture of autism is inseparable from the dismantling of other systems of oppression. Deconstructing the culture of autism necessitates the dismantling of neuronormativity and cisheteronormativity. Further, both concepts are built upon notions of white supremacy and colonization which are often left out of intersectional autism research. To further promote the queering of autism, autistic people with various marginalized identities must be affirmed and centred not only in research but also in policy and culture. Catala et al. (2021) defines neuronormativity as follows:

Neuronormativity refers to the prevalent, neurotypical set of assumptions, norms, and practices that construes neurotypicality as the sole acceptable or superior mode of cognition, and that stigmatizes attitudes, behaviors, or actions that reflect neuroatypical modes of cognition as deviant or inferior (p. 9016).

Those who are neurotypical, and therefore in a position of privilege, are often unaware of the impact that neuronormativity has on the lives of neurodivergent people, often described as “neurotypical ignorance” which parallels “white ignorance” in its social impact (Catala et al., 2021, p. 9016).

Armstrong (2011) argues that the environment can have a significant impact on whether or not a neurodivergent person can be successful in life. He argues that in this world, there are many microclimates or niches that a person can find themselves within. Finding the right one that works for their neurotype and interests is essential to living a life with the least amount of disablement and the most amount of happiness. The term niche to describe this phenomenon arose out of biology, describing how an animal makes changes to their environment to increase

their chances of survival. The example that Armstrong provides is that of the beaver dam, whereby through the construction of this new habitat, the beaver has created a safe space for themselves. Much like beavers, people who may not thrive in the natural world without making changes to it, can create their own niche so that they too can live a full life.

Applying Armstrong's niche construction to my own story, I believe that the construction of niches in my earlier days would have provided greater opportunities for the development of a positive self-concept and acceptance of my neurodivergence. Not realizing there were more affirming and fitting spaces outside of the ones I was in, my lack of exposure to niches that better fit my neurotype kept me feeling isolated, alien, and defective for much of my life up to this point. As an adult, I have shifted my efforts toward finding more niches that better fit me, and less effort into forcing myself to fit into areas that aren't a good fit for me. The development of many of these niches across many aspects of life over time has enabled me to lead a minimally disabling life. Temporarily leaving these niches has shown me that without them, I would be struggling through life much more than I am currently due to my constructed niches. Leaving these niches I have built for myself often results in greater stress, increased anxiety, and higher chances of experiencing overstimulation. This often results in shutdowns, which have been described as an internalized meltdown which results in being frozen and in emotional pain (Phung et al., 2021). Experiencing shutdowns then results in such dysregulation that results in not being able to function in ways I often can in many areas. It is especially seen in basic aspects of living, including being able to eat enough food, sleep properly at night, and have normal digestive functions.

It is commonly mentioned in the autism community to have concerns around food intake, and the literature has also documented that Avoidant Restrictive Food Intake Disorder (ARFID)

has significant overlaps with autism as well (Koomar et al., 2021). I have found personally that if aspects of my life are left unsupported and unaccommodated, I am significantly more likely to experience symptoms of ARFID. This is the same for other common issues documented in the literature and autistic community around sleep concerns, and digestive problems (Madra et al., 2020; Schreck & Richdale, 2020). When living a supported life with niches that are the right fit for me, I have noticed many of the issues that are described as core struggles for autistic people melt away. For months, I can live my affirming life with positive niches and supports built for a life of success, at times feeling almost disconnected from the collective struggle that the autism community rallies around. Very quickly after I step out of my carefully built regiment, such as by going on vacation, I realize that these issues come right back, and I am living the struggles that the community describes they live through daily. When I step outside of my niches, these sleep, eating, and digestive problems arise as symptoms of the greater issue of being in an environment that isn't the right fit for me. In the past, I have believed that I should be able to find ways to make myself fit the environment, and therefore try to tolerate or fix the problems that I face since others can be in that environment without the problems that I experience. I now try to accept my differences and find ways to bring my niches into challenging spaces as they arise. In a blog post about travelling as an autistic and ADHD person, I described (in different words) how I tried to bring along successful niches from home into my travels to accommodate and reduce the stressors that inevitably arise during travel (Dekker, 2022). I shared that much of my trip planning was based on neurotypical travel norms, not based on what I would enjoy most and be able to keep up for the remainder of the trip. I made some important changes to my trip, such as visiting the same place at least twice to create routine and familiarity, rather than trying to see and do as many different things as possible. By being aware of the important niches in my life

that are critical to my well-being and functioning, I am now working on ways to integrate them into all aspects of life to ensure that I can live life to the fullest.

It is also important to recognize the privilege I have to build the niches that have supported me to build a sustainable life without feeling like I am constantly facing insurmountable barriers to living well. Despite having similar autistic differences and impairments as others, I have had access to supports and adaptations which prevented them from becoming barriers to achieving my goals. Many of these adaptations have allowed me to be less impacted by other aspects of daily living which can disable us. Seeing others within the autistic community with similar experiences but lacking access to supports, they have faced more roadblocks to success. My communication abilities, and access to higher education, allow me to attain and sustain above minimum-wage employment. My educational funding which provides access to supportive technology and support services like ADHD coaching were essential to my success in education. My successful applications for disability funding required significant time from friends and family whom I am fortunate to have. For example, at first, my Canada Student Grant for Services and Equipment – Students with Disabilities (CSG-DSE) application for a psychoeducational assessment was rejected due to already having an autism diagnosis. But through an appeal with letters from my accessibility advisor and family doctor, my appeal was successful. The additional time and stress to appeal this decision was difficult to navigate while trying to adjust to the start of my graduate studies. Once my appeal was accepted, I received the \$2,000 for the psychoeducational assessments, which is the maximum amount they provided under the program. Without any support or referral services being made available to me with this new funding, I had to search on my own for a psychologist who would take significantly less than the average price in Ontario to administer the assessment. The numerous hours on Google,

emails sent, and phone calls made to try to find someone almost left me unable to use the funding that I had fought hard to receive. In the end, I found an affordable assessment centre and had a very poor assessment experience which was documented in the vignette *Malingerer or Autistic?*

Rejections and additional barriers have been experienced by fellow neurodivergent peers when they have applied for the same funding and support that I received. For example, I received funding for ADHD coaching under the CSG-DSE, but my friend was deemed ineligible for it despite also having an ADHD diagnosis from a psychiatrist (personal communication, November 17, 2023). However, not all my efforts have been successful. My appeal to have a psychoeducational assessment readministered with a different psychologist was rejected due to them supporting the psychologist over my claims of bias. In addition, my request to have more than a single session for autism support with an occupational therapist was rejected by the regional support centre due to their assessed threshold for severity, against the occupational therapist's recommendation for more sessions. For these failed applications and other successful ones with Developmental Services Ontario, I had a parent, friend, and ADHD coach who acted as a support person and advocated on my behalf.

The external support and validation of my claims have been instrumental in being seen as believable and getting access to support and services. Though I have experienced apprehensions about my credibility from a medical professional, it is no small feat that I have been successful in most of my attempts to secure disability support, funding, and assessments. I have seen others unable to experience these successes. Not having a parent who would support and validate their claims, not having the time and energy to dispute rejections, and struggling so much with the complicated processes and bureaucracy, they give up on support applications. These include

trying to get a publicly funded autism assessment as an adult, applying for the Ontario Disability Support Program, Disability Tax Credit, and access to Developmental Services Ontario with a later-in-life diagnosis. These institutional and systemic barriers continue to keep people who have discovered their autistic identities from attaining diagnosis, support, and therefore also preventing them from being able to build sustainable lives.

My story of being diagnosed with autism during the pandemic is not a unique one. Though my autism identity journey started years before the pandemic, the moment I took on autism as a key identity label for myself was during the pandemic and was especially prevalent during lockdown. The experience of being confronted with many life issues during lockdown was not unique to me, but a fairly common experience documented in a subreddit for autistic women (u/turnontheignition, 2022). One of the important aspects of the autistic community is connecting online. Even a decade ago, our autistic culture was documented as being primarily experienced online (Straus, 2013), and our engagement in these digital spaces is a cornerstone of feelings of connectedness to our culture (Botha et al., 2022). Though arguments have been made against autistic culture, they have centred around deficit models, neuronormative concepts of culture, and most importantly, not by autistic people themselves (Davidson, 2008; de Vries, 2021). Discovering autistic, ADHD, or other neurodivergent identities during lockdown due to the changes in life and social media use was documented online among autistic adults (Londero, 2022), news media (Krouse, 2022), and even studied academically (Aragon-Guevara et al., 2023). My story of autism identity during the pandemic also supports the many stories of late-identified autistic adults who have made this discovery on their own.

Emerging out of the autistic rights movement of the 1990's, literature on autistic gain, or autism being seen as a difference rather than a deficit started to take shape, especially as the

internet started to gain popularity (Armstrong, 2010). Autism researchers tend to frame autistic interests in the non-social as a deficit, rather than seeing our deep and immense inner worlds as deeply fulfilling ways of creating a life. Armstrong (2010) describes autistic lives which are deeply immersed within their special interests also being a good life, even if they are markedly less social or differ significantly lives than those who are not autistic. One of the strengths of many autistic people is our detail-oriented nature. This includes being able to score higher than average on manipulating blocks in two-dimensional patterns in the Wechsler Intelligence Scale. While not all autistic people can drive, I have utilized my visuospatial strengths and ability to attend to many details to drive well. I have attuned these natural abilities to create a mental map in my mind of where all the cars are around me, their speeds, and where they will be at their rate of acceleration in comparison to mine to navigate driving effectively. This includes paying attention to the minute details of how many cars slightly veer or change pace before they switch lanes, and keeping track of the rate of acceleration or instability of their speeds to accurately map where each car will be at any given time. Especially while driving on a four to eleven lane wide highway going in the one direction in the Toronto area, I often watch and assess the behaviour of each car, predicting how the flow of traffic will go both far ahead, directly around me and behind me. I often put so much mental effort into this constantly updating visuospatial mental map and enjoying the game of predicting vehicle behaviour that I forget to also attend to my directions and intended destination. With Google Maps navigation, I can be prompted to turn as needed so that I can drive well and arrive at my intended destination. Other aspects of autistic gain for me includes my rich inner life which is marked by intense satisfaction from my special interests and hyperfixations. While my special interests are not in high-achievement areas like mathematics or savant-like abilities in painting or memorization, they still bring me great joy and are one of my

primary activities in life which enrich my life and facilitates what it means for me to live well.

Research exploring the subjective well-being of autistic adults who engage with special interests has found results which align with my experiences as well (Grove et al., 2018). Despite diagnostic criteria of autism framing special interests as an abnormal intensity and focus on restricted topics, I see it as an important component of living well as an autistic person.

Chapter Six: Conclusion

The vignettes chosen for this work highlighted how my experiences of heteronormativity, neuronormativity, and misidentification within culture and society prevented me from discovering I was autistic until I was in my 20's. Sharing stories about my autistic traits and experiences showing my divergence without the focus on deficits was also intentional. Sharing extremely difficult stories about deficits, difficulties, or differences is already very present in the literature and was not necessary to make critiques of culture and advocate for changes to autism conceptions within society.

Major takeaways from this work include critically examining if heteronormativity is present within one's own conceptions of autism. This includes gendered beliefs about appropriate play styles, self-expression, and emotional regulation. Examples of this was shown within the vignettes under *Being Autistic Without Knowing It*. Further considerations must be made for people who are more socially marginalized may be engaging in impression management or compensatory techniques for their own safety. The development of education initiatives led by diverse autistic people can support these efforts to educate and question the heteronormativity currently embedded within current cultural and clinical understandings of autism. My stories shared here are also first steps towards the critical reflections of the negative ways in which society can impact undiagnosed autistic children, and the ways in which advocates like my mom can positively impact autistic children's lives.

Each person in society, not just researchers and medical professionals, have an important role to play in the queering of autism. Individuals learning about the negative impacts of neuronormativity and heteronormativity within their own lives is an important first step to addressing it within society. Then with that knowledge, examining one's own perceptions to

address any biases will at some point be used when the topic of autism comes up in a conversation or interaction with others. By queering autism within society, I believe more people, especially people who have marginalized identities, will be able to recognize themselves as autistic and begin to positively shape their lives and identities around this discovery. This journey of reflecting on and examining my lived experiences has facilitated significant development towards a deeper understanding of my queered autistic identity. With more of society accepting and recognizing autism in the diverse bodies and lifestyles, the social stigma and struggles of autistic people can be lessened. Increasing the visibility of autistic people within society also supports the earlier identification of the next generation of autistic people.

Research Next Steps

Further research on the intersection of heteronormativity and autism identity needs to be expanded to explore the experiences of more autistic people. Through interviews and focus groups with autistic people who have discovered their autism later in life, more barriers and common experiences may be identified. The documentation of autistic ways of living and identity development continues to be limited in the literature, so further exploration of this topic may find areas in which autistic identity development differs from what is currently recorded in the literature on allistic samples. This documentation should also go beyond the inclusion of autistic voices, but centre, highlight, and promote autistic perspectives. This means ensuring the voices of autistic people are integral to the research at every stage, within the research team, within advisory committees, and by reviewers who are both community members and academics.

Expanding on the takeaway of accepting non-normative ways of living, seeking participants across various genders, ethnic backgrounds, socio-economic status, and sexualities would support further exploration of this topic. Further, exploring potential methods of queered

autism knowledge dissemination from other autistic people who have found success in doing so in their own lives may be useful for broader educational efforts. Collaboration during the research development process with autistic advocacy networks or an autistic advisory committee would also ensure that the direction and end results of the research would be designed and executed according to autistic community perspectives and values. Even with an autistic researcher such as myself doing autism research, my position and perspectives are still limited and would benefit from working more closely with different autistic people for better depiction.

Further exploration into the themes of neuronormativity, heteronormativity, and misidentification found throughout the vignettes is warranted in future exploration of autistic people's experiences. In addition, listening to other autistic adult's stories about their past and recording their stories, we may find other important themes relevant to the goal of queering autism. Further studies could also collaboratively explore how autistic adults conceptualize and live out their autistic identity post-realization. The changes that occur in self-concept and daily living was discussed but not in-depth in this work. Research and storytelling that focuses on autistic living and autism conceptualization from a diverse group of autistic people should be the foundation of how to re-write autism conceptions at both the academic and cultural level. Even without a plethora of data and available perspectives on the lived experiences of autistic people from every walk of life, much work can still be done to mobilize the preliminary knowledge and emerging stories that are available at present.

Methods of enacting the queering of autism in culture includes education initiatives, especially in school and healthcare environments. As was described in this work, psychologists without a broader understanding of autism in non-cisgender boys continues to be of major concern, having a significant negative effect on many autistic people. Targeted education and

awareness campaigns towards psychologists and people who support unidentified autistic people (such as early child educators, teachers, and professors) would have an immediate positive impact on the lived experiences of autistic people. For example, offering a seminar which qualifies for professional development hours on queered concepts of autism, whereby participants would be taught to identify diverse presentations of autistic traits and how to adjust their work to better support these individuals. These brief education opportunities introducing the concept of queered autism gives those who do not specialize in autism the opportunity to at least recognize and support or to know when to refer out to find more suitable next steps.

Further education initiatives can take place in school environments in a similar way that other awareness campaigns have been implemented. For example, many schools have assemblies which teach children about diabetes, multiple sclerosis, breast cancer, and healthy eating. Some autism awareness campaigns already exist and have been present for many years, however they have largely been run by non-autistic led charities which much the autism community has boycotted and protested against due to ableism, infantilization, and perpetuation of white cis male centred autism stereotypes (Zeidler, 2019). The design of an affirming autism education initiative developed and presented by autistic people to represent more diverse group would increase the awareness of queered autism. It is incredibly important to have autistic presenters disclose their autism during the presentation. This shows any potential autistic individual in the audience that there are autistic adults who look like them. Especially among autistic young people, having exposure to autistic role models and real-life examples can positively support their concepts of self in the world. Even for those who aren't autistic in the audience, seeing autistic people who look very different from one another, and their own stereotypical conceptions of autism can teach them that an autistic person can be from any ethnic background,

have a variety of different spoken language abilities, and be of any gender. Further, the mobilization of these education programs could provide employment opportunities for autistic people, who like other people with disabilities, are more likely to be unemployed. In the most recent Canadian Survey on Disability (CSD), it was reported that only 69.6% of people with disabilities were in the labour force, compared to 84.2% of people without disabilities (Statistics Canada, 2024). Though this significant gap is closing, with a 5 percentage point improvement since the 2016 CSD, there is still significant room for improvement within workplaces to increase the social inclusion and employment of autistic people (Statistics Canada, 2023).

Limitations

As with all autoethnographic research, my writing is focused on my own experiences and perspective. This methodology lacks a diverse participant group as I can only speak from my own knowledge and experiences that may differ from other autistic people. As a white autistic person, my story will differ from and I cannot speak for the lived experiences of Black, Indigenous, People of Colour and other autistic people with marginalized identities. I have tried to include the perspectives of autistic people who have different intersections than I do in this work to provide some of that perspective. Still, it is significantly less valuable than the direct exploration of those individual's experiences. Being a white settler in Canada socialized to have biases towards whiteness and colonial supremacy, much of what I write as suggested policy or cultural change may further marginalize Indigenous perspectives on these issues (Bees, 2022). My research may be complicit in the continued marginalization of Indigenous peoples through the normalization of white scholarship (Schick, 2014).

As a person who can speak and write, with concentrated effort in a manner that appears to be non-autistic, I have also experienced much neurotypical privilege. Though this is relatable

for many autistic people, my experiences have been significantly different from non-speakers. My conceptions of autism identity development had the foundation of everyone around me believing that I was “normal” and not a person with a disability. Some late-diagnosed autistic people who had disability diagnoses prior to their autism realization may have a different experience than me. My starting point of not identifying as a person with a disability before discovering my autistic identity may have influenced my conceptualization of autism identity development. It would be worth intentionally exploring the experiences of late-identified people who had already identified with having another disability to see if there are differences in disability-related identity development. Another limitation of this work was my struggle to document other life experiences that I had intended to include. Ultimately, many of the original stories I had planned to write about were too vulnerable for me to resurface, so I had to share alternative stories that I have processed.

Reflection

In discussions about evaluating agency, feminist perspectives consider gender roles and hegemonic masculinity as important factors. Dyi Huijg (2020) adds to these factors by placing neurotype as a social category that can have an impact on the power relations that impact agency. Arguments about what is required for a person to have agency includes the presence of inner speech, foresight into the consequences of a person’s actions, and intentionality. As an autistic person who lacks or struggles to do these things by this definition of agency, one could argue that I lack or have limited agency.

To complete this work, I had to depart from the typical procedure of conducting an autoethnographic thesis, even from the proposal draft stage. This included using a mixture of conversation recordings, speech-to-text software, drawing, writing digitally in a note taking app,

talking through each vignette and section with my ADHD coach, therapist, friends, and family. This work was rarely worked on individually. Instead, I organized my thoughts through conversation with others, determined next steps with that support and wrote most of the words in this document via coworking in others homes, libraries, or coffee shops. Being able to write this many words about myself was impossible to do alone, but doable with my support network. I think it is vital to emphasize the importance of support in completing this thesis because if other people see completing a thesis as too difficult, it may be doable for them with the same level of support which I benefited from.

When determining which vignettes to use in Part 1, I started writing stories as I remembered them in day-to-day life over one year before the proposal was written. As I struggle to recall specific stories that address certain topics on the spot, I allowed myself the time and space to be reminded of them as I lived my daily life. Many of the stories that I recalled were very difficult to write about in detail due to the negative emotions that arose. Despite trying my best, I was unable to communicate many as I had intended to in writing or using speech-to-text software. For a while, I felt disappointed in myself because I could not do what I set out to do. Even after extending my intended completion date of my thesis and working with a therapist and coach to be able to share these stories, I couldn't. I shared other stories that still illustrated the points that were important, though they were less dramatic and impactful than the stories I could have shared. In the end, I believe the stories I chose reflect the intention I set out to share to the best of my capabilities. I am happy with what I have shared.

Even once the vignettes were chosen, outlines made, then details filled in, I struggled to review my own experiences for themes and takeaways. Rather than analyzing my vignettes for themes independently using a document or spreadsheet to collect findings, I started this process

collaboratively. For example, for the vignettes *Playground Analyst* and *Where Did You Go?*, I recorded and transcribed conversations with my mother to reference when writing them. Then, once they were drafted, I read and reviewed them with her and others to then determine the most important themes and takeaways. This verbal processing and conversation is an essential part of my process for all other vignette themes and takeaway decision making.

In the case of my vignette titled *Autistic or Malingering?* I also reviewed the clinical report over multiple sessions with my therapist and ADHD coach. Once I had recorded most of what I thought I wanted to include in the vignette, I discussed it with a close friend who had a similar experience with what I had written about. During our discussion about my vignette, she brought up her own similar experiences and discussed important aspects of her experience that were related to my own in ways that I hadn't previously considered. We also conversed about the similarities of our experiences, the shared pain that resulted, and both lamented about bringing up once more those negative feelings that we'd left in the past. This experience led me to add more to the vignette about my own experience, adjusted my takeaways, and I added in some of her experiences, too. This process of discovering and learning together paralleled in some ways the indigenous research method called yarning. In my academic year before the writing of this thesis, an assigned course article introduced us to the research method called yarning, which is when "[p]eople talk to each other to convey information or to receive information, which once received and processed can lead to different understandings of the subject matter at hand." (Bessarab & Ng'andu, 2010, p. 38). Even though I did not intend to participate in this research method, the steps I took to write large parts of this work paralleled the idea of discovering new meanings together through conversation.

Dyi Huijg (2020) stated that their book *Neurodiversity Studies* proved the capacity of neurodivergent people's agency, though the process may look different than neurotypical writers. Similarly, I am writing an autoethnographic thesis on my own autistic experiences, displaying how the typical writing process of non-autistic writers differs from my own process. Though I struggled to write about and reflect on my own experiences and took longer than expected to do so, I was able to complete it with assistive technologies and support persons. Despite much research stating that autistic people have deficits in the areas of understanding and thinking about oneself and one's own thought processes, I have demonstrated in this project that with support along the way, this was achieved by an autistic person. I hope that this work and the exploration of how I wrote it challenges notions of autistic agency, metacognition, and contributes to queered conceptions of autism and autistic people.

Being aware of my privilege, especially my whiteness and having invisible disabilities, I have tried to decolonize my perspectives throughout this work. With increased focus on questioning my original takeaways and why I was including the vignettes I chose, I discovered that my initial conclusions had problematic assumptions. Examining my position as a white settler who struggled to fit into my own colonialist culture, I noticed my original goal of more fully engaging with this culture which oppresses neurodivergent ways of living may not be the best way forward. First, my primary takeaway was to queer conceptions of autism to increase our inclusion within society. Through further questioning of why I wanted to be accepted and included in society, I realized that this belief was based on wanting to find a space where I felt safe, connected, and able to find purpose in life. I believed that full participation in our current society was the only way to feel this way. In reality, this society in its current form is not

something that I am eager to mold myself into, nor am I comfortable advocating for other autistic people to integrate themselves into it when there are other potentially better avenues.

Through discussing my concerns about the direction of this work with others, I pivoted my discussion to the development of niches for autistic people and the creation of lives that instead work best for their interests and needs. This change in direction was chosen because even with accommodations to bridge the differences between autistic and allistic ways of living, I concluded that it was more important to emphasize the acceptance of differences and to support the development of niches for autistic people to live divergently. There have been times when I wanted to find ways to be a normal person within society, spending time learning strategies and changes that I could make to get myself to achieve the most normal life possible. Many autism support programs and therapies exist already with much criticism for their perpetuation of neurotypical norms and harm caused to autistic people. Not wanting to contribute to that in any way, I pivoted to a more individual approach of supporting the plethora of ways an autistic person may want to build a life for themselves. I now argue for the importance of accepting differences, enabling the development of these differences through niches, and for greater awareness of these equally valid different ways to live life. Education and knowledge sharing on queered autism is essential for this to take place. Similarly, the literature still needs to move towards a neurodiversity-affirming approach, and simultaneously, autistic people should have the power to choose their level of integration and participation in society without the assumption that engaging with society in ways closely paralleling allistic participation is best. Queered autism is enacted through being aware of and affirming the many ways autistic people present themselves and act in this world.

Queering Validity

The utilization of vignettes and storytelling is itself a challenge to the predominant narrative on autistic abilities and their validity. Autistic storytelling and autobiography is described to be lacking in many ways, all centring around the concept that autism is an inability to think and act in the same ways as non-autistic people. Scholars have denied the “narrative capabilities” and “narrative value” of autistic people, which perpetuates the issue that autistic people cannot know their own experiences and speak to them (Yergeau, 2018, p. 7). Due to the perceptions of autistic people to lack the ability to reflect, and to act with intentionality, we have been described as arhetorical, and dehumanized as a result. This thesis illustrates how even though I had tremendous struggles to reflect, act, and complete this work with the intention that I set out to reflect upon, I did so in a way that was not entirely intentional. I was in many ways operating in a demi-rhetorical way. This demi-rhetoricity has been used against autistic people to purport that we can’t speak to our own experiences due to the inability to describe and reflect on our own experiences in the same ways they can. And at the same time, the abilities we do have to speak to our own experiences have been used to state that this then makes us not autistic enough to speak authoritatively on autistic experiences. Challenging stereotypes and dehumanized notions of autism through autistic storytelling threatens the neuronormative and heteronormative systems upon which society operates upon. Autistic reflection, criticism, and calls for queering, challenge the foundational concepts of normalcy within society. The queered process of writing this work, requiring supports and adjustments to the typical academic methods of goal setting, writing, and analysis shows how autistic ways of being can both operate within society while simultaneously queering it. By queering autism, autistic people could have increased access to autistic identity, community, and livelihoods.

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