

**dis/Humanity and Autism: Dehumanizing and Rehumanizing**

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By  
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## Abstract

This thesis aimed to explore the lived experiences of Autistic people, as articulated in online blogs written by Autistic authors. Experiences of dehumanization and counternarratives of rehumanization were the focus. This study was motivated by my lived experiences as an Autistic person. It included exploring my experiences as points of reference and comparing those expressed by the Autistic bloggers in this study. Autistic people have used the internet as a location to reclaim their voices and create counternarratives to the negative paradigms around autism. As part of my goal to explore counternarratives created by Autistic bloggers, I studied how Autistic people experienced intersections of marginalized identities. Non-Autistic voices in society predominate, including researchers, doctors, and parents. To promote Autistic narratives, one must look for their representatives where they organically thrive. The internet is one of these locations. For this study, I used a curated resource list created by an Autistic blogger of blog sites created by Autistic people. Using this resource, I constructed a narrowed list of Autistic bloggers who identified as having intersectional and marginalized identities. These identities included disabilities other than autism, 2SLGBTQIA+ identities, poverty, and race.

Philosopher Rosi Braidotti (2013) told us that the classical ideal of ‘Man’ was the measure of all things. Braidotti said this ideal subject was equated with consciousness, universal rationality, and self-regulating behaviour, whereas those deemed “Other” were equated with inferiority. Those branded as Others are viewed as the negative counterpart of the conscious, universally rational, and self-regulating ethical subject. Their humanity is reduced through othering. Braidotti said “Anti-Humanism,” which rejected the restrictive notion of what counted as human, was a vital step in arriving at the idea of the “Post-Human.”

Disability studies, intersectionality and post-humanism are used in the thesis as a framework to examine prevailing beliefs about the source of rights and agency and justify the reduction of rights and agency. An examination of this kind requires careful criticism of the roles played by structures in society in reducing rights and agency for certain individuals. Anti-humanism encourages holding to account those who historically and currently benefit from structural inequality and othering. Post-humanism encourages the continuation of momentum past this process of accountability, to a reconstruction of agency that includes those who would have been less-than-human subjects, non-human subjects, and even into an exploration of how the world we have historically thought of as non-living affects and is affected by agency. This thesis looked at the question of how safe it is for Autistic people to reject the centring of the human in a society where they still struggle to have full access to human rights and agency, and indeed, if there was a point in trying to reform restrictive notions of agency rather than creating a new understanding.

In this study, I performed a critical discourse analysis. Through this analysis, I found that Autistic bloggers pushed the boundaries around restrictive ideas of agency and reconsidered the utility of moving forward with the concept of “the human” intact. They advocated for rehumanization in areas that intersected with multiple identities and facets of “the human” experience. I was prepared to find the questions I posed in this thesis indirectly alluded to by the bloggers through accounts of their life experiences. Instead, I found the bloggers displayed a keen awareness of how restricted notions of “the human” excluded Autistic people. They also demonstrated their ability to use the vocabulary of academia and advocacy, reinforcing the idea forwarded by Autistic self-advocates and critical scholars, that too much gatekeeping is done regarding who is considered experts in autism. The Autistic bloggers included in this study did

not focus solely on their own experiences, preferring to expand their lens to take in the Autistic community and the allistic people around them. They advocated for the rehumanization of Autistic people in myriad ways, including redefining expertise and re-education of allistic people considered experts when they failed to include Autistic voices. This included research that was informed, directed, and performed by the Autistic community, academics, and advocates.

**Key terms:** Dehumanization; rehumanization; agency; critical disability theory; critical discourse analysis

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Not all of us can say, with any degree of certainty, that we have always been human, or that we are only that. Some of us are not even considered fully human now, let alone at previous moments of Western social, political and scientific history. (Braidotti, *The Posthuman*, p. 1)

## Chapter One: To Be, Or Not To Be, Human

### 1.1. My Story, My Thesis

For me, beginnings and endings are the most challenging part of writing. The introduction to this chapter was rewritten with every draft, never quite meeting the hopes and expectations of my thesis advisors or myself. The first draft heavily favoured my voice, focusing on my family experiences. In subsequent drafts, one of my thesis advisors asked for a brief history and explanation of autism. This produced a muddled, voiceless, contradictory mess. Following another of my thesis advisor's advice, I read *Constructing Autism* by Majia Nadesan (2005), a professor of communication. A few pages into the book, I realized why my introductions felt like they were getting worse with each draft. It was not the fault of the thesis advisor who asked for history and an explanation of autism, nor my fault for not providing a succinct and accurate response to this request. The problem was rooted in the contradiction between the medicalization of autism and the social construction of autism. The social construction of autism has gotten short shrift between the negative paradigm of autism and its medicalization. As Nadesan wrote, autism is defined and delimited by what an Autistic person is perceived to lack compared to the neurotypical norm.

I am Autistic. I come from a family where half the members are also Autistic. It is integral to who I am and to our family culture. To establish a shared understanding, explanations are needed for several vocabulary choices. The first of these was the word "Neurotypical." Nick Walker (2021, p. 40), professor of psychology, explained the word to mean "having a style of neurocognitive functioning that falls within the dominant societal standards of 'normal.'" According to Walker, the terms "Neurodivergence" and "Neurodivergent" were coined by

Kassiane Asasumasu (Autistic rights activist and blogger) in 2000. Walker described neurodivergence as a mind that functions significantly differently from what society deems "normal." A person may be considered "Neurodivergent" without being considered disabled. Walker said that neurotypical is the opposite of neurodivergent. However, they also said that neurodivergent and Autistic are not synonyms. Therefore, Autistic and normal are not opposites. Walker coined the term "Neurominority." They said that a group of people could be called a member of a "Neurominority" when all the following are true: they share the same form of neurodivergence; the shared form of neurodivergence is mainly innate and inseparable from who the person is; and the shared form of neurodivergence is one that is viewed with discrimination, prejudice, and misunderstanding that is reinforced by the pathology paradigm.

An example of using "Neurodivergent" as Walker defines it would be, "My family has members who are neurodivergent, although not all of them are Autistic. For example, I have a family member who is Dyslexic." Most of the time, when I write about neurodivergent people, it is Autistic people I write about. Therefore, I use the term "Autistic." If I were talking about all the neuro divergences in my family, it would not be appropriate to say "Autistic." One member of my family is Autistic, but they also have had TMIs, like mini strokes. If I were trying to address this, it would be more accurate to say that they are neurodivergent or "Multiply Neurodivergent."

Disability studies scholar Simi Linton (1998, p. 5) wrote, "Although the dominant culture describes that atypical experience as deficit and loss, the disabled community's narrative recounts it in more complex ways." Disabled scholar and activist Mike Oliver replaced the term "Medical Model of Disability" in their understanding of disability. They understood disability in terms of two models: the individual and the social. Regarding what is commonly thought of as the medical model of disability, Oliver (2004, p. 20) said, "The medical view of disability tends to regard

disabled people as ‘having something wrong with them’ and hence the source of the problem.”

Oliver said the understanding that underpinned what they called the individual model was based on personal tragedy. On the other hand, Oliver (p. 20) said that “the idea behind the social model was that of externally imposed restriction.” Oliver (p.21) made the following three points about the social model of disability:

(1) it is an attempt to switch the focus away from the functional limitations of individuals with an impairment on to the problems caused by disabling environments, barriers and cultures.

(2) it refuses to see specific problems in isolation from the totality of disabling environments: hence the problem of unemployment does not just entail intervention in the social organisation of work and the operation of the labour market but also in areas such as transport, education and culture.

(3) endorsement of the social model does not mean that individually based interventions in the lives of disabled people, whether they be medically, rehabilitative, educational or employment based, are of no use or always counter-productive.

The social model focuses on how structures in society and social institutions contribute to disablement. According to Sociologist Janine Owens (2015, p. 385), the social model of disability challenges “discrimination and marginalization, linking civil rights and political activism and enabling disabled people to claim their rightful place in society.” This model suggests that some people are disabled from participating equally in society because of how society is structured. Disability studies researcher Fiona Kumari Campbell (2014, p. 79) said one perspective of ableism is that it is a “form of prejudice that indicates a preferential treatment that devalues and differentiates disability through the valuation of able-bodiedness equated to

normalcy.” Campbell said this is sometimes referred to as “Ability Favouritism.” According to Campbell, “Ableism” and “Disablism” are often used interchangeably. In Campbell’s book *Contours of Ableism*, Campbell (p.80) said that they note that “disablism focuses on the negative treatment towards disabled people.” Campbell (p. 80) said, “ableism is *not just* a matter of ignorance or negative attitudes towards disabled people; it is a trajectory of perfection, a deep way of thinking about bodies and wholeness.” Much like how intersectionality focuses on the convergence of multiple identities, Campbell (p. 80) said that they understand ableism as the convergence of a set of processes and practices that bring together ontology and epistemology.

Preferences regarding “Person-First” versus “Identity-First” vocabulary choices expressed by Autistic people indicate what many of us think about the social model of disability versus the medical model of disability. Taboas, Doepke, and Zimmerman (2023, p. 566), academics in the field of psychology, said “person-first language (PFL) has been promoted to counteract negative attitudes toward those with disabilities and to emphasize a person’s unique strengths, challenges, and experiences.” On the other hand, Taboas et al. (2023, p. 566) said that critics of person-first language “believe that identity-defining features (e.g. autism) cannot be separated from the individual.” Taboas et al. noted that most of the research on this debate was informed by a 2016 study by Lorcan Kenny, the national research lead for Autism at the National Health Services of England, and co-authors. Kenny et al. (2016, p. 443) said, “The term ‘Autistic’ was endorsed by a large percentage of Autistic adults, family members/friends and parents but by considerably fewer professionals; ‘person with autism’ was endorsed by almost half of professionals but by fewer Autistic adults and parents.” This supports the work such as that done by Botha (psychologist) et al. (2021) in “Does language matter? Identity-first versus person-first language use in autism research” and Bury (psychologist) et al. (2020) in “It defines who I am, or It’s



something I have: What language do [Autistic] Australian adults [on the Autism Spectrum] prefer?” that suggested Autistic adults prefer the social model of disability over the medical model because it recognizes the structural barriers that Autistic people face. Nonetheless, despite the preferences of most Autistic adults, language included in the medical model of autism continues to be utilized pervasively.

A further vocabulary choice that I have made in this thesis emerges from the person-first versus identity-first discussion. In this thesis, I have chosen identity-first language. I will capitalize the terms “Autistic” and “Autist” throughout, but leave the term, more commonly used for those who are peripheral to the Autistic community, “autism” not capitalized. My decision was informed by Autistic advocates such as Lydia X. Z. Brown, who said they do it to represent community and identity (Autistic Hoya, FAQs, n.d.). I have considered what to do about pronouns when individuals have not stated their pronoun choices. In English, “They” and “Them” pronouns were traditionally used when the appropriate was unknown. There are instances where the pronoun choices of the bloggers chosen for this study were not stated. The same is true of the people referenced in this study. Thus, I will attempt to call people by their names whenever possible. When I cannot use names, I will use they and them pronouns instead.

## **1.2. Kanner’s Autism**

The history of how autism came to be identified and defined provides context to how Autistic people have been dehumanized and continue to be dehumanized today. It gives context to why resisting the medical model of disability is a crucial element to the re-humanizing efforts of Autistic people. Understanding this history requires knowledge of the roles played by Leo Kanner and Hans Asperger in the identification and definition of autism.

An examination of the history of the term “autism” will help to understand the controversy between the medical and social models of autism, as well as the controversy regarding person-first language. Prize-winning Historian Edith Scheffer (2018) wrote a history of how autism was identified and defined. The term “Autism” was first introduced by Swiss Psychiatrist Eugen Bleuler in 1911. Bleuler used the term to describe schizophrenic patients, who were the focus of Bleuler’s work. Scheffer named Leo Kanner as the first person to introduce “Autism” as a standalone diagnosis. Leo Kanner, an Austrian born during the Habsburg Empire, had a close professional association with Physician Georg Frankl and Psychologist Anni Weiss, all of whom worked at the Curative Education Clinic in Vienna. Hans Asperger was also based there. Due to the desperate post-war economy in Germany, Kanner emigrated to the United States in 1924. Frankl’s and Weiss’s articles, written while working with Kanner, described children who had trouble creating social connections with other children. However, in the face of growing anti-Semitism, Weiss left Vienna in 1934. Leo Kanner, who sponsored the entry visas of hundreds of Jewish physicians, helped Frankl get out of Vienna in 1937 and found a job alongside them at John’s Hopkins.

Frankl discouraged the pathologization of the characteristics they had observed in children at the Curative Education Clinic. This contradicted Erwin Lazar, the founder of the Austrian clinic, which had “unwittingly expanded a system that in time would ultimately control and condemn ‘dissocial’ children” (Scheffer, 2018, p. 37). Although Lazar’s stated intention was to consider the whole child, Lazar’s work ended up dovetailing with the Austrian welfare system in that it gave the system another tool to measure the ways these children labelled as dissocial by the Austrian welfare system failed to meet the standard of being functional, economically productive, and law-abiding members of the community. Lazar’s work was increasingly used to

undergird eugenic actions against youth and children who were falling outside the boundaries of social norms in a country steadily becoming ruled by fascist ideals. This unwitting direction set by Lazar might have been set right by Clemens von Pirquet, whom Lazar recruited to support their vision for the Curative Education Clinic in the Vienna Children's Hospital. Pirquet was known for supporting socially progressive causes such as establishing food programs to improve childhood malnutrition in post-war Austria (World War I), collaborating with women and Jews, and encouraging experimentation with play-based approaches to children's medicine. However, the altruistic direction Pirquet might have taken the clinic was derailed by Pirquet's early and unexpected death. Franz Hamburger, Pirquet's successor, did not have the idealistic history Pirquet had cultivated. Hamburger was a founding member of a society for racial hygiene at the University of Graz, known to foster right-wing extremism. Hamburger's leadership caused the Children's Hospital to be enthusiastically thrust toward eugenicist ideology.

Meanwhile, Kanner had established a practice at John Hopkins Hospital. Kanner published "Autistic Disturbances of Affective Contact" from this new location in 1943. Kanner's description of a subject the study referred to as "Donald T." demonstrated that the children exhibited social withdrawal and restricted emotional relationships. Kanner (1943, p. 218) said the following about Donald:

He has no apparent affection when petted. He does not observe the fact that anyone comes or goes, and never seems glad to see father or mother or any playmate. He seems almost to draw into his shell and live within himself.

The way Kanner pathologized Donald's reaction to being touched alarmed me. I also would not show affection for someone touching me, especially without consent. According to Kanner, Donald exhibited repetitive language, behaviour, and preoccupation with objects. For example,

Kanner (p. 218) described Donald developing “a mania for spinning blocks and pans and other round objects.” Kanner (p. 219) said of Donald, “Most of his actions were repetitions carried out in exactly the same way they had been performed originally.” This also served as an example of the children in Kanner’s study being described by Kanner as preferring routine. Kanner (p. 219) also said of Donald’s limited speech:

He seemed to have much pleasure in ejaculating words or phrases, such as ‘Chrysanthemum’; ‘Dahlia, dahlia, dahlia’; ‘Business’; ‘Trumpet vine’; ‘The right one is on, the left one is off’; ‘Through the dark clouds shining.’ Irrelevant utterances such as these were his ordinary mode of speech. He always seemed to be parroting what he heard said to him at one time or another.

The above characteristics became part of what became known as “Classic” or “Kanner-Type” autism. Kanner used the term “Early Infantile Autism” to describe symptoms that Asperger also described, although Asperger believed the children in their study to be far less “impaired” than those Kanner observed. Frankl and Weiss did not believe the symptoms they observed in subjects should be pathologized, whereas Kanner saw them as impairments. Asperger did not pathologize the subjects' behaviours in their study to the same degree as Kanner did with their subjects.

Asperger had already determined that their subjects might benefit from remediation. However, Asperger pathologized the behaviours of those children rejected from the Vienna Children’s Hospital study to such a degree that it amounted to a death sentence in the social context of the Third Reich.

The time frame in which Kanner and Asperger developed their ideas and approaches was the same. Even the geographic context of their work was initially the same. However, with Kanner having moved to the United States of America and Asperger remaining in what became

Nazi Austria, their work's social contexts differed. Kanner's move physically separated them from the rising antisemitism and fascism in Germany and Austria. In other words, it separated Kanner from the progressively dehumanizing propaganda pervading Austrian and German society, including the dehumanizing rhetoric directed at disabled people.

### **1.3. Asperger's Autism**

In Asperger's 1944 postdoctoral thesis "The Autistic Psychopaths in Childhood," Asperger expressed the belief that the children in their study displayed above-average intelligence. However, Asperger acknowledged that some people thought this was isolated to the special interests the child displayed. Asperger (1944, p. 45) said:

We see here something that we have come across in almost all individuals, a special interest which enables them to achieve quite extraordinary levels of performance in a certain area. This, then, throws some light on the question of their intelligence. However, even now the answer remains problematic since the findings can be contradictory and different testers can come to different estimates. Clearly, it is possible to consider such individuals both as child prodigies and as imbeciles with ample justification.

Asperger also believed that the originality of vocabulary choices made by the children in their study demonstrated their originality of thought. Asperger (p. 71) said, "Behind the originality of language formulations stands the originality of experience. Autistic children could see things and events around them from a new point of view, which often shows surprising maturity." Asperger (p. 37) believed that a high level of original thought and experience sometimes compensated for the serious social difficulties observed in their study's children. Asperger (p. 37) thought that this ability to adapt could often lead to exceptional achievements in later life. Asperger used the example of one subject named "Fritz V." to explain how they believed children like those in the

Vienna study could successfully attend standard schools. Asperger (p. 49) said, “Despite the difficulties we had in teaching this boy we managed to get him to pass successfully a state school examination at the end of the school year.” Regarding the ability of the children in their study to adapt to their environment and form relationships with people, Asperger (p. 58) said:

Another important point is this: normal children acquire the necessary social habits without being consciously aware of them, they learn instinctively. It is these instinctive relations that are disturbed in autistic children. To put it bluntly, these children are intelligent automata. Social adaptation has to proceed via the intellect. In fact, they have to learn everything via the intellect.

Asperger believed that nobody liked Autistic children, which added to their inability to create relationships and caused them to be loners in the community.

Within the social context of Austria in the Third Reich, characterizing children as lacking the ability to be functioning members of the body politic could be tantamount to a death sentence. According to Scheffer (2018), interpersonal relationships and social spirit were thought to be intrinsic to the concept of “Gemüt.” This concept is not easily translatable into English. Gemüt was viewed as a vital aspect of humanity, referring to a deep part of one’s interior. It connotes love for society as a collective but also the desire to conform to a collective identity. It includes concepts such as empathy and compassion. A child who was thought to be incapable of Gemüt would also be considered subhuman. Awareness of this did not stop Asperger from using this language to describe Autistic people. The Nazi psychiatrists and psychologists, apparently, loved children and readily applied the concept of Gemüt to them. However, most children who went through the Vienna clinic were considered subhuman. Therefore, they were not extended Gemüt or thought capable of possessing Gemüt. This highlighted the lines the Nazi party drew between

whom they deemed human and viewed as not possessing humanity. Paul Schröder, one of Asperger's mentors, wrote a lot about the concept of Gemüt. Schröder believed Gemüt was a necessary precondition for membership in a social collective. As a protégé of Schröder's, Asperger would later say that children with Autistic psychopathy lacked Gemüt. These were the same children Schröder said had no need or understanding for tenderness, and who did not form close attachments or friendships (Scheffer, 2018).

Asperger's work was influenced by a different group of researchers and physicians than Kanner's. In the spring of 1934, Asperger took a leave of absence from the Curative Education Clinic to train under Schröder. According to Scheffer (2018, p. 68), Schröder was "increasingly taking up National Socialist themes in their positions on eugenics, the hereditary ill, and homosexuality. They served as a medical assessor to the Hereditary Health Court in Leipzig from 1934 to 1937, evaluating individuals for forced sterilizations." However, even after it became safe to distance oneself from the National Socialist Party, Asperger still did not disavow Schröder. Asperger cited Schröder's influence as formative to their thinking. There was another researcher Asperger appeared to be influenced by who appeared to have had strong ties to the Nazi eugenics program. Scheffer (2018, p. 70) states that Asperger "would cite others sparsely in his seminal postdoctoral thesis on Autistic psychopathy in 1944—referring to only nine authors in sixty-one pages." However, Erich Jaensch, whom Scheffer described as a Nazi psychologist who had established the dominant racial typology, was cited twice by Asperger in their postdoctoral thesis on Autistic psychopathy.

Kanner did not stop caring about the fate of their Jewish colleagues after they moved from Austria to the United States of America. Kanner sponsored hundreds of Jewish physicians to move to the United States of America after the Curative Education Clinic in Vienna purged the

Jewish physicians on staff. On the other hand, Asperger took this as a chance to advance their career, demonstrating a willingness to benefit from the dehumanization of those around them (Scheffer, 2018). Some people would say the purging of so many staff left a vacuum on the staff of the Curative Education Clinic that Asperger was simply available to fill because Asperger was present, a doctor, and not Jewish. Nonetheless, Asperger's legacy has benefited from these kinds of subtleties in complicity. Scheffer (2018, p. 16) said:

Asperger is often depicted as compassionate and progressive, absorbed in his research during the Third Reich and opposed to Nazism. He was a devout Catholic and never joined the Nazi Party. Asperger also had a reputation for defending disabled children from Nazi persecution. Many people believe Asperger emphasized the special abilities of the children in the Vienna study and their potential value to the state in technical professions to protect the children from being killed in the Nazi "euthanasia" program. In this view, Asperger was using the autism diagnosis as a psychiatric Schindler's list.

This framing of Asperger as a person making the best of a bad situation, using their position in small ways to push back against the Nazi regime, has been a standard part of attempts to redeem Asperger's legacy. Asperger's words and actions were often antithetical to this framing.

However, the same could be said about Nazi psychiatry in general. How the term Gemüt was understood and how the Nazis treated fellow humans demonstrated the disconnect between some of their rhetoric and actions. Clearly, the empathy and compassion that were supposed to be intrinsic to Gemüt were not extended to those the Nazis believed to be subhuman, such as Jewish people and many of the children who entered the Curative Education Clinic during the Third Reich.



Contradictory rhetoric that called for physicians to treat children in their care with compassion might not have seemed like such a contradiction to the Nazi psychiatrists who sterilized children and condemned them to death; not if they did not view the children they condemned to death as human. Scheffer (2018, p. 177) said, “Asperger’s murderous mentor, Franz Hamburger, stressed the importance of championing disabled youths ‘even if we believe optimism is not warranted.’” Of Ernst Jekelius, probably the most murderous of Asperger’s colleagues, Scheffer (2018, p. 177) said:

Even Ernst Jekelius, as head of Spiegelgrund, defended the worth of disabled youths. The goal of curative education, he declared, was to “integrate as many children and youths as possible into the processes of German and work life,” and he boasted that careful teaching had helped “many formerly ‘difficult children’” who would otherwise “probably would have gone to the dogs.”

However, Jekelius was so known for the murder of disabled children that hospitals began to refer disabled children to Spiegelgrund specifically for “Jekelius Action.”

Although Asperger’s words and actions often contradicted each other, it should be noted that Asperger strongly and consistently stressed that physicians needed to differentiate between remediable and irremediable children. Scheffer (2018, p. 178) wrote that Asperger maintained that Autistic children had the potential for achievement “as long as they are intellectually intact.” Scheffer (2018, p. 178) said, “Since Asperger did not dwell upon those at the ‘less favourable’ end of his ‘range,’ his emphasis was on one type of child gave a misleading impression of what he meant by autistic psychopathy in general.” Paradoxically, Scheffer (2018, p. 178) said it was Asperger’s eugenicist focus on the “favourable cases” in Asperger’s thesis that obscured the extent to which they were a eugenicist. Considering how often Asperger wrote about children

being remediable with intensive and personalized care, Scheffer said it has been difficult for people to reconcile the two-sided nature of Asperger's actions and role in child euthanasia. Unlike all of Hamburger's other protégés, Scheffer suggested that Asperger not having joined the National Socialist party kept Asperger from being completely discredited following the war. Asperger admitted later in life that they were aware of the full extent of the euthanasia program and the fate faced by the children transferred out of their program into Jekelius's care.

#### **1.4. A Brief Look at the Legacies of Kanner and Asperger**

Kanner's and Asperger's contributions to how autism is understood and perceived have created a legacy in autism research and treatment. The insistence on dividing autism along the lines of being impaired to a greater or lesser degree, or functional to a greater or lesser extent, is something Autistic people contend with to this day. As Autistic people push back against functioning labels, some researchers are writing papers about how this activism makes it impossible for them to describe autism accurately. For example, in "A full semantic toolbox is essential for autism research to practice and thrive," the Co-Founder and President of the Autism Science Foundation Alison Singer and co-authors (2022) wrote about feeling restricted by the expectations to change their vocabulary choices. Singer et al. also criticized the way the responsibility to consult relevant research stakeholders is enacted, referring to Professor of Medical Ethics and Co-Authors (2020, p. 498) in "Ethical advocacy across the autism spectrum: Beyond partial representation" where they coined the term "Partial Representation." McCoy et al. coined this term to describe situations in which one subset of a population claims to speak for an entire group without consulting all relevant stakeholders" Singer et al. (p. 498) said that McCoy et al. (2020) argued that legitimate representation must reflect input from all relevant stakeholders. Singer et al. said they believe a fraction of the autism community is dictating the

terms used. Perhaps you are thinking their argument was that ableist terminology was being dictated by a small fraction of the autism community who have traditionally been recognized as having expertise and authority. That would be a natural hope for what they were arguing. However, that is not what they meant.

Singer et al. argued it was more important for vocabulary to be precise and meaningful in medicine and science than it was to use what they called “Euphemism” to discuss autism. They complained that most of the surveys used to establish Autistic people preferred certain vocabulary choices were “impossible for most who are more severely impacted by autism” to understand and complete on their own (Singer et al., p. 498). This reinforces a common observation made by the bloggers included in this study, that if Autistic people attempt to question and correct academics who have traditionally held power in the autism community because of being considered experts, a process of delegitimizing their right to speak about autism as experts is activated. Singer et al. stated it as a given that Autistic people who were really affected by autism (aka real Autistic people) would not be able to understand or independently answer a questionnaire about their vocabulary preferences and that their answers would not be legitimate if they could not give them independently. These assumptions come from the history of dehumanizing Autistic people and reducing their agency.

Singer et al. also complained that certain language was pre-excluded from surveys based on the idea that Autistic people found it offensive. Singer et al. used the example of “Person with Autism,” claiming Ruth Monk (postdoctoral research fellow in the Centre for Brain Research at the University of Auckland) and co-authors (2022) stated in “The use of language in autism research” that only eighteen percent of participants in their survey approved of the term. Since the general argument Singer et al. made seemed to be that all members of the autism community

should have a say in how it is defined and the language used to describe autism, it seems unlikely that Singer et al. referenced surveys that only asked Autistic people their opinions. Since non-Autistic people outnumber Autistic people in the autism community, it stands to reason that the potential for ableist vocabulary to be perpetuated would be higher than if only Autistic people were asked.

Kanner's and Asperger's legacy can also be seen in the practices of Applied Behaviour Analysis, even the ones considered reformed and gentle. Unlike Frankl and Weiss, who did not believe behaviours by Autistic people should be pathologized, Kanner and Asperger pathologized the behaviours of Autistic children. Kanner did not reject children from their study based on the idea they were irremediable. However, Asperger rejected children as subjects based on the idea that they were irremediable, condemning them to grim fates. Asperger believed that intense intervention could remediate the children they selected as subjects. This carried through to the practices of Applied Behaviour Analysis. In an interview with Journalist Paul Chance in 1974, Psychologist Ole Ivar Lovaas said they believed Autistic children had the raw materials to be human children. However, in this interview, Lovaas said they believed that Autistic children required a person with the expertise to use these raw materials to build a human child. Lovaas believed such an expert would have to work forty hours a week for two years to build a human child from the raw materials of humanity found in Autistic children.

### **1.5. Expanding the Diagnosis**

Nadesan (2005) said Kanner and Psychiatrist Leon Eisenberg altered the criteria for an autism diagnosis in the mid-1950s. Kanner never agreed that their observed disorder's symptoms fit closely enough with those of infantile schizophrenia to be grouped under it as a subcategory. However, Nadesan said it continued to be grouped this way until 1980 when the implementation

of the *Diagnostic and Statistical Manual of Mental Disorders (DSM) III* moved it. Nadesan stated that the *DSM-III* defined the symptoms of “Infantile Autism” as a lack of responsiveness to others, preference for routine, language difficulties, and attachment to objects. According to Nadesan (2005, p. 11), the *DSM-III* also specified the absence of schizophrenia features and that autism showed onset after thirty months. In 1987, the *DSM-III-R* loosened the diagnostic criteria for autism. It recognized a more comprehensive range of variations in social interaction, speaking and non-speaking communication, and repetitive, stereotyped, or ritualistic behaviour. Widening the denotation and further deemphasizing the age of onset allowed more children to fall within the diagnostic criteria.

It is possible that Asperger would have faded from relevance in child development if not for Psychiatrist Lorna Wing taking up Asperger’s work in 1981, which led to others doing the same (Scheffer, 2018). This eventually led to the inclusion of what Wing described as “Asperger’s Syndrome” in the fourth edition of the *DSM-IV* in 1994. Also, in the *DSM-IV*, the designation of “Infantile Autism” was replaced by “Autism Disorder.” At this time, Asperger’s syndrome was distinguished from Kanner’s disorder. In 1993, Wing suggested that Asperger’s Syndrome and autism be viewed as part of a continuum of developmental disorders that came to be known as the “Autism Spectrum.”

### **1.6. Understanding “the human”**

The question of who qualified as human in Asperger’s eyes was fundamental to how Asperger described their subjects. It also affected the outcomes faced by the children who went through Asperger’s Vienna clinic. Scheffer (2018, p. 179) said:

Asperger denied the humanity of Autistic children he saw as more impaired. Throughout his thesis, Asperger referred to them as ‘intelligent automata,’ and spoke of ‘the

automaton-like nature of the whole personality.’...Asperger’s idea of automata referred not only to the children’s lack of productive value to society, but also to their incapacity for social feeling.

The subjects Asperger described did not include those Asperger and Kanner acknowledged as more impaired, like the ones in Kanner’s study. Asperger had already judged the humanity of these more impaired subjects and found them lacking. Most of these children were referred to Jekelius.

Philosopher Rosi Braidotti (2013, p. 13) told us, “At the start of it all there is He: the classical ideal of ‘Man,’ formulated first by Protagoras as ‘the measure of all things.” This “He” that Braidotti (p. 13) described as being the starting point for Humanism was conceived as an idea of bodily perfection that doubled up as “a set of mental, discursive, and spiritual values.”

Braidotti (p. 15) said:

Subjectivity is equated with consciousness, universal rationality, and self-regulating ethical behaviour, whereas Otherness is defined as its negative and specular counterpart. In so far as difference spells inferiority, it acquires both essentialist and lethal connotations for people who get branded as ‘others.’ These are the sexualized, racialized, and naturalized others, who are reduced to the less than human status of disposable bodies. We are all humans, but some of us are just more mortal than others.

Post-humanist theorists tend to emphasize the agency of nonhuman and matter, as a reaction to the dominant centring “the human” agency in humanist philosophy. According to Marija Grech (2018, para. 2), a lecturer in English literature and critical theory, the capacity for agency is not limited to human bodies in post-humanist theory, or even to animate bodies. Grech (para. 3) said:

By extending agentic capacities to nonhuman and even non-animate actants, new materialism distributes agency across a wide range of entities, structures, and processes. As such, agency cannot be restricted to a bounded subject, but is diffused across multiple entities and achieves its capacity within assemblages.

Grech (para. 4) cautioned that the expansion of agency past the notions of humanistic philosophy does not absolve humans of responsibility for the damage done during the Anthropocene era.

My contention in this thesis is that humans must not only have equal rights and agency, but that the notion of rights and agency must be expanded to include all Othered. Braidotti pointed out that those branded as Others are viewed as the negative counterpart of the conscious, universally rational, and self-regulating ethical subject central to the humanistic theory. Their humanity (rights and agency) is reduced through othering. Othering and dehumanization were evident throughout Asperger's work with Autistic children.

The "Anti-Humanism Movement," which Braidotti (2019) described as part of the evolution of their thinking, encouraged holding to account those who historically have benefitted from structural inequality, othering, and the denial of agency. Braidotti said anti-humanism's rejection of the restrictive notion of what counts as a human is one of the keys to understanding how we even got to the idea of the post-human. Rejecting this restriction is fundamental to disability rights movements and the rehumanization process. On the other hand, post-humanism is a philosophy that would confer equal rights and agency for all matter, including how objects, things, and humans affect and are affected by others (including non-humans). A question worth puzzling about is whether a human, who has been treated as less than human with fewer rights and individual agency under humanism, can/will take up post-humanism. Will they embrace artificial intelligence as one of them, having been compared to AI so often, and argue for the

rights of their new-found kin? Having been compared to animals, will they take up the cause of arguing for the rights and agency of animals?

Critical disability studies researchers Dan Goodley and Katherine Runswick-Cole (2014) described the concept of “dis/Humanism” as a helpful framework for striking a balance between claiming the rights and agency of “the human” while maintaining the ability to trouble the category from within. Dan Goodley, Rebecca Lawthorn, Kirsty Liddiard, and Katherine Runswick-Cole (2018, p. 342) said:

Our community of scholars and activists—critical disability studies—are, we believe, perfectly at ease with the posthuman because disability has *always* contravened the traditional classical humanist conception of what it means to be human (Goodley, Lawthorn, and Runswick-Cole, 2014). But, we argue, disability also invites a critical analysis of the posthuman (and for that matter humanism).

Goodley et al. (p. 345) said that their desire to disavow “the human” led them to:

develop *DisHuman Studies* which, *we* contend, simultaneously acknowledges the possibilities offered by disability to trouble, reshape and re-fashion the human (crip and posthuman ambition) while at the same time asserting disabled people’s humanity (normative and humanistic desires).

In this thesis, I also wanted to examine how the Autistic bloggers in this study troubled, reshaped, and re-fashioned “the human” while asserting their normative and humanistic desires.

It is an unfortunate reality that many Autistic people have a tenuous hold on human rights. The United Nations Human Rights Office of the High Commissioner wrote for World Autism Day, 2015, that Autistic persons should be embraced, celebrated, and respected as part of human diversity. The High Commissioner also pointed out the sad reality that discrimination against



Autistic people is the rule rather than the exception. The concept of dis/humanism provides a way to push for changes for full inclusion in human rights. This inclusion would help make it safe for Autistic people to reject the concept of “the human” in preference for a posthuman philosophy.

This thesis looked at what Autistic bloggers said about how safe it is for Autistic people to reject the centring of “the human” in a society where Autists struggle to access human rights and agency fully. At the same time, it asked whether there was a point in trying to reform restrictive notions of humanity. Would such reform protect the human rights of disabled people? Or would it be more useful to construct new frameworks to expand the understanding of what is human so that it includes (as in post-humanism) all entities? By examining the texts created by the Autistic bloggers included in this study, patterns of consensus were revealed in the thoughts these bloggers expressed on these matters. These patterns of consensus focused on understandings of how Autistic people have and continue to be dehumanized, and ways Autistic people can rehumanize themselves.

### *1.6.1. Understanding “the human”: What is normal?*

Later in this thesis, I briefly address the prevalence of autism in Canada. The question of the prevalence of autism relates to the concept of the “Normal.” Professor of Educational Equity and Cultural Diversity Subini Annamma (2013, p. 1278 said:

The concept of normal pushes humanity towards the average as ideal. The word normal continues to imply *good* across multiple social disciplines...Yet, conceptualizing normal as a phenomenon desired by these powerful disciplines maintains that difference is conceived as deviance...

The question of the prevalence of autism demands that one portion of the Canadian population be identified as different than the rest of Canadians or as abnormal. Trying to determine the

prevalence of autism is an exercise in measuring some aspect of society that is considered deviating from what is considered ideal.

Estimating the prevalence of autism in Canada has been complicated. Epidemiologist and Professor in the Departments of Public Health Science and Psychiatry, Ouellette-Kuntz et al. (2012) said that in 2001, few provinces had the infrastructure for autism spectrum disorder surveillance. Canada is a vast and varied country with inadequate services in many areas, making it challenging to gather accurate information. Services provided by provincial and federal governments are inadequate in many areas. However, they are still the only thing available to the people in those areas. Thus, they are the most likely to be able to gather accurate information about the prevalence of autism spectrum disorders.

### ***1.6.2 Understanding “the Human”: Personal Connections***

I always understood there was something different about me. I did not fit into the “Normal.” After my cousin and sibling received diagnoses in the 1980s, I debated asking my parents to seek one for me. In time, I realized that having such a diagnosis would put me at more risk of bullying and oppression outside my home. As I got older, I began to reconsider why I had rejected the idea of diagnosis for such a long time. I concluded that it was related to my need to mask my symptoms of autism. I will more thoroughly explain “Autistic Masking” later in this thesis. For now, Autistic masking is the suppression of behaviours and traits that are typically associated with autism (Price, 2022). Autistic people engage in Autistic masking because they do not want to be identified as out-of-step with the normal.

Years later, after I began my teaching career, I finally gained regular access to a computer and the internet in my home. I began to search the internet for relatable blogs. It did not take long for me to determine that reading the blogs of other teachers, single mothers, or divorced women

would not provide the insight I sought. A piece was missing in all these stories, a set of lived experiences not represented. When I began to read blogs written by Autistic authors, I discovered the narratives I was seeking. Soon I added my voice to the discourse. Blog writing helped me come to understand myself as an Autistic person. It helped me come to terms with how I had been dehumanized and begin the process of rehumanization. That included reversing decisions I had made from fear of people seeing behind the mask. For example, I was afraid of openly admitting I was Autistic because I was scared about how it would impact my ability to be a teacher and a single parent. Rehumanization, for me, involved taking steps to shed the mask safely.

My original thinking was that the internet was a location where one could find unfiltered, flourishing Autistic voices. Upon further reflection, I questioned whether pure voices could ever exist. Our voices always end up filtered through culture and power. Professor of Inclusive Special Education and Disability Studies Christine Ashby (2011) said, “Too often, stories are told *about* people with disabilities and the emphasis is on the voice of the professional, not the voices of the person.” However, the internet is where many Autistic people have reclaimed their voices and created a counternarrative to the negative paradigm around autism. To reiterate, this thesis aimed to explore the lived experiences of Autistic people as articulated in online blogs written by Autistic authors. I studied the ways Autistic people experienced intersections of marginalized identities. I researched how they experienced dehumanization as articulated in blogs. Additionally, I looked at how they pushed back against dehumanizing narratives. I also made recommendations for researchers, legislators, policymakers, and those who hold power and are in the position to take away or reduce the agency of Autistic people. Sociologist Nicki Lisa Cole (para. 1) described societal structures as the “complex and interconnected set of social forces,

relationships, institutions, and elements of social structure that help shape the thoughts, behaviours, experiences, choices, and overall life courses of people.” In this thesis, I was particularly interested in how societal structures affected agency as expressed by bloggers.

As an Autistic person who writes a blog, exploring my lived experiences is appropriate. Katie Reid (School of Education), Paul Flowers (Social and Public Health Sciences, and Psychologist Michael Larkin (2005, p. 1) described lived experiences as when a person is an expert on their own experiences and “can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, and in as much detail as possible. My understanding of lived experiences is that they are an individual perspective of the truth that considers social and cultural context. It occurred to me that I might have benefitted from the online spaces we take for granted today, back when I was muddling through my undergraduate degree. While it is true that the internet provided access to Autistic voices I did not previously have, it also is where many of my fears were reinforced. As I read blog posts of other Autistic bloggers, I began to see commonalities in our experiences, including the bad ones. I began to see patterns and themes, often including denial of agency. I saw how Autistic bloggers experienced dehumanization, but I also recognized the work so many Autistic bloggers did in rehumanizing Autistic people. When I decided that I wanted to switch from a course-based master’s program to a thesis program, the reason was to examine more thoroughly the blog work by Autistic people about their dehumanization and their work towards rehumanization.

### **1.7. Rehumanization and Beyond**

I first encountered the idea of disabled people recognizing the concept of “the human” as needing to be troubled upon reading an article written by Goodley and Runswick-Cole (2014)

called “Becoming dishuman: Thinking about the human through dis/ability.” Autists (a term used to indicate people who are Autistic) have been included in “the human” through a hard fight, and our rights are tenuously maintained. Our society has enabled some people more than others.

There is an analogy I sometimes refer to when trying to explain how this is true. I ask people to imagine a building where all the entrances are elevated off ground level. Even though the entrances are all elevated, no stairs were built to any of them. This causes everyone trying to enter the building to be disabled by the structure's design. However, after complaints, the building owners construct staircases for the entrances. Now the only people disabled from entering the building are those who are mobility impaired and cannot climb the stairs. Society has structures like this building that are poorly conceived and create disablement. This disablement causes some people to be unable to exercise their agency in the same way as others. They have been disabled, by what has become, for them, a disabling structure which has restricted their agency. Disability studies scholar Dan Goodley (2014, p. 3) said, “Disability theory emanates from the perspective that disability is a sociological, economic and cultural thing rather than a psychological, embodied or medicalized problem.” Thus, “ableism” and “disablism” greatly influence how society constructs its rules, regulations, codes, and discourses. Goodley (2014, p. 7) said the social model of disability, “provided a vocabulary for contesting the processes of *disablement*: social, economic and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters.”

Abandoning restrictive conceptions of “the human” is a step towards rehumanizing Autistic people. It is not incompatible with the position put forward by Goodley and Runswick-Cole (2014), that disabled people require the protection of “the human.” The mere act of writing this thesis is a form of troubling “the human” from within. I am uncertain where I lie on the

imaginary spectrum between reforming restrictive notions of “the human” and evolving past them to a more inclusive concept. I do not always mind being compared to non-human animals or robots if the comparison is made by people who do not assume the inferiority of either. I have spent enough time in Indigenous communities as a teacher and mother of Indigenous offspring I appreciate the animism they attribute to natural elements that my western white culture would not typically think of as part of “the human.” However, I still fear the implications of dehumanization. It feels risky to open the door to the re-examination rehumanization would require. Disabled people's fragile claim to human rights might make embracing Posthumanism and Animism dangerous. I explored this tension in my study.

Humans are made sub-human through many processes and for many reasons. My purpose in studying Autistic authors' blogs included getting confirmation that I am not alone in my experiences but also taking the opportunity to understand the breadth of the Autistic experience. Through a qualitative approach—critical discourse analysis—I aimed to portray some of the variety of these experiences and to interrogate some of the contexts that produce them. I wished to understand better the intersections of oppression Autistic individuals experienced, as articulated by Autistic bloggers, including autism, race, gender, sexuality, unemployment, poverty, othering, educational oppression, and medical oppression. I also wished to look at the lack of opportunity, borrowing the phrasing of Professor of Digital Studies and English Melanie Remi (Yergeau) (2017), to author our own Autistic experiences, due to the denial of Autistic voice.

### **1.8. Research Focus and Question**

My research focused on the question of the human and how Autistic people are dehumanized and how they work to rehumanize themselves. At the intersection of marginalized

identities, dehumanization comes from being set outside of what is considered a normal part of “the human.” Rehumanization means challenging what is considered normal within “the human.” For this thesis, I wanted to know how intersections of identity and marginalization affected the dehumanization of Autistic people. I wanted to know what role challenging the restrictive conception of “the human” plays in the rehumanization of Autistic people. I wanted to know how the personal experiences of Autistic people affected their perceptions of dehumanization and multiple marginalization. I wondered if people would be better allies if they understood how Autistic people experienced dehumanization. Would that make them more effective in participating in the rehumanization of Autistic people?

I hoped the payoff at the end of this critical discourse analysis would be an expanded understanding of the tensions plaguing the “the human” category and forming a clearer picture of how to trouble the concept of “the human” from within. I was equally open to abandoning the idea of reforming restrictive notions of “the human” and moving forward to posthuman possibilities. I wanted to learn from the voices of other Autistic people how they experienced “the human,” and about their experiences with dehumanization. I also wanted to learn what they said about their experiences at the intersection of marginalized identities. I hoped my study of the work published on the blogs of these Autistic authors would tell me if there was a strategic claim for the category of “the human” that allowed Autistic activists to fight for fundamental human rights such as access to education, employment, shelter, and health care from within the safety of the category. I hoped to understand whether they claimed or rejected “the human,” or if they found a way to do both.

## **1.9. Research Methodology**

My research focused on understanding what Autistic bloggers expressed about their experiences and advocating. Thus, a qualitative research methodology was selected. These expressions of experience and advocacy were best accomplished through qualitative research. In addition, Psychologist Michelle O'Reilly and co-authors (2015) said qualitative research methods were suited for studying disability. I was interested in critically examining the written expressions and thoughts of Autistic bloggers as they pertained to the structures of the dominant culture. Thus, I used a critical discourse analysis framework, which is particularly well suited to trace critical description, interpretation, and explanations of social inequalities and marginalization. The Merriam-Webster Dictionary says that discourse is the interchange of ideas, whether verbally or in writing. It can be formal or informal (Merriam-Webster Online Dictionary, n.d.).

To choose appropriate bloggers, I sifted through a curated list of Autistic bloggers posted on “An Autism Observer” (2020) blog site. Using a purposive sampling approach, described by the Dovetail Editorial Team (2023) (reviewed by Cathy Heath) as “a technique used in qualitative research to select a specific group of individuals or units for analysis,” I narrowed the field presented in this list of hundreds of blogs written by Autistic authors and allies down to fifty bloggers I felt most effectively fit my study criteria. I was interested in looking at blogs from Autistic people who identified as having multiple intersections of marginalization (the criteria will be further elaborated on in Chapter 3). Once I had used my judgment to reduce the number of bloggers to fifty, I used an online random selection tool called the “Wheel of Names” to narrow the total number to fifteen bloggers. The reason I used this tool for the last narrowing of the field was to be able to remove my judgment from the final selection. This felt important to me



because Autistic people often face judgment of the value of their experiences as opportunities for analysis and reflection. In this final sampling stage, it did not feel right to scan through what they had written and weigh some experiences as more valuable than others. I hoped I would discover that these randomly selected Autistic bloggers from the curated list shared consistencies in their ontologies, epistemologies, and axiologies. I intended to develop themes based on these consistencies. I also wanted to understand their unique differences as well.

In all, I selected fifteen Autistic bloggers to include in this study. I examined a selection of the blog material they created, analyzing how they experienced dehumanization and the ways they worked to rehumanize themselves. I also looked at how they experienced intersections of multiple identities.

#### **1.10. Limitations**

I acknowledge that some Autistic people do not have access to the internet, do not post online, or choose not to post about their experiences with autism. However, my intent has remained the same—to explore how Autistic people create counternarratives in online spaces based on their Autistic lived experiences.

The focus of this thesis was Autistic bloggers located at the intersection of marginalized identities. When I began the process of narrowing the range of bloggers who would be included in the random drawing of names for this study, I eliminated bloggers who did not identify as having another marginalized identity, besides being Autistic. This eliminated all white, heterosexual, cis-gendered Autistic bloggers raised as males. Leaving any Autistic people out of conversations about autism limits the scope of the discourse. However, in this thesis, I wanted to focus on under-represented Autistic perspectives.

## Chapter Two: Literature Review

### 2.1. The Social Model

Disability studies scholar, Tom Shakespeare (2017), said that doctors and medical professionals tend to see disability as something that needs to be cured. However, Shakespeare said the priority should be to look for ways to remove disablement from environments in which disabled people exist. They said that the social model defines disabled people as an oppressed group and the product of relationships between disabled people and the disabling society in which they exist. They specified that sometimes the people and groups claim to be advocating for disabled people who are perpetuating disabling narratives. Shakespeare (2017, pp. 195-196) said, “Civil rights, rather than charity or pity, are the way to solve the disability problem.”

Psychologist Guy Dewsbury et al. (2004, p. 145) said, “The ‘Social Model’... has undoubtedly been the dominant paradigm in researching and understanding disability in recent years.” There is a lot of push-back against the medical model of disability within Autistic advocacy, given that it is based on the idea of disability being a description of deficit, where they promote the idea of it being a form of diversity. Since push-back in Autistic advocacy continues against the medical model of disability, Autistic advocates have doubts that the social model of disability has become the new norm for research and representation. Dewsbury et al. (p. 145) said, “We are concerned with why it is that the various commitments and concerns of what we class as the social model are proving of little help to us.”

Dewsbury et al. claimed that the social model of disability has changed our idea of “Expertise.” However, they indicated a danger of disabled people being told they do not have the expertise to theorize about their own experiences. Psychologist Simon Baron-Cohen,

Neuroscientist Uta Frith, and Psychologist Alan M. Leslie (1985) posited that Autists have deficits in Theory of Mind (ToM), making it difficult for Autists to understand that other people have needs, wants, desires, or intentions that may differ from their own. Remi (Yergeau) (2018, p. 12) said:

ToM is the ability to understand that other people have their own unique mental states, feelings, beliefs, and desires. It is the ability not only to recognize intentional stances, but to apprehend that intentional stances exist to begin with. Yet contemporary theorists about ToM also invoke and assert other cognitive phenomena—including, but not limited to, mentalizing, metacognition, self-awareness, imaginative play, and expressing empathy. In other words, to lack a ToM is not simply to lack a theory of other's minds—it is also to lack an awareness of one's own mind.

Thus, Autistic people might be told they are not equipped to understand the full significance of their experiences. Dewsbury et al. (p. 151) said, “In one version, ‘experience’ might be de-privileged because features of the social world, though not immediately observable, nevertheless have effects.” Although the experiences of Autists are to be valued, Dewsbury and the co-authors say there are aspects of those experiences that other people will not be able to interpret because they are not immediately observable. Autistic people are best positioned to offer insight into their own experiences. They are most capable of explaining the parts of their behaviour that are not observable, including their motivations and desires.

Sociologist Damian Milton's Double Empathy Problem (developed in 2012) applies here. The Double Empathy Problem posits that if Autistic people have deficits in the Theory of the Allistic Mind, the reverse is also true: non-Autistic people have deficits in the Theory of the Autistic Mind. Building on Milton's work, Autistic Professor of Linguistics Gemma L. Williams

(2021, p. 122) said “recent studies have begun to provide a persuasive body of evidence highlighting the difficulties that non-autistic people also have in understanding autistic people, such as a difficulty in inferring autistic affective and mental states.” Remi (Yergeau) brings to life this idea further. Remi (Yergeau) said (2013, p. 2):

I've had to get used to not existing, rhetorically speaking. I will say something about autism, and someone will assert that nothing I've said matters or applies to anything.

Because I am self-centered. Because I do not have the capacity to intuit other minds or to understand the life experiences of others. Because it is just my autism talking.

Milton (2020) also suggested that Autistic experiences have real-world effects, regardless of whether non-Autistic people can easily observe and understand them. This debate about whether disabled people could be the experts of their own experiences fascinated me as I set about doing my research. It inspired me to look at blog material written by Autistic bloggers, whom I consider experts in their own experiences. It also made me want to demonstrate what I think of as one manifestation of the social model of disability, which is Autistic researchers writing about autism.

## **2.2. Neurodiversity Paradigm and Approaches**

According to Walker (2014), the “Neurodiversity Paradigm” refers to three fundamental principles. The first is that neurodiversity is a natural and valuable form of human diversity. The second is that thinking there is only one “Normal” (or healthy) type of brain, mind, and way of thinking is fiction. They suggested that this fiction is on par with the idea that there is only one normal or right ethnicity, gender, or culture; the perpetuation of the idea contributes to maintaining the status quo. Walker (para. 19) said the third is:

The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of ethnicity, gender, or culture). These dynamics include the social power inequalities and the dynamics by which diversity, when embraced, acts as a source of creative potential. In this thesis, I focused on Autistic bloggers who had intersections of marginalized identities. This helped bring out the ways the social dynamics that manifest regarding neurodiversity are like those that manifest in other forms of diversity.

According to Autistic psychology Ph.D. student Patrick Dwyer (2022), the neurodiversity approach defines disability as the product of the interactions between the disabled person and the world around them. Dwyer said that reshaping the environment disabled people interact with can mediate how their environment disables them. The goal should not be curing the disabled person or encouraging them to pass as typical. Dwyer (p. 5) said, “Diversity of minds and brains should be valued and individuals with neurological disabilities should be accepted for who they are.” The disability community argues for examining the concept of normal, the social construction of disability, and autism. In a 2015 interview for Maclean’s magazine, Science Writer Steve Silberman told Journalist Emma Teitel that neurodiversity is a more holistic and humane way to see the positive aspects of Autistic minds and recognize that our society is stronger for their existence. The same is true for other forms of human divergence. For example, divergences in gender, race, age, culture, language (etc.) make our society stronger through their existence.

### **2.3. Intersectionality**

Disability is a marginalized identity that can encompass people who experience intersections of oppression. In a foundational article in disability studies, Paul Abberley (1987, p. 7) said:

To argue that we need to analyze the position of disabled people as a form of oppression is not to make the claim that we can arrive at a monolithic theory of oppression into which we can fit women, black people, disabled people or gay people depending on which particular oppressed group is under discussion at the time.

This speaks to the need to look at this oppression from the lens of intersectionality. Abberley (1987, p. 7) quoted a statistic (which they derived from Lecturer of Social Policy Jo Campling (1981) and the Confederation of Indian Organizations (U.K., 1986)), saying, “It is also important to note that probably more than half of disabled people in Britain today suffer the additional burden of racial and/or sexual oppression.”

Psychologist Carla Rice et al. (2019, p. 411) described “Intersectionality” as having its roots in Black feminist thought. Carla Rice et al. (2019, p. 409) said:

Intersectionality involves the study of the ways that race, gender, disability, sexuality, class, age, and other social categories are mutually shaped and interrelated through forces such as colonialism, neoliberalism, geopolitics, and cultural configurations to produce shifting relations of power and oppression.

Rice et al. (2019, p. 410) said that the concept of intersectionality began to be developed “over 30 years ago by African American feminist and critical race scholars to overcome exclusion in secondwave feminism,” adding that the concept has been taken up and adapted by scholars looking to understand how people’s lives are affected by multiple axes of power. There is a long history, beginning in the nineteenth century with Sojourner Truth, of Black women taking up the concept of intersectionality.

Professor of Social and Cultural Studies Nirmala Erevelles and Professor of Educational Leadership Andrea Minear (2010, p. 33) argued that an engagement in “an intercategorical

analysis of intersectionality enables us to foreground the structural context where the social categories of race, class, gender, AND disability are (re)constituted.” The way I read this, Erevelles and Minear argue that an inter-categorical analysis will allow the troubling of how elements of humanity are socio-culturally defined, which is a similar goal as my own.

Within feminist legal studies, as early as 1989, American civil rights advocate Kimberlé Crenshaw asserted the intersections of identity, including race, disability, and feminism. Crenshaw (1989, p. 140) said that “Black women are sometimes excluded from feminist theory and antiracist policy discourse because both are predicated on a discrete set of experiences that often does not accurately reflect the interaction of race and gender.” As an example of the need for an intersectional approach, Crenshaw identified discrimination against white women as the standard for sex discrimination. Crenshaw said that anything that deviated from the norms set by this standard constituted a sort of hybrid. Since Black women have been seen as hybrid, their claims of sex discrimination rarely get mentioned in conjunction with the “standard” sex discrimination claims. An example of this would be the predominance of white women in public-facing positions in the fight for the Equal Pay Act (of 1963) in the United States of America. White women have been considered appropriate representatives of all women, while Black women have been viewed as only capable of representing other Black women.

Crenshaw (1989) said, “Intersectionality is a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking.” Black Feminist Scholar Jennifer Nash (2016, p. 4) said that intersectionality has become an industry deployed in many disciplines. Nash (2016, p. 6) said that Feminist Philosopher Anna Carastathis wondered if intersectionality is being appropriated without engaging significantly with Crenshaw’s work and

is “used in ways that distort and even invert the meaning of the concept.” This is supported by Crenshaw’s frustration with how their work has been taken up. According to Nash (2016, p. 3), Crenshaw said, “My own use of the term ‘intersectionality’ was just a metaphor. I’m amazed at how it gets over and underused; sometimes I can’t even recognize it in the literature anymore.” My intention was to examine how multiple forms of inequality and marginalized identities compound to contribute to the dehumanization of Autistic people as reflected in this definition of intersectionality.

## **2.4. Autism and Autistic People in Academia**

### ***2.4.1. Autistic Spaces in Academic Settings***

In a 2017 article Margaret Prior, a lecturer in human resource management, wrote that only three percent of higher education students are Autistic. On the other hand, Alison Nuske (2019, pp. 280-281) of the Department of Disability and Community Inclusion at the University of Flanders and co-authors said:

It has been reported that the number of individuals with ASD [Autism Spectrum Disorder] enrolling in higher education has been increasing. This may be because of the increasing inclusion of individuals with disabilities within higher education, as well as the increase in prevalence of ASD over the past 20 to 30 years. It is also predicted that the number of individuals with ASD seeking to enrol in higher education is likely to continue to rise.

I mentioned earlier that it is difficult to get accurate statistics concerning the prevalence of autism in Canada. It also is difficult to get accurate statistics on how many Autistic people make it to post-secondary educational institutes. According to queer, Autistic author and activist Erin Ekins (2017, Nov. 14), only 16% of Autistic people in the United Kingdom enter post-secondary and



the workforce. It was unclear what portion of that 16% were the ones who got into post-secondary schools and what portion were the ones who got jobs. Although the trends regarding Autistic people who disclose their autism diagnosis upon entering postsecondary school are changing, Nuske et al. (2019) indicated that the statistics still show an imbalance.

Autistic people who have viewed and absorbed the information mentioned above might feel they will not successfully translate academic achievements (if achieved) into career success. Knowing there is a good chance that pursuing post-secondary education will not help them gain adequate employment, these Autistic people might hesitate to commit their time and financial resources to post-secondary education. Increasing the number of Autistic representatives in academia is tricky if potential students never enter the institutions' doors. Also, just because Autistic people go to university does not mean they will engage in research or write about autism. Just as it is difficult to know the true prevalence of autism in Canada or post-secondary institutions or even the prevalence of diagnosis, it is difficult to know how many researchers writing about autism are Autistic. While students and researchers might be more likely to disclose, they are Autistic today than twenty years ago, it is still difficult to know when a researcher is Autistic unless they explicitly identify themselves as Autistic. This matters because it makes it difficult to measure how more representation in academia, research, and employment creates positive change for Autistic people.

#### ***2.4.2. Critical Disability Studies and Critical Autism Studies***

Disability Studies emerged in the 1970s and 1980s, arising from people seeing the need to add disability activism to the social justice movements that gained ground in the 1960s. In a paper about the first Disability Studies Summer Institute hosted by the Ontario Institute for Studies in Education (OISE) at the University of Toronto in July 2011, Tanya Titchkosky (2012)

stated that fifty emerging and established scholars attended the event, representing more than ten disciplines. The field has expanded since this 2011 event. It has also taken on a more critical lens, with the creation of Critical Disability and Critical Autism Studies. The Director of Disability Studies at the Wyoming Institute Michelle Jarman and Associate Professor of Feminist Studies Alison Kafer (2014, p. 1) wrote:

in recent years we have witnessed the development of new programs, an increased demand for courses at the undergraduate and graduate levels, an expansion in online offerings, a rapid proliferation of disability studies publications, and wider recognition of disability studies as a field.

Jarman and Kafer added that one way the field needs to continue growing is to draw attention to the relationship between disability studies and disability activism. Tied to that would be the continued focus on centring the connection of Autistic activism to critical autism studies. Jarman and Kafer said that part of this process is to acknowledge how indebted disability studies are to disability activism, and that the continued growth of the disability studies field requires innovative approaches, increased access and accommodations, and consistent inclusion and collaboration of disabled people in research about disability.

Author and filmmaker Simi Linton (1998) said that at one time, there was no difference between the dominant cultural narrative of autism and the academic narrative. However, disability studies provided a way to trouble the academic narrative, challenging traditional researchers on disability in sociology, psychology, and education to do better. Linton (1998, p. 2) wrote, “Disability studies takes for its subject matter not simply the variation that exists in human behaviour, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations.” The social context of disability is fundamental to

disability studies. The predominant academic narrative on disability had taken up the negative cultural paradigm of disability. It reflected the negative paradigm of disability established in the academic work of people like Asperger and institutions such as the Curative Education Clinic in Vienna. That is why it is so vital that the voices of disabled people are included in the discourse. It is important to understand what disabled people make of the variations, not just non-disabled people.

Beyond the field of disability studies is the field of critical autism studies. Scholar of disability studies Mitzi Waltz's (2014) referenced *Worlds of Autism*, edited by critical disability studies scholars Joyce Davidson and Michael Orsini, saying:

As the introduction by co-editors Orsini and Joyce Davidson notes, the 'criticality' comes from investigating power dynamics that operate in discourses around autism, questioning deficit-based definitions of autism, and being willing to consider the ways in which biology and culture intersect to produce 'disability.'

Critical autism studies offer a space to challenge the deficit-based approaches of the medical model of disability, a stance I take up in this thesis. Critical autism studies scholars Richard Woods and Krysia Waldock described the origins of the field as returning to Jim Sinclair's Autistic self-advocacy speech, "Don't Mourn For Us," which Sinclair gave in 1993 (Sinclair, 1993). In this speech, Sinclair stated what seemed to be a revolutionary suggestion that parents embrace the Autistic identity of their children rather than mourning the loss of the non-Autistic child they had expected. The involvement of non-academic and academic Autistic people in work being done currently in critical autism studies, as initiated by the founders of self-advocacy like Sinclair, indicates that their efforts to centre Autistic experiences and encourage Autistic

participation in research are paying dividends, including a shift away from the medical model of disability towards the more inclusive social model of disability.

## **2.5. Examining Autistic Lived Experiences of “The Human”**

Autistic researcher Trento (2020, p. 91) reflected upon Remi’s (Yergeau’s) work, saying, “As the Autistic scholar Melanie Remi (Yergeau) (2018) discusses, a neuroqueer body-mind is always in constant motion, being relocated from one identity category to another, from humanity to animality and vice-versa, subject to an excessively strict rhetoric model.” The reality of life as an Autistic person with intersecting marginalized identities is one of code-switching between identities based on circumstances. In this thesis, I looked at categories or aspects of “the human.” Aligning with categories explored by Goodley and Runswick-Cole (2014), the aspects of “the human” that I examined in this thesis study included citizenship, (neoliberal) capitalism, labour, race, gender, sexuality, normativity, science, medicine, autonomy, choice, education, family, and advocacy. These authors explain their use of the prefix “dis” with these categories to indicate a disruption, pausing, questioning, or clarifying of what follows. For this study, following Goodley and Runswick-Cole, what follows the prefix “dis” are aspects or categories of “the human.” I wish to draw on the voices of Autistic bloggers to disrupt the categories and question who is perceived as human.

According to Professor of Comparative Literature Jenny Bergenmar, Professor of Sociology Hanna Bertilsdotter Rosqvist and Professor of Comparative Literature Ann-Sofie Lönngren (2015, p. 207), “The proliferation of published life writings [by Autistic people] corresponds to a rapid increase of blogs, video logs, and web communities where Autistic identity, personhood, and citizenship are major subjects.” The rapid increase of Autistic life writings in the form of blogs made blogs an excellent source of material to examine for writings

that addressed these aspects of “the human.” I examined Autistic relationships to “the human” by studying online blogs written by Autistic bloggers. My research contributes to academic writing and autism research on how Autistic people understand the concepts of humanity, life, and citizenship through their personal experiences. It also proves that Autistic people are analyzing these questions even when they are not part of academia and autism research. It speaks to the history of misrepresentation, dehumanization, violence, and exclusion in autism research and writing.

### *2.5.1. dis/Citizenship*

Erevelles (2013) said that transforming individuals into citizens is one of the most important roles of education in society. Drawing on the work of the philosopher Jerrold Levinson, Erevelles noted that a citizen is supposed to work toward the common good while still supporting people as autonomous agents who are free to pursue their interests. However, Erevelles (p. 146) said:

scholars such as Pateman (1988), Young (1990), and Mouffe (1996), among others, have challenged the universalism implicit in these formulations of citizenship by pointing out that notions of the ‘common good’ and ‘equal treatment’ presume a homogeneity among individuals and render difference invisible and/or unimportant. In fact, the historical struggles for the rights to citizenship by people of color, women, gays and lesbians, and disabled people have demonstrated that citizenship, rather than being a universal category, represents “a terrain of struggle over the forms of knowledge, social practices, and values that constitute the critical elements of the [liberal democratic] tradition.” (Giroux, 1988, p. 5)

This reminded me of the quotation that was part of the inspiration for this study, from *The Posthuman* by Braidotti (2014), included at the beginning of this thesis.

In Canada, citizenship rights encompass many aspects of life, including marriage, voting, employment, travel, free speech, and having children. BIPOC individuals, women, QUILTBAG (standing for Queer/Questioning, Intersex/Indigender, Lesbian, Transgender/Two-Spirit, Bisexual, Asexual/Agender/Aromantic, Gay/Genderqueer/Gender Non-Conforming (The Trans Language Primer, n.d.)) individuals, and disabled people are among those struggling for citizenship rights who cannot say they have always been considered human or that they are only that now. As Educational Researcher Paulo Freire (1998, p. 161) wrote, one who suffers discrimination does not enjoy the full benefits of citizenship since freedom is a fundamental part of the exercise of citizenship. If one cannot exercise their citizenship rights, which include fundamental freedoms such as autonomy, they are sometimes treated in legislation and mainstream culture as less than fully human. Examining the life stories of Autistic bloggers provided an opportunity to read about how the inability to exercise fundamental citizenship rights made people feel dehumanized, and how asserting their fundamental citizenship rights helped rehumanize them.

There are many examples of how Autistic people continue to have the exercise of their citizenship rights infringed upon. For example, Filmmaker and Activist Dominick Evans said that many Autistic people cannot afford to participate in the institution of marriage because they would lose their disability payments (Evans, 2018). Their partner might be unable to help cover the cost of medications and treatments that would have been part of these benefits. Science Journalist Sarah Deweerdt (2017) wrote that the idea that a person on the spectrum could be a parent was considered unthinkable for a long time. Risks are involved in being an openly Autistic

parent in a world that still struggles to believe an Autistic person could be a good parent. Activist and Journalist Alaina Leary (2018) noted that in the global north, there is a reasonable risk that an openly Autistic person could lose custody of their children for no other reason than their disability status. According to Leary, Autistic parents like me are at particular risk of having their children removed. Leary wrote that parents with a psychiatric disability are subject to the removal of their children at rates as high as 70-80%, and for parents with intellectual disabilities, the rates are 40-80%. Leary contrasted this with parents with physical disabilities, who report discrimination in custody cases at a rate of 13%. These numbers indicate that an Autistic parent would be more at risk of losing custody of their child than a physically disabled person.

Low income and underemployment are some of the intersections of marginalization I will examine in this study. People with low incomes cannot exercise the full extent of their citizenship. Some extreme conservatives in the United States argue that low-income and particularly non-land property-owning individuals should not have full citizenship rights, particularly the right to vote. An example would be how people with low incomes were forced into workhouses in the past. The same attitudes continue today, with people who believe welfare recipients should have to work for their benefits, regardless of how impractical the job might be in the context of their location or life. We also see it in policies that require welfare recipients to take drug tests before they receive payments. Some people even suggest the idea that recipients must take courses in subjects such as parenting before they get payments. Disabled people are among those subjected to such policies. At present, many disabled people face a kind of conditional citizenship. Social worker Kathryn Mackay (2011, p. 932) said: “The concept of citizenship had been frequently used to consider the relationship between the state and its people; its nature and component rights have been changing and contested over time.” Mackay (p. 933)

added, “Citizenship cannot be defined as a set of legal rules and neither can it be defined in relation to the size of the welfare state: it is a set of social relationships that are fluid, negotiated and change through time and terrain.”

Runswick-Cole and Goodley (2015, p. 5) wrote about the label “Benefits Scroungers” and how our cultural understandings of impairment labels disrupt the meanings of the term “Scrounger.” Runswick-Cole and Goodley (p. 4) discussed the stigma around low income related to disability, particularly when that disability was mental illness:

In contemporary cultural contexts, and on Benefits Street, the label of ‘person with learning difficulties’ functions in different ways from the label of ‘person with mental health issues’... Being labelled with learning difficulties, in neoliberal Britain, can act as a label of forgiveness for those who admit their ‘handicap, social stigma, dependence, isolation and economic disadvantage’; those accepting the stigma may benefit from the politics of redistribution and welfare benefits.

In other words, if you were developmentally disabled in the United Kingdom, you would not be stigmatized for receiving benefits. However, you would be if you were mentally ill. The former group of people is considered the “worthy poor.” They are not stigmatized as mentally ill people are, but they are considered unemployable. Mentally ill people are stigmatized and considered scroungers because mental illness is perceived as something that can be controlled. Runswick-Cole and Goodley (2015, p. 4) said that only “10% of disabled people with learning disabilities are in paid work.” Runswick-Cole and Goodley got this statistic from an article called “Social inclusion through employment: the marketisation of employment support for people with learning disabilities in the United Kingdom” written by Professor of Health and Life Sciences Lee Anderson Humber in 2013. If only 10% of learning-disabled people in Britain are in paid



work, they will live in economic instability unless they are independently funded. Even being able to collect disability benefits would not make them economically stable.

Mackay (2011) defined “Conditional Citizenship” concerning disabled people as individuals with the autonomy to make choices limited by statutes that make their financial support contingent upon compliance with certain types of care and treatment. Making the receipt of disability benefits contingent upon compliance with certain conditions has been justified by the idea that people are not supposed to be dependent. Social Psychologist Devon Price (2022, p. 93) said:

“Adults” are supposed to be independent, though of course no person actually is. We all rely on the hard work and social-emotional support of dozens of people every single day. You’re only seen as less adult, and supposedly less of a person, if you need help in ways that disrupt the illusions of self-sufficiency.

Our society often shames those who require assistance in their daily lives. Sometimes this shaming goes further, attempting to restrict the agency of people who cannot live independently. These attempts make these individuals appear to be in a prolonged state of childhood since it is the agency of children that adults typically restrict, rather than that of other adults.

### ***2.5.2. dis/Race.***

Disability Counsellor Educator Joy E. Weeber (1999) talked about the pain of ableism, saying the pain of ableism was the same as that of racism. Weeber (p. 21) said the societal assumption that everyone is or should be “Normal” causes pain. In this context, normalcy is being white and cis-gendered. In other words, BIPOC people (Black, Indigenous, and People of Colour) have racism directed at them in similar ways that disabled people have ableism directed towards them. As imperialism and racism were co-constructed, disability scholars have shown

how racism and ableism developed together. Professor of Special Education Subini Annamma, Professor of Special Education David J. Connor, and Professor of Inclusive Education and Disability Studies Beth A. Ferri (2013, p. 6) said, “racism and ableism are normalizing processes that are interconnected and collusive...racism validates and reinforces ableism, and ableism validates and reinforces racism.” The reality of how issues concerning race, disability, gender, and heteronormativity intersect makes a strong case for studying these questions in conjunction with each other.

Reflecting on Legal Scholar Angela Harris (1997), Erevelles and Minear (2010, p. 2) said: Harris points out that even though feminist scholars like Catherine MacKinnon recognize that different women have different experiences, they, nevertheless, continue to center white women as the norm, while relegating other oppressive forces such as racism to the footnotes so as to “nuance” the general analysis.

Centring white women in discussions about the oppression of women mirrors centring white Autistic people in discussions about the oppression of Autistic people.

Erevelles and Minear (2010, p. 2) further reflect on Harris (1997), saying “nuance theory constitutes black women’s oppression as only an intensified example of (white) women’s oppression and is therefore used as the ‘ultimate example of how bad things [really] are’ for all women” (p. 15). This phenomenon is something that the bloggers in this study reflected upon in their writing. Crenshaw (1989, p. 139) said that part of the problem with having a single-axis framework is that race and gender are treated as mutually exclusive. This often results in the voices of white Autistic people being prioritized over those of BIPOC Autistics and the voices of white Autistic women are often prioritized over BIPOC Autistic women. This becomes visible when organized group advocacy happens, such as when Autistic people start awareness

campaigns on social media and the internet. The goals of these campaigns often end up based on the needs and priorities of white Autistic people, taking it as given that this will meet the needs of the majority.

In this thesis study, I wanted to see if the Autistic bloggers I studied looked at autism as socially constructed, just as race is a social construction. I wanted to understand if certain circumstances caused the Autistic bloggers included in the study more oppression than others. I was interested in discovering if autism was an identity that could be hidden. I wanted to know if people felt more negative pressure from their Autistic identity than they did from their racial one. I was interested in seeing if the bloggers I examined thought there was a more positive social construction of race, gender, or sexuality versus disability. These questions tied back to the ways intersections of identity affect Autistic people.

### *2.5.3. dis/Sexuality*

Autistic Writer Jason Smith (2015) said that because Autistic adults are often viewed and treated as children, some people do not ascribe sexuality to Autistic people or consider that Autistic people might want sexual relationships. An example of this is the character of Sheldon Cooper in *The Big Bang Theory*. Sheldon was coded as asexual for most of the run of the show. Thus, it became a revolutionary act for *The Big Bang Theory* to make the evolution of Sheldon's romantic love for Amy Farrah Fowler the focal point of the last few seasons. If one assumed asexuality to be the socially acceptable sexual status for Autistic people, one must ask whether that would leave out all Autistic people who identify sexually, including QUILTBAG people.

*The Extraordinary Attorney Woo* (2022) storyline deals with autism and agency from the beginning of the series. In Season One, Episode 10, the ability of a person labelled as disabled to differentiate between love and rape and the desire others (so-called "normal" people) possess to

control their choices is dealt with thoroughly and sensitively. The final scene demonstrated how Attorney Woo related what happened with the young woman and her client, fearing that her ability to make consensual sexual and romantic choices could be similarly restricted because she is Autistic. I recommend that readers of this thesis watch the episode. It demonstrates how perceptions of an Autistic person's capability to enter romantic or sexual relationships consensually relate to how their agency is perceived and potentially limited. We see the perceptions about Autistic people's ability to enter romantic relationships questioned in a scene where Jun Ho, Attorney Woo's colleague and romantic interest, was at a bar with their friends. One of Jun Ho's friends told them they had once dated a pitiful girl out of kindness but that it was not a relationship. Jun Ho dove at their friend, knocking them to the ground. The others intervened and broke them apart. The incident provided a clear picture of the negative societal paradigms Attorney Woo and Jun Ho would be up against if they pursued a romantic relationship.

I wish to discuss the final scene in episode ten, season one of *The Extraordinary Woo* in more length. Attorney Woo and Jun Ho spoke alone at the end of a date. The following is a transcript of the scene:

Attorney Woo: "If you have a disability, I think merely liking someone is not enough.

Because even if I say it's love, if other people say it's not, then it's not."

Jun Ho: "Are you talking about the case today?"

Attorney Woo: "I'm not sure if I'm talking about the case or myself."

Jun Ho: "Even if other people say it's not, if you say it's love, it's love."

Attorney Woo: "Loving me is hard."

Jun Ho: "Yes. It appears so."

Attorney Woo: “But you’re still going to?”

Jun Ho: “Yes.” (Moon Ji-won, 2022)

I wanted to share this scene to demonstrate how perceptions of an Autistic person’s capability to enter a romantic or sexual relationship consensually affect Autistic people. Attorney Woo feared their right to make this decision could be taken out of their hands.

Applied Behaviour Analysis teaches children that their bodies are not their own. Activist and Author Maxfield Sparrow (2016) wrote that years of ABA therapy taught Autistic children to follow the orders of those in authority. It tells them they are at fault when they experience socially uncomfortable situations. They are made to believe their survival needs will only be met when they are compliant, and they will be rewarded with love and praise only in return for meeting expectations. This has the potential to lead to a higher rate of sexual exploitation. Member of York University’s Faculty of Health Jonathan A. Weiss and Psychometrist Michelle Fardella (2018) confirmed that the victim education Sparrow talked about tends to follow Autistic people into adulthood when they are at increased risk of abusive relationships. Price (2022) talked about a former ABA therapist who wrote an anonymous blog where they confessed their fears of what issues their lessons might cause with the children in their care. Price (p. 101) quoted this anonymous blogger as follows:

Upset about being treated like a circus animal? Not my problem, kiddo. I’m here to lure you with candy and manipulate you into doing my bidding, no questions asked. Which will make you excellent prey for sexual predators, abusive teachers, caregivers, and partners later in life.

In a study from 1988, Psychologist Charlene Y. Senn explored the vulnerability of Canadian people with developmental disabilities to sexual assault. Senn (1988, p. 20-21) stated, “Anecdotal

evidence, case histories, and assumptions hidden in related texts, all show that sexual abuse of children with developmental disabilities is a problem.” These numbers are hard to estimate accurately, due to under-reporting and other complications, but as Senn stated, there is reason to believe that people with disabilities are already more vulnerable to sexual abuse than the non-disabled population. Thus, any factor that might contribute to this problem needs to be considered.

Several articles I reviewed for this thesis suggested Autistic people were more likely to be sexually abused: “Sexual abuse of children with autism: Factors that increase risk and interfere with recognition of abuse” by Professor of Clinical Psychology Meredyth Goldberg Edelson (2010) and “Evidence that nine Autistic women out of ten have been victims of sexual violence” by Fabienne Cazalis from the Center for Analysis and Social Mathematics and co-authors (2022). This makes me think there needs to be an academic study to determine if an Autistic person who has been through ABA is more likely to be sexually abused than an Autistic person who did not go through ABA. Include a short sentence linking this section back to your purpose and thesis statement.

#### ***2.5.4. dis/Normativity***

Advocate and Author Yenn Purkis and Psychologist Wenn Lawson (2021) noted that the idea of gender as binary is changing, as reflected by the 2014 Facebook introduction of fifty-eight options for gender identification. Purkis and Lawson (p. 40) said:

While 58 was a good start, it could be argued that gender is an individual consideration, meaning there are around 7 billion genders, each one specific to each human being...Gender, as well as being biologically determined, is a societal concept which, like a number of things, is socially constructed.

The idea that gender is completely different for everyone is reflected by more than one of the bloggers in this study.

Gender and sexuality are socially constructed, like disability and race (citation in academic/activist literature). Differences between how traditional and postmodern dictionaries define these words reflect the social construction of gender and sexuality. The Cambridge Dictionary (2021) defines gender as “the physical and/or social condition of being male or female.” Merriam-Webster (2021) provided a broader description of gender as partly arbitrary and based on distinct characteristics. Merriam-Webster (2021) also offered a “Usage Guide” section about the difference between sex and gender. In the Urban Dictionary (online). Thisisnotapseudonymorisit (2020, Nov. 7) humorously described gender as “a scam invented by bathroom companies to sell more bathrooms.” The Cambridge Dictionary (2021) defined sexuality as “someone's ability to experience or express sexual feelings.” Merriam-Webster (2021) described sexuality as “the quality or state of being sexual, the condition of having sex, sexual activity, and expression of sexual receptivity or interest especially when excessive.” The Beige24 (2020, Feb. 10) expanded the meaning of sexuality in *The Urban Dictionary* to include seven types of sexualities, all treated as valid.

Disidentification with gender is something I have seen with an Autistic person in my life. Professor of Comparative Literature Jordynn Jack (2014, p. 185) said:

Autistic individuals may understand gender as a sort of disidentification. From this perspective, one relates one’s own sense of gender identity to observations of available gender roles or performances and finds a lack of coherence.

This Autistic person in my life does not identify with their body, sexuality, or what they observe to be traditional gender norms. Purkis and Lawson (2021) said that figures from some studies

suggest that gender dysphoria and other gender and sexuality issues are higher within the Autistic population. Purkis and Lawson (p. 41) said, “Gender dysphoria individuals are living with extreme discomfort and the literature states around 40 percent attempt suicide.” Non-Autistic people also experience gender dysphoria. However, there are aspects of gender dysphoria experienced by Autistic people that are intensified due to a general sense of not belonging. (See Appendix A)

Autistic people experience many forms of othering in their lives. Autistic people are often othered when they do not conform to traditional gender identification. Jack (2014, p. 185) said:

Traditionally “proper” gender identification has been considered a marker of a person’s social development and children were expected to identify unproblematically with their biological sex by the time they reached school age, although attention to alternative gender identities has lessened this expectation somewhat. We now understand gender identification as a process that happens incrementally, and not always without conflict.

It makes sense that people who do not develop in the same way as the neurotypical norm would identify with gender identities under the “non-Binary” umbrella. Non-binary in this thesis is an umbrella term, meaning not identifying with either male or female binary, and is included under the umbrella of “trans,” although not all non-binary people identify as trans (LGBT HERO, n.d.).

According to Associate Professor in Social Development Studies Margaret F. Gibson and Associate Professor in Disability Studies Patty Douglas, President Obama described the attempt to change a person’s sexual and gender identity as an immoral and violent act in their 2016 call for the end of gay conversion therapy (Gibson & Douglas, 2018). Given that the coercion of a person to change their sexual preference and gender identity is an unethical and violent act, it is interesting that the damage caused to Autistic people through Applied Behaviour Analysis, an



approach coercing them to suppress their Autistic traits, is not similarly recognized as abusive. Gibson and Douglas cited Activist and Author Amy Sequenzia’s suggestion that one way to thrust this understanding into the collective consciousness would be to add “Autistic Conversion Therapy” every time we said or wrote “Applied Behaviour Analysis” or “ABA.” Gay Conversion therapy and Autistic Conversion therapy Applied Behaviour Analysis are the noxious fruit of a pestilential tree, namely Applied Behaviour Analysis and the work of Psychologist Ole Ivar Lovaas. Creating Applied Behaviour Analysis is the most notable work Lovaas is recognized for. Even though it is the bedrock of gay conversion therapy, Lovaas’s work on the “Feminine Boy Project” is less known. Historically, those who have deviated from gender and sexual norms have met with similar treatment as those who exhibited symptoms of autism. ABA and Gay Conversion Therapy originated with the same researcher and have had similarly damaging impacts. As with the conundrum of the chicken and the egg, it is difficult to say if the assumption that Autistic people are asexual or homosexual came first or if it sprouted from the association with Ole Ivar Lovaas.

## **2.6. Examining Autistic Lived Experiences of Social Institutions and the Regulation of “The Human”**

### ***2.6.1. dis/Medicine.***

The medical model of disability is built around the assumption that disability and disease result in reduced agency. Remi (Yergeau) (2018, p. 7) said:

autism is medically construed as a series of involuntaries—of thought, mode, action and being...involuntary dominates much of the discourse on autism, underlying clinical understandings of affect, intention, and socially appropriate response.

The focus within the medical model of disability tends to be on curing the “Disease,” which results in contributing circumstances that might aggravate or accelerate the outcomes of disability not being acknowledged. For example, fiscal conservatives tend not to believe it is incumbent upon society to provide marginalized people access to nutritious food even though diabetes puts a considerable strain on the healthcare system. Abberley (1987) wrote that medicine generally divides most impairments into two categories: the product of severe illness or the result of ordinary wear and tear on the body. In this view of impairment, causation comes down to ‘germs’ or ‘life.’ Social causation through factors such as oppression, low income, or war is seen as peripheral.

The medical model of disability made disabled people responsible for how much disability affected their lives. If they could not “Overcome” their disability and develop methods of participating in a society that did not enable their participation, they were deemed at fault. Autistic people were expected to accept the idea of cure or remediation or were considered at fault for their continued disablement. Some bloggers included in this study have been asked whether they would take a cure if it were available. They have also experienced being challenged on their answer that they would not want a cure often enough to feel the need to justify their response. For example, Alex Forshaw (2019, Jan. 16), the author of the *My Autistic Dance* blog, wrote about this subject in “A bed of roses still has thorns.” Forshaw talked about the connection they feel to other Autistic people as being very important in their lives, saying they viewed anything that threatened their connection to other Autistic people as a threat to their lives. Forshaw (2019, Jan. 16, para. 21-23) said the following about the subject of taking a cure if one were available:

Would I like to never again feel overwhelmed and disoriented by complex noise or too-bright lighting? Would I like to be able to remember what I came into a room looking for?

Would I like to be able to keep my apartment organised?

These are areas where I want assistance. If there was a way to “fix” them while leaving everything else intact would I be interested? Maybe, but I’d need to be sure the cure wouldn’t have unintended consequences: side-effects.

So there’s my answer: a definite maybe, if it’s not too much trouble and it wouldn’t do anything I didn’t want it to. I’ll take help if it’s going, I might consider limited treatments, but I would never want to not be Autistic. I don’t want to be “cured” because although I accept that I’m disabled, I don’t see myself as broken.

I agree with the bloggers in this study who expressed similar sentiments. I would also like support in various areas of my life, but I do not want to be cured of being Autistic. How does one remedy who they are? Do people wish to find a cure for having exceptional focus? Do they want to be cured of their unique perspective on the world? I tend to lean toward what Graphic Artist and Author Julie Danchez said in an interview with Activist and Filmmaker Andrea LaMarre (2017), that stigma causes me more harm than autism. None of the bloggers in this study said they would choose not to be Autistic. That does not mean there are not some Autistic people who would choose to be neurotypical if that were an available option.

For many Autistic people, the question is less about wanting or not wanting a cure as much as it is about priorities. A cure (for them) represents spending money on something of questionable value when they could enact real quality-of-life changes with these funds. This is not reflected in the priorities of one of the major autism organizations, Autism Speaks. ASAN (para. 4) said:

While they removed the word ‘cure’ from their mission statement, Autism Speaks continues to fund biomedical research focusing on identifying the causes of autism, rather than quality of life research that aligns with the priorities of the Autistic community. Autism Speaks (n.d.) self-identifies its MSSNG Project as the world’s largest autism genome database. This project makes up a large part of the approximately 24% of the Autism Speaks budget (fluctuating slightly depending on the year) that the Autism Self-Advocacy Network (2021) stated in its flyer titled “Before you donate to Autism Speaks, consider the facts” was spent by Autism Speaks in 2019. Autism Speaks (n.d.) said about the meaning of the project’s name, “The omitted letters in MSSNG (pronounced ‘missing’) represent the missing information about autism that the research program seeks to deliver.” After learning this, my mind leapt to all the things the medical model focuses on being missing in Autistic people from the long list of deficits the medical model has used to define autism.

The Autism Self-Advocacy Network (2021) addressed some facts about how Autism Speaks used the money they raised in 2019 in the flyer mentioned above. The Autism Self-Advocacy Network (para. 1) started by saying, “Very little money donated to Autism Speaks goes toward helping Autistic people and families.” ASAN (para. 1) stated that only 0.16% of the Autism Speaks 2019 budget was allotted to “Family Service” grants. By comparison, Autism Speaks spent 21% of its budget on fundraising in 2019. Besides the question of what Autism Speaks prioritizes when allocating the funds they raise, there is the question of the ethics of how they have chosen to raise money. ASAN said Autism Speaks spent 19% of its budget on awareness and lobbying. Activist Elsa Henry (2013, Nov. 13) characterized the awareness campaigns designed by Autism Speaks as exploitative and fearmongering. The most infamous of

these fearmongering advertisements was the “I Am Autism” Autism Speaks campaign from 2009. (Please see Appendix B for the full transcript)

While the medical model of disability focuses on a cure, legitimate medical science does not support unresearched, untested, and unproven approaches such as ingesting bleach as an enema or a drink. However, pseudo-medical practitioners, primarily following the environmental disease model that proposes autism is a disease that one can recover from if environmental causation factors are addressed, sometimes convince parents that practices such as ingesting bleach as an enema or a drink might offer the cure they seek. There appears to be some degree of reluctance from the public to criticize any way parents, perceived as acting out of desperation and love in equal measure, choose to experiment on their Autistic children. These treatments, unresearched, and found online, include a broad spectrum of approaches, from changing their diet to cut out gluten, which most people would deem reasonably innocuous, all the way to giving an Autistic child bleach enemas or even making them ingest what is essentially a form of bleach (Patel, 2019). Miracle Mineral Supplement, or MMS, consists of sodium chlorite and hydrochloric acid, which becomes chlorine dioxide, or bleach when diluted with lemon juice. The chlorine dioxide solution is then taken (or given) orally or by enema. Writing for *Altogether Autism*, Glenn Lambert-Vickers (n.d.) issued a warning about the use of MMS as an attempt to cure autism. Lambert-Vickers (para. 1) said about the claim that MMS can cure autism, “Health authorities state there is no basis to these claims and ingesting the solution can cause serious health risks and is potentially fatal.” Further, health authorities state no evidence to back claims that MMS is a successful intervention for any condition, adding that ingesting bleach is harmful. The US Food and Drug Administration states that high oral doses of this bleach, such as those recommended in the labelling, can cause nausea, vomiting, diarrhea, and symptoms of severe

dehydration. In this warning, Lamber-Vickers mentions the case of a person sentenced to thirty-four years in jail for selling this substance as a cure for autism.

In an article by Kerri Rivera, an author who calls themselves an expert in the pseudo-medical practice of using Miracle Mineral Supplement as a cure for autism. Rivera claims to have helped 38 children recover from autism. Articles like this are part of the reason so many people are not satisfied with the question of a cure being personal. Knowing things like this are being done to children who have no agency to prevent or choose it, all in the pursuit of curing their autism, breaks my heart.

The medical model of disability situates Autistic people as ill or disordered, needing to be cured, recovered or remediated. The incentive for a cure situates Autistic children as not valuable. The dis/Medical approach says focusing on a cure causes harm and fails to help Autistic people. As an extension of the suggestion that Autistic people would be better off being neurotypical, one might infer that the world would be better off without Autistic people.

### ***2.6.2. dis/Autonomy, dis/Choice, dis/Agency***

We expect our parents to make certain decisions for us when we are young, generally assuming these decisions are in our best interest. For example, parents have the right to decide where their family will live, so long as the needs of the children are met. However, there are other decisions that perhaps children could make. For example, does a child's gender need to be defined when they are too young to define it themselves? Other examples are so extreme, that the United Nations declared them a child's rights, trying to prevent them from happening. These might include parents giving their child in marriage to anyone, regardless of whether it is an adult or another child.

Autistic children and youth are not thought of as having the same degree of autonomy and agency as their non-Autistic peers, making it more likely that the public will not question the decisions parents make for their Autistic children. The reduction of Autistic children's autonomy and agency is made worse by Simon Baron-Cohen's "Theory of Mind," because it assumes Autistic children are not able to understand their own minds well enough to make an informed decision about what is in their best interest. Referencing Helen Tager-Flusberg (psychologist), Simon Baron-Cohen (psychologist), and Donald Cohen (psychiatrist), Anne E. McGuire (Professor of Equity Studies) and Rod Michalko (Sociologist) (2011, p. 165) defined Theory of Mind as a "concept that psychology uses to signal the ability to 'attribute mental states (such as beliefs, desires, intentions, etc.) to [oneself] and other people, as a way of making sense of and predicting behaviour' (Tager-Flusberg, Baron-Cohen & Cohen, 1993, p. 3)."

ABA is an approach that systematically deprives Autistic children of autonomy and agency. Douglas (2010, p. 114) described ABA as an approach the Ontario Ministry of Education endorsed in "Effective educational practices for students with autism spectrum disorder: A resource guide" (2007). Autism teams frequently recommend it to teachers and families as a tool that could be used to normalize Autistic children and make them more governable, thus more easily included in the regular classroom and school culture. Douglas (2010, p. 114) said this approach:

compels enterprising teachers and educational assistants to work directly on Autistic bodies in an attempt to normalise movements, use of time, occupation of space, pattern of eye gaze, and engagement with academic work, in this way 'readying' such students for the project of inclusion. At the same time, more distantiated tactics such as parental

involvement are invoked, as families are asked to practise at home in order to increase student capacity to learn, and develop socially and academically.

The choice of the word “Compels” to describe how ABA sometimes comes to be implemented in classrooms is interesting, because indeed, not everyone who ends up involved in the implementation of ABA in schools feels as if they had a choice. However, it remains the dominant approach used by many schools and parents. Sometimes this is simply because the schools and parents do not believe any available and effective alternatives exist.

Remi (Yergeau) talked about how facets of Autistic personhood are pathologized within ABA. Remi (Yergeau) (2018, p. 11) stated “behavior analysis stories the Autistic through observation, bodily comportment, and external behaviour.” Remi (Yergeau) (p. 104) said ABA included “punishment, saturation, compliance, and routine surveillance.” Applied behaviour analysis is a mechanism of controlling and directing Autistic body-minds. Remi (Yergeau) (2018) said that ABA’s fixation on cure brought a lot of support from parents, who became the most enthusiastic adopters of ABA. However, Remi (Yergeau) (p. 95) said:

Applied behaviour analysis and similar behaviorist frameworks faced critique not only from clinicians who held dear their psychogenic frameworks but from literary critics, philosophers, linguists, and educators, including Kenneth Burke, Maurice Merleau-Ponty, Noam Chomsky, and Jerome Bruner.

Remi (Yergeau) (p. 95) said that in the early stages of ABA, some psychoanalysts and other academics framed it “as an evil, a behaviourist methodology that supposedly transformed humans into little more than dogs, machines, or automatons.” It made some sense when, according to Remi (Yergeau), parents of Autistic children reacted to the resistance of psychoanalysts to ABA by forming lobbies and political organizations, writing books, opening residential schools, and



returning to college so they could replace the experts they despised. Many of them had been hurt by the historical blame directed at mothers for their children being Autistic. The “Refrigerator Mother” theory of autism claims that a lack of maternal warmth causes autism. It is little wonder parents of Autistic children would enthusiastically throw their support around an approach that did not pathologize their parenting (Douglas, 2013, “Refrigerator Mothers”; Douglas forthcoming (book); McGuire, 2016, *War on Mothers*).

There are a lot of questions of agency and autonomy to explore regarding the practice of ABA. Virginia Bovell (2020), a member of the Islington Learning Disability Partnership Board, provided a list of questions to test the ethics of autism interventions. Bovell (p. 45) suggested that people ask who should make the choice about whether cure or prevention was sought, when the decision was made, and why it was made. They should ask what is involved in the proposed intervention, if it causes discomfort, whether it involves immediate and long-term adverse side effects, how likely it is to be effective, and how its effectiveness is measured. Bovell said it should be important for people to ask about the autonomy and consent issues at stake, and at what age or intellectual capacity this starts being considered important. Bovell said people should ask themselves what moral issues arise for an intervention that might affect the sense of identity of a developing person and at what stage of development it is morally acceptable to instigate or abandon such interventions. Could focusing funding on interventions for the young have adverse effects on Autistic adults who are older? Will parents and families be pressured to take up interventions they do not believe are best for their children because it is seen as good for society to eliminate the responsibility of caring for Autistic people? When a choice regarding interventions is put forward, how is this choice framed for the individual affected? These are questions everyone involved in autism intervention should ask themselves. If there is a trend in

the answers that reveals a reduction of autonomy and choice, they should reconsider if the intervention they are part of or considering becoming part of is really in the best interest of the Autistic child.

McGuire and Michalko (2011, p. 171) said, “Baron-Cohen’s work proposes that Theory of Mind is an intrinsic human characteristic, a characteristic moreover, which is ‘nature’s choice.’” Baron-Cohen portrayed their ToM as an intrinsic element of what constructs “the human,” implying that Autistic people were somehow subjects that nature had failed to eliminate through natural selection. Referencing Baron-Cohen (1995), McGuire and Michalko (p. 171) said, “In fact, he suggests that ‘natural selection’ has latched onto mindreading as ‘an adaptive solution to the problem of predicting behaviour and sharing information’ (Baron-Cohen, 1995, p. 30).” Remi (Yergeau) (2018, pp. 11-12) said the following about ToM and ABA:

Whereas ToM stories autism in terms of internal states and cognitive processes, behavior analysis stories the Autistic through observation, bodily comportment, and external behavior. Taken together, ToM and ABA construe the Autistic as involuntarily willed and involuntarily drafted—beholden not only to neuronal desires but to the desires of therapists and caregivers and social norms.

ToM implies that Autistic people do not have autonomy or choice by suggesting that they are involuntarily willed, and ABA treats them according to this implication.

Thinking about how Autistic people’s autonomy and choice are viewed as reduced because they are thought to have “mindblindness” (Baron-Cohen, 1995) is hurtful. I can see how Autistic people could be perceived as not understanding other people's minds, but I agree with Damian Milton’s assertion that it is a mutual failure to understand each other’s minds. If Autistic people have difficulty understanding the minds of non-Autistic people, it is equally valid to say

that non-Autistic people have trouble understanding the minds of Autistic people. Damian Milton outlined this concept in their article, “On the ontological status of autism: the ‘double empathy problem,’” a theory they published in 2012. I also believe that the emphasis needs to be on cultivating mutual understanding between Autistic and allistic people, as per Milton’s Double Empathy Problem.

In this thesis, I examined blog content created by a selected group of Autistic authors to see how Autistic people see themselves as autonomous and allowed to be autonomous. Saying an Autistic person is construed as involuntarily willed is another way of saying they are perceived as not having autonomy or choice. It is presumptuous to believe you understand other people's mental states. In addition, I considered the effect denial of agency might have on Autistic people. Associate Professor of Occupational and Recreational Therapies Anne V. Kirby and co-authors (2019) showed that death by suicide rates between 2013 and 2017 among Autistic people raised as girls in the global north were three times higher than non-Autistic. This study also showed that young Autistic people in the global north were at twice the risk of death by suicide than non-Autistic people the same age. These statistics lead me to believe that the denial of agency, which would be more acutely felt by youth entering the stage of life when they are supposed to be taking ownership of their agency, might put them at increased risk of depression and suicidal ideation. I wanted to know if the bloggers in this study expressed any feelings of depression and suicidal ideation because of the denial of their agency and the pathologizing of their ways of being.

Agency and autonomy are essentially synonyms. Referring to the theory of new materialism, all things have agency. Professor of Media Arts Felicity J. Colman (2018) described agency as an act of doing or being that connects the body and the mind. Lecturer in the School of

Childhood, Youth and Education Studies David Ben Shannon (2021, p. 8), reflecting on Margaret Price (2015) who coined the term “Bodymind” in their book *Mad at School*, said that historically, the British social model of disability “tended to emphasize ‘apparent’ disabilities (em-body-ment) at the expense of ‘non-’ or ‘intermittently-’ apparent disabilities (em-mind-ment).” According to Shannon, disability scholars have used the term ‘bodymind’ to account for the erasure of intellectual and neurological differences. Reflecting on Margaret Price (2015), Shannon (2021, p. 8) said:

Rather than a stand-in for body-and-mind, then, Price (2015, p. 271) argues that ‘bodymind’ does theoretical work; she defines the bodymind as a “socio-politically” constituted and material entity that emerges through both structural (power-and-violence-laden) contexts and also individual (specific) experience.

In other words, the concept of bodymind is socially constructed, informed by societal power dynamics and personal experiences. This makes the blogger’s personal experiences of disability particularly relevant to how their bodymind is constituted.

Reflecting on Sami Schalk in “Coming to claim crip: Disidentification with/in disability studies” (2013), Shannon (p. 8) said that bodymind is important in discussing the intersections of disability and race. The same would be true of the intersections of disability and various marginalized identities, making this thesis's focus on these intersections relevant to understanding the construction of bodymind. Shannon (p. 9) said:

Thus, my use of the term body(mind) does not indicate a dualism...

I extend this work further by bracketing ‘mind’ as body(mind): here, the mind is parenthetical, not distinct from the body, but also not forgotten. This also allows me to refer to ‘bodies’ across a more-than-human milieu with the same term, encompassing

those bodies that cannot be said to have a mind in the common sense understanding of the term.

Unfortunately, disabled bodies are sometimes considered not to have a mind in the common understanding of the term. This can be seen in how Autistic people are considered to have trouble with or lack ToM. Psychologist Iris Berent, Rachel M. Theodore (Associate Professor of Speech, Language, and Hearing Services), and Erick Valencia (developmental cognitive neuroscience) (2022, p. 1) started with the question of whether “Dualism,” which is considering the mind to be ethereal and distinct from the body, arises from ToM. They posited that “People” were naturally dualists, saying that if dualism arose from ToM, then autism should reduce the natural state of dualism in Autists. Their study found that Autistic people were more likely to view the body and mind as one and not to believe that the mind continued to function in some other form after death. By their way of phrasing their research questions, the researchers essentially concluded that Autists were less “People” than non-Autists. Shannon’s statement that they use the term body(mind) so as to not indicate Dualism would set them outside of whom the researchers above called “People.” However, Shannon’s work falls into posthumanism. It demonstrates that Shannon has already stepped away from the restrictive notions of “the human” found in the roots of humanism.

### ***2.6.3. dis/Education***

Since ABA is an approach that does not require medical credentials to practice, it is most appropriately examined through the lens of education. ABA dominates the approaches currently being used in the education of Autistic children in many North American countries.

According to McGuire (2016, p. 47):

For cognitivists, the assumed pathological nature of autistic behaviour is not an end in and of itself but is, rather, an *indication* of an underlying difference in the mind and/or brain. Cognitivism is distinguishable from its antecedents—psychoanalysis and behaviorism—in a number of critical ways. Unlike behaviorism, which holds observable behaviors as its focal point, cognitive psychology is primarily focused on internal mental states (beliefs, desires, and so on) (Baron-Cohen, 1997; Firth and Firth, 1999).

ABA does not spend enough time looking at the inner mental state, feelings, or desires of Autistic children. Behaviourism gained ground in the autism community as a response to the trauma caused by cognitivists such as B.F. Skinner and Eugen Bleuler. However, it does not tend to look at the child as a whole or treat the child as having legitimate reasons for behaving in certain ways. Its primary objective is to bring the child’s behaviour in line with what is considered normal and typical.

As previously stated, there is a deep divide between those supporting ABA and those who do not. Some people are involved with it because they do not have a choice. For example, many teachers and educational staff would use another approach if allowed and trained. The question becomes, who is promoting the specific use of ABA? Why are they focusing on the use of ABA in particular? It is important to look at those who have the influence and power to affect these decisions and who stand to gain or lose money by promoting and maintaining the use of ABA. ABA continues to be the primary approach in Ontario schools, for example. Is it because it is the most visible approach? Is it because many parents advocate for its use? Is the industry promoting its use with those with policy-making power? Assistant Professor at York University Jake Pyne (2020, p. 342) said, “ABA received \$333 million in government funding (Ontario, 2016).” In *The Autism Industrial Project*, Professor of Education Alicia A. Broderick (2022, p. 191) said the

following about Autism Speaks lobbying for legislation that would streamline the process of harvesting health insurance funding for ABA intervention:

If health insurance funding were identified early on as a potential revenue stream to subsidize access to ABA intervention, then it would be necessary to invest some time and media saturation in the production (and consumption) of autism as a disease in order to make the subsequent argument that ABA intervention was ‘medically necessary,’ and therefore, logically, appropriately funded by health insurance dollars.

In other words, there are both huge financial stakes and human consequences in promoting ABA as the primary approach for autism interventions. The question is, who is being paid out of these funds? They would be included in those with a stake in maintaining ABA as the primary approach. According to Pyne, legal challenges to ABA have resulted in more, instead of less, behaviour modification. Pyne (p. 342) said, “ABA is not only legal, but legally mandated for provision in some educational settings (Ontario Ministry of Education, 2007).”

There also are widely differing opinions about what behaviours should be considered dysfunctional and must be replaced with adaptive ones. Should they be considered dysfunctional if they cause no harm to others but are unfamiliar? If someone thought they should be, the next question would be why the discomfort of those around the Autistic person should be considered more important than the Autistic child’s discomfort. For example, are stims considered dysfunctional? Erin Felepchuk (Ph.D. Student at Carleton University) (2021) said the following about the meaning of the words “Stims” and “Stimming”:

Stimming is an embodied, repetitive, and sensory practice with which many autistic and other neurodivergent people engage. Medical culture constrains stimming through strict clinical designations and pathologizing definitions, referring to it as stereotypies or ‘self-

stimulatory behaviours.’ Autistic people, however, often define stimming more broadly as repetitive sensory practices used to regulate emotional states, to cope with external sensory stimuli, or for purposes of self-expression. The word *stimming* is frequently used by the autistic community and is reclaimed from the medical term ‘self-stimulatory behaviours.’

If a stim is unfamiliar but causes no harm to the stimmer or those around them, why should it be considered dysfunctional? These questions might arise in schools when an Autistic child stims in the classroom. Stimming might provoke a parent to complain that their child is being distracted. Does that mean the Autistic child should be removed from the classroom? Some people would say they should be. I contend that Autistic children have a right to be in the classroom, receiving the same quality of education as non-Autistic children.

The Director of Programme Design at ProjectManagement.co.za, Tania Melnyczuk (2019, para. 4) said, “Lovaas did not consider Autistic children to be people until they had undergone his ‘therapy to build a person.’” In 1974, Lovaas did an interview with Paul Chance: "After you hit a child, you can't just get up and leave him; you are hooked to that kid." Lovaas (1974, p. 76) said in this interview:

You see, you start pretty much from scratch when you work with an Autistic child. You have a person in the physical sense – they have hair, a nose and a mouth – but they are not people in the psychological sense. One way to look at the job of helping Autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person.

The “Lovaas Model” of ABA calls for children to undergo forty hours a week of clinical setting intervention per week, in addition to at-home reinforcement. Lovaas expected Autistic children to



endure what amounts to a full-time job, on top of the full-time occupation of attending school, all while the ABA program is taking away home as a sanctuary. Melnychuk (2019, para. 5) said, “Some ABA is done at home by parents themselves, replacing normal parent-child relationships.” However, parents are not always willing subscribers to ABA. Melnychuk (2019, para. 38) said, “In some countries, such as the USA, the government pays for autistic children to undergo ABA, and parents may even be forced to keep their children in ABA.” This harkens back to the reasons that government intervention in certain pseudo-medical approaches that might cause harm is resisted because parents feel like their autonomy to parent their children as they see fit is being wrongly interfered with by governmental power.

According to Psychologist Saul Mcleod (2023), B.F. Skinner called their approach “Operant Conditioning.” Mcleod (2023, para. 5) said:

Skinner is regarded as the father of Operant Conditioning, but his work was based on Thorndike’s (1898) law of effect. According to this principle, behavior that is followed by pleasant consequences is likely to be repeated, and behavior followed by unpleasant consequences is less likely to be repeated.

However, denying rewards based on what the child loves the most turns the rewards into the ever-present possibility that what they love will be used against them. Many people do not see this as aversive therapy, since the child is provided with love, kindness, respect, food/clothing/shelter, and everything else they require to exist. In the article “5 important reasons even ‘new ABA’ is problematic” Kaylene (n.d.), the author of the *Autistic Momma* blog, outlined five reasons that ABA is still abusive in its new form. The first reason Kaylene gave was that changing behaviour remains the primary goal of ABA. It continues to ignore what the behaviour is trying to communicate regarding the child's mental state. Kaylene said the second reason was

that the new ABA focuses on compliance. Third, the new ABA focuses on positive rewards rather than negative consequences. This sounds like it should be a point in favour of ABA. However, it amounts to the same thing as negative consequences when it means a child's reward is denied because they did not comply. The fourth reason was that, just like the ridiculous hours recommended by Lovaas for ABA, the new ABA still requires huge amounts of the child's free time. The final reason was that it promotes the idea that an Autistic child must change to fit in. ABA is meant to teach children to function within society. This supposes that the way society is constructed is ideal for most, if not all people, therefore, therefore it is ideal to educate children to function within the expected parameters of this construction. dis/Education pushes back against this assumption.

Autistic researcher Michelle Dawson (2014) wrote that the best outcome Lovaas (the creator of ABA) reported was 47% success for the pre-school-aged Autistic children in his experimental group who underwent 40 hours per week of ABA training for two or more years. Lovaas's measure of success was that the children were indistinguishable from their neurotypical peers. Disturbingly, Dawson stated that the only way to get to the 47% success rate with ABA is to use aversives that included slaps, hair pulling, food and sleep deprivation, physical restraint, and even electric shocks. If the only way to get this relatively low success rate is to abuse Autistic children, one must question the point of putting children through ABA in any form. How can ABA claim to cure autism when autism is far more than a collection of behaviours considered aberrant? Autism is often passed down through families, suggesting it might be in a person's genetic makeup. It is in the way a person processes the world. In other words, it is a fundamental part of who a person is. If one dismisses the idea that ABA can cure autism, one also must question the purpose of putting children through the traumatizing practice. Gary Shkedy (Director

of Research, Alternative Teaching Strategy Center), Dalia Shkedy Alternative Teaching Strategy Center), and Aileen H. Sandoval-Norton (Psychologist) (2021) came to the same conclusion about the continuation of ABA as I did: That it caused much harm for questionable benefits.

Part of the reason ABA is so dominant in educational settings is that people do not believe there are viable alternatives. It is hard to see other approaches making much headway when they are up against an approach with so many jobs attached to it and such hefty financial resources behind it. It is debatable if all the treatments and programs parents and educational settings put Autistic children through are valuable. What works for one child might not work for another. However, the most debated and worthy of scrutiny is ABA.

#### *2.6.4. dis/Family.*

Douglas (2013), who mentored me, discussed the blame/praise dichotomy in one of their papers. On the praise side of this dichotomy, they said there is the emerging “Autism Mother” described as a “Feminine Warrior.” Douglas (p. 167) described the feminine warrior as, “Motivated by her fierceness, grief and love, this mother works for a future in which her child (and indeed the world) is free of autism, as an assurance of their future happiness and well-being.” I can understand how a person may feel grief when facing reality different from expectations. On the other hand, the Autistic child born is not gone. Douglas (p. 167) said:

Already alluded to in my opening quotation, autism mother identities that grieve the loss of this subject and enact love through campaigns against autism thus contain a most “hateful” and unethical duty (Derrida, 1995): the implication of an autism mother’s very love and identity in the normative violence imposed on transgressive bodies within western bio-medical, colonialist, and global capitalist regimes.

The quotation Douglas opened with came from Sinclair (2012, 1993). Sinclair was encouraging people to grieve if they must but to realize that the disabled child is waiting for them to stop grieving and recognize they still exist. Douglas suggested in the above quotation that some parents, rather than embracing their child's embodiment, refocus their grief on fighting campaigns against what they feel took their child away. Jack (2014, p. 57) said that "if autism is depicted as an enemy of the defeated, ABA becomes the weapon leading to resolution, the sword in the mother's scabbard, completing the quest." In the campaign against autism, one of the weapons wielded by the warrior feminine is ABA. As mentioned in the previous section regarding education, ABA demands forty clinical hours per week, with extra practice hours at school and home. The fact that so many parents see ABA as a weapon in their scabbard means that there are a lot of Autistic children being stretched thin, which in many cases probably results in the opposite outcomes the parents are hoping for since they probably let out a lot of their frustration and fatigue in the home and on the family.

As mentioned previously, psychoanalysts such as Bruno Bettelheim blamed Autistic children on their mothers. Douglas (p. 170) said that "mid-century neo-psychoanalytic approaches would quickly rise to eclipse these biological beginnings and place the blame for autism (and other troubled offspring) squarely on the mother." To further support their evidence that blame for autism has been placed on the mothers of Autistic children, Douglas (p. 170) said:

Under the 'paternalistic' guidance of (predominantly white, male, western) science, this shape of mother-love or lack thereof had emerged as both the originator of autism and 'the regulator of the 'normal' development of the child and subsequent 'healthy' development of the state as a whole' (McGuire 2011b, 82).

If a child demonstrated trouble forming bonds and relating to others, it was because their mother did not show them enough affection; the mothers were cold, like refrigerators. In the past, it was accepted logic that cold and unloving mothers were the cause of autism in children, leading to the coining of the term “Refrigerator Mom.” Waltz (2015, p. 353) said, “autism parenting is rooted in a discourse of mother blaming persistently woven into the history of autism, even before the condition was named and defined.” Waltz wrote that mothers could only save their children with the help of professionals. They could not be assumed to possess instincts for how to correct, teach, and care for their child. If they did it incorrectly, their child would burden society. According to Waltz (2015, p. 354), the children would be “weak-minded, badly behaved, aberrant adults with a propensity for crime and radicalism.”

Mothers are not overtly blamed for their child's autism these days. However, Waltz (p. 355) said, “today's ‘autism mom’ is supposed to be a child-saving hero, expected and encouraged to do anything and everything in pursuit of normalcy, from special diets to special schools, from medications to therapeutic toys.” By extension, one must conclude that mothers continue to be assigned blame for not meeting these expectations.

Regarding how fathers are perceived, I started this process incorrectly believing fathers skirted blame compared to mothers. While fathers were rarely blamed for causing autism by their denial of warmth, more current narratives have redistributed blame between the parents. Jack (2014, p. 155) said:

In other circles, fathers of Autistic children are depicted as deadbeats, failing to cooperate with their wives’ rigorous therapy, research, or diet regimen, to participate in support groups, or to accept their child’s disability.

Jack wrote about media personality Jenny McCarthy's statements about autism. According to Jack (p. 155), "McCarthy also notes that 'the divorce rate in families with Autistic kids is very high.'" Jack (p. 155), citing Huffington Post columnist Shelly Hendrix Reynolds, said that Reynolds wrote about how the divorce rates in the autism community "verge on 70% within the first five years of diagnosis and 90% within the first ten." Jack asserted that these claims were false but commonly believed to be true. Jack (p. 155) said:

Some studies show a somewhat higher divorce rate among parents with an Autistic child than among parents of children without disabilities...A study conducted with Brian H. Freedman, Luther G. Kalb, Benjamin Zablotsky, and Elizabeth A. Stuart found that 64 percent of children with ASD were in families with two married parents, compared with 65.2 percent of children without ASD.

Basically, the divorce rates in families with an Autistic member, as stated repeatedly by media personalities such as Jenny McCarthy, are inaccurate. It would take rigorous studies to determine if having an Autistic family member was a statistically significant causational factor in increased divorce rates within families with Autistic family members.

Because so many people believe that having an Autistic child in a family causes divorce, subsequent beliefs spring up that some members of families might hold resentment toward their Autistic family member. Believing the Autistic child caused their parents to divorce (or might cause them to) is only one of the things the siblings of Autistic children are thought to resent their Autistic sibling for. Associate Professor in Applied Disability Studies Priscilla Burnham Riosa and co-workers (2022) wrote about sibling experiences of autism. Burnham Riosa et al. said that a disproportionate number of family resources are spent on the Autistic child. Burnham Riosa et al. (p. 1) said:

Children on the autism spectrum may require additional assistance with basic care needs (e.g. toileting, personal hygiene), resulting in more parental time and attention than non-Autistic siblings. Heightened care needs may be especially pertinent to families with an Autistic child with complex needs, including those with co-occurring intellectual disabilities. In circumstances where caregiving demands are greater, this may limit employment opportunities and constrain family household income, decreasing family participation in social or recreational opportunities.

Circumstances might cause one child in a family to have a disproportionate number of resources spent on them, but this does not necessarily mean that the other children in the family will resent them. Further, studies have demonstrated that while some parents express stress due to the money they must spend on their Autistic child, they consider their Autistic child a blessing. Burnham Riosa et al. indicated that many parents believe having an Autistic child made them better parents and people.

On the other hand, Burnham Riosa et al. said that the neurotypical children in a family often feel a great deal of responsibility for their Autistic sibling. Burnham Riosa et al. (p. 2) said some of the things they felt responsible for included:

increased responsibilities include caring for their Autistic sibling, babysitting the sibling on the spectrum, taking on greater family responsibilities than their siblings, and assisting their sibling with activities of daily living.

However, resentment was not the primary emotion expressed by the neurotypical siblings in response to this overtasking. Burnham Riosa et al. (p. 2) cited a study by Psychologist Elizabeth K. Cridland and co-authors (2016) that said:

some non-Autistic siblings in their sample reported experiencing burnout related to greater responsibilities across multiple environments (i.e. school and home), limited appreciation from their Autistic siblings, and occasional punishment (e.g. criticism) for attempting to help.

The non-Autistic siblings also experienced impacts on their mental health. These included impacts on their self-esteem, relationships (limiting their social opportunities), and activities. They also experienced increased feelings of embarrassment toward their Autistic sibling.

Despite these negative experiences, there are many positive ones too. Burnham Riosa et al. said that Psychologists Lucy Watson and Paul Hanna, and Behavioural Therapist Christina Jones (2021), reviewed 15 qualitative studies focusing on the siblings of Autistic children.

Watson et al. said that much of what non-Autistic siblings of Autistic children listed as negative were not listed as negatives by other non-Autistic siblings. Burnham Riosa et al. (p. 3) said:

Research on non-Autistic sibling attitudes about additional obligations has varied. Non-Autistic child and adolescent siblings have reported a heightened positive sense of responsibility and concern for their siblings' safety and social well-being. These responsibilities may persist over the lifespan and include advocating for their Autistic sibling. Interestingly, cultural factors may influence how siblings qualify and make sense of their sibling experiences, including perceptions about their responsibilities.

In other words, there is some empirical evidence for the idea that autism causes strain on sibling relationships in families with an Autistic family member. Still, there also are equal reasons to think it provides unique and positive aspects to relationships.



### 2.6.5. *dis/Advocacy*

Activist Jim Sinclair (2012) talked about the early history of Autism Network International and the “Neurodiversity Movement” in an essay included in *Loud Hands*. While researching the history of self-advocacy by disabled people, Sinclair discovered a pattern of opposition whenever disempowered people attempted to challenge the status quo, dispute the presumption of their incompetence, and redefine themselves as equals. According to Sinclair, the first stage of the pattern was to deny that the persons making the challenge belonged to the group they claimed membership to. I have encountered people who have tried to refute my Autistic identity rather than engage with the points I have made. It seems to go for me: If you can speak, you are not Autistic enough to require being listened to. However, if you cannot speak, you cannot communicate and require someone to communicate for you. As Sinclair (2012) indicated, questioning an Autistic person’s right to talk about autism as an expert is a way to delegitimize their Autistic identity. According to Sinclair, the next step was to imply that the people making the challenge were not a typical or accurate group representation. Next, prejudices and stereotypes are appealed to, implying that the people making the challenge could not understand what was in their best interest. Sinclair wrote about creating Autistic spaces safe from parents and autism experts trying to dominate the discourse. McGuire (2016) wrote about how this process has been especially important considering how many organizations that claim the right to speak for Autistic people fill their organizations' decision-making and policy-making roles with non-Autistic people. New organizations have emerged, such as “Reframing Autism” in Australia, where Autistic people lead while parents and educators follow. “A4A” and “Autistics United” in Canada have also emerged, broadening the representation of Autistic voices in the discourse.

There are two primary forms of advocacy concerning autism: Autism advocacy and Autistic advocacy. The former is the advocacy taken up by all members of the autism community, including corporations that have a financial stake in practices and approaches that the Autistic community does not support. The latter is the advocacy taken up by the Autistic community, consisting only of Autistic people. Kapp (2020, p. 10) wrote the following about advocacy: “The neurodiversity movement’s approach holds Autistic and neurodivergent people responsible not for the origin of our problems (social barriers exacerbating biological challenges), but for leading the effort to solve them.” In other words, Autistic people should lead the movement for change.

Historian Sarah Pripas-Kapit (2020, p. 23) said, “Jim Sinclair’s 1993 essay “Don’t Mourn for Us” stands out as almost singularly influential.” Pripas-Kapit (p. 23) said the essay continues to be a touchstone of the neurodiversity movement. Since then, Sinclair has gone on to do many things, including co-founding Autism Network International (ANI). Reflecting on the content of Sinclair’s essay, it is frankly uncomfortable to think about how a concept that seems as if it should be natural, such as parents of disabled children not mourning their children as if they are dead just because they are disabled, has made such a huge impact because of how revolutionary and controversial it seemed. According to Pripas-Kapit (p. 23), Sinclair’s essay has served to instigate conversations about parental expectations after an autism diagnosis. It has helped many parents find a way to accept that their expectations for their child would have to change, but this shift did not need to be considered a tragedy. On the other hand, according to Pripas-Kapit (p. 23), many parents continue to accuse Sinclair of not understanding their perspective. Sinclair’s work revealed how many conversations needed to happen. It also highlighted the conflicting goals of Autism advocacy versus Autistic advocacy.

Walker (2021) said that discourse around autism needed to undergo a radical paradigm shift that would cause the redefining of terms and force us to readjust our language, questions, and the way we interpret data. It would push us to rethink our approaches. A revolutionary change cannot come from outside the Autistic community. There should be no research on Autistic people unless Autistic people are involved at the decision-making level. Better yet, Autistic academics should be the ones doing the research. However, Autistic advocate Lydia X. Z. Brown (2018) noted that most people do not understand how privileged they are just to be able to enter higher educational environments, let alone to be able to leave those institutions with a degree in hand and the ability to gain employment, respect, credibility, influence, and power.

Reflecting on Orsini (2009), Associate Professor in Sociology Hanna Bertilsdotter Rosqvist and Psychologists Charlotte Brownlow and Lindsay O'Dell (2015, p. 115) said:

Orsini (2009) makes a distinction between the 'autistic movement' and the 'autism movement.' Orsini refers to the 'autistic movement' as 'the efforts of activists to create a positive identity for autistic people using, albeit not exclusively, a disability rights frame.' This movement includes people who self-identify as autistic as well as nonautistic sympathetic others supporting the general goals of the movement. Orsini refers to the 'autism movement' as 'activists or advocates more interested in pressing for policy change around the treatment for autism and concern with its causes.'

Bertilsdotter Rosqvist et al. (2014) wrote that in the past 20 years, Autistic experiences had been filtered through the lens of parents and families. However, things have been changing since Sinclair's writing of this pivotal piece of advocacy. Neurodivergent Activist and Author Jennifer Brunton and Jenna Gensic, who is an author and disability advocate (2021), created a roadmap to Autistic advocacy in which they recommended building an advocacy base by learning and

listening through the emphasis on acceptance. Brunton and Gensic opened their recommendations for step one by recommending that parents love their children for who they are right now, recognizing their value and worth without assuming they need to change. This already represented a huge shift, perhaps due to Sinclair's pivotal piece telling parents to stop mourning for their disabled children, who were not deceased. They talked about how Autism Acceptance, a new civil rights movement, is helping change how autism is represented in literature, television, and movies. Brunton and Gensic (p. 35) said that thanks to advocacy, "it's now possible to find conferences and educational events led by Autistic people, and, at the very least, follow public Autistic advocates on social media and ready articles about advocacy that are authored by people on the spectrum." (Please see Appendix C for tips Brunton and Gensic made about how to be better autism advocates)

In this thesis, I pursued tensions between the "Autism Movement" and the "Autistic Movement" in the past and how that is changing today. The approaches that dominate autism intervention today came out of ideas that autism was primarily found in white males, and this made it worthy of remediation. Marginalization has been embedded in the autism community from its inception. The Autistic community has not universally risen above the marginalization of its members. A history of being expected to comply with authority has made it safer for BIPOC Autistic people to learn how to comply. That has made some BIPOC Autistic people deprioritize resistance to ABA in their advocacy. As they develop approaches to autism in their communities, Indigenous people are looking to the paradigms offered by their traditions that affirm diversity and neurodiversity as a gift. The historical neglect to recognize Autistic people raised as girls, which amounted to a death sentence in the Vienna clinic when Hans Asperger condemned girls to Jekelius Action, has continued in many forms. This includes sexism and violence within Autistic

advocacy. In addition, it has been a struggle for Autistic parents of Autistic children to be recognized and supported within autism and Autistic advocacy.

For this thesis, I wanted to know if the Autistic bloggers included in my study felt their voices were overpowered by the autism professionals, parents, and advocates. I wanted to know how this overpowering made them feel. What did they believe could make a difference? How could Autistic people push the movement towards being centred around their voices?

## **2.7. Summary**

Many humans are marginalized, discriminated against, barred from full participation in society, and dehumanized for various reasons. These reasons include (but are not limited to): Economic marginalization, racism, sexism, QUILTBAG identities, environmental racism, colonization, and ableism. Autistic people are on a spectrum, the same spectrum that humanity in general lives on: from rich to poor, from white skin tones to black skin tones, from physically abled to mobility disabled, from cis-gendered to QUILTBAG, from people excluded from full citizenship because of their intellectual abilities, etc. My goal in this thesis study was to contribute to understanding how Autistic people experience intersections of marginalization such as economic exclusion and oppression, racism, sexism, and QUILTBAG identities. Part of examining how these Autistic bloggers understood the breadth of their humanity was to look at how they experienced dehumanization as expressed in blogs.

## Chapter Three: Methodology

### 3.1. Qualitative Research

Autistic people can have trouble getting their expertise acknowledged. Autists are often believed to be unable to determine their own fates. Thus, they are often dismissed. Additionally, there is a perception that Autistic people cannot be trusted to understand their own experiences. In chapter two, I revealed research that demonstrated that some neurotypical researchers discredit Autistic agency and are therefore unlikely to listen to them. I think it is especially important, as an Autistic researcher, for me to use qualitative research in this thesis study. Only qualitative research can examine the richness of lived experiences.

Some Autistic researchers work in fields of study related to Disability Studies, many of whom are conducting qualitative research. (Please see Appendix D for a list of some Autistic researchers cited in this thesis). I discovered it isn't always easy to find information stating if a researcher is Autistic, particularly if they are not specifically working in Critical Disability Studies and Critical Autism Studies. There may be researchers included in this study who are Autistic but have not publicly disclosed that information. Again, I imagine this is more likely for researchers not working in the two fields mentioned above. I have not found research that quantifiably demonstrates the Autistic to non-Autistic ratio of researchers in any specific school or academic field, even for Critical Disability Studies and Critical Autism Studies.

Sometimes the things Autistic people write about autism are condescendingly referred to as sincere but not credible. Yet, sincerity is one of Professor of Human Communication Sarah J. Tracy's (2010, p. 849) eight quality markers in qualitative research listed. Their list includes "worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and

meaningful coherence.” Reflecting on Professor of Communication and Women and Gender Studies Laura Ellingson (2008), Tracy (p. 849) said, “Good qualitative research is like a crystal, with various facets representing the aims, needs, and desires of various stakeholders including participants, the academy, society, lay public, policymakers, and last, but certainly not least, the researcher.”

For Tracy’s (2010) first marker of good qualitative research, sincerity, there is a problem with who is viewed as a credible expert regarding autism. For Tracy, as a marker of credibility, if an Autistic person was viewed as an object of study rather than a purveyor of knowledge, they had not been viewed as credible. Psychologists Alliyza Lim, Robyn Young, and Neil Brewser (2021, p. 490) hypothesized that “autistic adults may be erroneously judged as deceptive or lacking credibility due to demonstrating unexpected and atypical behaviors.” However, it is more than unexpected and atypical behaviours that reduce the credibility of Autistic people. By extension of their belief that autists lack ToM, folks like Simon Baron-Cohen question the credibility of Autists perceptions of the minds of others, and even of their perceptions about themselves.

Tracy said good qualitative research should have a worthy topic. There is a problem with who gets to decide what is a worthy topic. Unlike untested and unproven pseudo-medical approaches to autism cures, Tracy said studies should have rigor in data collection and analysis. Tracy (p. 840) said research should be relevant, significant, and interesting. Research findings should have resonance and be relatable and applicable. The many connections between theory and findings found in this study acted to echo, amplify, and expand what was said in theory. Tracy defined a significant contribution as significant conceptually, theoretically, practically, morally, methodologically, and heuristically. Tracy (p. 840) said that ethical research considered

procedural ethics (such as human subjects), situational and culturally specific ethics, relational ethics, and exiting ethics (leaving the scene and sharing the research). Ethical issues in this study were discussed with the thesis advisors and the university at the onset of the research and revisited throughout the writing process. The theories presented in this thesis, along with the literature studies, were directly connected to the findings and interpretations, as per Tracy's (p. 840) point that for meaningful coherence, the thesis must use meaningful interconnecting literature and research in tandem with the research questions, findings, and interpretations. In accordance with Tracy's points, this thesis used methods and procedures that fit its stated goals.

Autistic people might have a different idea of what fits the standards of good qualitative research than non-Autistic researchers. This emphasizes the urgent need for more Autistic researchers in Critical Disability and Autism Studies. It also highlights the need for more Autistic involvement in all forms of research that involve autism. By investing and recognizing Autistic blog writers as experts on autism, this thesis builds on work emerging from research being done by Autistic academics and non-Autistic academics working in Critical Disability Studies and Critical Autism Studies by invested and recognized Autistic allies.

## **3.2. Theoretical Framework**

### ***3.2.1. Post-Structuralism***

The idea of post-structuralism suggests that rather than one objective truth, an individual's experiences, or situatedness can change how they perceive issues. In this thesis, I looked at the lived experiences of Autistic bloggers for context on how they perceived the restricted idea of "the human," how they felt dehumanized, and how they worked towards rehumanization. According to Kimberly Q. Andrews (2022, para. 1):



‘Poststructuralism’ refers to a way of thinking that emphasizes the radical uncertainty of knowledge (particularly knowledge in language) and posits that ‘truth’ is not a fixed concept, but instead constantly changes based on your cultural, political, social, and economic position in the world.

Post-structuralists opposed the idea that differences were innate and did not change from what was initially observed. This makes connections in my mind to the goal of this thesis to look at how the intersections of marginality are affected by the restrictive concept of “the human.” There is a history of framing race as an innate difference rather than a social construction. For example, when BIPOC people experience increased rates of police violence, some people say it is because BIPOC folks are innately different in a way that warrants increased police violence, rather than considering the possibility that these experiences are the result of systemic racism. If a disability is considered innate sometimes depends upon whether it is considered remediable, or whether there are things a person is perceived to be capable of doing to increase the likelihood they will continue to be disabled or become disabled. For example, if there is a cure for a disability and someone chooses not to participate in this cure, that would change the way people think about the person. Another example is how people treat those who have heart problems because they are morbidly obese or smoke differently than they treat someone who was born with a heart condition.

One of Philosopher Michel Foucault’s major contributions to theory was reconsidering how power works. This thesis, which followed the framework of a critical discourse analysis, aimed to understand better the intersections of oppression Autistic bloggers experience, including autism, disability, race, gender, sexuality, socio-economic status, othering, educational oppression, medical oppression, and the denial of agency. As participant blogger Tiffany

Hammond (2022, Jul. 1) described for their goals, I too aimed to set aside discourses about red flags and symptoms and talk about the breadth of Autistic humanity by considering multivariate Autistic experiences. This goal resists power by pushing back against dominant narratives that work to dehumanize Autistic people.

Foucault was considered a post-structuralist. Foucault was in part inspired by their mentor, Georges Canguilhem, who researched biopower. Anthropologist Jen Pylypa (1998, p. 21) said that Foucault coined the term “Biopower” to refer to the “ways in which power manifests itself in the form of daily practices and routines through which individuals engage in self-surveillance and self-discipline, and thereby subjugate themselves.” According to Foucault, biopower is a tactic of power that focuses on individual bodies rather than systemic structures. Pylypa (p. 23) said:

Foucault visualizes power as operating at two poles: the human species and the human body. The former concerns a "bio-politics of the population"--the regulation of populations through the application of science to interventions into reproduction, mortality, and morbidity. The latter concerns the manipulation and control of individual bodies.

Quoting Foucault, Political Scientist Mareike Gebhardt (2020, p. 120) describes the shift from sovereignty as the “old right [...] to take life or let live” to the “opposite right [...] to make live and let die” (Foucault, 2003, p. 241). This is an important concept in the context of the rise of eugenics. Eugenics is a practice aimed at controlling biological processes to achieve social and political change. This is an important concept to explore concerning the goal of the thesis to examine how Autistic people are dehumanized and how they come to be rehumanized. Agency over one’s body is considered integral to “the human.” Thus, a lack of agency over one’s body

limits humanity. Philosopher Samuel Talcott (2014, p. 255) said of Philosopher Georges Canguilhem, “His analysis was based on the notion that it is inauthentic to treat a living being as an error, even if living things are capable of making errors in the domain of knowledge.” This notion is relevant to the goals of this thesis. As I demonstrated at the beginning of this thesis, autism has many links back to the eugenics activities of the Nazis. Eugenics is generally based on the view that some living beings are errors. In looking at Autistic people’s blog writing for the ways they have experienced dehumanization, I sought examples of how Autistic people are still sometimes treated as errors.

Foucault believed domination must be resisted. According to Historian Michael Bess (1988, p. 1), Foucault said:

We have to rise up against all forms of power—but not just power in the narrow sense of the word, referring to the power of a government or of one social group over another: these are only a few particular instances of power. Power is anything that tends to render immobile and untouchable those things that are offered to us as real, as true, as good. We must resist any form of education that would separate us from what is “true” and “good” or “renders” us “immobile” and without voice. Foucault said in an interview with Bess (p. 2), “Power should not be understood as an oppressive system bearing down on individuals from above, smiting them with prohibitions of this or that. Power is a set of relations. What does it mean to exercise power?” Foucault used the example of breaking an object. Foucault said power was not the action of breaking an object. However, if the person broke the object specifically to upset someone else, and this action succeeded in the goal, then the person who had broken the object had successfully exercised power by influencing someone else’s state of mind.

### 3.2.2. *New Materialism*

Cultural Sociologist Lis Højgaard and Social Psychologist Dorte Marie Søndergaard (2011, p. 341) described socio-cultural categories, like the ones explored in this thesis, as not being stable and fixed. Instead, they suggested that these categories develop and evolve through discourse, and through being challenged by subjects and communities. Højgaard and Søndergaard (2011, p. 342) stated that poststructuralist concepts of subjectification involve:

embedded normativities and how these normativities were patterned along lines of particular socio-cultural categories and ideas about appropriate/inappropriate behaviour related to gender, age, class, and ethnicity, as well as along more specific categories...

The normativities developed through such socio-cultural categories would point to some of the premises for subject positioning.

Examining how such embedded normativities within socio-cultural categories impact Autistic people, and how Autists make meaning from these, was one of the goals of this thesis. Højgaard and Søndergaard (2011, p. 342) said that analysis of these embedded normativities would include looking at how meaning is made, including the sources of inspiration for meaning-making. These could include family, friends, teachers, the internet, television, movies, video games, books etc.

Højgaard and Søndergaard (2011, p. 345) said that Physicist Karen Barad focused on how “matter can be known differently depending on the apparatus it is known through.” Barad (2007, p. 137) said:

Matter is produced and productive, generated and generative. Matter is agentic, not a fixed essence or property of things. Mattering is differentiating, and which differences come to matter, matter in the iterative production of different differences.

According to Colman (2018), the “New Materialism” theory suggested that all things have agency. Philosophers Jerry Lee Rosiek and Scott L. Pratt, and Ph.D. student of Critical and Sociocultural Studies in Education Jimmy Snyder (2019, p. 332) said, “The phrase ‘agential realism’ refers to the idea that agency is not just a human capacity but a quality manifest in all aspects of reality.” Rosiek, Pratt and Snyder (p. 333) said, “Agential realism is a relatively recent development in the philosophy of science literature. Karen Barad was writing about it as early as 1996.” However, Rosiek, Pratt, and Snyder (p. 332) said:

Indigenous thinkers and scholars developed ideas about non-human agency thousands of years earlier than contemporary philosophers of science. That being said, different communities may come to similar understandings of the world through different conceptual paths.

Colman (2018) said that Barad stressed the non-human aspects of agency. Colman (2018) said that Barad did not express the viewpoint that agency existed for the purpose of creating something. Rather, Colman (2018) said that Barad viewed agency as an enactment that is part of a cause-and-effect process that emerges out of the entanglement of matter. This seems to reject the idea that it is an innate attribute. Barad’s way of looking at agency seems to draw from enactivism’s body-mind connection.

#### ***3.2.4. Post-Humanism***

Most people question what it means to be human and if they are human enough at some point in their lives. They ask themselves if there are other beings out in the universe who are like them. They fear the possibility that there are beings who are infinitely better than them, all while questioning what form that superiority would take. They are repulsed by artificial intelligence that reminds them too much of themselves yet are missing something they cannot quite put their

finger on; a phenomenon described by Robotist Masahiro Mori that has come to be known as the “Uncanny Valley” but was probably more correctly translated as the “Eerie Valley.” Sadly, Autistic people sometimes find themselves thrown into the uncanny valley by people who see them as appearing like they are human but missing some element of humanity. For example, on January 17, 2016, *The New Yorker* published “Seeing the Spectrum: A New History of Autism” by Steven Shapin. In this article, Shapin compared the eyes of Autistic people to black mirrors.

Braidotti and Psychologist Emily Jones (2023, p. 28) described “Critical Posthuman Theory” as developing:

at the convergence between posthumanism and post-anthropocentrism, seeking to dismantle hierarchies between humans, such as gender, race and class but also to debunk the idea that the human sits in hierarchical supremacy over other subjects...

This examination of intersections of identity mirrors the intentions of this thesis. Researcher and freelance writer Stefan Herbrechter (2018, p. 94) said:

*Critical posthumanism* is a theoretical approach which maps and engages with the ‘ongoing deconstruction of humanism’ (Badmington, 2000). It differentiates between the *figure* of the ‘posthuman’ (and its present, past and projected avatars, like cyborgs, monsters, zombies, ghosts, angels, etc.) and ‘posthumanism’ as the contemporary social *discourse* (in the Foucauldian sense), which negotiates the pressing contemporary question of what it means to be human under the conditions of globalization, technoscience, late capitalism and climate change....

This definition describes the approach taken by the bloggers included in this thesis. They deconstruct humanism, differentiating between the philosophy of the posthuman and how it expresses itself in their lives and the discourses that affect their lives.

Braidotti (2019, p.6) said that philosophy tended to define “the human” by what it was *not...not* an animal, *not* extended and inert matter, *not* a pre-programmed machine. In the case of Autistic people, the list of things they are *not* might include the following: Not comfortable looking people in the eyes, not able to understand other people have inner lives, not able to express empathy, not comfortable with being touched, not able to understand sarcasm etc. Since Autistic people are also not thought to be experts on their own experiences, the perceptions of non-Autistic people would be more likely used to form the list of what they are *not*.

Braidotti (2019, p. 41) believed that “Subjectivity” must include the “relational dependence on multiple non-humans and the planetary dimension as a whole.” Braidotti (p. 41) stated that the Humanities are expanding to “deal with objects such as forests, fungi, dust, and bio-hydro-solar-techno entities, but also codes, software and digital waste.” Subjectivity within post-humanism is being reconstituted to remove the idea of the centralized “He” possessed with consciousness, universal rationality, ethics, and self-regulation. Braidotti (p. 42) said, "Bodies are both embedded and embodied, and have relational and affective powers. As such, they are capable of different things and different rates of becoming.” Adding to this concept, Laura Malinin (2016, p. 1), Director of the Nancy Richardson Design Center, said “The *embodied* thesis argues that cognition encompasses both the mind and the body.” According to Malinin, “Embedded is how people exploit physical and social environmental features to increase their cognitive capabilities, an important concept when it comes to disability. Accommodations are based on making it easier for disabled people to exploit their physical and social environments. Malinin (p. 1) said that “Enaction” describes “cognition as dependent upon a person’s interactions with the world.”

It was important to look at how the bloggers built their understanding of the world through their interactions with the world. For Braidotti (p. 42), one's ability to influence others without needing to hold power over them was fundamental to having "relational and affective powers." Exercising relational and affective powers is an important tool in rehumanization. The act of blogging is a form of exercising relational and affective powers from a power-neutral position unless the person blogging holds much social power and uses it to deflect criticism. One's power as a blogger comes from utilizing a platform to influence other people's thoughts. Affective power can be thought of as emotional power. Bloggers have affective power because in relaying their personal experiences, they have the ability to influence other people's thoughts, perceptions, and understandings. Wielding these powers can help Autistic bloggers rehumanize themselves.

The relational dependence Braidotti (2019, p. 41) talked about forming subjectivity is important for Autistic people. Too often, our society judges one's agency and ability to be autonomous on one's ability to live independently. How one's independence is judged often can feel arbitrary, biased, or changeable. For example, before World War II began, most people in England would have been considered independent if they had the ability to buy what they needed to survive. However, once the war began, being viewed as independent in England would include one's ability to grow a garden to supplement their food rations. Another example might be two hypothetical people who live in a remote area. The first of these hypothetical people is wealthy, and only goes to this home during cottage season. The other lives full-time in a small cabin they built themselves and lived off the land. The first person would be considered independent in most scenarios, even more so than the one who is eking out a rather marginal living off the land. However, if circumstances cut these hypothetical people off from supplies, the one living off the



land would continue to be independent, while the other one would probably need to turn to them for help.

The way independence is sometimes judged when it comes to disabled people is even more arbitrary, biased, and changeable. For example, some people might always deem someone with a mobility disability as dependent unless they are able to find a way to overcome the disability and do the same things, at the same speeds and with the same success, as the average person who does not have a mobility disability. Little would be changed by the disabled person having the financial resources to pay someone to do the task for them. That would still be considered dependence, even when people who did not have a mobility disability paid people to do the same things, out of convenience alone. One way that posthumanism helps rehumanize Autistic people is that it provides a conceptual framework to challenge the ideas of independence that contribute to the dehumanization of Autistic people.

#### **3.2.4.1. Animism**

Braidotti (p. 8) stated, “The posthuman condition encourages us to move beyond the Eurocentric humanistic representational habits and the philosophical anthropocentrism they entail.” Braidotti (p. 7) thought it was important to remember that the binary distinction of human/non-human sprang from Eurocentric humanistic philosophy but that many cultures worldwide do not have such a binary. Braidotti (p. 7) said, “This is the strength of the insights and understanding that can be learned from indigenous epistemologies and cosmologies.” Indigenous epistemologies and cosmologies do not draw rigid lines between human, animal, and non-living subjectivity. Reflecting on Anthropologist Eduardo Viveiros de Castro, Braidotti (p. 7) said that Viveiros de Castro (1998, 2009) argued that:

Indigenous perspectivism posits a ‘multinatural’ continuum across all species, all of which partake of a distributed idea of humanity. This means they are all considered as being endowed with a soul. This situates the divide human/non-human not between species and organism, but as difference operating within each of them.

European philosophy has typically thought of humans as the only beings having souls, and even then, the restrictive concept of “the human” has been used to exclude some people. As a caution, Braidotti (p. 7) said:

To call this approach ‘animism’ is to miss the point, because Amerindian perspectivism teaches us that ‘each kind of being appears to other beings as it appears to itself—as human—even as it already acts by manifesting its distinct animal, plant, or spirit nature. (Viveiros de Castro, 2009, p. 68)

This idea has had some interesting expressions in Indigenous speculative fiction, including Rebecca Roanhorse’s “Trail of Lightning” and the collection called “Deer Woman: An Anthology.”

Animism often has been mischaracterized. Curator and writer Anselm Franke (2018, p. 39) said:

‘Animism’ designates a cosmos in which theoretically everything is alive and communicating, and potentially possesses the qualities of being ‘a person’ or, at the very least, an agent of some kind. It describes a world in which all social and ontological boundaries are porous and can be crossed under specific circumstances, a world of becomings and metamorphoses, in which no entity precedes the sets of relations that bring it into being.

The idea of everything being alive and communicating, even if that communication is not universally understandable, is relevant to Autistic people because not all Autistic communication is understandable by those around them. This causes Autistic agency to be questioned. Franke said the ability to make one's communication understood has links to the concept of the soul.

Franke (p. 39) said that animism:

inextricably links questions of communicability and media with long-embattled questions over the soul and its relations to materiality. Is the soul an enclosed property of human beings alone or a realm of mediality, the condition of possibility to be-a-medium-of-communication?

The soul has been considered something that only humans possess, bringing up the question of whether Autistic people have souls. Janele Hoerner (2019, June 11) the blogger of the "Catholic Mom" suggested you must look beneath autism to find an Autistic person's soul. However, the possibility of being a medium of communication might act as a gatekeeper for Autistic people being perceived as having souls.

### ***3.2.5. Critical Discourse Analysis: Norman Fairclough***

Post-structuralism's focus on how an individual's experiences can change how they perceive issues led me to choose to examine the online content of Autistic bloggers for context on how they perceived the restricted idea of "the human," how they felt dehumanized, and how they worked towards rehumanization. The dehumanization of Autistic people partially developed from how philosophy tended to define "the human" by what it was not, thus defining Autistic people through negative comparisons to neurotypical people. However, rehumanization comes from subjectivity within post-humanism being reconstituted to remove the idea of the centralized "He" and the restrictive conception of "the human." Using the qualitative research approach of Critical

Discourse Analysis in this thesis, I aimed to examine the intersections of oppression experienced by a group of Autistic bloggers. This included examining the intersections of autism, disability, race, gender, sexuality, socio-economic status, othering, education oppression, medical oppression, and the denial of agency.

Text is not always written. According to Linguist Norman Fairclough (1995, p. 4):

A text is traditionally understood to be a piece of written language... A rather broader conception has become common within discourse analysis, where a text may be either written or spoken discourse, so that, for example, the words used in a conversation (or their written transcription) constitute a text.

Fairclough argued that it was important to analyze what Fairclough referred to as the “Texture of Texts.” By this, Fairclough meant the way a text was formed and organized. Text, discourse analysis, and sociocultural practice were the three elements of the framework Fairclough (p. 9) used for Critical Discourse Analysis. Fairclough (p. 9) said, “Analysis of texts should not be artificially isolated from analysis of institutional and discursive practices within which texts are embedded.” For example, we cannot assume all television broadcasting channels put forward an unbiased commentary on current events and politics. We must look at the institutional values and pressures that help shape the way the news is put forward to the public.

Fairclough (p. 4) also thought it was necessary to be sensitive to how texts might serve as indicators of “sociocultural processes, relations, and change.” Looking back at the tension between the vocabulary put forward by the medical model of disability versus that used by the social model of disability, there is a breakdown in how text is used, described, and interpreted. This tension indicates sociocultural processes, relations and change, as Fairclough suggested (1995, p. 5). In the case of the relationship between the medical model of disability, the social

model of disability, and Autistic people, the tension is a signpost for the rise of the Neurodiversity Movement, which pushes back against ableist language (among other priorities).

Fairclough believed that text could not exist separately from how the text was created, received, and interpreted. Fairclough (1995, p. 6) stated:

Texts are social spaces in which two fundamental social processes simultaneously occur: cognition and representation of the world, and social interaction. A multifunctional view of text is therefore essential. I have followed systemic linguistics (Halliday 1978) in assuming that language in texts always simultaneously functions ideationally in representation of experience and the world, interpersonally in constituting social interaction between participants in discourse, and textually in tying parts of a text together into a coherent whole (a text, precisely) and tying texts to situational contexts.

Fairclough (1995, p. 6) believed how the text was created, received, and interpreted was influenced by the experience of events from a particular perspective. This is why it is so important to look at the blog material of Autistic bloggers to understand their experiences and how they impact the way they perceive issues. Fairclough (p. 19) said:

I think that CDA [critical discourse analysis] ought in contemporary circumstances to focus its attention upon discourse within the history of the present — changing discursive practises as part of wider processes of social and cultural change — because constant and often dramatic change affecting many domains of social life is a fundamental characteristic of contemporary social experience...

In other words, Fairclough believed discourses and social systems to be dynamically adaptive to changing social contexts and mutually co-constructive. Fairclough believed discourses could not help being affected by ideology.

Dehumanization of disabled people results in an imbalance of power between disabled and non-disabled people. Fairclough (p. 15) said, “Power is conceptualized both in terms of asymmetries between participants in discourse events, and in terms of unequal capacity to control how texts are produced, distributed and consumed....” Fairclough saw human self-hood as coming from one’s past discourses and experiences, changing with each discourse community you enter. Fairclough believed it was necessary for identity to be able to change quickly, dependent on the discourse community in which one is participating. For example, your role in your family is very different from your role in your friend groups. Texts, like those produced by the Autistic bloggers included in this study, provide space for the fostering and contestation of discourses.

CDA has been applied to multiple fields of study. Real people use language to talk about real issues in their lives that are important to broader social systems. The social systems and variables tackled by critical discourse analysis include race and racism, gender and sexism, media representations, bureaucracy, language in relation to education, and the restructuring of capitalism and neo-liberalism. CDA is an approach to language analysis that concerns itself with language, power, and ideology. CDA focuses on language as it is used by real people with real intentions, emotions, and purposes. As an interdisciplinary approach to the study of discourse, CDA views language as a form of social practice, explaining society and culture as the result of social structure and individual agency. Fairclough believed that the way society was ordered was caused by historical events. Therefore, current events could change the order of society. According to Fairclough, social order was not maintained by the wills of individuals but rather by how wide versions of reality spread. It is well suited to examine expressions of the lived

experiences of Autistic people, including those who experienced the intersections of multiple identities, such as those mentioned above, the central topic of this thesis.

### **3.3. Discourse and Critical Discourse Analysis**

In this thesis, I adopt the qualitative approach of Critical Discourse Analysis to understand better how Autistic people are dehumanized and how they are rehumanized. I aimed to focus on the breadth of Autistic humanity by examining the work created by multiple Autistic bloggers, examining their multivariate experiences. Autistic people have chosen to locate a lot of texts on the internet, in articles and personal blogs where they address matters of dehumanization, rehumanization, identity, oppression, and power. The Autistic bloggers chosen for this study used their online text to challenge the intersections of oppression and the rigid concept of “the human” that helped create them. I looked at the intersections of identity and oppression experienced by the selected Autistic bloggers. These intersections included autism, disability, race, gender, sexuality, socio-economic status, othering, education oppression, medical oppression, and the denial of agency. I also looked at how power affects Autistic people with multiple intersecting identities asymmetrically compared to how it affects Autistic people with only autism as a marginality. I combined a critique of the autism discourse with an explanation of how it creates disability for Autistic people, using this as a foundation for a call to action to improve how autism is addressed in representation and research.

If there was a point in history when a person would not have been considered fully human, they will be situated differently in relation to power than people who have always been considered fully human. White people raised as girls have historically been situated closer to power than BIPOC people raised as girls. Therefore, white people raised as girls have not had to struggle against imbalances of power to the same degree as BIPOC people raised as girls. Their

struggle has not been as prolonged or as intense. They have benefited from being closer to the power historically held by white, heterosexual people raised as boys. White, QUILTBAG people raised as boys have historically been situated closer to power than BIPOC, QUILTBAG people raised as boys. They have historically benefited from being closer to power. Thus, their struggle against imbalances has not been as prolonged or as intense as it has been for BIPOC, QUILTBAG people raised as boys. Although all Autistic people have historically been situated further from power than non-Autistic people, there are some Autistic people who have historically been situated further from power than others. Being Autistic does not erase the historical advantages of being white, raised as a male, or wealthy.

Texts created by the Autistic bloggers in this thesis study are bound to be received and interpreted very differently, depending upon whether the reader approaches autism through the lens of the medical or social model of disability. Brown (para. 13) said, “Language is not viewed as powerful on its own but is seen to gain power by the use people make of it.” CDA [critical discourse analysis] examines how power is enacted. Subjectivity is constructed at the level of texts, in this case, the blogs written by a selection of Autistic authors. This thesis study looks at how discursive practices contribute to unequal power relationships that cause Autistic people to be dehumanized in various ways. It also examines how Autistic people use power to disrupt oppressive and exclusive discourse to push back against these narratives to rehumanize themselves.

The way texts are constructed is closely related to structures of power in society. Associate Professor of Critical Digital Literacy Cheryl Brown (2019) said CDA’s strength is its multidisciplinary and diverse approach. The Autistic bloggers in this study come from various



locations and intersections of identity, making an inclusive approach ideal. Brown (para. 6) said CDA is also concerned with the “critique of ideology and the effects of domination.”

Regarding the role culture plays in discourse analysis, Psychologist Ian Parker (2002, pp. 123-124) said that discourse, “comprises the many ways that meaning is relayed through culture, and so it includes speech and writing, non-verbal and pictorial communication, and artistic and poetic imagery.

Autistic people are more likely to communicate through non-speaking means than are non-Autistic people. I am using non-speaking rather than non-verbal because it is the preference of Autistic people (The Guild for Human Services, 2021, Nov. 29; Neuroclastic, 2021, Aug. 14). The Merriam-Webster dictionary describes “Non-Verbal” as not involving the use of words and lacking the ability to engage in speech, which non-speaking Autistic people do not feel is an accurate description of their ability to communicate. On the other hand, “non-Speaking” is described as not involving spoken words, which non-speaking Autistic people claim to be a more accurate representation of their communication. It is particularly important to look at discourse as comprised of speaking and non-speaking communication, in multiple forms of text.

The focus of this thesis of examining the blogs written by Autistic authors would line up with discursive psychology’s focus on the analysis of audio or video recordings of people interacting in natural settings. Traditional social research involves having a question and then searching for the answer. Using that approach for this thesis probably would have restricted the possibility of exploring subjects brought up by the Autistic bloggers that fell outside of the questions posed for the study. Psychologists Michelle O’Reilly and Tom Muskett and Professor of Inquiry Methodology Jessica Nina Lester (2015) said that discourse analysis’s focus on language and communication puts it in a good position to facilitate autism research. According to

O'Reilly et al., it is a useful way to examine the lived experiences of Autistic people like the ones included in this study. It provides space to be critical of the predominant discourses, societal power structures, and the scientific rhetoric that affects Autistic people. In other words, discourse analysis is positioned to be useful in studying the disabling discourses around autism, including the tension between the medical model and the social model of disability.

O'Reilly et al. observed that while there was a fair amount of research about the communication of Autistic people as individuals, far less is known about how Autistic people worked together to achieve communication. Furthermore, there is the question of how people use language to talk about autism. According to O'Reilly et al. (p. 357), the examination of how autism is talked about “opens up a further level at which to consider language, communication, and ASD – that being how the diagnosis is described and represented at a broader socio-cultural level, including within media and popular culture.” These researchers said that research has demonstrated that DA (discourse analysis) and CA (conversational analysis) can generate questions about how autism is represented in media and communication. This is helpful for my approach because it will expose those narratives harmful to Autistic agency.

Professor of English Rabindranath S. Polito (2011) wrote about Critical Discourse Analysis that the first goal was to analyze a text's real-world context. The second was to study the production, interpretation, and context. The third was to look at social issues in the text. Fourth, it should draw readers' attention to injustice and social imbalance manifestations. Fifth, it should support people who experience oppression. Polito said it should use accessible language.

Professor of Communication Marialena Bartesaghi and Associate Professor of English Kate Pantelides (2017) wrote that due to the goal of the research being to reveal how text and talk are used to maintain social control and oppress people, researchers seeking to dispute the text need to

be clear and transparent about power relations, rigorous in their analysis, and write in a manner that is accessible to the average reader.

Studying the lived experiences of Autistic bloggers provided an opportunity to examine examples of how text and talk are abused for oppression and control, looking at how the bloggers drew attention to the imbalances of power and injustice they experienced. Author and Filmmaker Simi Linton (1998, p. 5) wrote:

The cultural stuff of the community is the creative response to atypical experience, the adaptive manoeuvres through a world configured for nondisabled people. The material that binds us is the art of finding one another, of identifying and naming disability in a world reluctant to discuss it, and of unearthing historically and culturally significant material that relates to our experience.

Choosing blogs as the medium of study was a way to tap into the cultural stuff of the Autistic community. It was a window into the adaptive maneuvers Autistic people make to navigate a world configured for nondisabled people. It also resulted in less time spent deciphering jargon since the authors generally wrote their material to be accessible to a broad spectrum of readers.

### ***3.3.1. Critical Discourse Analysis: Vocabulary and Language***

According to Jonathan Potter (2004), the following seven points provide a place to begin understanding the term “Discourse”:

- Discourses can be found at work in texts (p. 147)
- By the authors commenting on the terms they have chosen to use, a discourse comes to reflect upon its own way of speaking (p. 148)
- By reflecting upon what other authors have said, a discourse refers to other discourses (p. 150)

- “Discourses are the sets of meaning which constitute objects” (p. 152)
- “The object that a discourse refers to may have an independent reality outside discourse, but is given *another* reality by discourse. An example of such an object is the subject who speaks, writes, hears or reads the texts where discourse lives” (p. 152).
- “Discourses are located in time, and are about history for the objects they refer to are objects constituted in the past by discourses or related discourses. A discourse refers to past references to those objects” (p. 153).

Foucault helped shift modern ideas of power, leading away from the idea that it is something that can be owned by the privileged and wielded against the marginalized as an instrument of coercion. Foucault promoted the idea that power was everywhere, permeating discourse and there to be taken-up. Discourse Analyst Jessica M.F. Hughes, reflecting upon Linguist Ruth Wodak and Michael Meyer (2009), Professor of Business Administration, said:

Starting from theories of power, ideology, and social inequity “directed at the totality of society in its historical specificity,” (Wodak & Meyer, 2009, p. 6) critical discourse analysts aim to understand, critique, and intervene in social processes that perpetuate wrongs in society.

Language is not a weapon, according to Brown (2019). However, language can be used to claim power, if used correctly. If you agree with Foucault’s idea that power is conceptualized in terms of the asymmetries in how it is produced, distributed and consumed, the Autistic bloggers included in this study demonstrated they had the ability to take up power available in discourse. They can enact change in the discourse through their use of online platforms that allow them to reach more people. The creation of online blogs has changed discursive practices, which has led to many marginalized people, including the Autistic bloggers included in this study, to enact

wider social and cultural changes. This has allowed the Autistic bloggers included in this study to challenge discourses in ways that rehumanize them. Sociologist Alec McHoul and Wendy Grace, who is on the Faculty of Arts at the University of Australia (1993, p. 36), stated that Foucault redirected discourse “towards the questions: what can be said? and what can be thought?” This is particularly helpful as I analyze Autistic blogs because of the questions around which voices are considered valid and are affirmed.

Van Dijk (1997) said the three main dimensions of discourse analysis are language use, communication of beliefs, and interaction in social situations. Language use is something that has caused me a great deal of frustration when I have tried to engage in advocacy. I have experienced a lot of aggravation about how much time I have been forced to spend explaining and justifying my vocabulary choices. This is related to the dominance of the medical model of disability outside of the Autistic community versus the social model of disability within the Autistic community. Having a clear and shared understanding of the vocabulary is important. This is why so much space is given to vocabulary explanations and justifications in academic papers on disability. Disabled activists sometimes lament the struggle to talk about anything beyond the correct words when referring to disabled people. This comes from an understanding that advocacy issues they wish to discuss are being derailed. Since vocabulary and power are supposed to be negotiated, dismissing your vocabulary preferences reinforces unbalanced power dynamics.

I already discussed person-first language choices in chapter one. However, I will revisit this subject briefly since language choices are so important in CDA. CDA troubles how dominance and inequity are reproduced through language. One thing about person-first language choices I did not previously address was the issue of the terms “High Functioning” and “Low

Functioning.” Another important term to discuss is “Profoundly Autistic.” These are what are known as “Functioning Labels.” Sociologist Steven Kapp (2023, p. 1) said:

Recently the *Lancet* published a Commission on the future of care and clinical research of autism, which included a side panel arguing for the adoption of “profound autism,” a term intended to describe autistic people who require constant supervision or care, thought to usually have significant intellectual disability, limited or no language, and an inability to advocate for themselves.

For many people, it seems obvious that there should be a quick way to distinguish between Autistic people they think of as high-functioning and those they think of as low-functioning. However, many other people question why this is so important to those people. These people have the right to be considered experts on their own lived experiences questioned. They have been told that if they can speak, they are not Autistic enough to be considered autism experts or that they are pulling people's limited attention away from the issues that affect people with higher support needs. Conversely, Autistic people who cannot speak are said to lack the ToM to theorize about their lived experiences. If they use facilitated communication, a typing technique learned with a trusted support person (Sequenzia, 2013, Nov. 7), accusations are sometimes made that it is not the Autistic person who is communicating, but rather, it is their facilitators passing their communication off as the Autistic person's. It is hard to imagine what it must feel like to work so hard to communicate, only to have your communication dismissed.

### ***3.3.2. Critical Discourse Analysis Framework***

Douglas gave me access to her adapted (with permission) “Discourse Analysis Research Tool” created on the Neurodiversity Matters project by Ph.D. student Bridget Livingstone and Associate Professor in Social Work and Social Development Margaret F. Gibson (October 27,

2020).<sup>1</sup> This tool allowed me a place to begin analysis of the blog content. It began with basic bibliographic information. The framework posed questions about each blog article's language and linguistic features. (Please see Appendix E for the questions included in the framework)

### **3.4. Narrowing the Field**

This study aimed to understand better the intersections of oppression experienced by a selection of Autistic bloggers. “The Actually Autistic Blogs List,” curated on the “An Autism Observer” blog page, was the initial resource I used to locate Autistic bloggers and their blogs. This blog included more options than I could hope to look at for this thesis study. As such, I needed to use filters to reduce the options. I was particularly interested in looking at the intersection of marginalized identities. In addition, I was cognizant of how autism has traditionally been considered a “Condition” that predominantly affected white, assigned boy, middle-class individuals. These two factors made me decide to filter out blogs written by individuals who identified as men unless they identified other intersecting marginalized identities. I needed a few more filters to winnow the potential blogs for consideration. I applied filters that included the number of posts and the date of the last post. If a blogger did not have at least ten blog entries that could be relevant to the study, I eliminated the blog from the list. If a blogger had not written any entries in more than a year, I eliminated the blog from the list. This helped me reduce the potential blogs for consideration from over eight hundred, down to around forty. This number was still too high. However, I was not certain how many blogs I wanted to include in the study. After consultation with my supervisors, I settled on having fifteen blogs.

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<sup>1</sup> ([https://uwaterloo.ca/scholar/sites/ca.scholar/files/m23gibso/files/discourse\\_analysis\\_research\\_tool.pdf](https://uwaterloo.ca/scholar/sites/ca.scholar/files/m23gibso/files/discourse_analysis_research_tool.pdf)).

This seemed like a number to give a good cross-section of viewpoints while still being manageable in scale.

Some selected bloggers have been producing content since the start of the millennium. That meant there was an overabundance of potential content to include in the analysis. Thus, I required a way to filter this content to begin to understand what might be the most useful. On the other hand, I wanted to avoid skewing the selection to what I thought was more important or what would be the most useful for my thesis. My thesis supervisors informed me of the “Nvivo Qualitative Data Analysis” software, available for graduate students for free through the university. I cannot pretend to have used this software proficiently, but it was a good initial sorting tool.

I began by doing a general word frequency query for each blog. I put these results on “Google Sheets” for each blog. I sorted and colour-coded the results according to how often they appeared, moving them around to show the results that appeared the most often on the top and at the front. Afterward, I used Goodley and Runswick-Cole’s (2014) table to sort the results further. The words that most closely fit the categories in the table were moved up and forward, even if they had fewer results than others. I built “Parent Nodes” and “Child Nodes” for the words that expressed themes being looked at and those revealed to be important by the bloggers.

I wanted to ensure the final selection of blogs would have an element of randomness. After thinking about how to accomplish this, I remembered seeing a “Wheel of Fortune” type tool used by people in my northern Saskatchewan community when they did online line-draws for fundraising. The way this worked is that you would type in all the names and the program would put them on a spinning wheel like you would see on Wheel of Fortune. You could set the



program to eliminate by spins all but fifteen of the names, or you could select the names brought up on the first fifteen spins. I decided to use the latter method.

**Table 1**

***Autistic Bloggers Included in this Study***

<b>(Pen) Name and Blog Site</b>	<b>Blog Address</b>	<b>Intersections of Marginality</b>	<b>Identity</b>
<b>Decosta</b> , Solidad and Metonymical	<a href="https://www.metonymical.net">https://www.metonymical.net</a>	Neuroqueer, Queer, trans, intersexed, bipoc, Autistic	Fine arts degree from the California College of the Arts
<b>Ekins</b> , Erin and Queerly Autistic	<a href="https://queerlyAutistic.com">https://queerlyAutistic.com</a>	LGBTQIA+, queer, woman, Autistic	-Written for The Independent, Huck Magazine, and Neuroclastic -Author of <i>Queerly Autistic: The Ultimate Guide for LGBTQIA+ Teens on the Spectrum</i>
<b>endeaver*</b> and Homo qui vixit	<a href="https://anotherqueerAutistic.wordpress.com">https://anotherqueerAutistic.wordpress.com</a>	Queer (Aspec), Trans (Neutrois), Low-income (ssi), Disabled (Crazy + Autistic)	-They/them/theirs or Xi, xem, xyrs -semi-verbal -AAC/ASL user
<b>Forshaw</b> , Alex and My Autistic Dance	<a href="https://myAutisticdance.blog/">https://myAutisticdance.blog/</a>	Mother, trans, woman, Autistic	
<b>Hammond</b> , Tiffany and Fidgets and Fries	<a href="https://tiffywrites.substack.com">https://tiffywrites.substack.com</a>	Black, woman, Autistic	Focuses on living and writing as a whole person
<b>Kraemer</b> , Ira and Autistic Science Person	<a href="https://Autisticscienceperson.com">https://Autisticscienceperson.com</a>	Woman, Autistic	-Master degree in Neuroscience -self-advocate
<b>Leong</b> , Dawn-Joy and Bunnyhopscotch	<a href="https://dawnjoyleong.com">https://dawnjoyleong.com</a>	BIPOC, woman, Autistic	-Singapore -Autistic artist researcher presenting autism as parallel embodiment
<b>Liu</b> , Grace and Unwritten Grace	<a href="https://unwrittengrace.wordpress.com/">https://unwrittengrace.wordpress.com/</a>	Mixed Race, lesbian, woman, Autistic	Taiwanese Author of novel
<b>Miranda</b> , Kitin and Asian Aspergirl	<a href="https://theasiangirl.com">https://theasiangirl.com</a> Site is being remained "Kats Café" soon	Bipoc, woman, Asperger's Syndrome	Phillippines, Asian
<b>Queer Disabled Writer</b> and Stims, Stammers and Winks	<a href="https://stimstammersandwinks.blogspot.com">https://stimstammersandwinks.blogspot.com</a>	Queer, disabled, Autistic	

<b>Sequenzia, Amy</b> -Ollibean, Neuroclastic, Thinking Person's Guide to Autism	<a href="https://ollibean.com">https://ollibean.com</a> <a href="https://neuroclastic.com/tag/amy-sequenzia/">https://neuroclastic.com/tag/amy-sequenzia/</a> <a href="https://thinkingautismguide.com/tag/amy-sequenzia">https://thinkingautismguide.com/tag/amy-sequenzia</a>	Non-speaking Multiply disabled Woman Autistic	-Non-speaking -epileptic -cerebral palsy
<b>Seventh Voice</b>	<a href="https://seventhvoice.wordpress.com">https://seventhvoice.wordpress.com</a>	Woman, Asperger's Syndrome	
<b>Sky, Aria and Mamautistic</b>	<a href="https://mamautistic.site">https://mamautistic.site</a>	Woman, mother	Mother
<b>Uncultured Anthropologist</b>	<a href="https://unculturedanthropologist.wordpress.com">https://unculturedanthropologist.wordpress.com</a>	Queer, bipoc, woman, ADHD, Autistic	-Anthropologist -Autistic mother of Autistic child
<b>Uninspirational</b>	<a href="https://theuninspirational.wordpress.com">https://theuninspirational.wordpress.com</a>	Queer, ADHD, myalgic, encephalomyelitis, hypermobility joint syndrome/EDS, Autistic	Europe

### 3.5. Limitation of the Study

The bloggers selected were people with access to the internet and a computer, know how to use the internet, and could communicate in English. This restricted the people who could be selected for this study, and subsequently, the points of view included.

This study focused on the intersection of autism with other marginalized identities. Asperger and Kanner believed that the Autistic subject was white and raised as a boy, which led to white boys being thought of as the norm for autism. White people raised as boys are also considered to hold the most privileged position in our social structures. These factors led me to conclude that this study should be limited by eliminating white Autistic bloggers raised as boys as potential subjects if they did not identify as having a marginalized identity other than being Autistic. Any study about Autistic people suffers in some way from the exclusion of certain kinds of Autistic people. However, this was done to focus on the intersection of autism with other

marginalized identities. People at this intersection have traditionally been underrepresented in conversations about autism

### **3.6. Summary**

My approaches were primarily influenced by post-structuralism, new materialism, and post-humanism. I used a critical discourse analysis framework by Livingstone and Gibson (2020) and Douglas' adaptation to gain insight into the blog content chosen from each of the fifteen bloggers. This framework asked critical questions such as: What language is brought along with subjectivity? Where is agency located? Who is represented as being experts and knowledge keepers? These questions helped position the bloggers regarding their views on the restrictive ideas of "the human." It helped me understand how they experienced dehumanization and what they believed needed to happen to rehumanize Autistic people.

## **Chapter Four: What Autistic People Have to Say About Autism**

When I began writing this thesis, the last thing I wanted to do was get into a lengthy justification of the language and vocabulary I chose to use, particularly because it related to my identity. As far as I was concerned, Autistic people before me had used enough of their platforms and advocacy energy to justify the language they used around their identity. However, the more I resisted this discussion, my points became muddled. In this chapter, the othering of Autistic people is impossible without referring to the vocabulary applied to Autists from outside themselves. Once one understands the immense negativity of this language, one will begin to understand why so many Autistic people mask their Autistic identity. They will see how issues of gender and normativity play into the decision to mask. When they look at the fundamental need to make a living or have financial resources, they will recognize what is at stake for Autistic people who would rather not participate in masking. They might begin to see why rejection of the rigid notions of “the human” could be appealing, and why Autistic people might want to look towards possibilities offered by post-humanistic philosophy.

### **4.1. Naming and Labels**

Since labels are forced, it is important to Autistic people that the correct labels are used. I formed this contention because all the bloggers wrote about how labels impact Autistic people. This question of the use of labels also is why the debate around identity-first versus person-first language still gets a lot of discussion in the discourse. The use of labels does as well. People are classified within the labels that are attached to them. This debate is another topic that all bloggers touched upon at least once in their blogs.

All the bloggers in this study explained autism in at least one article. Having a shared understanding of the main topic being discussed is important. In the case of autism, getting to this shared understanding often requires pushing aside commonly held western belief of autism as a deficit that contradict the understandings being used to frame the discussion. “What is autism?” becomes an aggravating question to answer constantly. Alex Forshaw (2017, Apr. 2, para. 4) said:

Autism is big. Really big. You just won’t believe how vastly, hugely, mind-bogglingly big it is. Oh, wait, that’s what Douglas Adams wrote about space. Silly me! But seriously, autism is a really broad diagnostic definition covering a whole bunch of stuff from developmental delays to sensory processing/integration issues.

I love Forshaw for this *Hitchhiker’s Guide to the Galaxy* reference. My first thought was that Forshaw shared the aggravation expressed by more than one of the bloggers in being constantly asked to define autism, maybe feeling it came at the expense of progressing discourse to what might create more substantive change in the lives of Autistic people. The more reading I did, the more I understood how the use of clarifying language in discourse and working towards a shared understanding of vocabulary was a form of advocacy on its own, holding the potential to create substantive changes in the lives of Autistic people.

The power inherent in naming can be applied in negative ways. Black Autistic blogger Tiffany Hammond (2022, Jul. 1) said that when asked to define autism, they rarely answer. They said people who demand a definition from them seemed to want the impossible—for Autistic people to be able to produce a collective answer for an individual experience. According to Hammond, the simple answer would be that autism is a difference in thinking, feeling, and doing. However, they questioned if such a response would be helpful to most people. What Hammond

did not think was useful was quoting the DSM, medical pages, long lists of book and article references with overly technical language and pointing out social media content that breaks down autism into little bites and lists of red flags.

Hammond said they could not easily produce a description of autism that would satisfy most people. Hammond (2022, Jul. 1, para. 4) said that the headspace they would have to enter to do this tends to induce “memories of the moments in which I had to prove to others I existed within this spectrum. Do I fit the lists? The perfectly curated symptomatology lists created by those decades younger than I...”

Ira Kraemer (2018, May 20, para. 11) said getting a diagnosis did not make people understand or accommodate them. Rather, confusion was produced when people compared how they perceived the blogger and what they believed autism to be. Kraemer (para. 12) said, “They project their ideas of the word ‘autism’ onto you...Other people do not care about your own understanding of your brain.” Forshaw (2021, Apr. 21, para. 4) discussed the effect labels had on their childhood self, saying:

She started collecting labels the way she would collect books and Lego: shy, quiet, deep, clever, moody, reserved, introspective, neurotic. Some she liked, others not so much, but they all had one thing in common; they had all been given to her by other people. She wore them, made them into a mask so that what people saw when they looked at her was what they expected to see.

Forshaw (2021, Apr. 21, para. 7) said their childhood version of themselves broke down because of these dysmorphic thoughts when they were thirteen. Forshaw (2021, Apr. 21, para. 14) said:

Labels have their uses and their places, but the name is not the thing. Like in the famous Magritte painting, “Ceci n’est pas une pipe.” (*This is not a pipe.*) A depiction or

description is not *me*. But hopefully it bears close enough resemblance that you'd be able to recognize me from it. Deep thinker!

As a long-time high school English teacher, I might have gone with a Shakespeare analogy here, saying that a rose by any other name would smell as sweet. However, Dr. Janet McVittie (one of my thesis advisors) asked if we should name a rose at all? Do we limit the rose through naming it.

The idea of red flags or lists of symptoms, and projecting incorrect ideas of autism onto Autistic people all point to the harm that labels can do when they do not align with who you believe yourself to be. Amy Sequenzia suggested it is not Autistic people who insist upon labels. Regarding labels, Sequenzia (Does it matter?, n.d., para. 14) said:

Because the neuromajority needs labels and arbitrary classifications, we, the ones who are very different, the ones who can never pass for “normal”, are immediately otherized.

“Normal” people do not want to be associated with us, “the weird looking,” “the pitiful,” “the needy.”

Owens (2015, p. 386) said, “An individual is evaluated and labelled through a process of power which then serves to separate them from mainstream society, education, work or social interaction, because they deviate from the dominant norm and difference is not valued.” Tension is created when how others label us differs from how we label ourselves. This tension might result in increased separation of groups and individuals from mainstream society, education, work, or social interaction. This would be particularly true when, often, the preferences of people outside your group are prioritized over your own. Naming is a form of power. People and things rarely name themselves. Those who name them exert control over defining who or what they are.

Reflecting on Professor of Education Alicia Broderick and Autistic Activist Ari Ne’eman regarding the power of naming in the neurodiversity movement, O’Dell et al. (2016) said:

The concept of neurodiversity can serve to challenge cognitive normalcy and to offer alternative, positive, interpretations of autism and autistic identity. Neurodiversity discourse enables a challenge to dominant understandings of autism as a neurological *deficit* instead focusing on autism as neurological difference. It also offers a way of naming non-autism and rendering visible power structures that naturalise an NT world. The discourse has been widely drawn on, in some cultural spaces, by social movements dominated by adults with autism (Broderick & Ne’eman, 2008).

Diversity is considered a strength, whereas a deficit is considered a weakness.

Walker (2021, p. 38) described neuro-divergency as a mind that functions significantly differently from what society deems "normal." Normalcy for most people hinges upon the idea that when enough people have certain characteristics, those characteristics qualify as normal. Contrarily, when relatively few people have certain characteristics, those characteristics might be labelled as “Abnormal,” even when they do not cause harm. Hammond juxtaposed the idea that autism was a “Human Experience” with stipulating that it was not considered a “Normal” human experience. They said they were not interested in dissecting definitions of autism or discussing preferred language. Hammond (2022, Jul. 1, para. 15) said, “I want to make people feel. I want people to see us. I want to be more than organic masses of red flags and symptoms. More than representations of the latest terms. I wanted the right to explore the breadth of our humanity.” Examining the breadth of Autistic humanity was the task I set myself when I began this thesis. Reading the research, and more importantly, the materials created by the bloggers included in this



study, made me realize how absurdly huge a project it would be to explore the breadth of Autistic humanity.

In the month of December, 2022, Twitter was buzzing with discussions about a recently published article by Singer et al (2022): “A full semantic toolbox is essential for autism research and practice to thrive.” This article argued that autism research was being hampered by not having access to a “Full Semantic Toolbox” for describing autism. Program Director in Curriculum and Instruction Kristin Bottema-Beutel (2022, Dec. 14) said on Twitter, “The premise of ‘the commentary’ is if researchers can’t use ableist (and unclear) terms like ‘severe’ or ‘profound,’ they can’t accurately describe some Autistic people.” Like Bottema-Beutel, I question why Singer et al. felt they could not describe Autistic people if they were restricted to words that did not limit and categorize the breadth of Autistic humanity. If you believe autism could be reduced to a list of disordered behaviours, in theory, there could come a point when enough of these behaviours were checked off to qualify a person as “Severely” or “Profoundly” Autistic. The ability to label someone with words such as severely or profoundly Autistic against their will is related to the power of being able to name another. Sociologist James Valentine (1998, p. 2) said that naming is a form of power that can impose one’s understanding of their identity upon other people. Perhaps this is why so many people refuse to use the chosen names of trans people, because by using their chosen name, they feel as if they are being forced to acknowledge their trans identities.

Names act the same way as labels in most cases. Reflecting on Sociologists Howard Becker (1963) and Edwin Lemert (1967), Sociologist Jón Gunnar Bernburg said the following about “Labelling Theory”:

The theory assumes that although deviant behavior can initially stem from various causes and conditions, once individuals have been labeled or defined as deviants, they often face new problems that stem from the reactions of self and others to negative stereotypes (stigma) that are attached to the deviant label (Becker, 1963; Lemert, 1967).

Therefore, labelling is also a form of power. Labels act as a form of binding, confining, and limiting for many people. This is particularly true when the name is imposed upon them against their will. Valentine (1998, pg. 2) said that naming is critical to the question of identity. When something cannot be identified, it cannot be named. In other words, naming is essential to “the human.” Valentine (p. 2) said, “names are ascribed, and can be forced on recipients against their will. Such names (like the labels indicated by labelling theory) may be difficult to shake off.”

Names can be viewed as a form of a label or vice versa. A negative label can be pushed on people against their will and can be difficult to overcome. Valentine (p. 2) said, “Contrastive identification, of us *against* them, is just as significant.” They said that the self can end up unnamed against the negative constitution of the other. Another way of saying this is that the unnamed self becomes thought of as the standard, default, or normal.

Negative feelings come up from having others impose names and labels. The other does not have to be explicitly stated for the sense of ‘us against them’ to develop. I think of this as white, able-bodied, cisgender and heterosexual people being the default assumption. If people are being othered, those who are not will be the default described above. They resist using labels for themselves, like referring to themselves as white people, because they are accustomed to them being the assumed normal or default, thus not needing to be explicitly named and labelled. Rather, they are accustomed to being the ones doing the naming.

## 4.2. Othering Autistic People

### 4.2.1. Aliens

Solidad Decosta, Erin Ekins, Alex Forshaw, Ira Kraemer, Dawn-Joy Leong, Queer Disabled Writer, Amy Sequenzia, Seventh Voice, Aria Sky, and Uninspirational wrote about Autistic people being compared to aliens in their blog content. Forshaw (2014, Jan. 4) said they are determined to use themselves as an example of how Autistics are people, not an alien species. Kraemer (2018, May 20, para. 3) said about their own thoughts, “Oftentimes, you genuinely wonder if you are an alien. You wrote about aliens since you were 8 years old...People joke about you being a vampire, or an alien, and you joke back, masking your anxiety.” Forshaw (2012, Feb. 2) described the fatigue caused by having to wear a mask of normalcy so that they are not perceived as alien. As part of the discourse framework used for this study, I examined the conversations that happened in the comment sections of the blogs, looking for tensions and agreements with what the bloggers had written. In the comment section of the Seventh Voice (2014, Dec. 7), “CMG” (not included in study) said that their brother used to jokingly call them an alien, which never sat well with them because, to some extent, they believed it to be true. A commenter (not included in this study) on the same blog post who called themselves “Through My Autistic Eyes” (2014) said they thought of non-autistic people as robotic or alien. An autistic person who called themselves “Wingedwolfpsion” (not included in this study) left a comment on a Seventh Voice blog post where they reversed the application of the “robotic” and “alien” labels.

This relation of Autistic people to aliens ties back to Asperger’s view of Autistic children. Scheffer (2018, p. 179) said that Asperger denied the humanity of children who passed through their clinic who they viewed as being more impaired than the children in their study, referring to them as automatons. “Wingedwolfpsion” (2016) said, “I never found that ostracism by other

children made me doubt my sense of self or my value. When young, I considered them an alien species I was unfortunately forced to deal with. In truth, that feeling didn't change much once I hit my teens." I found that the bloggers often expressed feeling like aliens, suggesting the power of ableist discourse in these bloggers' lives and identities and the possibility for resistance.

Kraemer (2021, Jan. 25) said they enjoyed reading *A Field Guide to Earthlings: An Autistic View of Neurotypical Behavior* because it made them feel better about not being alone in navigating Autistic to non-Autistic social dynamics. Ekins (2017, May 25) said they often feel like an alien who has forgotten to put up their shields. Kraemer (2018, May 20) said that Autistic people must create a false identity to cope with a world directed by non-Autistic norms, which sometimes makes them feel like an alien on this planet. Sky (2016, Oct. 6, para. 12) said the following about feeling like an alien:

After becoming engrossed in Star Wars, added to my love of Star Trek, I had come to the very obvious conclusion that I must be an alien (being reasonably certain I wasn't a robot) and I informed my middle school band-mates of that fascinating tidbit about myself.

Another friend declared her alienness as well and we had a grand time telling each other about the protocols on our respective planets.

Until they realized they were not the only person in their group who felt excluded, Sky said they felt like they were on the outside. That realization made them feel a sense of inclusion.

Feeling like an alien is closely related to feeling excluded. All the bloggers wrote about various ways Autistic people are excluded, often focusing on their own feelings of exclusion. Sometimes they wrote about how the Autistic community excluded other Autistic people because their beliefs did not align with the priorities dictated by the community's loudest and most visible segments. Bloggers talked about being excluded from groups such as: autism researchers, autism

experts, humanity, and adulthood. These kinds of exclusion all contributed to some of the bloggers feeling as if they were aliens. Other bloggers expressed the sense that the world around them was alien. Leong (overwhelmed, n.d., para. 8) described “struggling through alien and inclement systems to forge some kind of independence, hoping to make a tiny contribution to our worlds.” Reflecting on the difficulties of accessing and navigating post-secondary institutions, Leong (traction, n.d., para. 9) said:

Knocking on doors along the hallowed hallways of higher learning has been daunting. Especially because the one knocking on doors is autistic and operating within an alien milieu that is already harsh enough for anyone from within its native culture.

Leong (accommodating self, n.d., para. 9) also said, “But I also realise now that I need to create accommodations for myself, because the world designed according to neurological-normative systems is a harsh, alien and hostile one for my fragile sensory networks.” Other bloggers expressed similar feelings that the world around them was alien, and they were simply coping with this alien environment.

Uninspirational (2016, Nov. 4) said that many parents frame their Autistic child as a problem to be solved. They said that when these parents speak about their disabled children as if they were aliens, completely different from themselves, they promote ableist views. The same narratives are repeatedly presented that something is wrong with Autistic people. These same narratives often present Autistic people as the inception point of tragedy and disaster in the lives of the people closest to them, particularly their parents. Sequenzia (2013, Sept. 9) said there is plenty of evidence that parents who have murdered Autistic children can be treated as heroes. Their Autistic victims are framed as the cause of their deaths, while the parents who committed murder are framed as heroic and selfless. Sequenzia said the language used to describe Autistic

people takes on a supernatural tone, with the Autistic murder victims being referred to as if they were possessed or were aliens. Sequenzia also said that not a lot of thought goes into the thoughts and feelings of adult Autistics, as Autistic adults who were living meaningful lives were treated as aliens from an imaginary place.

The bloggers included in this study talked about how often Autistic people are made to feel as if being outside of humanity would be preferable. Looking back at Titchkosky's (2012) work as interpreted by Goodley and Runswick-Cole (2014, p. 7):

She is especially concerned about the rigidity of what we often pass off as human. It remains the case today, she argues, that despite the universal human condition of embodiment, and even with efforts to establish a universal and transcendent sense of human, not all bodies are granted the status of persons (let alone of human). In this sense, she concludes, 'segregated from life, disability appears as though it is detached from the wider question of what it means to be human.'

Autistic people can be led to be frustrated by what passes as humans and wonder if they are better off standing apart. Leong (2021, Mar. 30) said, "My childhood dream was to flee from humans and go live in a cave." Among the bloggers in this study, Leong seemed especially ambivalent about being included in "the human." Leong (2020, Jun. 16) said that the pandemic led them to come to an uncomfortable conclusion: That humanity was non-essential on this planet. They said that those who took the position that humans and animals had things to teach each other, and that humanity did not take precedence over non-human species, were in a minority even among Autistic people. Leong (2020, Jun. 16) said:

Those of us who see this truth are the minority within a minority. And our precious intense yet fragile connection with this wonderment that is the sentient material universe

is constantly threatened by the fact that we still belong to the human species, no matter what secret mysteries our souls have uncovered, we are all trapped inside our human embodiments. And it is my human-ness that caused me to jump into the fray and swirl around the frothing sea with the flotsam and jetsam – yes I even wrote a blog post in response to this silliness. Clever me, eh? No, just human me.

In this quote, Leong expressed a sense that they were a minority within a minority because of their beliefs about the rights and agency of animals. Leong describes their connection to this truth as fragile and threatened by their connection to “the human.” They said being trapped within their human embodiment puts the potentiality of their other connections at risk.

#### ***4.2.2. Animals and Robots***

Compared to the other bloggers chosen for this study, Leong embraced post-Human possibilities. Thus, Leong talked about comparisons of Autistic people to animals and robots more than the other bloggers. Alex Forshaw, Ira Kraemer, Dawn-Joy Leong, Queer Disabled Writer, Amy Sequenzia, Seventh Voice, and Aria Sky wrote about comparisons of Autistic people to animals and robots. Leong responded to an article from *Spectrum* about how Autistic people are often compared to animals or robots. Leong (2020, Jun. 13) said that the *Spectrum* article derisively mentioned robots, characterizing “the associations between the study of animals, robots and autism as ‘ugly parallels to apes and robots’” that reflect poorly on their knowledge of the “actual work of Autistic researchers in these areas.” Leong’s response was notably different than what most people might expect, considering the purported purpose of the article was to promote Autistic scientists making waves in fields with a history of comparing Autistic people to animals and robots. Leong described the inspiration they were provided by the work of Anthropologist, Primatologist, and Ethologist Dawn Prince-Hughes, who worked with

gorillas. Leong (2020, Jun. 13, para. 6) quoted Prince-Hughes characterizing themselves as being under the tutelage of captive gorillas, saying this allowed them to revolutionize how they saw the autism spectrum. Prince-Hughes (2020, Jun. 13, para. 6) said that it was apes who taught them to be social and have helped other people in the same way. Prince-Hughes (2020, Jun. 13, para. 6) said, “If there is indeed no shame in being neurodivergent then we should praise animals under a neurodivergent rubric rather than recoiling at their differences.”

Leong does not have a relationship with apes like Prince-Hughes. However, they have a close relationship with their dog Lucy. They said the content of the *Spectrum* article articulated a way of thinking that demonstrated ignorance of the multidimensionality of Autistic researchers and their work in autism. Leong (2020, Jun. 13, para. 8) said:

The realm of Autism is a complex and beautiful one, and should be studied and respected from more than just the obsessively human-centric viewpoint. I, for one, am not ashamed to learn from non-speaking humans and non-speaking non-humans. I don't study the great apes, but my research in Autism has found much inspiration from studying canine communication.

Leong suggested we view animals and robots as potentially powerful channels of learning, discovery, and connectivity rather than seeing a comparison to them as insults to our humanity. In an interview with Lu Andrés, Braidotti talked about the concept of “Becoming.” Braidotti (2019, Apr. 2, para. 5) said the idea of becoming is essential; we need to be open to the idea that we are subjects always developing into something new. Within this process of becoming, there are opportunities to open up the meaning of identity to include relations with a multiplicity of others, including animals and robots. Braidotti used an example of the increased use of robots in industry. They proposed that there was a question of whether we should hate the robots because



certain jobs are being eliminated because of their use or if we should take advantage of the fact that they are making our lives easier. After sitting with this thought for a minute, I realized that hating an object accorded it a certain amount of agency. What I mean by this is that we generally assume some degree of intent to feel hatred toward someone or something. Leong said Rachel Nuwer (2021, May 12), author of “Finding strengths in autism,” the *Spectrum* article’s author, assumed that comparing Autistic people to animals or robots was insulting, without context or caveats. Leong said that Nuwer introduced an insult where one had not existed previously. The blogger said they have learned much about their Autistic humanity through non-human species. Leong (2020, Jun. 13, para. 8) wrote:

Humans have a great deal to learn from the ones they despise and feel superior to, mostly from imbalanced and uninformed assumptions. Neurotypicals view Autistics as inferior because our communicative rhythms and patterns differ from the normative – are we not applying the same kind of biases towards animals when we say it is nauseating to be compared with them?

As used here, the word “nauseating” means that it is considered repugnant to be compared to animals.

The comparison mentioned before was assumed insulting because of the underlying assumptions about how animals and Autistics are viewed. It is assumed that people view non-human species as inferior. Therefore, if Autistic people are compared to non-human species, the assumption is that they are saying Autistic people also are inferior. Indeed, it is ground-breaking within Westernized white European culture to treat humans and animals respectfully, although Indigenous people have believed it all along. Referring to the teachings shared in “Indigenous worldviews and critical animal studies: Decolonizing and revealing truncated narratives of

dominance,” Ruth Koleszar-Green and Atsuko Matsuoko (2018, p. 342) of the Faculty of the School of Social Work at York University said:

These teachings tell us human animals that we are not superior to other animals. In Indigenous worldviews, humans are not seen above animals. This worldview is unlike Western perspectives, which erased other animals from the consciousness of human animals, relegating them to the status of objects to be used instrumentally.

If we do not assume that humans are above animals, we do not have to assume being compared to an animal is inherently negative.

The idea Leong put forward was that it is their Autistic mind that allows them to achieve specific kinds of insights is revolutionary. Reflecting on Martijin Dekker (2000), Professor of English and Politics Chloe Silverman (2008, p. 327) said that according to Autistic activists such as Jim Sinclair (1993), Martijin Dekker (2000), Amanda Baggs (2007):

Inspired by the disability rights movement and specifically Deaf advocacy, self-advocates proposed that autism is a valid identity that ought to be protected against the encroachment of aggressive behavioral therapies (Baker, 2006, p. 27; Dawson, 2004) or prenatal genetic tests that might be developed in the future.

The argument was that Autistic people should be considered a cultural group, qualified for protections under the law that would apply to other cultural groups. It did not imply that Autistic people have essentialized differences in their minds. It argued that their status as a group stemmed from a shared culture formed around their Autistic identity, not essentialized differences in their minds. Cloe (p. 327) said:

By emphasizing both the validity and distinctiveness of autistic experience, self-advocates have encouraged both anthropologists and journalists to explore the idea of autism as a

culture, a project that has its precedents in classic studies of Deaf culture (e.g. Cohen, 1995).

Chloe (p. 328) warned that people should not assume everything an Autistic person expresses that is counter to social norms should be considered a reflection of being Autistic. An example of this might be if an Autistic person expressed racist viewpoints. Those racist viewpoints should not be considered a part of Autistic culture. This is important to remember because although there is an Autistic culture, each member of that culture belongs to individual social contexts. Autistic culture exists at the intersection of a multitude of other identities.

“Leong (2020, Jun. 13, para. 8) described their research as focused on “alternative empathic connectivity intrinsic in the autism paradigm.” Leong was not the only blogger in this study who talked about empathic resonance. In fact, it was an idea discussed at length in the comment section of a Seventh Voice (2013, Nov. 16) article comment section. The article reinforced why it was unsafe for Autistic people to move towards these posthuman possibilities, particularly when it comes to embracing the idea of robotic and artificial intelligence having agency. There is a sense that if animals and artificial intelligence are ascribed agency, it might not result in Autistic agency being reinforced. Rather, it could further undermine the agency of Autistic people. The perception that non-human species are inferior to humans and the precarious nature of Autistic humanity makes it dangerous. Leong (2020, Jun. 13, para. 10) said:

Of course, I am incensed when non-Autistic ‘experts’ lump Autistics together with animals, because their assertions lack any deep and thorough understanding of the Autistic paradigm and that of animals. Of course, I am traumatised when non-Autistic ‘experts’ try to use robots to teach Autistic children about normative social skills (not Autistic social skills, mind you, because we do indeed have our own social system)

because these ‘experts’ lack empathic understanding of both autism and robotics. When one is face to face with disrespectful lack of true expertise wanting to dominate one’s own domain, of course, one’s reaction is that of vigorous and vehement rejection.

Leong said their problem with the animal-Autistic and robot-Autistic comparisons lay with how they were presented by non-Autistic people. If these comparisons were rooted in research conducted by Autistic people, who connect with the non-human, the fundamental approaches and assumptions would be different. Since “Neuronormative” researchers outnumbered Autistic researchers, their approaches and assumptions also are dominant. This poses a potential danger for Autistic people. Leong said that of the many things they disagreed with Temple Grandin about, the idea that animals make us human was not one of them. However, it becomes a threat when Autistic people are compared to animals and that is taken to mean they are inferior to non-Autistic people.

Reflecting on Professor of English Stacy Alaimo, Professor of English Jeffrey Scott Marchand (2018, p. 292) said the following about why it is necessary to explain non-human agency even though we all know that what we think of as “Things” do things regardless of human intervention:

The bulk of the reason is the concept of agency within literary critique, and more generally the Humanities, has long been associated with notions of intentionality, rationality and voice; in short, agency has traditionally been intricately tied to extremely limited notions of subjectivity and power, or, as Stacy Alaimo rightfully acknowledges, ‘within the province of rational—and thus exclusively human—deliberation’ (2010, p. 143).

In other words, defining non-human agency is necessary because of the dominance of the restrictive notion of “the human.” Marchand (p. 293) said new materialists are “attempting to articulate a reconfigured vision of the human located within a constant flux of material flows that enable uncertain becomings with (and within) a lively and agential more-than-human world.” Marchand (p. 293) said that post-humanism also deals with recognizing the plurality of non-human agencies. Marchand (p. 294) suggested that our tendency to think of human agency as transcendent might be curbed by the “recognition of non-human agencies as entwined participants in our becoming.” Marchand (p. 294) said that addressing the concept of non-human agency might force us to:

reconfigure and ‘reterritorialize’ the human within a volatile mix of agencies, beings and forces, where the human is only one among a multiplicity of agents who are active in determining and enacting our (human or not) future possibilities.

Leong leans towards the idea that this kind of reframing has the potential to lead to the enactment of our future possibilities.

Leong focused more on the question of whether Autistic people should be angry or object to being compared to animals rather than robots. This could be because animals are considered similar to humans, in the sense that they are living beings, but are considered hierarchically beneath humans. The question Leong asked about whether Autistic people should be offended by being compared to animals is based on what it means to be human and what people believe separates us from animals and robots. If agency is not perceived to be located in the non-human, it follows that being compared to the non-human would identify you as also not possessing agency. Thus, being compared to the non-human becomes an insult and a threat. However, if a person rejects rigid ideas of what it means to be human, including where agency is located, there

is potential to see positive aspects of being compared to the non-human. Further, the label of “Autistic” ceases to be an insult or a threat.

### ***4.2.3. Changelings***

Queer Disabled Writer was the only blogger who wrote about the concept of changelings. The mythology of the changeling, although varying depending on factors such as location and time period, was that if a faerie child was born they considered deformed or intellectually disabled, the faeries would surreptitiously switch this child for a human one. According to Gloria Lotha of the University of Pittsburg (2023, April 30, para. 1), “The return of the original child may be effected by making the changeling laugh or by torturing it; this latter belief was responsible for numerous cases of actual child abuse.” It should be noted that it was disabled children being tortured in these cases, since a child would have to be considered deformed or intellectually disabled to be thought of as a changeling. Wing (1997 pp. 13-14) observed that some stories of real human babies being stolen by the faeries and replaced with faerie children sound like Autistic children.

The points made by Queer Disabled Writer about the concept of the changelings in relation to autism were so well made that despite the topic not being taken up by other bloggers in the study, I would like to address the comparison of Autistic people to changelings. Queer Disabled Writer (2013, Sept. 12) said “Changelings” could be considered othering. Alternatively, it could be taken as the reclamation of an aspect of Autistic history and how Autistic people have been portrayed in mythology. Queer Disabled Writer said they were sitting in a “Foundations of Disability Studies” lecture when they connected the historical and mythological views of disability and their hobby of playing “Dungeons and Dragons.” Changelings in the role-playing game “Dungeons and Dragons” are shapeshifters, wanderers, masters of disguise and

concealment, and make excellent spies and criminals. Queer Disabled Writer said there is a social stigma around being a changeling in the role-playing game, so they often do not appear in their proper form. The blogger said the social stigma around changelings carried over from the mythology. Vittoria Lion (2015) said the comparison of disabled children to changelings has been a consistent part of disability studies. For this thesis study, “Changeling” is understood as a fairy child put in the place of a human child. Sometimes there are darker versions, where it is a demon child rather than a fairy. In these versions, the child was switched as a punishment for the parents. The fairy babies placed in the cribs of the human children were thought to take the stolen human baby’s form. The parents believed there was something different about the child. They were difficult in some way, defying societal expectations in ways like spending too much time reading or not speaking.

Queer Disabled Writer (2013, Sept. 12, para. 9) said the Dungeons and Dragons characters were believed to be “predestined toward crime, are pre-infantilized, are something other and eviller than human, are unstable and stigmatized.” Dungeons and Dragons lore mirrors the suspicion with which people historically regarded changelings. According to the blogger, Autistic people today are often accused of not having moral judgment and are thought to be too anti-social to have a shared group culture. This is reflected in the portrayal of the changeling characters in the Dungeons and Dragons game. Queer Autistic Writer (2013, Sept. 12, para. 15) said, “We are seen as doppelgangers, as less than human.” Again, that is the way changelings are portrayed in Dungeons and Dragons.

Queer Disabled Writer (2013) suggested the way the word “Changeling” was used historically established the presence of an Autistic culture long before medical science came up with the word “Autism” and applied it to what they saw as a list of deficits. On the other hand,

the historical connotations of the word are ugly, and even the connections to Dungeons and Dragons are characterized by stigmatization. Although the word should no longer have real-world relevance, it unfortunately is still sometimes used to identify and stigmatize difference.

Regardless of whether I would personally adopt the word, the connections made by the blogger between Dungeons and Dragons, Autistics, and changelings make sense considering how pervasive masking is among Autistic people.

Lion (2015) said that Autistic children in modern popular culture have been portrayed as empty shells. This idea of a human body being an empty shell was notoriously popular with the Nazis. Lion (p. 100) said,

The legacy of belief in changelings can be found in the words of Suzanne Wright, who co-founded Autism Speaks with her husband, Bob Wright: “If three million children in America one day went missing – what would we as a country do?”

The largest autism-related corporation has represented Autistic people as being missing and a stranger put in the place of normal children.

#### ***4.2.4. Monsters, Burdens, Broken Versions of Normal***

All of the bloggers wrote about language describing Autistic people as monsters, burdens, and broken versions of normal. Sequenzia (2014, Nov. 1, para. 6) said, “Be prepared to be mocked. And to be called a monster. They will say you are broken. They’ll blame you for it all.” The idea of being a monster or broken is a comparison to something. What I mean is that “Monster” is a negative description. It is typically considered a large, ugly, and frightening creature. Nikita Mazurov (2018, p. 162), a security researcher focusing on privacy issues, said the following about the concept of the monstrous subject:



The essentialist spell of subject formation is undone not merely by the bringing to the fore of the latent foil, the anti-human, its malingering other without which the liberal subject, the (hu)man, would be unable to constitute itself, but through a destabilization of the entire notion of congealed subject-formation in the first place via a repudiation of its inescapability. The unhuman is thus not a simplistic negation of the human, but a polymorphous, monstrous aberration of the unitary, humanistic and anthropocentric subject form in its entirety.

Mazurov suggested that the monstrous subject destabilizes “the human” by reminding us of the fragility of subject formation, and how easily it can be undone. A monster is only a monster because there are normal people or creatures to compare them to. The same applies to the idea of a living entity being considered broken. There might be forms of brokenness that are objectively obvious, like a broken leg. However, some brokenness in people is not obvious, yet are assumed because of how the person is perceived compared to those considered whole.

According to Walker (2019), the language of the “Neurodiversity Movement” recognizes that if there is a word like “Neurodivergent” applied to describe one group of people and there is no word created to describe other groups of people, the implication is that the other people are normal. Sequenzia recalled how they were treated as a child. Sequenzia (This Autistic wants to say, n.d.) said that children who could speak and move easily were assumed to be capable of learning and were considered normal. In contrast, they were treated as abnormal and incapable of learning. It seems important to analyze what the bloggers in this study have experienced about how society interprets and portrays the idea of normalcy, especially regarding how it relates to Autistic people. As I indicated above, the production of the ideas of monsters, burdens, and brokenness all depend on the existence of something considered normal.

Forshaw (2011, Jul. 19) described being harassed and bullied for not reacting the way neurotypical people expected, as if they did not have feelings because they said they did not show their thoughts and feelings in typical ways. Forshaw said they were inclined to give people the benefit of the doubt that they unconsciously tried to find ways to relate when they pushed their buttons to elicit a reaction they recognized as normal. Forshaw (2011, Jul. 19, para. 6) said:

I've got a theory that it's a tribal mindset people have: the world is grouped into us and them. If you're not one of us then you're less than us. If you don't look like us or act like us it means there's something wrong with you. So we'll persecute you. We'll hound you until you give up and crawl away. This seems to be "normal" human nature.

The blogger said the extreme manifestation of this is when people are murdered for being different, and then blamed for provoking their murder.

Forshaw (2013, Oct. 22) said our society judges disabled people as less valuable than others because they can't accomplish things normally or need help accomplishing tasks. The blogger listed things they cannot do in "Typical" ways. Forshaw said they are not great at non-speaking communication, which means they are sometimes impaired in social situations. Conflict resolution is difficult for them because of their anxiety. Depression interferes with their concentration at work. However, they said none of these listed indicated them being broken versions of normal. The blogger said that the idea of brokenness is not synonymous with disability. Forshaw (2013, Oct. 22, para. 5) said, "Broken implies a loss of integrity. It implies that I am not a whole person, that my disabilities are somehow making me less than a person, less than human, inferior." The blogger said that admitting needing help with the things on the list does not justify treating them as less than other people. They pointed out the irony of being judged as abnormal, given that judgment is normal human behaviour. However, Forshaw said

that disabled people are being judged for the wrong things. They resisted this judgment within their blog, suggesting people should be judged on how they treat others rather than on their independence.

Ekins (2017, Jun. 7) discussed the additional language of burden, othering, and dehumanizing disability used in articles about the austerity measures leading up to the 2017 general election in the United Kingdom. They talked about how dangerous it was that the media framed disabled and poor people as “Scroungers” and “Burdens.” Sequenzia (Disability history, n.d., para. 20) said, “Being neurodivergent is still not fully accepted and embraced. Looking disabled still elicits pity and sometimes aversion. Being disabled is seen as burdensome and tragic. Our lives are not valued.” Ekins said that the United Kingdom media and government echoed this language in the leadup to the 2017 general election. Ekins (2017, Jun. 7, para, 17) said, “Disabled people, as well as poor people, are increasingly seen as burdens on society. We are viewed with suspicion; idle liars scamming the system unless we can prove that we are definitely disabled enough.” They said that their intersectional marginalized identities of being poor, queer, disabled and a woman leave them constantly feeling frightened. Ekins said that the media and government in the United Kingdom (under austerity measures) are trying to paint a picture where “Disability Pride” advocates do not want to be cured because they enjoy forcing other taxpayers to care for them financially. They are portrayed as lazy and liars. These portrayals force disabled people into uncomfortable positions of having to enact self-preservation through the public embracing of attitudes from the medical model of disability rather than the social model.

The concept of being a burden historically has been dangerous. In a blog post in response to the attempted murder of an Autistic child named Issy Stapleton, Sequenzia said the idea of

someone being a burden can cause acts of violence against Autistic people. Sequenzia (2014, Nov. 1, para. 1) said the apologists argued that “every parent of an Autistic child as ‘difficult’ and ‘violent’ as Issy should understand the urge to murder the child.” Sequenzia said the media decided they should give the attempted murderer a broad platform to demonize Issy, and all Autistic people, with the assumption that the victim has no thoughts or feelings at all about what happened to them. The idea of the poem is to tell people what it might be like to be Issy. This connects to the example of the Third Reich labelling people as “Useless Eaters.” Mostert (2002, p. 155) said:

The idea of societies disposing of people with disabilities was hardly new at the dawn of the 20<sup>th</sup> century. There is ample evidence that both medical and legal debates across Europe, including in Germany in the 19<sup>th</sup> century, included fatal solutions for inmates of asylums and others with physical, emotional, and intellectual disabilities. These historical attitudes gathered momentum, however, in the late 19<sup>th</sup> and first half of the 20<sup>th</sup> centuries. For the Nazis, the first approach for dealing with disabled people was to forcibly sterilize them, so there would be no chance their genes would continue to circulate in the country's gene pool. Eventually, the Nazis turned to deadly solutions. The Aktion T9 campaign set about killing people considered burdens to the state. Unlike the murders of Jewish people, which were not widely resisted (although it is argued this was because many people did not understand that it was happening), the Aktion T9 project was hotly debated (Mostert, 2002, Scheffer, 2018). According to Co-director of the Institute for Disability and Bioethics Mark Mostert (2002), Jurist Karl Binding and Psychiatrist Alfred Hoche made an economic argument. As Mostert (2002, p. 157) interpreted, Binding and Hoche believed disabled people “were ‘useless eaters’ whose ‘ballast lives’ could be tossed overboard to better balance the economic ship of state.” Mostert (2002, p.

157) said that Binding and Hoche explicitly called for killing people who had no will (agency) or sense of living. They believed the right to live was earned, not assumed, and could not be earned if the person could not contribute economically to society. The perception that disabled people must earn their humanity by proving their economic usefulness to the capitalistic project stemmed from the assertions made by people like Binding and Hoche. How does this dehumanize those who cannot contribute to capitalism? How might challenging the idea that someone's humanity is contingent upon their ability to contribute to capitalism help rehumanize them?

As shared by Mostert (2002, p. 157), Binding and Hoche said the following about disabled people:

Their life is absolutely pointless, but they do not regard it as being unbearable. They are a terrible, heavy burden on their relatives and society as a whole. Their death would not create even the smallest gap—except perhaps in the feelings of their mothers or loyal nurses.

Binding and Hoche further indicated that disabled people could not be trusted to perceive their own life's worthiness accurately. This reminded me of ToM's insistence that Autistic people cannot be trusted to understand their perceptions about other people, essentially saying they cannot trust their own minds. As I already indicated though, the Aktion T9 project was widely contemporaneously criticized by German people. However, the debate was muddied by the viewpoints of those closest to the subject, other than the disabled people themselves. Parents did not voice the same objections that other Germans were widely voicing at the time. Mostert (2002, p. 157) said that the Director of an asylum in Saxony, Ewald Meltzer, believed their charges enjoyed their lives despite their challenges. This made me think about how the bloggers in this study expressed frustration and fear regarding the centring of allistic parental voices when autism

is being discussed. I have found that if I am part of a discussion where a parent of an Autistic child is involved, and that parent holds negative views of autism, allistic people involved in the discussion will acquiesce to the parent even when I voice disagreement. Meltzer, unfortunately, centred the perspectives of parents of disabled people in their attempt to support their assertion. Presumably, it did not occur to Meltzer that they could consult the disabled people directly. Meltzer surveyed their patients' parents to find out their opinions about euthanasia. This survey indicated that although they felt emotional connections to their children, they also expressed various positive attitudes toward killing them (Mostert, 2002, p. 157). This probably helped prolong the Aktion T9 project despite wider criticism.

### **4.3. Masking**

#### ***4.3.1. What Is It?***

All the bloggers wrote about masking aspects of autism as a strategy to achieve the appearance of neurotypical normalcy. Decosta (2018, Sept. 10, para. 1) defined masking as “passing as allistic, either as a means to an end, or out of necessity.” Sometimes masking is something that an Autistic person does without being consciously aware. Other times, masking is something Autistic people are trained to do. Uninspirational (2018, Mar. 29) said they have been accused of being a bad parent because they would not subject their child to interventions to teach them how to be normal. Uninspirational (2018, Mar. 29, para. 7) said, “It’s controversial to treat your Autistic kid with respect. It’s controversial to protect your Autistic kid from harm and teach them that they are fine, just like they are. It’s controversial to point out their humanity.”

Kitin Miranda (2018, Aug. 8) said that they masked when they were younger because they wanted to be accepted by their classmates and friends. Ira Kraemer (2018, May 20, para. 16) said, “Some days I cannot tell whether I am being my mask, ‘being a person,’ or being me.”

Referring to post-structuralist theory, McVittie told me a post-structuralist's answer to this question would be: The person is the mask. McVittie (2021, Jul. 14) said, "Whoever you are when you are 'wearing' the mask is who you need to be, and who you can be. You can (and need to) put on other masks in other situations." These are one's multiple selves. The constant need to put on these kinds of masks is the real problem. Kraemer (2018) said being a person was an act they put on to cope, wasting their life wondering if they were human. They wrote about the ways they have described themselves over the years; descriptions including being a bit different, an alien, a robot, a little strange, and a ghost. The author expressed concern that they were not human in all of these. The language Kraemer used implied they do not identify with being a human, but how they feel about this is unclear. This contrasts with Leong's much less ambivalent feelings about their humanity. Leong wrote in blogs, including *human* (2020, Jun. 24) and *non-essential* (2020, Jun. 16), about feeling ashamed of being a human. They expressed a preference for imagining a future where humans and non-human species are viewed more as peers, each in a position to teach the other.

Decosta (Masking, 2018, Sept. 10) discussed several masking facets. The first and second facets they list are similar: "Camouflaging" and "Passing." They defined camouflaging as adopting a role to fit in. They defined passing as presenting themselves specifically as neurotypical to fit in. Sky (2017, Apr. 1) characterized passing as the accommodations we make for allistic people. Miranda (2018, May 22) said that people generally want to feel like they belong and are accepted by society. This requires more work from Autistic people because the non-Autistic world does not meet Autistic people halfway. Miranda (2018, May 22, para. 1) said, "We tend to rely on a coping mechanism called "social masking" or camouflaging in order to keep up appearances." Miranda said that the process of social masking is exhausting for Autistic

people. Still, they do not feel they can stop using the strategy because it is their only option to blend in with their colleagues and friends.

The third strategy Decosta (Masking, 2018, Sept. 10) discussed was what they called “Compensating,” more commonly referred to as “Scripting.” Decosta (Scripting, 2018, Sept. 25, para. 1) defined scripting as “making your way through a conversation based on memorized interactions.” They pointed out that scripting was a common part of social skills training for Autistic people. Decosta (para. 8) also said, “Sometimes, scripting (if possible) is necessary to avoid getting harassed, arrested or worse, but that’s not necessarily the same as doing it because it’s getting you something you want or need, past ‘surviving the moment.’” The final strategy Decosta mentioned was “Mimicry” which they defined as taking on a new persona to fit in.

Leong (2012, Jul. 22, para. 1) said:

I know many Autistic people, extremely high functioning, who have finely honed skills in NT mimicry. Yes, we do it so well that nobody would know we are Autistic, if we didn’t self disclose. So, does this level of successful self intervention strategy work for us, or against us? Because we are so ‘normal’, everyone presumes they understand us perfectly.

How, then, do we ‘frame’ our autism? As a disability still, or as a hyper ability?

Miranda (2018, Aug. 8, para. 4) said, “Masking, in my experience, means knowing what exactly to do in particular social situations, knowing what exactly to say and what not to say, what behaviors are accepted and not accepted, and ‘putting on a face’ depending on the situation.”

Maybe I am being too literal, but I have never felt like masking gave me a sense that I knew what to do. For me, it was a best guess. It was implementing a set of observations in a situation that seemed appropriate. The blogger said the masks they put on differed depending on the situation.



Miranda (para. 5) said, “Doing this allowed me to not only be socially accepted at those moments, but it also allowed me to ‘survive’ in a way.”

Most people engage in social mimicry to some degree. For example, they might change the way they dress to fit into certain environments. They might refrain from speaking about certain topics of interest to them in certain crowds. People engage in this social mimicry to be perceived as acceptable to others. However, when Autistic people engage in social mimicry, it is more intense and harms the Autistic individual’s well-being. In my experience, the more I do it, the more being normal feels unattainable. This is particularly true when I have been trying to fit in and seem normal for a long time but still have the same outcomes. However, the fact that allistic and Autistic people engage in social mimicry for the same reasons to different degrees is something they share. That makes it a location of potential exploration that holds the possibility for opening wider ways of being human that might benefit all.

#### ***4.3.2. BIPOC Autistics***

All the bloggers in this study wrote at least once about something that fell at the intersections of disability and race. Decosta, Hammond, Leong, Grace Liu, Miranda, and Sequenzia were most prolific in their writing on the topic. For these writers, all of their blogs included something about the intersection of disability and race. However, that does not mean they were consistently writing about how race added another layer of dehumanization to what they already experienced as a disabled person. Hammond was the most prolific on this topic.

Sequenzia (2016, Aug. 30) said that disabled people are underrepresented in media and popular culture, often perpetuating negative stereotypes when the subject of autism is included. Sequenzia said that when an Autistic person is included in an event or as a central character in popular culture, they are often well-educated and employed. Sequenzia (2016, Aug. 30, para. 6)

said that while such Autistic individuals deserved recognition and praise, they wanted to focus on less visible Autistic people: The ones who do not finish school, cannot consistently control their bodies, communicate in atypical ways, require assistance in most tasks, need time to organize their thoughts and type their messages, do not look ‘pretty,’ act ‘weird,’ are not considered ‘successful’ by ableist standards, and are BIPOC (particularly when black). Interestingly, being BIPOC was at the end of Sequenzia’s list of Autistic people who are relatively invisible in popular culture, as if everything on the list that proceeded applied to BIPOC Autistic individuals. Looking back on Professor of Disability Counselling Joy E. Weeber’s (1999) view that the pain of ableism was the same as the pain of racism, this makes a lot of sense. Professor of Agriculture David J. Connor, Professor of Inclusive Education Beth A. Ferri, and Assistant Professor in the Department of Special Education Subini Ancy Annamma (2016, p. 10) said historical beliefs about race and ability that were based on White supremacy have become intertwined, leading to situations such as segregated special education classes being filled with poor and BIPOC students. Connor, Ferri, and Annamma (p. 10) said, “A disproportionate number of non-dominant racial, ethnic, and linguistic students continue to be referred, labeled and placed in special education, particularly in the categories of Learning Disability, Intellectual Disability, and Emotional Disturbance or Behavior Disorders.” For young people who grew up seeing a disproportionate number of BIPOC youth isolated in special classes, this would subconsciously reinforce negative stereotypes that causally linked disability to race, perpetuating the cycle of disproportionate numbers of BIPOC youth being labeled and isolated in special education classes.

Hammond (2022, Sept. 24) said that their children are not given the benefit of the doubt or extended any grace like white Autistic children might be. The idea of BIPOC children being

constrained by double standards was spoken to by Kraemer as well. Kraemer (2021, Jan. 9, para. 10) said:

It doesn't help that society puts on the layers of constraint if you're an autistic person who's raised as a girl and/or a person of color. The gendered notion that kids raised as girls must be polite at all times is absolutely infuriating, and I witnessed this double standard growing up with two older brothers. I'm sure it's even more constricting for people of color raised as girls and women of color.

Hammond (2022, Sept. 24) said the constraints caused by double standards and higher expectations for BIPOC Autistic individuals have meant they have needed to prioritize their advocacy needs as a family differently than the "Majority" of the Autistic community. Hammond (para. 17) said, "I am not safe enough in this world to be as free as 'Autistic' would afford me. I cannot let go of masks when I still code-switch. I cannot be free to stim when this skin is considered maladaptive." Sequenzia (Grading people, n.d.) talked about the idea of parents being unwilling to let their disabled children make mistakes, which reminded me of Hammond's insinuation that black parents cannot afford to allow their children to make mistakes, because black children are not given the benefit of the doubt. Of parents who always made sure it was mentioned that their child was "High Functioning," Sequenzia (Grading people, n.d., pp. 14-15) said they "don't allow the children to make mistakes, or act in any manner that appears to be how they say a "lower functioning" person would act." When taken up by Autistic people, this attitude has come to be known as "Aspie Supremacy," making one think of the term "White Supremacy" and what the attitudes might have in common. It shines a light on how disability and race were co-constructed, thus making the concepts of ableism and racism co-constructions.

This relationship is particularly evident when disabled people use racism to explain ableism. For example, Sequenzia (Autism rights are human rights, n.d., para. 6) said:

You don't have to be an American to know how black/African-American people were openly ostracized, hated, denied basic rights and dignity, and murdered. In the eyes of many privileged whites, blacks/African-Americans did not belong, they were not accepted, they were part of a lesser group of human beings. And this assumption was simply because of who they are, because of their identity....

They went on to use this as a comparison to the way disabled people are treated. Sequenzia (para. 10) added:

The sad comparison continues: we are tortured, restrained, made fun of, called "retard", "weird"; we are ignored in conversations about us; we are excluded from participating in events about us; some people resent us when we speak up. We are said to be fakes, not really Autistics, or too incompetent to have an opinion.

Kraemer (2021, Jan. 6) talked about the unconscious comparisons that happen all the time because of the existence of the contrastive identification of us *against* them that was mentioned by Psychologist James Valentine (p.2). Kraemer said that it can be difficult to talk yourself up, for purposes of things like job interviews or just for self-esteem, when you are pushing against the weight of the standard, default, or normal. Kraemer used the difficulty of being body positive when your racialized body type is compared to the invisible standard of white women's bodies as an example. Again, this intertwines the pain of ableism and racism.

Decosta (2018, Oct. 1) discussed the "Take the Mask Off" campaign on Twitter. They said it started with important narratives about the health risks of masking and other Autistic identity affirmations. Decosta (2018, Sept. 10, para. 3) said "it also was very white at some

points, in terms of presenting masking as something to aspire to (which I agree with) while not talking about the risks in doing so for Autistics of color.” Hammond also wrote about how campaigns that appear on social media often exclude voices that have a different take on the issue. Hammond said the problem often is worse than being excluded. They said that when the majority takes up a cause, they tend to conclude that anyone who does not take up their cause quickly and with gusto is their enemy. Decosta said this was quickly addressed. It would be interesting to know if there were people who would not agree, like possibly Hammond.

Decosta (2018, Sept. 10, para. 4) said that sometimes “masking is seriously (and violently) gatekept for neurodivergent people of color, and at times, white and light-skinned passing Autistics as well.” The blogger suggested that if we can create safe spaces to unmask for multiply marginalized Autistic people, we should be doing it. The blogger suggested one of the easiest ways to help other Autistic people unmask is to meet their needs. Decosta said that with people who were interested in helping their needs be met, it didn’t seem to matter if they didn’t understand what meltdowns were or didn’t like the impression they made. There was at least a basic understanding that they were human. They described people in their lives who wanted to help meet their needs during times when they had episodes of selective mutism or echolalia. Decosta said that in some ways the help some people offered was ableist. However, it was not ableist in a way that denied their humanity.

A viewpoint expressed by Senior Researcher Elizabeth Mendoza, Director of Academic Assessment Christina Paguyo, and Associate Dean of the School of Education Kris Gutiérrez (2016) spoke to me. Mendoza, Paguyo, and Gutiérrez (2016) referenced Historian Vine Deloria (1999), saying that White American identity is incomplete and defined by the distance they create between themselves and the other. They (p. 80) said Deloria, “defined White American identity

by what she perceived it lacked: culture.” I have worked for years in Dene communities in northern Canada, teaching English literature. I would read a story called “Welcome to your authentic Indian experience” by Rebecca Roanhorse with my students. The story is about an Indigenous man who works for a virtual reality company that offers people the chance to have an “authentic Indian experience.” He encounters a client who begins to insinuate himself into his real life. I will not say more about the details of the story because I do not want to give you spoilers. In any case, the theme of the story involves cultural appropriation. When I would read this story to students, I would give them context by showing them newspaper articles about a real event that helped inspire Roanhorse. Rebecca Roanhorse had read about a “self-help guru” who caused the death of some people who paid thousands of dollars to be part of their training, which included a sweat lodge that was run very irresponsibly. The people died of overheating and shock. I would start a discourse with my students about why these people would pay so much money to consume Indigenous culture in this manner. My students almost always responded the same way. They would tell me their grandparents had told them to feel sorry for white people because they were lost. Their grandparents had told them that white people do not have culture, so they must try to buy and consume other people’s cultures. I find it ironic that according to Deloria (1999), White people use othering to separate themselves from BIPOC individuals. Yet, it is the existence of BIPOC that ends up defining them by revealing what they lack.

Mendoza et al. (2016, p. 80) said White Americans were privileged to retain individualism, rather than being defined by group identities; a privilege denied BIPOC people who are viewed as monolithic. BIPOC are lumped together as one group, losing their individualism. The same is true of Autistic people. Those with intersecting marginalized identities would experience this acutely. However, this made me cast my mind back to what

Psychologist Michael Tomasello and co-authors (2005, p. 676) who said, “We propose that human beings, and only human beings, are biologically adapted for participating in collaborative activities involving shared goals and socially coordinated action plans (joint intentions).”

Suppose one combined the thinking of Tomasello et al. with that of Mendoza et al. (2016). In that case, they might conclude that the actions White people take to distance themselves from BIPOC individuals actually results in their own dehumanization, since not being part of group goals and socially coordinated action plans.

#### ***4.3.3. The Cost of Masking***

Another important aspect of masking that the bloggers talked about was the cost of masking. All of the bloggers wrote about aspects of masking. Thus, it makes sense they also wrote about the effects of masking. endeaver\* (2019, Apr. 5) said that years of masking, passing, and fitting in were detrimental to their health. Autistic meltdowns and burnout are part of the costs of masking. Co-director of the Academic Autism Spectrum Partnership in Research and Education Dora M. Raymaker (Autistic burnout, n.d., Stimpunks, para. 1) said:

Autistic burnout is a state of physical and mental fatigue, heightened by stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs.

Uncultured Anthropologist (2019, Oct. 11) listed their burnout triggers as habitual overextending, interconnectedness-of-all-things-thinking (which is a Dirk Gently reference), lack of sleep, letting anaemia kick in, and not taking care of themselves. They also talked about the burnout they have gone through because of their experiences in academia. They listed the signs of burnout as follows: lack of motivation, loss of executive functioning, difficulty with self-care, meltdowns,

loss of speech, physical exhaustion, digestive issues, illness, memory loss, inability to mask, increase in stereotypical Autistic behaviours, and a period of manic energy followed by a collapse. They listed the causes of burnout as follows: passing as neurotypical/masking, doing too much, stress, aging, changes, sleep deprivation, poor diet, dehydration, illness, and sensory overload.

Sky (2017, Apr. 1, para. 30) said, “Burnouts, meltdowns, and shutdowns are the results of sustained “passing,” even when done successfully, because of the sheer amount of energy it takes to maintain even a minimally acceptable autistic façade.” Miranda said that Autistic meltdowns are often misunderstood. They said that in high school they believed the narrative that their meltdowns were just tantrums. However, as their education about autism expanded, they understood that meltdowns were a response to overwhelming situations. Miranda (2018, Jan. 23, para. 1) said, “A meltdown happens if there’s too much sensory or external stimuli, too many unpredictable things happening at the same time, or if there’s too much emotional or information overload.” Miranda said that tantrums are enacted for a reason, generally to draw attention. Once that goal is reached or it becomes clear the goal will not be met, the person stops enacting the tantrum. The same cannot be said for an Autistic meltdown. A tantrum would naturally depend upon being observed for its continued existence. An Autistic meltdown will happen regardless of whether it is witnessed or acknowledged by an outside observer. Miranda also said meltdowns will differ across age groups, situations, and individuals. There is one thing Miranda says is consistent about Autistic meltdowns that are not shared by tantrums. Miranda (para. 12) said, “One thing is sure for me though- no matter what kind of meltdown it is, once it is going, there is no stopping it.”



One of the costs of Autistic burnout talked about by Stimpunks was regression and stalling. Autistic advocate Cynthia Kim (2013, Dec. 19, para. 21) said that being Autistic requires constant adaptation, but sometimes our ability to cope is overwhelmed. This causes regression and the loss of skills. The kind of regression and loss of ground described by Kim is not only caused by Autistic burnout, but when Autistic burnout happens, it almost always comes with regression and loss of ground. These periods of Autistic burnout result in a loss of executive function that can impact an Autistic person's ability to hold a job. This causes Autistic people to experience high levels of unemployment and underemployment. Those going through Autistic burnout experience chronic fatigue (Raymaker et al., 2020). They might also experience loss of memory, appetite, skills, and language in the form of selective mutism. Author Jorn Bettin (2018, Jun. 30, para. 47) said, "When autists attempt to blend in it is to avoid suffering the consequences of non-conformance – and not to gain or maintain social status." Autistic burnout is one of the costs of masking, which is the attempt to avoid the negative consequences of non-conformance. Bettin (para. 4) said:

Autistic people must take ownership of the label in the same way that other minorities describe their experience and define their identity. Pathologisation of autism is a social power game that removes agency from autistic people. Our suicide and mental health statistics are the result of discrimination and not a "feature" of autism.

This is relevant because suicidality and poor mental health are also part of the negative consequences of Autistic masking. Bettin suggests that this will only change through Autistic people owning how they are labelled and named. There are recent studies by autistics and allies beyond Raymaker that might be good to be aware of/cite if you want.

#### 4.4. Gender and Normativity

Decosta, Ekins, endever\*, Forshaw, Kraemer, Leong, Liu, Miranda, Queer Disabled Writers, Sequenzia, Seventh Voice, Uncultured Anthropologist, and Uninspirational wrote about gender and normativity. The idea that gender is completely different for everyone is reflected by more than one of the bloggers in this study.

endever\* (2018, Nov. 10, para. 1) described their gender as autism, saying “This is not a singular noun that names something I ‘have,’ this is one of the adjectives that describes my gender, because it is one of words that describes me as a whole.” Some other words they named as part of their identity were “Trans” and “Non-binary,” saying that their gender does not fit into normative social expectations associated with womanhood and manhood. The blogger said that sometimes when they watch a group of men and women interacting, they feel like another species or an alien. The blogger cannot make sense of their body language, the invisible dialect that runs between them alongside their verbal language. endever\* (para. 7) said:

Neurogenders are genders specific to neurodivergent people whose experience of gender relates to their neurotype or who feel they can’t fully understand gender due to their neurotype. So one of the words I use to describe my gender is neuro-enby.

Enby is short for nonbinary. The blogger’s idea of neuro genders and how they define them is very inclusive and respectful of agency.

Gender is socially constructed in a similar manner as disability and race. Jack (2014, p. 183) supported this, saying that neurodiverse perspectives may challenge gender norms and offer new insights into how gender is socially constructed. Jack (p. 13) interpreted Gender Studies Author Judith Butler as saying, “Gender, Butler reminds us, is constituted differently in different historical contexts, and it always intersects with other ‘modalities of discursively constituted

identities' such as race, class, sexuality, region, and ethnicity." This makes gender and normativity relevant to the study of the intersection of marginalized identities.

Forshaw made a fascinating comparison between body dysmorphia and changing your neurology. Forshaw (2016, Apr. 11, para. 2) said:

It's like body dysmorphia projected onto the ego, the sense of self. The antithesis of neurodiversity's principles; an inability or refusal to accept one's differences. I see this as a result of thinking coloured by the medical model of autism that sees it in terms of pathological deficits, as opposed to the social model which instead looks to society's failures to provide suitable accommodations and acceptance as the causes of disability. The comparison between seeking a cure for autism and dysmorphia is fascinating. Social and traditional media are flooded with hateful speech toward trans people. Yet so much of society believes that Autistic people should stop being Autistic (or stop existing). Forshaw (2016, Apr. 11, para. 1) said:

I don't want to change who I am: I'm comfortable with my identity as an Autistic trans woman with all that entails. Changing my body doesn't affect my personality, my thoughts: I remain me. Changing my mind makes me into somebody else. I would lose the essence of what makes me this particular unique individual, and the thought of that fills me with dread.

It was also interesting to see Forshaw (2014, Oct. 17) talk about gender dysphoria in terms of viewing certain body parts as alien in one of their blog posts, considering frequent comparisons of Autistic people to aliens.

Lecturer in Health and Social Care Nathan Keates, Ph.D. Student Eleanor Dewar, and Assistant Lecturer Krysia Emily Waldock (2022, p. 50) said that current research into trans

people with intellectual disabilities assumes their gender dysnormative behaviour is another symptom to be managed. The Autistic bloggers in this study do not see aspects of their intersecting identities to be symptoms of their disability, to be managed medically. Decosta (2018, Jul. 8) discussed the “Queer/Trans Autisinal Intersect,” saying that for themselves, autism and queer/transness blur together. Decosta (para. 1) said, “It’s \*all\* part of the same fabric of oppression, teasing it out in terms of what happened diagnostically is murky at best.” They said that everything in their life seemed focused on intervention. Decosta (para. 3) said, “Autism, queerness, transness, problem behavior, asocial behavior, all the same tapestry of ‘stop doing that.’”

Queer Disabled Writer (2013, Aug. 5) said they found queer to be a compliment because it connects them to a rich history of rioters, anarchists, computer programmers, soldiers, scholars and people who found love in unlikely or forbidden places. They said that like many reclaimed words, queer has pride built right in. Queer Disabled Writer (para. 7) said:

Queer is a compliment precisely because as we identify in our desires and feelings and relations, a distinct alienation in regard to the world of solid gender and sex ideas, we find a multiplicity of performances which excite and confuse our sensibilities.

On the other hand, queerness is a marginalized identity that puts queer people in the position of stretching their physical, mental, and emotional resources to advocate for themselves and survive in a hostile society. Ekins (2017, Jun. 7, para. 29) said:

Every morning, I awake to a world of dread. I am tired. There are deeper battles that should be being fought, battles for smaller and vulnerable oppressed communities, but the weight of basic human survival is too great to switch focus from.

This emphasizes the negative effects of othering. It also demonstrates how tiring marginalization is on people. This helps us understand why the goals of these groups and individuals become stuck in the quagmire of meeting basic survival needs.

#### **4.5. Labour and (Neoliberal) Capitalism**

All fifteen of the bloggers wrote about employment issues. They also wrote about other labour and capitalism-related matters. Liu wrote a lot about their struggles with employment. Liu (2018, Mar. 25, para. 1) said:

For my 25<sup>th</sup> birthday last week, I asked my mum for a job. Not a massive pile of presents. No party. Just an actual paid job that I could keep for more than one day. Not an unreasonable request, right?

They talked about how they do volunteer work to keep sharp and busy and to distract them from the “soul-crushing” job search process. Leong (Seeing clearly, n.d.) expressed frustration with the advice that volunteer work would make their resume look more filled out. Leong (para. 9) said:

When I asked for an honorarium to speak at events, I was told variously that I should be grateful for the “exposure,” or that I should work for the benefit of my “own community,” or that experienced artists should give talks without payment to “inspire” young people. Strangely enough, these people were paid to do their jobs in whatever enterprise they represented.

Leong said that this experience reinforced for them the principle that disabled people need to be included and paid for their involvement in disability advocacy. As for paid employment, Leong (threat, n.d., para. 3) said:

employment that allows us to execute our strengths and talents is at best an uphill scramble. In some ways, people with disabilities are all the more abled, plainly because they have to overcome so many challenges in order just to exist.

Sky (2016, Sept. 10) said that the stigma around autism affected their ability to be employed because of how they had assimilated the stigma into their sense of self. Sky said they had assimilated the label of “Failure” into their sense of self from their parents. Sky (2016, Oct. 4) said this sense of failure was reinforced by their inability to hold a job for more than a year before they were totally burned out.

Stigma perpetuated in popular culture plays into how employable Autistic people are, according to Sequenzia (2015, May 26). Interestingly, Sequenzia pointed out that one stereotype that has disproportionately made Autistic people raised as boys more unemployable was the label of “loner.” Sequenzia said this term has become coded language in the media to refer to people who are a risk of becoming mass shooters. Sequenzia (2015, Oct. 17) said that although only 5% of gun related crimes are committed by people with mental illnesses, the stigma that people with mental illnesses are threats causes a lot of harm. Sequenzia (para. 17) said:

There is already too much stigma and poor people without family or community support face bias and threats like losing custody of their children, losing their jobs, being homeless. – even when they are not a danger to others.

Forshaw (2014, Aug. 13, para. 9) said mental illness is so stigmatized that a person disclosing they are mentally ill “can be a sure-fire way to lose friends overnight. It might lose them their employment.”

Liu wrote about how factors like what they referred to as “autistic miscommunication” made gaining and retaining employment more difficult for Autistic people. According to Liu,

their parents believed that Autistic employees should start with longer probationary periods. Liu (2018, Jun. 24) expressed gratefulness they were just able to improve their job performance enough to qualify for an extension of a probationary period at one job, blaming Autistic miscommunication for not passing outright. Liu said that the improvement at work that earned them an extension on their probationary period came at a cost. Basically, Liu had to put in a lot of unpaid labour, practicing certain skills by going in early and staying late. Liu talked about how they felt like being Autistic made them less employable. Liu (2018, Jan. 28, para. 3) said:

I sometimes think that having a learning difference and trying to find a job is the human equivalent of being one of the “less adoptable” pets at an animal shelter, overlooked because they have a medical condition, or are old, or need to be rehomed in a specific kind of environment. And lets face it, having Asperger’s does make some things harder. It also makes other things easier. But it’s the potential disadvantages that most people worry about.

Liu cited the social demands as one of the greatest barriers for Autistic people to maintaining employment. Liu stated that in their experience, both physical and processing speed had been a barrier. Liu would have to ask people to pause when giving lengthy instructions and break it down into smaller segments. Liu (para. 4) said, “Then of course they’d rephrase everything, and I’d have to ask again.” The social difficulties included trouble interpreting other people, contributing to the slower processing speed. Liu said that a lot of the time, the reason they worked slowly was that they wanted to do everything perfectly. Perfectionism or extreme attention to detail is a common trait for Autistic people. Liu suggested that given the right circumstances, various characteristics often related to Autistic people could be considered

positives for employment rather than barriers. For example, perfectionism and the need to follow rules could be considered positives rather than negatives.

Liu (2018, Mar. 12, para. 7) wondered about the dangers of disclosing an autism diagnosis, asking how they could know whether autism would be a social turn-off for their employer, tying back to Forshaw's concerns about stigma and disclosure. Kraemer (2018, Oct. 21) stated that when presented with the question of whether Autistic people should disclose their diagnosis to their employer, the Autistic community is divided. Kraemer said the advice on whether to disclose to an employer that you are Autistic generally came down to how much you trusted the person to understand autism through the social model of disability. Kraemer's opinion on whether to disclose was less divided than the community's. Kraemer believed disclosure was a lose-lose situation for Autistic people, saying that not disclosing could make Autistic miscommunication worse, since people would tend to misread your body language and tone and assume the worst, seeing you as anxious and deceitful. Kraemer (para. 5) said that, on the other hand, if you disclose:

These same people who may think of you this way, when you mention the word “autism” or “autistic” to them, may then assume you lack Theory of Mind, so you cannot understand other people's feelings, intentions, or social cues. They may think that you must not feel much emotion. They may assume that because you are autistic, you are incompetent at even simple tasks. They may talk down to you, as if you are a child. They may also assume (implicitly) that your opinion is not as important as someone else's, due to potential “theory of mind” problems or potential communication problems.

While such a dominant negative paradigm of autism remains, disclosure continues to be a risk.

On the one hand, we cannot move forward as a society if people do not push back against the



negative paradigm. However, Autistic people's ability to be employed is precarious and generally cannot withstand the notion of Autistic candidates challenging potential employers to do better. This is a situation where allistic employers, having less at risk, need to take more initiative to make their work environments safe for Autistic people to disclose their diagnosis.

The need for assistive technology is of particular importance for Autistic people. For many Autistic people, it means the difference between claiming the assumption of competence and agency or being treated as if they are in a permanent state of childhood, as burdens, or as products. Social Psychologist Devon Price (2022, p. 93) (Autistic) said they masked so they would not seem childish. This made the need for assistive technology difficult because self-sufficiency is expected of people once they are no longer children, even though all adults depend on the hard work of others around them for myriad things every day. Price (2022, p. 93) said, "You're only seen as less adult, and supposedly less of a person, if you need help in ways that disrupt the illusions of self-sufficiency." How might the lives of all people change if we were allowed to depend on others without facing ridicule or condescension?

Sequenzia (Real consequences, n.d.) wondered if the people attaching defeatist descriptions to Autistic people have considered how investments in assistive technology and education would help Autistic people be more productive. Sequenzia implied that the focus appeared to be more on freeing parental time to be more productive. Perhaps this is because, as endever\* (2018, Nov. 28) suggested, when disabled people use assistive technology, it is thought to only lift that person's potential for productivity to a basic functioning level. This often still does not include the potential to contribute to capitalism through their labour, which is what it is all about. Ekins (2017, Nov. 14, para. 2) said:

I am aware that the fact that I have managed to be in almost continuous employment since I was sixteen; even if those jobs were difficult, and even if I struggled in those roles, the fact that I was able to be one of the only 16% of Autistic people in full time employment makes me a lucky person.

Ekins questioned if they would still hold the same value in society if they were not part of the 16% of Autistic people with full-time employment or did not have a post-secondary education. They admitted that other aspects of their life do not set them up as a typical success story without employment.

Queer Disabled Writer (2014, Jun. 25) expressed concern that access is often left out of key disability policies such as the ADA [Americans with Disabilities Act], generally only used to reference the most obvious physical manifestations of access, such as wheelchair ramps. They said that policymakers try to replace the concept of access with that of independence. Queer Disabled Writer said disabled people are supposed to obscure their real needs for optics. They are supposed to pretend they don't know how disability designates one's body and psyche as different, placing them in a group and removing their right to be seen as an individual. To regain their individuality, disabled people are sometimes required to channel their identity through whiteness or class. This isn't necessarily done for the purpose of wielding social power. Rather, it could be done to gain access through social power. However, this channelling of identity through whiteness or class might inadvertently cause the further marginalization of others.

Queer Disabled Writer (2014, Jun. 25) said that when policy includes access, it isn't done for the purpose of supporting disabled people. Queer Disabled Writer (para. 5) said that its "function is not actually to support disabled people but often either to make money from disabled people (and fuel the social services and healthcare industries), to make it look like the

government is supporting disabled people or to normalize disabled people.” They said that in many cases, it appears as if accessibility is designed only to meet the standard of making centres of power, influence, academics, and employment (etc.) accessible rather than being accessible in ways that are not surface level. Accessibility that would support Autistic voices in the political process is not a priority, according to the Queer Disabled Writer.

Post Graduate Researcher Kerri Betts et al. (2023, p. 61) (including Autistic Research Fellow Anna Stenning and Autistic Graduate Student in Neuroscience Alyssa Hillary Zisk) said:

However, alongside these narratives of disempowerment, the necessary shift to remote working meant accommodations that had seemed impossible or impractical prior to the pandemic were suddenly found feasible. Accessible technology and home working and studying became a requirement for the abled majority, and, through this fundamental reconfiguration of labour models, many found these pandemic adaptations enabling. As workspaces became online spaces in this unprecedented moment of lockdown, the possibilities for fostering community, cultural life, and connections with others from across the world seemed more tangible.

I saw the bloggers in this study express frustration that what has been a consistent barrier to their employment, the difficulty working in certain environments, was so quickly and eagerly overcome when it meant keeping allistic employees working during the Covid-19 pandemic. They wondered why society was so willing and able to accommodate people for work-from-home during the COVID-19 pandemic when they have rarely been willing to accommodate disabled employees so they could do this all the time.

Assistant Professor of English Melanie Remi (Yergeau) (2018, pp. 49-50) said that Autistic bodyminds become seen as forever works in progress in need of intervention to gain

functionality. Remi (Yergeau) said that the gradations of the concept of functionality entrap them in a cycle of being seen as economically unworthy until they undergo interventions that benefit stakeholders in the economy that rarely include themselves. Autistic bodyminds being considered in need of treatment and cure keeps them trapped in a capitalistic system where they are the products of a service industry. What consequences would there be to the capitalistic service industry built around Autistic bodyminds if they were thought of as uniquely whole? What changes would be enacted in the ways Autistic people could exercise agency within this service industry?

Raymaker et al. (2023, p. 65) (with Autistic researchers Dora Raymaker and Steven Kapp included) said, “Autistic people experience disparities in employment which may be exacerbated for individuals in skilled employment. Little is known about the experiences of autistic people in skilled employment or how they define success.” However, the Autistic bloggers included in this study wrote about their experiences with the disparity in employment. Raymaker et al. (p. 65) said that common themes included: High stakes of disclosure, unconventional pathways to careers, disconnects with service and support systems, mental health challenges from trauma/burnout, autistic advantages in the workplace, and complex dimensions of discrimination. Raymaker et al. (p. 65) said that their study participants defined success as: Opportunities for growth, work/life balance, financial independence, sense of community, and feeling valued, accepted, and meaningful work.

The bloggers echoed the issues outlined by Raymaker et al. I have also experienced some of these issues. I have debated the wisdom of disclosure out of fear of negative impacts, gone without accommodations, had the special advantages I bring to a position overlooked, and experienced being dismissed without cause because of a combination of fear and ignorance.

Retaining good skilled employment is a minefield, in my experience. This perception is supported by the Autistic bloggers included in this study.

Anne McGuire (2013, p. 99) said the connection between a 2007 Autism Speaks campaign and the Starbucks corporation clarified that a relationship exists between autism, advocacy, time and consumption. Capitalism and labour depend upon the concepts of “Products” and “Productivity.” Productivity often measures the value people hold in society. Reflecting on Philosopher Karl Marx (1977, p. 592), Chief Executive of CCS Disability Actions David Matthews (2021, January 1) said:

individuals unable to work due to impairment were often reduced to members of the reserve army of labor. This surplus population constitutes a disposable resource for capital as a pool of potential labor to be exploited when needed that “disability is exploited as a serviceable condition, giving rise to a service economy.

The flip side of the value of a person’s life being determined by their ability to be productive and contribute to capitalism is that if a person cannot meet this expectation, society seeks to assign value to them by turning them into a product. Seventh Voice (2014, Jun. 22, para. 1) said, “The idea of turning ‘care’ into a commodity that can be bought and sold instead of acknowledged as a virtue of the human spirit that can be given willingly, is not a new one.” Doctors, nurses, psychologists, ABA practitioners, social workers, and support workers are all the people who benefit from the care industry. Do not get me wrong. People deserve an income for the work they do. Some jobs portrayed as supportive include aspects of abuse.

#### **4.6. Post Humanistic Possibilities**

Posthumanism argues that technology, objects, nature, and animals all have recognized agency. Several of the bloggers who wrote about comparisons of Autistic people to robots and

animals discussed post-humanistic possibilities in their content: Forshaw, Kraemer, Leong, Queer Disabled Writer, Sequenzia, Seventh Voice, and Sky. Leong particularly seemed to embrace posthuman possibilities. They expressed embarrassment at being part of “the human” and a dejected sense of resignation at knowing they were not safe to reject membership in this group. They went as far as to say that our humanity deprived us of a more universal experience. About being compared to animals, Leong (*human*, n.d., para. 3) said:

But for me, my anger is because those comparisons are derogatory, made by non-autistic people who view animals as beneath humans, and therefore deem Autistics not-human enough. There is another side to this, for me, at least. You see, I am not insulted at all when compared with the exquisite beauty of animals by those who can see what I see. In fact, I know in my deepest core of Beingness that animals are far superior to humans in their elemental purity.

Leong (2020, Jun. 16) said we are so busy being insulted by someone comparing us to animals that we do not stop to realize we do not deserve to be compared to animals.

Leong had a lot to say in more than one article they wrote in reaction to an article written for *Spectrum* magazine regarding the issue of how Autistic people are sometimes compared to animals and robots. Leong (2020, June 16, para. 8) said that we even most Autistic do not seem to recognise work from Autistic researchers such as Dawn Prince-Hughes as a gift for humanity, showing us the connection with animals that Autistic minds could help us learn. I see some truth in what Leong wrote. If we were not so busy being insulted by being compared to animals and robots, we might learn more about our existence. Leong (2020, June 24, para. 5) said that the “field of research by Autistic or non-Autistic researchers is deemed less important than those pursuing the human conundrum.” They said that if humans were less obsessed with humanity,

they might have a chance to realize how many solutions to our problems can be found in the non-human world. An analogy Leong used took me by surprise. Leong (para. 13) said:

that part in the Christian bible that describes how Jesus died – of a broken heart, because the weight of the world came upon his shoulders? It makes me think that Jesus – as he is portrayed – must be Autistic. All the details, every aching screaming excruciating bit of the human world, on his shoulders. Of course, he died of a broken heart.

It is time to stop killing our planet because we think we are above learning from the natural world. Perhaps it is time to stop breaking our hearts because we need to be seen as separate and above animals that could teach us a better way.

The problem is that Autistic people are still compared to animals and robots. I realize this sounds like a contradiction. I mean that Autistic people are still compared to animals and robots within a paradigm that says animals and robots are beneath humans and are not ascribed agency. Autistic people do not have a choice but to fight against such comparisons until there is a drastic paradigm shift in society. Autistic people are already marginalized. They do not have a choice but to fight against any description, attitude, policy, or legislation that might keep Autistic people marginalized or worsen their already marginal existence. Many Autistic people have multiple, intersecting marginalized identities. They experience oppression on multiple fronts. They cannot afford to surrender an inch of ground when fighting for their humanity.

#### **4.7. Summary.**

Naming is essential to identity. Labelling, being one form of naming, plays a huge role in the identity of Autistic people. Labels are not always harmful. However, they become very harmful when they are used to other Autistic people, creating situations where Autistic people are excluded from “the human.” Autistic people who experience a lot of othering in their lives often

express feelings as if they are aliens. Sometimes the othering they experience includes being compared to animals, robots, changelings, and aliens. This intensifies their feelings of dehumanization. However, none of these comparisons are intrinsically insulting. It is the belief of the person labelling Autistic people this way that the comparisons are negative that turns them into insults. For example, Leong suggested that being compared to animals should be an honour. It is only the assumption of people who compare Autistic people to animals that animals are inferior to humans that turns the comparison into an insult. If we were to ascribe agency to other forms of life than humans, it would follow that comparisons such as those mentioned above would stop being insulting. In this respect, embracing post-humanism could help Autistic people rehumanize themselves by pushing back against restrictive notions of “the human.”



## Chapter Five: The Role of Agency in “The Human”

Autistic agency is constituted and reconstituted through robust discussion of autism and disability through the examination of texts produced by Autistic bloggers, and not as an afterthought or addition to discussions of race, class, and gender, although the way these issues intersect with disability is part of the discussion (Erevelles, 2000, p. 32). Erevelles (2000, p. 32) said, “Post structural theory has disrupted humanist notions of the rational, unified, and individualistic subject-agent and has replaced this with the indeterminate subject constituted and reconstituted through language in multiple, imprecise, and conflicting ways.”

### **5.1. Theory of Mind and the Double Empathy Problem.**

Six bloggers in this study explicitly wrote about ToM: Forshaw, Kraemer, Leong, Sky, Seventh Voice, and Uninspirational. Even though not all of these bloggers explicitly discussed the intertwined concept of the Double Empathy Problem, they addressed it by expressing how they felt the misunderstandings were mutual. All of the bloggers wrote about times when they felt like or had been accused of not understanding other people's minds, meaning they all wrote about ToM. Three bloggers in this study wrote explicitly about Milton's Double Empathy problem: Forshaw, Kraemer, and Sequenzia. However, all the bloggers wrote about problems with allistic people not understanding their minds or showing empathy towards them.

Leong (2012, Sept. 28) said that if Autistic people lack a theory of social human minds, then “Social Humans” (as Leong refers to non-Autistic people) lack theory of Autistic minds. Kraemer asserted the same, saying that Autistic people's ToM is measured by how well they interact with non-Autistic people. Kraemer (2018, May 31) also said Autistic people are presumed to have difficulty responding to people correctly because of ToM deficits. On the other

hand, in Autistic people's opinions, the allistic people they interact with often respond incorrectly to them. Non-Autistic people's ToM is not measured by how they interact with Autistic people. Since Autistic people usually interact with non-Autistic people more often, by merit of there being more non-Autistic people in the world, it is fair to say that Autistic people are not as weak in the Theory of non-Autistic Mind as they are sometimes depicted to be. Ira Kraemer made up numbers to illustrate their point. Kraemer (para. 3) said, "Autistic people likely interact with non-Autistic people (or assumed to be non-Autistic) 90% of the time." This number is imaginary because this would be difficult to quantify. However, it illustrates the blogger's perception of how outnumbered Autistic people are by allistics. For most allistic people who do not have Autistic people in their immediate circle, Kraemer (para. 4) said, "Non-Autistic people likely interact with Autistic people less than 10% of the time, and even less of the time are interacting with openly Autistic people (1% of the time?)." Given that the prevalence of autism is difficult to pin-point accurately, the numbers stated by Kraemer are meant to demonstrate the kind of disproportionate interactions Autistic people have with non-Autistic ways compared to the reverse. The point Kraemer made was that given the disproportionate interactions, Autistic people have found ways to understand non-Autistic people and to get along with them at least as well as non-Autistic people have found ways to understand and get along with Autistic people. Therefore, non-Autistic people should not be credited as having theory of Autistic minds while simultaneously accusing Autistic people of lacking the theory of non-Autistic minds.

Liu (2021, Feb. 21) talked about how there are double standards for allistic and Autistic people. They said that when neurotypical people failed to understand Autistic people, it was blamed on Autistic people being complex and confusing. When the tables were turned, Autistic people were told they could not understand other people because of an inherent inability to

understand other people's minds. When non-Autistic people struggled to empathize with how Autistic people felt, it was still blamed on Autistic people. The Autistic person was too unemotional or robotic. In other words, in both instances, the problem was thought to lie within the minds of Autistic people. When non-Autistic people cannot read an Autistic person's body language, they are not accused of being bad at reading body language. Rather, the Autistic person is accused of using inappropriate body language. Autistic people are accused of being unpredictable, rather than neurotypical people are accused of being bad at predicting how we might react to various situations. Liu (para. 8) said:

Many neurotypicals are only willing to bend so far to understand Autistic people better, and are quick to alienate anyone who is different to them. Meanwhile, most of us on the spectrum have experienced constant pressure to adapt to and make sense of other people's social expectations, yet we are the ones who are deemed bad at communicating.

Leong (2012, Sept. 28, para. 1) echoed this: "While I strongly disagree with the claim that Autistics lack empathy, I do agree that we lack the Theory of Mind of the social human world." They said "Social Humans" set the norms that Autistic people are expected to follow. They set the standards Autistic people are measured against. When there is a conflict between an Autistic person's norms and those of social humans, it is Autistic people who are expected to make concessions. Leong (para. 9) framed this capitulation as an Autistic survival method.

While Leong mentioned strategies they have to employ to cope with social interaction with whom they referred to as social humans, Kraemer (2018, May 31, para. 18) suggested that interactions with other Autistic people tended to be easier:

Autistic people have theory of mind for other Autistic people. Neurotypical people have theory of mind for neurotypical people, not for Autistic people. Neurotypicals have a

communication and education issue. We do not have a “theory of mind” issue. I hope non-Autistic people start listening.

This is an expression of the Double Empathy Problem without specifically using that term.

Research Associate in Sociology Elizabeth M. A. Späth and Karin R. Jongsma from the Department of Health in Utrecht (2020, p 75) said that Autistic people’s need for assistance is often taken as an “a priori argument against their potential of be(com)ing autonomous.” They said this is reflected in the conflation of autonomy and ToM. Späth and Jongsma (p. 75) said that ToM seems “to indicate that autistic people do not grasp other people’s goals and intentions, nor that they are able to develop or organize a way of life according to their preferences, goals and interests.” They said that the observation that Autistic children do not appear to grasp others’ intentions and perspectives means that they also do not grasp their own intentions and perspectives. Späth and Jongsma (p. 75) said:

This line of thinking fuels some parents, professionals and advocacy organizations to suppose that autistic people do not actually know what is “good” for them and that their behavior negatively affects others and therefore need to learn certain skills to cope with their environment. This becomes problematic, when interference (denying negative liberty) becomes the default without critical reflection whether that is justified or when the desirability of interference is assumed due to ill fitting with social norms/desirable behavior.

ToM dehumanizes Autistic people, making the necessity of rehumanization even more urgent. If a person is thought to have deficits in ToM, they would also be thought to have reduced agency.

I want to reflect on what Tomasello et al. (2005) wrote about only “human beings” being biologically adapted for participating in collaborative activities that involved shared goals and

joint intentions. If a person believed ToM to be fact, they would also have to conclude that Autistic people were incapable of forming group intentions because they could not understand the minds of others or their own minds. Therefore, this person might label Autistic advocacy as illegitimate. Perhaps this is at the root of the push-back against Autistic advocacy. If that is the case, it is not likely to improve until more people begin to embrace Milton's Double Empathy Problem theory.

Since Autists are considered to lack ToM, they are considered unreliable to be experts on autism. Autistic people having their voices ignored in discourse is a manifestation of this assumption. An extension of this disregard for their voices is having their agency ignored. Autistic researcher Gemma L. Williams (2021, pp. 121-122) said that difficulty with ToM is thought to cause a pragmatic impairment of communication that results in Autistic people being overly literal and focused on surface-level meaning and a failure to "view conversations as a means of modifying and extending the cognitive environment of a conversational partner," resulting in overall difficulties in the realm of social language use.

## **5.2 Denial of Autistic Agency.**

A common concern the bloggers included in this study expressed was the denial of agency. Their discussions of agency ranged from Autistic people being considered permanent children, including not being able to decide for themselves about things like spending their money or getting into sexual relationships, all the way to not being seen as competent to make decisions for their own children. Within this wide range, the bloggers in this study explored many forms of denial of agency.

## ***5.2.1 Parenting Autistic Children and Parenting While Autistic***

### **5.2.1.a. Parental Denial of Agency.**

When it comes to parenting, discussing a stranger's or even our own parenting is easier than discussing our parents in a negative light. This might be especially true of disabled people, who are more likely to require ongoing assistance from their parents. Thus, naming a percentage of the bloggers in this study who wrote about an experience where their parents denied their agency might give a false impression of how many of them experienced this kind of denial of agency. However, all fifteen bloggers included in this study at least once wrote about parents of Autistic children denying their agency.

Sequenzia generally viewed their parents as exceptionally willing to learn how to support them, referring to some early missteps as a "Learning Curve." Sequenzia said that their dad had a learning curve regarding how to support them and advocate for their needs. Their dad's initial participation in advocacy included walks for the cure because that is what people in their circle were doing. Sequenzia (2013, Sept. 9, para. 8-9) said that while feeling out groups to be part of, their parents encountered people who did not seem to give a lot of thought into how Autistic adults felt or thought. However, Sequenzia said their parents pivoted away from such groups and individuals. They wrote about how their mother would affirm their competency with statements like, "Amy can!" Sequenzia (2013, Sept. 9, para. 4) said about their parents, "They created a foundation, employed disabled people; my mom made a series of small documentaries and won an EMMY. My dad got me in the best school available at the time, and he went on helping other families."

Kraemer was an example of one of the bloggers who spoke about some of their experiences with their parents regarding agency. They said their parents never *explicitly* restricted

their agency by controlling their body. However, they said they felt pressured in a way they could not articulate. Kraemer (2018, Jul. 23, para.7) said they felt like they must be to blame for their own masking, since their parents had not specifically told them to mask their Autistic traits. Kraemer (para. 9) said, “No one has to look into your face and tell you to behave differently to change the core of who you are for other people.” Kraemer suggested that you are more easily bent to another’s will when your self-esteem is eroded until you are made more flexible.

Kraemer (2020, Jul. 17) said what they called the “Spoiled Brat Syndrome” was a particular problem for Autistic people raised as girls. They experienced increased pressure to mask their Autistic characteristics, thus, denying them the agency to be themselves. Leong said something like Kraemer. Leong (bunny-contrary, n.d., paragraph 5) said:

My older siblings, mother and teachers all decided that the extreme imbalances of abilities exhibited were due simply to my wilful lack of compliance. Deliberate. I was purposely and purposefully contrary. I would only do what I ‘wanted’ and ‘liked’ to do, and to hell with anything else.

This fits in with what Kraemer called the spoiled brat syndrome, which assumes that the Autistic child does not conform to expectations out of stubbornness and a desire to be contrary.

Not all Autistic people have been exposed to controversial therapies. However, that does not mean they were not conditioned to mask. Leong (heteroclitite, n.d., para. 7) said about the way they were raised:

There was no such thing as ABA or CBT [cognitive behavioural therapy] or whatever else they now have in place to pummel, squeeze and force autistics into the neurotypical molds of acceptable ‘normalcy.’ The methods used on me by my elders was what they used on all children alike. I just happened not to respond in unexpected expected? ways,

because, of course, I was not neurotypical ‘normal.’ That meant that, according to neurotypical measurements, I was a delinquent.

Leong also talked about regaining their Voice (capitalized by the blogger) after many years of feeling it had been denied to them. They said their dad was probably Autistic, which made them relate to each other. However, they had a fraught relationship with their mother. Leong (rainbows, n.d., para. 5) said their mom once said, “Do you think I ever wanted a child like you?” Leong (para. 5) commented on this experience, saying:

How is it logical that one could genuinely feel any real love, acceptance and loyalty towards anyone else if one hates the other’s intrinsic qualities that make them who they are? This is not the same as hating a poor decision or a crime the person has committed. Eg. drug abuse, criminal behaviour etc. People with disabilities and of diversity do not choose to be the way we are. Our diversities ARE intrinsic and part of who we are.

Leong wrote about how their mother trained them to disregard their sensory experiences. Leong (missing?, n.d., para. 5) said:

What was going on? Every hypersensitive fibre in me began to scream the usual silent scream. I wanted to flee. But the part of me that has been so trained to disregard my own sensitivities as ‘bad,’ the way my mother viewed them, the way I was forcibly brainwashed into perceiving my innate idiosyncrasies. Hence, I once more coerced myself to stay.

Feeling as if their mother had conditioned them to disregard their sensitivities negatively impacted the relationship Leong had with their mother.

Through years of being taught to disregard their sensitivities, Leong was conditioned to take up the work of denying their own agency. This kept Leong at a job (the subject being



discussed in the quotation) far longer than they might otherwise have stayed. Kraemer echoed Leong's experiences of being taught to disregard their sensitivities. Kraemer (2020, Jul. 17, para. 21-22) described being gaslighted with statements like:

“It’s just a little wound. Are you going to be a big girl about it?”

“It’s not that bad. You’re just trying to get attention.”

“No, it’s not that hot. Eat it already.”

“Princess and the pea,” said with scorn.

“You’re such a little manipulator/drama queen/princess.”

Once again, Kraemer points back to the gendered aspect of what they called the spoiled brat syndrome. This kind of gaslighting, according to Kraemer, is more commonly directed at Autistic people raised as girls than those raised as boys.

It is important to note that Leong also wrote many posts about how they were repairing their relationship with their mother before their mother passed away. Leong expressed wishing they had been given more time to do this work.

There is a difference between helping and protecting your Autistic child and restricting their attempts to grow their capacity for exercising agency safely. Non-Autistic children are more often allowed to take risks and make mistakes. Autistic children should be allowed the same. I know that as a parent, it is particularly difficult to allow these capacity building exercises when your child is sitting at the intersection of multiple marginalities that all place them at higher risk of victimization. When your child is Indigenous, queer, raised as a girl, and Autistic it can be incredibly difficult to allow them to take risks. That is why you cannot avoid “The Talk” about how to be safer in an unsafe world with your Autistic children. It is like saying you never intend to allow them to be on their own in the world.

### **5.2.1.b. Parental Violations of Autistic Children's Privacy.**

Three bloggers in this study explicitly expressed concern about how parents of Autistic children spoke about their children in public forums, specifically expressing concern about the privacy of Autistic children. These bloggers were Leong, Sky, and Sequenzia. To be fair, they said that parents also violated the privacy of their non-Autistic children online. However, they suggested that exposing private information about Autistic children could potentially have more long-term implications for Autistic children than privacy violations would have on non-Autistic children.

The three bloggers in this study who explicitly wrote about parental violations of their Autistic children's privacy suggested that how parents spoke about their children in public forums often influenced the perception of Autistic people. Sky (2018, Mar. 9) expressed concern about how parents of Autistic children violate privacy online. Even though Sky is Autistic, they write anonymously because they do not want to expose their Autistic child(ren's) private matters to the public in a way that would be identifiable. Sky (2017, Feb. 11) said that even though they do not often blog about specific things relating to their children, they endeavour to be as vague and unidentifiable as possible. Sky wrote about parent-content creators and writers who exploit their child(ren's) most private moments for the material. Sky (2018, Mar. 29, para. 6) said they have seen posts where parents violated their Autistic children's privacy in ways that could make them less employable in the future or targets for bullying. Sky wondered why they do not post anonymously, if they genuinely feel they are helping someone by posting it.

Part of the problem with what parents are choosing to share online about their Autistic children is that in an age where people are making their living from online content creation, financial motivations sometimes obscure what is in the children's best interest in their parent's

minds. Sky has been accused of not wanting the neurotypical parents of Autistic children to have a voice. Sky (2018, Mar. 9) said, “Most of us are concerned primarily because these books are damaging our community and spreading further misinformation that is used to abuse, murder, and otherwise mistreat both Autistic adults and children.” However, the concern Sky and the other two bloggers who wrote specifically about the issue of Autistic children’s privacy was that the children’s agency to decide what gets revealed about them online must be respected and protected. Bad parents exist, but when a parent sounds as if they care about their child, we are likely to believe they have their child’s best interest in mind. We are also likely to think that the parent’s idea of what is in the best interest of their child would be something the child and the public would agree was in the child's best interest. This tendency to give parents the benefit of the doubt when they appear to care makes it more likely that parents of Autistic children will not be challenged about what they post regarding their Autistic children and will be defended even when the person raising concerns is Autistic. Sky (2018, Mar. 9, para. 4) said “These parents are sharing many of these damaging things as facts and not as opinions/experiences. It’s one thing to have fleeting thoughts of, say, sterilizing one’s child in a really dark moment; but when an author writes a bestselling book including that idea without also providing some post-damaging-thought critique, it becomes dangerous.” These parents of Autistic children share sensitive stories about their Autistic children that could impact them later in life, like when they try to get jobs. It is as if the parents have already concluded that their child will not have future possibilities that could be affected by what they have written, which is sad. Even if they were sure that their child was not going to be part of the job market in the future, that does not make their private information fair game.

### **5.2.1.c. Parenting Strategies for Autistic Children versus Non-Autistic Children.**

All the bloggers included in this study seemed to try to be generous towards parents they believed to love and want the best for their children. However, all of the bloggers in this study had at least one post where they used pointed language about harmful attitudes and parenting strategies non-Autistic parents have historically or currently are using with their Autistic children. Sky (2017, Aug. 10) specifically pointed out how they have encountered non-Autistic parents of Autistic children who deemed mainstream parenting approaches inappropriate for use with Autistic children specifically because they did not aggressively target behaviours that would make it difficult for them to pass as neurotypical. Sky said that during their time in “Gentle Parenting” groups, they became dismayed that it was still considered controversial to apply gentle parenting strategies to all children, including the Autistic ones. The blogger said it always shocks them when they meet parents who don’t agree with the basic principle that all children deserve to be treated with respect and kindness. When it comes to Autistic children, Sky said it was important not to make assumptions about the child’s intentions. They said Autistic children were often assumed to be intentionally defiant, an attitude that aligns with the spoiled brat stereotype.” Sky (Gentle parenting, 2017, Apr. 10, para. 9) said, “It’s very common in our society for parents to assume the worst of their children, especially when children are very young, neurodivergent, and/or aren’t verbal.” When a parent educates themselves about age-appropriate development and behaviours and notices their child isn’t hitting those markers, they sometimes believe their child is being defiant. The more likely explanation is that the child has a slower processing speed. Sky (para. 16) said:

Punishing a child for an inability to respond quickly isn't going to teach them to respond more quickly next time. It's going to more likely result in a fearful broken child who has learned that their parents are fine with hurting them for being somehow inadequate.

Autistic children should not be subjected to punishment for not meeting developmental milestones in the same time periods as neurotypical children.

Sky made an excellent point that all children are born non-speaking, yet their parents listen to them. Being listened to is fundamental to the exercise of agency. Sky questioned why it should be any different if the child continues to be non-speaking. They said that it was unfortunate that so many parents, even within gentle parenting circles, believed there should be quick and easy answers for parenting Autistic children, even when they acknowledged that non-Autistic children required patience and kindness. Sky (para. 22) said, "Autistic children grow up in their own time and on their own curve." This sentiment reminded me of the Māori way of looking at autism. The Māori word for autism is "Takiwatanga," which means "in his/her own time and space" (Opai, 2017, para. 4). They pointed out that you can't force a child to mature and learn a skill they aren't ready for. Sky (para. 24) said, "Yes, parents will need different tools for different children, different neurologies, different needs, different situations, etc. That's part of what makes gentle/respectful parenting challenging: There are no quick fix solutions across the board." Different tools should not mean different attitudes towards parenting. Autistic children should not be treated harshly or with impatience compared to the non-Autistic children around them.

#### **5.2.1.d. Parenting While Autistic**

Five bloggers in this study wrote about being Autistic parents: Forshaw, Hammond, Sky, Uncultured Anthropologist, and Uninspirational. These bloggers expressed concern about how

the parenting skills of Autistic parents might be evaluated and judged by non-Autistic people.

Sky expressed fear that their agency to be a parent would be denied. Sky (2017, Feb. 11, para. 10) said:

Simply put, my life hasn't been simple. Some of the experiences I would like to blog about aren't things that are considered compatible with successful parenting. Those things largely happened before I ever had children, but they could still be pointed to by someone who wanted to paint me as potentially unfit.

Sky said they cannot understand why someone would attack their ability to be a parent, but they have been hurt by being too trusting in the past and err on the side of caution now. They also said that they worried about attracting unwanted governmental attention, given how political autism advocacy is often perceived to be. Sky (para. 15) said they knew people whom officials had targeted for being transparent with their identity while being publicly outspoken, and recognized they might be in a similar situation under other circumstances.

It rarely appears to occur to the people who cast aspersions on the ability of Autistic people to be good parents that they might be better parents of Autistic children than non-Autistic parents. Uninspirational (2016, Feb. 15, para. 1) said, "When I talk to teachers, psychologists and doctors as a parent to an Autistic child, I often find the interpretations people make of my child to be absurd or even preposterous." They described how occasionally people accept what they have to say about their child, but more often, it is ignored or rejected. They were told they overestimated their child and "projected their issues" onto them. Uninspirational (para. 4) said they worried they would be seen as untrustworthy as a parent if officials knew they were Autistic. They also said they worried about being accused of projecting if they claimed to understand something about their child better than a professional because of insider knowledge.

This is something I have experienced, a little differently than described though. When I had one of my children assessed as a child, I was told they only seemed to have Autistic traits because I was projecting mine onto them. They were diagnosed without hesitation when they were an adult and old enough to speak for themselves. As a single parent of two children, I worried about how my parenting ability might be judged. I did not pursue a diagnosis when my children were young because I thought social services might decide to interfere in my parenting or even try to take my children away. I imagine many Autistic parents stay “in the closet” due to similar fears.

#### **5.2.1.e. Parental Participation in ABA**

All the bloggers in this study wrote about ABA. Thus, the final parenting issue I would like to address in this section is how ABA affects the agency of Autistic children. ABA is a parenting issue because the parent must participate in the behaviour conditioning, reinforcing it in the home. They also played a role in helping ABA become the dominant approach to autism in childhood.

Sequenzia (Assumptions and ableism, n.d.) quoted Psychiatrist Laurent Mottron, who suggested that childhood interventions should focus on strengths rather than trying to eliminate differences Autistic children had from neurotypical children. Sequenzia lamented that it took a non-Autistic researcher saying something like this for the media to present it as a serious option, even though they said the Autistic community had written and talked extensively about it.

Sequenzia (para. 4) said:

(The) Neurotypical researcher now knows that autism and intellectual disability are not intrinsic but we are expected to succeed in some of the areas he claims give us more value, we are expected to “prove” that we are “intelligent.” If we fail to prove that, we are

graded down (another ableist concept), back to the “severe, tantrum-prone and violent” group. The ones called “a burden on our families.”

Sequenzia suggested Autistic people often must prove they have something of value to contribute to society, expressly to make up for the extra work their existence represents.

Sequenzia suggested that ABA is an exercise of forcing Autistic children to prove their worth to their families and society. In paragraph fifteen, they posed the question, “Why (do) some of us need to prove anything before deserving respect for our humanity?” Sequenzia said that many people claim ABA teaches life skills. Sequenzia (2017, Sept. 6, para. 3) said, “The most important life skill anyone can learn is independent thinking. ABA does not believe Autistics should have independent minds, unless they conform to the neurotypical idea of desirability.” Sequenzia said that they are reclaiming words that exercise their self-determination.

The demand for compliance directly impacts Autistic humanity in the minds of bloggers included in this study. Kraemer (2020, Jul. 17) described being expected to display “Personhood-upon-demand.” ABA could be described this way since it primarily focuses on suppressing behaviours that would keep an Autistic person from passing as allistic. This implies that many Autistic people do not feel or are made to feel as if they are not a “Person” consistently, specifically when they are not successful in passing for allistic.

Hammond (2022, Aug. 12) said that refusal of BIPOC parents of BIPOC Autistic children to participate in a course of treatment that is perceived as making participants fitter to participate in the capitalistic project could only make things worse for them. Black people have lived with the compulsion for compliance in our society. Hammond (2022, Aug. 12) said that their parents teach black people compliance at a young age to survive in this world. Hammond said the reason



that ABA gets so much pushback in the Autistic community is that it takes what has always been expected of black people and applies it to white bodies. Hammond (2022, Aug. 1, para. 1) said:

Honestly, ABA is “abusive” because it has spread its blanket of coverage onto you. I have stated this before and I will say it again. We witnessed this phenomenon with the overturning of Roe. Black and Brown bodies have maintained that the extreme governance of our bodies was wrong, hurtful, dehumanizing and this fell from the ears of those whose lives were not touched by the restricting hand of your laws, your mindsets, and your mistreatment.

Hammond observed that white Autists find ABA especially pernicious because it applies to them the same extreme governance of their bodies that BIPOC people have been subjected to all along.

Asperger (and Kanner to a less vocal degree) thought of autism as something likelier to present in white, middle-class people raised as boys. Thus, they did not fit into the ranks of those who would be marginalized as BIPOC, poor, or raised as girls. This made them more worthy of remediation. Reflecting on Associate Professor of Social Development Studies Margaret F. Gibson and Patty Douglas (2018), David Ben Shannon (2021, p. 263) said:

A/autists and queers were prime subjects for behavioural rehabilitation because (neuro)queerness predominantly presented in white, middle-class, and physically and academically abled males: or as “marker[s] of children who did not fit into pre-existing categories of the “unfit” (Gibson & Douglas, 2018, p. 7).

Shannon (p. 263) pointed out that according to Gibson and Douglas (2018, p. 8), Lovaas and their colleagues believed they were ethically required to salvage the otherwise ideal subject within Autistic children to prevent future generations from being overwhelmed with individuals who had “baby brains in adult bodies.”

For Lovaas, it was about remediating those flawed subjects who would otherwise be considered ideal. Shannon suggests that the idea that one's child could be transformed into an ideal subject through ABA made it appealing, allowing it to gain ground toward being the primary approach used with Autistic children. While ABA was proposed by Lovaas as a means of remediating otherwise ideal subjects, the use of ABA with BIPOC people is viewed a little differently. Interpreting Disability Studies Scholar Chris Bell (2011), Connor et al. (2016, p. 2) said:

Chris Bell (2011) described the work of understanding raced and disabled bodies as one of recovery and detection. Recovery is needed because raced bodies whose stories we are often quite familiar with (such as Harriet Tubman, Emmett Till, and James Byrd) are bodies also marked by dis/abilities that remain generally unacknowledged...Narratives of these individuals often insist on misrepresenting their bodies and neglecting situatedness at the intersections of race and disability (along with other markers/shapers of identity). This reminded me of how Autistic people raised as girls find their Autistic identities are often obscured because of the adults in their lives being distracted by the ways they do not conform to gender social norms. In the case of BIPOC Autistic people, their autism is obscured by the rhetoric of race. In this light, Hammond's position of not resisting ABA makes sense to me. One identity cannot be overlooked or missed by outside observers. The other identity is often overlooked and missed because of the previously mentioned identity. On the other hand, the second identity can raise the risks of the first identity. When a black person is faced with a police officer ordering compliance, Autistic traits might put them in danger of deadly police violence. Therefore, if ABA can teach the BIPOC Autistic person how to control their Autistic traits in

high-stakes situations, it makes sense that the parent of a BIPOC Autistic person might believe it was worth trying.

However, that should not be the end line. We should not just shrug our shoulders and say that since police and institutional violence appear unavoidable, we just have to accept that BIPOC Autistic individuals might be safer and more successful if they participate in ABA. Therefore, it is incumbent upon white Autistic and allistic people to devote as much time to anti-racist, intersectionality advocacy as they spend on fighting ABA. In addition, considering the Indigenous Autistic person in my life, I can begin to understand the fear of what might happen if they did not comply with the expectations of a police officer or if they stand out in certain environments more than their skin colour already makes them. My fear that the police will hurt the Indigenous people (particularly the ones raised as girls) in my life is not as strong as my fear that a white man will prey on them. As a white Canadian, I have not experienced racialized violence. I can understand why a parent would have their child participate in ABA if they thought it might help prevent a tragedy. On the other hand, I cannot bring myself to reverse my position on ABA. Regardless of my position on ABA, I do not feel like I have contributed more than what Hammond calls “Slacktivism” to the issue.

### **5.3. The Extension of Childhood**

Seven bloggers wrote about Autistic children being treated as immature or like permanent children: Ekins, endever\*, Forshaw, Leong, Liu, Sky, Sequenzia, and Seventh Voice. It seems like for each age-appropriate standard milestone and marker an Autistic person misses, their progression is paused in the minds of those around them. It does not seem as if some people find it easy to shift gears to think of the child as developing in their unique way.

This problem is magnified for Autistic people who do not communicate verbally or do so inconsistently. For example, endever\* found themselves second-guessing the wisdom of using visual supports for communication as an adult. endever\* (2020, May 20, para. 3) said:

*But visual supports are just for kids, right?* a voice nagged at the back of my head. No, no: they're not. Disabled people grow up! The idea that picture schedules and other visual supports are only meant for children actively discourages disabled adults from accessing tools they need.

Disabled people do not stop needing support just because they grow up. Suggesting accommodations and supports are only meant for children has a possibly insidious undertone (depending on how one interprets it) that there are an expectation disabled people will not continue to exist into adulthood.

The need to use devices or have assistance to communicate also increases the likelihood that an Autistic person will be dehumanized. Sequenzia said there was a time when they had to struggle to be seen as human. Sequenzia (Presumption of competence, n.d., para. 14) said:

When I had to struggle to be seen as a sentient being, as a thinking person, my self-esteem could not find room to manifest itself. I was constantly looking down at myself because that's how I was looked at. There were no expectations for me to fulfil because I was 'nothing.'"

The need to access accommodations becomes a drain on disabled people's self esteem because of the expectation that people should be able to function in society without assistance.

Liu (2020, Feb. 16) said that when Autistic people express passion for things not considered age-appropriate, the stereotype of them being permanent children is reinforced.

Autistic people are viewed as being permanent children yet are teased and shamed for enjoying

“Childish” things. The fear of being perceived as childish places limitations on the agency of Autistic people to enjoy their passions. Liu said that Autistic people are pressured to express interest in “Age-Appropriate” things. Liu (para. 1) said, “One of the earliest traits of Asperger’s is unusual interests- that is, things that might not appeal to people of a similar age.” One could say, based on this statement, that one of the first experiences Autistic people have with autism is having their passions pathologized. As far as I am concerned, non-Autistic people can express passion without it being pathologized while non-Autistic people are teased and shamed. It isn’t right. I knew a group of teenagers who loved to get high and watch *Teletubbies*. Nobody said anything about it, except for the drug use. However, if an Autistic person wants to watch *Yo Gabba Gabba* out of sheer love for it, they are called childish. When non-Autistic adults dress up in “Cosplay” [costume play] and go to a fan convention, they are called “Nerds” and “Geeks.” However, unlike being called childish, these terms have taken on positive attributes since the rise of technology sector billionaires. On the other hand, an Autistic person cannot do the same thing without being teased for it with a sentiment much less often meant to express an appreciation for their differences. Liu (para. 2) said:

A recurring debate within this topic is to what extent should Autistic children – and adults – be persuaded to take an interest in similar things to their peers? This is a tricky one, and it can be a morally grey area. Is it helping the person to learn and grow so that they are not stuck in the same patterns throughout adulthood? Or is it forcing them to be someone they’re not, just to please the rest of the world?

It is understandable that parents would want their children to fit in with their peers. However, Autistic children should be able to express their passions in the same way as their non-Autistic peers.

Social Anthropologist and Autism Consultant Cos Michael (2021) wrote about a time when they were treated as if their adulthood needed to be bestowed by someone else rather than being assumed by physically being an adult. Our ability to exercise agency expands exponentially when we become adults, meaning Autistic people who are seen as permanent children would also be viewed as possessing less agency. It is not uncommon for Autistic people to experience an imposed state of permanent childhood. Sometimes this is related to their special interests not being considered age-appropriate. Autistic Ph.D. student in Developmental Psychology Kayden Stockwell and co-authors (2021) described special interests as an intense interest in a specific topic, often considered acceptable in non-Autistic people, but generally considered dysfunctional in Autistic people. Stockwell et al. (p. 3346) said:

When investigating SIs in autistic children, however, researchers have found that family members are concerned about both their children's interest intensity and topic.

Specifically, they express concern that their autistic family member's SI is socially unacceptable, will not lead to a career, and/or is tiring to listen to.

The findings of Stockwell et al. support ideas expressed by the Autistic bloggers included in this study. For example, Liu (2017, Nov. 23) pointed to there being a continuing debate about if it is in the best interest of Autistic children for the adults in their lives to try controlling what Autistic children express passion for. I will provide an example to clarify why this is so problematic. I have never heard of a wide-ranging debate about whether non-Autistic adults should be allowed to paint their faces with their favourite football team's colours and go cheer them on in a crowd. Imagine the uproar if the staff of a school started enforcing a rule that no sports team logos or colours could be worn by students because it might cause conflict within the study body. The right of non-Autistic people to express their passions in ways that do not harm others is assumed.

This is because their agency is assumed. On the other hand, people feel entitled to debate what is appropriate for Autistic people to express passion for. This is because their agency is not assumed.

Devon Price (2022) talked about the mind-body connection brought forward by phenomenology. Price (p. 26) said, “Because the neural and cognitive features of Autism are so pervasive, it affects almost every aspect of a person’s body and brain.” Price went on to talk about how Autistic people show interest in things. Price (p. 26) said, “Autism can influence how intensely we focus on an activity, and how we perceive textures, tasks, and sounds. Autism can predispose a person to having fanatical interests (often referred to as *special interests*) and to following rules very rigidly.” These special interests are often a focus in the othering of Autistic people. Price (p. 151) said, “When it comes to special interests, Autistic brains are total sponges, absorbing facts and figures at a rate that seems kind of inhuman to neurotypical people.” Price talked about the cruelty of how ABA punishes Autistic children for talking about their special interests. Price (p. 152) said that it is common for children to have intense interests that they feel less passionate about when they become adults. However, Price said that ABA teaches Autistic children to suppress their passion for a subject long before adulthood to blend with narrow social standards of normalcy. Price (p. 152) said, “Being passionate about a video game, comic book, or wild animal species is often viewed in society as childish and limiting, and so Autistic children are expected to hide their enthusiasm.”

This reinforced what the bloggers in this study said, although it is a little more forgiving in the speculation about the motivation, saying it was to keep them safe. Price also commented on how Autistic adults are treated for their special interests. Price (p. 152) said that adults were only shamed for having obsessive interests that were too strange, and would not help them make

money. The bloggers would say that this acceptance would still not apply if the interest were considered too childish. At least during childhood, Autists are denied agency when the things they are permitted to show passion for are denied to them. This often continues into adulthood through being told the things they love are childish and will not help them make money.

#### **5.4. Medical Professionals**

All the bloggers touched upon the medical profession and how they affect Autistic agency at some point in their blog writing. Fear of doctors is common, but it is far less common to be so relieved about being treated with respect by one's doctor that it makes you cry. This is an experience Kraemer (2018, Jul. 1) talked about. (Please see Appendix F for a list of things the doctor *did not do* that impacted Kraemer's experience.) Kraemer said that they handed their doctor a note to explain themselves. When the doctor took it and read it without condescension, it was such a relief that it made them cry. Kraemer (para. 6) said, "They didn't ask me why I was crying, or why, or how I was feeling. They just said, 'You are safe here.' I was suddenly less worried about expectations to speak verbally or act a certain way." Kraemer said it was rare not to feel gaslighted and ignored by their doctor. They wrote a blog post article where they advised doctors about actions the doctors could take to make the experience better for their Autistic patients and themselves. Kraemer's first suggestion was that if a doctor were to be handed a note where their patient introduces themselves and their diagnosis, especially if it focused on how it might impact their communication with the doctor, the doctor should do as the doctor in their example did and take it without condescension.

Bloggers included in this study talked about things that have happened to them when medical professionals limited their agency. It is widely acknowledged that there is a disparity in medical services for BIPOC people. The Government of Canada (2020) said:



Social, economic, and political factors shape the conditions in which individuals grow, live, work, and age, and are vitally important for health and wellbeing. Inequalities in these conditions can lead to inequalities in health. When these inequalities are systematic, unfair and unavoidable, they can be considered inequitable...Discrimination against Black people is deeply entrenched and normalized in Canadian institutions....

It is also widely accepted that women's pain is often dismissed by doctors. They also discussed their fears about what could happen if their agency were disregarded (Bevar, 2022, Dec. 13; Harvard Health Blog, 2017, Oct. 9; Pagán, 2018, May 3). In other words, it is more difficult for Autistic people with intersections of marginalized identities to be taken seriously by their doctors. The bloggers in this study talked about examples of things that have happened to other people when their agency was limited or dismissed. Sequenzia (Disabled lives and respect, n.d., para. 12) said:

All around the world there is a movement to “get rid” of undesirable bodies and “deficient” minds. Unless we prove ourselves “productive and self-sufficient”, we are deemed too burdensome for society. We have to fight for basic services to merely survive, and we are blamed for “not giving back.”

Getting rid of undesirable bodies and deficient minds does not look the same in all places.

However, it should be noted that “getting rid” is meant literally in some places.

Sequenzia talked about legislation that legalized the murder of disabled new-borns in one country, a politician that proposed lethal injection for disabled people in another, courts granting parents the right to euthanize disabled children who are not terminally ill, and parents who murder their disabled children and never see the inside of a jail cell. Sequenzia (Disability history and pop culture, n.d.) also talked about how laws in some countries only requiring families of

disabled or ill people who want to submit them to euthanasia to have a doctor testify that their life is tragic. Sequenzia (Disabled lives and respect, n.d., para 17) said, “How people talk about us matters. It matters in a life-or-death way. Words that reduce our existence to ‘takers,’ ‘pitiful,’ ‘incompetent,’ ‘subhuman,’ ‘needy’ and non-sentient beings create the perception that we don’t deserve to live, the perception that we are suffering.” Sequenzia said that not only does society give disabled people significant cause to fear doctors and what could be done to them with the assistance of a willing doctor, but they also gaslight disabled people about being afraid.

Sequenzia (2014, Nov. 11, para. 25) said:

there are the ones who like to deconstruct our fears, an attempt to show us how wrong we are in our conclusions. They refuse to accept that we, and our non-disabled friends who are parents of disabled children and who value disabled lives, do fear intensely when our deaths are seen as acceptable, even desired.

This gas-lighting includes telling us that we are reading too much into statements, and are being too sensitive.

Autistic Psychologist Monique Botha wrote a Twitter thread about a phenomenon they are studying as part of their fellowship: “Epistemological Violence.” Botha (2023, Apr. 6) defined epistemological violence, saying, “This is a fancy way of describing the negative interpretations we make against certain groups where the data is otherwise ambiguous.” Botha wrote the thread in response to a tweet from Inclusion Associate and Expert by Experience Ann Memmott PgC Ma@AnnMemmott on Apr. 6, 2023. The tweet critically reflected on a new research paper claiming autistic people worry too much about their health. They referenced a study by Psychologists John Galvin and Gareth Richards, published in 2023. Botha said, “This study measures health anxiety between autistic and non-autistic people and assumes that any

between group differences can be reduced to autistic traits. Essentially, that being autistic will correlate with what they describe as irrational fear of poor health.” According to Botha, the paper by Galvin and Richards did not control for pre-existing illnesses yet characterized being concerned about health as irrational or hyperbole. Botha said, “We already know from a distinctly robust body of work that autistic people are more likely to have poor physical health including long term disability, non-communicable diseases, and to die on average earlier than their non-autistic counterparts.” According to Botha, in light of this data, the researchers did not treat what should be considered reasonable concerns about health as valid. Botha (2023, Apr. 6) said:

How much of the health anxiety effect can be explained by current health? I’d hazard an educated guess that the more complex your health care needs the more likely it is to be on your mind. That’s not irrational, it’s a way of monitoring changes that could be meaningful.

Botha’s research is relevant to this thesis study because their perspective on epistemological violence is reflected in the experiences shared by some of the bloggers included in this study, discussing experiences of medical gaslighting.

### **5.5. The Autism Cure**

Decosta, endever\*, Ekins, Forshaw, Hammond, Kraemer, Leong, Miranda, Sequenzia, Seventh Voice, Sky, and Uninspirational wrote about curing autism. The push for a cure assumes that autism is a disease that causes suffering to the person with the disease and those around them. endever\* (2019, Apr. 5) asserted that although autism is not always pleasant, it is a part of themselves they would not change. This harkens back to Sequenzia (2014, Mar. 19; 2013, Feb.

23), who asserts people's right to be part of the common human experience of suffering.

endeaver\* (2019, Apr. 5) said:

Being autistic is not always fun or even manageable – both for reasons explicable by the social model of disability as well as reasons that perhaps don't fit that model. But that doesn't mean I wish someone (doctors, gods, doctors who think they're gods, whoever) would "cure" me! I wouldn't be me if I weren't autistic.

When thinking about what Sequenzia and endeaver\* asserted, I was reminded of a fictional book called *Tales from the Gas Station*. One of the characters in this book believed that by murdering people, you reduce the sum of suffering in the world because you erase all the potential for suffering that person's life represented. Sequenzia suggested there is nothing special about the suffering of a disabled person, compared to that of non-disabled people, that warrants it being eliminated. Sequenzia expressed anxiety that suggesting otherwise might lead to someone suggesting the kind of solution presented by the murder cult in *Tales from the Gas Station*.

Hammond suggested that for Autistic people, claiming autism as part of their identity becomes important to the maintenance of their agency. Hammond (2022, Sep. 30) said:

The harm many claim we push onto others because of how we identify is predicated upon what those outside of this community might do. They might view Autism as a disease. They might want to cure it. They might deny one access to this world. Thing is, they do this even when acknowledging identity first. There are parents who refer to their children as Autistic and still push for cures. Disability is both feared and pitied, regardless of what we refer to ourselves within our diagnoses, life will forever be complicated, challenging, and harmful.

Unfortunately, there will always be people who feel entitled to tell others to change parts of their identity because they find them offensive. This behaviour will always infringe upon the other person's agency, regardless of whether the person doing it thinks they are saving the person from suffering.

Decosta (2019, Jan. 4) clarified the difference between a tool and a cure. They said that a tool is something you control, including something you get help controlling. Decosta described a cure, including those that do not work, as a solution to a problem. The goal of a cure is to make the perceived problem disappear—in this case, the problem is autism. Many of the approaches that are considered steps toward a cure are based on bad information. They can cause trauma and even death. Decosta said that autism should not be treated like a problem, disease, injury, or disorder. They said that although some strategies can help support the needs of Autistic people, cures generally do not work. The approaches Decosta said were helpful regarding Autistic support needs were more appropriately placed in the category of “Tools.” Decosta characterized Applied Behaviour Analysis and “Remedies” that are generally unproven and lack scientific efficacy (sometimes literally being toxic) as “Cures.” They listed Cognitive behavioural therapy (depending on the context and usage), self-regulation, interests, musical therapy (depending on the practitioner), and occupational therapy (if the practitioner is not focused on fixing stims) as “Tools” that are often utilized by Autistic people.

Queer Disabled Writer criticized organizations that focus on “Cure.” Queer Disabled Writer (2013, Mar. 25, para. 4) said, “one can easily see where the push for a cure leads. Eugenic advances in prenatal testing has led to a 34 percent reduction in the number of babies born with Down Syndrome.” The blogger (para. 8) said:

Eugenic thought pushes for a groomed population. As part of that push, Eugenic scientists seek ways of breeding out negative traits. But what is designated as a negative trait is completely a matter of the social, cultural and political environment which one inhabits. Society treats autism as a negative trait. Queer Disabled Writer (para. 10) said, “science and religion has predominantly embraced ableist and functionalist attitudes, defining the value of lives based on things like income potential and the potential for achievement of mythical independence.” Queer Disabled Writer said medical science was used to find cures for diseases that exclusively cause suffering and pain.

Sequenzia (2015, Apr. 22) said that assuming they are suffering erases their humanity. Some people assume that because Sequenzia experienced physical pain on a regular basis, that meant the state of Sequenzia’s existence could be described as “suffering.” First, people are allowed to suffer and still be alive. They should not be made to feel like people are just waiting for them to give the sign that they would like doctors to help “end their suffering.” Another example of this dehumanization that Sequenzia pointed out was that people assumed that because Sequenzia had challenges in communicating their ideas, it meant they did not have any ideas worth communicating.

Queer Disabled Writer indicated that focusing on a cure for autism does not only compromise the agency of Autistic people, but the agency of non-Autistic people as well. They (2013, Dec. 20, para. 11) suggested that research fellows “are coerced by the money and power of a movement to cure autism but likely do not recognize that the nonprofits at the heart of this "movement" are entirely funded by major medical corporations.” Realistically, they are at the least persuaded to arrange their research priorities to align with those of their funding sources. Queer Disabled Writer (para. 13) questions:

Who would make money off of any Autism cure? Certainly not the academic that discovered it, not the government, not even Autism Speaks (though I'm certain they would get large donations from their corporate backers). The people who have the most money to gain from Autism Speaks' mission of finding a cure for Autism are the CEOs and executives of major healthcare and health insurance corporations.

The agency of researchers to set their priorities according to their interests, evidence, and best practices may be overwhelmed by the will of those who stand to gain the most money. Associate Professor in Educational Policy Studies Ben Jongbloed, Professor of Higher Education Management Jürgen Enders, and Educational Economist and Author Carlo Salerno (2008, p. 308) said:

Some higher education institutions are particularly committed to the goal of reducing social and spatial inequalities. Others may see research excellence as their top priority. It is also important to note that for a university the choice of mission or profile and, consequently, how the institution relates to its stakeholders, is never shaped entirely by its communities, but also very much path dependent. History and geography—in other words, institutional contingency and regional contingency—will also shape the relationships a university has with its stakeholders.

Financial accountability to stakeholders can alter even the best of intentions from researchers.

Associate Professor and Division Director of the Division of Occupational Science and Occupational Therapy Nancy Bagatell (2010, p. 33) wrote about the tension caused between the autism and Autistic community that arises from the debate about whether “autism is a condition in need of a cure or a way of life.” McGuire and Sociology Rod Michalko (2011, p. 163) said:

Gathering together all of the pieces of the puzzle that is autism and putting them together does not, interestingly enough, give us the whole of autism. Instead, it gives us the way to eliminate autism, to prevent it, to cure it, and failing this, to treat it so that its negative effects are minimized, if not completely erased.

In other words, the end goal of gathering the ‘missing puzzle pieces’ of Autistic people is not to create a whole Autistic person. It is to transform the Autistic person into an allistic person.

### **5.6. Research, Researchers, and Researched**

All the bloggers wrote about researching various topics for their education. They also all wrote about research on autism, even if it was indirectly, not specifically mentioning the researchers. Decosta, Ekins, endever\*, Forshaw, Kraemer, Leong, Liu, Queer Disabled Writer, Sequenzia, Seventh Voice, and Uncultured Anthropologist wrote about how autism researchers did not listen to Autistic people when setting their priorities. Only a few wrote explicitly about how autism research infringed on Autistic people’s agency. endever\* (2018, Dec. 26, para. 2) wrote a poem that included these themes, including the following:

but mostly, i am from people  
i am from people who have been stigmatized  
institutionalized  
fetishized, pathologized  
disenfranchised  
sterilized, experimented on, exterminated

However, endever\* (para. 5) also wrote in their poem that despite this past they also come from people who:

crashed the conferences where professionals like to talk about us without us



designed the research no one else is doing to increase our quality of life

taught our teachers what are actually our real names

The history of autism culture includes advocacy pushing for inclusion in discussions and research about autism.

Regarding the kind of autism research that gets funding, some troubling projects get financed. It is reasonable for Autistic people to be suspicious about the end goal of these projects, especially when Autistic people presenting questions and concerns about the projects do not slow down their progress, indicating the concerns might not be getting due consideration. This is not surprising with so much money on the line. Sequenzia (2014, Jul. 8, para. 16) said:

I want you to learn that autism is not a disease. We have a different neurology and yes, we are disabled, even if many of our disabilities is a social construct, a lack of acceptance and accommodations. This should not be an excuse to use our genetic information for the profit of others. I noticed that there are no plans whatsoever to use profits for better services. We don't need pharmaceutical predators, and we don't need eugenicist researchers trying to rid the world of us.

Bloggers in this study expressed frustration about what research got funded and who was listened to and consulted when it came to the research data. Sequenzia (2013, Feb. 5) said autism awareness should be about supporting research to help with digestive system issues, sensory overload, or communication. Sequenzia (2013, Feb. 5, para. 11) said, "Instead, a lot of money is spent on trying to find a cure – that does not, and will not, exist – and on 'cause' that sound more like a blame game – and bad science." Sequenzia (Assumptions and ableism, n.d.) said that Autistic people have warned parents about the damage resulting from "Therapies" designed to make Autistic children indistinguishable from their non-Autistic peers. Sequenzia (para. 19)

clinched their point in this article by saying, “The neurotypical researchers, so excited about their not quite-new discovery have a long way to go before they catch up with us, with our knowledge about how our brains work.” Of course, this process of catching up cannot happen if Autistic people are not included in research.

Queer Disabled Writer indicated that part of the problem is the overrepresentation of certain points of view in research. Queer Disabled Writer (2013, Jun. 18, para. 4) said:

One of the most cogent points made by disability rights and disability studies is not that medicine and the empiricist sciences hurt disabled people, but that those perspectives are oppressive when they are the ONLY perspectives. The motto "nothing about us without us" is well recited within the disability rights contingent. Curious about autism? Ask an Autistic.

Responding to the lack of diversity and inclusion in autism research, Experimental Psychologist Lydia Hickman (2022, para. 2) and their co-authors:

formed the U21 Autism Research Network, a collaboration among seven research groups around the world. Last year, we hosted an international panel discussion with autistic people and autism researchers, who highlighted ways to improve diversity and inclusion in the field.

Hickman (para. 3) said one of the main takeaways of this effort were the generation of “practical tips for engaging with communities that are underrepresented in research, and for using ‘autism consultancy groups.’” Hickman (para. 4) said that the autism community includes a wide range of people in terms of demographics and traits, and if their sampling does not reflect this, it cannot capture the full picture, which would result in false assumptions and conclusions. This reminded me of what Mendoza et al. (2016) said about White people being able to retain individualism

while BIPOC were viewed as monolithic. Researchers need to remember that Autistic people are not a monolith. Hickman (para. 7) said, “One underrepresented group in autism research is autistic people who speak few or no words. This group makes up 25 to 35 percent of the autism community, but few studies include them.” Speaking is sometimes treated as the gatekeeper to being able to have a voice and agency. Hickman (para. 8) said more needed to be done than just including more non-speaking Autistic people in research studies. They said steps needed to be taken to remove barriers to non-speaking Autistic people who were capable of communicating their responses so that their non-response does not get misconstrued as a behavioural or cognitive difference. In other words, we need to remove the gates erected against non-speaking people’s voices being included in the research. The final insight from Hickman that I will share is that they said we need to recognize the role played by intersectionality in the lives of Autistic people.

According to Lecturer in Health and Social Care Nathan Keates, Kryisia Waldock, and Eleanor Dewar (2022, p. 4347), in response to Professor of Education Linda M. Bambara and Psychiatrist Stephen Camarata (2022), it is understood that evidence should guide practice. When it comes to autism, the quality of evidence is getting better through more attention being paid to power dynamics and empowerment in ethical codes as well as participatory and inclusive research. Keates, Waldock, and Dewar (2022) indicated that the efficacy of autism research is improving, especially with the increase of participatory and inclusive research, but that power imbalances in studies is an ongoing concern. Psychologist Laura Crane, Autistic researcher Abby Sesterka, and Professor of Education Jacquiline de Houting (2020, p. 1802) said, “Autism research has traditionally been conducted on, about, or for autistic people and their families, without the involvement of those with insider expertise.” This exclusion of Autistic voices in research about autism and Autistic experiences is beginning to change. However, there remain

imbalances in power between Autistic participants and allistic researchers that pose potential problems. For example, about studies that seek to teach social skills, Keates et al. (2022) said the presence of potential willing participants does not guarantee long-term harm is not caused. Self-stigmatization is still a source of disempowerment. Keates et al. (2022, p. 4347) said, “Interventions should not disempower autistic people and should allow for autonomy and agency.” Keates et al. said that even when no harm is intended and the participants are willing, their natural neurodivergent behaviours could be stigmatized, leading the participants to feel disempowerment and loss of agency.

### **5.7. Communication**

All the bloggers wrote about non-speaking Autistic people or non-speaking forms of communication. Decosta, endever\*, Sequenzia, and Seventh Voice, in particular, wrote multiple blog posts about assistive devices, facilitated communication, and other forms of non-speaking communication. The use of non-speaking communication is often related to the restriction of agency. endever\* (2018, Nov. 28) talked about how they have had to ask permission to use their communication devices and strategies. They said assistive technology only gets framed as “special” or “extra” when disabled people use it. Sometimes the same methods and devices referred to as “Lifehacks” when used by non-disabled people are referred to as “Assistive Technology” when used by disabled people. endever\* (para. 14) said:

It says a lot about the value society puts on disabled people that supports we need are labeled “special” or “extra”, while the tools abled people use are considered just mundane details, or perhaps cool lifehacks.

endever\* (para. 14) said that Autistic people are shamed for needing accommodations, unlike the things that make life easier for neurotypical people. Since this technology does not result in the

person using it to contribute more labour to the capitalistic project, it is viewed as “Special” or “Extra.”

endeavor\* does not see the things they use to accomplish tasks as “Special” or “Extra.” They see them as necessities. However, people around them do not look at it the same way. Since they need them and most other people do not, the needs are deemed “Special.” There will always be people who see anything someone gets that is different as proof of inequality, regardless of whether that special consideration is meant to level the playing ground.

“Overcoming Disability” is a pervasive narrative in disability rhetoric. In the introduction of *Beginning with Disability: A Primer*, Lennard J. Davis (2018, p. 10), an author in Disability Studies, talked about how the concepts of “Inspiration Porn” and “Supercrip” were born out of the media highlighting stories about disabled people accomplishing astonishing things for the purpose of inspiring non-disabled things, with the subtext being “If they can do it then what’s your excuse?” In a chapter called “Disability Rhetoric” in the above-mentioned book, Disability Activist and Author Jay Dolmage (2018, p. 28) talked about how the narrative of overcoming disability affected an Indigenous historical disability figure named Sequoyah’s life. The discourse encouraged people to pity Sequoyah for their disability but praised them when they were able to do things people thought unlikely for those with disabilities to accomplish. Dolmage (p. 29) said:

Sequoyah is an intensely rhetorical figure because when people tell stories about him overcoming his disability, this persuades the public (both disabled and temporarily able-bodied people) that disability must be overcome or compensated for in order for the disabled individual to have value.

However, just as there are people who point to employment equity programs for BIPOC people, there are people who see accommodations as giving disabled people unfair advantages.

Psychologist Benjamin J. Lovett (2021, p. 2) said that educational accommodations provide a benefit that could be perceived as an unfair advantage if the distribution of the accommodation is unfair, or it is based on facts unrelated to educational needs, such as gender and race. Lovett (2021, p. 2) said:

Unfortunately, the available research suggests that demographic factors do play a causal role in determining whether a student will receive accommodations. Specifically, students with higher socioeconomic status (which does vary by ethnicity) are more likely than their peers to receive accommodations.

Lovett (p. 3) stated that students in the wealthiest 20% of schools were almost twice as likely to have as students in the poorest 20% of schools to have accommodation plans, and those in the wealthiest 1% of schools were almost four times as likely as those in the poorest 1%. Lovett (p. 3) said that accommodations do not only boost the academic performance of disabled students. Extended time on tests and quiet rooms in which to write them would boost the academic performance of any student. Lovett (p. 3) said, “When accommodations are provided to more privileged students who do not actually need them, the accommodations function as an unfair advantage that increases inequities in both educational access and performance outcomes.” This is part of the reason accommodations are sometimes viewed as an unfair advantage. When they begin to be withheld out of suspicion of being distributed incorrectly, it is disabled students who are the most adversely impacted.

Communication is among the many tasks assistive technology makes accomplishable for disabled people. Senior Lecturer in English Stuart Murray (2008, p. 20) described “Facilitated Communication” [FC] as involving a facilitator whose role was to aid the Autistic person in typing on a keyboard or pointing at letters. In FC, the goal is to slowly reduce the amount of

physical support given, believing the Autistic person will become more independent in their communication. However, Murray (2008, p. 20) said, “A number of studies of the efficacy of FC showed that it was the facilitator, and not the person with autism, who was doing the communicating.” This was an accusation that Amy Sequenzia expressed encountering.

Facilitated communication is something that has been seen a discredited and false communication. Co-Director for the Institute for Disability and Bioethics Mark Mostert (2010, p. 31) said:

By 2001, Facilitated Communication (FC) had largely been empirically discredited as an effective intervention for previously uncommunicative persons with disabilities, especially those with autism and related disorders. Key empirical findings consistently showed that the facilitator and not the client initiated communication.

It is difficult to imagine how defeating it must have been for Amy Sequenzia, to see their mode of communication dismissed as invalid. Although some academics considered the question of the validity of FC to be closed around 2001, there were others who challenged this conclusion.

Psychiatrist Anne Emerson, Psychologist Andrew Grayson, and Medical Sociologist Adrienne Griffiths (2001, p. 98) said:

A research project to investigate the validity of the augmentative communication strategy FC began in 1995 in a community which is home to over 170 people with a range of disabilities, the majority of whom have communication disorders... this project, using a range of research protocols, has continued to provide evidence for the effectiveness of FC in expanding the expressive abilities of some clients with communication disabilities.

These findings were pointed out by Mostert (2010, p. 31):

the FC literature since 2001 also shows increasing acceptance of the technique, ignoring empirical findings to the contrary. Further, more recent pro-FC literature has moved beyond acknowledging that FC is “controversial” to a working assumption that it is an effective and legitimate intervention.

As already mentioned, it is difficult to imagine what it would be like to have people question your communication's legitimacy and assume someone is passing off their words as yours.

### **5.8. Representation and Advocacy.**

All the bloggers wrote about aspects of how Autistic people are represented. They also all wrote about aspects of advocacy. Decosta, Ekins, endeavor\*, Forshaw, Hammond, Kraemer, Leong, Queer Disabled Writer, Sky, Sequenzia, and Seventh Voice were particularly prolific on these topics. There are two aspects of representation and advocacy in relation to agency that I wish to address. The first is that Autistic voices are often supplanted by non-Autistic voices. Sky (2018, Feb. 9, para. 10) said, “Allistics (non-Autistics) who do not listen to Autistic voices are wholly unable to accurately represent Autistic perspectives and yet they are often the ones considered ‘Autism Experts.’” They asked their readers to imagine how they would feel if the only people considered experts on their religion were people from a different religion, who not only did not share their perspective but were outright hostile towards it. Sky (para. 15) said:

This means that society’s views of you or your deeply held beliefs are solely based on these ‘(Hostile Opposing Viewpoint) Expert’ opinions. In fact, as soon as you mention that you hold the views you do, you’re dismissed as not being able to contribute anything to the discussion because you’re clearly biased if you hold those views. Untrusted by others to convey your very own process of reasoning as books are being written and speeches are being given about you but not for you.



In other words, having opinions based on lived experiences marks Autistic people as unreliable to contribute to discussions about autism.

As a marginalized identity, there are fewer Autistic people than non-Autistic people. That leaves Autistic people feeling like they must constantly soften and adapt what they wish to say to appeal to non-Autistic audiences or at least to avoid accruing their ire. To add insult to injury, they must watch people get jobs as “Autism Experts” while they remain unemployed or under-employed. Sometimes these people do not have more education or experience than them, but the education they do have falls in line with what the non-Autistic community feels is appropriate for working with Autistic people. For example, if I want to get a position as an “Autism Consultant” in Saskatchewan (Canada) schools, I will have to be invested in behavioural theory. I say this because I have personal experience (2022) of looking at job postings for “Autism Consultant” positions in all of the Saskatchewan school divisions and seeing this was a requirement. As of the last time I looked (2022), neurodiversity also was not represented as an area of jurisdiction in postings for “Diversity Consultant” positions in the Saskatchewan school division either.

Queer Disabled Writer shared their vision of the world after a “Neurodivergent Revolution.” Queer Disabled Writer (2013, Jun. 16, para. 4) said, “I imagine Neurodivergent community centers and committees, in every local area, with representation at every discussion of proper accommodation. I imagine databases organized which consist of patient-knowledge of varying neurodivergent ways of existence.” Queer Disabled Writer said that all the work people like Ari Ne’eman and organizations like ASAN are doing is vital, but it also is not enough. Queer Disabled Writer (2013, Aug. 14, para. 14-16) said:

All the rights legislation that can be passed remains at risk unless the neurodiversity movement provokes longer lasting cultural changes. I do not wish for Ari Ne'eman and

the Autistic Self Advocacy Network to stop working for policy change and promoting advocacy efforts, this work is important. But I do wish to provoke fellow supporters of Neurodiversity to not get so caught up in the absurdity of short-term political battles.

The bloggers agreed that it is difficult not to get caught up in short-term political battles because of the immediate fear of losing ground. It is difficult not to focus on the multitude of micro-aggressions experienced each day because of how certain dominant “Autism Advocacy” organizations choose to direct the autism discourse.

Hammond (2022, Aug. 1) said that BIPOC parents are pressured to oppose ABA because the majority of Autistic people prioritize resistance to ABA. Hammond said in this context “Majority” means the loudest and most aggressive (and usually white) Autistic advocates. Hammond stated that the white Autistic community controls a lot with their anger, trauma, and rage. Hammond said that the experiences of BIPOC parents that inform their decision to put their child through ABA are usually only start to be felt by white Autistic people when they are subjected to ABA; namely how the expectation to comply with authority affects people. Hammond suggested the rage of white Autistic advocates stems from ABA forcing compliance to authority, an experience Hammond suggested is uncomfortably new for white Autists. Hammond (para. 1) said:

Honestly, ABA is “abusive” because it has spread its blanket of coverage onto you. I have stated this before and I will say it again. We witnessed this phenomenon with the overturning of Roe. Black and Brown bodies have maintained that the extreme governance of our bodies was wrong, hurtful, dehumanizing and this fell from the ears of those whose lives were not touched by the restricting hand of your laws, your mindsets, and your mistreatment.

On the other hand, BIPOC Autistic people are usually raised by other BIPOC people, who understand that teaching your BIPOC children to comply with authorities might be the only way to keep them alive.

When individuals such as Hammond describe their views on how teaching compliance can help BIPOC children survive in a racist world, they are placed in a position of being treated as enemies for not throwing support behind the anti-ABA movement. Hammond (para. 20) wrote, “Do y’all think we want to spend an innumerable amount of energy on ABA? Nah, not at all...but this community and its advocacy will go the way of its loudest and most aggressive.” Hammond suggested that the loudest and most aggressive element lash out at anyone who does not take up their priorities, treating them as traitors to a cause.

The most controversial part of what Hammond said about the interrelationship of racism and ableism might be the statement that white people cannot “Do Both.” Hammond said that white Autistic people are not expected to dismantle ABA while also fighting against violent systems that disproportionately put bodies like Hammond’s at a disadvantage. They said that white Autistic advocates do not know how to deal with nuance because they are used to being centred. Hammond (para. 17) said the biggest reason these people have gotten angry with them was that they have told them, “No, y’all cannot. You cannot ‘do both.’ Because you don’t live both. Your lives govern our own. So much so that I must live by your trauma and you don’t ever have to live by mine.” I imagine it is difficult for people to hear someone suggest that the things they give time and support to do not constitute real activism. Hammond (2022, para. 19) has characterized a lot of advocacy strategies as “Slacktivism.” They also said that other Autistic advocates are so busy giving each other approval for these efforts that they do not take the time to

consider if what is being shared and suggested has the potential to affect real-world progress for everyone, only a few, or nobody at all.

I cannot hold myself above this criticism. After explaining to two young Indigenous people close to me why they must comply with police officers, I realized that my parents had not felt it vital to have this discussion with me (a white child). Considering the difference between the rules Indigenous children must live by and the lack of rules that I take for granted, Hammond's perspective on why white Autistic advocates might find ABA so problematic resonates as true for me. Hammond (2022, Aug. 1, para. 20) said:

You rampage against leaves like ABA and not systemic trees with rotten roots? That's your trauma. The overwhelming, overpowering, overbearing way in which this community will take shears to trim hedges and bushes but leave the roots? That's your trauma.

Upon reflection, ABA is not even my trauma. I never went through ABA, yet I often prioritize the push-back against ABA over many considerations more immediate to my life. With someone close to me (who is also Indigenous) freshly diagnosed, it seems as if it would be more productive for me to funnel my advocacy energy to where there is not already a chorus of voices saying the same things. What I mean by this is that the anti-ABA movement already has a chorus of voices. In addition, both myself and the person close to me were not affected by ABA and are not in danger of being compelled to participate. However, as an Indigenous person assigned girl at birth, it was difficult for this person in my life to get a diagnosis. They were assessed in kindergarten, only for it to be said that they were "too social to be Autistic." The person assessing them said the reason they seemed Autistic was that an Autistic person was responsible for their socialization. My point in mentioning this is that after thinking about what Hammond said about

advocacy priorities, it makes sense that I should focus my efforts on actions that might make it easier for Indigenous Autistic people to get a diagnosis. My hesitation here is that I question if it is my place as a white woman. That is why I need to listen more than I speak. I need to take direction from this person in my life.

I think the problem I am encountering is that except for listening, I don't know what actions I can take if I cannot "Do Both." I can tone down what I say about ABA, allowing nuance to enter the dialogue. After all, when I listen to nuance, I understand Hammond's points. It would be frustrating not to have insurance-covered options other than ABA. Sometimes other options are unavailable, regardless of whether you are willing to pay out-of-pocket. In addition, some alternatives to ABA simply do not provide the same kind of protection offered by teaching your BIPOC child to comply when a police officer gives them a command, for example, or how to pass in certain environments to increase their chances of not being victimized. I also understand social services and schools' pressure on parents to comply with ABA. My parents received social assistance despite also working full time. I understand the tacit understanding that when one accepts social assistance, you might be forced to allow the government to co-parent your children because they believe you are not as competent as parents who do not need social assistance. I know that they hold that money against you and twist your arm to do things you do not think are in the best interest of your children. I know that schools also have the power to force parents who do not have the option of homeschooling into complying with their recommendations. In this case, ABA as an instrument of institutional power restricts and removes the agency of Autistic people and their parents or guardians.

Advocacy is a collaborative activity that involves shared goals and socially coordinated action plans. The existence of Autistic-led advocacy organizations, if one were approaching what

it is to be human from the assertion of Tomasello et al. (2005) referenced earlier concerning group activities, would be evidence of Autistic participation and membership in “the human.”

### **5.9. Summary**

The idea that Autistic people lack agency affects so many parts of Autistic people’s lives. Späth and Jongsma (2020) said interventions are justified with the assumption that Autistic people are not capable of being the authors of their own lives. Späth and Jongsma (2020, p. 73) said Autists are aware of their strengths and critical of social norms, which makes a good place to start reconsidering the beliefs of Autistic people’s capacities. Autists’ perceptions of their strengths, their criticism of social norms, and the capacities of Autists were all considered in my examination of the blog material created by the bloggers included in this study. Späth and Jongsma (2020, p. 73) said, “Our analysis shows that many autists are hindered to be(come) autonomous due to unjustified interference, unreflected assumptions about their self-determination, or by paternalistic actions.” This statement was reflected by the bloggers included in this study. Some parents of Autistic children do not use the same parenting methods with their Autistic children that they use with their non-Autistic children, sometimes specifically because the methods are not restrictive enough. Some parents deny their Autistic children the right to decide what is on the internet about them. Autistic children could not be part of ABA if they parents did not agree and participate. Sometimes parents are convinced to use pseudo-medical approaches that are harmful for their Autistic children because they are told the approach might cure their child. Autistic adults are sometimes treated as if they occupy a permanent state of childhood. They are sometimes not listened to by their medical practitioners. They are left out of research, denied the ability to communicate, and misrepresented in media and advocacy. All of these things affect the ways Autistic people are able to exercise their agency.



## Chapter Six: Moving Forward

### 6.1. Critical Discourse Analysis Framework: Revisited

#### 6.1.1. *What Language Is Brought Along with Subjectification?*

I began this project because of inspiration from reading an article written by Goodley and Runswick-Cole (2014, p. 1) that characterized the concept of *dis/human* as simultaneously acknowledging the “possibilities offered by disability to trouble, reshape and re-fashion ‘the human’ (crip ambitions) while at the same time asserting disabled people’s humanity (normative desires).” This idea was at the core of what I wanted to explore in this thesis study. I wanted to know about how Autistic people experienced “the human.” I wanted to know how they experienced dehumanization and how they worked toward rehumanization.

The conceptual framework used in this thesis was post-structuralist, new materialist, and post-humanist. I used a critical discourse analysis framework (see Livingstone & Gibson, 2020, pp. 1-3) to gain entry to the blog content in this study. When looking at the blog content, some essential questions about the language around subjectification emerged. These questions included: What language is brought along with Subjectification and the blogger’s relationship to “the human”? And/or, what language is contrasted with Subjectification and the blogger’s relationship to “the human”? Does the language used imply/explicitly identify/exemplify any binaries or tensions (for example, the text endorses neurodiversity but uncritically uses language around functioning levels)? Regarding the blogger’s relationship to “the human” and their own Subjectification, are there any metaphors, euphemisms, figures of speech, or other noteworthy words or phrases used, and to what effect? Do these recur across various texts?



Decosta, Ekins, Forshaw, Kraemer, Leong, Queer Disabled Writer, Sequenzia, Seventh Voice, Sky, and Uninspirational wrote about Autistic people being compared to aliens in their blog content. Forshaw, Kraemer, Leong, Queer Disabled Writer, Sequenzia, Seventh Voice, and Sky wrote about comparisons of Autistic people to animals and robots. Dehumanizing words such as alien, animal, robot, and changeling are applied to Autistic people as a means of othering. As reflected by McHoul and Grace, Foucault (1998) argued that othering is an exercise of power, trying to make yourself look stronger by pointing out a perceived weakness in another. Some blog posts written by the bloggers in this study speculated about why people used dehumanizing language toward them. Some did not feel like the words were negative unless one assumed negative intent. I already said that Leong did not feel that being compared to animals was an insult unless you believed the person making the comparison thought that animals were inferior to humans. However, the bloggers also thought that often, when dehumanizing terms were used against them, the intent was negative.

This brings up the question of why the blogger in this study might have thought people they did not even know had decided to set them up as enemies through their use of vocabulary. The bloggers believed that in some cases, the interests of Autistic people ran counter to the interests of non-Autistic people, at least in some situations. Some of the bloggers pointed to autism research based on the medical model of disability, advocacy corporations that have found it easier to fundraise money using fear or pity over more empowering methods, and people with training and time invested in careers that use approaches to an autism intervention that is not approved of by the Autistic community as examples.

Parents, non-Autistic autism advocates, and non-Autistic people considered experts in autism need to make a habit of referring people to the voices of Autistic people first. They need

to work on centring Autistic voices. They must learn to absorb criticism from Autistic people who tell them they are doing advocacy wrong and reflect on it before responding. They also need to learn to look for Autistic voices in discourse and put weight on what they say. If they look and discover no obvious Autistic voices, they need to ask themselves if this is a discourse that they should continue to be part of.

### ***6.1.2. Where Is Agency Located?***

Questions around agency were included in the critical discourse analysis framework I used as a starting point for my analysis, including: Where is agency located/who is represented as acting? Who is ‘doing’? What ‘happens’? Who ‘is it done to’? Who is not present? Are there instances where the “doer” of an action is erased? What tensions/conflicts are expressed by the blogger regarding their view of where their agency was located? Or that of autistic people as a monolith, compared to where the public believes this agency is located?

Ekins (2017, Jun. 7) located Autistic agency with Autistic people. However, they said this agency is under constant stress and pressure. For many Autistic people, it does not exist. Austerity measures have been used as an excuse to give disabled people inadequate benefits to sustain an independent life. They are forced to depend on the generosity of others, live with strangers or in shared situations, or become homeless. The blogger discussed social programs that attach conditions to the support needed to survive. I previously referred to these kinds of programs as “Conditional Citizenship.”

Sequenzia (2016, Jan. 1) did not explicitly use the term “Agency.” However, the word is implicit throughout the post. Sequenzia argued that disabled children have agency that their parents do not always acknowledge. This is particularly true when disabled children do not communicate in typical ways. Sequenzia (2015, Apr. 22) wrote about assumptions that erase their

humanity. For example, some people assume that because they have challenges communicating their ideas, it means they do not have any ideas worth communicating. Some people assume that because they have high support needs, they do not have agency over their body and mind.

Sequenzia (2014, Jul. 10) firmly declared that no matter how high their care needs or how much facilitation they require to communicate, their agency remains within their power to control. They said that despite the accusations made by bullies, their self-determination had not been overpowered by the influence of their communication facilitators.

Moving forward, key ideas can be gleaned and applied from what the bloggers in this study wrote. First, Autistic people should not be given conditional citizenship. In other words, their ability to exercise their rights or get the support they need to survive should not be conditional to their consent to treatments they do not agree with or their participation in programs that infringe upon their agency. Next, Autistic agency must be viewed as located with Autistic people. This is a truth that needs to gain acceptance and support. This should not be viewed as altered by a person's level of care needs. It should not be viewed as changed by their ability to speak. The input and consent of Autistic people for treatments must be vigorously pursued. Supposing consent is impossible to attain, decisions must be prefaced with an ethical review that includes questioning if the treatment will infringe upon the agency of the Autistic individual. The value of Autistic lives should not be assessed using a formula that weighs how much potential they have to earn with how much it costs to support their needs.

### ***6.1.3. Who Are Portrayed as Authorities? Experts? Knowers?***

Some more questions posed by the critical discourse analysis framework provided to me by Douglas from Livingstone and Gibson (2020) included: Who is portrayed as an authority/knower/expert? What tensions/conflicts are presented between their idea of who is an

authority/knower/expert compared to the public? Does this align with normative understandings of expertise or challenge/subvert them? For example, does the text take for granted that clinicians are experts in working with autistic people or question clinicians' expertise and reposition autistic people as experts?

As discussed in chapter five, the bloggers discussed the problem of researchers, doctors, treatment practitioners, parents, educators, and autism advocates being considered experts over Autistic people. Studying these blogs, I was impressed by how well-informed the bloggers were about current research, issues that were discussed in academia and the media, and how fluently they used both academic and advocacy vocabulary. I wondered, if biographical information and confessions of being Autistic were withheld, if any person who would normally refrain from referring to the bloggers as autism experts (because they were Autistic rather than academics) would still hold back from acknowledging their expertise.

One of the easiest ways to improve relations between Autistic people and doctors would be to educate medical candidates better on autism. The bloggers expressed fear of doctors, saying they experienced being gas-lighted by doctors who did not listen to them when they stated their needs. They also had anxiety about how much power doctors had to impact decisions around whether they would receive financial support. Doctors are required to participate in the diagnosis process. For people who spent most of their lives masking, that meant having to prove their identity by demasking and making themselves vulnerable. Sometimes this vulnerability and demasking resulted in the doctor deciding the person's competence could not be assumed. This sometimes caused their ability to make medical choices for themselves to be limited. For some bloggers in this study, this brought up cultural memories of doctors' roles in eugenics programs and how all eugenics programs start with stripping agency from disabled people. Autistic people

should provide specific education to medical candidates on how they can recognize and support the needs and agency of Autistic people. Proposed projects should have to get approval from an independent ethics committee that has ample Autistic representation. Additionally, more effort should be made to help Autistic people access medical school and to support their success.

Leong wrote over sixty posts specifically involving researchers and autism. Sequenzia wrote forty-two. Forshaw, Kraemer, Miranda, Seventh Voice, and Sky wrote between twenty and thirty posts. Liu wrote seventeen. Queer Disabled Writer wrote eleven. Ekins wrote eight, Uncultured Anthropologist wrote six, and Decosta wrote five. endever\* and Uninspirational wrote four each.

All the bloggers selected for this thesis study said at least once in an article examined for the study that they wished non-Autistic people would prioritize and listen to Autistic voices when it came to the autism research and conversations about autism. This was true of how they felt about the way decisions were made about what research gets funded. Sequenzia (2013, Jan. 2) wrote about absurd theories about the causes of autism that keep getting circulated because of lazy research that lacked peer review. This highlights another problem related to ignoring Autistic voices, in this instance, regarding how research priorities are set. Sequenzia implied that the tendency to view researchers and doctors as experts over Autistic people, even when practicing bad science, might be laughable if not for the terrible results. As already stated, bloggers in this study expressed frustration about what research got funded and who was listened to and consulted when it came to the research data. Words like eugenics were used to describe many of the research projects discussed. Some bloggers wrote about troubling projects that got huge amounts of funding. One of them was the autism genome project that Autism Speaks self-advertises as the largest autism DNA project in the world. Bloggers expressed fear about the

existence of databases with lists of Autistic people and samples of their DNA. They cited the horrific history of eugenics. They pointed to reasons to think the attitudes that allowed eugenics to be taken up as policy in many places were not far below the surface today. They talked about being accused of being hyperbolic for expressing these fears. They talked about being attacked by parents for prioritizing their fears over the suffering of parents. This is one of the topics where they said they got feedback that they are not real Autistics if they could communicate so effectively. Therefore, they should stay silent and stop pulling focus from the needs of real Autistics and their families.

We need to see Autistic researchers setting priorities in accordance with the wishes of Autistic people. We need to see Autistic people themselves asked about what needs to be prioritized, not their parents, families, teachers, therapists, or autism professionals. We need peer-reviewed studies that provide quantitative data on these perspectives. However, we also need to see qualitative research being taken seriously. In this thesis, I worked with blogs. The next step would be to identify Autistic people in a different way and interview them. I could interview Autistic people in the workplace, talk to high school students, revisit the effects of environmental ableism on Autistic people, and collate data from these studies to create a list of questions for a questionnaire. However, I will admit to fear around this prospect. I have been teaching high school students for years, but I still cannot help remembering the list of deficits that tell me I am bad at verbal communication.

Unfortunately, I cannot control the spread of misinformation online or the continued publication of articles based in the medical and deficit model of disability. Increasing the visibility of quality, peer-reviewed research is more important than ever. Independent ethics committees with ample Autistic representation to help set funding priorities and to help with peer

review is also an important step to replicate. As with doctors, facilitating access to post-secondary education that would allow Autistic people to become researchers and supporting their success is also vital moving forward.

Moving forward, it is important to get Autistic people included in autism research. This includes researchers and advisors. Autistic people should not have to have specific degrees to be considered experts on autism. On the other hand, it would help to have Autistic people with those credentials working on projects. Thus, there needs to be a concerted effort to support Autistic academics in their pursuit of education that would put them in a position to be widely regarded as experts, both experientially and educationally. It is also important to look to Autistic advocacy groups for direction on what should be prioritized. Finally, look to the Autistic community to inform your choices of what research to consume. Consider factors such as whether Autistic researchers participated in the research. Consider whether Autistic people were consulted as part of the research process. Look at whether the research was based on the medical model of disability or the social model. Consider the vocabulary used in the study, specifically if it respects the preferences put forward by the Autistic community. Allistic people should also look to the Autistic people in their lives for expertise. Talk directly to Autistic people about their needs and ways they can be supported.

## **6.2. Intersectional Identities: Revisited**

I wanted to know how the bloggers included in this study experienced the intersection of marginalized identities. Each blogger identified at least one marginalized identity other than being Autistic. Six were identified as BIPOC. Eight were identified as QUILTBAG. Thirteen identified as raised as girls or as trans-women. However, I suspect that all the bloggers included in this study were either raised as girls or identified as women once they were able. Four were

identified as multiply disabled. It is generally important not to mix correlation with causation; however, endeaver\* insisted there was no difference regarding the intersection of their trans and Autistic identities. Hammond expressed a similar sentiment concerning race and autism, in that the same structural systems of oppression that created and uphold racism also created and uphold ableism. Hammond also said this puts BIPOC Autistic people at increased risk of systemic violence. They said that because race is so visible for BIPOC individuals, their autism often becomes invisible. Regarding being raised as a girl, many bloggers said the masking that was disproportionately expected of them exacerbated their mental health issues. Some bloggers said that their needs as Autistic people were sometimes ignored because of their other disabilities (or the other way around).

More discussion and research are needed to push forward an agenda of troubling, reshaping and re-fashioning “the human.” There is also more discussion and research needed in asserting disabled people’s humanity and normative desires, as well as the non-normative ones. In other words, there is a long way to go toward the rehumanization of Autistic people.

### **6.3. Own Voice Representation: Revisited**

#### ***6.3.1. Institutional Ableism***

All the bloggers in this study wrote about ableism, even when they did not specifically use that vocabulary. Sequenzia and Uninspirational wrote at least between sixty and seventy blog posts that were explicitly about ableism. Queer Disabled Writer wrote thirty-four, Ekins and Sky wrote between twenty and thirty posts, endeaver\* wrote eleven, Hammond wrote eight, Leong wrote seven, and Kraemer wrote six. Decosta and Liu wrote five each. These were only the articles that specifically used the word “Ableism.” All the bloggers in this study wrote about many micro-aggressions and major acts of oppression that qualified as ableism. They wrote about



systemic acts of ableism, from lack of access to policies that negatively affected Autistic and otherwise disabled people. They wrote about ways Autistic and disabled people were affected as individuals and as a cultural group.

Critical Disability Studies and Critical Autism Studies are newly emerged fields of study (Goodley et al., 2018). Critical Disability Studies considers how institutions and societal structures disable people. It looks at the lived experiences of disabled people as vital to understanding their place in the world and their relationship to power. It challenges the pathologization of difference and advocates for accommodation. Critical Autism Studies is guided by many of the same principles. The leading Autistic expert in “Pathological Demand Avoidance” Richard Woods and co-authors (2018, p. 975) said the sharp increase in interest in Critical Autism Studies has led to the development of three points of definition:

exploring power relationships that construct autism; enabling narratives that challenge the dominant negative medical autism discourses; and creation of theoretical and methodological approaches that are emancipatory and value the highly individual nature of autism and its nascent culture.

The bloggers included in this study also explored the power relationships that construct autism. By looking at the narratives of the bloggers in this study, I saw how they challenged the medical model of autism. I also saw how they offered ideas based on theory as well as their own experiences and the wider community. Thus, they are representing their own idea and the ideas of the larger Autistic culture. One major change that needs to happen is that institutions such as schools need to offer more Critical Autism and Critical Disability Studies programs. At this time there are only a handful of schools in Canada that offer the programs.

Another major change that needs to happen is that institutions, like schools at all levels, need to hire Autistic employees at all levels. It is perhaps the most important for Autistic administrators and educators to be hired. It should not be necessary for these potential staff members to have been educated in programs based in the medical model of disability to get jobs. I once looked at an Autism Consultant position offered by a Saskatchewan school division. Most of the public would not have seen a mention of behaviourism in the posting. However, when I began to apply for the position, a new set of requirements became visible. These included the requirement to be educated in behavioural interventions and ready to implement these in practice. The position was called “Autism Consultant,” but they appeared to be looking for an Applied Behavioural Analysis practitioner.

The performative adoption of the vocabulary of the neurodiversity paradigm will not change the marginalization of Autistic people. It will not change until Autistic people are employed in positions with the power and access to make policy changes within the institutions that govern and shape our society. When I say employed, that is exactly what I mean. What I explicitly do not mean is all the many occasions when they are asked to volunteer their labour doing things any non-Autistic person would be given money to do. In reference to the personal example I gave regarding Saskatchewan school divisions, things will not change until they prioritize employing at least one Autistic person as a Neurodivergence Consultant, under the same umbrella they employ other diversity consultants. Of course, this would have to be a separate and at least equal position as their currently employed autism consultants.

### ***6.3.2. Ignoring Autistic Voices***

#### **6.3.2.a. Childhood**

Like most people who write blogs, the bloggers in this study devoted at least one of their posts to childhood. Many of them wrote articles reflecting on their childhood experiences as Autistic people. Sequenzia and Sky wrote between eighty and one-hundred posts specifically about issues regarding autism and childhood, as well as parenting Autistic children. Forshaw, Kraemer, and Seventh Voice wrote between thirty and fifty posts. Ekins, Hammond, Liu, Miranda, Queer Disabled Writer, and Uninspirational wrote between twenty and thirty blog posts. Decosta wrote six, and endeavor\* wrote five. Again, these were the ones explicitly about issues related to Autistic childhood or parenting.

Either way, most of the bloggers identified as having been raised as girls or identifying as women now. They also wrote a lot about the way masking has affected them. Many of the bloggers were not diagnosed as children. This is common for Autistics raised as girls. They are also commonly pressured by social norms to mask their Autistic personhood. As previously discussed, for BIPOC Autistic people, masking sometimes is used as a defence mechanism for living as a BIPOC Autistic person in a world that is unsafe for such individuals. However, masking is not always a choice. It is forced upon Autistic children who are in ABA programs. Even Autistic children who are not part of ABA are sometimes forced to mask by their parents, who do not want them to engage in stimming or other behaviour they find maladaptive. Whether forced upon an Autistic person or chosen by the individual to avoid being stigmatized, agency is restricted by masking. Restrictions of agency with Autistic children do not end with being pressured to mask. As previously mentioned, they extend to things like invasions of privacy, being treated as permanent children once adulthood is reached, not being allowed to take risks

and make mistakes, being shamed for interests considered age-inappropriate, having your ability to be in a sexual relationship or to be a parent questioned and interfered with, etc.

Moving forward, people need to pay attention to the signs that a child being raised as a girl might be Autistic so that they can access assessment and the resulting support at an earlier age. This is hindered by people holding on to restrictive ideas of gender roles and norms. People raised as girls are pressured by society to engage in more masking, trying to assimilate to society's restrictive ideas of gender norms. This causes signs of autism to be missed or interpreted as something else. Misdiagnosis is common with Autistic women, most often being misdiagnosed with bi-polar, oppositional-defiant, obsessive compulsive, depression, and anxiety. Sometimes they are not misdiagnosed, rather, they are maligned with labels that make their behaviour a character flaw. Terms such as "princess-and-the-pea" and "spoiled brat" syndrome are applied. This often feels worse than being stereotyped by disability, because at least with disability people around you feel some amount of societal pressure to accommodate behaviours that are normally considered socially unacceptable.

Some of the biggest things that need to happen moving forward include raising awareness of what masking looks like, and how it impacts the person engaging in it. This is particularly true in regards to people raised as girls, since they are more likely to engage in masking. We need to work toward eliminating restrictive gender norms that make Autistic people raised as girls feel more pressure to mask. The same would apply to QUILTBAG individuals and BIPOC Autistic people who mask as a safety measure in a world where any additional attention drawn could endanger them. We need to work toward shifting the culture so that behaviours that do not harm an individual or anyone around them are not considered maladaptive. Laws must be created to protect disabled children's privacy, requiring parents to use pseudonyms for themselves and their

children when posting anything online about them. Laws also need to be made and enforced to prevent parents from using dangerous pseudo-science treatments on their disabled children, including the bleach enemas discussed earlier in this study. Autistic adults need to be recognized as adults. Children need to be defined as biological children, meaning a twenty-five-year-old cannot be considered a child even if their intellectual age is within the child range. This needs to apply across the board. For example, as hard as it might be to watch a fifteen-year-old who committed a horrendous crime go through the youth courts, we must recognize that they are not biologically adults. On the other hand, if a twenty-five-year-old person decides something for themselves, it needs to be recognized that they are biologically an adult and have the right to do this. They should also be able to enjoy things considered childish without derision. Autistic people should have their competence assumed until proven otherwise, just like other people. Other people are assumed competent to be parents until their incompetence is proven. The same should be true for Autistic people. This is rehumanization.

#### **6.3.2.b. Communication.**

Some of the bloggers talked more about communication than others. This was understandable, given that some bloggers communicate in atypical ways, either semi-verbal or non-speaking communicators. Sequenzia wrote around eighty-five posts about this subject. endever\*, Leong, Forshaw, and Queer Disabled Writer wrote between nine and twenty posts. Decosta, Ekins, Hammond, Kraemer, Liu, Miranda, Seventh Voice, and Sky wrote between one and eight posts.

Communication is a vital part of our lives as humans. Unfortunately, too often the ability to speak is used as a gatekeeper to being taught how to communicate in other ways. What I mean by this is that it is common for Autistic people who do not speak to also not be taught to read and

write, even in communities and schools that are privileged with the financial resources to invest in intensive programming. Too often, literacy education is replaced with behaviour management. If basic literacy is not a guaranteed part of education, access to communication devices and strategies that are alternatives to speaking can be considered especially precarious. Bloggers included in this study discussed encountering situations where someone tried to deny them their ability to communicate, question their need for accommodations, or even questioned the legitimacy of their communication.

Moving forward, literacy needs to be taught to all students, regardless of their ability to speak. In fact, if a person cannot speak, it only makes sense that even more effort should be put into literacy education. Communication devices and other accommodations should be normalized for all people. We should not be gatekeeping access to accommodations, because we do not know what invisible disabilities people have. Also, it is none of our business. People should not have to justify using a device that makes their lives easier. This shift would make it less likely that disabled people would be othered for using assistive communication devices or other communication accommodations. It should be illegal to take away someone's communication device or deprive a person of the ability to use it, and the existing laws should be enforced. This is rehumanization.

### **6.3.2.c. Representation and Advocacy**

Media and pop culture are a source of Autistic representation. It influences the discourse around autism, for better and for worse. There are so many ways the bloggers included in this study criticized how Autistic people are portrayed in the media. They talked about the dominance of "Parent Memoirs" meaning text produced about being the parent of an Autistic person. The bloggers said that some of these were well-meaning, and others fell solidly in the category of

promoting the parental suffering narrative. The bloggers also criticized the degree of invasion of Autistic children's privacy and agency over what gets shared publicly about them. An example of a text that pushes-back against the dominance of these kinds of books is *Sincerely, Your Autistic Child: What People on the Autism Spectrum Wish their Parents Knew About Growing Up, Acceptance, and Identity* (2021), written by the Autistic Women and Nonbinary Network and edited by Emily Paige Ballou, Sharon DaVanport, and Morénike Giwa Onaiwu.

Sequenzia wrote over one hundred articles on this subject. Leong wrote over seventy, Liu and Kraemer wrote over forty. Miranda wrote over thirty and Ekins wrote over twenty. Hammond, Kraemer, Queer Disabled Writer, Seventh Voice, and Sky wrote between ten and twenty. Decosta and endeaver\* wrote eight each.

The bloggers in this study also wrote many articles about Autistic people being murdered by their family members and caregivers. Sequenzia wrote around thirty-five articles on this subject. Decosta, Ekins, and Forshaw, wrote between five and ten articles each. endeaver\*, Leong, Liu, and Uncultured Anthropologist wrote between one and four articles each.

Sequenzia talked about the community outpouring of grief that happens every time this happens. Years ago, I wanted to test this, so I made a Google Alert (set to worldwide) that would let me know when articles were posted about the murder of an Autistic person by someone who was supposed to care for them. I have been getting alerts for years now, including new incidents about once a week. Based on this, I can confirm that the framing of these events is very generous regarding the motivations of these murderers and their ultimate guilt. The bloggers also expressed that this subject gets them accused of being hyperbolic when they write about its prevalence. It is a strange contradiction that Autistic people are accused of lacking empathy, yet the Autistic bloggers included in this study have been accused of blowing their concerns and grief about the

murder of Autistic people by their caregivers out of proportion. They are told these are isolated events, in no way indicative of a larger threat to the lives of Autistic people. The language used by the media represents a huge threat to Autistic people. The bloggers discussed how Autistic people are depicted as trapped, suffering, burdens, worthy of pity, and possessing a bleak future. Forshaw used this specific language in eighty-eight posts. Leong used it in sixty-five posts. Sequenzia used it in forty posts. Ekins, Queer Disabled Writer, and Seventh Voice used it between ten and twenty posts. Decosta, endever\*, Hammond, Kraemer, Liu, Sky, and Uninspirational wrote between one and nine posts using this specific vocabulary. The media echoes narratives that Autistic people are diseases, tsunamis, epidemics, and lost children that are proliferated by Autism Speaks. They do not spend much time scrutinizing the motivations and prioritizes of Autism Speaks before echoing their rhetoric.

Every article written about autism by these Autistic bloggers technically qualifies as advocacy and representation. However, many of the bloggers explicitly wrote about these topics. Sequenzia wrote around one-hundred-fifty of them. Forshaw, Leong, and Queer Disabled Writer wrote between twenty and thirty articles. Decosta, Ekins, Hammond, and Kraemer wrote between ten and twenty articles. endever\*, Liu, Seventh Voice, Sky, Uncultured Anthropologist, and Uninspirational wrote between one and nine blog articles. They expressed frustration about Autistic voices being overshadowed and supplanted by non-Autistic voices in discourse about autism. They talked about the Autistic community versus the autism community and how frustrating it was to have their voices drowned out by the autism community. They expressed dread at the approach of “Autism Awareness Month” in April, knowing it would mean they would get corrected, scolded, and silenced by the autism community for daring to push alternative talking points. They expressed annoyance at seeing non-Autistic “Experts” being the



go-to resource for most people, seeing their posts shared while their own get a handful of likes and shares. They also expressed annoyance at the need to tailor what they said to avoid backlash from the autism community. On the other hand, some bloggers said they felt pressured to fall in line with the priorities of the Autistic community. They felt pressured to echo the discourse of the Autistic community. They felt this discourse was often centred on a white Autistic perspective that did not serve their interests.

When it comes to how ignoring Autistic voices impacts the discourse around autism, it is important to mention parents of Autistic people. I think it is important to make the “Not All Parents” provision. However, based on how many of the articles written by the bloggers included in this study centred around the way parents impact the agency of Autistic people and the discourse around autism, it is necessary for me to address it. All bloggers in this study wrote more than one blog post about parents taking away their Autistic child’s advocacy. While all kids lack some agency, these bloggers described inappropriate denial of agency for an inappropriate length of time. Some bloggers had a massive quantity of blog material addressing this issue. Many bloggers wrote articles addressing parents in gentle ways they probably thought would be considered productive. Some of these bloggers seemed to hit a point of frustration and exhaustion, where their tone changed towards parents, or they shifted their focus to addressing Autistic people.

I want to revisit our role as allies briefly. Since disabled people are not a monolith, Autistic people are also allies. I was unsure how to support the unique needs of the Indigenous Autistic people in my life because that was not my experience. I had to look for voices speaking on this subject, including Grant Bruno who is working on their PhD in Alberta and work being done in New Zealand. The same was true for the QUILTBAG Autistic people in my life. My role

as their ally is to assume their competence, reinforce their agency, amplify their voice, and amend false narratives when I see them.

I also need to throw my support behind advocacy efforts created by the Autistic community. The primary one that comes to mind is the “Autistic Self-Advocacy Network.” Sequenzia wrote around one-hundred twenty blog posts concerning ASAN. Queer Disabled Writer wrote ten. Decosta, endeaver\*, Forshaw, Leong, Sky and wrote between one and five articles about ASAN. If I want to push the goal of centering Autistic voices, I must continue supporting and promoting the work of organizations with the same goals. This is rehumanization.

#### **6.3.2.d. The Autism Cure**

Sequenzia wrote around sixty articles about the subject of a cure for autism. Ekins, endeaver\*, Forshaw, Leong, Queer Disabled Writer, Seventh Voice, and Uninspirational wrote between ten and thirty articles. Decosta, Hammond, Kraemer, Liu, Miranda, and Sky wrote between one and nine posts.

Over and over, the bloggers in this study expressed love of their Autistic identity. They said they did not want or need a cure. They also said that the amount of money spent chasing a cure for autism was a waste, against their wishes, and better spent on programs to accommodate the needs of Autistic people. They said that having accommodation needs should not be a source of shame in society. The bloggers said that the cause of a cure being prioritized was the centring of non-Autistic voices in the discourse. Autism researchers tend to take their priorities from this discourse.

The bloggers admit that not every Autistic person feels the same way about the topic of a cure. If someone based their view of autism on how autism was described and discussed in diagnostic materials, they would conclude that autism caused suffering and pain to the Autistic

person and the people in their lives. However, this conclusion would be inaccurate. Diagnostic materials pathologize many behaviours and traits while not mentioning positive ones. The bloggers said that most of the time, the things Autistic people would gladly be rid of are not autism itself: Anxiety, depression, and loss of agency. The first two are predominately the result of the disproportionate need to mask their identity. The third is the result of the way Autistic disability is socially constructed.

#### **6.4. Conclusion**

I started out with a similar goal Hammond had for their blog writing. Hammond 2022, Jul. 1) said they wanted to set aside discourses about red flags and symptoms and talk about the breadth of Autistic humanity by considering multivariate experiences. I wanted to look at how Autistic people were dehumanized, and what they were doing to rehumanize themselves and encourage other people to become allies in their rehumanization. Examining online blogs written by Autistic bloggers allowed me to read multivariate perspectives concerning the breadth of Autistic humanity and experiences. One of the overwhelmingly consistent themes in the blog content was that the bloggers felt the need to remind people of their humanity. They felt the need to remind people that they were a person rather than a burden, tragedy, cause of suffering, unworthy, a tsunami, a health crisis, the side effect of vaccines, not quite human, or a changeling.

These narratives are some of the first that parents of Autistic children encounter. This reflects directly on how parents of Autistic people sometimes treat their children. Another consistent theme in the material was the expression of trauma experienced at the hands of adults in their lives when they were children. For example, parents post intensely private information about their Autistic children on the internet and include these intensely private stories in parent memoirs. They claim to be doing it for the purpose of education and helping other parents. Many

bloggers said that if the primary concern of these parent-creators were to educate other parents, they would be vague and anonymous rather than making it their social media brand. However, it is hard to build a brand on anonymity and non-sensationalizing. It is hard to get consistent eyes to your material when working anonymously.

Suppose the initial narratives parents of Autistic children encountered were not overwhelmingly negative, denying the agency and humanity of Autistic people. In that case, it seems reasonable to assume Autistic people would experience much less trauma during their childhood. Consequently, they would feel better and more secure about their humanity. In the meantime, this narrative and the resulting treatment leave Autistic people feeling like they might not be human. The bloggers talked about being gaslighted by their family, friends, and people who were well-intentioned and loved them. Besides leaving Autistic people questioning their relationship with humanity, they are often made to feel that being outside of humanity would be preferable. That presents the question of why more Autistic people do not embrace post-human possibilities. The answer comes down to Autistic people feeling like their energy is better spent having their humanity consistently recognized and supported. Our humanity is questioned and attacked through big actions and many micro-aggressions. The fight to keep from losing ground is so intense, Autistic people do not have the energy left over for exploring experiences more expansive and inclusive than “the human.”

## **Appendix A: Common Experiences for Trans and Gender-Diverse Autistic People**

Purkis and Lawson (2014) listed common experiences for trans and gender-diverse Autistic people, as follows:

- Having a sense of being different, often from a young age (but not necessarily attributing these feelings to gender).
- Being bullied due to autism and gender.
- Having difficulties accessing medical procedures.
- Being dismissed and invalidated by medical professionals.
- Having gender identity doubted or invalidated by others.
- Feeling a strong sense of pride as an Autistic person and a gender-diverse person.
- Feeling connected to the autism and/or trans communities.
- Having resilience and determination.
- Being patronized.
- Facing assumptions that a person is cisgender and asexual.
- Facing challenges accessing education and employment.

## **Appendix B: Transcript of Autism Speaks Advertisement (ASAN, 2009)**

I am autism. I'm visible in your children, but if I can help it, I am invisible to you until it's too late. I know where you live. And guess what? I live there too. I hover around all of you. I know no color barrier, no religion, no morality, no currency. I speak your language fluently. And with every voice I take away, I acquire yet another language. I work very quickly. I work faster than pediatric aids, cancer, and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don't sleep, so I make sure you don't either. I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain. You have no cure for me. Your scientists don't have the resources, and I relish their desperation. Your neighbors are happier to pretend that I don't exist—of course, until it's their child. I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up you will cry, wondering who will take care of my child after I die? And the truth is, I am still winning, and you are scared. And you should be. I am autism. You ignored me. That was a mistake.

And to autism I say: I am a father, a mother, a grandparent, a brother, a sister. We will spend every waking hour trying to weaken you. We don't need sleep because we will not rest until you do. Family can be much stronger than autism ever anticipated, and we will not be intimidated by you, nor will the love and strength of my community. I am a parent riding toward you, and you can push me off this horse time and time again, but I will get up, climb back on, and ride on with the message. Autism, you forget who we are. You forget who you are dealing with.

You forget the spirit of mothers, and daughters, and fathers and sons. We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations. We are coming together in all climates. We call on all faiths. We search with technology and voodoo and prayer and herbs and genetic studies and a growing awareness you never anticipated. We have had challenges, but we are the best when overcoming them. We speak the only language that matters: love for our children. Our capacity to love is greater than your capacity to overwhelm. Autism is naïve. You are alone. We are a community of warriors. We have a voice. You think because some of our children cannot speak, we cannot hear them? That is autism's weakness. You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands? You have not properly been introduced to this community of parents and grandparents, of siblings and friends and schoolteachers and therapists and pediatricians and scientists. Autism, if you are not scared, you should be. When you came for my child, you forgot: you came for me. Autism, are you listening? (ASAN, 2009)

## Appendix C: Tips on How to be a Better Autism Advocate

The points Brunton and Gensic (2021) in step, focused on how to emphasize acceptance of Autistic people, were as follows:

- Replace panic with steady growth in awareness/acceptance
- Reframe autism as a way of being (not a tragedy)
- Focus on eliminating barriers instead of so-called “bad” behaviours/attributes
- Work for change in society, cultures, and institutions, not Autistic people
- Be sensitive to the details but work towards the bigger picture (Brunton and Gensic, The #Actually Autistic Guide to Advocacy).

The points under Step 2, focused on adopting a balanced perspective, were as follows:

- Avoid assumptions about savantism
- Take the entire lifespan into account
- Avoid stereotyping by gender
- Acknowledge strengths and weakness as with all humans (Brunton and Gensic, 2021)

The points under Step 3, focused on how to encourage the presumption of competence of Autistic people, were as follows:

- Distinguish between autism and other intellectual differences and disabilities
- Understand that neuro-normalized methods are often used to determine competence
- Listen, listen, listen—even when someone isn’t talking at the speed you’d prefer
- Be aware that over-sheltering can prevent people from growing (Brunton and Gensic, 2021)

The points under Step 4, focused on how to advocate for individuals, are as follows:

- Embrace respectful story-sharing



- Be aware of the perils of blanket assumptions
- Always get to know the Autistic person first
- Never expect a one-size-fits-all-solution
- Beware of inspiration porn
- Honour the diverse aspects of Autistic people (Brunton and Gensic, 2021)

## **Appendix D: Some Identified Autistic Scholars Working in Disability Studies**

Some of the known Autistic authors included in this study are as follows: Hanna Bertilsdotter Rosqvist, Monique Botha, Damian Milton, Ari Ne'eman, Michael Orsini, Steven Kapp, Patrick Dwyer, Kimberly Crenshaw, Alison Nuske, Melanie Remi (Yergeau), Krysia Waldock, Anna Stenning, Yenn Purkis, Tania Melnychuk, TC Waisman, Maura Campbell, Dora Raymaker, Devon Price, Eric Garcia, Alyssa Hillary Zisk, Robin Roscigno, Gemma Williams, Cos Michael, Kayden Stockwell, and Abby Sesterka.

## Appendix E: Critical Discourse Analysis Framework Questions

- What language is brought along with neurodiversity? — This could include language around brains, biodiversity, community, pride, accommodations, and difference.
- What language is contrasted with neurodiversity? — This could include language around pathology, clinician language, ABA, cure, and functioning levels.
- What language is brought along with Subjectification and the blogger’s relationship to “The Human”?
- And/or, what language is contrasted with Subjectification and the blogger’s relationship to “The Human”?
- Does the language used imply/explicitly identify/exemplify any binaries or tensions? — This can include whether the text endorses neurodiversity, but uncritically uses language around functioning levels).
- Regarding the blogger’s relationship to “The Human” and their own Subjectification, are there any metaphors, euphemisms, figures of speech, or other noteworthy words or phrases used, and to what effect? Do these recur across various texts?
- What style is used? This could include scientific, professional, personal narrative, policy argument (etc.)?
- What pronouns are used (e.g. “they”, “we”), and to what effect? Think about how pronouns differentially position subjects/actors and help illustrate relationships of power, solidarity, authority, inclusion/exclusion, etc. Along the same lines, does the blogger use person-first or identity-first language?

- Where is agency located/who is represented as acting (e.g. who is ‘doing’, what ‘happens’, who ‘is done to’, who is not present, are there instances where the “doer” of an action is erased)? What tensions/conflicts are expressed by the blogger regarding their view of where their agency was located, or that of Autistic people as a monolith, compared to where the public believes this agency is located?
- Who is portrayed as an authority/knower/expert? What tensions/conflicts are presented between their idea of who is an authority/knower/expert compared to the public? Does this align with normative understandings of expertise or challenge/subvert them (eg. does the text take for granted that clinicians are experts in working with Autistic people or question clinicians’ expertise and reposition Autistic people as experts?).
- What cause and effect connections or relationships are highlighted? If relevant, consider whether these connections are commonsensical or if they challenge/subvert taken-for-granted cause and effect relationships.

Next, the framework asked the question, “Are any other texts/authorities/specific events highlighted or challenged? Interrelated questions included:

- Pay attention to any intertextual links.
- (How) are other voices and social actors represented? — This question can be collapsed with the one above (to do with expertise) if that’s easier. Are there significant voices missing? How are various voices/actors positioned relative to the authoritative voice and one another? What tension/conflict exists between how various voices/actors position themselves in the question of who has the authoritative voice regarding autism as a monolith and individual Autistic people.
- What conversations (if any) happened in the comment section? What did this reveal?

- Other— Reader reactions, surprises, quotes (with page numbers), connections noticed, questions raised, note if text is a candidate for in-depth analysis (if it's a particularly illustrative, representative, or clear example).

([https://uwaterloo.ca/scholar/sites/ca.scholar/files/m23gibso/files/discourse\\_analysis\\_research\\_to\\_ol.pdf](https://uwaterloo.ca/scholar/sites/ca.scholar/files/m23gibso/files/discourse_analysis_research_to_ol.pdf)).

## **Appendix F: What Kraemer’s Doctor Did Not Do (reducing marginalization)**

This list was written by Kraemer (n.d.) in “Update: Doctors visits and (lack of) judgment” on the *Autistic Science Person* blogsite.

- They did not try to get me to speak when I was looking at the floor and starting to tear up.
- They did not get annoyed or impatient that I wasn’t responding ‘correctly’ or quickly.
- They did not talk down to me or infantilize me (they talked in a normal tone, like I was an adult just like anyone else).
- They did not assume that I could not understand what they were saying, just because I couldn’t talk.
- They did not tell me my problems were not a big deal, and did not chastise me for decisions I made in my previous medical history (didn’t say ‘you should have done X’ or ‘why didn’t you do Y’).
- They did not make vigorous eye contact to see if I would look away, or try to see how I react to certain social things like tone of voice.
- They did not refuse to treat me.
- They did not refuse to read the paper explaining my circumstances.

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