

**Shaping Autism Self-advocates' Identities  
Through the Neurodiversity Movement**

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# **Shaping Autism Self-advocates' Identities Through the Neurodiversity Movement**

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## **Abstract:**

This thesis examines how and why the neurodiversity paradigm and movement influence autistic people's identities as they participate in autism self-advocacy activity. The neurodiversity paradigm dictates that autism and other neurodevelopmental conditions are the result of neurodiversity, or the natural variations of human brain development. In turn, the neurodiversity movement aligns with the social model of disability, stating that autistic people are not directly disabled by their neurological differences, but rather by the general lack of accommodations provided by their society. By participating in self-advocacy groups, autistic people can thus view their autism as something that makes them unique rather than something that is inherently wrong. This thesis will thereby examine how continual involvement in autism self-advocacy activity allows autistic people to negotiate and practice their neurodivergent identities as a way of resisting stigmatizing views of autism that still prevail among society.

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## **Introduction:**

This thesis aims to shed light on how and why some autistic people incorporate their autism as an element of their identities. As will be discussed, autistic people often do so by participating in autism self-advocacy activity, in which fellow autistic people come together to fight for each other's rights, as well as by subscribing to the neurodiversity paradigm, which proposes that autism results from natural variations in human brain development.

First, this thesis will provide a brief overview of the current definition of autism, otherwise known as Autism Spectrum Disorder in the DSM-5 (APA 2013), along with its history in medical literature during the last century. Autism is a relatively recent term in medical literature. Definitions of autism have changed considerably over the years. Its current clinical name, Autism Spectrum Disorder (ASD), reflects that there is also notable variability in autism's presentation. These aforementioned facts, along with a general lack of discussion of autism-related issues from the perspective of autistic people (Belek 2017), have led society's understanding of this condition to become rather skewed. As such, these factors may negatively impact the identities of a population whose needs are still often ignored.

As explained in the following section, many autistic individuals have created self-advocacy groups in order to counter this lack of inclusion. Organized either in-person or through online media, autism self-advocacy groups aim to give members of the autistic community the opportunity to discuss and fight for the accommodations they may need to fulfill their potentials within society (Waltz et al. 2015, 1175). Autism self-advocacy

groups and activity have gained increasing attention as more people from the autistic community make their positions known.

Secondly, I will discuss the subject of neurodiversity, and its subsequent paradigm and movement. The neurodiversity paradigm and movement proclaim that autistic people are disabled not because they are sick, but because marginalized status denies them many of the accommodations they need. Since autism self-advocates argue the need for greater equity, recognition, and acceptance, the neurodiversity paradigm and movement can thus be used to further propel these arguments. Both the neurodiversity and autism self-advocacy movements serve to reframe our understanding of the condition in a less stigmatizing manner, as they argue against beliefs that autism makes a person faulty, and instead state that this and other disabilities simply make people different, which is not inherently negative. How people who are autistic understand their diagnosis also has implications for how they identify as autistic individuals.

Identity is a major point of focus within the field of Anthropology. In recent years, there have been a growing number of theories used to describe identity development and autism in conjunction, including biographical illumination and social constructionism. Biographical illumination (Tan 2018) describes how people's self perception may improve after receiving a diagnosis, or after using their newfound diagnostic label to find social solidarity with other autistic people. Social constructionism, which proposes that our understanding of self can only exist in relation to other people (Burr 1995), also helps explain how many autistic individuals reshape their knowledge of autism through repeated social interaction within self-advocacy groups, and thereby ultimately develop a more positive identity surrounding their disability (Bagatell 2007; 2010). Although these two theories derive largely from sociology or psychology, they can nevertheless help us

describe the processes by which autistic individuals come to understand how their autism may form an essential aspect of who they are.

Anthropology itself would study autistic identities as something that people negotiate through habitual interaction within both autistic and neurotypical social realms, and alter over time and in different contexts. Autistic individuals may sometimes view their autism as a negative element of their identity if they have internalized any stereotypes about autism, which are often created and imposed by neurotypical people who often exercise their power to propose what constitutes *normal* human sociality. By contrast, society often subjugates autistic ways of being because they do not live up to hegemonic, neurotypical standards. This can thereby perpetuate negative stigma and stereotyping, and subsequently result in a greater decrease in positive self-perception.

As I will elaborate, anthropologists can use practice theory (Bourdieu 1977), and the theory of community of practice (Bucholtz 1999), to examine how autistic people improve their self-perception by presenting themselves as neurodivergent individuals, thereby resisting dominant, neurotypical social norms. Autistic people can maintain this identity through habitual engagement in autism self-advocacy groups (1999, 207-209). As more autism self-advocates declare their neurodivergent identities to resist some of the prevailing notions society holds about autism, they allow the neurodiversity and self-advocacy movements to grow. In turn, more autistic people are encouraged to assert their identities, as both movements allow autism to be better recognized and understood by society.

This thesis uses qualitative research to provide a detailed examination of how some autistic individuals subscribe to the neurodiversity paradigm and engage in self-advocacy activity, to assert why their autism forms an inseparable element of their identities. It is

worth noting that the data used for this thesis is not meant to represent the entire autistic community. Notwithstanding, we can use qualitative research methods to learn in depth about why many autistic individuals believe that the neurodiversity paradigm and the autism self-advocacy movement can help society better recognize the needs of the autistic community as the whole, without having to rely on out-dated, pathological approaches that can further subjugate people from this community.



## **Methods and Research:**

This thesis is based on data from seven participants, aged 21-50 years, that was collected through a series of one-on-one, semi-structured interviews. During the interviews, all participants were asked the same set of nine questions, which pertained to any of the topics of neurodiversity, autism self-advocacy, and identity, on which this thesis focuses. Some of the questions included: “2. A) Have you been involved in autism self-advocacy groups? B) How has your involvement helped your understanding of what it means to be autistic?”; “5. Has your understanding of neurodiversity shaped/contributed to how you think about your own autism?”; and, “8. Do you believe neurodiversity should be given greater focus when discussing autism-related issues?” (see Appendix A).

Following the protocols of semi-structured interviews, I also diverged from the main series of questions on occasion, such as by asking follow-up questions. By doing so, my interlocutors and I could better maintain our conversations about relevant ideas of the primary research topics. This also allowed interlocutors to collect their thoughts and approach these ideas in ways that were easier for them to answer.

So as to ensure that all identities remain confidential, pseudonyms are used for each of the contributors to the thesis. Additionally, I asked the interlocutors to state the pronouns by which they preferred to be referenced. As one participant used gender-neutral pronouns, singular they/their/them pronouns will be used in reference to them. The expected time frame for the interviews was approximately 45 minutes, with individual interviews spanning between 15 and 60 minutes. All participants were recruited on a volunteer basis.

The expected sample size for this research was between 6-12 participants. Particular interest for recruitment was taken in people who have been involved in autism self-advocacy groups. However, all adults who were aged 18 years or older, had an ASD diagnosis, and lived in the Halifax Regional Municipality, were eligible to participate. Potential research participants were recruited through Autism Nova Scotia, the Autism Research Centre at Dalhousie University, as well as through personal connections with colleagues, friends, and also participants who were already interviewed. Recruitment was aided by research advertisements that were distributed at Saint Mary's University campus and through the above-mentioned routes of connection, and also through recruitment letters, which were sent directly to potential research volunteers.

This thesis research was approved by the Research Ethics Board at Saint Mary's University in October 2018, and all precautions were taken to ensure that conducting this research project entailed minimal risks to the participants. I audio recorded each interview session to use as my data, after which I played it back, transcribed it, and saved it onto a password-protected folder on my laptop computer.

In this thesis, I use identity-first language (ie. autistic person) rather than person-first language (i.e. person with autism) when discussing the group of people being researched, which goes in line with the general preference of the autistic community. Using identity-first language also emphasizes the thesis' goal to demonstrate how autistic people integrate their autism as part of their neurodivergent identity to challenge potentially dehumanizing views of autism. Contrasting the fact that a number of autistic individuals are semi or non-verbal, all the participants in this research were fully capable of verbal communication. As such, while the data collected for this research can help

explain several of the issues faced by autistic people in general, note that this thesis represents a mere, yet detailed section of the whole autistic community.

The qualitative data used in this thesis also has direct implication for anthropological research. In anthropology, identities are regarded as complex, multi-faceted, and ever-changing products of lived experience and social interaction, and thus require a smaller-scale, detailed analysis to determine how they come to be. Therefore, it is most expedient to use qualitative research methods, such as through semi-structured interviews that pose questions about a variety of topics relevant to the interlocutors' personal experiences, to discern how the neurodiversity and autism self-advocacy movements help some autistic people understand their autism as an intrinsic part of who they are. We can also determine how autistic identities are revealed explicitly, or implied through nuanced social actions and interactions.

## **A Brief Overview of Autism and its History:**

As stated in the Diagnostic and Statistical Manual (DSM-5), Autism Spectrum Disorder (ASD) is a congenital, lifelong neurodevelopmental disability. It is typically characterized by deficient or atypical social communication development, as well as restricted and repetitive behavioural patterns (APA 2013, 50). Social communication signs can include difficulties in “social-emotional reciprocity”, whereas, “stereotyped or repetitive motor movements, [... and] hyper- or hypo-reactivity to sensory input” are examples of restricted and repetitive patterns of behaviour (2013, 50). Autism is considered a spectrum disorder because the associated traits manifest themselves to different extents in each autistic person. At the time that the DSM-5 was published, it was estimated that ~1 % of the global population had an ASD diagnosis, with varying frequencies across countries (APA 2013, 55). In 2018, approximately 1 in 160 children globally were estimated to have an ASD diagnosis (WHO 2018).

The term *autism* derives, “from the Greek word for self- *autos*”, and was used to describe a supposed disregard for the outside world, and a preoccupation with the inner self, amongst people who display characteristics of this condition. (Silberman 2015, 5) Our current understanding of Autism Spectrum Disorder, as it is defined in the DSM-5 (APA 2013), first emerged in the 1930s and 40s, courtesy of extensive research by two child psychiatrists, Leo Kanner (1943; 1973) and Hans Asperger (1944).

While Kanner and Asperger’s findings were quite similar, they were initially established in the DSM-4 as two separate diagnoses under the broader category of Pervasive Developmental Disorders, respectively as Autistic Disorder and Asperger’s

Syndrome (APA 1994). Considerations for classifying autism as a spectrum disorder began in the early 1980s, when scholars including Lorna Wing re-examined the overlap in traits found in both Kanner and Asperger's patients. This eventually led to a reclassification of Autistic Disorder and Asperger's Syndrome as two variants of the same Autism Spectrum Disorder, with the release of DSM-5 (APA 2013).

### **Autism in Medical Literature:**

Clinician Leo Kanner was the first doctor to use the terms *autism* and *autistic* as per their present day conceptions, to describe similar behavioural characteristics found amongst eleven of his child patients, who often seemed to be happiest when left alone (1943). Later, he decided to call his discovered condition *early infantile autism*, highlighting how children such as his patients showed signs of what would now be considered ASD, namely atypical social communication development (APA 2013, 50), within the first few months of life (Kanner 1973, 94).

Furthermore, Kanner stated, "while they are remote from affective and communicative contact with people, they develop a remarkable and not unskilful relationship to the inanimate environment" (1973, 94-95). Kanner noted that many of his patients were intently aware of the outside world, interacting with objects in repetitive manners, such as by constantly spinning toys. Thus, Kanner's patients navigated the world with "tense alertness to make sure that their surroundings remain[ed] static" (1973, 95). The characteristics that Kanner noted are also examples of restricted interests and repetitive behavioural patterns, as classified in ASD (APA 2013, 50).

One year following Kanner's discoveries, Viennese psychiatrist Hans Asperger documented similar findings amongst several of his patients (Asperger 1944). Asperger

expressed that compared to typically developing children, “who lived in constant interaction with their environments”, the manners in which his patients interacted with people and their environments were “severely disturbed and considerably limited” (1944, 38). Asperger also noted that the children he saw were quite verbose for their ages, with one patient having started talking when he was only ten months old (1944, 39). Despite early language acquisition, language use was often considered unusual. For instance, one of Asperger’s patients often struggled to answer questions if they were not repeated (1944, 44). Such findings demonstrate signs of atypical social communication development in ASD (APA 2013, 50).

The patients documented in Kanner (1943; 1973) and Asperger’s (1944) works shared many characteristics associated with what we would consider ASD today (2013). However, because Kanner and Asperger worked independently from each other, they thus believed their findings constituted two different conditions, as did many other medical professionals in their time (Wolff 2004, 204).

Then, in 1981, English psychiatrist Lorna Wing reviewed some of Hans Asperger’s original research, and suggested a new diagnostic label for children who shared many of the characteristics that Asperger described. In his honour, Wing proposed the diagnosis be called Asperger’s Syndrome (Wing 1986). In her proposition, Wing also pointed out the popular stereotype about autism, which was that “of a child who is agile, but aloof and indifferent to others, with little or no speech and no eye contact” (513). Such stereotypes more than likely arose from general knowledge about research from the early twentieth century, such as that of Kanner (1943), in which most of the patients documented were children who displayed notably atypical social communication and behavioural traits associated with autism.

Wing argued that this stereotypical view of autism dismissed children whose autistic characteristics were less pronounced, and especially those of autistic adults, who were often not documented in early research on autism (Wing 1986, 513). Wing also suggested that due to prevailing stereotypes of autism, “parents and professionals tend to be more receptive if told that the person has an interesting condition called Asperger’s syndrome” (513). In turn, parents and caregivers would be more inclined to seek the same management techniques provided for children with classic autism, which was then also called Kanner’s autism (Wing 1997, 18), without having to face the same stigma (Wing 1986, 514).

Outside the British medical system, the American Psychiatric Association later adopted the label Asperger’s Syndrome with their release of DSM-4 in the mid-1990s, when it was classified as its own diagnosis under the umbrella term of the Pervasive Developmental Disorders (APA 1994). Here, Asperger’s Syndrome was given as a diagnosis to individuals of average to above-average intellect, who displayed many of the repetitive behavioural patterns and delays in social skills associated with classic autism, but who also lacked significant impairment in language development (APA 1994).

Additionally, despite previously being considered two separate conditions, Wing proposed that there was a substantial amount of overlap between Kanner and Asperger’s discoveries. For her, the children studied in both Kanner’s and Asperger’s research therefore represented different areas of what she dubbed the autism spectrum. Eventually, the idea that autism was a spectrum disability made its way to the American Psychiatric Association, and the Pervasive Developmental Disorders in the DSM-4 (1994) were reclassified in the DSM-5 as a broader, singular term Autism Spectrum Disorder (2013).

Underlying the medical research (Kanner 1943, 1973; Asperger 1944) of what we now know to be ASD was the notion that patients who presented as autistic were in some way deficient as a result their atypical development. These ideas were highlighted through phrases such as “severely disturbed”, used to describe unusual social development (Asperger 1944, 38). Many supporters of the neurodiversity paradigm and movement argue that such attitudes align with the pathology paradigm, which proclaims that all traits associated with autism are inherently disabling to people who have the condition (Fenton and Krahn 2007, 1). As Nick Walker elaborates, “the pathology paradigm is inextricably entwined with the medical model of disability”, which in turn states that autistic people are disabled by their own medicalized symptoms, “and that having traits and needs that are incompatible with [societal] norms constitutes a personal deficiency” (Walker 2016).

As gathered from some of my own interlocutors, views that adhere to the pathological paradigm run the risk of making autistic individuals feel that their ways of being are unfavourable and must be fixed in order to fit into society. There have also been few opportunities for autistic individuals, many of whom indeed do not see their condition as inherently disabling, to talk about how they define autism. By excluding autistic people’s definitions of their condition, this skews society’s understanding of autism, and potentially leads to stigmatization and negative stereotyping about how autism disables people.

### **What does Autism mean to the research participants?**

Autism has most often been defined by non-autistic people, and by organizations that non-autistic people create to spread awareness of the condition. Some of these



organizations provide little room for people who are autistic themselves to talk about how their autism affects them, what sorts of accommodations they may need to best integrate in their society as autistic individuals, and also how their autism factors into how they perceive themselves. As I will explicate, one issue that arises from not allowing for first-person input on the subject of autism is the spread of misconceptions and stereotypes about this disability, which can potentially be harmful to people within the autistic community. I therefore argue that it is important to ask autistic people what autism means to them, so as to provide an opportunity to counter this lack of first-person perspective, and to verify or dispel some of the preconceptions about autism.

When I asked my research participants about what autism meant to them, they each described it as a major aspect of their being, and that it therefore played an important role in how they understood themselves, and navigated their worlds. Some interlocutors expressed their attitudes toward their autism changed depending on different social contexts and over different times in their lives. A few people expressed that they had more positive views of their autism when they were around other autistic people, while others noted how their self-perception changed, often for the better, from the time they were first diagnosed to the present.

The participants also held different opinions about whether they saw their autism as a disability or not. One participant disliked how autism is described as a disability, which can possibly reflect how some autistic people internalize stigma that arises from pathological views of disabilities. On the other hand, several more participants were not against describing their autism as a disability, thereby implying that other members of the autistic community accept the disability label to resist stigma. Additionally, at least one of my interlocutors addressed a rather hotly debated topic within the autistic community-

whether autistic people are disabled by their societies as opposed to any limitation brought on by their autism directly.

Besides these varying opinions, a few of the partakers defined their autism by metaphorically comparing themselves to different computer systems. This analogy demonstrates how the brains of autistic and neurotypical people are similar to programming codes, as both are capable of doing their job to operate their governing bodies. However, just as one code would be incompatible with another computer system, an autistic person's brain cannot operate exactly the same ways as that of a neurotypical person.

Firstly, most of the participants defined their autism as a mostly positive aspect of their lives. At the very least, it was an aspect that the interlocutors came to gladly accept over time. Judy, a 21-year-old university student who also has several autistic relatives, explained to me how, "a lot of my good qualities, like my intelligence, is heightened for me because of [my autism]." In this regard, Judy defined her autism as a positive factor in her life.

Sarah, a 48-year-old who works with the federal government, described how her definition of autism varied depending on the context. Sometimes, Sarah considered her autism as:

a different way of seeing and perceiving the world. [...] On the good days, sometimes that's all I'll think about it. And on the bad days, sometimes I might see that as a burden. As a stumbling block, when I'm having sensory overload, or it can be communication difficulties. Or, if I'm, you know, looking back at stuff in the past and thinking, maybe things might have been different if I had the diagnosis then. So, yeah, the definition varies depending on the situations that I'm in. [...] You know, whenever I'm with just other autistics, or whether I'm with all neurotypicals. Yeah, the context really can define how I define autism at any given moment.

Sarah's definition of autism, and in turn how she perceived it as an element of being, was therefore not fixed to a single context.

Asking what autism means to my interlocutors also revealed mixed views within the autistic community about whether or not autism should be considered a disability. For instance, 35-year-old Michael disliked using the word disability to describe his autism, and instead preferred to use terms such as "diversities" to describe autism and other neurodevelopmental conditions. In addition, Michael used an analogy between autism and, "operating systems on a computer". He explained that much like the thought processes of different people, "all [systems] have the same base function. But if you were to try to introduce the programming code of one operating system into another, it wouldn't understand it".

Michael also made an analogy when discussing about how there are some people who wish to "cure" autism. "If you do that, especially to someone who already has it, then you're taking away who they are. And, that to me, it's like you take away a bird's wings, it's no longer a bird." Michael used this analogy to explain how, just as taking away a bird's wings takes away their ability to fly and therefore function as a bird, "curing" autistic people of their autism would imply rewiring their brain, and their entire personhood.

Similarly, when I mentioned that penguins cannot fly, Michael agreed that they "are still technically birds, but they're birds in their own way. [...] That's exactly what autism is like." This analogy can be used to explain why there is no need to "cure" autism. That is, while autistic people may think and learn differently, they deserve the same respect as everyone else.

50-year-old Jackie, a journalist for another local self-advocacy group, added that being autistic in a largely non-autistic society is similar to being, “a Mac in a PC world- I’m actually a Chromebook, but anyway”! However, Jackie also argued against using, “‘different ability’, or all these cute little words that people try to come up - no”. They explained that people might refuse to use the word disability because disabilities have often been stigmatized as something that is inherently wrong. Increasingly, “there is a strong acceptance in the communities that I’m in, that there’s nothing wrong with the word disabled, that the quicker that we can get on accepting ourselves, the quicker we can get on with our lives”.

Aside from conflicting opinions about whether or not autism is considered a disability, Jackie also mentioned that there has been some debate over, “whether we’re disabled by society or the autism and the co-occurring conditions”. As they explained:

So, people are finally starting to understand that, what they’re seeing isn’t necessarily autism. The person smashing their head against the wall could also be epileptic and have seventeen other things happening, and that’s why their head is up against the wall. [...] Some of us have a lot of co-occurring conditions; those are what are presenting.

Jackie also emphasized that so as to be respectful to people with other conditions besides autism, people should be careful not to stigmatize the co-occurring conditions of autism such as epilepsy either. Jackie believed that because autism self-advocacy is meant to make autistic people feel assured about their own differences, that it was only fair for autism self-advocates and the general public to make people with other disabilities or co-occurring conditions unashamed as well.

From these above-mentioned conflicting views about autism and disability, I can interpret how stigma can negatively influence some people’s understanding of disability. As such, some autistic people describe their condition simply as a different way of

thinking, so as to distance themselves from the connotation that autism is a disability. Conversely, others choose to accept and even embrace the disability label as a way of explaining why they think differently, thereby resisting negative stigma surrounding disabilities in general.

Regardless of their stances on autism and disability, a number of self-advocates, including Michael and Jackie, compare their differences from neurotypical individuals by using analogies to computers or birds. Analogies to computer technology focus on how autistic people are similar to neurotypical people rather than how they are different by highlighting what they are able to function to the best of their own abilities, rather than how they are unable to meet neurotypical standards of ability. Also, analogies describing how penguins are still birds, despite the fact that they cannot fly, aim to explain that while autistic people may think, learn, and function differently from neurotypical people, that autistic people should not have to feel ashamed of these differences, and that these differences should not deny autistic people of their personhood. Such statements for viewing autistic people's differences as non-issues have led to the creation of several disability rights movements, particularly the neurodiversity movement.

## Neurodiversity:

Neurodiversity refers to the different ways of thinking and cognition that exist amongst humans (Walker 2014). Many people from both inside and outside the autistic community consider neurodiversity to be a fact, in the sense that everyone thinks and learns differently. For example, people who are strong auditory learners are best able to understand a classroom lesson by listening to what the teacher says, while someone who is a visual learner might better retain this information by reading what the teacher writes on the board. Whether there is the presence of a neurodevelopmental disability or not, the human species is therefore quite neurodiverse.

The neurodiversity paradigm, as expressed in but not explicitly worded as such in Silberman's *Neurotribes* (2015, 16), dictates that autism and other neurodevelopmental conditions, such as ADHD and dyslexia, are the result of such different ways of thinking. The neurodiversity paradigm also challenges the rather common notion that autism and other disabilities are inherently negative. As Silberman continues, supporters of the neurodiversity paradigm believe that autism should stop being viewed as an "error of nature", but rather, "as a valuable part of humanity's genetic legacy while ameliorating the aspects of autism that can be profoundly disabling without adequate forms of support" (2015, 470).

Adding to the framework of the neurodiversity paradigm, people who do not have a neurodevelopmental condition are often called *neurotypicals*, because they represent the types of thinking processes associated with typical neurological development. Like neurodiversity, the word neurotypical also became a household name in the late 1990s,

and was created by the Autism Network International, one of the oldest autism-based organizations run by autistic people (Silberman 2015, 440- 441).

Moreover, neurodiversity educator and scholar Nick Walker explained, “the neurodiversity paradigm provides a philosophical foundation for the activism of the neurodiversity movement”, which “seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent” (Walker 2014). Likewise, Andrew Fenton and Tim Krahn (2007, 1) illustrated how supporters of the neurodiversity movement aim for what he described as “neuro-equality” by challenging both the diagnostic methods that pathologize any traits associated with ASD, and the prevailing hierarchy of cognitive abilities that is modelled through social institutions.

One of the major tenets of the neurodiversity movement is an emphasis on equity. Many followers of the neurodiversity movement argue that autistic and otherwise neurodivergent people are disabled not because they are sick. Rather, autistic people are disabled due to social marginalization because their needs are not well accommodated for by their society. The neurodiversity paradigm and its movement are thus built on the social model of disability.

Since autism self-advocates argue the need for greater equity, recognition, and acceptance, the neurodiversity paradigm and movement can be used to further propel these arguments. As such, both the neurodiversity and autism self-advocacy movements argue against misconceptions or beliefs that autism makes a person faulty, and instead state that this and other disabilities simply make people different, and thus something that is not negative in and of itself. As such, these two movements serve to reframe our understanding of the condition in a less stigmatizing manner.

## **How Neurodiversity is Discussed in the Autistic community:**

My research participants had different levels of knowledge about neurodiversity and the neurodiversity paradigm. Several interlocutors recalled first learning about neurodiversity online, through reading about autism self-advocacy discourse. This is possibly because, as I will discuss further in the next section, much of autism self-advocacy activity begins online, and so the terminology use in such discussions are most easily found there. Moreover, one participant only learned about neurodiversity after hearing about this thesis.

Despite varying understandings of neurodiversity, and of the term's subsequent paradigm and movement, all my contributors found that their understanding of autism benefitted from this knowledge. Each of the participants also believed that neurodiversity, and its paradigm and movement, should be of greater focus when discussing current and developing issues surrounding autism. A major reason was because, unlike older approaches that pathologize autism, the neurodiversity movement focuses on autistic people's abilities rather than on their limitations. By having neurodiversity as main point of discussion, autistic people can resolve a lot of internalized stigma that posits autism as something about themselves that they can and ought to fix. Discussions of neurodiversity also have implications for how some autistic people conduct self-advocacy work, as one participant explained to me.

I learned some valuable information about neurodiversity during my interview with 33-year-old Jason, who is an executive of a major Autism based organization within Canada. Jason explained to me that neurodiversity is still quite misunderstood within society, and especially amongst people who are not part of the autistic community. He



added here is also a lack of understanding of the different terminology associated with neurodiversity. Both these issues, he argued, are made worse by the fact that many of the major autism-based organizations do not give autistic people equal opportunities to talk about their own experiences.

For instance, I learned that asking whether or not one agrees with the term *neurodiversity* itself, is too vague. As discussed previously, neurodiversity itself is very much a biological fact. Instead, one should rephrase by asking whether or not a person agrees with the principles of the neurodiversity movement, or if a person believes or declines the legitimacy of the neurodiversity paradigm.

Jason also informed me that in the context of neurodiversity, the proper term used to describe an autistic person is *neurodivergent*. A group of people who are autistic or otherwise neurodivergent would be called *neurodiverse*. As Nick Walker emphasized, “Groups are diverse; individuals diverge” (Walker 2014).

Jason added that while Judy Singer is accredited with coining the word neurodiversity, “[*Neurodivergent*] was coined by one of the most well known autistic activists ever: Kassiane Asasumasu.” Nevertheless, it was during my interview with Jason that I first heard about Asasumasu. Jason was not surprised because, “the mainstream Autism organizations don’t even tell you about her! [...] She is one of the most well-known autistic activists in the online autistic community; she’s considered to be the Malcolm X of the neurodiversity movement.” Here, Jason highlighted the issue of how autistic people are not often acknowledged in the discussion of autism related issues, and how this can skew people’s understanding of relevant issues within the autistic community.

While most of my research participants had heard about neurodiversity, each had varying understandings of the term. Michael, however, had not heard of the term neurodiversity until he read about this research project. Nevertheless, it did not take long for Michael to understand what neurodiversity, as well as the surrounding paradigm and movement, entail. As he explained, “one thing about me is that I’m pretty good with languages, so it wasn’t hard for me to figure it out.”

Furthermore, many of the participants stated that they first heard of neurodiversity online. For Marcia, it was when she began doing research as part of her self-advocacy work: “It was a Reddit study, [...] and I had to learn all the terms, and that was one of them”. Judy recalled first hearing about neurodiversity on Tumblr, “and then, I know my mom had gotten a pamphlet, and it had used the term *neurodiversity*. And so I was like, ‘Oh, so that’s a term we’re using now.’”

Others, including Jackie, first heard of neurodiversity when they began autism self-advocacy work. For Jackie, this term, “just made logical sense to me. Because, as a nature lover, I am very aware of biodiversity, and so I’m like, ‘Cool’! Neurodiversity is just biodiversity for humans.” Jackie also subscribed to neurodiversity paradigm, agreeing that autism derives from neurodiversity. They added, “I think you can especially thank the autism self-advocacy movement for completely pushing that ahead”. Moreover, they expressed how, “Steve Silberman’s book *Neurotribes*, I think is what finally made the word almost a household. You know, so that, it went from something that, you know, you’d only expect to hear in your silo circles, you know, in your advocacy circles, whereas now, you know, my mom has heard of it now”.

Many of the participants also told me that they liked the idea of identifying themselves as neurodivergent, and believed such terms helped to reframe their autism as a

different way of thinking and of navigating their society. After speaking with each of the interview participants, I could interpret that the neurodiversity paradigm and movement both had considerably positive impacts on shaping autistic people's identities as well.

When I asked 21-year-old Judy about how her understanding of neurodiversity shaped her self-perception, she told me, "I like the term a lot more. [...] It's more helpful to think about it as something that's just different about me, rather than something that's inherently wrong, or that you have to try to overcome. [...] It's just something that happens, and that's okay". She added that by describing autism as a result of neurodiversity may help so that, "new people getting diagnosed don't automatically see it as a negative thing that they need to overcome. Words just shape how we see things so deeply when we use them, that I think it's important to consider them when we talk about these issues". Judy also believed that discussions of neurodiversity in the context of autism could benefit other communities of neurodivergent people:

You know, there's other people who just have OCD, or who have ADHD, or only one specific thing that falls in on the spectrum, but can relate to the experiences that an autistic person has. And I think having [...] almost an umbrella term that can kind of link people together is a good way for people to find support and to learn about other people's experiences. And so, I think that can be very helpful, especially when it comes to self advocacy, and making the world more accepting by banding things together over common things.

People with different neurodevelopmental disabilities, or forms of neurodivergence, will often face similar experiences as outliers to neurotypical societal standards that autistic people face. Thus, self-advocates from many disability populations can engage in discussions of the neurodiversity paradigm as a broader community. Engaging a larger demographic of self-advocates can extend general society's understanding of the neurodiversity movement, and thereby promote an even greater appreciation for neurological differences.

Indeed, a number of autism self-advocates follow the neurodiversity movement. Jackie explained that in the autistic community particularly, neurodiversity was, “almost exclusively talked about in a positive way”. However, Jackie also said that are some people who object to the neurodiversity paradigm and movement. For instance:

there’s a group that has formed. [...] They’re called the Autistic Dark Web. They exist almost solely on Twitter. They are almost entirely male, [...] white autistics, who completely reject neurodiversity. Who are saying that it is harmful, that it is actually dangerous to intellectually disabled people- even though it’s about including everybody!

Other people who may refuse to accept the neurodiversity paradigm and movement include, as Jackie added, “parents who consider themselves ‘autism warriors’, and their child has been ‘stolen by autism’.”

To elaborate on the neurodiversity paradigm, and in the attempt to educate these people, Jackie often uses analogies to biodiversity in animals:

Several years ago, we had a white moose [appear on the highway], and people were pulled over for miles to take pictures of this moose, this white moose. And I’m like, ‘So, as humans, we jump out of our vehicles, endanger our lives to get pictures of this amazing, bio diverse creature, and then we treat our neurodiverse humans how?’ Why is it that these anomalies are in nature beautiful and spectacular, but what’s different in humans is seen as- needs to be cured, fixed, wrong, broken? [...] I challenge people’s thinking on that a lot.

Whereas variations in animal biology, such as a moose with a white coat, are often celebrated for their uniqueness, differences amongst humans who are autistic are often considered abnormal, and are thus denounced. However, if we maintain that, as per the neurodiversity paradigm, autism and other neurodevelopmental disabilities arise out of naturally occurring variations in brain development, then it is clear that neurodiversity in humans is very much the same phenomenon as biodiversity in nature. And so, by comparing neurodiversity to biodiversity, Jackie pointed out a double standard that paints disability in humans as something fundamentally negative and unfavourable.

As to why some people may object to the neurodiversity paradigm, Judy reckoned that, “maybe it’s a bit vague. My experiences with [my different] symptoms are going to be different than someone who just has, say, OCD, as an aspect of their identity.” It can be interpreted therefore that some people argue that the neurodiversity paradigm does little to explain how autism affects people differently, or how autistic people may have different experiences based on their condition than people with other forms of neurodivergence.

Nonetheless, the neurodiversity paradigm can explain how even within the autistic community, everyone has different cognitive styles. For instance, Marcia, a 22-year-old member of another local self-advocacy group, explained that, “I think mostly in pictures, whereas I know someone who thinks mostly in just words, and [...] verbalizes everything”.

Sarah stated that even within the autistic community, there are, “a variety of opinions [about neurodiversity], *and* sometimes there can be some very heated discussions”. She elaborated:

You have some people, you know, in terms of neurodiversity, who would say that autism is nothing more, you know, than a variation. You know, it’s never a disability. The only disability is that we’re not accommodated. And then, you get, you know, varying degrees of opinion throughout that where someone will say, ‘Well- you know, I do feel disabled.’ Or they’ll say, ‘You know, it is disabling [...] at certain times for me when I’m not accommodated, or in certain environments.’ And then you’ve got [...] the other end where you have some people who are adamant that, neurodiversity, that people [who] are advocating for neurodiversity just don’t understand it at all, that autism is a severe disability, and [...] if they’re advocating for that and they don’t see it as a disability, then they’re not really autistic.

As a recently proclaimed autism self-advocate, Sarah expressed feeling quite intimidated by the sheer intensity of many debates surrounding neurodiversity. “So, when you’re first, you know, kind of immersing yourself into that, and you don’t have a strong opinion to

begin with, because you're still figuring out what autism means to you, [you're just like]

'Oh my God'''. Despite the apprehension, Sarah concluded that:

I'm probably somewhere in the middle. So, it is a variation that should be accommodated. I don't agree with those who say it's never disabling, you know, 'that the only disability is the people not accommodating it'. [...] But yes, it does need to be, you know, be accepted, be accommodated in the workplaces and sometimes [...] you may not have to do anything more than just treat it as just a different learning or working style.

Nevertheless, all the participants agreed that neurodiversity and the neurodiversity movement should be of greater focus when discussing autism rights issues. Michael argued that neurodiversity:

helps people realize that, yes, while it *may* be a part of who we are, that, again, we're not broken. There's still things we can do. Plenty we can do. Something that's commonly known about people who have autism is usually they have one or a few areas of great strength, that they're really good at. Like, with me, that's languages; I also really like geometry. [...] Neurodiversity is important for people to realize that, that we have strengths that we can use to contribute to society.

The neurodiversity paradigm can therefore help society better focus on autistic people's capabilities rather than on their perceived limitations.

Jackie agreed that neurodiversity should be an important topic in discussing autism-related issues, and was eager to promote it:

As long as we are responsible in how we handle it. And so, as I was talking about earlier, I'm seeing some of the movement handling it by downloading the stigma onto the co-occurring conditions. [...] So instead of [...] the bad stuff being autism, put it on the epilepsy. [...] But, we're still not making the language good for the epilepsy part either.

Because the neurodiversity movement aims to help autistic people feel more at ease about their own differences, Jackie argued that it is only fair that its supporters aim to destigmatize epilepsy, so that people with the condition feel less ashamed as well. In Jackie's opinion, such is the neurodiversity movement's stance on equity in full practice.

For Jackie, handling the subject of neurodiversity also meant understanding the term as another way of, “just saying that [it’s] all people”. They continued:

So then, focusing on that helps bring focus back to that we’re humans. We’re part of humanity; we’re not exceptions to it. You know, some kind of exception- I mean, there’s some people out there who think that, we’re like, the next step in evolution! [...] Just, there’s a lot of different ways to see autism, and that’s why I just try to bring it back down to people. What is autism? It’s people”.

Jason concurred, but added that if neurodiversity is to be given greater focus when discussing these issues, “they absolutely have put autistic voices at the front and centre. [...] As I said before, many of these mainstream autism organizations, [...] they sometimes use the word neurodiversity, but they [...] don’t really grasp the concept of it. [...] The mainstream autism organizations need to start promoting these other autistic activists a lot better.”

Some of the participants stated that their knowledge of, and subscription to, the neurodiversity paradigm even challenged how they conducted autism self-advocacy work. For Jackie, “It has forced me to look at my own ableism a lot. It’s forced me to understand that you can be disabled and still be ableist”. Relating to their online journals, Jackie illustrated how some autistic people could not use the Internet:

I’ve recently become a lot more aware that I have to be a lot more inclusive in my language. I felt like I was. [...] Especially intellectually disabled autistics, right? There’s a lot of pushback from parents, especially, that we don’t care. People who [say] if I could be on Twitter, I obviously don’t need help- you know this isn’t true. But, you know, ‘My kid could never be on Twitter.’ And maybe they can’t. [...] So, that has really helped me understand I thought I was being inclusive, but yet, I wasn’t getting the range of [journal] submissions I wanted. And then I realized, ‘I’m only speaking to people like me!’ [...] And, what about autistics who don’t need the amount of information I download onto them. [...] I don’t know how to be succinct, necessarily.

Learning more about neurodiversity through their involvement in autism self-advocacy activity gave Jackie the chance to self-improve, and to, “understand [...] my own biases.”

Overall, my interlocutors believed that neurodiversity, and its paradigm and movement, should be of greater focus when discussing issues surrounding autism rights. For instance, the neurodiversity paradigm assured Judy that being autistic was not a flaw in her being. Judy also believed that discussing the neurodiversity paradigm could reassure and unite otherwise neurodivergent people, such as people with ADHD, who face common experiences of not conforming to neurotypical sociality. For Michael, the neurodiversity paradigm's focus on how autistic people are different also highlighted what autistic people are able to do as opposed to how their disability limits them. This emphasis on people's abilities instead of their limitations likely helped Michael, who disliked describing his autism as a disability, resolve some of his internalized stigma imposed by the pathological views of disability. Jackie's subscription to the neurodiversity paradigm influenced how they conducted self-advocacy activity, as it made them more aware about cognitive variations that exist even within the neurodiverse community. The neurodiversity paradigm and its movement can therefore influence autism self-advocacy discourse as well, as self-advocates foster a greater recognition and appreciation of natural differences in human behaviour, thinking processes, and sociality.



### **Autism Self-Advocacy:**

Talking about autism self-advocacy is important, as the autism self-advocacy movement is arguably the most major vector through which autistic people aim for equal opportunities within general society. The autism self-advocacy movement was important to nearly all my interlocutors, because such groups and activity have allowed them to find social solidarity with other autistic people who shared similar experiences and worldviews. Finding commonality within self-advocacy groups therefore made a number of the participants feel more at ease about being autistic, and more willing to discuss their autism with others both within and outside the autistic community.

Much like the neurodiversity paradigm, autism self-advocacy aims to assure autistic people that should not feel ashamed of themselves for the challenges their condition may impose. As one participant described to me, such challenges may include sensory overload, during which an autistic person becomes too overwhelmed by external sensory stimuli, such as loud noise. Indeed, both autism self-advocates and subscribers to the neurodiversity paradigm often argue that these challenges arise when autistic people's differences, which are most often beyond their control, are not well accommodated for by society. In turn, both the neurodiversity paradigm and autism self-advocacy movement argue that society ought to change to become more accommodating to autistic differences so that they do not prove to be major challenges to autistic people, and so that any challenges that do occur can be better mitigated. Therefore, self-advocacy groups and activity also provided a number of the participants with the opportunity to state the types of accommodations they needed to better integrate in the general population.

Autism self-advocacy groups are social gatherings in which people who are autistic come together to discuss autism-related issues, primarily with the goal of providing equal rights and opportunities for people who share their condition. Autism self-advocacy groups also work to help society as a whole understand what autism is by explaining the condition from the perspective of autistic individuals, and to foster a more positive self-understanding amongst people who are involved in these groups (Waltz et al. 2015, 1174). The structure of autism self-advocacy groups varies. Some groups serve as small-scale social gatherings where autistic people can meet friends, while others are more formally orchestrated, federal level organizations that aim to promote widespread accessibility and other opportunities for disability equality.

Self-advocacy activity has existed for several decades already, having first gained significant attention in the 1960s with the advent of the Independent Living movement. As Waltz et al. (2015) explained, the Independent Living movement both paralleled and inspired the current autism self-advocacy movement, as both movements valued the importance of, “self- representation, self-determination and de-medicalization of disability” (Waltz 2015, 1178). For both movements, self-advocacy helps give people from the disabled community the skill sets and empowerment to make personal decisions about their rights when interacting within their society (Waltz 2015:1178). Autism self-advocates value their own rights and strive for equal and fair treatment of people with shared life experiences, and so anyone from the autistic community can get involved in self-advocacy.

Self-advocacy activity centred on autism has been prevalent since at least the 1990s, beginning with groups such as Autism Network International (Silberman 2015, 450). Today, major autism self-advocacy organizations have developed around the world,

including the National Autistic Society in UK<sup>1</sup>, and the Autistic Women & Nonbinary Network<sup>2</sup> in the US. A number of these groups, such as the US- based Autistic Self-Advocacy Network<sup>3</sup>, garner affiliate groups within their nations of origin and even internationally.

Autism self-advocacy activity itself can take place in-person or through online environments including social media websites. In-person and online self-advocacy groups function in very much the same manner, and only differ depending on what types of support and the nature of the self-advocacy these groups entail. For instance, both in-person and online self-advocacy groups whose main objective is to help autistic individuals connect with others who have had similar life experiences on account of their autism often reach their objective to the same extent.

That said, Ben Belek (2017) documented how online environments often prove to be more convenient and effective in carrying out autism self-advocacy discourse. He proposed a few reasons for why so many autism self-advocacy activities take this route, including the fact that online environments diminish the social challenges many autistic people may face during person-to-person interactions (Belek 2017, 57).

Belek explains, “Autism is typically understood as involving difficulties in the discernment, expression and interpretation of emotions” (2017, 62). He argued that while these difficulties in interpreting and expressing emotion can subject autistic individuals to “a position of emotional inferiority,” these challenges can be alleviated through the use of online environments. This way, “autistic people are no longer disadvantaged in terms of their social, or indeed emotional, connectivity and expressivity” (2017 63). In turn, online environments give many autism self-advocates, “a heightened motivation to engage in

emotion talk,” as they become more confident that their arguments will hold more authority (63).

The participants in this research had varying experiences with autism self-advocacy groups. Just as Belek (2017) discovered in his ethnography, much of this experience derives from online activity, which can include chat rooms, blogs, and especially, social media groups.

Online autism self-advocacy activity is useful, Sarah argued, because, “we’re [...] kind of small, you know, in terms of percentage of the population, so you’ve got to be prepared if you really want to [...] get to meet people, [...] sometimes you have to go out online.” Social media websites and other Internet services such as email, therefore help bridge the gap between populations of autistic people around the world, thereby streamlining the discourse of autism self-advocacy.

Michael also explained that some autistic people might not have the means to physically travel to many of the local self-advocacy groups. As he explained, “a lot of these groups lack outreach- I guess you could say. Some people don’t have cars; [...] we don’t have a car. So, we have to rely on either taxis, or- I don’t like buses. They really make me anxious- so it’s either taxis, or transportation from personal friends.” Adding to that, he believed that if more autism self-advocates in need had reliable means of transportation, “*in order* to get involved, then getting involved would be easier”. Because of this, Michael argued that online groups have made it easier for many self-advocates to get involved.

Confounding these issues, Michael also has a severe allergy disorder that make him unable to travel alone. “I don’t want anyone else to have a legal liability to give me an epipen or something. You know, it has to be someone who knows how to do that. [...] I

wouldn't expect any of these groups to do that for me. [...] So, I always have to have someone with me in case that happens". As for which groups or activity Michael has seen, many of them were on Facebook and other social media sites. "There's one that I really like that [...] advocates the idea of environmental enrichment. Basically, building the person's living space to not only make them more comfortable, but to enrich their experience. That's something I would like to have access to. I think it's nice."

Moreover, Jason explained that much of his advocacy work began online, "because there aren't many [self-advocacy groups] around here." Alongside his online advocacy work, Jason was also involved in kick-starting a new chapter for an existing autism self-advocacy group in Canada, for which he is now an executive.

Sarah told me that she was "just getting started" in self-advocacy work: "I'm exploring where I fit in in this, and where I feel comfortable". As was the case with many of the participants, Sarah began to engage in self-advocacy through social media, as well as in small in-person groups. She told me that her first instance of self-advocacy work was in helping coordinate a web cast project that was planned for a program that aims to help autistic people gain employment:

I told them that I think you need an autistic employee to do the opening and closing remarks. And that was my first time [...] really being out in public really kind of talking a little bit about my experiences, as an autistic employee who didn't have access to employment support programs. So yeah, I'm starting to get involved, but yeah, trying to figure out still what my long-term niche is.

One way that Sarah continues involved in autism self-advocacy included, "when there's new employees joining our team," in which case "I make sure they know that I am autistic, because [...] it is going to dictate certain things in how you relate, and you need to understand if I'm having, like, sensory overload, or, you know, why I'm wearing [...] ear defenders in a meeting, and things like that, or, why I'm in a closed office."

During my interview with Sarah, I learned how autism self-advocacy activity foster a greater understanding and acceptance of neurological differences as well. Getting involved in autism self-advocacy groups help Sarah empathize with people who, “in the past, I might have just written off [...] because I didn’t understand myself, you know, that I was autistic.” Receiving her autism diagnosis gave Sarah a new framework upon which she could draw experiences, thereby helping her relate to other neurodivergent people.

Likewise, Judy’s participation in self-advocacy groups made her realize how vast the autism spectrum can be, “because I’ve [really] for the longest time, only known my family! And then to see other people and to see how they were similar and different to us. [...] That really opened my eyes.”

Many of the research participants were not diagnosed with autism until their teens or later. While there is no major implication for how they subscribed to the neurodiversity paradigm, age of diagnosis may very well be a contributing factor to the interlocutor’s with self-advocacy groups. People who discover they are autistic may not have much experience with, or knowledge of, the resources available to autistic people, simply because they were unaware of their diagnosis beforehand.

Judy, for instance, was in high school before she discovered that she was autistic. This meant that she never participated in any autism-focused groups until recently, despite having several relatives with autism. Likewise, Andrea was quite busy in University when she was first diagnosed, “so it was not something I had to deal with when I was in school. I was just kind of like, ‘Oh, well I’ve got the diagnosis. That explains a lot.’ And then I kind of stopped thinking about it.”

Aside from not having much experience in autism self-advocacy, Judy and Andrea nevertheless became more knowledgeable about what it means to be autistic in other

ways. For example, Andrea began reading online blogs about other people's experiences of being autistic. Similarly to what Belek (2017) described in his research, Andrea's attention to online discourse, again, demonstrates why online environments can help the autism self-advocacy movement spread.

By engaging in autism self-advocacy activity, either through in-person gatherings or through online environments, my interlocutors were able to find social solidarity with other autistic individuals. For Sarah and Judy, continual interaction within self-advocacy groups helped her garner a better understanding and appreciation for neurological differences, and of the accommodations neurodivergent people may require as a result. Because habitual participation in autism self-advocacy groups allowed my interlocutors to find unity with others, and to better appreciate human neurodiversity, this also connects to how they were able to understand their autism as an element of identities.

## **Identity:**

Identity is a major subject within Anthropology. When anthropologists study identity, they examine how people participate in series of social actions and interactions to express their positions within society, and how they perceive themselves. How people understand their own being and their social status will change depending on both social and temporal contexts, which means that their identities are continuously shifting.

Anthropologists have rather recently begun to study identity and autism in conjunction. They often do so by adopting frameworks from the fields of psychology and sociology, such as biographical illumination (Tan 2018) and social constructionism (Burr 1995; Bagatell 2007). While they are not strictly anthropologically oriented, biographical illumination and social construction are nevertheless useful to describe how autistic individuals see their condition as an important aspect of their being.

Scholars can adopt other anthropological frameworks such as Pierre Bourdieu's practice theory (1977), and Mary Bucholtz's theory of community of practice (1999). We can use the former framework in particular to examine how neurotypical people and the organizations they run have the authority to perpetuate stereotypical views of autism, and how autistic people resist dominant social norms by using their own sets of beliefs to practice their identities as neurodivergent individuals (Bourdieu, 1977). Furthermore, both theories can be used to discern how autistic people define their own neurodivergent identities through practice in autism self-advocacy activities, rather than how people from outside the autistic community define autistic people (Bourdieu 1977; Bucholtz 1999).



By viewing autism as constituting a component of people's identity, anthropologists can realize why people's perception of self may change after they discover that they are autistic. Viewing autism as an element of identity also helps anthropologists understand why autistic individuals use their diagnostic label to navigate social realms, and why their self-perception is further ameliorated as they find solidarity with other autistic people.

### **How Anthropology approaches identity:**

French anthropologist Pierre Bourdieu was concerned with how individuals exercise their authority to shape the social world through practice. In Bourdieu's theory, practice had two main components. First, *habitus* is the set of habitual dispositions of action based on the individual's history, as well as their position within society. *Habitus* gives individuals the agency to alter social and cultural forms (1977, 81). Second, *hexis* describes how the individual habitually presents their dispositions of action, such as through certain bodily gestures (1977, 87).

Through practice, individuals are seen as human agents who exert their *habitus* and *hexis* and shape their society by creating, altering, and distributing a variety of taxonomies.<sup>4</sup> Taxonomies are sets of beliefs, presuppositions, and symbolic representations that "organize perception and structure practice" for each member of society (1977, 97). Through habitual practice, some taxonomies come to dominate within society, especially if they held by people or groups in authority. Dominating figures in social relations often impose their beliefs onto the beliefs of others. Full imposition of dominating taxonomies obscures their arbitrary nature, thereby causing other members of society to take these presuppositions for granted as objective reality (1977, 164-65). How dominant taxonomies become known as the "natural" order is what Bourdieu called *doxa*

(164). Moreover, and as I gathered from my interlocutors, where people stand in relation to the *doxa* of their society can impact how they view their identities.

Autistic individuals may frequently internalize stigmatizing knowledge imposed by dominating taxonomies that posit autism as a disease that must be cured. Autism Speaks, for example, is one of the world's largest autism support organizations (Belek 2017, 57). As such, many parents rely on Autism Speaks to help them find help and treatment for their autistic children. However, this organization is infamous for many reasons, namely their stance on the importance of finding a cure for autism. As Belek explained, and as will elaborate more in the next chapter, Autism Speaks has been known to use scare tactics to present autism as a dangerous illness that robs children of their humanity (58). Jackie explained that it was for this reason that a number of parents profess their duties as “autism warriors” who must fight to return humanity back to their children who have been “stolen by autism”. People who proclaim themselves as “autism warriors” take the presupposition that autism must be cured for granted as the natural order, or *doxa*.

People who are autistic themselves may also internalize these views as the way the world ought to be. Michael recalled that when he was younger, “I always thought of it as, ‘This is something that’s wrong with me.’ [...] You know, always beat myself up over it- ‘Why can’t I be normal? Why does nobody like me? Why can’t I be like them?’” In knowing that they cannot live up to neurotypical standards of sociality, autism can negatively impact autistic people’s perception of self, just as it once did for Michael.

At the same time, autism self-advocacy groups can provide space for autistic individuals to practice new taxonomies surrounding the neurodiversity paradigm. As Michael continued, following autism self-advocacy activity helped him, “understand that this is just who I am.” Autism self-advocacy groups impose onto autism self-advocates

such as Michael the presupposition, “that I shouldn’t have to change, and that people should accept me for who I am. I’m not trying to change them, so they shouldn’t try to change me.” Moreover Sarah stated that autism self-advocacy and the neurodiversity paradigm helped her understand that it is not true that we must try to cure autism,

Because it’s neurological! So you know I can’t change. You know, I can change certain behaviours, I can change the way I think of certain things, view certain things. But, [...] there are just certain things that are just innately part of me, you know characteristics [...] that are just always going to be there, because that’s how I’m wired.

Autism self-advocacy groups therefore practice taxonomies that proclaim the condition as a naturally occurring neurological variation, and impose these taxonomies onto autism self-advocates to reshape their knowledge of themselves. For autism-self advocates, the *doxa* is that autism constitutes a form of neurodiversity, and that this difference should be accommodated for rather than cured.

Bourdieu’s theory of practice (1977) has inspired many more anthropologists to examine how and why people negotiate their positions in society, and their understanding of self, by practicing different ways of acting and presenting. Questions about how people practice elements of their being to negotiate their identities often pertain to issues such as gender and language use (Bucholtz 1999), but can also be posed in relation to other factors of personhood, including autism.

Sociolinguist Mary Bucholtz tackles the questions of gender, language use, and social identity, in much the same way that this thesis approaches the subject of identity in relation to disability. In her article “Why be Normal?” (1999) Bucholtz used the community of practice model to examine how, “female nerds [...] negotiate gender and other aspects of their identities through practice” (1999, 203).

Adding to Bourdieu's practice theory, the community of practice model explains how individuals who share similar forms of *habitus* and *hexis*, or ways of acting and presenting, engage in collective social practice to create and maintain a common social community. Similarly, this thesis presents how autism self-advocates negotiate their condition as part of their identity, through how they subscribe to the neurodiversity paradigm in their participation in self-advocacy activity. For instance, after becoming involved in autism self-advocacy groups, Marcia reshaped an identity surrounding her autism as opposed to one that adhered to the hegemonic, neurotypical societal norms. By regularly participating in shared social communities, individuals strengthen their habitual manners of acting and presenting (207-209). Likewise, Marcia maintained her identity as a neurodivergent individual through continuous practice in autism self-advocacy rhetoric and activity.

Bucholtz pointed out an oversight in the field of sociolinguistics when discussing social identities. Traditionally, sociolinguists would examine issues of language and identity by using the speech community model. As Bucholtz (1994, 204) explained, "The disciplinary autonomy of theory based on the speech community is unproblematic for traditional sociolinguistic research, which uses social information to account for linguistic phenomena such as sound change." Bucholtz argued however, that the concept of speech community does little to explain, "language use based on sociological variables such as age, social class, and gender" (203), because it only examines "sociolinguistic phenomena on a macro level" (204).

Conversely, "when sociolinguists reverse the direction of analysis - asking instead how linguistic data can illuminate the social world, as language and gender researchers seek to do - then connections to social theory beyond linguistics become imperative".

(Bucholtz 1999, 204) Using the community of practice model to study identity formation, she continued, “permits us to draw on the linguistic and social information necessary to understand the production of nerd identity” (1999, 204). By doing so, Bucholtz argued that the nerd identity was, “a purposefully chosen alternative to mainstream gender identities which is achieved and maintained through language and other social practices” (1999, 204).

Unlike Bucholtz’s research, this thesis is not oriented toward sociolinguistic anthropology. Even so, Bucholtz’s theory of community of practice is still a useful framework through which scholars can study how autism not only forms a variable of human sociality, but also how autistic ways of being can illuminate the social world. Getting involved in autism self-advocacy groups in which people practice their subscription to the neurodiversity paradigm helps autistic people understand their condition as a difference that is not inherently wrong.

Autism self-advocates actively choose identities as neurodivergent individuals and maintain them through continual social practices within self-advocacy groups. These social practices illuminate the social world for both the autistic and neurotypical community, in the sense that they allow self-advocates like Marcia to create and reproduce more positive views about autism when interacting in neurotypical social realms. Subsequently, as more people from outside the autistic community understand autism as a mere difference rather than a flaw, they are more likely to accept it. With increased acceptance, autistic people become more willing to integrate their autism as part of their identities.

### **Biographical Illumination:**

Catherine Tan proposed and applied the concept of biographical illumination to her analysis of autism diagnosis narratives to express, “how autistic self is structured by but transcends medical articulation to shape understandings of identity, personal expectations, and community membership” (2018, 161). Biographical illumination, “describes a transformed conception of self that is facilitated by but extends beyond medical meaning and context, enriching personal biography and social relationships. The self is not negotiated; rather, through a medical framework, it is cultivated and refined” (2018, 161).

This concept is built upon, and also directly contrasts with, the concept of biographical disruption, which describes the negative impacts the diagnosis of a chronic illness or terminal disease may have on personal identity. That is, “researchers have applied and developed [biographical disruption] to examine a range of health events, such as cancer [...] In biographical disruption, selfhood faces re-evaluation as previous perceptions of self, expectations, pursuits, and relationships no longer comport with the new realities and limitations of being ill” (2018, 162). Conversely, Tan added that many neurological conditions including ADHD, “are closely tied to understandings of identity and citizenship” (2018, 161).

In Tan’s research, biographical illumination is often experienced by autistic people upon receiving or gaining knowledge of their diagnoses later in life. Particularly, people who were undiagnosed with ASD until adolescence or adulthood often report having poor self-esteem due to not knowing why they may act or think differently than their peers, thereby interpreting these deficits as inherently negative traits. In turn, receiving an ASD

diagnosis helps people understand the reasons for these differences, giving them the chance to re-evaluate past events through a framework based on their autism (2018, 164-65).

The participants in this research described their autism as a trait that became increasingly positive in nature with time, especially after meeting and interacting with other people who have had similar experiences. For instance, Marcia explained that before she became involved in autism self-advocacy groups, “I wouldn’t really talk about [my autism] to anyone. But now, [...] I’m always flying jokes about it”! Similarly, Andrea, who found out she was autistic quite recently while she was a university student, stated how receiving an ASD diagnosis felt like a relief, “because it explained why I am this way, and [that] I didn’t need to feel bad about it anymore”.

Similarly, when Jackie first received their ASD diagnosis seven years ago, it took them nearly six months to accept it. However, Jackie also told me that receiving an ASD diagnosis, and subsequently participating in autism self-advocacy, improved their stance on life, “Because, now I have a framework to bounce back on, why everything was so difficult- seemed like I was born on a different planet, kind of feeling”. Jackie described themselves as a recluse before their diagnosis. During this time, Jackie would seldom leave their own house. As a teenager, they were even diagnosed with manic depression, or Bipolar Disorder. Then, within six months of learning they were autistic, Jackie’s life changed for the better. They told me:

This is how I describe it to people: If you always know who you are, you go through [the stages] of life, you know, [...] you hit your milestones, you know, and puberty, and you go through the whole cycle. When you don’t know who you are, and you’re neurodivergent, and you find out later in life, you actually start that cycle again, almost. And so, you go through the whole exciting early years, and then you hit that puberty time, and then you get through your teen years. And here in year seven, I feel like [...] I’m finally coming into the more mature part of it.

And so [...] I wouldn't be here at this point without it. I wouldn't be able to have the connections I have. It's very difficult, feeling so different for over four decades, and then [...] finding where you do fit. [...] Being part of social groups, [...] and that kind of hands-on advocacy, [...] it keeps me alive, actually.

And so for Jackie, receiving their ASD diagnosis resolved over forty years worth of negative self-perception and hardship. This relief expressed by Jackie, and by Marcia, can reflect a positive transformation of self-image as expressed according to biographical illumination.

Tan also explained how participants would use their newfound diagnostic labels, “to locate autistic communities, which expanded their social networks and contributed to a more positive concept of self. In this way, communities facilitate biographical illumination” (2018, 166). As an example, Andrea used her diagnostic label as an opportunity to seek out environments that discuss autism-related issues, even though she was not yet involved in any self-advocacy groups. In a sense, Andrea was already involved in autism self-advocacy discourse, albeit indirectly, by following online self-advocacy blogs. Interestingly, Andrea also mentioned how she even began to notice autistic characteristics in people that she met in passing, something that is perhaps aided by her knowledge of how autism affects herself. Andrea's attention to autistic traits in others similar manner to how Sarah could better relate and empathize with other neurodivergent people.

Moreover, the positive reformation of identity described by biographical illumination occurs not just at the time of diagnosis, but can persist long thereafter. Tan explains that, “[as] the diagnostic label organizes new understandings of self, it also implies commonalities with others who possess the same label (2018, 166)”.



When Jackie started participating in self-advocacy activity, they expressed at long last finding social solidarity. Not knowing much about autism beforehand, or about other autistic people in their community, participating in self-advocacy groups also helped Jackie “not feel like an impostor” about their diagnosis. Thus, after attending their first autism self-advocacy group session, “I understood what love at first sight meant. Because, for the first time in my life, I saw an accurate reflection of myself. It was beautiful!”

Jackie not only expressed sharing more in common with other autistic people, but they also felt more comfortable when participating in autism self-advocacy groups. To describe how they felt:

I’ve invented the term *autistic oxygen*. [...] And so, what I have found is that [...] when I am around other people with autism- or autistic people- it’s like we give each other breath- we give each other oxygen. We give each other a type of air that I can’t get anywhere else. I don’t have to [...] mask [hide my autistic traits] as hard, and so [...] I can be myself.

Conversely, a couple of the participants initially felt ambivalent, and sometimes negatively, about receiving their diagnoses. Judy described her initial reaction to being diagnosed as being “kind of negative for a while”. Judy therefore did not experience biographical illumination right away.

For Sarah, her understanding that autism is a lifelong disability was actually what made her feel rather depressed when she was first diagnosed. As she explained to me:

Yes, there’s relief, there’s understanding. But then, [...] you’re kind of looking back at *everything* in your life [...] and revisiting it, and then kind of realising that certain things [...] that maybe one day I hoped I could kind of change, or fix or whatever to kind of be like everybody else, I wasn’t going to be able to do that, because this is innate. [...] So, it did sometimes at first contribute to [...] sadness and depression.

However, “now that I’m kind of emerging from that, understanding that- ‘Okay, you know what? This is just the way that I am. [...] Take it or leave it’. And also, [...] if I

have certain needs, [...] I'm not being unreasonable. This is what I need to thrive, because this is the way I'm wired". And so, after the initial shock of realizing she was autistic, Sarah now saw her autism diagnosis as an opportunity to fight as an autism self-advocate for the types of accommodations she required to thrive in the workplace and in everyday life.

Of course, Tan explains that not all autistic people may experience biographical illumination upon receiving knowledge of their disorder, and that there are some of the limitations to her theory. For instance, people who are involved in autism self-advocacy organizations are more likely to view their autism more positively, which she argues is because their affiliation with such organizations suggests a stronger agreement with the autism rights agenda (2018, 164). Additionally, continual interaction within autism self-advocacy organizations that support the neurodiversity movement can foster in those who are involved a greater acceptance of their own autism.

### **Social Constructionism:**

Social constructionism is a sociological theory that has its roots George Herbert Mead's symbolic interactionism (Burr 1995, 7). There are several propositions of this theory, including that all knowledge is subjective and should therefore not be taken for granted as the true representation of reality (1995, 3). Similar to what Pierre Bourdieu described as *doxa* in his theory of practice (1977), knowledge that autism and other neurodevelopmental disabilities are deficient forms of human development is often considered true because it is largely touted as such within our society (Walker, 2016).

Moreover, all knowledge is constructed and maintained through repeated social interactions (1995, 3-4). This knowledge includes what people understand about their own beings. People may perceive of themselves in a positive or a negative manner depending on the type of knowledge that is perpetuated within different social realms.

Nancy Bagatell drew her research from a series of interviews with young man named Ben, who was diagnosed with Asperger's Syndrome (2007, 413). In this research, Bagatell explained how autistic people may often construct negative identities surrounding their autism as they navigate within social environments and institutions that perpetuate, "the deficit-driven views of autism", which, "emphasize [that] individuals with autism have difficulty with social interaction and communication" (2007, 414). In such environments, autistic people often come to realize how they do not meet the neurotypical standards sociality. The failure to live up to societal standards can thereby instil in many autistic people the sense that they are "abnormal" (2007, 417-421).

As was expressed earlier, Michael recalled that as a child, he would often feel ashamed of his differences, and wondered if he could ever grow up to become "normal". These feelings dissipated once Michael became involved in online autism self-advocacy groups, which, because they often subscribe to the neurodiversity paradigm, frequently emphasize that being autistic or otherwise neurodivergent is perfectly acceptable.

As Bagatell notes (2007) continual involvement in autism self-advocacy groups often allows autistic individuals to develop a more positive understanding of their condition, which can reflect in the way they perceive themselves. And so, at least in the context of autism self-advocacy activity, social constructionism highlights a positive shift in the nature of people's identities. As was also previously discussed, Marcia was initially reluctant to talk about her autism to many people. However, as Marcia learned more

about how autism is a form of neurodivergence through repeated participation in self-advocacy groups, she was then able to form a more positive dimension to her identity.

Social constructionism helps explain how social contexts in which knowledge of the neurodiversity paradigm and of autism self-advocacy are produced help autistic individuals, as in the case of Marcia and Michael, develop more positive dimensions to their identities (Burr 1995; Bagatell 2007). Biographical illumination (Tan 2018) dictates that the nature of identities shifts over time and in different contexts. This theory demonstrates how Jackie was able to resolve years of poor self-perception due to not knowing why they seemed so different from their peers after receiving their ASD diagnosis. This theory also highlights how Judy and Sarah could use their newfound ASD diagnosis to navigate autism self-advocacy social realms, through which they were able to further ameliorate their perception of self. And so, while neither social constructionism (Bagatell 2007; Burr 1995) nor biographical illumination (Tan 2018) are strictly anthropological frameworks, both compliment anthropology's stance that identities are fluid entities.

Moreover, Bourdieu's practice theory (Bourdieu 1977), and Bucholtz's theory of community of practice (Bucholtz 1999) help us understand how autistic people can practice their identities as neurodivergent individuals through their participation in self-advocacy groups. Practice theory (Bourdieu 1977) demonstrates how, as Jackie explained, people proclaim themselves as "autism warriors" because they perceive taxonomies that dictate that autism must be cured as the natural order, or *doxa*. Conversely, we can see how autism self-advocacy groups allow Michael and other self-advocates to adopt new taxonomies that profess that autism and other forms of neurodivergence are perfectly acceptable. Through the theory of community of practice

(Bucholtz 1999), scholars can examine how autism self-advocates, including Marcia, practice their identities as neurodivergent individuals to redefine what autism means to them, and to illuminate their social world.

Each of these theories can therefore help anthropologists comprehend how the neurodiversity paradigm and autism self-advocacy activity help autistic individuals see their condition as an important aspect of their being. In turn, we can see how autistic people can express their identities that develop out of their adherence to the neurodiversity and self-advocacy movements, to counteract current notions that still view the autism as pathological.

### **Current Movements to Autism Awareness and Acceptance:**

Despite the growing movements of both neurodiversity and of autism self-advocacy, several opposing views of autism still prevail within society. Just as Jason explained earlier, one major reason as to why autism self-advocacy organizations in particular have gained increasing attention over the years is due to the concern that many autism-based organizations do not include autistic people, and their perspectives of their condition, in their discussion of autism-related issues. For example, Autism Speaks is one of the most recognized autism based organizations in the world. As Belek (2017) noted however, much of the narrative this organization uses to promote “autism awareness” is considered equally controversial.

One infamous example arose on 11<sup>th</sup> November 2013, when co-founder Suzanne Wright published a “call for action” on the Autism Speaks website to raise awareness for autism. In this call for action, autism was described as a “crisis” in which, “three million children in America went missing [or] one morning fell gravely ill” (Wright 2013, quoted in Belek 2017, 58). Here, autism was described as a disease similar to cancer, which would rob children of their personhood, and would make parents live in constant fear of, “what they will get into next. Will they try to escape? Hurt themselves? Strip off their clothes? Climb the furniture? Raid the refrigerator? Sometimes — the silence is worse” (2017, 58). As such, this campaign depicted autism as something for which people needed to find a cure.

Many of the research participants, and the majority of autism self-advocates in general, also oppose the idea that autism needs to be cured. Because autism is a pervasive

neurodevelopmental condition that exists from birth, as Michael stated, “if you do [cure it], then you’re taking away who they are. [...] It’s not something that breaks us”.

Wright’s call for action does not mark the first time that Autism Speaks has been controversial. Indeed, this organization was also criticized several times for promoting research to cure autism, as well as for, “advocating of pseudoscientific causation theories” (Belek 2017, 57). However, this instance received an almost unprecedented level of backlash from the autism self-advocacy community. Much of the feedback from autism self-advocates was delivered online through blogs and social media websites, which could very well explain the sheer amount of backlash Autism Speaks did receive from the autism self-advocacy movement.

As Belek noted, “The online march also incorporated a “twitter bomb,” whereby protesters mobilized to “occupy” relevant twitter accounts — primarily that of Autism Speaks itself, but also those of its sponsors and supporters — with frequent and recurrent tweets. [...] The protesters also made appeals to consumers to boycott these companies until they comply. Ultimately, throughout the course of a single day, the hashtag #boycott autismspeaks had featured in hundreds of tweets” (61).

Certainly, the emotional rhetoric used in Suzanne Wright’s “call for action” was met with equally powerful rhetoric from many autism self-advocates. Whereas Wright’s call for action described autism by drawing on feelings of fear and despair, one self-advocate and blogger who goes by the name Neurodivergent K (quoted in Belek: 2017), argued otherwise: “Autism is deep love. People write it off as special interest or obsession, but even if it’s not something I can excel at, I can excel at loving what I love, loving what I do, loving who I love. Autism is being able to be consumed by love and interest, it is giving 100% because it is an insult to the thing one loves to give any less....

No one ever said that being Autistic is easy. But we do say that it's worth it. We're okay. We love and deserve to be loved" (2017, 61).

Autism Speaks also has been criticized for its lack of inclusion of autistic people in their discussion of autism-related issues (Belek 2017, 57). By not providing the perspective of those who are autistic in the discourse of autism support and advocacy, society's understanding of this condition can become skewed. This fact, indeed, is also the major reason why autism self-advocacy groups were developed, and have gained increasing attention in recent years.

Many of the participators agreed that more needs to be done to shed light on issues related to autism from the perspective of autistic people overall. In addition to the general lack of inclusion of autistic individuals exemplified in the Autism Speaks scenario, there has not been much academic research conducted about autism-related issues by people who are autistic themselves. In recent years however, a number of autism self-advocates have begun to participate in research projects surrounding a variety of topics relevant to autistic people<sup>5</sup>. Similarly, Marcia was involved in a few research projects conducted at a university she attended. In fact, it was through doing research that Marcia became interested in pursuing autism self-advocacy in the future.

Judy added that the lack of input from autistic people on autism-related issues also extends to how autism is portrayed in television, literature, and other media. The majority of autism representation, she argues, "comes from non-autistic people, for sure [...] And there's not a lot of variety of representation either, it tends to be the more extreme cases." She also said that many of the representations fall back on stereotypical views of autism including, "that all autistic people are 100% non-verbal. And it's like, no- there's a lot of



variety”. Due to these stereotypical representations and a lack of variety, “every time I tell people that I’m autistic, everyone’s shocked!”

Sarah noted that several improvements for providing services for autistic individuals could be made. Namely:

I’m 48- right? And there is really nothing out there about autism in the later years. And especially, autism in the later years for people who are actually independent. [...] There’s really nothing to help and to give information about how to navigate middle age, you know, later stages of life, appropriate, let’s say, housing when you can’t live independently anymore, that actually work for autistics. And being able to make some of those choices, just to create the needed living environment, to help with what will probably a decline in executive function at that point, [...] which many of us already struggle with to begin with- I mean, we may learn our coping mechanisms- but, I can certainly see as we *age* [...], it’s going to be harder to manage those. I don’t really see anything in terms of supports.

Having said that, Sarah noted that there have been some improvements, as nowadays, “you are seeing more in terms of [...] programs that are looking now at that transition from high school to either some sort of employment, or university, [...] and] to young adulthood.”

Additionally, Sarah deplored a lack of proper accommodations for autistic students:

You hear horror stories, you know, kids being physically manhandled, especially in the States where they’re calling the cops on kids to remove them from the schools! Because, and a lot of times it’s because their sensory needs aren’t being met; they’re brought to a meltdown situation, and then they just keep *picking at them*, instead of learning to just *step away*. [...] Yes, there’s stuff to be said for mainstreaming, but maybe you still need to cater their schedule or their school day to meet their particular needs, so that it doesn’t become just a stark choice between having them in a classroom all day that they can’t handle, or the only other option is homeschooling, where the parents may not be equipped to do, and maybe economically can’t pull it off. There’s like, *next to nothing* that’s in between.

In addition, a few of the participants proposed that rather than just raising awareness for autism, people need to aim for increased autism acceptance. Jackie argued that whereas Autism Awareness merely suggests that people fight for equal rights for autistic people, Autism Acceptance implies actually taking actions to make autism rights

a reality. And so, “my communities don’t have a lot of patience for Autism Awareness anymore, either”. They explained that:

Autism Awareness doesn’t lead to Autism Acceptance. Awareness can actually harm people. [...] If you would’ve asked me five years ago, I would have been, ‘Team Awareness!- Right? What could be wrong with Awareness?’ Everything. The word Autism was invented *80 years ago*. 80 years- we’ve had eight decades now. We’re aware, [...] so we cannot stay on this Awareness thing anymore. [...] I really think now that we just need to get to the action, which is Acceptance.

Jason agreed that, “most autistic people are tired of awareness”, adding that many autism-based organization have not done a satisfactory job of raising acceptance for autism. He stated that:

Autism Awareness was started by the UN in 2007, But Autism Acceptance Day was coined by an actually autistic person in 2011- Paula Durbin- Westby is her name. [...] Some organizations have started to try to do Autism Awareness and Acceptance month. [...] You’ve probably heard [...] of Light it up Blue [for autism awareness], which [...] many autistic people do not like. So it was in 2015 when a Canadian autistic activist started a counter-movement to that: Walk in Red, or Red Instead [for autism acceptance].

Jason mentioned how one local autism self-advocacy organization, “they tried to do both red and blue”. He argued that what this organization did was hypocritical, “because trying to do both blue and red betrays the principles that Red Instead is founded upon, which was specifically to oppose Light it up Blue. [...] because as you know Light it up Blue is an initiative of Autism Speaks, which is *widely despised*”. Jason also explained that the local organization plans to switch to exclusively promoting Autism Acceptance, and dropping Autism Awareness altogether: “So I’ve been telling them, ‘Okay, guys. Now drop Blue, and switch to Red 100%.’ [...] If you’re going to do Acceptance, you’ve got to drop Blue. Otherwise, I’m not convinced you’ve changed”.

Judy was somewhat ambivalent on the matter, and said that, “I think, inherently, autism awareness is a really great thing to promote”. Nevertheless, she agreed that, “it’s

always better to amplify the voices of actual autistic people, and people with family members on the spectrum, who have personal experience with it”. Ultimately, Judy believed that, “*anything* is better than nothing. [...] It’s good to have people meaning well and trying, and then to be able to try to correct it, as opposed to not talking about it at all”. For Judy, this also meant that parents and caregivers of autistic people should still have a place to talk about such issues. She continued, “I mean, I don’t think you should be speaking over your child who’s trying to communicate. But, I also feel like [...] the parent [...] nine times out of ten has got a pretty good sense of what their child needs; especially if there’s not more conventional ways to communicate”.

In addition, Andrea stated that the current focus on autism-related issues such as Autism Acceptance, “certainly has been getting better. Because now, autistic people are starting to step up and talk about their own experiences. [...] I think definitely, there’s still a lot that can improve, but, [...] we’ve come a long way”. The autism self-advocacy movement has quite likely helped reassess society’s presumptions of autism by shattering previously held stereotypes, and by allowing autistic individuals to voice what they know to be true on the matter.

Michael agreed, so much so that he added, “enough is being done that can be done at this point. They’re doing their best, I guess you could say. I think there’s a lot of work that needs to be done. [...] But, I think at this point, we are doing as good as we can”. And while Michael doubted that the autism self-advocacy movement’s mission for autism equality would ever be over, “I say as long as we keep going, someday we’ll get there”.

Current movements to raise awareness for autism attempt to define what it means to be autistic, and also presume what sorts of accommodations people in the autistic community need to thrive in society. However, as many of my interlocutors argued, these

movements do not provide an accurate or complete picture of how autistic people understand themselves. As Bucholtz states (Bucholtz 1999), identities develop through practice as individuals come to understand themselves by living their everyday lives, and not just by how other people define them. Autism Speaks and other organizations, which are composed of neurotypical people, often rely on stereotypical notions to define and understand autism. In terms of identity, such organizations cannot accurately define how autistic people understand themselves. Moreover, because individuals' identities are developed through social practice and not by how others define them (Bucholtz 1999), we can therefore see how autistic people can effectively resist stereotypical definitions of autism as they negotiate their neurodivergent identities through the autism self-advocacy movement.

## **Conclusion:**

The neurodiversity movement can help autistic people develop a more positive dimension of their identities through their participation in self-advocacy activity. This influence can be examined through practice theory (Bourdieu 1977), the theory of community of practice (Bucholtz 1999), as well as through the theoretical frameworks of social constructionism (Bagatell 2007; Burr 1995) and biographical illumination (Tan 2018).

Bourdieu's practice theory (Bourdieu 1977) demonstrates how seemingly objective knowledge about autism derives from taxonomies, or sets of beliefs, that get taken for granted as *doxa*. We can understand why autistic people risk facing stigma when stereotypical notions of autism are taken for granted and perpetuated within neurotypical social realms. Conversely, we can examine how autism self-advocates can resist these stereotypical views by adopting new taxonomies surrounding the neurodiversity paradigm.

Moreover, the community of practice model (Bucholtz 1999) demonstrates how autistic individuals negotiate their condition as part of their identities within the dominant, neurotypical society, by subscribing to the neurodiversity paradigm in their involvement in self-advocacy activity. Consequently, autistic individuals strengthen their identities as neurodivergent individuals through regularly participating in self-advocacy activity.

Through social constructionism (Bagatell 2007; Burr 1995), the participants often came to understand themselves as being different due to their autism through repeated

social interaction within a primarily neurotypical society. Subsequently, these differences typically became seen as positive aspects of the participants' identities, courtesy of repeatedly interacting within autism self-advocacy groups and activities.

As per biographical illumination (Tan 2018), after the interlocutors received their ASD diagnoses, they expressed feeling more at ease with themselves, as the diagnosis clarified several long-held questions as to why they felt so different. My interlocutors developed a more positive self-perception, either near the time of their diagnosis or gradually thereafter. Their newfound diagnoses allowed the participants to seek out the company of other autistic people who shared similar life experiences, which further improved their self-perception.

Some of my research volunteers were highly involved in autism self-advocacy activity, while others had just started to familiarize themselves with what options for autism self-advocacy and support are available to them, and with the discourse within the self-advocacy movement itself. While their participation in self-advocacy occurred through in-person social groups or through online environments, reflecting Belek's (2017) research, online environments served as a starting point for most of the participants to get involved and familiar with this activity.

Once again, online environments often facilitate the spread of autism self-advocacy discourse. However, while Belek (2017) noted that online self-advocacy activity alleviates some the social communication challenges autistic people can face, my interlocutors explained that this form of advocacy also provides the opportunity for people who may be unable to attend autism self-advocacy groups in person. Moreover, the Internet and social media websites prove to be a reliable way to inform aspiring self-advocates about relevant issues surrounding autism. It is also through the Internet that

many autism self-advocates, and my participants specifically, learn about neurodiversity and its surrounding paradigm and movement.

The participants in this research also considered the neurodiversity paradigm and movement to be influential to how they understood their autism. They also largely believed that neurodiversity should be of greater focus when discussing issues related to autism. Particularly, the neurodiversity paradigm emphasizes how autism and other neurodevelopmental disabilities constitute naturally occurring differences in human brain development. Understanding autism in terms of neurodiversity can devalue the stigma that autistic individuals may face and also promote greater autism acceptance.

The discourse of neurodiversity, autism acceptance, and autism self-advocacy work conjointly. Thus, a greater acceptance and de-stigmatization of autism that results from the neurodiversity movement can motivate autism self-advocates even more. Ultimately, this can help the autism self-advocacy movement grow stronger.

When discussing current and developing issues regarding autism, the voices of people who are themselves autistic should at least be given equal weight. By listening to what autism self-advocates know about their condition, such as how autism is understood through the neurodiversity paradigm, scholars can reassess the major assumptions of their research on autism, and therefore allow society to better understand what it means to be an autistic person. With better understanding, society can more fully support the needs of autistic people in the future.

## Notes

<sup>1</sup> "The National Autistic Society | Autism | Asperger Syndrome," The National Autistic Society, <https://www.autism.org.uk/>.

<sup>2</sup> "Autistic Women & Nonbinary Network," Autistic Women & Nonbinary Network, <https://awnnetwork.org/>.

<sup>3</sup> Autistic Self Advocacy Network, "Affiliate Groups," Autistic Self Advocacy Network, <https://autisticadvocacy.org/get-involved/affiliate-groups/>.

<sup>4</sup> In *Outline of the Theory of Practice* (1977), Bourdieu also referred to taxonomies as “classificatory systems”.

<sup>5</sup> Such research projects include those conducted by William Mandy (Bargiela, Mandy, and Steward 2016), whose research team often recruit autistic people as consultants on their projects.



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## **Appendix: Interview Questions:**

This is the list of the nine questions that provided the basis for conducting my series of semi-structured interviews. The questions below, while not written verbatim, are listed in order of how they were presented in each interview.

1. What does Autism mean to you?
2.
  - a. Have you been involved in autism self-advocacy groups?
  - b. How has your involvement helped your understanding of what it means to be autistic?
3.
  - a. Have you heard of the term Neurodiversity?
  - b. How did you first learn about the term?
4. How has neurodiversity been discussed among the self-advocacy/ support groups in which you participate?
5. Has your understanding of neurodiversity shaped/contributed to how you think about your own autism?
6. What are your opinions on current movements that aim to promote Autism awareness?
7. Do you think enough has been done to shed light on autism- related issues from the perspective of autistic people?
8. Do you believe neurodiversity should be given greater focus when discussing autism-related issues?
9. Why else should neurodiversity (*the neurodiversity paradigm and neurodiversity movement*) be given greater focus?