Illuminating Autism:

Exploring Identity Transitions among Adults Diagnosed with Autism

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Abstract

Autism Spectrum Disorder (ASD) is a relatively new diagnostic label that has undergone some changes in the latest edition of the DSM. This research is a study of individuals diagnosed during adulthood with ASD. Its aim is to understand the impact of diagnostic labels on the identity of autistic adults and examine how these individuals negotiate the labels within their social environment. To this end, the study focuses on exploring four key aspects of the subject-matter in question: (1) the labelling process from informal labelling by peers, families, and institutions to formally acquiring a diagnostic label; (2) identity formation as a consequence of informal and formal labelling; (3) needs of autistic adults who are formally diagnosed; and (4) autism advocacy as a means of making life more inclusive for high functioning autistic adults. Given the study's focus on the lived experiences of individuals diagnosed with ASD during adulthood, participants 18 years of age or older who were formally diagnosed with either AS or ASD were interviewed. The study's findings show that for autistic adults receiving a diagnosis is often a positive experience that, in many cases, enables them to finally understand their "self" and develop a feeling of belonging; however, the lack of knowledge, services, resources and policies attuned to their needs is the main obstacle to removing barriers preventing autistic individuals from participating in social life as independent and autonomous members of society.

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Illuminating Autism: Introduction

The focus of this study is adults diagnosed with Autism Spectrum Disorder during adulthood—i.e. adults who lived much of their lives without an explanation for their "differentness" and who, because of this, had negative social experiences. Without the framework to understand themselves, many of these adults formed negative perceptions of themselves. Many never received any support, or resources, before receiving a diagnosis, and some received the wrong diagnosis leading to additional mental health issues (Lewis 2016a). Not much is known about the lived experiences of these adults from their own perspective, and this lack of knowledge is directly related to them having very limited resources available to address their needs as a 'vulnerable population.' What motivates this study, thus, is gaining a deeper insight into the identity transitions of late diagnosis autistic adults, and to better understand the kinds of resources and support they need to reach a better quality of life.

To achieve this, I make use of qualitative open-ended interviews with 20 adults diagnosed with autism after the age of 18. This data comes from a larger project funded by a SSHRC insight development grant under Dr. Chris Sanders and Dr. Antony Puddephatt, and as such, they assisted in doing some of the interviews. The interview questions and analysis were designed to explore four key aspects of the subject-matter in question: (1) the labelling process from informal labelling by peers, families, and institutions to formally acquiring a diagnostic label; (2) identity formation as a consequence of informal and formal labelling; (3) needs of autistic adults who are formally diagnosed; and (4) autism advocacy as a means of making life more inclusive for high functioning autistic adults.

In order to explore these themes, the study considers the following questions: (1) 'what motivated adults to seek a diagnosis?'; (2) 'did the perception of "self" change from pre- to post-diagnosis?'; (3) 'how did they adopt, interpret, and negotiate their label?'; (4) 'what kinds of resources did they access?'; and (5) 'what do they need from their environment to achieve a better quality of life?'. By pursuing these questions, the study first addresses the experiences of autistic adults before being diagnosed to understand how their identity was impacted by their social environment; it then explores the diagnostic process to investigate the barriers to and problems of obtaining a diagnosis; thereafter, it explores how identity is again changed once the individual is classified, and how a self is reconstructed in light of the new label. Next, it explores the political aspects of the autism identity construct, and how participants interpret these and navigate them socially, through strategies such as masking or disclosure. It also identifies what resources and supports individuals accessed, whether these were helpful, and what autistic adults themselves feel they need in order to have the same chances at success as neurotypicals.

The presentation of the research process and its findings is organized into four chapters. Chapter 1 provides a review of the literature about autistic adults and identifies some the gaps addressed by this study. Chapter 2 presents the study's theoretical framework of symbolic interactionism (Mead 1934; Blumer 1969; Prus 1996), grounded theory, and qualitative research methods (Charmaz 2014) to study identity transitions of adults diagnosed during adulthood with autism, understand how identity is formed through the labelling process (Scheff 2009), understand how it is navigated socially, and gain insight into the general needs of autistic adults. It also discusses the methods used to gather data, and the methodological choices made throughout the study. Chapter 3 is the first of two parts that focus on the results of data analysis and interpretation. Titled "Self and Identity," chapter 3 explores identity formation from pre- to post-diagnosis and focuses on autistic adults' self-perceptions, their perceptions of how others see them, and the evolving nature of these throughout the diagnosis process. Chapter 4—titled "Navigating the

Identity Politics of Autism"— is the second part of data analysis and interpretation. It first assesses the discursive terrain between the neurodiversity movement and the medical establishment in terms of contentious definitions of autism, how it should be labelled, and what it means; it then examines how autistic people manage their identity in relation to others; thereafter, it considers resources and the types of support for autistic adults post-diagnosis; finally, it explores the advocacy done by autistics to raise awareness and help others in their community, and the needs of high functioning autistic adults.

Some of the study's key findings can be summarized as follows: (1) receiving a diagnosis was often a positive experience that, in many cases, enabled autistic adults to finally understand their "self" and, for the first time in their lives, develop a feeling of belonging; (2) there are currently not many services and supports for high functioning adults on the spectrum, due to the lack of knowledge about this group and/or the absence of policies that would facilitate provision of services tailored to high functioning autistic adults; (3) contrary to the literature, most of the study participants felt that the change of classification of autism and Asperger syndrome was positive for the autistic community, bringing it together by eradicating the existing hierarchy between "low" and "high" functioning autistics; (4) despite the autistic community being brought together, concerns about the stigma associated with the autism label still remain (especially among those who chose to keep their AS label).

Overall, the study is inspired by the social model of disability which argues that "it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS 1976: 14). In other words, in order for people with impairments to participate in social life, we must remove societal barriers that prevent them from doing so. From this viewpoint, autism ought to be thought of as a ‘disabling condition’ that prevents a group of individuals identified as autistic from fully participating in social life, because they are not provided with opportunities to access what they need to be successful as independent and autonomous members of society (den Houting 2019). To remedy this, the needs of autistics—communicated by autistics themselves—have to be heard and taken as the basis for instituting policies, services and resources that will lead to removing societal challenges and barriers standing in a way of their full and meaningful participation in society.

Chapter 1: Literature Review

Introduction

The aim of my research project is to explore the social experiences of adults diagnosed with ASD during adulthood and consider the effects of this label for their identity, overall sense of self, and social relationships. The main objectives of this study are to: (1) explore how adults adopt, interpret, and negotiate the diagnostic label they have acquired from the medical establishment; (2) examine how this identity is shaped and developed through formal and informal networks of support; (3) learn about the positive and negative experiences of adopting the label, and compare how life after adopting the diagnosis compares with life pre-diagnosis; and (4) learn about the political aspects of their new identity within changing neurodiversity discourse and shifting meanings of the disorder in the DSM; (5) develop strategies for masking or disclosing the disorder to others; and (6) in some cases, build on their personal experiences with these identity politics to become involved in advocacy themselves.

Given the project's research aim and objectives, the autism literature reviewed focuses on the issue of self and identity from the pre-diagnosis phase to the post-diagnosis phase. The chapter first reviews the perspective of symbolic interaction and labelling theory as it relates to the analysis of self and identity. It then turns to the literature on the history of autism as a diagnostic label and on the changes in the latest Diagnostic and Statistical Manual (DSM) of mental disorders, considering its positive and negative impacts of the process of diagnosis. A review of this literature reveals that the fairly recent change in labels in the DSM-5 had a significant impact on the identity of autistic individuals—something that is crucial to understand how, or if, this change is still having an effect on how individuals see themselves in terms of their label. Furthermore, most studies reviewed found that diagnostic labels were mostly positive on identity formation, but that there was still a lack of awareness resulting in negative stereotypes about autistic individuals. This was consistent with the experiences of participants in this study, many of whom spoke about ‘camouflaging’ as a strategy used to hide their stigmatizing features.

The second part of the chapter reviews the literature on the process of diagnosis for adults—including seeking explanations, self-diagnosis, seeking an official diagnosis, and the literature on the challenges in obtaining an official label. This literature proved to be important as many of its findings pinpointed the issues similar to the ones discussed by the study participants. Thereafter, the chapter considers the research that focuses on the problem of the lack of knowledge about autism by clinicians, the lack of resources and services for adults, and the lack of public awareness that contribute to the stigmatization of autistic adults. Finally, the chapter discusses how the autistic community is raising awareness about autism through advocacy, and what supports are needed by autistic adults to help them enhance their life opportunities.

1 An Interactionist Approach to Self and Identity

The objective of this research study is to gain a better understanding of the impact of diagnostic labels on the identity of autistic adults. Specifically, of interest is how adults are able to construct their new sense of self out of the meanings available from medical as well as neurodiversity discourse. I am also interested in how the autistic identity can become political, how this is negotiated, and whether and how people begin to participate in advocacy. Adopting a symbolic interactionist framework (Blumer 1969; Prus 1996; Puddephatt, Shaffir and Kleinknecht 2009; Charmaz, Harris and Irvine 2019) allows for an exploration of how the self and identity are shaped symbolically, and through a social process, as adults are diagnosed during adulthood. This will not only further our insight into how self and identity evolve through divergent forms of discourse, but might also help to combat social stigma and contribute to a better public awareness of the condition. This is especially so for high functioning autistic adults selected for this study, as much of the focus in the existing literature is often on children and those autistics with higher levels of support needed. Understanding the process of self and identity development will provide insight into how adults choose to incorporate the available resources and social networks into their own lives. This is also important to know about if we wish to understand how to meet their needs in social policy and daily social interactions.

In order to understand how recently diagnosed adults with ASD cope with both problematic and empowering definitions of their identity, and actively interpret and redefine this in their everyday lives and relationships, the study's theoretical framework draws on both the symbolic interactionist (Blumer 1969; Prus 1996) and labeling theory (Hacking 1995; Scheff 1999) traditions. Rather than presuming that people take on ASD labels automatically, the perspective of symbolic interactionism is used to explore the diagnosis and associated changes in self and identity as an interpretive social process (Prus 1997). Self and identity are linked but should be distinguished for the purposes of this analysis. Self refers to one’s inner world of experience and consciousness, oriented through action in the world, but also through the inner dialogue of self communication (Mead 1934; Wiley 2016). Identity is the symbolic representation of self as an abstraction, which can be referred to by the self and others for the purposes of social action and fit within institutional orders (Scott, 2015; Charmaz, Harris and Irvine 2019). Both are mutually constitutive and overlap, but are not exactly the same, hence making the distinction here is necessary. Most crucially when autistic adults discuss their inner experiences and difficulties, it is assumed they are referring to the concept of self. When they are conceiving of what autism means as a socio-political label and category to be negotiated with others, it is assumed they are referring to identity.

By focusing on the symbolic nature of identity, the interactionist perspective also allows for insight into how people actively negotiate labels (medicalized, deviant, etc) to construct their own identity in relation to social relationships and obligations. Scheff's (1999: 89) labelling theory argument helps to focus attention on the fact that individuals who are diagnosed with a disorder begin to think in terms of the stereotyped role. This, in turn, becomes validated by others, completing a cycle that further embeds and structures the new social identity. This is what Ian Hacking (1995) calls the "looping effect" of human categorization, which is the process by which people tend to fit in with, or actively respond to, labels others attribute to them, which serves to further shape the labels and how they apply.

When studying how the self (understanding and experiencing inner experience) and identity (negotiating labels with others in the social world) evolves within social life, we have to view this within a dynamic and interactive social process. An interpretivist approach provides a way to explore the meaning people attach to situations and how they go about constructing their activities and sense of selves in coexistence with others (Prus 1996). According to Prus, human life is intersubjective and "[a]ny "science of human behavior" should respect both conceptually and methodologically, the intersubjective features of the human condition" (Prus 1996: 14). Therefore, in order to gain a better understanding of the self as a set of symbolic constructs, we must get at the roots of the intersubjective nature of human experience. That is, self and identity does not form autonomously, but rather, interdependently and intersubjectively within the world of others. As Prus (1996: 152) writes: "self-other definitions are not only situated within those realities, but are also influenced on the ongoing shifts of perspectives that people normally undergo over time and across situations.” As such, we must be attuned to how the autistic identity is obtained from multiple and often shifting social sources over time, and how these are interpreted and negotiated in the ongoing construction of the autistic self.

2 A History of Autism and the Politics of Medical Labelling

This section considers a brief history of autism, how the categorization of the disorder and associated labels have changed over time, and how some of the more contentious changes may have impacted the experiences of those diagnosed. Autism was first discovered in 1943 by physician Leo Kanner who used the term to describe children who had difficulties with social interactions and who had restrictive, repetitive behaviors and interests, and was classified under the broader categories of childhood psychosis or childhood schizophrenia. Historically, this disorder was thought to have been caused by ‘cold’ parenting, though this explanation was rejected over time (Autism Canada, 2020). Today the causes are still unknown. However, genetics, differences in brain function, pre- and post-natal brain development, environmental factors, viral infections and immune deficiencies may all be factors. Similar to Kanner, in 1944, Hans Asperger also made observations among a particular group of children who shared similar features (Barahona-Corrêa and Filipe 2016). At the time, both Austrian-born physicians were writing about their discovery but were unaware of each other's writing. In their findings both borrowed the term 'autistic' from Eugen Bleurer who used it to describe schizophrenic patients that showed symptoms of extreme withdrawals and self-centeredness. However, both distinguished their respective disorders from schizophrenia because the symptoms they observed began at an early age and seemed to improve over time (Barahona-Corrêa and Filipe 2016). Autism appeared officially in 1952 by Leo Kanner in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM II) and was defined as a psychiatric condition. In 1994, Asperger's Syndrome was added as a separate category from autism in the DSM IV.

Prior to the 5th edition of the DSM, autism was classified as either Autistic Disorder (AD), Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) or Asperger's Syndrome (AS). Individuals who exhibited the classic symptoms of autism but who did not meet other criteria for Autism or Asperger's syndrome were diagnosed with PDD-NOS (Autism Canada). Despite these differences AD, AS and, PDD-NOS were all characterized by the primary symptoms of problems with communication and social interaction, as well as repetitive interests and activities (Autism Canada). Therefore, when the DSM-5 was released, they were grouped under one classification of Autism Spectrum Disorder. While there are main characteristics that define ASD, each person diagnosed with this disorder is unique and each have different abilities and symptoms ranging from mild to severe (Autism Canada 2020). What impact these changes may have had for those with the relevant disorders are discussed later in this chapter.

Prior to the release of the DSM-5, high functioning autistic individuals were classified under the label of Asperger syndrome. However, due to the many similarities between the two disorders, professionals worked on a proposal of changes that would modify, remove and create new labels in the upcoming edition. There were three main reasons why this change was to take place. First, there were many 'Not Otherwise Specified' (NOS) categories, which were meant for those who did not fulfill the criteria for a disorder but who needed treatment. This category was not very useful because it gave little information on prognosis, cause or treatment. The second reason was that in the previous DSM a person either had, or did not have, a disorder but there was no indication of the degree of severity of the disorder. The third reason was the high rates of co-morbidity (for example, more than 60% of individuals in the Netherlands who suffer from depression also suffer from another disorder, with anxiety being the most common; however, Verheoff (2010: 468) argues that this was "not a reflection of the true existence of two or more psychiatric disorders at the same time, but an artifact of the current DSM-IV"). These changes led to the absorption of Asperger's syndrome into the autism classification in the new edition. People formerly diagnosed with AS were now diagnosed with ASD and were placed within a spectrum to measure severity of symptoms instead of simply fitting them into a category (Giles 2013). When the DSM proposed that AS be grouped under ASD, Wing et al. (2011: 771) expressed that, although there are commonalities between the two, what distinguishes AS from other forms of autism was that, while individuals with AS had deficits in social interactions, social communication and imagination, they had an average or high IQ and good language skills.

Another reason for the AS/ASD debate may be because, from the very beginning, these disorders were characterized differently by their founders. For example, Kanner characterized autism as a disorder and thought of its features in terms of criteria of diagnoses, while Asperger viewed it in terms of a group of children who possessed exceptional qualities not seen in other children. According to Asperger, his patients "... often had extremely original thought, … tended to cultivate abstract and intellectualized interests, often had a rare maturity of taste in art, and even a peculiar, fascinating physical appearance, with finely boned features, of almost aristocratic appearance (Asperger in Barahona-Corrêa and Filipe 2016: 2).

The third reason for the AS/ASD debate had to do with the fact that important differences were found between the two disorders, which Asperger himself pointed out in his writings, and that later these differences were recognized by other authors in the field (Barahona-Corrêa and Filipe 2016). For example, patients who had AS were distinguished from patients with autism by their exceptional cognitive ability and language development. Also, even though both disorders had impairment in social interaction, autistic children seemed uninterested in social interaction while children with AS wanted to connect to others but lacked the ability to do so (Barahona-Corrêa and Filipe 2016).

2.1 Politics of Medical Labelling

The absorption of AS by the new classification of ASD has sparked much controversy for many reasons. Studies show that AS and ASD are perceived to be different from each other in important ways and therefore should not be grouped under one classification (Barahona-Corrêa and Filipe 2016, Kite, Gullifer and Tyson 2012). Kite et al. (2012) surveyed health and educational professionals on their views about the differences between the ASD and the AS label and found that the majority thought that there was a difference between the two. In a study on the terminology of ASD, a parent participant who had both a child diagnosed with autism and a child diagnosed with AS said that these should be distinguished because they are so different that it is confusing to others referring to both her children as having autism. In her comment, she said:

> Asperger's should continue to be a separately described condition from autism. We have 2 boys, one has Classic Autism with Complex, Profound and Multiple Learning Disability, the other has ADHD and Asperger's. Using ASD to describe them both is counterproductive because people don't understand the differences (Kenny, Pellicano, Hattersley et al. 2016: 455).

Based on extensive evidence, studies have shown that many researchers, mental health professionals, and mental health service users are opposed to the removal of the AS category (Giles 2013: 180). Baron-Cohen (2017), for example, argues that to date science has not had the chance to test for biological differences between AS and autism and that—since there is no proof whether they are genetically identical or different—it would make sense for the DSM committee to wait for solid proof before lumping them together.

Adopting a new label could be detrimental to the understanding of oneself (Ben-Zeev, Young and Corrigan 2010). A letter written to the DSM-5 committee by the Asperger's Association of England requested that AS remain unchanged because of the significant role it played on individuals who identified with the label (Ben-Zeev et al. 2010). The Wing et al. research on the changes of the DSM-5 commented that

> Many people with the diagnosis of Asperger’s syndrome object very strongly to the possible loss of their label, which they much prefer to that of autism spectrum disorder or just 'autism'. They also worry that their current diagnosis of Asperger Syndrome will make them ineligible for medical or social services if DSM-V comes into use in the future (Wing et al. 2011: 771).

This worry for denial of services was also reflected by the autism society before the release of the DSM-5. When describing criteria of AS, the site expressed:

> In the end, parents should be more concerned that their child find the appropriate educational treatment based on their needs, rather than spending too much effort to find the perfect diagnostic label. Most often, programs designed specifically for children with autism will produce greater benefits, while the use of the general PDD label can prevent children from obtaining services relative to their needs. (Autism Society)

According to Ben-Zeev et al. (2010: 324), many people diagnosed with AS feared that there would be an increase in social stigma because autism was perceived as more severe than AS, and that "resistance to the new classification can be conceptualized as fear of groupness and perceived homogeneity – being viewed by the public as having much in common with the more severe, highly stigmatized label of autism”. In their study on the perception of the AS disorder, Kite, Gullifer and Tyson (2012) found that some professionals were reluctant to diagnose clients with autism because of the stigma associated with the label, even though both AS and autism have some commonalities.

Giles (2013) studied ASD and AS online community forums to explore how its members felt about the proposed changes. As expected, some accepted the new diagnoses, some feared it, some rejected it, and some were suspicious of it. Those who accepted the changes felt that it would be beneficial to include AS in the spectrum because it would foster a sense of belonging within both AS and ASD communities. As well, they felt that merging the two might help to eliminate the assumption that people with AS have a superior IQ to people with autism, and would also help eliminate the elitism status held by people with AS over those with high functioning autism. In the end, solidarity was more important to this group than having diagnostic accuracy and different treatments.

Giles' study also found that those who feared the changes thought that, with the elimination of their diagnostic label, they would no longer be eligible for benefits and would therefore lose mental health and other services they were receiving for their disorders (this belief was supported by McPartland, Reichow, and Volkmar (2012) in their study of 933 individuals who were reassessed using the proposed change). Of those individuals, 75% would not receive a diagnosis of autism under the new criteria. Some feared that the loss of their label would take away their identity. For example, one of the members wrote that by losing her label, she was afraid that she would be made responsible for her socially unacceptable behavior, as her label provided her with an explanation of her oddness. She expressed that the label of AS was just as important to her identity as her blood type.

There was also a sense of guilt expressed by some members in adopting the autism label because they felt that autism was much more severe than AS. For example, one member wrote: "I won't call myself autistic. Somehow that seems an insult to the families who do have to deal with a relative suffering from traditional autism" (Giles 2013: 187). There were members who completely rejected the new DSM label on the premise that psychiatry itself is biased and/or unscientific. One entry wrote: "Psychiatry will never know the answers of those questions till

Neurology and real science find out a way to biologically define autism and biologically detect its genes and its impact on the brain … Psychiatry is too biased and subjective" (Giles 2013: 188). Some also defied the new label saying that the AS community had become too big and could survive independently from professional discourses around mental health and psychology.

Finally, there were those who were suspicious of the change saying that the APA was simply reacting to media messages that AS was being over-diagnosed and that by eliminating the category it would enable the medical authorities to narrow the eligibility criteria (Giles 2013). This suspicion was not unfounded. In an interview with the chair of the DSM committee, when asked about the rise of autism cases in children in the past years, he answered:

> A substantial part of the recent rise can also be ascribed to the current DSM-IV. I don't want to blame the creators, but it is clear that the thresholds for bipolar disorder in children, autism and ADHD are too low. This caused 'unreal' epidemics of those disorders. (Verhoeff 2010: 468)

Giles (2013) argues that the new classification in the DSM-5 would not matter if it was solely meant for mental health professionals; however, in today's digital communication society, many people use it to shape their identity, and various online communities form their groups around these criteria. When the labels change, this affects these communities who used them as a tool to understand themselves.

Since the changes in the DSM-5, many studies have been conducted to explore whether the ASD label is seen more negatively than that of the AS label. For example, Brosnan and Mills (2016) did a study with 120 college students using on-line survey to measure attitude towards students who are diagnosed with AS, ASD and schizophrenia, as well as towards students who exhibited behaviors of these disorders but did not have clinical diagnoses. Results showed that there was no difference in attitudes between those diagnosed with AS, ASD or schizophrenia; however, there was a negative attitude towards the group who exhibited the behavior but was not clinically diagnosed with a disorder. This suggests that awareness of a diagnosis can have a positive impact on behavior towards those with mental disorders, and that there is no difference in attitude towards the different labels of mental disorders. A similar study by Butler and Gillis (2010) reached the same conclusion that a clinical label did not increase stigma, but that the behavior in the absence of a label did. Both studies were done with students and therefore results could be attributed to the fact that the post-secondary environment tends to be more inclusive. However, a study by Ohan, Ellefson and Corrigan (2015) done on stigma among adults between the ages of 19-74 had similar results as the ones using college students; therefore, it may be that people are just more sensitized to mental illnesses and are thus more likely to be more accepting.

2 Autistic Identity and the Social Self

Having established the changing context of how autism is professionally defined over the years, we now explore literature on the personal experiences of taking on an autistic identity. The following section will review the literature on how individuals (1) experience challenges in seeking and obtaining a formal diagnosis; (2) interpret a positive diagnosis to furnish a new sense of self; (3) experience stigma; and (4) seek to obtain supports.

2.1 The Challenges of Seeking and Obtaining a Diagnosis

Before the DSM-5 introduced the spectrum in its latest addition, there was little awareness of milder forms of autism. Consequently, those who did not have cognitive delays or serious language impairments were likely to be missed or misdiagnosed. With the introduction of the spectrum, it is now known that autism takes on many forms and that symptoms vary from one individual to another. However, in many cases it is difficult to detect them as many individuals develop coping strategies (such as masking) which hide core symptoms of autism, making it challenging for clinicians to diagnose. Some of these coping strategies start during childhood, which make the detection difficult even for parents (Fusar-Poli et al. 2020).

During adulthood, obtaining a diagnosis can be difficult for various reasons (Fusar-Poli et al. 2020); first, some criteria, such as historical behaviors/symptoms during childhood and adolescence, may be impossible to access; second, standardization of diagnostic tools which are based on male samples makes it harder for females to be diagnosed, as females tend to use coping strategies and camouflaging to a higher degree than males; third, females experience symptoms more internally than externally, and these are commonly interpreted as anxiety or depression rather than autism, which results in a misdiagnosis; fourth, females without accompanying intellectual or language delays often get missed because of milder core symptoms.

In a 2017 study, Lewis found that many adults who do not have cognitive delays, but who have symptoms of autism, live a large part of their lives without a diagnosis. This is because many can live independently, maintain paid employment, and participate in dating or be involved in serious relationships. However, these abilities vary from one person to another because these individuals are often socially isolated, have difficulties completing educational programs or maintaining employment. Furthermore, many experience comorbid disturbances (such as depression and suicidal thoughts) that seriously impact their quality of life. It is likely that these symptoms are even more severe for those who are undiagnosed, as they are not aware of their disorder and have no support to cope with the symptoms (Lewis 2017). Lewis's previous study (Lewis 2016b) found that adults self-diagnosed on average 3.25 years before obtaining an official diagnosis. For many, these self-assessments came from online information, television shows, and autobiographies by autistic individuals. Self-diagnosis was found to be an important step before the formal diagnosis process, as it allowed individuals to find self-acceptance and an understanding of their strengths. Consequently, some follow through with a formal diagnosis.

According to Hull et al. (2017) study, many mothers sought a diagnosis as a result of their children receiving a diagnosis. These women recognized similar autistic traits and, as a result, decided to seek a diagnosis. The existing literature does not seem to focus on this particular aspect of adult diagnosis, although it is mentioned that mothers often seek a diagnosis as a result of their children's diagnosis. This turns out to be a theme that stands out in the study, as more than a quarter of participants mentioned they came upon their diagnosis by first observing their children being diagnosed.

2.2 Receiving a Diagnosis and Furnishing a New Sense of Self

Overall, the autism literature that focuses on the social environment of autistic adults from pre-diagnosis to post-diagnosis (e.g. Fusar-Poli, Brondino, Politi et al. 2020, Shattuck, Roux, Hudson et al. 2012, Southby and Robinson 2018) shows that—given the relatively recent discovery of a milder form of autism—many adults live without a diagnosis for a significant part of their lives. Although some autistics who are undiagnosed can function relatively well in mainstream society, some have difficulties in coping with their social environment and end up experiencing some degree of social isolation. As a result of not accessing the support they need to cope with their difficulties, these individuals are at a greater risk of developing comorbid conditions. As the literature points out, the process of obtaining an official autism diagnosis is difficult for adults: first, information may be missing to satisfy some criteria; second, for women this process is even more challenging, as standardization of diagnostic tools which are based on male samples makes it harder for them to be diagnosed; and third, because females experience symptoms more internally than externally, it is difficult for clinicians to assess them.

Interpreting the official diagnosis for a new sense of self is one of many challenges for adults on the spectrum. In her autobiography, Limburg (2016) discusses three ways in which a person can view their autism diagnosis: (1) the medical model, which sees autism as an impairment that is inside the person all along and is identified and revealed following an assessment; (2) the social constructivist model, which sees identity formation as a result of the dominant way in which society views the disorder; (3) autobiographical writings by autistics[1], which—while accepting that it is inherent in a person—argue that autism is not just a set of deficits, and that—while symptoms of autism do make life difficult—society's failure to accommodate also contribute to these impairments.

Unfortunately, due to the lack of knowledge about autism by clinicians, many adults are left without resources and supports to cope with their new diagnosis. As a result, they must find their own resources. Many find online support, as well as connecting with others, to be helpful in coping with their difficulties. Another challenge autistic individuals face is the lack of general public awareness about autism. The literature (e.g. Ma 2017) finds that the media often portrays autistics in a negative light and is one of the major contributors of misinformation on autism. This, in turn, contributes to the lack of opportunities for autistics. However, autistics themselves are

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[1] Often, the authors of autobiographical writings are adults that actively choose to seek a diagnosis during adulthood and, therefore, their identity is shaped not only by a medical label but through texts of autistic experience. When narrating one's story, a work of self-construction is coming into being as the self is separated from the story being told. Therefore, talking about one's story calls an identity into being, creating a looping effect. For example, in her autobiography, Limburg (2016) states that the language she used to talk about herself after being diagnosed began to change and that the way she was narrating her story was shaping her new identity: replacing words such as 'fidgeting' for 'stimming', and her dislike for loud noises for 'sensory sensitivities', was creating her new autistic self.

working on changing these stereotypes and raising the public awareness through advocacy groups such as the neurodiversity movement. The aim of these groups is to alter the perception of autistic individuals as neurologically different from, but equal to, neurotypicals, and to have society accommodate their needs so that they can be fully participating members of society.

Lewis (2016a) explored the effects of receiving an autism diagnosis as an adult. In her study she asked 77 adults to describe their experiences of their diagnostic journeys. Many themes pertaining to identity emerged from the data. For example, most participants expressed that they had always felt different than others. While some experienced this in a positive way, most had negative perceptions of themselves as a result. Many said that they felt like something was wrong with them or that they felt misunderstood and misunderstood others, and, consequently, sought a diagnosis. However, prior to seeking a formal diagnosis, they self-diagnosed with the help of online information.

Lewis's study revealed that, after the diagnosis, there was a range of emotions, from denial to acceptance. Many participants found a sense of belonging through autistic narratives. Many expressed that, for the first time, they found others who had similar experiences and traits as themselves. For most, however, the sense of relief was significant. Obtaining a diagnosis was reported to provide an explanation for past behaviors and difficulties. It was also relief to be able to put into words the combination of symptoms they had felt their whole lives (Lewis 2016a).

Self-acceptance was also a theme that emerged from participants. Many expressed that they had to reflect on who they were and reconstruct their identity through an autism lens or revisit their past to make sense of their experiences. Furthermore, some reported that a diagnosis allowed them to be themselves, but many still felt that they had to hide who they were in order to fit in (Lewis 2016a). The findings of Lewis's study showed the challenges and the successes of participants who received a late diagnosis. Overall, it was found that there were significant benefits to obtaining a diagnosis; however, participants believed that an earlier diagnosis would have had a positive impact in their quality of life. Furthermore, the study showed that, often, adults identify with the ASD classification much before receiving their formal diagnosis. As a result, once they receive it, they feel relief because it explains much of their past experiences.

In a study conducted on the process of adults seeking a diagnosis, Jones et al. (2014) found that out of 128 participants just under half reported that they themselves decided to seek an ASD diagnosis. The most significant reason was problems with social communication, followed by mental health difficulties. Furthermore, most participants expressed that they were satisfied with their diagnosis and that they agreed with it. In selecting from a list of both positive and negative feelings they felt when receiving their diagnosis, participants generally expressed relief. However, a notable number expressed feeling anxious, confused, upset and angry. Jones et al.'s study mirrors Lewis's findings that—as expressed by participants—receiving an earlier diagnosis would have been helpful.

For many adults who lived without a diagnosis for a large part of their lives, receiving one had a positive impact on their lives and how they perceived themselves. For example, in Punshon, Skirrow, and Murphy's (2009) phenomenological study of 10 individuals diagnosed with Asperger's syndrome during adulthood, participants reported having negative experiences prior to their diagnosis, including the feelings of not being accepted and not fitting in with their peers. These experiences were difficult for participants as many were targeted by bullies; consequently, many of the coping strategies used resulted in self-isolation. Almost all participants in the study reported always knowing that they were different and being aware that others knew they were different. However, they did not know what to make of it. Punshon, Skirrow and Murphy hypothesized that without a diagnosis, the study participants lacked the framework to explain their difficulties, which—because they had no other way to understand themselves—led to many internalizing the negative perception that others had of them and reporting that this contributed to other mental health issues. Obtaining a diagnosis was reported to have many positive outcomes for participants' identity: many reported that having a diagnosis provided a framework for understanding themselves and also for explaining themselves to others; some felt absolved of blame for past difficulties. One of the most significant impact of diagnosis reported by participants was the friendships they formed with other people with AS and the feeling that for the first time, they fit in. Findings from their study provided two key insights: (1) that negative perceptions of others and lack of understanding of the self can negatively impact identity formation; (2) that obtaining a diagnosis can be positive for forming new identities by providing individuals with a way to understand themselves and their social environment, and can give opportunities to live new positive experiences such as developing new friendships.

3 Stigma

Despite the overall positive impact an autism diagnosis has on personal identity, there is still a strong stigma attached to autism. Consequently, many autistic individuals have learned to camouflage what Goffman (1986) calls their 'discrediting' features. Camouflaging is defined as hiding autistic behaviors using strategies that make one appear 'normal', so as to prevent others from seeing stigmatizing features (Hull, Mandy, Petrides et al. 2017). Hull et al. (2017) explored the subject of camouflaging among 92 adults on the spectrum in order to get a better understanding of the dynamics of camouflaging. They found that camouflaging was a common strategy used by autistic adults to fit into their social environment. As well, the study revealed that although most autistic adults were successful at ‘passing’, this strategy led them to extreme exhaustion and anxiety, and often resulted in severe negative consequences on mental health, identity, and access to support. However, despite the negative consequences, camouflaging was reported by participants to be essential during social interactions.

Although, both autistics and neurotypicals engage in camouflaging to gain social acceptance, autistic individuals are at risk of increased mental health problems as a result of using this strategy. Camouflaging is extremely effortful for autistics and has a great impact on their identity management. In addition, having to keep up a socially acceptable persona leads to high incidence of anxiety and when unsuccessful may lead to high stress, low mood and low self-esteem (Hull et al. 2017).

In a review done on how the media covers mental disorders, Ma (2017) found that there were often portrayed in a negative way. Since much of society’s perception and knowledge comes from mass media, individuals with mental disorders often become stigmatized. In high income countries, for example, it is reported that 35 and 50 percent of people with mental disorders most often do not seek help because of the stigma associated with mental disorders (Ma 2017). Furthermore, stigma reduces life opportunities in obtaining and keeping employment and having adequate housing. At the societal level, this stigma prevents people with mental disorders in participating in public and economic life, thus taking valuable human resources away. As well, Ma found that media has a strong influence on public attitudes and behaviors, and that how the media frames mental disorders has a big impact on public perception. However, he also found that, while media portrays mental disorders in a negative way, there are variations and that some sources do report on it in objective and informative ways. Ma concluded that, if employed strategically, media can be used as a tool to combat social stigma about mental disorders.

Autistics themselves are also combating social stigma through social movements such as the neurodiversity movement. Autism advocacy groups emerged in the 1970s to fight for the legitimacy of the disorder. At the time, these groups were primarily led by parents of autistic children who wanted to classify autism as a disability in order to be able to receive benefits. In the late 1990s, with the rise of the internet, groups of people diagnosed with autism started forming their own online communities. Even though a formal diagnosis was often expected to qualify as a member of these groups, its members turned away from autism as a disability and embraced it as its own culture (Giles 2013). The neurodiversity movement emerged to counter the medical model approach to autism and rejected negative language such as 'disability', 'impairment', or 'deficit' (Kenny et al. 2016, Ortega 2009).

The idea behind the movement was that people with ASD should be viewed as having a different neurological wiring than typical individuals, rather than having an illness or a disease that needs to be cured, and that this differences should be regarded like any other difference in society (such as sex, race or any other attributes) (Ortega 2009). However, Grinker (2015) pointed out that even if biological differences between those who have autism and those who do not were to be established, the way autism is perceived in society would not change. In his view, certain behaviors, such as those attributed to autism, only become a disorder if society deems them a disorder, the same way a disability becomes a disability when the social environment cannot accommodate those who are different. This argument about disorders vs. differences was also reflected by a participant in a study by Kenny et al. who said: “Autism is not the disability. The disability occurs where there aren’t sufficient supports. Just like a person in a wheelchair wouldn’t have as many problems if all places had ramps and stuff” (Kenny et al. 2016: 448).

Those who align with the neurodiversity movement are those who identify with their label and see it as part of who they are because it is in every aspect of their being. This is why some refuse to be labeled 'person with autism' and prefer ‘autistic’ or ‘aspie’. They reject the person-first language which refers to individuals first and then, if necessary, to their disability because they believe that, even though it is well intentioned, separating autism from the person gives the impression that autism is not something that one can be proud of (Kenny et al. 2016). Furthermore, this type of language violates the principle that positive pronouns should precede nouns (for example, if a person is intelligent, they would be called an intelligent person and not a person with intelligence). In contrast, the identity-first language implies that autism is positive (Kenny et al. 2016: 443).

However, not everyone in the autistic community accept the notion of neurodiversity. Many parents and advocacy groups who face difficult challenges with autism push for treatment to alleviate these difficulties and ultimately hope for a cure (Kenny et al. 2016). Because of the wide range within the autistic spectrum, not all people diagnosed with autism, or their family members, accept the disorder as being part of their identity. A reason for this may be society's negative perception of autism and, also, society’s reluctance to accommodate differences, making life for those with this diagnosis and for their family members hard. Although well intended, media messages of autism as a disease—because of how they are framed—may influence how those diagnosed with the disorder and their families see autism. For example, the New York University’s Child Study Center conducted a campaign for mental illness awareness and treatment called 'Ransom Notes', which was advertised on bus stop shelters and in other print media. These ransom notes were letters from kidnappers to parents which read: "We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning..."and was signed "Autism" (Grinker 2015: 347). These types of messages contributed to the perception that autism was a disease that one should want to get rid of instead of being a difference to be celebrated. Ortega’s 2009 study points out that advocacy groups who see autism as a disease and who are pro-cure also find that those who support the neurodiversity movement insult the suffering of patients and families who are affected by it.

Even though there is more awareness about mental illness, autistic individuals are still stigmatized and often have to cover up their autistic identity in order to be accepted in society. In his autobiography, Peter who was diagnosed with AS at the age of 13, chose to use a pseudonym rather than be added as a co-author because he felt that—although his autism symptoms were atypical (because he was highly verbal and articulate, and had no issues with gross and fine motor skills)—disclosing the diagnosis would hinder his chance for future employment (Badone, Nicholas, Roberts et al. 2016: 481). Similarly, in a study done by Johnson and Joshi (2016) one of the respondents who was diagnosed with ASD chose not to disclose her disorder at work for fear of having indirect consequences as a result. When asked about accessing support at work, some respondents feared negative stigma-related career consequences. One respondent who chose not to access support at work said:

> I guess one obvious example is a tendency to think you are going to be evaluated poorly, that supervisors are going to say hurtful things. Therefore, I may not have asked for the help that I have needed when I have been struggling. (Johnson and Joshi 2016: 437)

The fear of disclosing one's diagnosis reflects the stigma that people still face regarding their mental health: ASD is still misunderstood and sometimes disclosing one's diagnosis can be more stigmatizing.

4 Obtaining Supports

A 2012 study on research pertaining to services for autistic adults found that there was very little written on the subject (Shattuck et al. 2012). Out of 11,000 studies published in PubMed, only 23 were about services such as supporting success in work, education, and social participation for adults on the spectrum. The countries included in the study were Canada, the United Kingdom, Australia, and the United States. Among the 23 studies that did discuss services, most came from the United-States and none came from Canada. The authors concluded that "The evidence base on services for adults with an ASD is inadequate for informing policy and program decisions to meet the needs of this growing population" (Shattuck et al. 2012: 7). The study concluded that most participants reported the lack of services for adults on the spectrum.

Without adequate services for autistic adults, it is no wonder that clinicians may find it difficult to provide appropriate service-referrals for this population. A study conducted by Zerbo et al. (2015) found that most clinicians reported not having adequate knowledge, skills and tools in treating autistic adults, and many reported that they needed training to be able to care for their patients. Furthermore, they found that those who were knowledgeable about the disorder were from pediatric departments. While most clinicians could recognize the core characteristics of autism, some believed that it was a childhood disorder and were not aware of the disorder in their own patients. Consequently, many autistic patients reported lower satisfaction and felt that their needs were unmet. Zerbo et al. (2015) concluded that there was a gap in training for clinicians dealing with autistic adult patients.

Camm-Crosbie et al. (2019) also found that autistic adults lacked treatment and support. Similar to Zerbo et al., they attributed the gap in services to the absence of training of clinicians in recognising and understanding ASD. However, they also added that there was a lack of appropriate therapies and proper assessment to identify mental health problems in autistic adults. In their study, they focussed on autistic adults without intellectual delays as they found that—since, for them, access to services took longer—this particular group was more at risk than autistics with intellectual delays. Thus, without any support, this group had an increased risk of depression and suicidality.

To find support and information, many autistic adults turn to Facebook autism groups. In their exploratory study that aimed at characterising the purposes of Facebook groups related to autism, Abel, Machin, and Brownlow (2019) reported that, due to difficulties in social communication, many autistics sought out groups online in order to connect to others. Their findings revealed that 60% of autism groups—with the most members—were support groups, and that the intentions of these groups were to facilitate emotional support, seek and receive information, and provide advice between members. Second to support groups were social groups in which members joined to either connect with others for social companionship or to share in their special interest. Zhao and Wu (2019) suggest that topics derived from these online groups can help healthcare professionals understand issues most salient to autistic adults and inform clinicians on how to provide better care.

The study by Southby and Robinson (2018) shows that autistic adults do not receive sufficient support in society: many have comorbid health issues, are unemployed or underemployed, and often experience workplace discrimination; furthermore, they are often socially isolated and struggle with relationships. Therefore, to improve their quality of life, proper supports need to be put in place. According to Southby and Robinson, in the United Kingdom, policies were implemented to provide preventative services and low-level support, as this was identified as a gap in the services for the autistic community. Low-level support is defined as:

> any non-intensive service aiming to provide general support, which is not directed at treating a clinical problem or deficit, to people in their everyday lives. The focus of low-

> level support can be wide ranging and can be delivered through a variety of settings, such as health services, social care, the community, and telephone and internet-based services. (Southby and Robinson 2018: 512)

Southby and Robinson conducted their study on the effectiveness of providing low-level support to high functioning autistic adults by using the Leeds Autism AIM (Advocacy, Information, and Mentoring) service as a model. Leeds Autism AIM is a low-level program that provides information and signposting, advocacy, and mentoring to high-functioning autistics—and their families—with little to no funded support. This program required very little resources since many of the positions were filled by volunteers from the community and supports provided were all free at the point of use. The findings showed positive outcomes with regards to "employability, education, volunteering, and access to support, social isolation, health and wellbeing, managing day-to-day, access to information, communication skills, and autism awareness" (Southby and Robinson 2018: 514). The authors found that this type of service filled a need that otherwise would not have been filled, as those who are considered high functioning often have limited to access to other forms of support. Furthermore, they found that it could help improve wellbeing and social outcomes.

Müller, Schüler and Yates (2008) did a study from the perspective of people diagnosed with AS to learn what social supports they found to be helpful. Joint focus activities—especially special interest groups—were important to the participants because they provided the opportunity to meet others like themselves and to share common interests. They also liked small groups, such as study groups, because they could observe group dynamics and then apply what they learned in their interactions (several participants said that they learned how to interact socially by observing non-autistic individuals and then mimicking these behaviors). Many participants said that structured social activities—such as a religious service, or the 12-step program—were helpful because they provided them with the chance to interact with others while at the same time feeling comfortable because of the predictability of the situation.

Müller, Schüler and Yates's study also found that communication support was another type of support that almost all participants felt was important. Participants expressed that when communicating with them, the use of clear, straight language with no sarcasm or metaphors was the best way for them to understand. Alternative modes of communication (such as internet-based relationships) were also very important to participants as they allowed them to communicate more effectively. Finally, participants expressed that a non-judgemental attitude, empathy and patience from others were key factors for establishing and maintaining relationships to others. In his study, Davidson (2008) argues that since people with AS often have difficulty in face-to-face communication (because of the difficulties associated with reading body language, and responding naturally to cues from others), the internet creates a perfect medium.

Conclusion

The aim of this chapter has been to review the literature on autism that focuses on the issue of self and identity of autistic adults from the pre-diagnosis phase to the post-diagnosis phase. Key themes in the literature review can be summed up as follows: (1) adults who lived a large portion of their lives without a diagnosis reported always knowing that they were different and that others also perceived them that way; (2) often, these individuals searched for explanations of their 'differentness'—and self-diagnosed—before seeking and/or receiving a formal diagnosis through online information and social media; (3) there are multiple reasons why many adults were either missed or misdiagnosed; (4) most adults, once diagnosed, expressed a sense of relief because the classification offered a framework that offered explanations for their difficulties and past experiences, and many expressed feeling as though they finally belonged somewhere because they found others like them and felt part of a community; (5) having a label—or labels—can have negative effects, however, as there is still much stigma attached to autism-related classification(s); (6) in order to combat stigma, autistic adults—similarly to non-autistics—are known to use the camouflaging (i.e. 'impression management') strategy to fit in with others and their social environment, which sometimes leads to identity-related and mental health-related issues; (7) many adults on the spectrum do not want to seek help for fear of being stigmatized, since autism is often portrayed negatively in mass media; (8) the negative portrayals influence society's attituded towards autistics and do a disservice to autistic people in terms of reducing their life opportunities; (9) the neurodiversity movement, developed by autistic people in the 1990s, aims at shifting perceptions of autism from the medical model to a social model of disability, and—directly or indirectly—pushing for the low-level social support hubs (such as special interest groups, small study groups, structured social activities) for adults diagnosed with AS; and (10) a lack of resources available to provide support for adults on the spectrum leads many to turn to online groups to get information and help.

Much of the findings reviewed in the literature are consistent with the experiences of participants in the current research project. My research found that adults had new self-understandings post diagnosis, which generated a sense of relief. They often reported negative experiences pre-diagnosis in terms of their social relationships. They also reported, as noted in the literature, that it was difficult to receive a diagnosis growing up prior to the mid 1990s, and it was even more difficult for females, who tend to mask the behaviour better than males. Further, many of the participants in my study detail passing or camouflaging their condition as a way to try and fit in with others, and to manage stigma. Finally, participants in the current study report difficulties accessing services and supports since they are high-functioning, though those supports they could access seemed to be beneficial.

In contrast to the literature reviewed, the current qualitative interview study was designed to try to understand the changes of identity, via diagnosis, specifically through the framework of symbolic interactionism. This sociological perspective sees the self as an ongoing construction that evolves in dialogue with the social world. I was also interested in how all of these identity changes happen in the context of the background medical / political contestation of the labels and their shifting meanings. Changes in the DSM definitions and the evolving nature of the neurodiversity movement are well known, but it is less understood how these dynamics are experienced by, interpreted, and meaningfully acted upon by the individuals on the ground. Finally, this study is concerned with how personal experiences with autism often connect to the political aspects of identity, and in some cases, inspire advocacy and engagement.

Chapter 2: Theoretical Framework and Research Methodology

Introduction

Here, the general framework of symbolic interactionism is presented, with a methodology chosen in line with its core assumptions and aims. As well as utilizing an interactionist perspective and method (Blumer 1969; Prus 1996; Puddephatt, Shaffir and Kleinknecht 2009), I also build on the grounded theory tradition, particularly as it is interpreted by Kathy Charmaz (2014). Having established these foundational theoretical and methodological assumptions, I proceed to detail the more specific methods and approach to data analysis for this study.

1 Theoretical and Methodological Approach

As one of the most central interpretive approaches in sociology, symbolic interactionism (SI) emphasizes the ways in which people make sense of their life experiences and how they go about their day-to-day activities with others (Prus 1996). According to its founder, Herbert Blumer, foundational to SI are the following three premises:

> The first premise is that human beings act towards things on the basis of the meaning they have for them. … The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters. (Blumer 1969: 2)

Blumer uses these premises as an argument against hypothetico-deductive styles of research that tend to force the social world into the conceptual categories generated from armchair theory. Instead, Blumer believed in building theory from the ground up, through the use and refinement of flexible, sensitizing concepts. These concepts would emerge through embedding oneself within the social life of the other, gaining intimate familiarity with their social world of meanings.

Building from these premises, Prus (1996: 15-17) states that symbolic interactionists operate with a set of basic assumptions. First, human group life is intersubjective. Interactions are shaped through a shared meaning of language or symbols, and human behavior is always derived from this shared meaning. Second, human group life is (multi-)perspectival, in that people interpret reality differently, since the meaning of things is shaped by interaction with others. Rather positing a subjective or objective explanation for meaning, interactionists prefer an "intersubjective" explanation, since it is a community product that derives through interaction with others. However, every group establishes different meanings and individuals, in the course of their social life, belong to a number of different groups, or what Prus (1997) terms "subcultural mosaics." Therefore, each individual has contact with and may develop multiple, intersubjectively shared realities.

Third, for Prus (1996), human group life is reflective. In the course of social interaction, humans can take the viewpoint of others in forming meaningful understandings of both objects external to themselves and of themselves. This capacity enables the individual to become an object to oneself, to attribute meaning to oneself and to others on the basis if this ability, and to act accordingly. This study is aimed at exploring such reflective processes on the part of participants' sense of self post-diagnosis. Fourth, human group life is activity-based, with a focus on "doing, constructing, creating, building, forging, coordinating, and adjusting of behavior" (Prus 1996: 16). Fifth, human group life is negotiable. Its dynamic and reflective nature manifests itself in the processes of influence and/or the resistance to influence in human interactions. Sixth, human group life is relational. In other words, in the context of community life, people tend to associate with those with whom they share a particular bond or affiliation, and their senses of self evolve in response to these relationships. Lastly, human group life is processual. It is the process that shapes people through their ongoing social interactions with others. As such, autistic identity is seen to develop over time through a kind of career, as meanings of the disorder are encountered and interpreted by the participants in the study.

Blumer's (1969) initial premises, combined with Prus' (1996, 1997) assumptions about the nature of human group life, mean that symbolic interaction lends itself strongly to a qualitative methodological approach. Since interactionist researchers are most centrally interested in the meanings and definitions carried by social actors in understanding their behaviour, researchers must reach out to the world of others if a genuine understanding of these meanings can be achieved. As such, Prus (1996, 1997) recommends a largely ethnographic approach based on the Chicago school of sociology. This places emphasis on participant observation and interviews, supplemented with qualitative analyses of documents and records. As this study is focused on identity transitions through the life-course via the diagnosis of autism, interviews were emphasized as a way to understand the lived experiences of autistic adults. These interviews were supplemented with a review of online literature, biographies, and social media discourse surrounding autism in both highly organized and more informal forms. As an interpretive theoretical framework, SI offers a productive set of conceptual tools for understanding the process of identity formation in autistic adults who received their diagnosis later in life, and who—because of having gone through a significant portion of their lives without a diagnosis—experienced difficulties in understanding their "selves" and their social worlds (Scott 2015; Charmaz, Harris, and Irvine 2019). Using SI allows for an inside look into the lived experiences of these adults throughout their lives—from living without a diagnosis, to living through the diagnostic process and, finally, to life after being diagnosed.

To enable this interactionist research focus I also draw on the grounded theory tradition begun by Glaser and Strauss (1967), but recently expanded to adhere to a constructionist epistemological framework by Kathy Charmaz (2014). According to Charmaz:

> grounded theory methods consist of systematic, yet flexible guidelines for collecting and analysing qualitative data to construct theories from the data themselves. Thus, researchers construct a theory 'grounded' in their data". Grounded theory begins with inductive data, involves iterative strategies of going back and forth between data and analysis, uses comparative methods, and keeps you interacting and involved with your data and emerging analysis. (Charmaz 2014: 1)

Given the grounded theory foundation of this study, interviewing was chosen as a methodological strategy of choice because it was the most effective way of getting a better understanding of how individuals perceived the world and made sense of their everyday lives by allowing them to tell their stories. This method enables participants to talk about their experience in a way that was meaningful to them. I also made use of both Prus' generic social process scheme of "achieving identity," (1996: 152) and Charmaz's (2014: 66-67) construction of an interview guide meant to study a life change, which helped to develop open-ended questions in a stepwise manner to understand participants narratives about selfhood and identity.

2 The Interview Method

Largely working from the interactionist and grounded theory approaches discussed above, the interview was chosen as the study's primary methodological tool. Interviewing were conducted by way of a semi-structured interview guide designed to focus on the three phases of the diagnosis process: the pre-diagnosis stage, the diagnosis process, and the post-diagnosis stage (see Appendix II). The pre-diagnosis section of the interview was useful for learning about and comparing the pre-diagnosis life to the life after adopting the ASD label; the diagnostic process section was useful for learning how the interviewees adopted, interpreted and negotiated the diagnostic label; finally, the post-diagnosis section was useful for getting some insights into participants' perception of ASD in relation to their own sense of identity and how this manifested in their social lives. As these interviews were part of a larger SSHRC funded project, Drs. Chris Sanders (principal investigator) and Antony Puddephatt (co-investigator) were also helping on some of the interviews. I participated in conducting 18 of the 20 interviews, and did 13 of them independently. 2 of the interviews were collected by Dr. Sanders.

A semi-structured but open-ended interviewing format was used to ensure that research questions were answered while allowing room to probe for clarification or to obtain a more detailed understanding of the issue. At times, a more unstructured approach was used when participants took the lead early in the interview. However, in these circumstances, questions were asked either for clarification, to get more detail, or because important issues were not raised without the use of some questions from the guide. Overall, the interviews provided valuable insights into how individuals experienced the diagnosis process, accessed support and resources they needed, and how diagnosis was negotiated in everyday life. An advantage to qualitative interviews is that they are flexible: the open-ended questions can be modified according to the participant and if there is a desire to obtain deeper meaning or clarification, the researcher can ask probing or follow-up questions (Adler and Clark 2011). This strategy again allows for the emergence of new ideas and themes in unexpected ways, very much in the spirit of grounded theory (Charmaz 2014).

Since the interview format was semi-structured, the list of questions, or interview guide, was prepared ahead of time. The advantage of this is that all topics related to the research question are covered so that the interviewer does not forget to ask important questions (Adler and Clark 2011). However, with some participants, the researcher would shift to a more unstructured format. This often happened when participants took the lead and seemed to know what they wanted to share. This unstructured format allowed them to share information that otherwise may have been missed, because it was not figured into the initial question. In an unstructured interview, it is not so much the questions that are important, as it is understanding the participants' meaning and viewpoints behind their statements. Therefore, digression is just as important as the information that is sought (Adler and Clark 2011).

The interview guide was separated into 3 sections: pre-diagnosis, diagnosis process, and post-diagnosis. In the first section, the objective was to explore participants conception of themselves and how others saw them before they were diagnosed. This section would be used to compare what life was like after adopting the ASD label to life pre-diagnosis. This included questions such as: "Were there any initial signs of autism symptoms growing up? If so, please describe these experiences and what sense you made of them at that time", "How did you see yourself and how did others see you (pre-diagnosis)? What did you make of these differences?", "Did these early symptoms cause any problems or issues in your relations with others, in family, social-circles, school or work? Please describe as best you can" and, "How did you decide that it would be beneficial to seek a diagnosis? Did anyone help you to decide to be diagnosed? Did you have a sense of what the diagnosis might be?" (see Appendix II). The objective of the second section was used to explore how participants experienced the diagnosis process by learning how they adopted, interpreted and negotiated the diagnostic label. The participants were asked questions such as: "How was your diagnosis explained to you, and what literature and informational resources were recommended? Did this seem to match how you felt?", "How did you react to the diagnosis? Were you happy to have an explanation for things?" (see Appendix II). In addition, this section was focused on discovering how the diagnosis was delivered to the participants and if informational material or resources were offered by the clinicians who diagnosed them. Finally, the third section dealt with how participants coped with their diagnosis. The objective was to get some insight into participants' perception of ASD in relation to their own sense of identity and how this manifested in their social lives. There were asked questions such as: "Since receiving your diagnosis, have you connected with or joined any autism or Asperger's networks or social support groups? Which ones? How have they been useful? Have you experienced any challenges here?", "Did any of these support groups (e.g. medical, informal, online) help you to process and accept your diagnosis and shape your sense of self-identity? How has your sense of yourself been affected, if at all, by the diagnosis?" and, "Are you aware of the "neuro-diversity" movement, and how do you see yourself in relation to this?" (see Appendix II).

Prior to starting the interviews, the research team met to revise and modify the interview guide in line with our study aims. First, it was found that there were too many questions, which led to eliminating those that seemed either redundant. Therefore, the list of questions was reduced from 25 to 15 questions. Second, the three sections were kept intact; however, the order was changed (in line with Castillo-Montoya's suggestion that questions most connected to the study's purpose should be asked after building rapport (Castillo-Montoya 2016)). Originally, the first section addressed the pre-diagnosis phase, but it was determined that it made more sense to start with the diagnosis process, since these were questions that were more technical and easier to answer. After participants were warmed up, we could then move on to past experiences and issues of identity that may be more difficult to discuss.

After the first few interviews, new information emerged when we asked participants if they wished to add information that we did not cover. Consequently, we modified our guide again to include questions that would capture this information. For example, participants spoke about the lack of awareness and education about autism. Consequently, we added this question: "Do you think that training in how to educate one’s social environment would be helpful rather than all the focus being on how a person on the spectrum can adjust?”.

Adler and Clark (2011) state that each interview can be tailored to the participant and the situation so that it can be done in any place, at any time, and can—in accordance with the agreement between the participant and the researcher—last as long as it needs to. In this study, individuals were given the choice to participate in an interview either by telephone, through video conferencing, or by email. This would enable the participants to choose the method that worked best for them, and it would also allow to reach people that otherwise would not have been able to participate. Participants were advised that interviews would last approximately 60 minutes, though in practice some interviews were faster (30 minutes) while some lasted considerably longer (up to 130 minutes).

Out of twenty individuals that participated in this study, eleven chose the telephone option, four chose email, four chose video conferencing, and one chose face-to-face. Offering participants, the option of choosing their preferred method and time was challenging, due to being in different time zones. Consequently, some interviews had to be done late in the evening and finding space to conduct them was a challenge. Prior to starting the interviews, the information letter and consent form were again revised to ensure that participants understood the study aims and consented to participate. In the case of email interviews, the questions were sent once participants confirmed that the information was read, understood, and that they consented to participate. To ensure that participants could provide as much description and detail as possible, no time limits were given for returning the answered questions. However, all email interviews were completed between 2 days and 2 weeks.

Early in the interview process, it was found that email interview responses generally lacked the breadth and depth of information that was obtained by person-to-person interviews as there were no opportunity to ask for clarification or to probe for a deeper understanding of participants' experiences. At this point, the email option was kept open, but the strategy in the initial communications changed. Instead of asking potential participants which method they preferred, they were—while keeping the email option open—instead asked if they would be willing to participate in a phone or Zoom interview. If participants did not want to do a phone or Zoom interview, then the interview was conducted by email.

Using media synchronicity theory, Price and Puddephatt (2018) compared communication technologies used in long distance interviews to understand how some forms of communication produced more data than others. They found that email interviews produce what they call 'lean' data (very little information) while video interviews produced 'rich' data (a lot of information). The data produced through phone interviews was somewhere in between. Price and Puddephatt concluded that this was because of the presence or absence of certain types of information in each medium, and that, therefore, a communication medium with more types of information will yield richer data. For example, video interviews are synchronous (meaning that the feedback is immediate), which allows continual interactional exchanges. These exchanges enable the interviewer to probe or ask for clarification when necessary and allow for a dialogue where both interviewee and interviewer reach a shared understanding of meaning. This, however, is not available in asynchronous forms of communication, such as email, where interviewees have more time to think about and write their answers to questions that may require more reflection (one interviewee in our study, for example, stated in her email that she needed time to reflect on her answers as she had difficulties in providing information in real time). Price and Puddephatt also mentioned that in some cases of disabilities asynchronous form of communication, such as emailing, was a good interviewing option. In terms of our study, since some autistic individuals are known to be uncomfortable with face-to-face interactions, offering the email option was important in order to maximize their comfort level. Except for email, phone and Zoom interviews lasted between 30 minutes to 130 minutes—with Zoom interviews lasting longer than phone interviews. All phone interviews were recorded and transcribed by a third party. Zoom technology has a built-in feature for cloud-recording that later transcribes the interview.

After the interviews were transcribed, NVivo software was used to code interviews and an open coding method (Charmaz 2014) was applied to develop the coding scheme. The themes changed many times throughout the analysis process, going from a timeline to themed sections. In the end, the data was separated into three sections: diagnosis process, pre-diagnosis, and post-diagnosis. Using a codebook when coding interview data is a crucial part of the analysis process because it allows the researcher to make sense of the data and have a clear definition of each code, so that anyone using the codebook could replicate the same findings (DeCuir-Gunby, Marshall and McCulloch 2011). It is also one way of maintaining a transparent audit trail in order to improve the trustworthiness in research (Lincoln and Guba 1985). The NVivo software provides an option that allows the exporting of existing codes into a codebook to a word document. This option was used to recode the data a second time in order to sort out what matched the new themes. Then, a new codebook was reformulated manually and inputted into a new project in NVivo.

3 Recruitment and the Sample of Participants

Given the study's focus on the lived experiences of adults diagnosed with ASD during adulthood, participants 18 years of age or older who were formally diagnosed with either AS or ASD were recruited using a variety of methods. Ethics approval was obtained in the summer of 2019. Recruitment began in December 2019 and was expected to be completed in spring 2020. It was difficult to anticipate how many individuals would come forth to participate in the study. The recruiting target was set for 20-30 participants based on the time frame to complete the study and the amount of funding available for honoraria and transcription. With the advent of the Covid-19 epidemic, recruitment was halted in March 2020 but still finished with a total of 20 participants.

Participants had to satisfy three criteria to be considered for the study: (1) they had to be 18 years of age or older, (2) they had to have been formally diagnosed with either Asperger's Syndrome or High Functioning Autism Spectrum Disorder during adulthood and, (3) they had to be currently residing in Ontario at the time of the interview. A variety of methods were used in order to recruit participants: local autism organizations were reached by phone, email, and in-person; a poster advertising the study was posted in local coffee shops, libraries, and around the Lakehead University campus. Further, a snowball sampling method was used, by approaching personal contacts and asking them to spread the word to their own personal contacts and networks. As well, an advertisement was posted on the Autism Ontario website in their section listing current relevant research.

Nineteen participants reached out through an email address that was set up for the study and one was referred through a personal contact. Once they reached out, a response was sent to introduce the researcher and provide a general overview of what to expect should they choose to participate. If they requested more information, a more thorough description of the study and its objective, and a detailed explanation of the interview process, was emailed to them. If they satisfied the required criteria and agreed to participate, a copy of the information letter and consent form (see Appendix I) was also sent to them by email, which they could review, and then send confirmation that they had read and understood the information, and if they consented to participate. They were also instructed to email or call the chief researcher if they had any questions or needed clarification. Additionally, an electronic master file of all participants who consented to an interview with the date and information of the process of recruitment and consent was kept.

Aside from one participant who was referred through a personal contact, all others reached out either because they saw the poster on the *Autism Ontario* website or on a Facebook post shared by a friend who had participated in the study. Consequently, many emails were received from individuals who wanted to participate but did not satisfy the geographical criterion of residing in Ontario. Initially, these individuals were declined; however, after some consideration the area of study was expanded to include all Canadian provinces. The choice to expand the geographical area was because of two factors: (1) the time period allotted for interviews was halfway through and including the potential participants outside of Ontario would ensure that there would be an adequate sample for the study; (2) by expanding the geographical area a greater understanding would be gained about services offered for adults diagnosed with AS/ HFASD across provinces. While it is based in Ontario, Autism Ontario does draw membership from around the country, which made the "Ontario boundary" less meaningful. There was also a concern about excluding people who had recently lived in Ontario but had moved away as they would still have valuable experiences to share—especially since the interview guide was not specifically about the experience of living in Ontario. Finally, since our study is much more interested in the social experience of receiving an autism label, we were not overly concerned about jurisdictional issues related to specific health care received.

Confidentiality of data was expressed as a concern for two of the participants in the study. The first individual reached out by email to communicate her interest in the study; however, she had concerns about how her personal information would be stored, at what point the interview recording would be destroyed, and if there was a separate question at the end of the interview pertaining to demographics. She explained that she had a bad experience in a previous study and was being cautious about participating in future studies. A reply was sent to her stating that there was only one question at the beginning of the interview about her demographics and that she could abstain from answering this or any other question during the interview, should she choose to participate. An attachment of the information letter and consent form were also included that gave more information about the study and specified how data would be handled during and after the duration of the study. She was satisfied with the additional information and agreed to participate. She also asked to receive the result of the study once it was completed.

The second participant had concerns similar to the first. At the beginning of the interview, she asked how the data would be protected. She said that she had recently experienced an attack in their system at work and had to increase the security measures, and therefore wanted to know how we would avoid this type of situation. A reply was sent stating that the data would be safeguarded on a password-protected laptop. She was also assured that this type of situation would be unlikely to happen as both the laptop and the coding software where data were kept were password protected. This participant was not overly concerned but was curious because of her recent experience.

Participants in this study ranged between the ages of 23 and 56 years old and were all residing in Canada at the time of the interview. Four participants were born in Europe, one in the US, and the rest were born in Canada. Although the literature revealed that males were more likely to get diagnosed with AS or ASD (Goldman 2013), there were significantly more females who participated in the study. It is possible that the criterion of a diagnosis during adulthood impacted the gender of participants because females tend to get diagnosed later in life (Goldman 2013). The adulthood diagnosis criterion was particularly relevant to our study as our objective was to explore how the self evolved from pre-diagnosis to post-diagnosis. These adults would have gone through a large part of their lives without a diagnosis and therefore their experiences and needs would have been different than those who were diagnosed during childhood.

As mentioned previously, one of our criteria was a diagnosis of Asperger syndrome or High Functioning Autism Spectrum Disorder. The Asperger syndrome label was included in the criteria because, although the DSM-5 does not carry this label anymore, many people were diagnosed prior to the last edition. It was important to capture this group as the literature suggests that the change in label may have had an impact on some patients' sense of identity (Giles 2013). This might be different than those who would have been diagnosed later with High Functioning ASD, as they would not have dealt with this transition. The term High Functioning ASD was chosen because the study sought participants who would have gone through their childhood and adolescent years without a diagnosis, due to their ability to function relatively well in society. We were mindful of the fact that labels such as these could be a point of contention, but we felt that—without having spoken to adults who had the diagnosis—'High Functioning ASD' best described our target population. Indeed, the interviews revealed that there were still many terms used to describe this group by clinicians as well as those diagnosed (terms used by participants during the interviews were Autism, High Functioning Autism Spectrum Disorder, Autism Spectrum Disorder Level 1, Autism, Mild Autism and Asperger's). It is important to note that some individuals were still being diagnosed with Asperger's Syndrome by clinicians even though this label is no longer officially used in the DSM-5. Additionally, some participants used the term interchangeably with the label of ASD.

4 Limitations of the Study, and Challenges in the Interview Process

Prior to starting the interviews, I did a literature review on the subject of AS and ASD and discovered that the change of label in the DSM-5 seemed to be a hot topic in the AS/ASD discourse. I was excited to do the interviews and find out what participants had to say on the subject. Consequently, a question pertaining to this issue was added to the interview guide. Once I started doing the interviews, I was shocked to find that the change of label was not an issue for any of the participants. This could be attributed to the participants being diagnosed after the change took place or because, with time, people got accustomed to this change and it was no longer an issue. I also expected there to be a more reactive response when I asked participants if they had heard of the neurodiversity movement and how they saw themselves in relation to this. The literature (e.g. Baron-Cohen 2017, den Houting 2019) showed that the movement was widely known, but this did not come out when questioned about it.

During the interview process, some participants became emotional when talking about their family and peer relationships. They spoke about traumatic experiences during their childhood and it was clear that discussing this part of their lives with me was very difficult for them. I did not anticipate these types of reaction although, in retrospect, I should have. I had read enough to know that many of the experiences of adults who were diagnosed with autism later in life were often negative and traumatic, and I should have been prepared to deal with these circumstances. In my previous role as a counsellor, I would have known what to do when confronted with individuals becoming emotional. However, as a researcher, I did not have prior experience. Also, because these interviews were done by phone and Zoom, I felt powerless to intervene adequately.

Subsequently, I consulted with my supervisor for guidance on the most appropriate ways to deal with these kinds of instances, and he provided me with the appropriate protocol.

Some participants expressed that they were happy that this type of research was being done and thought that it was important because of the lack of awareness about ASD, especially in adults. During the interviews, some expressed that often people have stereotypical ideas of what an autistic person should be like, and how—because many of them did not fit this stereotype—this made their reality much more difficult when they had to disclose their diagnosis. Many women in this study expressed that the characteristics of females with ASD were different than those of males, and that— because less is known about females on the spectrum—this was problematic within their social environment and in terms of the testing used by clinicians to diagnose autism. Furthermore, some expressed that they hoped that the study would shed light on the lack of resources available for adults diagnosed with ASD, particularly those who are on the high-functioning end of the spectrum, as most resources are aimed at children or people who are lower-functioning.

At the end of an interview, one participant asked me why I was doing this study and if I had a family member that was on the spectrum. He said that he had recently participated in a couple of studies on the subject and thought that it was interesting to know what motivated researchers to study this particular issue. I replied that my research interest in people who were diagnosed during adulthood was based in this not being a well-known area. My motivation for doing this study was later on again asked about by another participant, and I gave her a similar response. By this point, the issue of gender had also come up with a few participants and this became an additional interest in pursuing knowledge on the subject.

The aim of a qualitative research is to provide rich descriptions of lived experiences as it applies to particular groups within society. While these experiences cannot be generalized to the population, the purpose of the study is to uncover new themes and ideas surrounding the lived experiences of adults with autism. The sample of 20 adults, mainly from Ontario, but with others from other areas in Canada, is also somewhat limited. Nevertheless, theoretical saturation was observed across many of the themes, as many interview subjects converged on a number of the central issues and experiences shared (Low 2019). As such, the study does provide valuable insights into the lived experiences of adults diagnosed with autism during adulthood, and uncover some new themes not currently covered in the existing literature. In qualitative research, issues can be explored in depth, and are fluid enough that they can be adjusted in real time in order to improve getting at the meaning of human experience. As new information emerges, the research framework can be adjusted so that the researcher can capture these subtleties that otherwise would be missed in quantitative research. Many of the themes in this study did emerge somewhat unexpectedly as the researchers continued to learn from the participants.

Prior to the interviews, I had a strong interest in the neurodiversity movement and was looking forward to hearing from the participants about their views on the subject. Although I side with the belief that ASD is a neurological difference rather than a disorder, I knew that I would have to bracket this belief when asking and probing on the subject. In bracketing, according to Creswell and Poth (2016: 78), “investigators set aside their experiences, as much as possible, to take a fresh perspective toward the phenomenon under examination.” Therefore, doing this helped ensure that I would not be influencing the participant to provide me with the answer in line with my personal viewpoint, and that I would be able to interpret the data as objectively as possible.

Although complete objectivity is perhaps impossible, being aware of my biases made me reflective about them and ensured that I was representing my data as it was.

Conclusion

The aim of this study is to gain a better understanding of the impact of diagnostic labels on identity, and how these labels are negotiated in the social environment. To accomplish this, the study's conceptual framework was grounded in the symbolic interactionist perspective, grounded theory and qualitative research methods. The insights of symbolic interactionism were used to explore the diagnosis as a social process, where people actively negotiate labels to construct their own identity in terms of their social relationships and obligations. The qualitative interview was used to explore how individuals perceived the world and how they made sense of their everyday lives. Interviewing proved to be a productive method as it allowed the interviewees to share their experiences in a way that was meaningful to them. Most interviews were semi-structured. This provided room for participants to offer rich descriptions of their experiences while ensuring that the research questions were answered. However, some interviews ended up being unstructured. These interviews revealed experiences that were not captured by the questions but that nevertheless provided important information and context that may have been lost through the semi-structured format. The study's participation criteria were meant to zero in on a specific group that is often left out of research on autism, since autism studies—because of often having the goal of finding a treatment or cure—are frequently focused on children and people who are low functioning. The following two chapters report the findings from the interview study. Chapter 3 considers the development of self and identity through diagnosis, while chapter 4 considers the identity politics connected to the label and how they navigate this in the social environment.

Chapter 3: Self and Identity

Introduction

This chapter examines the development of identity formation among high functioning autistics from the pre-diagnosis to post-diagnosis stage and includes three sections: (1) reflecting on the self pre-diagnosis, (2) challenges in seeking a diagnosis, and (3) obtaining a diagnosis and re-interpreting self and identity. Using Cooley's concept of the looking glass self and Mead's theory of self and identity, the first section focusses on the pre-diagnostic stage and explores participants' conceptions of how they perceived themselves pre-diagnosis and how they thought others perceived them. The second section focuses on how adults encounter difficulties in obtaining a diagnosis, and turn to seeking information online, or recognizing autistic traits in themselves as a result of their of their children being diagnosed. Conceptually grounded in Mead's theory of the past, the third section explores the diagnostic phase, and investigates how participants made sense of their diagnosis and furnished a new autistic identity. In doing so, they reconstructed their pasts from the point of view of the newly adopted autistic lens, viewing past events in ways that would provide vindication and relief.

Overall, the process of identity change from informal labelling to formal labelling is important for understanding how self-perception evolves over time, and can provide insight into the positive and negative effects of a diagnosis on individuals. In this study, participants often searched for explanations for their different sense of self before receiving a diagnosis; once they found a fit with the ASD diagnosis, they began to understand themselves through the autism lens and develop a more positive self-perception. As such, relief was a major aspect of finally receiving a diagnosis, as it provided a more meaningful explanation of past events and a more positive understanding of the self.

1 Reflecting on the Self Pre-diagnosis

This section considers classic interactionist conceptions of self formation via the work of Charles Horton Cooley (1922) and George Herbert Mead (1934). Using these as the conceptual points for departure, this section will first address the issue of how autistic individuals come to develop a sense of self, and how this process can be more complex for autistics than for neurotypicals. This also illustrates how autistic adults provide an interesting contrast case to the basic assumptions of self development in both Cooley and Mead.

Cooley's (1922) notion of the looking-glass self is a concept used to understand the formation of an emotional attitude (or 'self-esteem') that one develops towards one's self. His key insight is the idea that the shaping of one's self-esteem—that is, of an 'emotional-core' of one's identity'—is directly influenced by one's perceptions of how/what others think about us. In other words, if one thinks that others have a negative perception of them, they will internalize this and have a negative emotional self-perception of themselves (see also Scheff 2003). According to Cooley, there are three phases to this process: (1) individuals imagine how they look to others; (2) they imagine how others would judge how they look; (3) based on this evaluation, they develop their self-image. Cooley argues that all social interactions shape an emotional core of one's identity and that this happens throughout one's lifespan. He also argues that identity is influenced not by the opinions of others directly, but, as in Mead, by what the individual imagines others' opinions to be. Therefore, individuals come to know themselves through imagined opinions, whether these are positive or negative.

Cooley's model influenced Mead's later theory of self development, which discussed the mechanics of the social process in a more detailed way. According to Mead (1934), the self develops early on through three principle stages: imitation, play, and game. At the imitation stage, the self is initially shaped by imitation of the actions of others (for example, when a child is using a miniature broom to sweep like they see their parents doing it). At the play stage, the self is shaped through role-playing—i.e. by learning the role of another person and understanding behaviors associated with a certain role (such as being a patient or a doctor). It also involves, crucially, the ability to "take the role of the other," by imaginatively assuming the other role so as to anticipate the others' actions and act accordingly. Thus, the child playing doctor must learn to take the role not only of the doctor but also the patient, so as to anticipate what the patient wants or needs and serve them more effectively. At the game stage, the self is shaped through game-playing where one learns how to play not only a single, particular role but also gets to understand the system of roles and what each role with that system entails, as well as the nature of one's own role within the system of roles. In other words, it emerges through the process of interaction between the individual and his/her 'generalized other' which Mead (1934: 154) defines as "an organized other … in so far as it enters—as an organized process or social activity—into the experience of any one of the individual members of it".

For Mead, the socialized self consists of two parts: the "I", which is the spontaneous self; and the "Me", which is the reflective self. The "I" only becomes known to the individual once it is reflected through the "Me"—i.e. once one takes into consideration the expectations and attitudes of others—and once the self becomes consciously aware of itself by using internalized responses to reflect on and judge one's own actions (Aboulafia 2008). These internalized responses are how we view and get to understand ourselves from the perspective of our 'significant others'. It is the complex interplay of this internal dialogue that allows us to prevision social action and choose behaviour that is more likely to be judged positively by others.

One of the key assumptions of the interplay between the "I" and the "Me"—and of the development of the self—is what Ian Hacking (2009: 1471) refers to as 'Köhler's phenomena': the ability to innately and intuitively recognise others' feelings, emotions, and mental states in their actions and expressions. Ryan McVeigh (2016) notes that this ability seems to map on to the neuroscience of "mirror neurons" in that people intuitively feel others' emotional states and needs. Since autistic individuals lack this kind of ability and are often unable to infer others' 'states of mind' from their behavior the same way neurotypicals do (McGeer 2009), they must develop different processes of predicting and explaining others' behavior. In Mead's terms, the intuitive act of "taking the role of the other" simply cannot be assumed. For example, Charlotte, one of the interviewees, talked about how she saw others in her environment as separate from herself, and how she could not situate herself in relation to others and as part of a social system:

> I didn't really see myself as like a person who was like a part of the class or something. I wouldn't – like I would watch other students and I wouldn't really think of myself as one of them. Like if you were researching bees for example like you would know a lot about bees and you would maybe even enjoy the company of bees, but you would not see yourself as one of them. And I think that was kind of an effect that I had from a very young age.

Rather than seeing herself as natural part of her social environment, Charlotte viewed the classroom as foreign and outside of herself, something she did not have direct access to. The inability of high functioning autistic adults to intuit and make interpretive sense of behaviors and the actions of others also manifests itself as a need to make conscious efforts to actively and systematically 'study' and 'decipher' others' 'symbolic gestures' so as to understand and process a social situation and their potential place/role in it. As McGeer (2009: 524) observes, a 2000 study done by Klin on high functioning autistics demonstrated that these individuals had to "rely on some explicit process of reasoning, something more like genuine theorizing." Hazel, for example, spoke about this when she said:

> I didn't know how to talk to people for a long time. I didn't know what to say. I would study people talking, conversations amongst kids at school, and then I would come home and write down the conversations and what was said, and whether or not people smiled, laughed, nodded. You know, and I had notebooks of conversations because I literally did not know how to talk to people. I never fit in. I never knew how to talk to people…

What the above statements demonstrate is that autistics do not process their social environment the same way as neurotypicals, and that they rely on different strategies to arrive at a conscious understanding of themselves and their role within a system of social roles. For example, using the analogy of bees, Charlotte explained that she could see that there was a system, and that individuals inside the system were interacting with one another, but that she could not personally connect with that system. Hazel further explained this when she spoke about studying social interactions. Like Charlotte, she could not intuitively understand how interactions worked. It was through observation and study that she could put the pieces together so that she could understand how each part of the system connected and worked together. However, since she could not understand the intentions behind (inter)actions, she could not predict or understand reactions of others. Thus, whereas for neurotypicals understanding their social world and their place/role within it comes intuitively and without premeditation, for autistics it is a matter of conscious and deliberate strategic efforts.

As already mentioned, high functioning autistic individuals do not have an innate ability to understand others' intentions or behaviors, but they do have the ability to understand situations through conscious observation and theorizing. The latter provide them with the clues about how others relate to them, and these are what they use to form a self-perception and an emotional attitude about it. Jolene's and Mona's remarks, for example, speak to this:

> Peers certainly knew I was different. I remember stimming in Grade 5 by rubbing an eraser against my face, and someone I thought was a friend told me that was gross and to stop because only weird kids did that. I just thought it felt nice, and it was quiet and didn't hurt

> anyone, so I didn't understand why it was bad. Nobody inviting me to their birthday parties was also a pretty big indicator that my peers thought I was different. (Jolene)[2]

> And so that made me think that I did not fit into either category because they thought that I was just very smart. But then when I went into these gifted programs, I had no interest and no understanding of what was going on. And so, I felt socially isolated because other people saw and noticed that I did things that they didn't do, and at the same time I felt like I didn't fit because I also was not gifted. (Mona)

For Mona, being placed in a program for the gifted made her feel like she did not belong to a "normal" classroom. Additionally, she reported that she did not belong in the gifted group either, which made her feel that she did not belong anywhere. Both of these made Mona aware and feel that she was different, because she was being placed in a class for different people.

For other participants, the realization of being different came from their family. Mona's interpretation of how her parents saw her provides a good illustration of this:

> …it was something that maybe I would just grow out of. Or maybe that I was just very shy and in other ways that something was wrong with me because I did not like hugs or that I had meltdowns, that I was fussy. And those were a part of how I believed that something was wrong with me.

Juliette also spoke about feeling like she was a problem for her family. When she recalled how her family made her feel, she said:

> I was growing up believing yes, I am unworthy, yes I am the one who is wrong because all my family they're quite clear that I'm the problem. But I didn't associate it with autism and I just associated it with "I'm the bad one."

As discussed previously, identity formation could be affected by the ability to understand one's social self and others' social selves within a system. Autistic individuals must rely on careful

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[2] Stimming is a term used by the autism community to describe one of the core features of autism which is characterized by stereotyped or repetitive motor movements. It is used as a coping strategy to regulate some sensory issues (Karp et al. 2019).

observation and study of social situations to understand their social world. However, they are incapable of predicting others' behaviors or intentions intuitively, which could lead to misunderstandings about how they interpret others' perception of themselves. Statements by Jolene and Mona demonstrate the processes it took to interpret how others perceived them which, in turn, impacted how they felt about themselves. For example, Mona developed a negative self-perception as a result of being placed in a special class in which she felt she did not belong. In addition, since she was removed from her previous class, she interpreted this to mean that she did not belong there either. Later, she reports that her parents said that she would grow out of it, which she also interpreted as something being wrong with her. This furthered a negative self-perception. Similarly, Jolene spoke about a situation where she was told that she was weird and then observed that other people were going to birthday parties to which she was never invited. She interpreted these situations to mean that she was not part of the group, which had negative consequences on her self-perception.

The interviewees above all reflect on their sense of self prior to diagnosis. Without an objective medical label, they were left to evaluate their differences from others on their own. Respondents noted that they would be treated differently, and often in negative terms by family and friends, and in institutional environments such as school. They also explained that they were not immediately able to feel at one with groups, and had difficult intuiting what people's perceptions of them were. Instead, they had to logically piece together assumptions from specific and generalized others in their communities in order to furnish a social self. Further research on this process of self-development may be interesting as the foundational assumptions of role taking in the looking glass self and Mead's theory cannot be taken for granted. Like in studies of the construction of the deaf identity (Meadow 1969; Leigh 2009), much may be gained to enrich the interactionist model of selfhood by delving deeper into autistics as a contrast case.

2 Challenges in Seeking a Diagnosis

Many adults reported difficulties early on in getting an official diagnosis. I consider the social and medical context of how shifting terminology and practice shaped the likelihood of receiving a diagnosis, or, conversely being missed, or misdiagnosed. Much of this is reasoned to be generational, in that high functioning autism or Asperger's disorder was not in place as a recognized category prior to the 1990s. Further, the fact that many ASD adults are high functioning, and that, particularly in the case of females, do not show many outward symptoms, they would often not get diagnosed at all, or report receiving misdiagnoses for other conditions that may have been more readily available to psychologists at the time. As a result of these difficulties some adults had to seek their own diagnosis, often through online research, or by indirectly self-diagnosing once their children were diagnosed with the same disorder.

Up until the mid-twentieth century, the disorder known as autism did not exist in any known culture. Once discovered by Leo Kanner and Hans Asperger in 1943, the disorder was thought to have affected 1 in 10,000 individuals. As such, up until recently, members of the general public as well as professionals including physicians, teachers and, social workers could have gone through their entire professional career without once encountering an autistic individual (Davidson and Orsini 2013). As such, and especially prior to its inclusion in DSM, Asperger's and high functioning autism was rarely diagnosed. In 1994, Asperger's Syndrome, considered a mild form of autism, was added to the DSM IV. Consequently, there was a dramatic rise in cases which brought some awareness about the condition. By 2010, it was estimated that 1 in 110 children were diagnosed with the disorder (Davidson and Orsini 2013). Individuals who reached adulthood after this time period were not likely to have been diagnosed with the condition. They were assumed to be quirky or eccentric unless their symptoms were problematic enough to warrant psychiatric intervention. Consequently, those who sought professional help were often misdiagnosed with other disorders or not diagnosed at all (The Autistic Self Advocacy Network 2012).

This was the case for many of the participants in this study. For example, Miranda, who grew up in the 1980s, reported that she could not have been diagnosed with autism as she was not showing severe symptoms seen in classic cases at the time. Furthermore, because she is female, it would have been even less likely:

> I grew up in the 80s, so nobody was really diagnosing anyone with autism, unless you're like super severe and like nonverbal and bang your forehead somewhere right that's what we saw on TV that was like rain man. That's what we thought about, and it certainly wasn't something that happened to girls right so that was like nobody had an understanding of that. So, I was just weird, quirky, but that was it.

Nadia reported that only severe cases of autism were known at the time she was growing up and that, because she did not fit the criteria, her school placed her in the special ed class.

> …it wasn't really well-known. Like, the only kids that ever got diagnosed with anything were those kids that really had a lot of cognitive delays and learning disabilities and stuff. No, they just said that I – they put me in the special ed class.

Selena also reported that at the time she grew up only people who were severely autistic were being diagnosed with the condition, and said that even her mother who worked with special needs children never considered her daughter to be autistic.

> I think back then you'd have to have pretty severe autism to get diagnosed with autism. Like I don't think they really recognized that kind of thing? My mom was a teacher and she taught kindergarten for a long time and then she did integration support with special needs kids and she knew autism. So, she feels kind of guilty that she hadn't even thought of that for me, but there weren't really kids like me that were diagnosed with autism, I don't think?

Robin, who exhibited symptoms of autism, was sent to a professional by her parents. However, because only the classic form of autism existed at the time, the psychiatrist did not know how to treat her:

> Well, my parents sent me to a shrink when I was 8. They knew I was different; they didn't know why. They were trying to find answers but in 1980 I was 8, the only diagnosis available then was classic autism and I certainly am not a classic autism profile, right? So, the shrink didn't know what to do with me.

Similar to Robin, Juliette did not fit the image of the classic autist and was misdiagnosed with another disorder:

> I mean so obviously I was born in the '60s and the term high-functioning autism didn't even exist back then so nobody would have expected it. But what was clear is that I was not conforming to social norms, I wasn't flapping, I wasn't doing anything of the stereotypical autistic things. … They had just written me off as Personality Disorder.

Because these participants were growing up in an era where only severe cases of autism were diagnosed, they were never diagnosed until much later in life.

However, there were some participants who were growing up after this era, where mild forms of autism were being recognized and who still were misdiagnosed with other disorders. This could be due to gender differences as girls with normal cognitive abilities show symptoms differently than boys (Hiller, Young and Weber 2016). It could also be possible that some individuals who seek psychiatric help get treated for comorbid conditions instead of being assessed for ASD (Aggarwal and Angus 2015). For example, Sydney, who is 28 years old, was diagnosed with many different disorders starting at 8 years old because her mother was concerned about her behaviors. She stated:

> I've been seeing mental health professionals since I was 8 but I never received the same diagnosis twice. I don't know if I was diagnosed ADHD when I was 8, but I was reassessed when I was 12 or 13 and they concluded I didn't have it. They noticed very high anxiety levels and depression. In high school I was diagnosed with PD-NOS and drug-induced depression (despite being depressed before ever doing drugs). I continued seeing doctors during this time and only ever got vague answers, and was put on several different

> medications, most of which just gave me bad side effects… I was diagnosed with BPD eventually, and then BPD with Avoidant and Dependent traits.

Mona, who is 25 years old, was also diagnosed with multiple disorders when she started struggling with mental health issues in university. In speaking about her diagnostic journey, she said:

> So, I primarily ended up seeking diagnosis over the years because during my early 20s and my first venture into university found 18, 19, I struggled with my mental health a lot. And I kept getting hospitalized for the doctors thought different – many different reasons, they had thought perhaps it was schizophrenia or bipolar or chronic depression. They had many thoughts about why I kept ending up hospitalized. But they just didn't understand. And none of the strategies and regimes for medication that they tried helped.

Hope, who was 23 years old, also reported being worried about her mental health in high school and sought help from medical professionals. However, she received many diagnoses of other conditions:

> I always thought I was different, but I didn't use the word wrong more in high school, when I was worrying about mental illnesses. And so, we tried to go to different psychiatrists and psychologists that they gave out, but I would get – in turn, I got misdiagnosed for other things.

There were many criticisms regarding testing that were made by women in this study. Some reported that ASD testing was problematic for females because women showed symptoms differently than males. For example, in talking about the assessment, Celeste said:

> The thing that scared me is the diagnosis process. There's no differentiation especially when they do the initial screening questionnaires, there's questions on there that seems so stereotype based…I know people are different, but it really seems like male stereotype focused. Certain things like being fascinated with numbers and dates and stuff like that.

Another participant said that the way the testing was done left no room for context, therefore making it difficult to assess individual strengths and difficulties. Hope, when speaking about her assessment, said:

> I think people are so different, you know, and just a series of tests won't answer a question about, like, how severe someone might be. I think labels are really hard with autism, because someone might be great at one thing and horrible at another thing, and I think it's

> just really hard for them to decide with just, like, open, multiple traits question and answer tests.

The assessment of "functioning levels" were also found to be problematic. One participant expressed that individual strengths and challenges varied from one person to the next and that the functioning levels did not really capture individual needs. She said:

> Someone like me who's highly articulate is considered a level one and yet I can't hold down a job. It has nothing to do with – it has to do with support needs from the perspective of do you need a support worker. And it has nothing to do with your executive functioning and it has everything to do with – everything that makes life hard for me is not covered by that functioning level. So, you know, it's a step forward in a way but it's certainly those of us in the community certainly don't feel that the diagnostic criteria is accurate enough yet.

Finally, one participant said that she found testing to be inconsistent from one medical practitioner to another, and that this was problematic when diagnosing individuals:

> So actually I went through the process with two different psychologists and their process on paper it looked to be quite similar, in real-life it was quite different…she subjected me to this partial ADOS Level 1 and another friend who I knew went to the same psychologist and he didn't have to go through any of these tasks at all, and he received a diagnosis. So, from there it was kind of inconsistent. I wasn't really happy with the objectivity of the process.

Many participants were diagnosed with other disorders before receiving their ASD diagnosis and some were assessed but no diagnosis came out of it. Most participants expressed that they knew from a much younger age that something was different or wrong about them. For some, this led them to seek information on the internet about the symptoms they were experiencing.

Hacking (2009) argues that autistic narratives such as autobiographies will shape what it means to be autistic for future generations of autistics. As autistics write about, or talk about, their autistic experiences, this in turn will influence how their autistic and non-autistic audiences will come to view autism. Some participants in this study reported that their prior knowledge about autism was based on stereotypical ideas such as seen in the movie *Rain Man* but that their conception changed after reading more about the disorder. Some reported feeling as though autism was the right diagnostic fit for them after doing online searches since they saw common traits. Eric, who was misdiagnosed with Obsessive Compulsive Disorder, reported coming across autism related information online and stated that the idea grew on him with time as he read more:

> It was after I had been regularly seeing my psychiatrist for a year maybe. I had seen him longer, but I didn't regularly see him for a year or so. We worked through issues of depression, anxiety, and what he thought at the time to be OCD (based on my pretty rigid rituals and routines). But I had stumbled upon the idea while researching mental health related stuff late one night. I didn't think too much of it, but it started to grow on me, and I read more.

This may suggest that as Eric kept reading different narratives about autism and information from different sites, some of that information resonated with him. At the beginning, some information may not have resonated, but with more searches he was able to form an idea of what autism meant for his self.

Sacha had a similar experience when she stumbled onto the idea of being on the spectrum through an encounter with a client at work. She eventually met with the client's wife who was on the spectrum to explore this idea further, which led her to seeking a diagnosis. In recalling this experience, she said:

> There's a document out on the web that's 40 traits of women on the spectrum. So, we went through that document together and I was pretty much hitting all of them, all of the traits in my own way and then she recommended that I go to Montreal because I needed my official diagnosis, just because I didn't want any self-doubt.

Sacha reported identifying with most of the traits but specified that she was hitting them in her own way. Therefore, she was making sense of the information according to her own personal experiences and redefining autism to match how she felt.

Since women are more likely to get diagnosed later in life, many of them only receive a diagnosis as a result of their children being diagnosed (Pohl, Crockford, Blakemore et al. 2020). This was the case with many participants in this study. One participant reported that after her children were diagnosed, it was recommended that she go for testing. Following her three children's diagnosis, Eva reported that she was recommended for testing:

> So William went through all of his testing and we had to do the sibling comparisons, on the day he got his final diagnosis that was when doctors at the time had said that, "Given the results of your sibling tests, we need to send your oldest in for testing" and given what he'd seen and experienced to that point, he said "You'd probably benefit from sending yourself in somewhere".

There were many participants who reported referring themselves to get assessed for an autism diagnosis after their children were diagnosed because they had many similar traits. Miranda, who did not consider being on the spectrum until her son was diagnosed, stated:

> After my son was diagnosed, I saw way too many similarities … I didn't really consider that at all for myself until after he got diagnosed and they said, there's too many things that fit here. It's like yes, you know I'm his mom. It makes sense. Of course, we can be similar. So yeah, that's what made me go get diagnosed.

Similar to Miranda, Nadia also sought a diagnosis after witnessing the process of her son's diagnosis:

> I got it because literally, like, a month and a half before that, my son was diagnosed with high functioning autism, and I saw a lot of similarities between me and him, so I got myself assessed.

Robin also reported seeking a diagnosis after her children were diagnosed. When explaining what made her think that she may be on the spectrum, she said:

> I was late diagnosed; I was 40 so about seven years ago… So, my kids and I, they were diagnosed before me, we all have Asperger's designations… my son had been diagnosed seven years before me and my daughter five years before me. So, I knew I had to be autistic, I had to be an aspi too.

These participants stated that they sought a diagnosis because they shared similar traits to their children who were on the spectrum. Although there are many autobiographies available online about mothers' experiences of getting diagnosed as a result of their children's diagnosis, limited academic literature is available on this specific issue.

Hull et al. (2017) argue that females may be underreported due to testing methods. As they put it:

> Current diagnostic practices focus on the core ASD characteristics that have been historically established from the behavioural presentation in males, and so do not necessarily reflect the areas in which females with ASD may display different behaviours to males. As a result, current assessments of females with ASD are restricted to the areas in which females are most similar to males, and those females who do not meet the male-typical behavioural descriptions are likely to be missed (Hull et al. 2017: 2520).

Furthermore, a greater prevalence of camouflaging in females further explains why they may be diagnosed later in life because they are able to hide their autistic traits more than males who are on the spectrum (Hull et al. 2017). This may explain why mothers in this study were diagnosed after their children were diagnosed. This point may be interesting to research in further studies, since whole generations of adults who missed their opportunity to be diagnosed would now be obtaining late diagnoses largely through their children. Having addressed the difficulties adults experienced in obtaining a diagnosis, the following section explores the experiences of eventually receiving one, and how it shaped their self concept.

3 Obtaining a Diagnosis: Being Officially Labelled

Drawing on the concepts of medicalization and labeling theory, this section focuses on the relationship between identity and labelling in relation to high-functioning autistic individuals and explores how labels can be liberating but also impose restrictions on identity. In addition, the section makes use of Mead’s theory of the past to explore the relationship between identity and one’s sense of the past and future and demonstrate that the past and future are never static but always dependant on individuals’ present situation.

Up until receiving an official label, most participants in the study reported having a negative self-perception because they could not understand themselves, their social environment, or where they fit. Looking for an explanation, they sought out a diagnosis that would allow them to understand past experiences and challenges they faced. Participants reported feeling positive about receiving an official diagnosis as it released them from the blame that many felt before being diagnosed. It also allowed them to make sense of past experiences and see them through their new autistic identity. However, having a label also imposed some restrictions on their identity formation as this ended the hope of ever achieving "normality."

According to Peter Conrad (2007: 5), the concept of medicalization describes a process whereby "a problem is defined in medical terms, described using medical language, understood through the adoption of a medical framework, or "treated" with a medical intervention." There are both positive and negative aspects to medicalization. One the one hand, once deviant behavior is seen as a medical problem, an individual is no longer considered responsible for the problem nor can he be blamed for being sick. Consequently, medicalization is thought to reduce stigma because the problem can now be fixed or treated through medical intervention. On the other hand, instead of focussing on social factors that could lead to "sickness," medicalization rests on the assumption that the problem lies inside the individual (Conrad and Schneider 2010).

Many participants in the study said that receiving an autism diagnosis was a positive experience for them, as having a medical label provided a frame for understanding themselves and took away the blame they felt for their past behaviors. For example, Mona said:

> People knew something was different, and I knew many of these things about me and because autism had been brought up to me by other people asking about it, it made me look into it more and I related… I'm quite familiar with the criteria in the DSM-5 for autism spectrum disorder and I relate to that.

Robin, a woman diagnosed at the age of 40, said that living without a diagnosis caused her significant mental health difficulties. She explained that, when she was growing up, there was no explanation for why she was struggling, which led her to believe that she was crazy. When talking about receiving her diagnosis, she said:

> When I got that autism, that Asperger diagnosis at 40, I cried for three days, I cried and shook for three days because the massive hurt that I had carried with me from childhood came crumbling down because I was vindicated by the diagnosis… I barely slept because of the relief of knowing that I wasn't crazy, that I wasn't making things up. The validation part was so huge.

John, who was diagnosed with Asperger's and depression later in life, said that he felt relieved when he received his diagnosis because his parents did not think of him as a problem anymore. Now, his behavior could be explained by symptoms of the disorder:

> I was just relieved because I knew it wasn't me. Or, it was me, but not in a way that was me being difficult. I have depression and Asperger syndrome, I'm not a bratty delinquent, right? …That changed when I learned I was an aspie. Then it made more sense. I was different, not a problem… I had a mental problem that wasn't my fault. Something I struggled with. As long as I was a trying to manage it or work through it, they called it, as long as I was working through it, I was not the problem. Being told, "oh you have Asperger syndrome" had that effect. I don't know that it helped them, but it helped me because it wasn't about me.

For the study participants, a medical label provided a framework that enabled them to understand themselves better. The feeling of being vindicated by the diagnosis was also expressed as they felt a sense of relief that there was an explanation for past experiences. Finally, some participants expressed that a medical label allowed them to be who they were without being blamed for behaviors that were now considered symptoms of their disorder, and that this relieved some pressure from family members who expected them to behave in neurotypical ways.

Mead's theory of the past is helpful for furthering an understanding of identity formation from a sociological perspective. It allows us to gain insight into not only how identity is formed through our social environment but, also, how past events are reconstructed to fit within this new perspective, and how this influences our future perspective. Mead (1929) argues that the past is not an immutable objective reality as usually conceived, but is shaped and reshaped from the perspective of the present. Much like future plans and horizons are constructed and change according to opportunities in the present, the same can be said about the past. This is particularly salient for the development of self, as we reflect on what our past selves mean in relation to our needs in the present. In discussing Mead's theory, Maines, Sugrue and Katovich (1983) argue that each present extends into past and future temporal periods, conceived as "continuity." The occurrence of new emergent situations, "discontinuity," leads individuals to reconstruct their past in order to fit the new situation and, in turn, change their outlook on the future. These new situations force individuals to reinterpret how they see their past, which then determines how they will act in the future.

In the case of receiving a diagnostic label of autism (introducing a discontinuity), past situations become reconstructed, which then becomes the new normal (forms a new continuity). Many participants communicated that after receiving their diagnosis, they were able to make better sense of their past experiences. They reinterpreted these experiences through an autism lens and reconstructed their past according to this new reality. This is consistent with Maines et al's. (1983) claim that, when an event occurs, individuals adapt by reconstructing their past experiences to align with the current situation. Reinterpreting the past self through the new lens of autism not only changed their perceptions of past events but found these to be healing and vindicate them for times when they felt guilty or bad about their actions.

In discussing past experiences with eye contact and then reflecting on these after receiving her label. Selena stated:

> For years and years, I just thought I had hearing loss because I lip read. I never look at peoples' eyes, but I didn't know why? I just thought I needed to look at their mouths to understand what they're saying. But when I try to look at peoples' eyes, I don't know what we're talking about anymore. I can't have a conversation if I have to look at their eyes. Yeah, I don't actually have hearing loss [laughs]…I think it gives me more understanding

> of why those things are a problem for me and it's better to have that as the reason, than you just aren't trying hard enough, right?

Justine understood herself in a different way after receiving her diagnosis and, in light of this new perception, re-evaluated her social environment. This allowed her to question her present reality and make changes accordingly:

> Not being aware of that part of my identity has been a whole new way of living. I'm questioning everything. Like, what's really important. Why I struggle with making decisions most people don't. Why I'm friends with people I'm friends with. Until diagnosis I didn't question whether I liked people. Only if they liked me. It's been liberating but also hard and isolating.

After receiving the diagnosis, Eric as well reconstructed his past to fit with his new self-perception. He stated:

> The diagnosis explained so much in my life and it freed me from a lot of the guilt I had from some of my shortcomings which were (and still are) explained by the diagnosis (such as difficulties with friendships as well as difficulties with socializing and making/keeping eye contact).

Revisiting the past seemed to be a healing experience for participants. It provided explanations for past difficulties because they were able to reconstruct their past through their new autism lens. This allowed them to be released from blame and guilt they had felt about their shortcomings until the moment of diagnosis. Seeing themselves through their new identity also altered how they perceived their social environment and how they anticipated their future. For example, after some retrospection on past events, Selena re-evaluated her current reality and questioned values she had pre-diagnosis. As well, she aligned her social environment with how she saw her new identity within it.

Conclusion

This chapter explored identity formation from the pre-diagnostic stage to the post-diagnostic stage. The first section addressed the issue of identity formation of autistic individuals in the pre-diagnostic phase, using Cooley's and Mead's theory of self and identity as a model. In the second section, early missed diagnoses and misdiagnoses were explored, until many of the participants began to seek information online, or became aware they might be autistic by recognizing similar traits in themselves as a result of their children's diagnosis. The third section explored the shaping of self concept at the point of diagnosis, applying the concept of labelling theory to understand their sense of relief, and Mead's theory of the past to understand how they could now better account for events pre-diagnosis.

Findings from the first section suggested that while Mead's theory of self is useful in understanding how identity is formed, additional conceptual tools are needed to fully understand this for individuals on the spectrum. The data from the study demonstrated that autistics are capable of understanding social situations but that they do so cognitively through observation and rationalization. In other words, high functioning autistic adults have the ability to understand others' intentions or behaviors in social situation through conscious observation and theorizing, and that this provided them with the clues about how others relate to them and the basis for developing a self-perception.

Section two reveals that receiving an autism diagnosis was a positive experience for study participants and that having a medical label provided a frame for understanding themselves that took away the blame they felt for their past behaviors. Further, a medical label offered a framework for study participants better understanding themselves and feeling a sense of relief for having an explanation for past experiences. Finally, a medical label allowed some study participants to be who they were without being blamed for behaviors that were now considered symptoms of their disorder, which relieved some pressure from family members who expected them to behave in neurotypical ways.

Findings from the third section demonstrated that obtaining a diagnosis had a positive impact on participants identities, taking away the blame felt for being different, providing a framework for better self-understanding, and having an explanation for often difficult past. Furthermore, the findings revealed that although a label was mostly positive for participants, it could also be limiting. Finally, the data also demonstrated that normal life difficulties could be interpreted as symptoms of the disorder once diagnosed; these “symptoms” then become internalized and the cycle is completed.

Chapter 4: Navigating the Identity Politics of Autism

Introduction

The previous chapter dealt with the shaping of identity from pre- to post-diagnosis, in which adults created a new sense of self through their new assigned medical label. Upon adopting the new medical label, adults with autism find themselves in a new world of identity politics. The very labels that have allowed for a new sense of self concept are themselves the subject of shifting meanings and political debate. I examine the discursive terrain between the neurodiversity movement and the medical establishment, which create dynamic and often contentious definitions of the disorder, how it should be labelled, and what it means. Given the contentious nature of these identity politics, I then examine how people manage their identity in relation to others. Participants report the decision to either mask their disorder and try to pass as normal to avoid stigma, or to disclose their condition so as to re-negotiate social relationships with others. As a result of these day-to-day difficulties, many in my sample of respondents chose to seek resources and supports to help them adjust. Most reported a dearth of supports available for high-functioning adults, but did report benefitting from those supports they were able to access. Finally, I explore how personal experiences in dealing with the identity politics of autism in their everyday lives and in the context of support groups led many to become more politicized and take on advocacy roles.

1 The Contentious Cultural Landscape of Autistic Identity

Limberg (2016) distinguishes between the social model of disability vs the medical model. The medical model, which most participants rejected, assumes that disorders, such as autism, are disabilities characterized by deficits and difficulties that need to be corrected, cured, or coped with in order for an individual to live in normal society (Jaarsma and Welin 2011). Most participants adopted the social model of disability, grounded on the premise that individuals only become disabled because their environment fails to accommodate their needs. This premise is one of the main philosophical underpinnings of the neurodiversity movement (den Houting 2019).

The neurodiversity movement emerged as a form of resistance against the medical model of disability. Individuals who embrace the neurodiversity philosophy believe that they are neurologically different, but do not see their differences as deficits. However, since society is not accommodating to their differences, they do see this as a disabling condition (den Houting 2018). The neurodiversity movement is widespread, and its philosophy is very popular within the autism community. Although most study participants did not explicitly say that they identified with the neurodiversity movement, or were aware of it, most adhered to its philosophy and were familiar with its lingo.

Hacking's concept of the looping effect can be used to explain why many participants in this study adopted the philosophy of the neurodiversity movement and used neurodiverse terminology to describe themselves. The looping effect is described as the process where people who are "classified in a certain way tend to conform to or grow into the ways they are described; but they also evolve in their own ways, so that the classifications and descriptions have to be constantly revised" (Brinkmann 2005: 774). This dynamic can be observed among many individuals in the autistic community who believe that autism is a variation in human functioning and an important part of a person's identity. John, for example, says:

> I think of mental illness as something that is debilitating. Difference isn't necessarily debilitating. My depression is a mental illness because it is debilitating to me, but my Asperger's is not. My Asperger's may make me different and 99% of people may think I'm weird or odd or awkward because of it, but that isn't debilitating to me.

John uses terminology that is common to the neurodiversity movement such as ‘different’, meaning that his AS is a neurological difference rather than a disability. His comment also reflects the social model of disability because he sees his AS as not debilitating but simply a different way of existing. As well, it reflects the medical model of disability because he thinks of his depression as debilitating.

Many study participants spoke of autism as part of who they are. They do not see autism as something they have and spoke of using people-first language as very problematic because of its negative undertones. Eva’s remarks about the problematic nature of people-first language, for example, provide a clear illustration of this:

> I’m autistic. I’m not a person with autism. I don’t like that, because to me that sounds like I have something, like I’ve contracted something. Whereas I have brown hair, I have brown eyes, I’m autistic. It’s part of your identity. I can't just take it away or take it off or hang it up somewhere.

The autistic community is often critical of people-first language because it suggests that “there is a normal person trapped behind the autism” (Jaarsma and Welin 2011: 21). In addition, the criticism is grounded in the belief that autism is an integral and inseparable part of an autistic person’s identity. Although Hope used first-person language to describe herself, she referred to autism as part of her biological makeup and said that it was “… more like just a genetic thing. I have an extra toe; oh cool, I have autism. It just works different and that’s how I want to be viewed by people.” Referring to autism as a difference rather than a deficit was common in the study.

Most participants reported learning to see themselves as being wired differently and wanted others to see them this way. They did not see autism as something that needed to be treated or cured and made a point to differentiate between a neurological difference and a disorder. For example, Sydney stated:

> I've learned to look at myself as having a difference in my brain instead of some disorder that needs to be treated and medicated and fixed…It helps immensely to realize that what you've been told your whole life is a mental illness or personality disorder is actually a neurological difference, and that it isn't something you need to fix. I don't have to compare myself to others constantly and wonder why I can't do what they can. I feel special in a new way, and I can say to myself that I like myself the way I am, and I like being autistic.

Celeste, when speaking of autism said: "It's interesting to me…it's so all encompassing, and it is you and it affects everything and colors everything and it's your brain and it's permanent…"

Many participants spoke of autism as part of their identity and used language such as autistic, as opposed to "having" autism, when describing themselves. In this post-diagnostic stage, participants seemed to have a more positive self-image. For example, when Celeste spoke about her autistic identity, she said it was interesting, and Sydney reported feeling special. It was clear from the data that participants used much of the language central to the philosophy underlying the neurodiversity movement. This is illustrative of the looping effect that Hacking (2009) discussed in his writing on autistic narratives when he argued that how autism is talked about will change how the public views autism and will, in turn, change autism as we understand it.

Connected to the disability politics of autism, there is the complicating factor of how Asperger's (AS) became grouped in with Autism Spectrum Disorder (ASD) in 2013. Eliminating Asperger's as its own term and placing the systems onto the broader autism spectrum meant new stakes for participants' sense of medicalized identity. When asked about the change in label from AS to ASD, participant reactions were mixed. Some welcomed the change as they felt it unified the autistic community, while others were opposed to it as they identified strongly with their label. Still others had mixed feelings about it for reasons relating to support for, yet stigma associated with, the ASD label. It should be noted that some participants in this study were diagnosed before the change in the DSM and some after, which could explain the mixed responses regarding the new label. Huynh, McCrimmon, and Strong (2020) did a study of 14 individuals who self-identified as AS to find out how they felt about the change and how this affected their identity. Their findings suggested that the removal of a diagnostic label could have negative effects on identity. As they put it,

> the loss of a clinical disorder may deprive people who would have met the diagnostic criteria for AS the potential to self-identify as members of the AS community. Consequently, some individuals diagnosed with ASD after 2013 may not experience the same sense of belonging as those who self-identify with AS and thus may lose their sense of social status. (Huynh et al. 2020: 390)

Interestingly, many of the study's participants expressed that the change brought the autistic community together, and so were opposed to the former criteria that divided AS and ASD. They also felt that functioning labels ('high functioning' and 'low functioning') limited life opportunities for those who are considered lower functioning, and were divisive within the autistic community.

According to den Houting (2019: 272):

> to dichotomise autistic people as 'high functioning' and 'low functioning' not only serves to erase these individual variations in ability, but can also be used to restrict access to support for those deemed 'high functioning', and to deny autonomy and agency to those deemed 'low functioning'. Furthermore, the phrase 'low functioning' serves to lower expectations and, by extension, limit a person's opportunities for success.

This was reflected in participants' comments about functioning labels. For instance, for Miranda, the meaning of functioning labels was misleading about a person's worth in society:

> So, we all have our struggles and our challenges, and it shouldn't be some sort of competition on who presents the best today. When I give my talks, I give the example of Stephen Hawking. He wears diapers. He had to be fed by somebody. He couldn't walk. He couldn't talk. Yet he contributed a great knowledge of science to the world and he wrote books and he gave presentations. So, what is his functioning level? How do you measure the value of a person?

Similar to Miranda, Justine, who is considered a high-functioning autistic, also saw functioning labels as problematic:

> I relate more to people I’ve met or follow online who are non speaking or were non speaking as children. Because of that, I think functioning labels are very damaging and divisive. I’m most comfortable not speaking.

The rejection of functioning labels is one way that we can see the looping effect. With the change of label, AS was absorbed by the autism label with a new wider spectrum. Consequently, individuals were no longer thinking of autistics as either high or low functioning but rather as being on a spectrum with strengths and challenges that vary from one person to the next.

Although most participants reported feeling positive about the change of labels in the DSM-5, some reported being conflicted about the change as they could see both advantages and disadvantages to it. For example, Eva, a mother of four, experienced the stigmatising effect of the autism label, but also benefited from the change since she was able to get financial support for her children:

> I'm on both sides of the fence. People have dealt with my kid because he has autism and they dumb stuff down. Because there seems to be an underlying preconceived notion of what autistic children are capable of doing…So we've had that where there's people that you meet where the preconceived notion of what Autism is, does not cover what my kids look like.

Eric also expressed being conflicted about the change:

> I am aware and I'm not totally sure how I feel about it. I have a good idea though. Part of me says that I'd prefer it be a separate condition because I feel it can more accurately describe me in contrast to a more umbrella-like diagnosis such as ASD. However, I do understand that there are plenty of similarities across different levels of severity and kind of like how the LGBTQ+ community bands together, I think that it is culturally practical - if not medically as well. When we get into a question of 'higher' or 'lower' functioning, it may have medical justification. But as far as the stigma goes, I can see how it could put people in tiers of judgment and alienation.

There were, however, some participants who held on to their AS label as it was an important part of their identity. For example, Robin, who was diagnosed with AS, resisted using the autism label:

> … just because the DSM manual moved on, doesn't mean my diagnosis is invalid. It was, you know, that was the criteria at that time, and I don't fit that criteria. That criteria don’t exist anymore, it's been swallowed by ASD 1, 2, 3 but it doesn't make my diagnosis invalid.

> The thing is so many of us, especially with late diagnosis, we've been battered by life for so long that when we finally get a diagnosis, it has meaning for us.

For some, the label represented a ticket to acceptance in society. For John, his AS label was part of who he was regardless of the change in official labels:

> Well I'm an Aspie and I always will be. I like it and I like it when people call me that. My sister calls me her favorite Aspie. I know she means it affectionately. And I like it because it means she accepts me and is being affectionate even though I can't necessarily reciprocate. So yeah, I call myself what I want and that can't be decided for me. What the docs put in their files is their call, but Aspie is a fun term. I won't have that taken away.

Another participant spoke about the stigma attached to the autism label and said that she would have preferred that AS and autism remained two separate diagnoses, even though she herself was diagnosed with ASD. Selena, a mother of two who is also on the spectrum, expressed that people often had stereotypical ideas about autism that did not fit with her children or herself:

> I kind of wish it was still Asperger's for both my kids and myself just because when I tell people my kid is autistic, I feel like they jump to a picture of more severe autism. I don't think it describes it well and I'm the same, like if you're high functioning, I don't think that's what people think of when you say autistic. I think their thoughts go to something more severe.

In this section, we saw how the change of labels with the added spectrum influenced how autistic individuals viewed themselves in relation to the autistic community. The data demonstrated that there is a real impact on individuals—both positive and negative—when diagnostic labels change. It appears that the change from functioning levels to a spectrum had a positive effect as it removed the hierarchy that existed between 'high functioning' and 'low functioning' labels. The negative impact was stigmatization of people that, in the past, would not have been classified as autistic. Although the public perception about autism is changing, and there is more public awareness about the disorder, there is still much misunderstanding about what autism is and how it manifests itself in individuals. Consequently, some resist the new ASD label and prefer to keep the AS label as it was perceived to be less stigmatic.

2 Managing Identity Politics: Choosing to Mask or Disclose the Condition

The politics of labelling as mentioned above carries certain costs in terms of managing stigma and identity in relation to the disorder. Participants discuss the choices they face in masking the disorder, or disclosing it to others. Masking seemed to be the favored strategy when dealing with strangers and less-known people in public situations. In contrast, disclosure seemed to be favored when dealing with more significant others such as close friends and family. The pros and cons of each strategy were discussed by recounting some of their personal experiences. Some social and institutional settings provided more ambiguous sites of interaction, in which masking and/or disclosure as interactional strategies would conflict. Participants then had to carefully negotiate what combination of strategies to utilize.

2.1 Masking to Fit in

Impression management is “the way in which the individual … presents himself and his activity to others, the ways in which he guides and controls the impression they have of him, and the kinds of things he may and may not do while sustaining his performance before him” (Goffman 1959: i). In this context, “passing” is a concept used by Goffman to describe a form of impression management—or, more to the point, stigma management—that individuals use in order to hide what are taken as ‘discrediting features.’ In other words, it is the act of concealing undesirable traits in order to be accepted by others. Stigma management is used mainly in public life with strangers or acquaintances as it is assumed that those close to the stigmatized individual would not be put off by discrediting features (Goffman 1986). Goffman argues that “because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent” (Goffman 1986: 74).

In this study, many participants discussed using this strategy of passing—referred to as "masking" in the autism community—as a form of concealment to hide undesired differentness. For example, one participant explicitly stated that she used passing as a way for others to know her instead of just her disability:

> I want them to see who I am and not just the diagnosis. Which is masking and mimicking because then people can see that I have – I am not intellectually impaired or that I like cats, or different things about me, but without seeing me as the autism diagnosis.

In line with Goffman's remark that there is a great psychological price to pay in passing, participants also reported that masking often left them feeling exhausted and in need of long recovery periods. According to Goffman (1986), the "passer" will inevitably have to live with a high level of anxiety as his management of stigmatizing features can collapse at any given moment. This was reflected in the statement by one of the participants:

> I can force myself to do it, but then I can't focus on anything else. Because I am spending so much energy focussing on looking at your eyes that I literally can't hear what you are saying. And I am thinking the entire time, is this long enough? Should I blink? Should I look away? Should I, you know, like, maybe look at their nose for a minute and look back at their eyes? This is all the processes that are going through my head as I'm doing that.

Although not all participants expressed feeling anxious in keeping up their mask, some said that it was something that they constantly had to think of in order to keep it up:

> …even transitioning, I think it goes hand in hand, trying to have a more female presentation in terms of facial expressions and learn how to smile all the time and I think I've just been giving up on that a little bit because people are asking me what's wrong. There's nothing wrong, and I'm just like, oh sorry, I forgot to put my face on.

In addition to feeling anxious, the passers can also feel alienated from the group they belong to. Goffman argues that a person can feel alienated from others like him because—by passing—he is betraying his "kind", which in turn can lead to him feeling alienated from himself since, by betraying his "kind", he is betraying his own sense of identity. Celeste's remarks, for example, speaks to some of this:

> I have a persona that's created for every single different person that I interact with on a regular basis. I'm not like writing it down and being like, oh, something like creating a role. It just happens naturally, it just evolves over time, like I talked more formulaic and use pickier words with some people. I use more slang and swear more with other people and talk really subdued with some people and bubbly with other people. And with some people when it's too far out of my range like especially when people are really bubbly and like goofy, you know, and I tried to be like near that and it really feels awkward and draining and I don't feel like I know who I am.

Constant vigilance is another aspect to passing, because the passers have to be aware of social aspects at all times because new situations can arise in which their tactics may fail. As talked about by Robin:

> If I go out to a poetry reading and I'm spending all of my energy on not flapping, not ticking, not expressing joy the way I naturally do, because I'm passing, did I enjoy the experience, did I even hear the poetry reading? …But you spend a lot of time and energy focusing on whether people around you perceive you as normal. And it doesn't leave you a lot of energy for actually doing what you went there to do or enjoying the experience you went there to enjoy. You know, so it's constant hyper vigilance of yourself in social situations, you know, was I too loud, was I too quiet, did I say – did I talk enough, did I talk too much, did I say the right thing, did I say the wrong thing?

Participants who used masking reported that it was a coping strategy that often left them exhausted and sometimes confused about their own identity. They often could not enjoy themselves in social situations as they had to keep up the act. With the exception of Mona, most did not seem to find the experience, as Goffman (1986) would put it, "rewarding."

In addition to using it as a strategy for one's own benefit, high functioning autistics in the study also use masking for the benefit of others. Celeste, for example, says:

> I wish people would realize just like… I feel like I'm putting that effort for people to feel comfortable because if I were just not talking to people much unless something really interesting came up and just never really have much of a facial expression or voice inflection and stuff like that, it would make people uncomfortable, but I'd probably have more energy.

This additional nuance to passing is significant for two reasons: first, because it extends Goffman's insights about passing as a stigma management strategy; second, because it challenges the hypothesis that autistics do not have an ability to take the perspective of others (Brewer, Young and Barnett 2017). Regarding the first reason, Goffman's discussion of passing leaves an impression that the motivation for passing is self-oriented and about trying to hide one's stigmatizing features in order to be accepted by others; however, what the study reveals is that passing is also others-oriented and about trying to mask in a way that would make neurotypicals more comfortable in the presence of autistics. With respect to the second reason, the study's finding about others-oriented nature of masking also confirms that autistic individuals are capable of taking the perspective of others into consideration and willing to spend much of their time and energy ensuring that others feel at ease when interacting with them. As previously discussed, for autistic individuals the process of taking on the perspective of others is not innate or intuitive but arises through conscious observation and intentional studying of social situations in order to put the pieces together and understand the nature of the 'game system'.

2.2 Disclosing the Disorder to Others

Participants often discussed the difficult decision to reveal their disorder to others, recognizing that doing so might lead others to judge them in a negative light. Cage, Di Monaco and Newell (2018), for example, found that neurotypicals tend to make quick judgments about people with ASD without really understanding the disorder. Although people have a general awareness about autism, there are still many misconceptions about how it presents itself in individuals. Consequently, this negative experience of acceptance from others is linked to feelings of depression, stress, and isolation in autistic individuals. Cage et al.' findings were reflected in some of the responses of participants who spoke about revealing their diagnosis to others. In their experience, disclosing their disorder was often not helpful, and in some instances, they found it to be harmful: not only did they not receive support, but they also got judged for not conforming to the stereotypical ideas of autism. In some cases, people doubted the severity or even the reality of their disorder and assumed they should try harder to fit in.

Scheff (1999) argues that labelling can have a major impact on peoples' sense of self, and hence, negotiating what labels are applied are important for identity management. In the case of autistic adults, without any formal label, it is in the hands of social others to do the work of labelling. As discussed in the previous section on pre-diagnostic identity, with no official diagnosis to work with, others would often judge the participants harshly and attribute identities that were quite stigmatic. Not knowing they were on the spectrum, people would label them as quirky, weird, anti-social, and the like. If powerful labelling processes are going to happen anyway, participants reasoned it would be better to get some control over this. John, for example, expressed this inevitability, when he said:

> …anyone who's awkward is likely to be assumed to be an Aspie. You'd have to disclose that you're not. It's a reverse situation, if you know what I mean? When you're different in this world, you don't have to tell people, they know! You have to tell them otherwise, but good luck trying to convince them most of the time.

Charlotte stated that she did not disclose her diagnosis for fear of being discredited by others in situations of conflict, and for fear of her position being dismissed as a result of her disorder:

> The downside of disclosing is that other people will use it against you to discredit you or to you know, maybe not look at their own part in a conflict. You know, just solely place the burden of responsibility on the person who has ASD.

Once an individual is labelled, they eventually come to see themselves from the viewpoint of their label. "In other words, an individual engages in a behavior that is deemed by others as inappropriate, others label that person to be deviant, and eventually the individual internalizes and accepts this label" (Skaggs 2016). For example, Sacha was never aware of her problematic behavior until it was brought to her attention. Afterwards, what she would have previously thought of as normal life difficulties became struggles caused by her disorder:

> It’s because it came out of the blue (her disorder). I think it's made me have to come to terms with a lot of different things, different aspects of how I struggle, which I didn't believe that I did or didn't want to acknowledge that I struggled.

Mona also expressed that a label limited her options in terms of how she saw herself. She stated:

> So, when it comes to having a diagnosis, I guess one of the things that was put in my mind as a child would be that one day, I would grow out of this. Grow out of these challenges…Knowing that I have a diagnosis unfortunately takes away that hope that perhaps I will also grow out of these things. Mind you it's been 25 years and I've yet to grow out of them but there is that part of me that wishes that I could be like other people…And also it was when it came to other people noticing something was different, without a diagnosis it's easier to pretend that maybe you aren't like that.

Although obtaining a medical label was reported to be positive for most participants, they also expressed that a label restricted their identity and locked them into the role of the person with a disorder. Once an individual ‘gets locked’ into this role, it is very difficult to get freed from it.

Sometimes disclosing the disorder to others would lead to negative consequences with people. The lack of awareness in the general public was discussed by many participants in the study. Some participants reported that when they disclosed their diagnosis, they were confronted with negative or unsupportive responses. For instance, Juliette reported that sharing her diagnosis was not helpful and made social situations worse:

> I’m realizing that this is – I mean I don’t have a problem sharing it but I’m realizing nobody understands what autism is, so it doesn’t help sharing your diagnosis. It puts you in a box of stereotypes, so responses are not necessarily positive, they’re more negative.

Charlotte had the same experience when she revealed her diagnosis. She found that there was a lack of empathy because her disorder was not physically visible:

> one person has expressed, verbally, that you know, you shouldn't get a diagnosis because you'll use it as an excuse to get out of stuff you don't want to do. Like life is hard for everyone and that doesn't mean that you get to stop trying. I think that's a very unfortunate viewpoint to have because you wouldn't say to someone in a wheelchair that they should

> try harder and forge, you know. Like yeah, they can participate in sports, but it's just so much harder.

Mona had a different experience as some of her autistic traits were more perceptible and people automatically assumed that she had an intellectual disability. Although she reported receiving very good support from her educational institution, she also said that, at times, there was a lack of awareness by some of the staff:

> … even at my old own school I go into the centre. I have a 4.2 GPA. I can obviously, if I'm in my college program, university program, spell, write and am clearly literate. Yet when I'm signing in to write a test they say, wow, you can understand what we test for. So, I can find my name on it and I can acknowledge to the person that I have three hours to write, and they're verbally commending me for this ability.

Robin expressed that neurotypicals often downplayed symptoms of autism and made it sound like these were common feelings that the general population experienced:

> … you know, that's a big problem in our society, the minimizing that neurotypicals will do. Oh, everybody feels that. Everybody feels that a little. I'm talking about this big monster pit that swallows me whole on a daily basis. That's not the same as everybody has a little bit of that, everybody can be a little anxious, everybody can be – and everybody has worries, that's fine, that's normal.

This kind of reaction was also mirrored by Hope's friend when she revealed her diagnosis to her friend:

> … when I told one of my friends, she was, like, everyone's a little autistic. I'm like, that's not true, but okay. And, so that response kind of bothers me. And then I tell people and they're like, no, you're not and that response bothers me too… the other one that people give me as a response, how do you know for sure, kind of thing.

Participants felt particularly frustrated when not receiving validation for their disorder, as others often did not understand the nature and depth of their difficulties. By trying to include autistics into a very broad spectrum of personality quirks shared by the general public is to deny the reality of their autistic self. Thus, even in cases where honest disclosure was attempted in an effort to bridge understanding, participants reported not being understood, and their symptoms and experiences being minimized or dismissed.

These types of frustrations are often an ongoing issue for autistic adults in their everyday lives. As such, many seek resources and supports to learn how better to cope with interpersonal situations as well as educate others. The following section considers this in detail.

3 Seeking Resources and Supports

The ASD spectrum is often thought of in linear terms, from low to high functioning. However, the matter is much more complex. As Nicolaidis, Raymaker and Kripke put it: "skills or challenges fall along spectra on multiple axes (spoken language, written communication, activities of daily living, need for consistency, sensory sensitivity, emotional regulation, and so forth)" (2014: 1171). Because of this, there are very few resources offered to individuals who require lower levels of support because they are assumed to have the skills to function in society. Furthermore, the resources that are available may not be that accessible for autistic adults. Vogan et al. (2017) found that adults on the spectrum are often assumed to have the skills to navigate the health care system, as their challenges are not always easily seen. Consequently, they may never access the services that could otherwise improve their quality of life. They also found that autistic adults were less likely to receive adequate healthcare and had to overcome more barriers to healthcare access than non-autistics. This could be a possible explanation as to why participants in this study reported the lack of services and barriers to access those services that were available.

When asked if they were provided any resources once diagnosed, many reported that they did not. Most participants responded that the lack of referrals to resources or informational materials were due to physician's assumption that— since most were specifically seeking an autism diagnosis—the patient was already knowledgeable about the disorder. For example, when discussing his diagnosis with his psychiatrist, Eric stated:

> it was more a discussion about symptoms and how they fit into the diagnostic criteria for ASD. With the criteria in front of us, we discussed each point with a fair bit of detail. I don't believe he gave me any literature or informational resources given that I was already pretty knowledgeable on it.

Sydney also said that it was understood that, since she was seeking an autism diagnosis specifically, the specialist did not have to explain or provide additional information. She said:

> He didn't recommend any info or anything to me, but because this is an adult assessment that you need to seek a referral for, most of his patients have done their research already.

Chris reported that his psychiatrist did not feel that he needed extra information:

> Joanne gave me the diagnosis but recognised that I understood what that meant, fundamentally…She didn’t need to give me anything. She has documentation but she – we had discussed this that she didn’t think I needed anything extra in particular.

One participant was advised to seek specialized services but was not given a referral. Consequently, she was not able to find the support that she needed. Miranda, in speaking about recommendations made by her physician, said:

> She recommended that I seek you know therapy for the sensory but then I couldn't find any GP’s that we're dealing with adults and especially autism.

Other participants reported similar experiences where they received a diagnosis but had nowhere to go from there and had to find information and resources on their own.

There were some participants who reported that the health practitioner who diagnosed them was helpful in providing them with additional materials. These may have been practitioners—like the ones mentioned in Zerbo et al.’s study (2015)—who had a special interest in autism and who had attended extra training and therefore had some knowledge and resources about the disorder. Even though Charlotte’s physician admitted that there were not many resources available for high functioning adults on the spectrum, he did provide her with some information:

> I had done a lot of reading on my own otherwise I wouldn't have self-suspected it of course, right. However, he gave me a few things, he told me outright that there's not a lot of resources available for adults, especially for those that are like gainfully employed.

John's experience was different than Charlotte's as his physician had many resources for autistics:

> I was a given a folder with various stuff in it. Survey, flyers, there was a sheet with a list of advocacy groups, there was another with places to go using the internet for information if I wanted to know what terms mean. He was adding stuff to the folder as we talked. I wasn't interested in individual counseling, so he didn't bother with those materials, but I was curious about social groups, so he included names and information for various groups online and that meet in person. It was like a shopping cart that was getting filled with what I wanted.

Hope also reported that her physician had many resources and provided her with those that were tailored to her needs:

> Yes, my doctor was very helpful. She gave me a whole list. She knew exactly what kind of media I consume, which is YouTube, and so she gave me so many YouTube videos to watch of her favourite YouTubers that talk about autism. And she told me to really go into there and figure out what they had to say about their experiences and see if I could relate and also learn something new.

While a few participants reported that they were provided with resources following their diagnosis, most said that they were not. A possible explanation for the lack of referrals could be that some physicians may not have experience with, or knowledge about, autism in adults and how to provide appropriate treatments. Zerbo et al. (2015) found that some physicians never received formal training in the screening and diagnosing of ASD. As well, most physicians they interviewed said that they had received little to no training on the disorder during medical school and their residency. Those that were knowledgeable about ASD were those who had a special interest in the subject and were either self-taught or had attended ASD training. Findings from the study suggested that despite recognizing autistic traits, physicians have "insufficient skills and tools for providing healthcare to patients with ASD and need additional training" (Zerbo et al. 2015: 4010).

Furthermore, a review done by Shore found that there was a lack of evidence-based treatments for autistic adults (Autism Speaks 2020). The article revealed that very little research was written about health outcomes in adults with autism and that the existing literature focussed on identifying co-occurring conditions. Shore argued that health outcomes included physical conditions, but also social and emotional well-being, and that research should focus on asking which outcomes matter most to autistic adults in order to recommend ways in supporting them through the life-course (Autism Speaks 2020). The lack of autism knowledge and training, coupled with lack of evidence-based treatments for adults on the spectrum, could explain why many adults in this study reported receiving little to no resources following their diagnosis.

Most participants in the study reported that resources were scarce for adults on the spectrum. Many said that services were more often geared to children or people who required higher supports. Furthermore, resources were reported to be expensive, which for many, was not a feasible option. For example, Mona found that there was very little that she could access in terms of services because she was diagnosed as an adult, and the services that were available for her age group were too costly:

> the majority of resources for those with autism are available to those 18 and younger. And I'm definitely not 18. And have not been for a little while and will never be there again. And the resources available to adults are fairly limited. So now there is some relief in being able to have the diagnosis and to have an idea of what strategies may be helpful for me, or what kind of therapy or counselling. There is very little options on where to do that or what to do. And the options that are available are often private persons and expensive. Or just simply unavailable. Or like this event that I went to with the crafts, it is geared for children.

Celeste reported that sensory toys were also geared towards children and parents of autistic children, and felt uncomfortable in accessing these because these sites were not designed for autistic adults:

> It's always aimed at children or like usually parents of children, you know, even if you want to buy stuff like something comforting like fidget toys and sensory things and

> whatever. It's a big complaint, you're buying stuff from sites. It makes you feel like you shouldn't be shopping there because it's aimed at children or parents.

Miranda reported that when she tried accessing services in her area, she was told that there was nothing available for people who required lower levels of support:

> I called for my local resources in my area they were like, well, what do you need, do you have problems, taking a shower? I said, No, I don't need help, taking a shower. And so, they're like, well, that's what we do. We help people do things like that. I didn't really find anybody that could do anything.

Jolene also reported that people who required less support were left without resources:

> I think the most relevant thing is that it is really disheartening to finally receive a diagnosis in adulthood, and finally think you might have some answers, only to find that there are no services and that the provincial funding for people with developmental disabilities (which ASD is considered one of) is not available to you because you are past the IQ cut-off. If I have a developmental disability, and knowing that many people on the autism spectrum do not have a low IQ but still struggle with things like taking public transit or taking part in social/recreational activities, why am I not eligible for funding?

This was echoed in Robin's statement when she said:

> But people like me who are obviously very articulate there's [laughs] this idea that if you're that close to normal sounding and looking, you don't really need anything…in our society, you have to perform disability to other people's expectations, otherwise you're invalid.

In addition to challenges of obtaining needed support, Sacha felt that services geared towards higher functioning autistic adults were inaccessible without government support:

> … as an adult, being diagnosed there's no resource for me, there's very little resources for me to get help in terms of trying to cope. It all has to be out of pocket. It's not severe enough to get a disability tax credit to get support.

However, governmental support also came with its challenges. Robin, a recipient of the *Ontario Disability Support Program* (ODSP), said:

> That's another problem, is because we live in poverty, most of us, it's really hard to get out. Because being an ED (Educational Specialist) didn't work out for me because I burned out, the only supports my doctor was able to give me was more meds…So at 47 years old I don't really have a hope of every changing my financial ability to provide for myself because of these external forces. And that is a huge impact on your mental health. The

> ODSP system is meant to help you but it really, it just barely keeps you going. And the stress of living in poverty is immensely impacting.

Many participants spoke about the financial burden they suffered because of the lack of support available for them. Baldwin, Costley, and Warren (2014) found that many adults on the spectrum were more likely to be unemployed, underemployed and malemployed, and were more likely to switch from job to job. Many participants in this study spoke about these issues. Some were on disability benefits because they had difficulties in holding a job or lacked supports at their workplace and, consequently, had to leave. Others worked part time which resulted in financial stress. The lack of financial resources such as disability credits was mentioned by a few participants. These credits would enable autistic adults to access services for adults on the spectrum that are often privatized.

Despite participants expressing that there was a lack of resources, some did manage to find services and supports following their diagnosis. Some sought counselling, some joined in-person or online autism/ disability groups, and some felt more comfortable doing research on their own. Participants who chose to get support through counselling sessions said that it was helpful as it provided a way for them to make sense of their social relationships and to understand themselves in their new identity. Sacha, for example, said:

> I have to say like my psychologist, I love her. She's a specialist in Asperger's and she's helping me so much because she's helping me interpret some of my husband's language as well and his behavior. In terms of like if I communicate something to him and he doesn't communicate or something or say something. It's like he just needs time to process the information right and that's what happened. He just needs time to process the information.

Similar to her, Nadia said that she sought counselling so that she could understand herself better with her diagnosis:

> I, on my own fruition, went and I'm seeing her monthly – once every two months, something like that just for myself, just so I can kind of learn more about what it means for

> me, because it's my norm, right? I don't know anything else – but it does answer a lot of questions about things that I struggled with growing up.

Educational support and accommodations were also reported to be valuable in achieving academic success. All three participants who spoke about the accommodations they received through their school said that it made a positive difference in their academic experience. Celeste, a mature student, reported that the *Center for Accessible learning* provided her with accommodations even before she provided them documents of her diagnosis and were very supportive and understanding of her needs. Robin said that it was thanks to accommodations provided by her school that she was able to succeed in her program:

> I went back to school, because I was diagnosed within two months of starting school, I got accommodations for the first time of my life academically. And lo and behold all of a sudden, I was living up to my potential… And I graduated with honours with dean's honours. It was the first time in my life I had done that well because of accommodations.

Mona found that, because of her accessibility counsellor, she was able to learn about the resources that were available for her:

> it was actually in the school that they connected me with more supports in particular because my Accessibility counsellor is actually a mom of an autistic child and taught in the autistic behaviour program and so she often works and deals with autism in the school and her familiarity gave me a chance to get to know the resources. But if I did not have her support and her knowledge and guidance it would be another story.

She also reported that her university provided opportunities for students to volunteer at her autism spectrum support group so that they could get a better understanding of autism:

> … in the group there are volunteers from the PSW programs at the school who come and volunteer to get to know us and ask questions about us to get a better understanding of autism and Asperger's in a way that is very casual and personal.

These types of exchanges provided students with the opportunity to meet autistic people and form new ideas about what it means to be autistic, while providing support and understanding to group members.

In addition to support and resources mentioned above, some participants also joined in-person autism groups. One participant, who was referred to an autism spectrum social group organized by her school, found that connecting to other autistics was helpful because she could be herself with people that were similar to her. In talking about the group, Mona said:

> … we have an autism spectrum social group. And so, I go to this every week during the school year to connect with my peers. I feel especially with the pressure of communication and in nursing I feel very good going to group and being able to just relax and be me and nobody says anything about my different behaviours because most of them display the same or similar behaviours …

Another participant said that she joined an Aspie Friends Group which consisted of a small group of women who met once a month to discuss various topics related to autism. Selena stated:

> So, I've only been to three of them now, but I actually really like going. Usually there's a topic and what I like about it – of course, I don't know what to say, so mostly I don't say a whole lot, but these people some of them are super quirky and I'm like, "Wow, I'm so normal." I know exactly what they're talking about and the feelings, and like they did this stupid thing and how embarrassing is that? I don't know, it's like oh my god these people totally get me, and I get what they're talking about. It's kind of nice. I like it when there's a topic and then if you have something to say you can just say it.

John also said that joining a group was helpful for him in terms of accessing resources to help him understand his disorder, but also in connecting with others who share similar life experiences.

> When I learned that I have Asperger syndrome, I didn't have anyone to talk to. I wasn't all that bothered by it in principle, but that didn't change the fact that I didn't exactly know what to do, or who to talk to you, or where to get good information or meet people. When I told you about getting resources from my doctor, even that put the burden on me.…I have participated in different meeting groups. One was just called the *Oakville Autism Chapter*, and I think it maybe was part of Autism Ontario or started through them, but I'm not sure…Very useful. Especially at first. The friends I've made in the group are just people I relate to…So it's a doorway or welcome mat now that I met them through group.

In-person groups were reported to be helpful for participants because they were able to make friends or acquaintances which for most had always presented a challenge. They also said that these groups allowed them to connect to other individuals who were similar to themselves and therefore made them feel understood. However, for some participants, one-on-one interactions were uncomfortable and they found online groups to be a better alternative in accessing support and information. They said that online groups were valuable for discussing mental health issues, seeking answers to questions relating to autistic behaviors, providing advice to others seeking information about autism topics, discussing topics relating to special interests, and seeking support from its members.

A study done by Zhao et al. (2019) found that social media played a significant role in providing health-related support and information for autism users. Analysis of posts and comments from Facebook autism-related groups revealed that members used the platform to seek/provide advice and receive/offer support and resources. This was similar to how participants accessed social media platforms in this study. The most popular social media platform accessed by participants was Facebook, but Reddit and Listserv were also mentioned. When talking about Facebook groups, Juliette stated:

> … for the first time you can connect with people having similar experiences as you do. And there's things like for example this one girl, she's just being diagnosed right now, she's finding something out and someone read somewhere that autistic people take things apart as children, like electronics of whatever they just take things apart. So she was putting this question on Facebook and say, you know, "Do you guys share that trick, have you done that?" and then you all of a sudden see an explosion of people responding, "Yes I'm doing that". It's like I didn't realize that was connected with autism and apparently, I didn't know this either but apparently this is one of the things autistic people do. So, you know, connecting with not so much a person but with individual traits, individual experiences, seeing other people go through the same thing, that is hugely helpful.

While Juliette appreciated Facebook for being able to learn about the different ways that autism traits can be exhibited, Charlotte appreciated the on-demand support that the groups offered:

> I mean it's great because it's almost like around the clock peer support. Like someone will post a problem that they have and within 24 hours they'll probably have like 10 different suggestions. And that kind of like on-demand, free peer-peer support is really valuable.

Eva found seeking advice from others in the group helpful to her. She accessed online autism support groups to seek advice for herself and her children because she found that medical professionals were not able to provide her with advice that was helpful:

> I added myself to a bunch of pages on Facebook. I think the issue is I tend to do more with the support groups and stuff as a way for me to help find things, because nobody on the spectrum is exact. So as much as there are some things that my kids overlap with me with that I can be like, “Try this”. That’s not always the case. So, for me, that was a big thing for me, was reaching out to try and find adults who were already past that point who could be like, “This is what I learned to do”. Because I found a lot of the advice from the experts (doctors), put quotations around that, has not been good.

Eric also joined groups on Facebook and other social media sites and even though he did not feel that he benefitted from accessing support or advice, he did say that learning about others’ personal experience and struggles improved his knowledge surrounding the disorder:

> The only thing I've really done is join a couple groups on Facebook for people with Asperger's as well as a subreddit on Reddit. And in these groups, I really just read bits of struggles others are having. A fair bit is relatable, but I don't know if I really benefit all that much besides simply improving my knowledge surrounding the disorder.

Many participants sought emotional support, advice, and autism information from other autistics from online groups. This suggests that they found this information valuable and useful. However, one participant found some problems relating to the administration side of online groups and found it problematic that they were run by non-autistics. Sydney stated:

> Recently I find that there are a lot of problems with moderation in these groups though. A ton of people get banned from some of them (i.e. Autistic Women Support Group sounds like you should ask an autistic but ok) for disagreeing with an admin, and the admins will be very snarky and condescending. Lots of people and pages have begun pointing it out, outside of these groups. I think rules and standards are important but the way they're implemented is unfair to autistic people who might have trouble communicating and learning. So, it's a bit of a problematic microcosm.

Except for the issue mentioned above, online groups were proven to be very helpful for providing information and support between autistics.

Messages from online groups have also been found to be helpful to members of the community who interacted with autistics. Zhao et al. (2019) suggested that studying topics derived from messages posted in autism support groups can be beneficial for designing autism websites and creating subject directories for social media. Issues with administration of online groups, such as the one mentioned by Sydney, could potentially be resolved with further studies (like the one done by Zhao et al.), as this would allow administrators to understand the audience who use such sites and help them to deal with issues in a more effective way. Furthermore, Zhao and Wu argued that "the revealed topics help healthcare professionals (content providers) understand autism from users' perspectives and provide better patient communications" (2019: 12). This argument could be applied to all healthcare providers to aid them in providing better care to their autistic patients, since many medical practitioners receive little to no training on ASD (Zerbo et al. 2015). Topics revealed through online messages could also be used as a road map to create training for medical practitioners and providing insights into issues that are most important to the autistic community, thus giving aid where it is really needed.

Messages posted on social media groups or autism communities could also be a way for autistics and non-autistics to share what Hacking (2009) describes as a Wittgensteinian "shared form of life." Hacking argues that autistics and neurotypicals speak a different 'language' and that to understand each other, a shared 'form of life' is needed. He envisions achieving this through autistic autobiographies through books, the internet, and television. These would provide non-autistics with an inside look at autistic life and provide a vehicle for changing how neurotypicals interact with autistics. Hacking argues that these personal accounts are important because they bring a new perspective to autistic experience that we never had before. In addition to learning about autism through autobiographical narratives written by autistics, neurotypicals could also learn about it through discussions shared on social media groups or autism online communities. These mediums could provide an inside look at struggles, needs and most salient issues perceived by autistics themselves, and could be beneficial in raising awareness and making the environment more inclusive for them. Participants noted that navigating these resources often leads to a greater awareness of the needs of autistic adults, and is a starting point for their own journey into the advocacy role. Getting involved in advocacy is the subject of the following section.

4 Turning to Advocacy: From Personal Experience to Collective Action

In an article about the cultural politics of autistic activism, Thibault (2014) argues that the neurodiversity movement is helping to shape what it means to be autistic. Like Hacking (2009), Thibault demonstrates how a movement led by autistics can help shift the public's perception of the autistic individual, not only for neurotypicals but also for those on the spectrum. He states that through contested debates between the neurodiversity movement and organizations focussed on the medical model, autistics are learning to make sense of their own lives while changing public assumptions about what it means to be autistic. Echoing Thibault's findings, many participants in this study expressed a desire to make positive changes in society. For example, Robin, who participated in a project on autism mental health literacy, stated:

> … I am part of the advisory board to the autism mental health literacy project out of York University. I've been involved with them since September of last year and their year wraps up in March and then we start again on the phase two of the project in April of this year, so that'll be kind of cool. It's called the autism mental health literacy project. So, we give advice – they're trying to create a pamphlet to share with physicians and the public across Canada on mental health specific to autism.

Chris joined Autism Canada and worked on raising awareness in his community by doing presentations in schools:

> I have joined Autism Calgary. I'm doing a lot of awareness work in the community. In fact, I've just come back from a meeting with the group this morning. It's a big part of my life right now, is to be very out, as an autistic person, and looking for ways of making people accept the diagnosis for everyone and how to integrate other autistics into their activities. Also, especially for schools, I make a big point of talking about it, because I'm trying to encourage kids who are autistic to accept that we can live perfectly fine in society, with some concessions and things like that.

Justine also joined Autism Canada as well as other advocacy groups online. When speaking of why she advocated, she said:

> I'll add that I feel it's very important to put my energy into making life better for young autistic children. I've been advocating for my 14-year-old to be assessed properly and understood for years. I'd probably still hide my diagnosis out of fear of rejection but knowing my teenager will probably be diagnosed means I can't hide behind shame. I need to start sharing my experiences or she will think there's something wrong with her.

Like Justine, Miranda started advocating because she wanted to make life easier for her son who is also on the spectrum. However, the well-being of all autistics became her life's mission:

> I got very heavily into advocacy, so I became involved with Autism Canada, and I went to their conferences and then three years ago, I joined the board. So, I'm on the board of autism Canada and last year I started a non-profit here in Montreal and we're hiring only autistics and intellectually disabled people. So basically, my life has become advocacy and creating opportunities for others to make it easier. It came out of trying to make it easier for my son to get a job when he gets older, but I just really want to see everybody kind of productive and not having the same kind of mistakes and issues that I had growing up. So yeah, just trying to make life easier for everyone.

Some participants chose to do advocacy on a more local level. For example, Jolene liked to do presentations at her university and liked to participate in research so that she could do her part in the cause. She said:

> I enjoy telling people about neurodiversity and have done multiple presentations at the university I attended, sharing my diagnosis and exploring how students on the spectrum and with disabilities in general may find ways to succeed in post secondary education. I also enjoy discussing neurodiversity with researchers, hoping that my experiences will help research get translated into policy/funded services that can help neurodiverse people, especially women and those diagnosed as adults.

No matter how participants chose to advocate, acceptance of oneself and acceptance by others was a reoccurring theme. All participants who spoke about advocacy reported that they wanted to make life better or easier for all autistics, and raising awareness was the main strategy used in achieving their goal. The issue raised by participants was not autism itself but the environment that made being autistic difficult. Therefore, it is important to take a social model approach and examine what can be done to make society inclusive for autistics.

During the interview, participants were asked whether it was important for them to educate those in their social setting and if they felt that this would be beneficial for changing the environment to accommodate autistics rather than them having to adjust to the neurotypical environment. All participants felt that education was important; however, responses were mixed when discussing who should be responsible in doing the educating. For example, Justine stated:

> I think it's incredibly important that they understand but I hate that it's my responsibility to continually educate. I can't do it alone…It's more than even educating, it's this responsibility of changing a deep view that they have formed. It's repeatedly advocating and educating to people who I'm not sure want to really understand… I think training needs to be more than a workshop but an ongoing open engagement…I also think allies, whether in a support group or a clinician, should have advocates that they collaborate with. Many autistics are un or underemployed which is the case with me. I think this collaboration would be a very smart way to employ autistics as well as educate the greater population.

While Justine stated that it should be a collaborative effort, Sydney expressed that the responsibility of educating should not be on autistics at all:

> I think if the onus is on the autistic person to educate, it's still similar to the focus being on adjusting, in that all the expectation is still put on the autistic person. I think the emotional labour involved in educating people is very tiring for us, especially people like me who struggle with verbal communication and social anxiety. It's never really fair to expect any marginalized group of people to educate the uninformed.

Miranda expressed that neurotypicals—although their intentions were good—could not understand the needs of autistics and therefore failed at providing proper accommodations:

> I'd say probably a lot of the education comes from when there are associations that are run by neurotypical people and they really do have their heart in the right place and they are trying, but they fail miserably at making it an accessible place for people…but I would say that neurotypical people overestimate their ability to make a place accessible for an autistic person… And so, there's some grocery stores and some airlines that are adopting it where you choose to put on the lanyard. And that is supposed to signify to the workers that you may need extra assistance or people should have extra patients with you. And I find that really annoying in the sense that, like why should I have to put a sign on myself for you to just treat me with respect …

Some participants spoke about services they thought would be beneficial for autistics. For example, Chris suggested that what was really needed for autistics was experts who could help them integrate into their social environment:

> We need integration experts. We need people who can help businesses and social groups to integrate those of us with mental health challenges in general. I'm thinking of my friend who runs the Inclusive Group in Montreal, and her job now is that she goes to businesses to make them aware of people with autism and other neurodiversity people, and how those people can be integrated into workspaces and work areas and what's the accommodations that are needed or can be suggested.

Celeste, when speaking about important needs of autistics, said that dating was difficult for people on the spectrum because of communication barriers. She reported that she did not know where to get such advice.

> One of the saddest things in my life is that I haven't dated anybody in over a decade, and I don't know what to do about that. Like what's the support ... that's one of the things that's like kind of impossible for people to give you advice.

Finally, Robin expressed that what autistics needed in Canada was a national policy that takes into consideration all disabilities when designing services or structures:

> One thing that we need here in Canada is a national disability program. Focusing on autism is all well and good but we need it for everything. We need universal design to be the first thought, not the last thought when it comes to our institutions, when it comes to our services, when it comes to our government. You're never going to be able to accommodate everybody perfectly but you can create a healthier environment …And so whether it's ASD, whether it's other developmental disabilities, whether it's deafness, blindness, whatever, that we need to be having a national conversation about what do we want our society to look like? And do we want to continue wasting the talent of these people who have been repeatedly marginalized.

Despite a range of responses, all participants who spoke about it felt that educating the public on autism was important and necessary for creating an environment that can better accommodate the needs of autistic individuals.

Conclusion

This chapter explored participants' experiences of living with their new medical label. The first section addressed the issue of identity politics in terms of how participants navigated the discourse between the neurodiversity movement and the medical establishment, and how the changes of medical labels in the DSM-5 impacted participants' sense of medicalized identity. Although not expressed explicitly, most participants shared the neurodiversity movement philosophy which embraced autism as a difference rather than a disability. When describing themselves, many used the language employed by the movement and rejected language that described autism as a medical condition. Furthermore, the change of medical labels had a real impact on individuals—both positive and negative. The positive impact had to do with removing the hierarchy that existed between individuals diagnosed with 'classic autism' and those diagnosed with AS, while the negative impact was stigmatization of people who, in the past, would not have been classified as autistic. Interestingly, even those who identified with the AS label, or had mixed feelings about the change of medical labels in the DSM-5, felt that functioning labels were detrimental as they divided the autistic community into an implicit 'high-vs.-low functioning autistics' hierarchy.

The second section focused on stigma management in terms of the strategies of masking and disclosing in the context of autistic individuals' interactions with others. For study participants, masking seemed to be the favored strategy when dealing with strangers and less-known people in public situations. In contrast, disclosure seemed to be favored when dealing with more significant others such as close friends and family. However, some social and institutional settings provided more ambiguous sites of interaction, which required participants to carefully negotiate what combination of strategies to utilize. In terms of disclosure, participants felt particularly frustrated when not receiving validation for their disorder because of others often not understanding the nature and depth of their difficulties. Even in cases where honest disclosure was attempted, participants reported not being understood and their symptoms and experiences being minimized or dismissed.

Findings from the chapter's third section revealed that there were very few resources offered to autistic individuals who required lower levels of support because they were assumed to have the skills to function in society. Furthermore, the resources that were available may not have been that accessible for autistic adults as—since their challenges were not always easily seen—they were often assumed to have the skills to navigate the health care system. As well, autistic adults were less likely to receive adequate healthcare and had to overcome more barriers to healthcare access than non-autistics. Despite a lack of resources, however, some did manage to find services and supports following their diagnosis through counselling, joining in-person or online autism/disability groups, and/or doing research on their own.

Finally, the fourth section of the chapter examined how autistic individuals' experiences in dealing with the identity politics of autism in their everyday lives and in the context of support groups led to becoming politicized and taking on advocacy roles. Many participants discussed actions they were taking to raise autism awareness: some became involved with autism organizations, while others were doing public presentations to not only raise awareness but to promote self-acceptance for those who have the disorder. Some participants expressed that they became engaged in advocacy to make life easier for their own autistic children but, as they got to be more involved, activism became a life mission with the goal of making life better for all autistics.

The last part of section four discussed needs of autistics voiced by autistics themselves. The question of who should be responsible for educating the public on autism generated mixed responses: some reported that it should be a collaboration between autistics and non-autistics; some said that it should be only non-autistics; and others felt that autistics needed to be involved because they knew their needs and knew what changes and accommodations were required. Participants identified integration experts, help in dating, and a comprehensive national policy as some of the key developments needed in society in order to improve the quality of life for autistic individuals.

Illuminating Autism: Conclusion

The focus of this study was adults diagnosed with ASD during adulthood who lived a significant period of their lives without a diagnosis and struggled to understand themselves and their environment. Many of them developed a negative self-perception, lived with no supports or resources, and were often misdiagnosed (which lead to additional mental health issues). It was only recently that milder forms of autism were recognized (Davidson and Orsini 2013), and the research on autism did not really focus on understanding this particular group of people from their own perspective. This, in turn, has been directly related to the lack of services and resources for autistic adults (Vogan et al. 2017). All of these made it important to investigate the issue in question and gain a deeper insight into the lives of autistic adults in order to better understand the kinds of resources and support they need to reach a better quality of life. Primarily however, it presented an excellent case study for the social construction of personal identity, especially given so much contention over what autism means from medical, cultural, and political points of view.

In pursuing this, I explored three phases of the diagnosis process. The research and analysis of the pre-diagnostic phase provided insights into identity formation of autistic individuals and allowed for a better understanding of how their identity is impacted by their social environment. In addition, the analysis was also useful for comparing how participants saw themselves from pre-diagnosis to the post-diagnosis. Thereafter, the research and analysis focused on the diagnostic process and explored the reasons for a late diagnosis and the steps taken to seek and obtain an official diagnosis. The next step was to gain insights into the post-diagnosis stage in order to better understand the impact that labels had on autistic individuals in terms of how they saw themselves, how their identity was changed/reconstructed, and how they saw their social environment and their opportunities within in (i.e. whether these were more or less restricting). Finally, the research and analysis explored the political aspects of their newly adopted identity given changing definitions about AS and ASD in the medical literature (Autism Canada 2020) and the neurodiversity movement. This led me to question how individuals navigated their social circles, primarily through masking or disclosure strategies. Given some of the difficulties raised, the question of resources/supports accessed by autistic individuals made sense, in order to better understand their needs from their own point of view and shed light on what society can do to enhance their autonomy and independence. Their involvements here would often lead to an increased sense of purpose around the advocacy, and lead some to become more involved in leadership roles.

While many of the study's findings were consistent with the autism literature consulted, the research and analysis led to a few novel and valuable insights as well. First, the symbolic interactionist framework (Mead 1934; Blumer 1969; Prus 1996) made a great deal of sense as a lens through which to analyze the identity transitions of adults who received a late diagnosis of autism. Autistic identity is not automatically given, but, as G.H. Mead (1934) would assume, evolves over time as symbolic understandings are received from the social community. In this case, the social community helping shape their self perceptions would be the medical community, internet resources, school and work, peer groups, and family. Through various difficult and liberating turns, individuals would come to see themselves through a career of identity experience. Having the validation of the autism construct as a label was extremely valuable as a symbolic resource, allowing them to re-interpret their past selves in a more forgiving, positive light, providing hope for the future (Mead 1929).

Second, many mothers reported that they were diagnosed as a result of their children being diagnosed. Some found that they had similar traits to their children and followed through with their own assessments, and others were advised to seek out assessments by their children's clinicians.

My exploration of the subject revealed that this phenomenon was not documented in the literature and that, therefore, further research is needed to better understand how these mothers cope not only with their children being newly diagnosed but also with their own diagnosis. Given that no research on mothers being diagnosed following their children's diagnosis can be found, one can assume that there are most likely no resources and supports for this group.

Third, in contrast to the autism literature that discusses masking as an impression management strategy (Goffman 1986) autistics use to hide their symptoms in order to pass as normal and avoid being stigmatized, the data in this study showed that autistic individuals also used masking as a way to make others comfortable in their presence. This turned to be a valuable insight as it revealed that autistics do have the ability to take on the perspective of others, although they do use alternative strategies to accomplish this. Not having the natural intuition to take the role of others as most have, they accomplish this through a more systematic logic, which raises interesting questions in regard to Mead's theory of self development. While this is a preliminary insight, it nevertheless offers an important starting point for further exploring the processes of how autistic individuals come to understand the others' state of mind. Shedding more light on this may, in turn, contribute to decreasing autism stigma.

Fourth, the autism literature shows that there is stigma attached to diagnostic labels for mental disorders and that this limits life chances for autistic individuals (Ma 2017). Therefore, I expected to find that diagnostic labels would have a negative impact on identity of my research participants. However, responses to the questions exploring this issue were overwhelmingly positive: most participants expressed that the label provided them with a sense of relief and validation, gave them a framework to understand themselves better, and enabled them to make a more meaningful sense of their past. This new understanding of themselves and their experiences, in turn, improved their self-perception and—for some—lead to more meaningful connections to other autistic adults. Overall, receiving the diagnostic label seems to have been a healing experience and a chance to start over with the new identity.

Finally, the autism literature indicates that the absorption of the AS label into the ASD categorization in the DSM-5 was an issue of contention in the autism community (Giles 2013). However, many of my research participants agreed with the change and said that having AS separate from autism divided the community and encouraged the use of functioning labels as a measure of someone's worth. There could be a couple of reasons for this: The time that some participants received their diagnosis might have influenced how they felt about the change (i.e. if they were diagnosed after the change, they would not have had a strong attachment to the AS label); since the absorption of the AS label into the ASD categorization happened a few years back, some participants might have gotten accustomed to the change and were no longer thinking of it as an issue. More extensive research would need to be done to shed more light on the reasons for the agreement. This, however, does not take away from the finding about participants agreeing with the change being a novel and valuable insight.

In the introduction to my research project, I stated that my study was inspired by the social model of disability and its claim that disability is best understood as the consequence of society imposing barriers that prevent people with impairments from fully and meaningfully participating in social life (den Houting 2019). Therefore, the ultimate purpose in undertaking this study was to illuminate some of the 'disabling conditions of existence' experienced by autistic adults and shed light on some of the means for transcending their condition of unnecessary isolation and exclusion from society. The fundamental insights that came out of the research in this regard are, first, that the path to full and meaningful participation in society for autistic individuals starts with listening to their voices and taking into serious consideration their thoughts and suggestions about the kinds of things they need to realize more independent and autonomous existence; second, that the path continues with the efforts to create a new vocabulary about autism (and disability in general) and embrace the existing terminology and philosophy of inclusion (such as the one underlying the neurodiversity movement) as the basis for offering more meaningful and nuanced understandings of autistic individuals and their condition and position in society; third, that the path carries on with translating these understandings into new frameworks, platforms and legislations that support and enable the creation of resources, programs and services (such as the low-level support services offered in the UK) of genuine aid to autistic individuals; and forth, that the path ultimately leads to a permanent and broad-based public demand for the kind of society that transcends the stigmatization of autism (and all other forms of disability) with an understanding that attending to people's 'disabling condition' of existence is not a matter of accommodation but, ultimately, a matter of fully realizing the promise of independent and autonomous existence for all.

Appendix 1: Information Letter and Consent Form

Dear Potential Participant:

Hello, you are being invited to participate in a research project titled “The Social Meanings and Identities of Adults Diagnosed with High Functioning Autism Spectrum Disorder,” funded by the *Social Sciences and Humanities Research Council of Canada*. **The purpose of this study is to find out about the experiences of people who have been diagnosed as adults with high functioning autism (HFA)**, which includes those previously diagnosed with Asperger’s Syndrome. You are being invited because you have identified yourself as someone meeting these criteria who have shown an interest in participating in our research project. This letter is to give you the information you need to make an informed decision about whether or not to participate. Before you decide, please read this letter carefully to understand what is involved. After you have read the letter, feel free to ask any questions you may have.

In this study, **we aim to explore the effects that an autism spectrum diagnosis has on a person's sense of identity and their relationships in the social environment**. In particular, we are trying to find out how adults deal with the positive and negative effects of the diagnosis, what life was like before and after, and the main steps taken in the adoption of this new diagnostic label for a sense of self. We are interested in how the medical literature, as well as (in-person and online) Aspies and autism support groups might aid in shaping this sense of self.

Participation is voluntary. If you choose to participate, a **one-on-one interview of approximately 60 minutes** will be conducted either in person, by telephone, Skype, or email correspondence. If you are participating in person, two copies of the information letter and informed consent form will be signed by you and the interviewer, so that each have a copy. For phone and Skype interviews, the forms will be provided in advance and reviewed prior to the interview. Verbal or email confirmation of consent will be obtained by the interviewer in the case of long-distance arrangements. Whether or not you participate will not affect your relationship to the researchers or Lakehead University, and it will **not affect your relationship to any support organizations** (they will not know if you participate).

While we do not foresee any major risks from participating, it is possible that during the interview, you may find it difficult to talk about some of your experiences, especially if they involved painful memories or traumatic events. In these cases, **you will be under no obligation to answer any questions that make you uncomfortable, and you will be free to withdraw from the interview at any time**. After the interview, you may contact us to withdraw from the study up until the time that your transcript has been made anonymous and pooled with the rest of the transcripts. Should you require any additional support for emotional stress as a result of the interview, a referral to the appropriate service will be provided. **The interview will be audio taped with your permission and later transcribed**. Field notes may also be taken.

The benefits of this study are to help counter social stigma and contribute to a better-informed public awareness of the condition. Additionally, it may help autism support organizations to better serve their clients. **A $100 honorarium in the form of an Amazon.ca gift card** will be given to participants as a token of thanks for taking part in our study.

HOW WILL MY CONFIDENTIALITY BE MAINTAINED?

To protect confidentiality, the interview transcripts will be anonymized by providing each participant with a code name. In the dissemination of results participants will be referred to by their code names, along with their gender and age, as well as the time they were diagnosed and relevant descriptive criteria. Only the research team will have access to the anonymized transcripts and no personal identifying information will be indicated in the reporting of the results.

WHAT WILL MY DATA BE USED FOR?

Our study will be of interest to health professionals and governmental officials responsible for assisting individuals diagnosed with autism spectrum disorders. We will present our research at autism and Asperger's community events and meetings, so as to increase the benefit of the research to participants and the larger community. We will also present our findings at major relevant Sociology conferences in Canada, prior to publishing our results in relevant peer-reviewed Sociology journals, on wider issues of health identity and related issues.

WHERE WILL MY DATA BE STORED?

Audio records and original transcripts of the interviews will be stored for five years on a password-protected Dropbox folder that will be hosted by the leader of the research team and only accessible by research team members. Printed transcripts will be stored in a locked cabinet in the principal investigator's office on campus, where they will be stored for a period of 5 years.

HOW CAN I FIND OUT ABOUT THE RESULTS OF THE STUDY?

A summary of the findings will be available to participants upon request. After December 2019, you may call or email the principal investigator, Chris Sanders (contact information below), to request a copy of the summary findings.

RESEARCHER CONTACT INFORMATION:

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RESEARCH ETHICS BOARD REVIEW AND APPROVAL:

This research study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca.

MY CONSENT:

I agree to the following:

- ✓ I have read and understand the information contained in the Information Letter.
- ✓ I understand the risks and benefits to the study.
- ✓ I understand that I am a volunteer and can withdraw from the study at any time and may choose not to answer any question.
- ✓ I understand that the data will be securely stored at Lakehead University for 5 years following completion of the research project.
- ✓ I understand that the research findings will be made available to me upon request.
- ✓ I understand that I will remain anonymous.
- ✓ All of my questions have been answered.
- ✓ I acknowledge receipt of $100 honorarium.
- ✓ I agree to participate.

By consenting to participate, I have not waived any rights to legal recourse in the event of research-related harm. I give my consent to participate according to the information above.

Participant name: ____ ID # __________________

Participant signature: ____________________________________ Date: __________________

Researcher signature: ____________________________________ Date: __________________

Appendix II: Interview Guide

Interview

Background

Can you tell me a little about yourself: how old are you, where did you grow up, where do you live now, what do you do for a living?

Getting Diagnosed

1. When did you receive your diagnosis, and from organization? What was the specific diagnosis in your case? Can you describe the process of testing and/or diagnosis?
2. How was your diagnosis explained to you, and what literature and informational resources were recommended? Did this seem to match how you felt?
3. How did you react to the diagnosis? Were you happy to have an explanation for things?

Pre-Diagnosis

4. Were there any initial signs of autism symptoms growing up? If so, please describe these experiences and what sense you made of them at that time.
5. How did you see yourself and how did others see you (pre-diagnosis)? What did you make of these differences?
6. Did these early symptoms cause any problems or issues in your relations with others, in family, social-circles, school or work? Please describe as best you can.
7. How did you decide that it would be beneficial to seek a diagnosis? Did anyone help you to decide to be diagnosed? Did you have a sense of what the diagnosis might be?

Post-Diagnosis

8. Since receiving your diagnosis, have you connected with or joined any autism or Asperger's networks or social support groups? Which ones? How have they been useful? Have you experienced any challenges here?

9. Did any of these support groups (e.g. medical, informal, online) help you to process and accept your diagnosis and shape your sense of self-identity? How has your sense of yourself been affected, if at all, by the diagnosis?

10. Are you aware of the “neuro-diversity” movement, and how do you see yourself in relation to this?

11. Do you generally choose to share your diagnosis with others? Have you found that disclosing your diagnosis with others helps in your social relationships?

12. How important do you believe it is to educate those in your social settings? E.g. family, friends, work and leisure? Do you think that educating people helps to restructure these settings and make them easier to get along in?

13. Do you think that training in how to educate one’s social environment would be helpful rather than all the focus being on how a person on the spectrum can adjust?

14. Has there been any negative aspects of obtaining a diagnosis? From your perspective, has it helped or harmed your overall sense of well-being?

15. Are you aware that Asperger’s is now considered part of the autism spectrum rather than a specific condition that is separated out from the Autism Spectrum? How do you feel about that change, and do you agree or disagree with it? Why?

Concluding Questions

- Is there anything important about the social experiences of receiving an autism-spectrum diagnosis that you would like to add?

Thank you so much for helping us!

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