Summer 2018

Toward a Sociology of Autism

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TOWARD A SOCIOLOGICAL MODEL OF AUTISM

A Thesis
Presented to
The Faculty of the Department of Sociology
Western Kentucky University
Bowling Green, KY

In Partial Fulfillment
Of the Requirements for the Degree
Master of Arts

By
Jessica N. Simpson

August 2018

TOWARD A SOCIOLOGICAL MODEL OF AUTISM

Date Recommended 7-17-2018

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Graduate School Dean   Date

everything I forgot.

       Lastly, I dedicate this thesis to my daughter Siren. You are the reason for everything I do, my inspiration, my one true love, my walking purpose. My hope is that I have made this look easy and that for you I have paved the way such that finding your passion and achieving your dreams will not seem like something for "other people" as it once did for me.

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Autism Spectrum Disorders (ASDs) are characterized by difficulties in social interaction and communication. Recent studies within the social sciences have espoused a need to reconceptualize autism out of the domain of the intrapersonal and into the realm of the sociocultural. Semi-structured in-depth interviewing was used to examine the self-perceptions and experiences of twelve people who identified as on the autism spectrum. Social scientists have tended to grant the topic of autism to the domain of psychology; as a result autistic perception has been stigmatized resulting in the exclusion of autistic perspectives in knowledge production on the lived experiences of autistic actors.

The first-hand accounts examined in this study lend support to the idea that symbolic interactionism provides a more nuanced framework for studying how autistic perception influences autistic experience in contrast to the functionalist-reductionist approach of cognitive psychology. From this perspective we can position autistic differences in disposition and interaction as socioculturally situated rather than as solely a result of individual cognitive impairment. The application of microsociological concepts to autistic perception and interaction has the potential to expand knowledge on both autistic experience and the social construction of normative order.

Keywords: symbolic interactionism; self; autism;

Chapter 1: Introduction

Since it was first identified by Leo Kanner and, independently, Hans Asperger in the 1940's, there has been and continues strong debates about what autism "is" and what it is caused by. Currently autism is understood as a "lifelong developmental disability that affects how a person communicates with and relates to other people. It also affects how they make sense of the world around them" (NAS, 2012). Autism is commonly characterized as deficits and impairments in social interaction and communication. The literature on the nature of autistic selves espouses the view that these impairments critically prevent or complicate the ability to empathize and hinders the development of self and relationships between self and other.

Most studies of the self and autism have relied on Baron-Cohen's concept of Theory of Mind (ToM) and focused on autistic actors' difficulty inferring others' state of mind (Baron-Cohen, Leslie, & Frith, 1981). This study discusses the role of ToM in the discourse of autism and not its overall value to any discipline. Little research has sought to elucidate how or what autistic people think of themselves and their relationship in and to the social world. The consequence is that autism is understood as resulting in differential self-development and studies of autistic people have focused on these differences as deficits and dysfunctions. A criticism of this framework is that what is deemed pathologically deviant is a result of larger social forces which designate the parameters of normalcy (Milton, 2017; 2014; 2013).

What does it mean to have a self? Or to have no self-- to imply that some people lack the necessary components for personhood, relationships, equality, and thus, humanity? This study adds to critical autism studies by using symbolic interactionist (SI)

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theories to provide an alternate framework for studying autistic selfhood that moves the discussion out of the neurological and cognitive realms and into the sociocultural realm. The purpose of this study is to demonstrate how, from a sociological perspective, difference itself is not sufficient to imply deficiency but that differences have resulted in the stigmatization of autistic selfhood and interaction.

Chapter Two is a review of psychological social psychology literature on autistic selfhood and sociality and a discussion of the theoretical assumptions prevalent in the research on autism that denies autistic individuals full personhood. Chapter Three outlines the SI view of self and interaction and reviews research that demonstrates specific SI tenets of what it means to have a self. Chapter Four outlines the present study—a SI investigation of how socialization and self are experienced and perceived by autistic actors representing a shift from the individual to the social. Chapter Five discusses the finding the present study. Lastly, Chapter 6 summarizes the present study and suggests directions for research toward a sociological model of autism.

Chapter Two: Psychological Social Psychology and the Self

Historical Understanding and Construction of Autism

Autism has historically been understood as a disorder of the self. Bleuler (1911) is credited for first coining the term autism to describe what he viewed as a particular type of schizophrenia observed in children that he described as having a unique type of self-absorption. Both Leo Kanner and Hans Asperger adopted the term autistic in their research on, respectively, "early infantile autism" and "autistic psychopathology." Although now largely discredited, Bruno Bettelheim (1956) utilized a psychoanalytic approach to autism, drawing parallels between the behaviors of autistic individuals and those who experienced trauma in German concentration camps. Bettelheim believed that traumatic experiences in early childhood resulted in autism, and like Bleuler, conceptualized autism as a form of schizophrenia. It was not until the late 1970's that autism was reconceptualized as a developmental disorder, and only recently has it been again reconceptualized as having a neurological basis (Damasio & Maurer, 1978).

Today autism is regarded as a developmental and neurological disorder that occurs along a spectrum from high-functioning to severe. Those described as high-functioning may be highly verbal, possess a higher than average intelligence, and have few social and communicative impairments that require accommodation. On the other hand, low-functioning or severe autism is characterized by acute learning disabilities. Noting that autism has a high degree of comorbidity is important (Mannion & Leader, 2013). It is common for an individual to have multiple diagnosis including other developmental or physical disabilities or mental disorders including epilepsy, food

allergies, unspecified mental or intellectual disabilities, and behavioral disorders that may impair their daily functioning. That being said, for some individuals considered low-functioning, autism may not be their primary diagnosis. Depending on the complexity and severity, those with multiple social, communicative, and physical impairments are typically considered on the low end of the spectrum.

Autistic scholars have argued that this language and conceptualization reinforce the idea that autism is bimodal. Terms such as high and low-functioning paint a picture of autistics that denies the strengths of those understood as low-functioning while de-emphasizing the challenges faced by those labeled as high-functioning. These terms are considered offensive and believed to obscure the nature of autism. Larry Arnold, director and trustee of the National Autistic Society, describes his own experience of autism as follows:

> … it is like a palette of colors that can be assembled from the primaries. To me it is like a landscape where one can move within a specific territory. It has mountain tops and deep valleys and if one were to set one's altimeter at average elevation and fly across it one could not do so without crashing in a mountain or missing out on the valleys. It has overlapping territories and dual citizenships which are fought over. I live where it borders dyslexia and others live close to the territory of Tourette's for instance…" (Arnold, 2013).

Arnold is drawing attention to the fact that the literature describing autism, autistic symptoms, and autistic perceptions is often too simplistic, not representative of, and conflicts with the actual experiences of autistic people. Thus, a more nuanced understanding of autism leads one to view autism as not one thing with degrees of severity but rather a collection of traits that manifest in varying degrees for each individual, some of which are not wholly unique to autism (Arnold, 2013). More succinctly, no two individuals are alike and all people have unique strengths and

weaknesses, which for autistic people is often limited by the structure of the social and physical world far more than any perceived personal physiological or psychological deficiencies. Furthermore, Arnold's view questions who can be called authentically autistic.

From a methodological perspective determining who is "authentic"—representative of the autistic community—is imperative. Some researchers have included students with learning differences or intellectual disabilities and/or other individuals that do not necessarily meet the diagnostic criteria for autism. Others have criticized the predominance of high-functioning autistics arguing that their symptoms lack the severity to aptly represent the nonverbal autistic population. They are not autistic enough. An additional criticism is that most of the research has focused on children and adolescents, yet little research has explored actors later in the life course. Focusing studies of autism on the young has important implications for treatment, support, advocacy, and policy change. Work needs to be done to better understand autistic adults who also need acceptance and support. As one can easily see, autism is an extremely contested terrain.

The Self and Autism in Psychological Social Psychology

Currently, discourse surrounding autism is dominated by the fields of clinical, cognitive, and developmental psychology and neurobiology which all adhere to the disease, disability, and deficiency (medical) model of autism (Milton, 2012). One popular concept used across these disciplines, Baron-Cohen's Theory of Mind (ToM), claims that autistic people are unable to understand that others have their own unique mental states, lives, and experiences (Baron-Cohen, 2007). From Baron-Cohen's point of view, this is not merely a peculiarity, but something that people *suffer* from. According to ToM,

autistic individuals do not share the human experience of "mindreading" and thus lack

empathy. ToM scholars refer to this as *mindlblindness*—the term used by developmental

psychologists to refer to children and adults, particularly those with "the biological

condition of autism," who 'suffer' from and fail to develop the "capacity to mindread in a

normal way" (Baron-Cohen, 1995, p. 5). This viewpoint suggests that if an individual

cannot perceive their own mind or the minds of others, then they effectively do not have a

self.

Much of the current research on autism has sought to determine physiological

differences that effect cognitive processing. For example, Lyons and Fitzgerald (2013)

have investigated the neuroanatomical basis for atypical self-development in autism

spectrum disorders (ASDs) stating:

> a great majority of self-related processes that are mediated to a
> significant extent by the right hemisphere are impaired in individuals with ASD.
> Additional lines of investigation indicate that an unintegrated sense of self in
> autism is also potentially associated with abnormal functional connectivity and
> an impaired mirror neuron system. Consequences of this atypical sense of self
> are the well documented impairments individuals with ASD experience in the
> social and communication.

Lyons and Fitzgerald represent the view that ASDs are a developmental and

neurological disorder characterized by physical and processual impairments in brain

functioning that results in a fragmented and incomplete sense of self. They contend that

autistic selves are atypical as a consequence of these impaired bodies.

While Lyons and Fitzgerald acknowledge the perspective of difference is "not

necessarily deficient and that diminished self-awareness and differences may contribute

to autistic gifts and talents or otherwise be advantageous," other scholars double-down on

the deficiency perspective. For example, in discussing the relationship between ToM and

self-development claims have been made that autistic people are "undomesticated humans" (Badcock, 2016) and compared with "great apes" (Tomasello, 2005). Stephen Pinker has stated, "Together with robots and chimpanzees, people with autism remind us that cultural learning is possible only because neurologically normal people have innate equipment to accomplish it" (Pinker, 2002, p. 62). As we can see, ToM has led to a discourse that problematizes autistic selfhood and interaction to the point of dehumanization.

A methodological criticism of Theory of Mind concerns its validity, reliability, and replicability. A recent study by Kulke (2018) and colleagues involved a systematic attempt to examine the replicability of four widely used Theory of Mind anticipatory-looking false belief assessments. Their results concluded that only one (Lows & Watts, 2013) could be replicated and there were no correlations among the four paradigms in tests of their convergent validity. For Kulke and colleagues this indicates that experimental tests of ToM are not as reliable or valid as previously assumed which calls into question whether conclusions drawn from such assessments are useful. However, the assumption that autistic people suffer from a lack empathy and cannot develop a self has gone largely unchallenged by social scientists and professionals in the field of education.

Beyond the social world of psychological science, deficiency rhetoric has entered the mainstream domain and is now used by parents and other actors who have their own biases toward autism. Activists and social movement organizations routinely use scientific and/or medical language to gain credibility (Conrad, 1992; Schneider, 1985). Take, for example, the organization Autism Speaks. Autism Speaks mission statement states that they seek to "eradicate" autism. While it is generally agreed among scientists

that the search for a cure has been entirely unsuccessful and that trying to prevent autism

does not help individuals living with autism, each year the organization channels 35% of

their funding toward research seeking a cure—despite the fact most autistic activists say

that "autism is who we are" (Sinclair, 2005) and they do not want a cure and would prefer

acceptance and support.

    Autism Speaks budget states that only four percent is spent on family services

and accommodations. The language and rhetoric describe broken people that should be

fixed, drawing parallels to research on other minoritized groups, specifically the deaf and

gay communities (Davidson, 2008; Dekker, 1999). There is little prioritization of research

or advocacy that seeks to assist and accommodate autistic individuals. The implication of

this perspective is the assumption that autistic people should not exist.

    Neurodiversity is a term used to describe people with Dyslexia, Dyspraxia,

Tourette's Syndrome, Attention Deficit Disorders, as well as Autism Spectrum Disorders.

Autistic scholars and activists have begun to organize and speak out that dominant

discourse denies the autistic community's humanity and have argued for the validation of

autistic experiences from the perspective of neurodiversity or by the application of social

and cultural models of disability (Sinclair, 1993; Dekker, 1999).

    The social model of disability, according to Shakespeare (2006), is different from

the traditional medical deficit and disability model in that the latter conceives of autism

and other disabilities as individual impairments that need to be cured. On the other hand,

the social model of disability positions disability as a culturally and historically situated

phenomenon and identifies disabled people as a stigmatized group. This shifts the focus

from the individual to the social and highlights that non-disabled people, as well as the

social structure, contribute to the oppression of disabled people. This perspective is uniquely suited to examine autism as something that is more than just an individual disorder and deficiency.

Other social movement organizations such as The Autistic Self-Advocacy Network (ASAN) and the Autism Women's Network have organized in response to the lack of representation of autistic voices in advocacy and awareness. Identifying as part of the disability rights movement, ASAN aims to influence public understanding and legislative policy to promote "a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens, NOT a world without autism" (ASAN, Mission Statement, 2016). It remains the responsibility of scholars, however, to incorporate autistic experiences and perspectives into the literature by including autistic voices in knowledge production to challenge the assumptions and contest the myths surrounding the study of autism.

Contesting the Deficiency Paradigm

> Contemporary theories about ToM now invoke and assert multiple cognitive phenomena—mentalizing, meta-cognition, mindreading (i.e., understanding others' mental states), deducing intentionality, and expressing empathy (Boucher 2012, 229). In other words, to lack a theory of mind is not simply to lack a theory of other's minds—it is also to lack an awareness of one's *own* mind (Carruthers 1996; McGeer 2004). *And so, I am writing this essay, presumably unaware of my reader and my (non)self* (Yergeau, 2013, p. 7, emphasis added).

Autistic scholar and activist Damian Milton has argued that psychological social psychology research and rhetoric on autism has utilized a functionalist perspective (2012). Milton suggests that autism has been deemed pathological "due to the distaste of those doing the perceiving and their idealization of cultural and psychological norms" (Milton, 2013, p. 9). The application of this pathological label indicates individuals in need of treatment and has "focused on the needs of those around the individual, not the needs of the individual" (2013, p. 7). For example, the number of articles on the stigmatization of parents of autistic children is larger than that of the stigmatization of autistic people (Kinnear et al., 2016; Mak & Kwok, 2010; Gray, 2003)He argues that embedded within this discourse of autism is a struggle for power.

Melanie Yergeau, an expert in rhetoric, discusses her own experiences as an autistic scholar to demonstrate the ways in which autism discourse and specifically ToM denies "autistic people agency by calling into question their very humanity and, in doing so, wreak(s) violence on autistic bodies" (2013, p. 1). She notes that autistics are disembodied in research and describes her experience being admitted to a mental health facility against her will while being told that her protests to commitment were her "autism speaking," subsequently robbing her of agency and autonomy. She was speaking but her speech belonged, not to her *self*, but to autism. Theory of Mind is held as empirical fact and is said to be the distinct quality that makes one human. Because autistics are believed to lack ToM, they are rhetorically rendered inhuman.

In discussion of autism as neurodiversity, parallels have been drawn between deaf and autistic communities as "both populations have a communication style that is different from the norm" (Dekker, 2006), yet, the claim has never been made that the deaf

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lack a key element of humanity. In contrast to the deficit and deficiency view, autistics

argue that autism is a unique way of being in the world that is "different, not less"

(Grandin, 2007). Differences in autistic ways of thinking and perceiving should be

understood as both alternative communication and consciousness (Grandin and Johnson,

2005).

Drawing from the work of autistic activist Jim Sinclair, Lauren R. Strand

describes the theoretical links between autism, disability studies, and the interlocking

dimensions of oppression that impact the lives of marginalized people, also known as

intersectionality, stating that:

> Returning to the central tenets of intersectionality put forth by Smooth, it
> is evident that the neurodiversity perspective utilized by Robertson and Walker
> addresses the notion that social identity categories and power systems are
> geographically, historically, and culturally specific. Additionally, the authors
> recognize that privilege and marginalization can co-exist for individuals and
> within groups. The third tenet, a commitment to social justice, is inherent within
> the neurodiversity paradigm because its foundational premise is to create more
> recognition, acceptance, and celebration of diverse neurotypes. The fourth
> principle, the dedication to viewing identity categories through an anti-essentialist
> perspective, is present in both the neurodiversity paradigm, as well as in
> statements about those who identify as neurodivergent, such as "the great
> variability among the autistic population" in terms of desires, modes of
> communication, sensory sensitivities, and interests (Sinclair, 2010, Spontaneous
> Interaction section, para. 11; Strand, 2017).

A growing perspective is that autism results in a distinct cultural experience and

relationship to the social world. It has been said that the internet is to autistics as braille

was to the deaf community (Davidson, 2008). In other words, the autistic community is

where the deaf community was a century ago (Davidson, 2008). For example, Joyce

Davidson contends that "autistic differences in perception and processing tend to involve

Other ways of being-in-the-world, separate senses of selves and space that give rise to

distinctive cultural experience, and so also, cultural expression" (2008, emphasis added). Davidson's study of online communication among autistic individuals demonstrates that the internet is a useful and "accommodating medium for those on the spectrum, given characteristic preferences for communication at a socio-spatial distance" (2008, p. 1). Her research asserts that an autistic culture is flourishing online and that autistic individuals can connect with one another via a medium that virtually (in both senses of the term) diminishes their social and communication complications. Importantly, Davidson suggests that not only is online communication important for autistic sociality and mutual support, but it also provides a platform for organization, self-advocacy, and inclusion.

In reviewing autistic culture online such as forums and groups on popular social media sites, it is evident that autistics have hopes, dreams, fears, and express a full range of human emotion and self-reflection. Along with self-advocacy groups, scholars and outspoken autistic voices are beginning to challenge and replace the myths surrounding the abilities and dispositions of autistic actors with scholarship that accurately represents the autistic experience. Milton suggests a phenomenological approach based on the theories of Goffman, Garfinkel, and Cicourel and sociological concepts such as the social construction of disability, normalcy, and stigma to understand the nature of autism and social aspects.

This thesis explores how autistic actors perceive themselves and thus, the possibility of the development of a differential as opposed to a deficient self-concept in autistic individuals. As we have seen, research has focused on individual cognitive and neurological impairments to the exclusion of exploring the lived experiences of autistic actors. As we will see, symbolic interactionism can provide an alternate view, a different

yard stick so to speak, to both assess and validate autistic social and cultural experiences of self and interaction. This way, researchers, doctors, parents, and advocates can begin to accept and understand autistic people and their experiences from a sociocultural framework, rather than aim to pinpoint was is wrong with autistic people, to fix autistic people, or to create a world without autism.

Autism and Sociology

An interest in Theory of Mind has risen in fields such as the social sciences and humanities because of its social ramifications and associated meanings of autism diagnoses (Marinan, 2017). In his article *Greasing the Skids: Interdisciplinary Rhetoric and Mindblindness* (2017) John Marinan examines and summarizes how ToM and *mindblindness* began as a theory in neuroscience but has since entered the rhetoric and taken on significance in other disciplines. Marinan notes that "given the fact that Baron-Cohen's research is "theory," this has invited dialogue from other quarters to re-theorize the nature of autism and autistic identity" (2017, p. 579).

Few scholars have stressed the importance of the application of sociological frameworks to the study of autism and yet doing so provides an additional standpoint for analysis (Maynard, 2017; Milton, 2013; Durig, 1993). Doug Maynard has suggested that sociology demonstrates how autism is embedded in social interactions (Maynard, 2016). In 1993, Alexander Durig first suggested that the psychological concept of Theory of Mind may be the "stepping-stone to a microsociological theory" of autism. Indeed, much of the literature attempting to challenge deficiency paradigms and address autistic selfhood and agency have centered on critiquing Theory of Mind.

Alexander Durig (1993) developed *logical inference theory* and suggests that it is the only theory that has been able to account for all the difficulties in communication present in historical understandings of autism, namely those outlined by Uta Frith. In his book *Autism and the Crisis of Meaning* (1996), Durig allegedly "shows that everyday meaningful perception may be organized largely by a balanced ratio of inductive to deductive logics, and that autistic perception is comprised of significantly higher levels of deductive social inferencing relative to inductive social inferencing". Logical inference theory seeks to explain the logical structure of sense-making in everyday life. According to Durig, social interaction and inferencing is mostly an inductive process.

Durig contends that autistic experiences are better characterized as a preference/reliance on deductive logic (in particular) and that "the *appearance* of a lack of theory of mind would be a potential consequence of an individual processing interaction with others using deductive rather than inductive logic" (Milton, 2014, p. 5). For Durig, faculties of induction are deficient in autistic people noting that "all the subjective components necessary for the individual actor to anticipate, define, and interpret normative conversational interaction are inductive". He suggests that autistic people can apply logic to understand meaning in interaction but cannot do this across situations and "therefore, they cannot experience mind, meaning, language, self, and emotions the way most individuals do" (Durig, 1993, p. 12). This may have substantial merit, however, Durig's focus on logical processes of inferencing continues to situate autistic difficulties in communication as deficiencies in individual cognitive processes.

Additional concerns with Durig's research are that he (a) centers and assumes the debunked work of Bruno Bettelheim relying on Bettelheim's conception of autistic

people's lack of self and (b) the fact that his only source of data is the autobiography of one woman, Donna Williams. More importantly however, Durig claims that he uses a symbolic interactionist approach to autism, yet he suggests that symbolic interactionism has made a fatal flaw in understanding meaning by assuming that meaningful symbols are what create meaningful perception. For Durig, symbolic interactionists have it backwards as he argues that meaningful perception "precedes the use of meaningful symbols" (Cottrell, 1997). We learn how to meaningfully perceive as we learn meaningful symbols during the process of socialization. Symbols and their meanings can distort our perceptions. I posit that meaningful perception and meaningful symbols cannot be separated.

In fact, Mead emphasized how society controls mental processes such that symbols allow us to name and categorize our perceptions. In other words, meaningful symbols shape our perception and we learn each simultaneously such that they cannot be meaningfully separated. Otherwise we would be bombarded by all our perceptions and unable to parse out what was meaningful. Meaningful symbols and perception are what allow us to categorize and evaluate the social world; that is, to use inductive, deductive, and abductive logic. Moreover, symbols allow us to meaningfully perceive the past and the future as well as the minds of others, i.e., role taking. Durig's microsociological approach to autism seeks to explain the appearance of lack of ToM without critiquing its impact on research of autism. His approach seeks to apply his own logical inference theory to explain the most common features of the deficit and disability model in contrast to psychology theories which have so far offered only partial explanations and support of the deficiency paradigm.

Of any other scholar Milton's criticisms of ToM and approach to autism, which typically are phenomenological, demonstrate what microsociological analyses have to offer the study of autism. Regarding ToM, he holds it as merely "a partial heuristic regarded as empirical fact as Baron-Cohen suggests that intentions are observable 'things' in the mind" (Milton, 2013; McGuire & Michalko, 2009, p. 166). This view is also supported by McGuire and Michalko (2009) who argue that, "Rather than 'seeing' intention, we presuppose that all action, whether our own or that of others, is intentional and, as a way to make sense of action, we endow it with intentionality." They point out that "we are never able to gain access to the minds of other. Rather we are "always on the way to knowing the other" (2009, p. 176). Additionally, Milton contends that, "Autism is a social phenomenon because it has social effects. It is named by people in the social world and is lived by people in the social world. Theory of Mind on the other hand reduces autism to a modular brain function" (Marinan, 2017, p. 578).

The fact is that non-autistic people are also often misguided in their attempts to assume others' states of mind. We only *think* we know and this effort is made to make sense of the world around us rather than the result of any innate human capacity to perceive other's thoughts, motives, or intentions. No person can read the thoughts of others. We are all blind to the minds of others. This is an important ontological difference between a sociocultural approach and a psychopathological approach (Milton, 2012).

Milton centers the critiques of ToM on their implications and positioning of autism as a disorder of empathy and self. He states, "It has been suggested that a theory of mind and empathy are essential to that which makes humans what they are. Thus, the characterization of autistic people lacking such abilities suggests that they are somewhat

less than fully human and when linked to criminality and cruelty to others brings back images of the 'atavistic criminal" (Milton, 2014; Lawson, 2010). It is argued that depicting autistic people as 'lacking empathy' is an inaccurate and dangerous narrative to pursue. Implications of Theory of Mind include what Milton has called the *myth of no empathy*. No studies have explicitly focused on the narratives of the socialization experiences of autistic people or sought to validate autistic experiences of self.

Milton (2013) takes issue with Simon Baron-Cohen's essentialist view of ToM and its associated lack of empathy, arguing that autistic individuals do not lack empathy. Arguing that ToM rests on an inadequate assumption of the meaning of empathy, Milton states that, "empathy is a convenient illusion, and the phenomenon that people speak of when referring to it has more to do with language and a sense of 'shared' cultural meanings/ and symbols" (Milton, 2013) Relying on Garfinkel's concept of "filling in the gaps," Milton acknowledges that autistic people are often more literal, relying on available information rather than "filling in the gaps" with their inferences and interpretations of social acts that contribute to smooth social interactions. This supports Durig's observation that autistic people tend to use deductive rather than inductive logic. However, Milton suggests a difference in stock-knowledge rather than autistic individuals lacking the abilities to empathize or understand their minds or those of others. He suggests the existence of a *double empathy problem*.

If autism produces unique cultural ways of being, it is not just that autistic individuals do not understand neurotypical (non-autistic) styles of communication, it is also that neurotypical people lack the ability to understand and empathize with autistic styles of communication. Relying on Garfinkel, Milton suggests that autistic differences

in "mindreading" are a result of their differential socialization because autistic minds process information and thus perceive the social order in idiosyncratic ways. *Ethnos*, according to Garfinkel, refers to the availability to an actor the *common-sense* knowledge of a society. Thus, because of differences in perception, the world makes sense in a different way so that "autistic individuals can be described as inhabiting a unique and different *ethnos* than neurotypical people" (2013). This parallels the research by Davidson that lends support to the notion that autism produces a distinct communication styles and cultural experience.

According to Dinishak and Akhtar, use of the term mindblindness "obscures the nature of communication, creates negative connotations, influences neurotypical ascriptions of autistic behavior, and blurs the line between deficit and difference" (2013, p. 111). Marinan describes this rhetoric as relying on metaphor, specifically language that implies autistics *lack* (2017; see also Coleman-Fountain, 2016). Maguire and Michalko suggest that scholars "treat autism as a teacher and thus as having something valuable to contribute toward and understanding of the inherent partiality and uncertainty of human communication and collective life" (2011, p. 162).

Additionally, Milton calls attention to the social construction of normality and cultural patterns of interaction that when violated results in unsuccessful social interactions. The result is that autistic patterns of interaction and communication have been stigmatized and labeled as deviant. While it is widely acknowledged that autistic selves are atypical, the argument has been made that it is essentialism and rhetoric that classifies autistic ways of being as inherently deficient rather than (neuro)diverse.

From a microsociological perspective, developmental psychology and the concepts of ToM and mindblindness suggest that individuals on the autism spectrum "suffer" from an inability to "take the role of the other," a phenomenon that is critical to the sociological understanding of the development of self and processes of interaction. However, this is not to say that ToM and role-taking are identical concepts by different titles.

Franks (2012), in his *Handbook of Neurosociology* suggests that the key difference is that role-taking positions Mead's concept of the "act" as the unit of analysis which "stresses interactional processes that ToM does not necessarily do" (2012, p. 28). Citing a study by Thomas (1972), Franks further notes that maintaining the boundaries between ToM and role taking are important because role taking emphasizes interpersonal resources while ToM emphasizes "those stemming from one's personal capacities." He argues that this distinction is necessary because role taking is a distinctive sociological concept, but that ToM is useful because it can guide researchers to "the important places in the brain where a neurosociologist might look for correlates of role taking." However, role-taking is observed in interaction.

I posit that it is not necessary to search the physiology of the brain for "proof" of what has been and can be observed in interaction. Mead makes it clear that mind and self are social processes and this is why role taking focuses on the act. Studies of role taking have been researched and replicated while ToM is suggested to be both unreliable and difficult to replicate (Kulke et. al., 2015). Role taking nor perspective taking as concepts are a contested terrain while ToM is because the discourse surrounding it is linked to the "normalization of the psycho-emotional disablement of autistic people" (Milton, 2012).

As we have seen, the implications borne of ToM which render autistic people as less-than is largely supported by physiological and experimental psychological research. What differences, if any, can be seen with the application of a sociological framework particularly when autism is disentangled from other comorbid diagnoses? What insights can be gleaned by positioning autistic actors as the experts on their own experiences of self and interaction?

Chapter Three: Symbolic Interactionism and the Self

Both psychological social psychology and symbolic interactionism (SI) offer theoretical models for the development of selves. From an SI perspective, though genetics and biology underpin consciousness, people are not born with selves; selves are a product of social processes. Unlike psychological social psychology, SI is theoretically equipped to examine differences in development through the lens of social constructionism. To early sociological social psychologists, understanding self-development was of interest as an essential component of the process of socialization and the relationship between individuals and society. SI holds that the self and the social cannot be separated. SI scholars, as a basic tenet of the perspective, take the "social act" rather than the self as their primary object of analysis (Hewitt, 2007; Mead, 1934). Since the selfhood of autistic actors has been problematized, the current study will focus on the experiences of self of autistic actors from their own perspectives and in their own words.

It is interesting to highlight that both psychological social psychology and SI understandings of the phenomenon we call a self can be traced back to William James. Yet, modern psychology and neuroscience have taken a course that seeks to link our

experience of self to specific neuroanatomical sites and processes. This *reification* or *naturalization* reduces the phenomena of the self to specific regions, structures, and processes in the brain that deviate from a statistical norm (Kircher and David, 2003). Within the larger medical discourse, the focus has been on pinpointing and curing perceived deficits that are deemed pathological. This effort has so far been fruitless in terms of improving the lives of autistic people.

In contrast, symbolic interactionism "avoids distorting our diverse human natures in particular and narrow caricatures, but is also one that respects and emphasizes the value of theoretically guided empirical inquiry as of the best hopes of humankind for creating a better world" (Hewitt, 2007, p. 233). However, the difference between a sociological social psychology approach and psychological social psychology approach are often confusing and difficult to grasp. This section will outline the distinctions between the two approaches and explain what a symbolic interactionist approach to autism has to offer.

Peggy A. Thoits (1995) reminds us that we cannot expect psychologists to adequately explore theoretical processes that are uniquely sociological because "people's thoughts and feelings and behaviors are also explained by relational dynamics or mechanisms such as the social construction of reality, the formation of change in normative expectations, the ability to take the role of the generalized other, and the exercise of power, prestige, and authority" (1995; p. 1240). She states that the difference between psychologists and sociologists is that the former looks at intervening cognitive mechanisms and ignores the contextual and constraints of actors while sociologists are

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most likely to prioritize these variables which, from a sociological perspective, are necessary to explore key features of social psychological phenomena.

Moreover, cognitive psychology focuses on how people store and process information, which has been the fashionable and most common approach to the study of mind giving rise to Theory of Mind that has influenced basic assumptions and lines of inquiry. Psychological social psychology has sought to examine the influence of others yet consistently overlooks important factors such as status or social standing, that is, the relationship of selves to others.

On the other hand, sociological social psychologists and symbolic interactionists in particular "inspect the influence of specific and generalized others on the thoughts and feelings and behaviors of the individual—and their influence on specific others in the social order" (Thoits, 1995). Symbolic interactionism is able to focuses on actor's structural relationship to the environment, generalized expectations and norms that influence how we interpret autistic actors, how autistic actors are influenced by norms, and "the mechanisms through which the individual and society are mutually influenced" (Thoits, 1995; p. 1233).

Interestingly, psychologists have studied key symbolic interactionist processes such as role taking, interpersonal perceptions, impression formation and management more extensively and explicitly than sociologists (Thoits, 1995). For example, psychological social psychologists have distinguished between cognitive and empathic role taking and the different effects of these abilities on moral development (Thoits, 1995; Choplan et al., 1985; Kaplan & Arbuthnot, 1985). It is much less common for sociologists to prioritize uniquely psychological concepts.

The point is that sociologists and psychologists have different methodologies and different agendas. For Thoits (1995) the key distinction of a psychological perspective from a sociological perspective in social psychology is (1) psychology's pursuit of explanatory processes and (2) the lack of attention to status characteristics, role, relationships, and organizational or hierarchical concepts (1995, p. 1240). Therefore, even though social psychology is broadly characterized by an interplay between sociological and psychological concepts and similar topics of interest such as socialization and the self and identity, they illuminate different aspects of social phenomena.

When it comes to socialization psychological approaches are oriented toward child development and moral development. This partially contributes to the over representation of children in studies of autism which is often not generalizable to adults. Sociologists studying socialization tend to focus on processes of adult socialization such as gender socialization, age socialization and role appropriate behavior as well as the sources of socialization and transitions through the life-course (Thoits, 1995). Psychologists focus on details of how people learn. Sociologists focus on what they learn, i.e., what norms are learned and from whom (Thoits, 1995; Hochschild, 1983).

When it comes to the self and identity, psychologists typically focus on cognitive self-related processes, self-enhancement, and self-consistency. The use of brain imaging and experimental conditions reflects the "cognitive thrust" of the psychological discipline in general. In contrast, symbolic interactionists view the self as a social process and assume that enhancement and consistency are natural parts of human behavior (Thoits, 1995). This shifts their focus to the influences of social contexts and their effect on the

contents of the self such as self-efficacy and self-esteem and how selves and identities

function in interaction (Thoits, 1995).

To summarize, we have seen that psychological studies of autistic selfhood have

led to conclusions of impairments and deficiencies that often contradict each other as

well as other studies in different disciplines, but most importantly the experiences of

autistic people. From a symbolic interactionist perspective, it may be possible to refute

contested psychological notions of the nature of autism and autistic experiences. More

important, a distinctly symbolic interactionist perspective is equipped to prioritize both

social context and autistic experiences of self and how actors interpret the social world.

This contrasts with psychological approaches which positions experts who interpret

autistic experiences.

To frame a symbolic interactionist view of what a self is, how selves develop,

what it means to have a self, and how our mind and self shapes interaction, discussing

several concepts developed by William James, Charles Horton Cooley, George Herbert

Mead, and Erving Goffman is necessary.

Autism and the Self: A Sociological Application

The "I" and the "Me"

We often think of the self as something inherent in the individual. Many people

understand the "self" as an immutable core component of a person that is relatively

stable. Symbolic Interactionism offers a distinct view of the self as a process that actors

create and recreate through verbal and nonverbal interaction. William James first

articulated the conceptualization of the self as consisting of two parts, the "I" and the

"Me." The "I" facet of the self-process is the self as *subject.* The "I" is that which

interacts with our environment and others and responds to stimuli and situations. The "Me" is the facet of the self-process that is the self as *object*. We can imagine ourselves in interaction and, during thought and introspection, interact with our self. What we call the self is the process of the "I" and "Me" not as entities, but as states of consciousness that allow us to control our conduct (Hewitt, 1976).

For Mead, the mechanism for the development of self is reflexivity. We can take ourselves as an object and then evaluate ourselves—we respond to and act on ourselves like we do any other object. Mead demarcates his theory from other psychological conceptualizations of the self by embedding it in our social experiences and processes. It is important to point out that various sociological and postmodern scholars have argued that there is no self at all and that no one has a self (see Immergut, 2014 for a *sociology of no self*); yet, that is beyond the scope of the present discussion. Interestingly however, Mead did assert that no person can ever experience themselves directly—we are always without exception viewing ourselves from the perspective of *other*.

Beyond the process of the mind and self, Mead saw the "I" specifically as related to the larger social world in four important ways (Ritzer & Stepinsky, 2014):

1. The "I" is the source of novelty in social processes
2. The "I" is key to understanding our most important values
3. The "I" permits us to develop individual personalities
4. Mead saw an evolutionary process in history in which primitive societies are dominated more by the "me" while in modern societies there is a greater component of the "I"

Without the "I" component in the self-process actors would be completely dominated by external social controls. The concept of the "I" permits us to examine the role of agency in social change, both by individuals in their daily lives as well the larger

changes brought about by important historical figures. Could it be said that autistic

people are more influenced by the "I" than the "Me"?

Mead believed that our own biographies and personalities shaped the relationship

between each individual's "I" and "Me" such that each person is a unique mix of both

components where one never really dominates the other but at the same time are not

equal in influence. The *generalized other* is housed within the "Me" and Mead

characterized it as "conventional and habitual" (1962, p. 197). He believed that while all

people must balance conformity and individuality, conformists are dominated by the

"Me" and that it is through the "Me" that society dominates the individual. In fact, Mead

defined social control as the dominance of expression of the "Me" over the "I" (Ritzer &

Stepinsky, 2014). Mead added that some institutions are designed to stamp out

individuality. He cited the church. In the case of autistic actors it is all the institutions

within society that attempt to stamp out autistic ways of being, particularly the medical

and psychological communities who, through Applied Behavioral Analysis (Lovaas,

1965) attempt to force autistic people to conform to neurotypical sociality or else live a

stigmatized life.

The Looking-Glass Self

Unlike psychological social psychological theories of self-development,

symbolic interactionism views the self as a process that develops through interaction

rather than as a result of physical maturation. If we are not born with selves and they are

not biologically triggered at a particular developmental stage what is the process that

produces selves? To answer this question Charles Horton Cooley developed the concept

of the looking-glass self (1902).

For Cooley, children develop a sense of self through their interactions with adults and peers. He believed that through a three-step process we each learn to imagine ourselves as we believe others see us. The first step in the process is the phase where we imagine how we appear to others. The second step in the process is when we imagine how they would judge us. The final phase of the looking-glass process is when we feel some sort of feeling or emotion based on these imagined judgements.

For example, if we reflect on ourselves and believe that others would view us as unkempt, we may feel shame. Likewise, if we imagine that someone viewing us speaking in the front of the class as competent and prepared we are likely to feel feelings of pride. Cooley's looking-glass theory posits how actors perceptions of parents and others reactions to them can shape our sense of self based on what the actors believe they think. Cooley also points out that there is no self without others—that we all come to know our selves through the reflections found in interaction. This theory highlights how society shapes how we see ourselves and how actors desire to influence the way they are seen by society.

Previous research by Cage, Bird, and Pellicano (2016) used semi-structured interviews to explore the degree to which autistic adolescents are concerned about how others view them, i.e., their reputation. Their results revealed that participants were concerned with their reputations however, many reported that they were not interested in being "cool," struggled to understand the so-called rules of being "cool," and preferred to be authentic or "true to themselves." Their study also collected information from select school staff who could confirm information about the students' friendships and their reputations. School staff confirmed that autistic students are attuned to what others think

of them, are concerned with what others think of them, and are aware of and attempt to control their reputations (Cage, Bird, Pellicano, 2016). Some students expressed the knowledge that they were "different" and that they wished to have these differences accepted—that is, they wanted a reputation acknowledged as different.

Little if any research has solely focused on autistic self-perceptions, a gap which the present study seeks to fill. However, some research has shown that autistics are concerned about forming and maintaining friendships. Of note, this contrasts with the dominant view of autistics as inherently antisocial. Milton contends that, contrary to medical discourse and public opinion, autistic individuals are interested in and do desire friendships and intimacy but may lack the skills to develop social bonds (also see Bauminger, Cory, and Agam, 2003.) For example, Sebastian, Blakemore, and Charman (2001) concluded that autistic individuals are sensitive to and affected by social rejection resulting in low self-esteem and anxiety that further complicate and negatively affect future social interaction. This and similar studies suggest that autistic individuals do experience the looking-glass self. They are sensitive to the real and imagined opinions of others and do takes steps to adjust their behavior in hopes of social inclusion and success. Furthermore, comments from respondents in the Cage, Bird, and Pellicano study who wished to be seen as their authentic self lends credibility to the contention that autistic people have an internal sense of self that they know differs and is valued differently from the perspective of others. This particular point was also demonstrated by Coleman-Fountain (2017) in his study where autistic actors described themselves as "faulty" and sought different strategies to manage social discomfort caused by difficulties in interaction.

Role Taking

George Herbert Mead outlined what would become the symbolic interactionist theory of self-development as a cognitive and social process that most all people progress through in early childhood (Mead, 1934). His theory involves the passage through three stages (preparatory, play, and game stages), which culminates with the development of *the generalized other*.

During the preparatory stage children cannot distinguish self and other. Their experience of self is limited to imitating the behaviors of others. The play stage is marked by the learning of the ability to take the role of specific, real or imagined others and acting as they would act. Children may imitate a parent shaving, a parent cooking, or a sibling talking on the phone. They also engage in fantasy play and pretend to be queens, astronauts, or ship captains.

At this stage, children can only play a single role at a time (Mead, 1934). Often children switch roles— they are unpredictable, inconsistent, and unorganized. Mead believed that play is how actors learn to indicate to themselves and respond as others would. As children gain experience through play, their interactions became more complex and eventually they take on multiple perspectives. This is how actors gain a sense of a self.

The game stage involves learning to take ourselves as an object and viewing ourselves from the perspective of others. Games differ from play in that games are regulated by several rules and the actor must consider multiple expectations and perspectives of others. This is a skill. Mead called it "advanced role taking capacity."

Taking the role of several others leads to the development of the generalized other—or the perspectives and expectations of a network of others or the community as a whole.

Role taking involves the ability of assuming the perspective of others. When children can assume the perspective of others their awareness has increased and they are now able to consider and take into account the roles of others. Not to be confused with Theory of Mind, role taking is *not* about understanding individual states of mind but rather the actions and behaviors associated with the given *role* an individual occupies at a given time. Eventually children internalize these roles and begin to understand the sets of standards accompanying the culture in which they are socialized. They begin to take the perspective of the *generalized other*. This enables them to evaluate their own behavior according to these standards as well as to predict the behaviors of others.

Norman K. Denzin (1971) and Tomatsu Shibutani (1962) expanded upon Mead's theory of socialization in two important ways. First, Denzin emphasized that Mead intended no age sequence of the play and game stages. Some people may never progress to the stage of the generalized other. For Denzin, the self-development of children was dependent upon their "interactional age" which is linked to their interaction experiences. Shibutani points out that we do not simply internalize every perspective and detailed expectation of our culture such that actors possess a single, stable generalized other. The perspectives and expectations that we consider, according to Shibutani, are entirely contextual. Throughout the process of socialization we internalize many different *reference groups* and dependent on the situation, actors reflect on themselves according to the standards of a certain group.

In their study *Specificity, contexts, and reference groups matter when assessing autistic traits* Gernsbacher and colleagues concluded that "autistic participants are well equipped not only to self-report on their own traits, but also to self-report on their traits in different contexts and to self-report on how others view their traits" (Gernsbacher, Stevenson, & Dern 2017, p. 24)

Their research "join(s) other bodies of empirical evidence that argue against the popular, but empirically weak, assumption that autistic people lack a theory of mind." Moreover their data illustrates that both "autistic and non-autistic people's difficulty in interaction and communicating is contextually specific as both groups reported easier interaction with their in-group." They note that their research has important implications for accurately assessing traits and for designing environments that enable successful interaction and communication." (2017, p. 25).

Socialization and Self-Presentation

Goffman saw the self as a performed character—a representation, not an organic thing. He believed that the self "arises diffusely from a scene that is presented" and notes that "the crucial concern is whether it will be credited or discredited." For Goffman, authenticity is rooted fundamentally in how we act and how others respond to those actions as "having others think well of us means they will respond to us positively, defining us as worthwhile, appropriate, and desirable social actors." It also means they will be more likely to accept our projected *definition of the situation* and to "support our involvement in a variety of desired activities thus enhancing our social power and personal freedom."

As previously mentioned, Yergeau has explicitly illustrated how rhetoric and discourse surrounding autism discredits individuals on the spectrum in interactions with non-autistic people, in her case, resulting in hospitalization against her will. Her social position as an autistic person made her communication problematic and her perspective untrustworthy, which denied her personhood in interaction. Denzin points out this same issue when children, the mentally ill, and the elderly are examined (1978, p. 60). In Goffmanian terms, *discredited*.

Goffman emphasizes that we implicitly and explicitly announce our identities in a situation through our expressive behavior, costumes, and props. Goffman proposed that these aspects (setting, appearance, manner) give others useful clues about who we are, what role we are likely to play in a situation, and how they *"should* define and respond to us."* For example, in the biographic film of Temple Grandin, Ms. Grandin arrives on her aunt's farm and mentally takes note of a man. His boots, belt-buckle, hat, spurs, and chaps are signals to her of the individual's identity. She exclaims, "Are you a cowboy!" She is scoffed at by others present and her aunt quickly corrects her and changes the subject, implying that Temple has made a social faux pas. Why is this man not cowboy? To Goffman and to Grandin, all the signs and symbols were there, and Grandin made a logical conclusion yet was still regarded as a problematic actor.

It is also possible to examine how autistic actors present themselves. Scheeren and colleagues (2010) compared the self-presentation abilities of children and adolescents with Autism Spectrum Disorder to those of neurotypical children in real and hypothetical social contexts. In their study participants were asked to introduce themselves (without incentive) to the interviewer. This served as the baseline. For the real self-promotion task,

participants were motivated with a prize incentive. For this task the interview told participants, "A couple of children who participate in this study can enter a game where you can win lots of cool prizes. To determine who should be picked for this game with the prizes, I ask everyone to tell me something about him/herself" (2010, p. 651). To determine motivation each participant was asked to rate "how much fun" they thought the game would be on a 5-point scale. For the hypothetical self-promotion task, interviewers gave respondents the following vignette: "Imagine that you have new neighbors. You have heard that your new neighbors are looking for someone to do small chores in and around the house and they are willing to pay a lot of money for it. You can think of lots of nice things to spend that money on. Now you meet your neighbor for the first time and he/she introduces him/herself to you. What would you tell him/herself about yourself" (2010, p. 652).

The results demonstrate that participants with and without ASD increased their positive self-statements when they were motivated by a prize in the real task or a job/money in the hypothetical vignette. Importantly they note, "we did not find uniform support for a reduced strategic self-presentation in ASD." Children with ASD (6-12 years) equally expressed strategic self-statements during self-promoting as their typically developing peers both in real and hypothetical social contexts. (2010, p. 655). Moreover, "after controlling for verbal IQ differences children with ASD showed a tendency to be even more strategic than the typically developing group in the real social context" (2010, p. 655). Lastly, the study found that symptom severity, or the functioning labels of 'high' or 'low', "was not significantly correlated with strategic self-statements during self-promotion" (2010, p. 655). This study suggests that not only are autistic individuals able

to calculate a self-presentation sensitive to setting, appearance, and manner but sometimes can present themselves in a way that is *more* successful in promoting a favorable, i.e., an image of their self-credited in interaction that is responded to positively by others. In sum, studies such as this demonstrate that alternative theories beyond Theory of Mind, which immediately discredits autistic actors, are needed to fully understand autistic self and interaction.

When social selves are stigmatized, such as the case of disability, this may become the primary identifying characteristic, or what Hughes (1963) deemed a *master status.* Similarly, Goffman notes, "The lifelong attributes of a particular individual may cause him to be *typecast*; he may have to play the stigmatized role in almost all of his social situations, making it natural to refer to him, as I have done, as a stigmatized person whose life-situation places him in opposition to normal" (1963, p. 138).

An autistic person's self-perception, self-concept, and self-presentation are all autistic because autism cannot be disentangled from their physical body and social identity—the self in the situation is autism embodied and thus, influences their own perceptions of themselves and any interaction in which they engage. Due to the nature of autism and the stigmatization of autistic sociality, most, if not all non-autistic people view autistic people in terms of social deficits. The result is that fewer people allow themselves to recognize the individual within the diagnosis to acknowledge their humanity and personhood. Symbolic interactionism highlights how non-autistic people see a stigmatized person as opposed to someone with an alternate communicative, interactional, or perceptual style.

Stigma management is described by Goffman as "an offshoot of something basic in society, the stereotyping of 'profiling' of our normative expectations regarding conduct and character" (Goffman, 1963, p.51). He saw *stigma management* as a continuum between public life and interpersonal relationships. This view allows us to see that when autism is understood as a disease and something that should be eradicated this discursively renders autistic people as something less than human. Social differences are not to be accommodated but corrected or removed from the social world, which over the past has led to institutionalization and violence against autistic bodies and spirits by doctors, educators, parents and parents through the search for a cure and the application of Applied Behavioral Analysis.

To Goffman (1963, p. 103-104) a stigma is "anything which interferes directly with the etiquette of mechanics of communication obtrudes itself constantly into the interaction and is difficult to disattend genuinely." Thus, stigmatized individuals "may have to learn about the structure of the interaction in order to learn the lines along which they must reconstitute their conduct if they are to minimize the obtrusiveness of their stigma." Important to microsociology, he goes on to say that "one can learn about the features of interaction that might otherwise be too much taken for granted to be noted" which parallels the angle of other scholars undertaking a microsociological approach to autism studies beyond advocacy research (see Maynard). This further demonstrates the value of a sociological approach to the study of autism.

Moreover, Tyler (2018) describes how research on stigma "often side-lines questions about where stigma is produced, by whom and for what purposes" and ignores the political and social aspects of stigma, namely "how stigma is used by individuals,

communities and the state to produce and reproduce social inequality" (Tyler, 2018;

Parker & Aggleton, 2008). Tyler notes that a major concern is "rethinking stigma as a

'bureaucratized form of violence" (Tyler, 2018; Cooper & Whyte, 2017, p. 3). For Tyler,

one of the central aims in rethinking stigma is to center class and race within the study of

stigmatization to see it as a "classificatory form of power." The present study seeks to

extend this rethinking of stigma to neurodiverse peoples as a cultural community subject

to similar functions of power and control.

Similar to stigmas surrounding mental illness, efforts to reduce stigma by

emphasizing the biological over the social and cultural "veils over a whole host of more

fundamental, cultural, political and economic questions regarding the distribution of

distress" as it paints autism as beyond one's control (Tyler, 2018; Davies, 2017; Davies,

2016). When it comes to the prevalence of "success stories," both in the public discourse

of mental illnesses such as depression and here extended to the stories of autistic people,

Tyler points out that individualized stories "airbrush out" important sociological

questions about the causes of distress. To clarify, mental illnesses such as depression and

anxiety can be linked to larger social forces. In the same way, autism is named in the

social world and constitutes "arbitrary lines drawn in the sand between what constitutes

normality and psychiatric (or indeed neurological) deviance" (Milton, 2014, p. 3).

Aside from any individual cognitive difficulties in inferencing and social

interaction, autistic people find themselves functioning as stigmatized individuals "unsure

of the reception waiting them in face-to-face interaction" where they are subjected to

evaluations based on what Goffman referred to as a "virtual middle class ideal." Goffman

notes that "when we interact with strangers or intimates, we will find that the fingertips of

society have reached bluntly into contact, ever here putting us in our place."

Neurodiverse people such as ASDs and ADHDs communicate and perceive the world

differently and therefore interact with the world differently as a result.

Autistic ways of communication are routinely described as "odd" or "bizarre" and

therefore stigmatized. Any deviance from norms of perception is stigmatized. More

succinctly, autistic people are often misunderstood whether or not they are actively

engaging in stigma management—a double-edged sword. Autistic ways of

communication with others and the physical world have been perceived by police as

mentally ill to the point of arrest and even death. Goffman notes that stigmatized actors

"effort(s) to conceal may cause him to display other ones or give the appearance of doing

so: slovenliness, inattentiveness, stubbornness, woodenness, or distance, sleepiness seen

as day dreaming, drunkenness (1963, p. 85). Different ways of communicating can be

perceived as uncouth, uncivilized, "lying," "not making sense" or "mental illness,"

"egocentrism," or as suggested by Theory of Mind "lacking empathy."

Sticky Situations: The Autistic Self in Interaction

The social world for autistic people is dominated by non-autistics in their home,

school, and workplace. Only in extremely rare events are autistic actors ever in the sole

company of other autistic people. The neurotypical perception is that autistic people are

unable or impaired in their abilities of social bonding as demonstrated in the discourse

surrounding autism (Sinclair, 2010; Coleman-Fountain, 2017). Due to the assumptions

and contributions of ToM, people labeled autistic are discursively rendered *mindblind* and

thought of as having 'faulty' neurological and cognitive functions that result in supposed

reductions of emotional capacities and empathy.

Coleman-Fountain highlights that rhetoric such as "alone," "living in their own worlds," and "trapped inside a shell" are each spatial metaphors that reinforce a distance from "normal and ordinary" and "invoke notions of autistic separateness" (2017, p. 9). Coleman-Fountain (2017) drew upon Scully's (2010) metaphor of *stickiness* in interaction to reframe autistic sociality as having a property of inequality. He likens this concept to Milton's *double empathy problem* and discusses how the responsibility to manage interactions is placed on autistic actors to pass as neurotypical. Coleman-Fountain notes that Scully's metaphor "illuminates autistic people's efforts to avoid discomfort in interaction" (2017, p.9; McLaughlin, 2017) and his study examined the management of negative responses in autistic and non-autistic social encounters using the metaphor of *stickiness* to "acknowledge (autistic) sociality, non-autistic social power, and the relationality of social 'dysfunction'" (2017, p. 9).

His results demonstrated that autistic actors often described social discomfort as "awkward" which they considered a typical and pervasive facet of interaction. Many respondents in Coleman-Fountain's study described feeling embarrassed or awkward when social communication "broke down," feeling nervous, and lacking confidence in interaction particularly with new people.

Unlike embarrassment resulting from the breakdown in communication between non-autistic actors, for the respondents, these feelings were attributed to being autistic by both autistic individuals and non-autistic people—that is to say "autism directly contributed to awkward encounters" by undermining their success in interaction (2017, p. 13). Coleman-Fountain discovered the following themes when respondents discussed their encounters with non-autistic people: misunderstandings, failure of non-autistic

people to try to understand their point view and being made to feel 'weird'—each of which suggest a power imbalance. However, power imbalances occur frequently in encounters between non-autistic actors since power is a facet of all interaction (Hocker & Burton, 1985).

Importantly, Coleman-Fountain describes how autistic young adults do often see themselves as "faulty." He examined their attempts to manage difficulty in interaction by attempting to improve their communication skills to avoid being perceived as "weird" (Coleman-Fountain, 2017, p. 14; Brownlow, 2010). In many ways the strategies used parallel the efforts of non-autistic actors to reduce or avoid social discomfort. One way of doing this was to avoid places or seek out alternative spaces where they could be more comfortable—in other words, to isolate themselves. Other methods included bringing a friend along, reading books on social interaction to improve their own communication skills, self-monitoring during interaction, and reflecting on what worked in the past and what resulted in unsuccessful interaction. He points out two key facts: (a) autistic people seek to adapt to the social world, not adapt the social world and (b) this is form of hidden labor (see also Scully, 2010) to reduce social discomfort, feelings of failure, negative judgements, and misunderstandings that have the potential to disrupt autistic actors' daily lives.

Additionally, Coleman-Fountain suggests that autistic actors were accustomed to and expected *stickiness* in their encounters with non-autistic people. They anticipated unease because they routinely felt scrutinized and judged during interaction. These fears of failure and judgement fed into their self-monitoring and heightened their concerns for sociality, which they all considered important to their life but struggled to develop or

succeed at. Therefore, it is crucial to acknowledge the inequality in autistic and non-autistic interaction and explore how we can emphasize autistic differences in sociality and disposition to reduce the likelihood of *sticky encounters* rather than leave the onus of self-improvement on autistic actors. Coleman-Fountain suggests that this can be done by "finding ways in which non-autistic people can learn about autistic peoples need for recognition, comfort and care which non-autistic and autistic encounters can deny" (2017, p. 15). From a methodological perspective this means that we must center first-hand accounts of the experiences of autistic people.

Chapter Four: Methods

Intended Study

Most psychological social psychology and neurological theories and research of the self and its development center on a model of a deficit and disability and have focused on autism as a "disorder of self and understanding" (Zahavi, 2010, p. 547). There has been a reluctance to include autistic voices in research and little effort has been made by researchers to consider the autistic perspectives of self and interaction. This study seeks to illustrate how symbolic interactionism can provide an alternate framework to pragmatically, as opposed to clinically, evaluate autistic experiences. The aim is to point

out that from a symbolic interactionist perspective autistic people have a self as opposed to Theory of Mind which suggests critical impairments hinder the development of self.

Participants

IRB approval was obtained from Western Kentucky University. Purposive sampling was utilized to collect data from individuals who have been identified as autistic and can verbalize their perspectives. Permission was obtained from the directors of two student resource centers for students diagnosed along the autism spectrum at a state university to distribute a flyer requesting volunteers. Five of the twelves respondents in this study were recruited through the university. Initially the paper flyer was tacked onto various, presumably high-traffic spots on campus. After several months the director of one of the student resources was contacted and determined that providing the researcher with the opportunity to inform students entering and exiting the center about the study and invite them to volunteer. The remaining seven respondents replied to a digital copy of the flyer that was shared on three different social media sites from the researcher's personal accounts. The flyer was available online for four months prior to the end of data collection and is currently still available. It is impossible to determine how many people saw the flyer online. Fourteen people contacted the researcher and expressed interest but ultimately did not participate due to scheduling conflicts or reasons not disclosed to the researcher. To meet the criteria volunteers were required to be over the age of 18, a current or former university student, and must have sought a diagnosis or been diagnosed with an Autism Spectrum Disorder by a licensed clinical professional. All participants were asked to read and sign a consent form, included as APPENDIX A.

Participants were invited to participate in a review of the write-up; all participants declined this opportunity.

Data Collection

This study collected data from 12 adults on the autism spectrum through individual in-depth qualitative interviews. Interview questions were open-ended and focused on aspects of social life including experiences in institutions such as the family and school, as well as, agents of socialization including friendships, play, and various forms of media. All face-to-face interviews were audio recorded with participant consent and transcribed verbatim. The average length of interview conducted in person or video was approximately 1.5 hours. Interviews conducted via chat or email were digitally logged. The transcripts from these interviews provide the raw data for this study.

Instrument

Interview questions were developed to assess autistic perceptions of self and experiences associated with socialization. Symbolic interactionism holds that selves develop through interaction. A classic instrument used to evaluate the self was Manford Kuhn and the Iowa School's Twenty Statements Test (TST). This test was later simplified (McPhail and Tucker, 1972) by asking the single question "What should I say about you? If someone asked me who you were, what would you want me to say?" This is the first interview question in the present study. The adaptation was selected due to its conversational nature in lieu of the standardized assessment format of the traditional TST.

Subsequent questions were designed to elicit narrative data about socialization experiences and perceptions of self and others such as parents, educators, friends, and community members. College students were chosen because they could talk about their

experiences in public education as well as the transition to college and adulthood thus, the sample was limited by class and education. Respondents were asked to reflect and recount "important events that they would never forget" from their life. This line of inquiry was framed to recall events from early childhood ("Who took care of you when you were young?" and "What are your first or earliest memories?"), elementary school, middle school, high school, transition to college and adulthood, and hopes for the future ("Where do you see yourself in five years"), and what they wish non-autistic knew about autistic people. This allowed me to examine autobiographical life-course accounts of current and former college students who identify as autistic. Other purposeful interview questions include an important turning point in the moral career of an autistic person, the experience of diagnosis. The guide is included as APPENDIX B.

Analysis

Symbolic Interactionists have long advocated a naturalist strategy to the study socialization; researchers collect behavior specimens (Barker, 1968) to reproduce the experiences, thoughts, and language of those under study. By reproducing these experiences, a rich array of data can be analyzed to determine what forces individuals see as influencing and shaping their behavior (Denzin, 1977). A qualitative, inductive approach is purely data driven. The researcher investigates emergent patterns in the data, which in this study are the interview transcripts. Limiting the study to the exploration of how social experiences and self are perceived by autistic persons positions the respondent as the expert on their own experiences. This is important, as we have seen that autistic voices have been misrepresented in the literature.

Analysis of data utilized Smith, Flower, and Larkin's (2009) method of Interpretive Phenomenological Analysis (IPA). Interpretivism is an epistemological position that requires the social scientist to grasp the subjective meaning of social action (Bryman, 2012). IPA is a phenomenologically focused approach that collects "detailed, reflective, first-person" accounts from respondents (Larkin & Thompson, 2012). IPA requires open research questions and does not test hypotheses or build theory; it is used to "open up a dialogue with extant theory" while engaging with theoretically informed questions.

IPA has previously been used to examine how autistic individuals made sense of their diagnosis and thus, diagnostic label (Macleod, Lewis, & Robertson, 2013). Therefore, it is well suited to extensive interviews while positioning the respondent as the expert on their own experiences. This is important, as we have seen that autistic voices have been excluded from knowledge production in clinical and theoretical interpretations of autism (Milton, 2014).

Symbolic interactionism does not currently provide enough information to fully explicate how perceptual and communication differences may alter socialization, leading to differential paths or processes of self-development in terms of autism compared to neurotypical development. However, symbolic interactionism holds that individual's self-development is unique based on culture, personal biography, and the intersections of race, class, and gender. If we add autistic perception as another facet impacting experience, it is only through qualitative analyses such as autobiographical accounts of autistic actors or ethnomethodology and phenomenology that non-autistic people can begin to understand the interactional impact of neurodiversity from an autistic standpoint. A qualitative

interpretative analysis fits this study as it allows us to begin to formulate a new area of SI—a microsociological theory of autism. This may broaden SI theories of self-development, socialization, stigmatization, and interaction so that they are applicable to neurodiverse perceptions and ways of being.

Glaser and Strauss (1967, p. 255) note that it is important not to simply elaborate on an existing theory because this often leads to the suppressing of "rich data as well as potentially rich insights that could transcend the theory." Because SI is based on the perception and experiences of non-autistic individuals, a study of autistic self and socialization experiences should qualify the theoretical foundation of symbolic interactionism by pinpointing differences between non-autistic and autistic sociality. Simultaneously, it should support the theory by underlining similarities between non-autistic and autistic experiences of sociality, socialization, and self.

Analysis of data will specifically relied on symbolic interactionist themes and theories of self-development as it is the dominant perspective toward the self in sociology. Analysis included two types of coding, substantive and theoretical. According to Glaser (1978, p. 165) substantive codes fracture the data into bits and pieces while theoretical coding integrates the substantive coding to "weave the fractured story back together again [into] an organized whole theory" (1978, p. 165). Substantive coding determined the general category that an item represents. Theoretical coding specifically relied on linking sociological themes and theories of self and interaction to the illustrative examples emergent in the autobiographical accounts of the respondents.

Chapter Five: Findings

Most people have an "underlying sense of who you are—a sense that does not change dramatically from one situation to the next" but this is merely a sense. Our understandings of any 'real' or 'essential' self is (a) grounded in and confirmed by social experiences with others in a comfortable and seemingly natural way, and (b) social experiences that do not make you feel comfortable or genuine (Denzin, 1978). Due to neurological differences in perception and communication autistic ways of being complicate interaction and autistic social experiences are often described as lacking and unsuccessful. Thus, autistic selves are confirmed in interaction as strange, unusual, and ultimately stigmatized (Milton, 2013; Macleod, Lewis, & Roberts, 2012). The focus has been on what is "wrong" with autistic people and how autistic ways of being can be stopped or "normalized."

Symbolic interactionism was chosen as the theoretical orientation for this study because (a) autistic differences in social perception and communication are characteristic of and problematized in the predominant literature and (b) sociology's dominant theoretical approach to the self and interaction even beyond the branch of social psychology. The foundation of Symbolic Interactionism (SI) is pragmatism which provides the framework of viewing phenomena in terms of *what is occurring* in interaction rather than biological, neurological differences or deficits. This shift allows us to focus on how autistic people navigate the social world, not their individual cognitive deficits.

The central aim of this study was to analyze autistic self-perceptions and socialization experiences by collecting autobiographical accounts through in-depth

interviews. The purpose was to compare the explanatory power of symbolic interactionism to the dominant psychological literature. The narratives told by respondents provided many examples of self-processes critical to SI theories of self-development, socialization, and interaction. Respondents provided descriptions of self-concepts, anecdotes of socialization and social experiences, and articulated their biographical selves in the sense that respondents indicated an awareness of the link between their past, current, and future selves. The themes included in this study address basic sociological concepts critical to the development and presentation of self and the socialization experiences of people on the autism spectrum as well as their relationships to others. First, I discuss how the findings demonstrate that a sociological approach to autism is both (a) appropriate to the data collected in the current study and (b) supported by other research aimed at explicating the experiences of autistic actors.

Autism and the Self: A Sociological Approach

The "I" and the "Me"

Psychological social psychologists and symbolic interactionists agree that pronoun use is indicative of self-processes. This section will briefly describe the "I" and "Me" concepts emergent in one respondent's speech. Brevity is justified and appropriate because the reflexive relationship of taking one's self as both subject and object is apparent in most conversation and in all excerpts from the interviews in the current study. This may be largely due to the fact that the respondents were specifically asked to reflect on their experiences and to describe their "self." Moreover, concepts in symbolic interactionism, particularly the reflexive self process and the Looking Glass Self, are not easily disentangled, especially in conversation. This is because they are co-occurring

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phenomena which cannot be neatly separated. For example, the Looking Glass Self can be generally understood as our self-perceptions being an internalization of how others see us. The key difference in abstracting the self as the dialectical relationship of the "I" and the "Me" from the Looking Glass Self is that the latter can be observed through feelings of pride or mortification and potential adjustments of behavior which will be discussed in the following section.

If Theory of Mind posits that cognitive faculties prevent the ability to "read" the minds of others, thus critically impairing the development of empathy or self, then from a symbolic interactionist perspective autistic actors would not demonstrate the "Me" -- that is, must be unable to take themselves as an object and to reflect on themselves. According to symbolic interactionism pronoun usage demonstrates the reflexive self process in the use of language.

The respondents in this study frequently used pronomial language and there were no instances in the twelve in-depth interviews that the respondents mixed-up the use of "I," "Me" or other terms such as "you," "we," "he," or "she." If symbolic interactionists see the self as a conversation between the "I" and "Me," components which can be observed when actors use language, that is, actors speaking of themselves as the subject and at other times taking themselves as an object which together constitute the self, then theoretically this should be, and indeed was, reflected in their descriptions of themselves and their experiences. Take for example Benjamin describing his relationship with a close friend:

> I suspected that he was a lot like me is some regards. That's why I was drawn to him. I think that's kind of why we were drawn to each other. We were both kind of the social outcasts. But we were fellow outcasts.

(Benjamin,)

Here Benjamin demonstrates the "I" because he is recounting his own impulsive actions of "suspecting" and "being drawn to" someone after the initial act. When he states that "We were both kind of the social outcasts" he is demonstrating the "Me." The use of the term "social outcasts" reflects the *generalized other*. Benjamin is recalling an experience and then framing himself and his friend from the view of larger society. He was only able to understand why he was "drawn to" his friend by reflecting on his own actions and he is only able to interpret the commonality between he and his friend through the "Me," that is, considering their social positions as fellow outcasts. It is the aspect of the "Me" that allows Benjamin to align his own social position with that of his friend.

Since Kanner's earliest writings on autism in the 1940's atypical or incorrect pronoun usage has been characteristic of the speech and communication of specifically autistic children. It is important to note that all children are still learning to use language and that irregular pronoun use may be more typical of children or a particular developmental stage rather than autism. Several recent studies have explored pronoun usage in terms of autistic selfhood. Shield and colleagues study of communication of children who are exposed to American Sign Language and autistic found that the children were more likely to sign their own names in place of personal pronouns. Those with more developed sign language produced more pronouns. They suggest that even though individual names are longer to sign compared to signing "me" by pointing to one's chest all children did point spontaneously however, "It could well be that the differences we observe in language reflect not so much different experiences of selfhood but different

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attitudes toward the perceived precision of linguistic forms." Shield and colleagues suggest that signing one's name or the name of another may seem more logical since names are consistently specific whereas whom the pronoun refers to varies according to the speaker/signer.

Similarly, Geoff Bird notes that whether abnormalities in pronoun usage reflects a "difference in a sense of self or just in the way individuals with autism use language to refer to the self is harder to determine" (Bird, 2010). Additionally, Bird and colleagues are currently researching the comorbidity and difference between autism and alexithymia. Alexithymia is known as a condition that makes it difficult for individuals to differentiate which emotion they are feeling. Approximately 50 percent of autistic children are also diagnosed with alexithymia but it is also prevalent in approximately ten percent of the general population and linked to eating disorders (Nowakowski, 2013) and substance abuse (Morie, 2016). Shah (2016) also suggests that impairments in self (socio-emotional perception or *interoception*) are associated with alexithymia and not a result of autism. Moreover, Bird and colleagues found that it is alexithymia that results in impaired empathy and is not associated with autism, which is in direct contrast to Theory of Mind (Bird et al., 2010). More research is needed to examine the role of autism in the use of pronouns and the relationship and stability of self and other concepts, but these findings indicate that autistic actors exhibit the "I" and "Me" and thus a self in conversation.

First-hand Accounts of Empathy and Autism

Since Theory of Mind suggests that autism prevents cognitive empathy and symbolic interactionism has not, then it was likely that empathic understanding would be found throughout autistic actors' experiences and self-descriptions. In fact, this alleged

lack of empathy has been especially contested by autistic activists and scholars. During the analysis themes of empathy spontaneously emerged and it was therefore necessary to examine the context and expression of autistic empathy.

Several respondents provided descriptions of themselves as "kind" which can be understood as empathy is action. However, three respondents recounted social experiences and described feelings of empathy in individual interaction to reflect an understanding of others that sometimes transcended their immediate situation and demonstrated compassion not just for individual people but for people as members of humanity. For example, Ferguson recounted the mysterious arrival of an energy healer to his workplace:

> So, my boss, whom I love very much has a horrible, possibly terminal, okay she has a brain tumor. So, she's, so that's inoperable… She has a Reiki master come in …and I knew that if I took, knew that if I fucked up this lady's attitude… When she came in I was like "What do you want? Who are you" and she was like "I'm looking for Dee" and I was like "She's not here right now she's probably in the back" and she was like "Oh I knew I was early" so I was like "Who are you just so I can tell her like who is here" and she was like "Oh I'm her Reiki master" and I just, I like, I don't know if my face conveyed it but I heard like a death knell in my head. I was, to me I was face to face with a charlatan who was defrauding my boss.
>
> Ya know my boss didn't have any real medical recourse for this problem, but she has like ritual that could calm her down and bring her peace. And I knew, I knew that if I fucked up this woman's game that uh then it would affect the performance. So, I said nothing. So, my attitude, so a time that I've changed my mind I can see the value that this FRAUD is bringing to my boss because my boss has nowhere else to turn and it's kind of like putting, it's not like this person is putting off legitimate medical care, she's just providing a service of comfort but the line between that and legitimate danger is pretty thin. Like who knows who this person is hurting through medical neglect.
>
> (Ferguson, 31)

In this story the respondent is recounting how he made the decision to keep his skepticism to himself after realizing that the Reiki master provided his boss a comfort she likely could not find elsewhere. He realized that if he were to criticize Reiki medicine it would have upset his boss and he is aware that she is seeking "ritual that could calm her down and bring her peace." The respondent also adjusts his behavior to protect the performance of the Reiki master. Moreover, when he says, "who knows who this person is hurting through medical neglect" he expresses that though he did not say anything after considering that his boss has a terminal illness in this particular interaction, he nonetheless wonders about the other people this "fraud" and "charlatan" may provide services for who could potentially be in danger. In this interaction, Ferguson actually did nothing. However, by interpreting his point view one can see that this is an expression of empathy-- one that could not be seen without an account of his perspective of the situation. This finding furthers the contention that first-hand accounts of autistic experiences must be centered to position autistic actors as the experts on their own experiences of self and sociality.

Additionally, examples of empathy for the larger social community include two respondent's choices of career. Bill (age 41) described his interest in working as a physical therapist stating "That's one of my motives for getting into physical therapy. To help people as best as I'm able to." Patrick (age 27) a computer information technology scientist working on assistive technologies, described himself as:

> …particularly interested in applying insights from the social sciences into what are traditionally stem areas of research. Such as applying the insights of social sciences to the development of technology for people with disabilities. So, making sure that when engineers are designing things they are also considering factors like stigmatization and social interactions related to these technologies. Things like that.

Bill and Patrick made these statements in response to probes about how they thought of themselves rather than questions about their employment. This demonstrates that these three individuals saw empathic understanding as part of their self-concepts that directed their actions (as opposed to efforts to pass as neurotypical). To reiterate, these examples of autistic empathy were spontaneously provided in both their private encounters and their professional careers.

Autistic empathy can be evidenced yet not necessarily through stereotypical overt acts— at least among verbal autistic people with average or above average intellectual abilities. As stated before, it is a dangerous stereotype that autistic people lack empathy for which there is no scientific support.

Komeda (2015) and colleagues contend that autistic people show greater levels of empathy toward other autistic actors under experimental conditions (p. 145-152). They argue that this suggests an "atypical form of empathy with ASDs towards others with ASDs" (Komeda, 2015). The theory of the double empathy problem suggests that autistic actors are perceived as lacking empathy because of a breakdown in mutual understanding-- not because of "autistic cognition deficits." From a symbolic interactionist perspective this is supported by Scheff (2005, p. 158) who stated:

> … undecidability ignores the possibility that communication involves at its very core the process of taking the role of the other, of understanding the meaning of messages or texts not only from the receiver's point of view but also from the sender's.

The findings in the present study reinforce the double empathy problem set forth by Milton and qualitatively support the findings of Bird and colleagues which concluded

that "not all individuals with an autism spectrum condition, but only subgroups with interoceptive deficits, seem to be impaired on the empathic route to social cognition. This finding agrees with earlier research pointing to a large heterogeneity in cognitive profiles within the autistic populations (Pellicano et al., 2006; Whitt et al., 2009a, b) and cautions against overgeneralization of deficits commonly attributed to autism spectrum conditions to every individual on the autistic spectrum" (Bird et al., 2010). Taken together, these findings are aligned with previous and current research, which suggests a better understanding is that autistic people experience, act on, and display empathy differently in ways that are often overlooked by neurotypical people. This supports the idea that symbolic interactionism provides a more nuanced framework. Now we turn to how autistic people may experience self and socialization differently by focusing on the concept of the *looking glass self* or how autistic senses of self emerge and develop from the real or perceived judgements of others.

The Looking-Glass Self

Succinctly, the *looking glass self* means that we learn to see ourselves through the "reflections" of others. For Cooley, the archaic English word for mirror is nothing more than a metaphor for objective self-awareness. Theory of Mind or the inability to infer others states of mind would seem to prevent the looking-glass self process and the thus the development of a *looking-glass self*. The assumptions of ToM were not supported by the data in the current study. It was found in the excerpts that all respondents demonstrated the existence of the *looking glass self.*

For example, when asked her opinions on gender roles Lydia stated "Yes, but I have been assured they aren't very p.c (politically correct)". The use of the term "p.c."

here reflects the actor's efforts to smooth interaction and demonstrates the internalization of the generalized other and its role in shaping actor's conduct. Through previous interactions Lydia had learned that her honest answer which goes against the norm results in problematic interactions thus she writes her opinion off as "not p.c." She has been socialized to understand society's view of appropriate perspectives toward gender roles and is aware that she holds a different view. To illustrate following the three-step process of the looking glass self, in this situation Lydia has (1) imagined how her opinion on gender roles will appear to others; (2) imagined how others will judge her opinion, and (3) developed a self-feeling she described as "not p.c" and therefore judged her own opinion as an unfavorable response.

When describing the *looking-glass self* Cooley emphasized that it was the actor's interpretation of others' perceptions, regardless of whether they make a misjudgment. In this example when probed further with the assurance that the interviewer welcomed her honest thoughts and opinions she responded "…let's just move forward" an indication to the researcher to change the subject. Though I would not have judged her answer at all, least of all in the way she suspected, this demonstrates the symbolic interactionist tenet of the *looking-glass self* and how actors' self-images are influenced by the real or imagined judgements of others.

Through her observations of children at play and school Barrie Thorne suggested that children police each other such that dominant conceptions of masculinity and femininity are enforced and reproduced. Additionally, her work holds that parents and other socializing agents can challenge or reinforce the messages that children receive from their peers. For example, when asked, "Do you know how they say that somethings

are for girls and somethings are for boys? What do you think about that?" Kurt (26, male) provided an experience from elementary school which shows gender socialization in action and how the looking glass self and generalized other are dependent upon reference groups.

> "(Laughing) Um I think it's absolute garbage. Uh um, okay so… something anecdotal I could add to this, I guess. I used to have a doll. Umm it was one of my favorite toys because I loved snuggling up to it when I would go to bed, I guess. And I, I don't know why. It was just very comforting. I couldn't explain why today. So, I mean, people will get into that sort of thing. It shouldn't worry any parent because I mean, I turned out pretty masculine I guess. I mean, but um, like I just think gender roles are weird. It's like "you have these genitals, you're gonna do these things!". Like what exactly is the logic behind that, ya know?...I remember mentioning it once in class and everyone was like "Wait! You have a doll?" And I'm like "yeah". And like I realized why that was probably not a wise thing to say but honestly I didn't care…Like, I have a doll! So freaking what?! I mean, ya know! (laughing)"

This example illustrates a young boy learning the gendered norms for appropriate toys. The reactions of his classmates indicated that a doll was not an appropriate toy for his gender. These students were participating in Kurt's socialization, reflecting to him that a doll is not appropriate for a boy. Yet, it makes sense that Kurt would say that he didn't really care at the time. Sociological research holds that in early childhood the family is the primary agent of socialization and that peers gain influence during adolescence. This illustrates the development of a generalized other and how actors construct the concept based on the appraisals of significant groups or specific people. Kurt later professed that neither his mother nor his father protested him having a doll or "at least I don't remember them complaining about it" which had more of an impact on him than the ridicule of his classmates. Like Lydia, Kurt became self-aware that his conduct was against social norms.

It is believed that typically developing children become objectively self-aware between the ages of one and two years as indicated by recognition of themselves in a mirror. Research also indicates that autistic children exhibit a delay in this ability until the ages of 3-5 years (Bertenthal & Fisher, 1978). Moreover, ToM is also linked to directed gaze (Moll & Tomasello, 2004), object permanence (Moll & Tomasello, 2006), pronoun use (Hay, 2006), and mirror-self recognition. Ironically, literal mirror recognition experiments in psychological social psychology with children are also believed to demonstrate self-consciousness.

Mitchell (2001) examined two theoretical models regarding mirror-recognition; the kinesthetic-visual matching model of Guillame and Gallup's theory of self-recognition as dependent upon a self-concept. He concluded that the "self-concept model is conceptually incoherent and makes inaccurate predictions from premises which are themselves inaccurate" and the kinesthetic-visual matching model better explains recognizing oneself in a mirror. Morin (2010) also criticizes the "fashionable" link between Theory of Mind, mirror-self recognition, and the self-concept arguing that "organisms that display MSR most probably do not possess introspective self-awareness."

In contrast to ToM, symbolic interactionism holds different assumptions on self- and other- awareness. To the symbolic interactionist awareness of self and other are based on interactional experience not chronological age. It can be argued that mental age reflects interactional experience. According to SI, children have not developed the ability to take themselves as an object until they have passed through the play stage. At the ages of 18-24 months children are not capable of participating in role play and are typically

still in the preparatory store which is characterized by imitation and the learning of

learning of gestures and symbols. The symbolic interactionist perspective is therefore

already evidenced in studies which suggest that autistic children experience a delay in

mirror self-recognition but that their performance matched that of their mental-age

matched peers, i.e., children with a similar interactional age (Dunphy-Lelii & Wellman,

2012).

Van Themaat linked ToM to the symbolic interactionist concept of the looking

glass self "with regards to the development of self-concept in children and young people

with ASD." She "considers how sensory processing difficulties in autism can potentially

influence the development of early communication and interaction skills which will

impact on an individual's ToM abilities." Van Themaat correctly posits that a

consideration of the looking glass self has important implications toward the study of and

treatment of autistic people and constitutes a shift from traditionally encouraged

interactional dynamics. She suggests that:

> "This is in accordance with a stance like the interactive model of
> disability…the view that disability is the result of an interaction between
> an individual with a disability and society. What messages about their
> selves are we mirroring back to our learners with SEN as educators and
> significant others in their lives? Do we reflect back to them that we see
> children and young people with value and unique abilities who can play a
> meaningful part in their school, family and community; or do we reflect
> back to them a collection of deficits and passive dependence on others,
> and how does this influence the way they see themselves" (Van Themaat,
> 2016, p. 4).

Moreover, she notes that "this focus on the socio-communicative features of

autism" is under-researched compared to approaches that attempt to modify behavior

(Charman & Stone, 2006). Additionally, "the interest in interactive approaches with

individuals with autism follow trends and…grew out of a desire to move away from behavioral approaches and towards approaches in education that value process and understanding over product and skills" (Nind, 2000: 184; Van Themaat, 2016, p. 12). Van Themaat suggests that medical professionals, educators, and parents interacting with autistic children specifically should take care that "reflections must enable our learners to develop a self-concept that is meaningful to them and to see their difficulties not as deficits, but as a different, validated way of experiencing life" (2016, p. 13). This demonstrates that symbolic interactionism is useful in not only understanding autistic actors but is a valuable perspective in terms of informing and restructuring intervention and support.

Role Taking

A major criticism of studies examining theory of mind, perspective, and role taking abilities of autistic actors is that they are conducted experimentally and are therefore not comparable to real world social contexts (Loyd, 2011; Van Themaat, 2016). From a feminist perspective, marginalized people are often acutely aware that their subjective experience is distinct from the prevailing "cultural and micro-interactionally established definitions" (Ritzer, 2014, p. 438). Feminist scholars were the first to reject the traditional microsociological view of a "unified consciousness of everyday life" that is assumed. For example, Dorothy Smith highlighted how the everyday life of marginalized people, specifically women, can be understood as a divided reality where they develop along a fault line between their own subjective experiences and the established types available in the social stock of knowledge to describe that experience (Smith, 1979; 1987). Ritzer (2014, p. 438) summarizes how this experience may be

generalized to the subjectivity of all subordinated people in four key ways and how this

effects role-taking and the conception of the generalized other:

(1) Their experience for role taking is complicated by their awareness that they must learn the expectations of an other who by virtue of differences in power is alien.
(2) They must relate not to a generalized other but to many generalized other in both the culture of the powerful and the various subcultures of the less empowered and the disempowered.
(3) They do not experience themselves as purposive actors who can chart their own course through life—although they may be constantly told that they can do so, especially within the American ethos.
(4) Most pervasively, they live daily with a bifurcated consciousness, a sense of the fault line between their own lived experiences and what the dominant culture tells them is a social reality.

When we are very young we are only able to take the role of specific others.

Mead's theory of development suggests that procession through the play and game stages

culminates in the development of the concept of the generalized other, whereby we adjust

and conform our conduct to the standards of society according to the prescribed

behaviors that accompany our social position—that is larger society provides guideline

for how to coordinate our lines of action with others according to our role. Role taking

means that we draw on these guidelines to have successful interaction. Hewitt describes

how the "generalized other is, like a role, a perspective that the person must

imaginatively adopt in order to take it into account in forming his or her own conduct. It

is made up of standards, expectations, principles, norms, and ideas that are held in

common by the members of a particular social group" (2007, p. 69). For example, norms

regarding gendered behavior and appropriate conduct in specific social settings such as a

restaurant. The first example supports the contention that gendered socialization

experiences are like those of non-autistic children. The second example is highlighted to illustrate how the subjectivity of autistic actors often runs counter to prevailing norms.

When asked the question "Where did you learn gender roles?" Bill recounted an exceptionally detailed experience of gender socialization and more specifically role taking.

> I was like 10 and went to one of those fairs or whatever they are with the rides and carnies...a carnival. and I went there with these two girls who were like 12. I'm not sure why....it was something my aunt and uncle arranged, but it was fine with me.... believe me, I had no qualms. So, they wanted this prize that you get by knocking over cans with a ball and they tried a couple of times.... but then one of them said something like, "why are we trying to do this when we have this boy who can help us?" and at first, I'm thinking.... these girls are older than me, what are they talking about? but of course I wound up fulfilling my role as a boy and knocking down the cans multiple times and they got a bigger prize than they even wanted. I think it was the first time I realized that girls viewed boys and sort of that athletic, get the job done type....and that was the first time I realized that could be a pretty accurate view.... sure enough, they were right.

In the following example, Ferguson recounts a recent event dining with coworkers at a hibachi grill which illustrates role-taking ability that transcended the situation to consider historical context:

> So I'm watching this guy who's from China and goes by the stage name "Sexy Charles" who is ya know, doing this performance… We have a professor here at [local college] who specializes in like Asian culture or that sort of thing and something that his son said rang in my head while I was there. His son had leaned over to him and said "This is entertainment for colonizers"… So I had that quote in my head the whole time. I was just like "who is this guy?", "how does he feel about this?". And my boss is full-blooded Thai, and her parents are full-blooded Thai and they were there. I have an Indonesian immigrant coworker and the rest of us are white as the fallen snow. So it was just really, it was uncomfortable for those reasons and it was just uncomfortable because I'd seen these moves, most of these moves and schtick a thousand times before. I'd seen it before and I've seen it represented a thousand times before. So it was just like "ughck".

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…I had no idea how this dude actually feels about what he does. Or what his perspective on it is is. Like "Sexy Charles" became an enigma to me. And I was like "surely his name isn't Charles." It just became sort of sad thing for me and I really didn't like it and I was really uncomfortable. So there was that aspect to deal with. But I did want to support him as an entertainer because I know that a bitchy face can really sap your mojo. So, uh, I really tried but afterwards everyone got on me for my bitch face and my alleged attitude.

(Ferguson, 31)

In this instance Ferguson is describing what he was actually thinking when his fellow dinner partners inferred negative evaluations of his affect and demeanor throughout the course of their dinner. This highlights Milton's double empathy problem and provides Ferguson's own interpretation of events and his mental state during the alleged social infraction. It turns out that, in symbolic interactionist terms, Ferguson was taking the role of other (the performer in this case) and empathizing with him both as an individual performer and with his social position (including a vast historical context) as a Chinese immigrant performing what he deemed "entertainment for colonizers" that made him uncomfortable which, despite Ferguson's efforts, could be read through his paralinguistic communication.

Ferguson was unable to devote his full attention to his body language because his mind was focusing on unraveling the "enigma" of "Sexy Charles." In this instance Ferguson had no problem theorizing about the mind of Charles while at the same time struggled to manage the norms expected by his fellow dinner patrons. However, his dinner companions were wholly inadequate in their assessment of Ferguson's internal mental state and were likely over-monitoring his behavior because he possesses the social label of autistic. In other words, they "failed" to "read" Ferguson's mind and then sanctioned him socially for their own misguided judgements.

In this instance, the non-autistic dinner parties suffer from the problem of cognitive empathy. They were unable to "read" the mind of their fellow dinner patron and additionally made no attempt to consider the situation from the point of view of the Chinese immigrant despite many in attendance being Asian immigrants themselves. Milton defines the double empathy problem as a *disjuncture in reciprocity between two differently disposed social actors* and describes it as a "breach in the 'natural' attitude that occurs between people of different dispositional outlooks" (2012, p.3). In recent experimental research it has been shown that non-autistic participants are both unable to read the emotions of autistic people and tend to evaluate their sociality negatively. In this example, Ferguson's coworkers did both. The underlying issue is lack of mutual agreement on what aspects Sexy Charles were salient. To Ferguson, it was the larger social context in which the performance occurred. For his coworkers, the norms regarding viewing the performance were more salient and Ferguson's natural response to the performance and the context of the performance were first evaluated as wrong and then as rude. His coworkers ultimate understanding of the situation was that Ferguson's behavior was indicative of "typical" autistic social deficits. From his perspective, we can see that was not the case and we can see the post hoc efforts Ferguson made to account for his behavior and manage his impression.

Taking the Role of Other as Impression Management

Another relevant issue emergent in the data involves autistic actors' management of disclosing their diagnosis. Failure or reluctance to disclose an ASD diagnosis should be regarded as an effort to protect and control both internal self-concept and the external evaluations of self. It is an effort to control the *definition of the situation* and an example

of *impression management* that are only possible by taking the role of other. Because autistic sociality and communication is misunderstood and stigmatized, when autistic actors interact with non-autistic others they are subject to the threat of stereotyping. Attempts to control others' images of our self demonstrates an awareness of others' perceptions which do not match the individual's self-assessment. How actors present their self and what actors choose to disclose to manage impressions is contextually specific. When asked about disclosing his diagnose, Matthew provided the following account for why he chose not to disclose:

> Concern about stereotyping. I'd say in general working in a stem field especially, something like math is pretty good camouflage. Because like, I just described my boss shouting profanity out of his office. There's certainly lots of tolerance for idiosyncrasies let's put it that way. And then so, if you're a little socially awkward or don't, like with me, you make a conversation… if I'm having a conversation with more than one person it is challenging to know when to talk and if you're a little awkward like that people are willing to overlook it. At least in the departments that I've been in. And so generally not at work.

> (Matthew, 32)

On the other hand, Ferguson provided an example of choosing to disclose his diagnosis strategically in the workplace. Goffman described a formula for "disclosure etiquette" where "the individual admits his own failing in a matter of fact way, supporting the assumption that those present are above such concerns while preventing them from trapping themselves into showing they are not" (1963, p. 101). Ferguson describes this process as follows:

> It's been like a card to excuse my awkwardness or my mismatched tone of voice or my uh, all these sorts of things. I would tell it to coworkers. Okay so the way I see it is that it's my card to play…. So, for me to be like "oh that didn't really come off the way I wanted to, and this person probably thinks that I hate them or that I that I think they're a piece of shit" or that whatever. So, I'll say like, I'll throw the card down and say

here's the deal. Like, this is something that I deal with and hopefully you understand now. But all I have to say is "I'm probably on the spectrum" and they're like aware enough that they're good with that.

<div align="right">(Ferguson, 31)</div>

Ferguson goes on to describe his reluctance to use this "card" at work because of the potential to complicate future interactions stating:

The reason that I'm conservative about using that card is because I don't want my experience with them or their experience with me to be colored by that uh, by that label. Like ya know, I don't want to be, for instance, not taken seriously. Like, I don't know whatever preconceptions or popular culture conceptions might be applied to me.

<div align="right">(Ferguson, 31)</div>

Ferguson is highlighting that autism as a label can be perceived as stigmatizing (Huws & Jones, 2008) to others. Though he plays the card to excuse awkward behavior or to explain break downs in communication, he is hesitant to use it because cultural (mis)understandings of autism may color his future interactions and he seeks to avoid being stereotyped.

Additionally, Patrick described another dynamic in situations of disclosing as an attempt to account for break downs in communication-- feelings of frustration. He stated:

It's frustrating to have to prove something like that. I don't know. People, I don't know it's hard to explain why it's frustrating. Because when people don't believe that, that what I'm trying to explain is to some degree outside of my conscious control, umm, if I'm bringing it up it's because I am behaving in a way that someone normally wouldn't. And if they don't believe that I have this diagnosis or something then they will ascribe it to something that I could change if I wanted to. Uh, which is, umm, which changes how they view me as a person.

(Patrick, 27)

Here Patrick is describing how sometimes his attempts to explain his behavior as result of being autistic are met with disbelief by non-autistic people highlight the

problems associated with functioning labels. He attempts to convince non-autistic actors (with varying degrees of success) because he knows that otherwise they will assume that he is merely excusing bad behavior for which he has control over, when in fact he does not. For example, they may infer any number of negative valuations to his conduct such as rudeness, laziness, or lack of empathy.

On the other hand, autism as a label can also be stigmatizing to one's self when stereotypes about autism have been internalized within an individual's concept of the generalized other. For example, one respondent, Kyle (age 21), revealed that he never disclosed that he was a "person with autism" to anyone not even friends. He described that he had only told one close friend on an occasion when that friend asked him to join the military. Kyle admitted to his friend that he was not "eligible because I'm on the autism spectrum" and then qualified his statement with "even though it doesn't impact me much." His reasoning was that he always wanted people to treat him as a person "like any other person." Additionally, Kyle was offended by the interviewer's use of the term autistic because he felt he was "smarter than that."

When asked why he considered the term offensive Kyle replied that "someone being called autistic means that you're calling them someone that can't handle life at all, someone that doesn't know how to take care of themselves and basically doesn't know how to do most things that any of us can do." This suggests that Kyle has internalized the stigma attached to the label of autism prevalent in larger Zeitgeist which reflects a misunderstanding of what it means to be autistic. Kyle described how in taking the role of other he came to fear that others would think that he would be unable to do things for himself, may need them to do things for him, that they would fail to show him respect "as

an adult," and may possibly reject him and that he "wouldn't want to be in that kind of position." He sought to prevent these situations where his personhood was reduced by electing to never disclose his diagnosis to others.

This respondent highlights the effect of stigmatization of autistic people. An unpublished thesis by Jessica Benham (2015) links the preference for "identity-first" terms including "autistic" as linked to the concept of *disability pride* which she explored as a critical component of personal identity that must be given salience to align one's self with grassroots advocacy movements. When autistic people imagine how they are seen by others, that is, take the role of other and feel feelings of mortification as opposed to pride it has important implications—namely, the possibility of self-acceptance, self-esteem, and self-efficacy, especially in terms of advocacy but more important, psychological well-being. To summarize, these findings suggest how taking the role of other in a world that devalues autistic identities effects the self-concept of autistic actors.

Socialization and Self

> *I think that the real me... the guy who'd go to the prom with somebody just to be nice... he doesn't somehow come across in real life or perhaps he gets misunderstood.*
>
> (Bill, 41)

To the symbolic interactionist, socialization is more than the process of an actor being taught and internalizing the norms of their social group. It is also a process that produces the ability to think in the symbols used by the actor's social worlds thus enabling individuals to define situations, develop lines of action, and create joint acts with others to solve problems—the ability to think, act, and to interact. Interaction (either

with one's self or others) is, in fact, the process in which the ability to think is expressed and therefore thinking shapes and is shaped by the interaction process.

Primary socialization operates in two ways; actors' unique biographies shape their individual experiences and each actor learns society's rules and makes them their own. Denzin (1971) argues that socialization is bidirectional; that socializees and socializers (Sandstrom, Martin, & Fine, 2010) come together and jointly renegotiate the rules given their respective power. In this regard, the teacher is socialized as much as the student is. Socialization occurs through interaction with socializing agents and within social institutions, notably the family, the school and the media. Norms learned include appropriate conduct for performing roles in accordance with one's social position. Primary socialization is uniform in the sense that most all people experience the process as one that leads to the development of self. On the other hand, secondary socialization refers to the learning of specific or formal training learned later in life and is largely skill-based.

Research on stigmatization has been counterintuitive in many regards. For example, studies of disabled people have shown that they do not strongly identify with their disability and hold a positive self-image which may be (but was not mentioned) in contrast to other stigmatized identities such as for example, sex-workers (Olney & Brockelman, 2003; Watson, 2002). Watson (2002) and Milton (2014) suggest that some stigmatized individuals may question the discourse surrounding "normality" but it is assumed that Milton would disagree with any contention which suggested that being socialized into a stigmatized identity has little effect on a person's understanding of self or other. He notes that "Autistic identities can be said to be constructed within a context

of an uneven distribution of power, with a medicalized view of autistic difference and remediation at times acting as a hindrance to feelings of wellbeing and belonging" (Milton, 2017). McLeod, Lewis, and Robertson (2008) found that autistic higher-education students relied more on their first-hand experiences as more personally relevant and "conveyed strong self-images regardless of how or whether they identified with their diagnosis." The authors linked this finding to the sample characteristics suggesting that their "relative privilege in achieving higher education and therefore experiencing success and achievement to their personal strengths." The following section describes how the respondents in this study described their images of self.

When asked the question "If someone asked me who you were, what would you want me to say?" respondents' answers varied based on individuality. According to Kuhn's original coding categories of the Twenty Statements Test, most respondents thought of themselves positively and primarily described themselves in terms of their personal traits, i.e., smart, intelligent, kindhearted, caring, laid-back, mellow, fun-loving, etc. Less than half of the respondents (four out of twelve) described themselves in terms of their physical traits with "handsome" or "good-looking," "tall," and "strong" being the only examples. Even fewer respondents described themselves in terms of their social roles with the only examples being student, parent, and researcher. Only one respondent used terms that would fall under Kuhn's original coding category of "existential statements," e.g., "I am not my body."

To illustrate how autistic actors perceived themselves take Cormac who described himself as "intelligent, interested in actuarial analysis, and confident." He described himself this way because these were things that he was "very proud of." Patrick described

himself as a researcher who was somewhat introverted and thought of himself this way because these were things that "dominated" most of his waking moments. Likewise, Matthew also described himself as a successful researcher who was "curious, driven, and especially interested biology" which he had made into a career.

Benjamin thought of himself as "kindhearted and a good leader, someone who leads by example, who can coordinate and get things done." Austin described himself as intelligent, kind, decent, caring, and respectable with a "low tolerance for horseshit" as well as a "snappy dresser." Austin went on to qualify intelligent because of his audiographia. He believed that he gave the appearance of being intelligent because he was able to recall lectures or other things he had heard verbatim. He also described himself as a civil libertarian which he thought people should know because it related to his burgeoning career in the legal field and because he believed that this label let people know he was both principled and not easily offended.

Ferguson, Kurt, and Chad described themselves as "weird" with Ferguson adding "I'm hyperdimensional, a fucking alien." He meant this in the sense that he was varied from person to person and situation to situation. He further stated that he didn't "really have an elevator pitch" for who he was. Kurt wanted to be described as weird "to get it out of the way." However, for Chad, "weird" was associated with bravery. He stated that:

> I can take some pride in being weird because being weird in the world takes some bravery, anyone can be normal and fade into the background, nothing brave about that.

Similar to Ferguson's admission that he didn't really have what he called an elevator pitch, two women in this study gave short answers to the question and when probed asked to move on. For example, Lydia replied:

Sorry. I keep trying to answer like I know other people answer. People who say gamer, etc. But those are just things that I do. They're actually just things lots of people do.

Lydia is a single woman in her fifties with no children. Throughout the interview she discussed many of the interests and hobbies she has enjoyed throughout her life. She worked in the service industry and described as just a job such that it was not salient to her self-concept.

Of note, no respondent in this study wished to be known or described by others as autistic. Importantly, respondents were asked to describe themselves to the interviewer and the nature of the interaction within the context of an autism research study served as confirmation that being autistic was already known. Bill said that being autistic was something he wanted people to know about him but that it was something he worked "extremely hard to hide." So, this observation should not suggest that no respondent other than Bill regarded being autistic as an important part of their identity. It simply was not something they wished to be known or described as. However, this leads us to the next section on what it means to manage autistic ways of being, what Goffman referred to as "passing."

According to Goffman, people who share a stigma tend to have similar learning experiences which may have similar effects on their conception of self. Being socialized with a stigma produces a similar "moral career." One phase of this socialization process is when a stigmatized person learns the dominant viewpoint regarding people with their stigma. Recall Kyle mentioned earlier who was offended by the word autistic and never disclosed his diagnosis to anyone outside the medical or support communities. For Goffman this meant "acquiring thereby the identity and beliefs of the wider society and a

general idea of what it would be like to possess a particular stigma." Another phase of

autistic socialization is when a person realizes they possess a stigma and slowly learns the

consequences of possessing that particular stigma. The timing and the interplay of these

two initial phases of the moral career form important patterns, establishing the foundation

for later development, and providing a means of distinguishing among the moral careers

available to the stigmatized.

As mentioned previously, half of the respondents in the present study sought to

seek a diagnosis in adulthood. Goffman suggests that:

> The stigmatized individual defines himself as no different from
> any other human being, while at the same time he and those around him
> define him as someone set apart. Given this basic self-contradiction of the
> stigmatized individual it is understandable that he will make some effort to
> find a way out of his dilemma, if only to find a doctrine which makes
> consistent sense out of his situation. In contemporary society, this means
> that the individual will not only attempt to hammer out such a code, but
> that, as already suggested, professionals will help out. (1963, p. 107)

Huws and Jones (2008) asked autistic young adults to recall their experiences of

having their diagnosis disclosed *to them* and their own perceptions of autism. Their study

revealed the following themes; *disclosure delay, providing explanations, potential effects

of labeling, disruptions and opportunities, and acceptance and avoidance*.

The respondents in the present study differ in several key ways. First, the current

study had a larger sample size. Second, all the respondents in the Huws and Jones study

were under the age of 21 and diagnosed *prior* to that age. The ages at which respondents

were diagnosed varied from early or middle childhood (6) to adulthood (6). The youngest

age of diagnosis was four years while the oldest age was described as "late thirties." Half

of the respondents in the present study pursued diagnosis as an adult and were not

subjected to the "disclosure" talks that had to have been given by guardians. The perspectives given by Huws and Jones respondents may or may not reflect the experiences of the adult respondents in the present study. Therefore, the themes in their discussion converge and differ in important ways which allows us to consider the effect of diagnosis in adulthood and any additional themes in disclosure of diagnosis during adulthood.

Moreover, the theme "acceptance and avoidance" should be markedly different when examining the role of age such that older persons who independently sought their diagnosis are less likely to experience avoidance. Only one respondent, Patrick, experienced "disclosure delay" and his response differs from the respondents in the previous study. Patrick was diagnosed at age 12 but this was not disclosed to him until the age of 21. He said that it didn't come as a shock to him because he was already aware of having other diagnoses including dysgraphia, dyscalculia, and social communication disorder. These previous diagnoses may have provided a buffer such that one more label was not salient enough to affect his sense of self.

Two respondents diagnosed as children reported coming to question their diagnosis in adulthood. Kyle stated that he didn't he believe he was autistic. He described that he had matured since childhood and no longer needed the supports he had received as a young child. Kurt (age 27) who was diagnosed in the third grade stated:

> Sometimes honestly, I wonder if I actually do have it. I feel like there are times when I don't quite fit the spectrum and then there are times when I'm like Mommy help I'm autistic! (imitating whining child, then laughs). But no, I realize that I have some social issues that I'm still trying to work out a little bit. But for the most part I've made peace with it I guess.

Of the six diagnosed as adults five had positive responses and regarded their diagnosis as helping to explain and contributing to their understanding of events in their past. Matthew was referred for diagnosis after receiving treatment for depression. He had suspected before that he was likely on the autism spectrum after learning about it and seeing parallels in his own experiences. Matthew reported feeling "vaguely satisfied" that his suspicions were confirmed. Lydia, who was diagnosed in her late thirties after a referral by neurologist treating her epilepsy stated that it "gave me something concrete" and "explained my behavior." Likewise, Patrick felt that a diagnosis helped him to "contextualize who I am" and "explain my eccentricities and esoteric interests." Bill felt that receiving a diagnosis enabled him to "find certain abilities that I have and enhance them."

Conversely, Chad, who independently pursued diagnosis at age 30, described receiving confirmation of the suspected diagnosis as making him feel "forlorn and empty." He described feeling resentful of his parents saying he felt left to "develop coping mechanisms on my own." He believed that if he had been diagnosed at a younger age he would have had access to external resources stating "a little accommodation would have been nice. Might not have ended up such a cold, weirdo loner."

Ferguson was one respondent who stopped pursuing a diagnosis after the recommendations of loved-ones who were in the medical field (mother and friend) and an ex-girlfriend explaining:

> Now I'm just not sure what I really want to do with it. Because it's something that I've sort of accepted. It's brought me a little bit of peace just to accept it, to just say I'm probably on the spectrum has been useful just because it makes me feel like I have a greater understanding of myself. So, there's this like suite of ideas. And recently I'm hearing about executive dysfunction and I'm like gosh that makes so much sense.

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Despite the description of the growing number of adults receiving diagnosis as an "epidemic," Ferguson demonstrates that many adults are aware of their neurodiversity and autistic traits but question the relevance or necessity of an official diagnosis to their daily lives or general well-being.

To summarize, the respondents in this study diagnosed as adults paralleled the experiences of those in the Huw and Jones in certain ways and diverged in others. First, the respondents in this study did reflect similar accounts of the themes of concerns about labeling and diagnoses providing explanations for past experiences and disruptions and opportunities as revealed in the Huws and Jones study. Second, no respondents in the present study described feeling that their diagnosis disrupted any of their plans or as source of "new opportunities" (Huws and Jones, 2008, p. 103). This may be due to the fact that several students in the present study were already receiving accommodations and participating in therapy, however, so were the respondents in the 2008 study, thus they may have been thinking retrospectively. Third, one respondent in this study, Kyle, paralleled Huws and Jones experience of *avoidance* or wanting to distance himself from the label while nearly all others, by their accounts offered, accepted their diagnosis at the time of disclosure. Overall, the respondents in the present study held more positive views of their autism diagnosis than those in the Huws and Jones study.

Learning to pass is the purpose of the most commonly used interventions such as Applied Behavior Analysis and constitutes one phase in the socialization of the stigmatized person and a turning point in their moral career. ABA is carried out by both professionals and parents. Attempts to manage autistic symptoms are also part of the everyday of adult autistic people. Goffman describes that some stigmatized individuals

may engage in unwitting passing before they are aware that they possess a stigmatized

trait. To illustrate this example, Ferguson stated:

> I spent a long time asking my friend "So what do normal people do when…" or how do, like I'd ask my boss and my coworkers at the time, like "how do normal people this or how do normal people do that or how do normal people respond when somebody does blank?" And like, I thought it was cute to say, 'normal people' but I had no idea how to say, "how do I pretend to be neurotypical"?

The following excerpt serves as an example of Goffman noting that the

stigmatized individual "attempts to correct his condition indirectly by devoting much

private effort to the mastery of areas of social activity ordinarily felt to be closed off to…

those with his shortcoming" (1963, p. 10). Although Ferguson spent most of his life

unaware that he possessed a stigmatized identity, he did acknowledge that his way of

interacting and communicating resulted in difficulties meeting and theorizing what

expectations social situations may entail. He attempted to ameliorate and address these

issues by asking for advice and input from people he deemed to have the skills he wished

to possess and imitate. In a general sense of self-improvement and socialization, this is

not much different from any actor referring to significant others as representative of a

reference group. However, Ferguson's admitted engagement in self-therapy is a step

beyond that of a typical person and more akin to the antecedents and consequences of the

process of self-labeling in mental illness based on the concept of "residual rule breaking"

(Scheff, 1966). This parallels the work of Thoits and Scheff who describe that by taking

the role of the generalized other, people assess their own behavior and when they label it

as deviant and may engage in voluntary treatment seeking because they wish to improve

their understanding of themselves in interaction to make goal-orientation easier. Being

able to align our actions with others to meet situational goals is indeed the purpose of role

taking from a symbolic interactionist perspective.

Additionally, many respondents were aware of their attempts at impression

management and discussed their techniques. For example, one respondent even described

himself as an actor stating:

> I'm a decent actor. I sort of try not to come off as being socially
> awkward. I won't talk. I've learned not to talk extensively about my weird
> fascinations, the stereotypically autistic things. But when I do try to
> explain my quirks, to contextualize them by explaining that I am on the
> spectrum people often don't believe it because they have a preconceived
> notion, which is frustrating.

(Patrick, 27)

Similarly, Bill described that impression management at work and school was

exhausting and took a lot of effort but were necessary to achieving his goals. He

described it as "pretending to be neurotypical." Some of the techniques that Bill

described were faking eye contact, using informal language, i.e., "I might not pronounce

the word 'thinking' but instead say thinkin', not using his natural monotone affect

emphasizing his "Jersey accent" and remembering colleagues birthdays: "If I remember, I

blend in more and people may overlook the areas where I don't blend in well." What Bill

may not recognize is that all people manage their impressions in similar ways in the

context of work and school. Autistic people are no different from non-autistic people in

terms of feeling social pressure to conform to idealized notions of professional and

courteous, i.e., building rapport with clients and coworkers and speaking in a different

tone of voice that conveys personality and joviality.

A key point raised by Milton stresses the importance for autistic people to "experience

ways of being that are compatible with their dispositions" (2013, p. 64). When autistic

people are forced to mimic or believe that they must mimic neurotypical behaviors it acts against their well-being (Milton, 2013; Milton, 2012; Bogdashina, 2001). For Goffman, passing and covering as forms of impression management raised the issue of a "great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment" (1963, p. 87). These examples highlight the hidden labor and lengths that autistic people go to to successfully navigate and smooth interactions with non-autistic people which are in some ways distinct from the everyday interactions of neurotypical people.

Chapter Six: Conclusion

I undertook this study because of dual interest in microsociological concepts of the self and an interest in studying how inequality is perpetuated through language. Since the term *autism* first appeared, it has carried with it assumptions that autistic people are not just not "normal" people but that lack key elements of humanity. Generalizations about autistic deficiencies and disabilities have led social scientists studying autism down a path toward eugenics in the search for a cure. Examining how autistic people are discursively denied a self was of interest me because of my interactions with nonverbal and minimally verbal autists who undeniably exhibited a sense of self and other, cognitive and affective empathy, despite differences in perception and communication. The psychological literature on autism and lines of research often deny what can be observed in interaction and the experiences of autistic people. In contrast, symbolic interactionism as a perspective prioritizes both what is occurring in interaction and actor's individual interpretations of their own experiences.

There are several important areas where this study makes an original contribution to the social science research of autism and the application of symbolic interactionism as a theoretical framework:

(1) From a symbolic interactionist perspective autistic people exhibit a self. They demonstrate the "I" and "Me," exhibit the looking glass self, and take the role of other.

(2) Symbolic interactionism is uniquely suited to validate autistic empathy by elucidating individual sense-making during interaction.

(3) Symbolic interactionism both supports and is supported by the conclusions of recent psychological and neurological studies that challenge or refute earlier understandings of autism—the hallmark of interdisciplinary research that integrates knowledge and strengthens lines of reasoning.

Results and Limitations

Like most research concerning autism, it was beyond the scope of this study to examine education, racial, or gender differences. This is due to the fact that women/girls and racial/ethnic minorities are less likely to be diagnosed. Moreover, diagnosis is costly which serves as a class barrier to understanding for the family and any subsequent support or accommodations.

The design of this study purposefully confined level of education to those with some college experience. One respondent had obtained his doctorate. Two held a bachelor's degree and one was graduating in the semester during data collection. One respondent held an Associate's degree and five were on a plan toward obtaining their Bachelor's. One respondent had attended college for two years but did not have plans to graduate. This study was also unable to consider class as most respondents' parents

worked in professional fields requiring advanced degrees, many doctors themselves. All respondents were white and predominantly male. Only two respondents were women. The average age of respondents in years was 27.8.

This study was designed to be exploratory and interpretive in nature. I argue that the sample size of twelve should not be considered small. The key in determining an adequate sample size for qualitative data is reliant not on numerical size but the concept of saturation. This study aimed to collect in-depth biographical narratives which resulted in more than 300 pages of conversation. One interview lasted eight hours. This study seeks to highlight individual experience but it would be unreasonable to generalize the experiences of these respondents as representative of all people on the autism spectrum or representative of any group the individual may be a member of. At the same time this thesis is framed on the intent to illustrate that the selves of these respondents are entirely representative of humanity writ large and that autistic actors share difficulties in sociality.

There are several influences on how many interviews a researcher should conduct for a defensible qualitative study. Sampling continues until the researcher senses they have reached saturation (Guest et al. 2006; Mason 2010; Morse 1995). According to Bertaux, the researcher learns a great deal from the first several interviews. After this point the researcher recognizes patterns in the respondent's experiences. Thus, additional interviews confirm what the researcher has already observed and documented. However, there can be no hardline rules to determine when saturation will or has occurred. Guest (2006) and colleagues found that 12 interviews of a homogenous group is all that is needed to reach saturation. The respondents in this study were predominately white, college educated males and the decision to end data collection in this case was influenced

by the additional following factors: interview structure and content (Guest et al. 2006); the complexity of the interviews (Ryan and Bernard 2006; the nature of the sample being limited by the sampling technique (Browne and Russell, 2003).

Due to practical constraints there were a number of factors associated with difficulty in recruiting. Length of interview was time consuming and interpersonal. Timing of data collection was inconvenient to adults currently enrolled or working full time jobs. These factors made the research design off-putting to many people who met the study criteria.

Respondents had the option of a face-to-face interview, a face-to-face video call on Skype, a live-chat via Skype messenger, or an interview through an email chain. Each method has its own limitations but the element of preference of communication is important to this study. Because the flyer was distributed online there was a geographical limitation; in-person interviews were unfeasible for all but five respondents. Interviews conducted via chat or email were potentially a barrier to building rapport and observing paralinguistic behavior. However, anonymity in communication often makes some people feel freer to speak honestly and without fear of judgement. Though each interview method was unique, all interviews were successful and were the appropriate method for respondents who preferred the extra time to gather and articulate their thoughts.

Suggestions for Future Research

A sociological framework toward ASDs is necessary to examine the interactional processes between autistic and non-autistic people specifically in interactions with medical and education professionals. When it comes to the study of autistic selfhood we need to examine the discourse surrounding what selves are and examine what

interactional processes are being accomplished and which are not. Additionally, more research is needed to examine *sticky situations* using conversational analysis to determine underlying mental frameworks and sense-making mechanisms that may be atypical but successful nonetheless. This would theoretically support a difference but not deficiencies which validates autistic personhood.

Future lines of research may involve the use of identity theory and affect theory to examine autistic self-concepts and how society influences the self-concept in autistic actors—not just cognitive processes and experimental tests. Although recent lines of research examining barriers to well-being, reshaping treatment and intervention with autistic input, theoretically we must also explore how autistic actors are able to successfully move through the social world in ways that accommodate autistic difference. Lastly, autism should be of particular interest to sociologists because it can reveal to us the taken-for-granted world of interest to phenomenologists and the social construction of social order.

INFORMED CONSENT DOCUMENT

Project Title: Who Am I?: Symbolic Interactionism and First-hand Accounts
of Self-Perceptions in College Students with Autism Spectrum Diagnoses

Investigator: Jessica N. Simpson, Department of Sociology,
Jessica.simpson601@topper.wku.edu

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.
You must be 18 years old or older to participate in this research study.

I am Jessica Simpson, a graduate student in the Department of Sociology. I am doing research on the experiences and perceptions of college students with autism spectrum diagnoses. I am going to give you information and invite you to be a part of this research. Before you decide, you may talk to anyone you feel comfortable with about the research. This consent form may contain language that you do not understand. Please ask me to stop if you have any questions and I will take the time to explain.

If you then decide to participate in the project, please sign this form in the presence of the person who explained the project to you. You should be given a copy of this form to keep.

1.   **Nature and Purpose of the Project:** The purpose of this research is to collect valid information and firsthand accounts of the perceptions of individuals with autism spectrum diagnoses to better represent their experiences in the scientific literature. We believe that you can help us by answering questions about your life as a college student and your relationships with family, friends, and peers.

2.   **Explanation of Procedures:** During the interview I will sit down with you in a comfortable and private room at the Suzanne Vitale Clinical Education Complex. Next I will ask you some questions about yourself. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer will be present. The interview will be audio recorded but no one will be identified by name. Interviews are expected to last up to three hours.

3.   **Discomfort and Risks:** Risks are anticipated to be minimal but may cause some emotional discomfort. I am asking you to share some very personal and confidential information and you may feel uncomfortable talking about some of the topics. You do not have to answer any question if you do not wish to do so and that is also fine. You do not have to give a reason for not responding to a question or refusing to take part in the interview. You do not have to share any information you do not want to or talk about anything that makes you uncomfortable.

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Original - 5/17/2017

4. **Benefits:** There are no incentives for participating in this research. However, some people find that talking about themselves and their experiences provides catharsis. The intended benefit of this research is to the greater autism community.

5. **Confidentiality:** The researcher will not share identifying information with anyone outside the research project. The information collected will kept securely. Any information about you will have a number instead of your name. Only the researcher will know what your number is and that information will be kept under lock and key.

6. **Refusal/Withdrawal:** Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks.

_____   _____
Signature of Participant   Date

_____   _____
Witness   Date

- I agree to the audio recording of the research. *(Initial here)* _____

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Paul Mooney, Human Protections Administrator
TELEPHONE: (270) 745-2129

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1. If someone asked me who you were, what would you want me to tell them? Why?

2. Tell me about your life as a college student? Where do you live? What is your room like? Why? In what ways is your life different from when you lived at home?

3. What is your first/earliest memory? Tell me about your life as a child and your family? Who did you live with? Who took care of you? Did you have cousins, aunts and uncles, or babysitters or others who you felt safe with? What did you do after school?

4. You know how they say that some things are for girls and others are for boys? What do you think about this? Who taught you these things?

5. What did you like to play or play with when you were younger? Please describe your favorite games or activities? Why? How many friends did you have? Do you remember playing with other kids? What sorts of games or activities did you play with friends? Why did you play/enjoy that game/activity?

6. Tell me about going through elementary, middle, high school? What memories of this time do you recall or consider important events you will never forget? Why? How did that make you feel?

7. Tell me about how you spend your free time. What about the people you are friends with now? What qualities do you look for in a friend? Do you have a best friend? What makes NAME more special than the others?

8. Can you tell me about a time that you "changed your mind?" What happened? Why did you change your mind?

9. Are you interested in relationships with anyone? Why? What would the perfect partner for you be like? Why? Why do you feel you would make a good partner? Why?

10. What are your favorite magazines, books, commercials, television shows, or movies. Why? Favorite characters? Why? Role models? Why?

11. What do you worry about? Why?

12. Who do you respect? Why? Who would you not want to disappoint? Why? Can you say why you care so much about NAME?

13. When did you receive an official autism diagnosis? How did that make you feel? How do you feel about it now? Why?

14. Where do you think you will be five years from now? Why? What do you hope for the future? Why?

15. Is there anything you would like others to know about the thoughts and feelings of people on the autism spectrum? Why?

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