AUTISTIC WORKERS: INVISIBLE PEOPLE

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ABSTRACT

Existing literature about autistic workers concentrates on the troubles autistics have in the workplace; these problems are linked back to documented deficits in autistic people, thereby constructing a picture of autistic workers as people who need to be helped. There have been no academic studies asking autistic adults to give their general impressions on their work environments. The paucity of narratives from working autistic authorities has effectively made them into a hidden, or invisible population. We do not know if they agree with the views presented about them. We do not know what jobs they are in or in what levels of authority they are working. The only way to understand working autistic adults and their worth and presence in the workforce, is to ask them.

This exploratory, qualitative study asked 38 autistic adults (currently working or who have a past work history) 55 questions about their work environments. Most participants provided elaborative answers about their work experiences. Participant experiences often contradicted current literature about autistic adults or mentioned little known phenomenon. Confirmation of existing themes in autism literature was sometimes arguable. The narrative accounts gathered in this study give new opportunities for research into autistic adults and their places in society.
Current written works about autistic workers focuses on what they cannot do and what problems they experience, which gives the impression that autistic workers need help. It is not yet known what autistics think about their general work environments because there have been no studies published about this subject. Since there is little information about autistic workers and what opinions they may have, they have been effectively rendered into a hidden, or invisible population. We do not know if they agree with the views presented about them. We do not know what jobs they are in or in what levels of authority they are working. The only way to understand working autistic adults and their worth and presence in the workforce, is to ask them.

In this study, I asked 38 autistic adults about their work environments. Most participants provided detailed answers about their work experiences. Participant experiences often contradicted current literature about autistic adults or mentioned little known phenomenon. This may bring into question basic assumptions about the functioning of autistics in society. Confirmation of existing themes in autism literature was sometimes arguable, which suggests that a re-examination of those themes may be in order. The information gathered in this study give new opportunities for research into autistic adults and their places in society.
DEDICATION

This thesis is dedicated to the everyday worker.
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CHAPTER 1: INTRODUCTION

This thesis is about the experiences of autistic workers. There have been some important studies involving narrative accounts from autistic workers, describing their experiences (Hurlbutt and Chalmers 2004; Roux et al. 2013). However, these studies have focused on problems and how to overcome those problems. There have been no studies including broad accounts of working life as an autistic adult, from the perspective of those working autistics themselves. The fact that this population is not being listened to or acknowledged suggests that working autistic adults are a hidden, or invisible population. They do not exist unless they have a problem. There may be many interesting sociological events occurring regarding autistic adults in the workplace which are not being accounted for and could easily be explored further.

Current estimates by the Centers for Disease Control (CDC) are that 1 in every 68 people are autistic ((CDC) 2014). Now comprising 1.5% of the US population, autistics are becoming understood as minorities (Gernsbacher 2007). According to the American Psychiatric Association (APA), people diagnosed as being on the autism spectrum tend to have communication and friendship deficits, may be overly dependent on routines, highly sensitive to change or environment, and may display intense focus on inappropriate items (APA 2013). These behaviors must be present since childhood, and may vary per individual (APA 2013).

Estimations of working autistics vary widely and have little scientific basis. A commonly quoted statistic is that 90% of autistic people are under- and unemployed. An online “Google” search for the keywords “autism” and “employment,” returns results of web pages from Huffington Post and Autism Speaks quoting this number (Speaks 2012; Wilkie 2012). Research into online articles about autism and employment revealed unsupported anecdotes, with few references to empirical data; sources were often misquoted or negatively slanted by groups such
as Autism Speaks (Speaks 2012; Wilkie 2012). It is not possible to gain an accurate or holistic view of autistic workers from currently available data.

As of 2015, 59.3% of all Americans are gainfully employed (Statistics 2015). If 1.5% of the US population is estimated to be on the autism spectrum, and 59.3% of the US population is employed, 0.9% of Americans (or 2,870,100 American people) may be working autistics ((CDC) 2012; Statistics 2015). A 2005 study estimated that only 12% of adults with Asperger’s Syndrome (a form of autism) are gainfully employed (Howlin, Alcock, and Burkin 2005). I was unable to find estimations for all autism spectrum workers, and I was also unable to find any other estimations that traced back to empirical studies. Howlin et al.’s estimate is problematic because they assume that all people on the autism spectrum have been diagnosed and have officially disclosed their autism status to an employer or an employment service. All working autistic adults not meeting these narrow criteria are discounted. Not considering the contributions of successful autistic individuals paints a bleak picture for other autistic people and their families.

Research Problem

Other studies involving employment and autism have asked how autistics can gain and keep employment (Hendricks 2010; Hurlbutt and Chalmers 2004; Nesbitt 2000; Roux et al. 2013). In this study, I assume that a large number of autistic people are already present in the workplace, so far unaccounted for in academic autism literature. Given that they are present in the workforce, understanding work experiences of autistic people is an important first step.
CHAPTER 2: THEORETICAL FRAMEWORK

Literature Review

Social Science on Autism

Sociological research into the phenomenon of autism spectrum disorder (ASD) is relatively new (Eyal et al. 2010; Lester and Paulus 2012; Mercer 2007; Silverman 2008; Werner 2011). Some have questioned whether autistic people have formed their own community or culture (Mercer 2007; Silverman 2008). Others have examined how people from the non-autistic majority perceive autistic individuals (Eyal et al. 2010; Lester and Paulus 2012; Werner 2011).

Joyce Davidson and Michael Orsini coined the term “critical autism studies,” which is currently the only theoretical advancement in the realm of autism social scholarship (Orsini and Davidson 2013). Existing social science about autism is mostly from the perspectives of psychologists, social geographers, and social historians. Other groundwork has been covered by the online autism self-advocacy movement. Self-advocates occasionally reach into academia, either by being cited, like Amanda Baggs’ monumental viral video, “In My Language” or becoming a published academic paper, like Leif Ekblad’s article about his Aspie Quiz (Baggs and Baggs 2007; Ekblad 2013).

Autism as a Strength

Most of the current literature about working autistic adults focuses on problems that they experience (Baldwin, Costley, and Warren 2014; Hendricks 2010; Howlin et al. 2005; Hurlbutt and Chalmers 2004; Nesbitt 2000; Roux et al. 2013; Shattuck et al. 2012; Smith, Belcher, and Juhrs 2000). We know little about ways in which autism has aided an individual or how an autistic employee might be preferable over a non-autistic one. A greater understanding of these
positive experiences will improve understanding of what works and how things can be made even better.

Organizations typically measure the personal characteristics of workers in five standard ways: extraversion, agreeableness, conscientiousness, emotional stability, and openness to experience (Schermerhorn Jr. et al. 2012). Work-related stress most often occurs when there is little worker control or support, conflicting relationships in the workplace, poorly defined roles, and organizational change (Tehrani 2014). Table 1 (shown below) shows that autistic people possess many traits that are resistant to work-related stress, giving them abilities to deliver what organizations want.

Table 1: Company seeking versus work stress and autistic traits

<table>
<thead>
<tr>
<th>Company Seeking</th>
<th>Work-related Stress</th>
<th>Autistic Trait</th>
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<tbody>
<tr>
<td><strong>Extraversion</strong></td>
<td>Conflicting Relationships</td>
<td>Disinterest in “office politics”</td>
</tr>
<tr>
<td><strong>Agreeableness</strong></td>
<td>Poorly-defined roles/conflicting relationships</td>
<td>Likes to follow rules/likes consistency</td>
</tr>
<tr>
<td><strong>Conscientiousness</strong></td>
<td>Poorly-defined Roles</td>
<td>Honesty/superior visual processing (error detection)</td>
</tr>
<tr>
<td><strong>Emotional Stability</strong></td>
<td>Little Worker Control/Support</td>
<td>Superior distraction resistance/parallel perception</td>
</tr>
<tr>
<td><strong>Openness to Experience</strong></td>
<td>Organizational Change</td>
<td>Used to working in uncomfortable situations</td>
</tr>
</tbody>
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(Gernsbacher et al. 2008; Schermerhorn Jr. et al. 2012; Soraya 2013; Stevenson and Gernsbacher 2013; Tehrani 2014)

Autistic people were shown to excel in parallel perception (paying attention to multiple activities simultaneously), as well as distraction resistance, and abstract spatial reasoning, with no deficits as compared to non-autistic controls in spatial, numeric, or verbal reasoning tests
Autistic individuals have a superior ability over non-autistics in visual searches because they are able to more quickly identify correct targets among false ones (Gonzalez et al. 2013). This means that most autistic people are able to pay attention to multiple things (conversations, screens, papers, etc.) at once, are more likely to stay on task, can conduct fast and accurate visual searches, and can transform abstract thought into multi-dimensional visualizations. Autistic workers tend to be honest, prefer rules and consistency, and often struggle to see the point of “office politics,” which do not appear to them to have anything to do with their job (Soraya 2013).

For this thesis, I expect that autistic employees are already present in the workforce, giving organizations the type of diverse workers needed to accomplish diverse tasks. Autistic workers may have to sometimes pretend to be the type of employee that companies say they want (extraverts, open to experiences), but in order to deliver services and products, autistic workers help give companies the diversity they need. The “odd person out” in a company often performs important functions, such as breaking up groupthink, presenting alternate routes, and completing specialty work.

Negative Perceptions of Autistics

Autistic people are typically perceived as those who do not fit in. Media representations of autistics tend to focus negative attention on what is constructed to be the shortcomings or disabilities of a person on the autism spectrum. Many autistic people dislike being called “autistic” (Linton et al. 2014) or delay seeking a medical diagnosis because they do not wish to be seen as being like the autistic characters seen on television (Robison 2007). Jim Parsons plays Sheldon on the popular TV series “The Big Bang Theory.” After being repeatedly asked by fans if his character has Asperger’s Syndrome (a form of autism), he went to the show’s writers,
who told him “no” (Thielman 2014). Parson’s accepted this and passed the information on to fans, but said that he could see how Sheldon has many autistic traits (Thielman 2014). Online contributor and self-advocate Pensieve calls the show an “offensive parody” and that writers specifically created Sheldon’s character to be made fun of by the other characters (Roy 2011). If Sheldon’s character was officially said to be on the autism spectrum, his quirks would become symptoms and it would no longer be okay to laugh (Roy 2011). Another contributor suggested that Sheldon’s character is similar to parodies featuring white performers in blackface and typically developed performers as retarded (bizboy1 2012).

Academic literature specifically addressing negative attitudes and behavior toward autistic people is primarily from the perspectives of parents and caregiving professionals (Lester and Paulus 2012; Werner 2011). In a 2008 study, caregiving profession students ranked working with autistic students lowest out of a list of 13 options (Johnson, Bloomberg, and Iacano 2008). These students explained that although they had no practical knowledge of autism, their ideas that autistic people were unhygienic, unresponsive, and not “curable” deterred them from wanting to work with this population (Werner 2011). Both parents and teachers rated autistic children as having less co-operation, assertion, self-control, and responsibility than non-autistic children, and thus being more of a problem (Macintosh and Dissanayake 2006). In a later study, parents and teachers noted social distancing abnormalities in autistic children; with inappropriate touching, speaking volume, and a tendency to walk between others who were having a conversation (Kennedy and Adolphs 2014). When non-autistic adults are asked to talk about their autistic students and children, the adults tend to zero in on what they perceive as the child’s social failures. Other studies have shown that proximity to autistic people is associated with stress in non-autistic people (Dillenburger et al. 2010; Lester and Paulus 2012; Macintosh and
Dissanayake 2006). Individuals whose mere presence seems to make others around them uncomfortable can become targets for stigmatizing treatment.

**Stigma of Autism and Passing as Neurotypical**

A person whose appearance and/or behavior does not fit positive stereotypes is often classified as a stigmatized, negative stereotype (Goffman 1963b). Once the stigmatized individual (in this case, a person displaying autistic characteristics), is aware of the negative effect of her/is behavior, (s)he works harder to stay within normative boundaries, thus affirming the power of the other person’s social reality (Goffman 1963a; Link and Phelan 2014). In this way, autistics themselves help to perpetrate the problem. For the majority population, stigmatizing unwanted attributes helps to keep unwanted people down, in and away (Link and Phelan 2014).

What kind of labels or stigmas are autistics trying to avoid by putting so much effort into changing their natural behaviors? One negative stereotype is a pervasive common confusion between autism and mental retardation. Many websites targeting newly diagnosed autistics and their parents explain that autistic people are not retarded (Familydoctor.org 2014; Stillman 2015; Wallace-Iles 2015). The link between mental retardation and autism was established by faulty diagnostic techniques which have not been used in the past 25 to 40 years and have since been debunked (Edelson 2006). Contributing to this problem is the emerging use of the word “autistic” as a slur (Baskin 2013). The Urban Dictionary describes autistics as having “the intelligence of a baby, in which they can only scream, grab at your shirt, drool, and do other baby type stuff” (Alexi 2004). Members of an online autism forum voted “retarded” as being a more negative label than “crazy,” with 63%, or 24 members voting that “retarded” was worse (Campin_Cat 2015). “One could be good crazy or bad crazy. There’s no such thing as good
retarded” said a long-standing member. (Kraftiekortie 2015). Other members refused to type the full word, referring to it as the “R word” because they found it so offensive (Andrethemoogle and Adoylelb90815 2015).

Another offensive common label confused with autism is “idiot savant.” The term “idiot savant” was a nineteenth century medical term used to describe rare persons with IQs lower than 25 who had genius or prodigal skills in some areas (Treffert 2014b). Although “most symptoms of autism are deficits by nature” (Reynolds, Tammi Dombeck 2006), online articles estimate that 10% of all autistics are savants (Edelson 2015; Reynolds, Tammi Dombeck 2006). This figure is misleading. One in ten autistic persons were reported in 1978 by their parents to have evidence of savant ability, specifically musical abilities and above average memory (Rimland 1978).

Savant expert Darold Treffert currently counts only 319 known savants in the world, both autistic and non-autistic, with natural and acquired savantism (Treffert 2014a). Autistics should not be assumed to have savant abilities and savants should not be assumed to be autistic (Treffert 2009, 2014a, 2014b).

Perhaps the most offensive idea is that a person with a social stigma, such as autism, is not believed to be quite human (Goffman 1963b). Autistic people are systematically grouped with chimpanzees and robots as being dissimilar to human beings and lacking base humanity (Gernsbacher 2007; Hacking 2009b). The argument that autistics are closer to apes and robots is built on the idea that there is universal human social behavior that autistic people do not tend to exhibit (Gernsbacher 2007). Some have observed that autistic people elicit an “uncanny valley” response in non-autistic people; the autistic person is said to be “creepy” or “slightly off” like a humanoid simulating human actions (Mori 2012; Rabbitears 2011; WalkingThesaurus 2011). A study explored a collection of traits that were judged to be connected with humanness as
compared to animals and robots (Wilson and Haslam 2013). Performing repetitive tasks was judged to be something robots would do more often than humans; decreased facial expressions and fewer greeting gestures were associated with animals (Wilson and Haslam 2013).

It is disturbing to consider that some people are suspected of being less than human on the basis of simple mannerisms and habits that they have little control over. However, this gives us insight into why one might choose to keep one’s autism status a secret. It is a label written on one’s forehead in invisible ink; present at every job interview, first date, and PTA meeting. An autistic person never knows when others will pick up on this hidden label and how they will react. Living day-to-day with the possibility of having one’s identity spoiled or discredited by another person may be unpleasant, but harmless in most social arenas, such as in the grocery store, or while meeting a spouse’s friend. But when an employee, student, co-worker, or manager notices characteristics associated with being abnormal, of having a disorder, or of being a certain kind of person, this knowledge is dangerous (Goffman 1961, 1963b). An autistic person has no control over another person’s opinions or education about the autism spectrum, or who else might be privy to the identification that has just occurred (Diament 2005). It is therefore crucial for people on the autism spectrum to guard their persona from being discredited and present as normal a face as possible (Goffman 1963b). Over time, autistic people tend to form a sense of when it is okay to disclose or be oneself and when a “neurotypical emulator” (non-autistic emulator) is required (Hurlbutt and Chalmers 2004).

Resistance

Due to increased awareness and diagnosis of autism, a new autism community has formed, which is defining its own social rules (Raymaker and Nicolaidis 2013; Silverman 2008). A collective of individuals stigmatized by the majority population can create its own standards
for normalcy, where people can “refuse to be what they are supposed to be” (Berger and Luckmann 1966). Now part of a minority culture, the autistic individual undergoes a transformation from a “questionable person” trying to maintain a mainstream role to an “officially questioned” person who now fits into the new group with other “questioned” people (Goffman 1961). Autistic as a cultural identity instead of a diagnosis is now being formed as a result of discourse within this group (Davidson 2008; Hacking 2009a).

Autistic Minorities in the Non-Autistic Majority

It is important to listen to the experiences of autistic individuals as a minority population. Discrimination, manipulation and bullying of autism spectrum individuals is common (Balfe and Tantam 2010; Hurlbutt and Chalmers 2004). Autistic victims are often blamed for their mistreatment on the basis that they have deficits in social skills and are therefore unable to judge the social behavior of others. The burden of understanding is placed on the autistic individual, whose communication may not be perfectly in line with majority standards.

When non-autistics are offended by interactions from an autistic person, the non-autistic person often does not explain the offense to the autistic (Roy 2014). The autistic person comes away from the encounter confused and angry, “swept away” on the emotions from the other person, waiting for the situation to resolve (Roy 2014). Autistics who would be diagnosed as “high-functioning” or having Asperger’s Syndrome are frequently frustrated by the lack of understanding for their differences (Forbes n.d.). An autistic’s friends and family may not accept that their loved one is on the spectrum because (s)he is socially successful (Forbes n.d.). Autistics can and do work, drive cars, marry, have children, and may not show outward signs of autism (Forbes n.d.; Robison 2007). Just because an individual can pass social scrutiny, does not mean that individual is not on the autism spectrum, with differences that should be respected.
Autistic Work Experiences

What little scholarship is available about working autistics is centered on developmental psychology. Some narrative accounts exist for the challenges working autistic adults face (Hurlbutt and Chalmers 2004; Roux et al. 2013), but these studies focus on problems without first addressing some fundamental issues: Have autistic workers disclosed their autism status at work, and why or why not? The answers to these questions could tell us what leads to success and failure in the workplace for autistic employees. Not only is this important for sociology, but for autistic people, their families, and for companies seeking resources.

From the current literature, it is difficult to form a holistic picture of autistic people at work. Most of the literature I found was about the difficulties faced by autistic employees, with little about positive experiences. Existing positive literature suggests that autistic people can find success by pursuing fields involving their special interests (Grandin and Duffy 2008; Smith et al. 2000). However, a recent study found that in practicality, autistic careers stretch widely across all fields (Baldwin et al. 2014). Although prone to some unique difficulties, autistics report feeling satisfaction and pride when challenging themselves in their careers (Baldwin et al. 2014). Autistic people often encounter difficulties at work when attempting to keep up with social nuances, such as how many questions is too much, or not enough, or how long a sentence should be (Hurlbutt and Chalmers 2004). “Office politics” is a dangerous, confusing, but unavoidable problem for most working autistics, who often struggle to understand the point (Soraya 2013). With un- and underemployment for openly autistic people a constant threat, there is a great push to pass as non-autistic (Hurlbutt and Chalmers 2002). Passing requires a great deal of effort in learning or at least mimicking social skills, especially while completing job tasks, leading to high levels of anxiety and exhaustion (Hendricks 2010; Hurlbutt and Chalmers 2004). Many are
frustrated by a lack of room to advance in their careers without being required to deal heavily with other people (Baldwin et al. 2014).

Autistics have noted that friendships can be invaluable at navigating social space, because friends know when to step in and when to back off (Biklen 2005; Rossetti 2011). A friend or colleague at work can provide constructive feedback and explain social situations (Bissonnette 2014). People who are similar in location, behavior, interests, or personality traits tend to build friendships and adopt helping behaviors (Choi 2006; Festinger, Schacter, and Back 1952). Some examples of helping behaviors at work are to offer more information to co-workers about a project, to “cover” for a co-worker who needs a break, or to adjust personal habits to make a co-worker more comfortable. A recent longitudinal study found that three quarters of the adult autistics studied reported having more than one friend; 48% reported having two or more friends (Helles et al. 2016). I could not find literature directly addressing the role of professional colleagues for autistic workers; do colleagues have specific helping or negative behaviors? Do autistic workers help their colleagues more or less than non-autistic workers?

**Autistic Work Communities**

Autistic workers in an online forum have anecdotally noted that they work with other autistic people in what might be called autistic work communities (DigitalMelody 2014; DontASPme 2013; Edenthiel 2015; KraftieKortie 2015). There is little in academic literature to reflect these communities at any but a circumstantial level, such as when equal opportunity initiatives have been created to hire openly autistic employees (Chu 2015; McGregor 2015). A Silicon Valley worker assumed he had worked with many others also on the autism spectrum, but could not guess which ones were on the spectrum because no one specifically told him they were (Rocket 2015). Autistic professors interviewed for Diament’s 2005 article about autism
Disclosure in academia voiced a similar sentiment; they suspected others on campus of being either undiagnosed or undisclosing autistics.

It does not appear that the notion of autistic communities within workplaces has been formally studied, except to note it as a novelty (Ladika 2012; Wilkie 2012). Even well-known companies which continually seek large numbers of autistic employees or are mostly comprised of autistics, such as ASAN (Autistic Self Advocacy Network), German IT consultants Auticon, and International IT giant Specialisterne have no published articles about their internal work communities ((ASAN) 2015; Auticon 2015; Specialisterne 2015). It may be that autistic employees working together is too common a phenomenon to be noticed and therefore studied academically. Online contributors have referenced the existence of a “Specialisterne Survivor’s Group” for disgruntled former workers (DigitalMelody 2014; DontASPme 2013). Former workers describe Specialisterne Scotland as a hasty setup, with non-autistic, inexperienced management knowing nothing about autism and refusing to communicate even simple information with an all autistic IT staff (DigitalMelody 2014; DontASPme 2013). Online contributor DontASPme speculated that neurotypical or non-autistic workers would have had less patience with the situation and walked out soon than did the autistic workers (DontASPme 2013).

Disclosure

Disclosing ones’ autism status in the workplace is a delicate and potentially risky step in the life of an autistic adult. Given the current popular understanding of autism, disclosure could mean that a previously valued employee is suddenly reduced in the eyes of employers and co-workers (Murray 2006). An autism disclosure that may be meant to convey understanding and empowerment may instead be met with pity and questioning of the autistic speaker’s capabilities
Openly autistic professors have observed what they see as clear signs of autism in some of their colleagues, but say these other professors are either undiagnosed or keeping their autism status to themselves (Diament 2005). Even in the relatively accepting environment of a college campus, where focused knowledge is valued and diversity celebrated, the risk of being looked down on is too great (Diament 2005).

Disclosure of any disability status is only protected under the Americans with Disabilities Act (ADA) if the disability is medically documented (Jones 2012). Information that is voluntarily given by the disabled worker and information gained through third parties is not protected by the ADA and can be shared with others or for discriminatory purposes (Jones 2012). Some autism advocates say it is better to prepare an official script disclosing one’s strengths and weaknesses without using the words “autism” or “Asperger’s” (Dubin 2009). Many autistics successfully passing as non-autistic explain sensory problems and uncontrolled actions as allergies, hyperactivity or other socially accepted medical problems (Davidson and Henderson 2010).

Accommodations

In a recent study, 72% of autistic workers were not receiving help related to their autism spectrum disorder (Baldwin et al. 2014). In the same study, 66% would like to receive some kind of accommodations (Baldwin et al. 2014). Some workplace accommodations that can be helpful for autistic workers are written instructions, minutes after office meetings, natural lighting, a quiet work area, and flex time (Smith et al. 2000; Soraya 2013). Unofficial accommodations between autistic and non-autistic friends has been shown to exist, but helping behaviors between autistic and non-autistic colleagues has not yet been studied academically (Rossetti 2011).
Key Points from the Literature Review

I based my survey questions and general approach on the following key points, which were detailed in my literature review: There is not much academic research in social science available regarding autistic adults in general, and even fewer specifically addressing autistic workers; autistic traits may be viewed by organizations as assets rather than liabilities; existing literature about how autistics are perceived suggests that they are generally disliked; stigma against autistic traits may pressure many to pass as non-autistic or neurotypical; autism as a cultural identity is a small, but growing narrative; most literature about autistic workers describes their problems at work; there is no academic literature about autistic co-workers or autistics as supervisors; disclosure may be a risky step for an autistic authority; and in the only study about autism-related accommodations, most workers were not receiving accommodations related to autism.

Conceptual Framework

I am using an exploratory approach in this thesis, with a general lens of critical autism studies. There is little existing literature for me to work from in regards to autistic workers and their experiences, which makes exploratory research the most reasonable approach. My viewpoints are from critical autism theory, although current literature in that area does not address specific social environments such as workplaces. I am seeking to emphasize the experiential versus the explanatory side of autism with this research.

Critical Autism Studies

This investigation might contribute to the emerging field of critical autism studies (Orsini and Davidson 2013), a subfield of the sociology of autism (Eyal et al. 2010). Critical autism studies expands understandings of autistic individuals by approaching autism and disability as
human social constructs (Davidson and Henderson 2010; Hughes 2012). Special attention is paid to how and why autism is represented and collective efforts are made to advance new narratives and analytical frameworks that challenge those pre-existing (Orsini and Davidson 2013).

Evidence shows that people who could now be categorized as autistic have always been in various societies (Eyal et al. 2010; Grinker 2007; Silverman 2008). Although the Centers for Disease Control (CDC) estimates 1 in 68 are autistic, this rate varies per state and country (CDC 2012; Eyal et al. 2010). In some places, autism is diagnosed frequently and allocated many public resources; in others, autistic individuals are considered rare and given high cultural status (Eyal et al. 2010; Grinker 2007). Critical autism scholars view autism as a helpful way to describe a “behavioral syndrome” (Silverman 2012) which occurs in many cultures, but not a universally measurable phenomenon (Eyal et al. 2010; Silverman 2012). Critical autism studies is an academic form of the autism self-advocacy movement, who use the slogan, “Nothing about us without us” (ASAN 2015). All autistic experience is valued, all communication forms encouraged, and participatory, collaborative research is preferred over deficit-seeking methods (Baggs 2013; Raymaker and Nicolaidis 2013).

Within the emerging field of critical autism studies, there have been no studies of employment experiences of autistic people. This is a key area for autism research, as it involves an important aspect of most adult lives. Existing literature assumes that autistic adults have used specialized autism services, at least in childhood. These services did not exist for some adults working today and may not have been necessary for others. It is valuable to give working autistics a platform to discuss their disclosure experiences without requiring them to use an autism support service, which they may not need or want. Literature suggests that autistic people
have many positive attributes that could be serving them well in the workplace. Though this is an empirical question, this question emerges quite centrally from critical autism studies’ focus on strengths as opposed to deficits.

Exploratory Research

Exploratory research is an inductive data analysis method that allows the researcher to form research questions, data themes, and hypotheses based on data collection (Bernard, Wutich, and Ryan 2017). Exploratory research is appropriate to use when a subject is new, unexplored, or when very little is known about it (Neuman 2011). Very little information is currently available about autistic work experiences; what has been documented has only explored one-sided narratives suggesting that autistic workers cause and experience significant problems (Hendricks 2010; Hurlbutt and Chalmers 2004; Roux et al. 2013).

The combination of exploratory research with critical autism studies gave this population of autistic workers a new chance at representation. I did not expect that I would need to change focus in this project after data was collected, but I did expect to need greater flexibility than in most thesis projects, due to the paucity of information I was able to gather in the literature review. Exploratory research does allow a project to take shape and even change direction if needed based on the flow of data collected (Birks and Mills 2015; Neuman 2011). I wanted the ability to represent participant narratives accurately, with the speaker’s original intent intact, even if the narrative did not “fit” a general theme or aid in a point I was trying to make. Exploratory research is used to formulate theory, not to confirm existing theory (Bernard et al. 2017). I felt that using exploratory research gave this project a better chance at accurate representation.
I read through the current (and some fairly old) literature about autistic workers and about the general experiences of autistic adults. I also gathered information about work environments, friendships and helping at work, stigma, labeling theory, and passing. I tried to put this information together cohesively to write the literature review and to form a bank of survey questions for participants, with the understanding that some of my questions would bring no findings and others would lead me to a better understanding of this project, which could change with the participants’ data.
CHAPTER 3: METHODS

This is a qualitative research study using structured interviews. My questionnaire has both closed, selected-option questions and open-ended questions requiring narrative answers (Bernard et al. 2017). Research participants had an option to revise or change answers or to give extra information via email, telephone, Skype, or in-person. I also followed up with some participants in cases where a participant gave a narrative answer which I felt was unclear.

This study is a narrative analysis of the stories that autistic workers tell about their experiences in deciding whether to disclose an autism status at work. Participants had the option of giving elaborative responses about many other areas of their work life, in addition to disclosure. I coded these narratives to look for themes to emerge to help understand this phenomenon. I knew that other themes could possibly emerge that may change the shape of this project. More precisely, this project could stop being about disclosure in the workplace and start being about autistic work experiences.

Language

Autism and Asperger’s

The DSM V consolidated Asperger’s and other autism-spectrum disorders into one condition, Autism Spectrum Disorder (ASD) ((APA) 2013). This was a controversial change, partially because some thought Asperger’s Syndrome should remain a distinctive category (Linton et al. 2014). I occasionally mentioned “Asperger’s” to reference past studies when Asperger’s Syndrome was a separate diagnosis and to respect people who self-identify as having “Asperger’s” but not “autism.”
Identity-first language

I am using identity-first language (“autistic person”), instead of person-first language (“person with autism”). Identity-first language is most often preferred by the autism self-advocacy community (Brown 2015). I am referring to all individuals on the autism spectrum as “autistic” or “being on the autism spectrum.” Referring to a person as “having autism” implies that autism is a condition that can be removed or diffused from the individual (Brown 2015).

Other Identifications

I am referring to people not on the autism spectrum as “non-autistic,” “not on the autism spectrum,” or “neurotypical.” The term “neurotypical” is a term commonly used in autistic culture to refer to non-autistic persons, but is not technically correct as it excludes those with neurological conditions that are not autism. I do not use the term “typically developed” as it infers that autism is a developmental condition and that those who are not autistic do not have developmental conditions. I am not using new terms, “neurodiverse” and “neurodiversity” (neurologically diverse) to refer to people on the autism spectrum because there is current disagreement about what kind of person should be referred to as neurodiverse. Some argue that neurodiversity covers all people, others use “neurodiversity” only when speaking about people on the autism spectrum, and still others use the term to refer to autism and/or other neurological conditions, such as attention-deficit hyperactivity disorder (ADHD), bipolar disorder, etc. Issues of neurology and developmental normalcy are beyond the scope of this study.

Data Collection

Participants are over 18, currently/formerly employed or currently/formerly volunteering in a service position. Participants are able to read in English, use a computer, and have Internet access. Gender identification, sexual orientation, and race are not being noted. The survey did
not ask participants about gender identification or sexual orientation. Participants had the option to disclose some information such as gender and race for possible emerging themes. Not all participants chose to disclose race information and for that reason I did not look for themes regarding race. Some information, such as location by nation of the participants, was automatically collected by the data collection software and was analyzed for possible themes and subthemes.

Recruitment materials were distributed as following:

- A posting was made on www.WrongPlanet.net, an online autism community
- Three (3) electronic fliers were distributed to the Virginia Tech Sociology graduate email list (listservs) with a request that recipients share them
- Three (3) paper fliers were posted in designated community notice areas on the campuses of Virginia Tech and Hollins University
- Three (3) paper fliers were posted in designated community notice areas in convenience stores and coffee shops in the cities of Blacksburg and Roanoke Virginia in the United States

All fliers and postings referred participants to a Wordpress.com site for this project, which further directed participants to different methods in which they could conduct an interview (Nye 2016). A link for a Survey Monkey online questionnaire was available on the Wordpress for participants to take in lieu of an in-person, Skype, mail, or email interview (Nye 2015). Some participants forwarded the link to the Wordpress via social media or other means, which was not anticipated (Nye 2016). Some participants forwarded the project email address (AutAtWorkVT.gmail.com) directly to other people, which was also not anticipated. This seemed to result in a few more participants.
How Cases Were Selected

Participants were asked how they were diagnosed with autism. Only participants who received an autism diagnosis through a medical professional, an educational professional, a social service professional or from a self-administered autism test were selected. In Baldwin et al.’s 2014 study, participants were asked if they received a medical autism spectrum diagnosis. Potential participants in Baldwin et al.’s study who self-identified as autistic, but had not been diagnosed were not selected (Baldwin et al. 2014). My method of selection included autistic individuals who have not sought out a medical diagnosis. I am assuming that many autistic adults do not bother to pursue a medical diagnosis. If an adult has personal knowledge that (s)he is on the autism spectrum and is not in need of services that could be obtained from a formal, medical diagnosis, there would be little point in confirming one’s personal knowledge with a medical diagnosis. This study should gain a more holistic picture of autistic workers by accepting participants with any kind of autism diagnosis (self-diagnoses included).

Number of Cases

I initially gathered a total of 40 participants. Two participants were then excluded because they did not include an informed consent document. There are a total number of 38 active participants in this study. Participants were required to be either current or past workers in paid or unpaid (volunteer) employment. In Baldwin et al.’s study, which was similar to this one, potential participants who were not currently working in paid employment were not selected (Baldwin et al. 2014). Volunteers generally have the same work structure as paid employees (coworkers, a person to report to, responsibilities, work tasks). I contend that past work experiences have the same validity as experiences from current employment. In order to gather the most
complete picture of “work” for autistic people, I include both non-paid work and past work experiences in this study.

Special Considerations

Informed Consent

I provided participants with a three-page informed consent. Standard online informed consents are about a paragraph long and paper informed consents are about one page long. I consider autistic adults to be a sensitive population, who are likely to be suspicious of autism research. In a recent study, 95% of respondents with Asperger’s Syndrome (a form of autism) reported experiencing being bullied by others, with a vast majority of respondents also reporting feelings of victimization and exploitation (Balfe and Tantam 2010). A UK researcher working with autistic teenagers as participants created a tailored informed consent process to ensure that her participants truly understood the process of consent and of participating in research (Lloyd 2012).

In order to create trust and promote understanding of the project and the consent process, I provided participants with the introduction and literature review to this research study to provide them with full informed consent. I included a link with a one-page summary (with two pages of citations) on the Autatwork Wordpress cite. On rare request, I provided a 29-page Introduction and Literature Review with full citations and a custom cover sheet with committee members’ names removed to participants. One participant elected not to participate after reading the supplemental information.
Communication Format

I gave participants a wide selection of communication formats in order to increase participant comfort: In-person (Southwest Virginia only), Skype, telephone, online questionnaire (Survey Monkey), email, and mail. Autistic people as a population have differences (or deficits) in communication ((CDC) 2012; (WHO) 2014), and so may have higher skills in one communication method over another. The structured interview format allowed participants to answer the questionnaire either with very little or quite a lot of detail. Most participants provided lengthy narrative responses to every questionnaire question, which was an unexpected result.

Communications with study participants were predominantly online through the use of web applications (Wordpress, SurveyMonkey) and email. In-person interviews and skype interviews were available as an option, but no participants chose this option. One participant chose a phone interview to provide additional information. All participants initially accessed the Wordpress website, where they were directed to either continue in an online format or to contact the researcher for alternate communication of study materials, through email, phone, Skype, or in-person. Participants could elect to bring a social advocate with them to in-person interviews or have another person present during any communication. No participants used a social advocate on their consent form. Additional instructions were added to the Wordpress site at the request of several participants with step-by-step instructions for full anonymity. In order to obtain the best possible narratives from autistic participants, it is important to communicate with participants in a way that offers options for personal comfort. Individuals with difficulties in standard communication and also individuals who wish to remain anonymous are best served by these methods.
Analytic Technique

How I Recorded Observations

I used a Wordpres web application to deliver information about this study to participants, and to give them an interface for taking questionnaires. It can be viewed at https://autatwork.wordpress.com/

The Wordpress links to a SurveyMonkey web form application. Participants completed the closed- and open-ended short answer questions, which were saved on a SurveyMonkey secured server. I downloaded survey results to an encrypted FIPS drive (a transportable “thumb” or “pen” drive), which is kept in a locked filing cabinet. Written and printed notes are kept in a locked filing cabinet. All materials pertaining to this study are to be destroyed 10 years after the Institutional Review Board (IRB) application was filed, or in 2025, but I intend to file for a request before 2025 to preserve the records further.

Duration of Data Collection

I began data collection in July 2015 and closed data collection on November 30, 2015. I corresponded with some participants via email through June 2016 to clarify answers from some of their responses.

Duration of Analysis

I spent from December 2015 to June 2016 analyzing data to isolate and code themes.

Limitations

I used participants from WrongPlanet.net, from the campuses of Virginia Tech and Hollins University, and from the areas of Roanoke, Virginia and Blacksburg, Virginia, both
located in the United States. WrongPlanet is an international site, with contributors all over the world. I was not able to identify cultural differences.

People on the autism spectrum who have never encountered difficulties as a result of being autistic are unlikely to have been diagnosed or to notice a research project like mine. I will be unable to document the experiences of this kind of person, who should be assumed to exist.
CHAPTER 4: ANALYSIS

I used an exploratory research approach to link participant’s responses to the literature review and to include new major themes that emerged from the data.

Pre-Testing of Questionnaire Using “Test Pilots”

I asked three participants to act as “test pilots” to read through a questionnaire draft for this study before the study began. The test pilots gave me feedback for improvements. I selected participants who had signed up early for the project and represented a diversity of genders, occupations, locations, and ages. All three test pilots signed informed consents before looking at drafts of the survey. These participants have two separate identifiers in my encrypted notes; their “Test Pilot” identifier and then their regular, study identifier. The Test Pilots were referred to as Test Pilot One, Test Pilot Two, and Test Pilot Three. The original questionnaire version that the Test Pilots reviewed contained 48 questions. Below are the most pertinent items changed after the Test Pilots reviewed the questionnaire draft:

- Test Pilot One suggested that I ask participants if they thought they had co-workers who may be “unknowingly” autistic, suggested additional questions about autism awareness, and ways to define employment and leadership.

- Test Pilot Two ignored many opportunities to elaborate on questions, therefore a question was added to the survey asking if I could follow-up with additional questions (which allowed more of an “interview” type dialog via email); clarification about present versus past tense was added after Test Pilot Two’s feedback; changed some wording for greater clarification per his suggestion (example: “are you happy with your position” was changed to “are you
satisfied…” because Test Pilot Two comment that very few people are “happy” to work).

- Both Test Pilot Two and Test Pilot Three commented that “work friends are not real friends” so this option was added as an answer.
- Test Pilot Three suggested that more “I don’t know” answer options be added and helped me clarify wording in a few questions to improve readability for more literal thinkers, questions about confidence in social skills were also added after reviewing her general comments.

**Procedure**

I performed open coding with frequencies and diagramming, focused, axial coding, and then theoretical coding to organize data into themes.

**Open Coding with Frequencies and Diagrams**

I read all of the participant responses and used color coding and minimal memos to make three-dimensional (3D) paper diagrams. These can be imagined to be “stacks” of data. I organized broad themes only during this stage, to screen for the possibility of themes, which I marked to look into later with greater depth. I counted frequencies as a way to confirm themes and trends. Sparse notes were kept on each diagram, which helped me to quickly access and sort participant data. For example, a diagram section might contain notes such as “female” “passes often” “anxiety” etc in reference to each data theme.

**Focused, Axial Coding**

Axial coding is a way of cross-referencing data in order to see data trends in qualitative analysis, similar to a regression model in quantitative analysis. It allows the “identification of
patterns and relationships” (Birks and Mills 2015). I performed this by placing the 3D diagrams in subject matter stacks and then reading them for similarities, which I then noted in memos. These may look like more frequencies in my writing, but are meant to be axial coding. For example, I made a stack of all participant folders who worked in IT and Computer Development. I found several strong data trends in this small group. I reproduced the entire section below for reference:

**Information Technology and Computer Systems Development**
This made up the largest career category with 10 participants. Half of these participants (5/10 or 50%) were in analyst/administrator positions. Two (2) participants were project leads, two (2) were developers or designers, and one (1) was a Vlogger. Most participants in this career category were current, former, or occasional supervisors (7/10 or 70%). All participants in this career category were male. Most (8/10 or 80%) had a college education and half (5/10 or 50%) had a Master’s degree. Most (9/10 or 90%) were located in the United States. Two (2) of the participants in this group used “othering” language for their co-workers (see “Othering of Non-Autistics” on page 87). I did not see any other similarities in this group.

*Table 2: IT and Programmer Attributes*

<table>
<thead>
<tr>
<th>IT and Computer Systems Development (Computer Programmers) n=10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervisors</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>College Educated</td>
</tr>
<tr>
<td>Advanced Degree</td>
</tr>
<tr>
<td>Used “Othering” Language</td>
</tr>
</tbody>
</table>
I was using axial coding to show what attributes are often present in each subgroup. In this case, autistic people who work in Information Technology (IT) and Computer Systems Development (programming) tend to be male, a supervisor, and highly educated. It is also worth noting that an unexpected finding (othering language of non-autistics) appeared in two participants in this group, out of a total of four people who used this language in this study. So here, it is not accurate to say that the IT/programmer group is likely to use othering language, however it is accurate to say that when looking at the othering group, half of that small population is located in the IT/programming career group. I believe that it is most accurate to note such a connection in both places, even if the connection appears less significant when present in the IT/programming career group.

Theoretical Coding

Finally, I cross-referenced my existing themes, still represented as 3D diagrams, with each other and with the literature review. My intent was to see which themes overlapped or could be merged together. I used this final step to come up with my themes as represented in this thesis. Some themes seemed to only arguably fit the literature review, but did not seem different enough to warrant generating a new theme. I noted these instances when discussing the theme and its data.

Representation of Data

It should be noted that nearly every participant gave an extensive, elaborative answer to nearly every questionnaire question. I was unable to use quotes from a large number of participants due to length restrictions on this thesis project. I chose five participants to represent the other participants with quoted answers. I coded each participant’s answer and have represented the majority result in a numbered frequency in each section. I summarized
elaborative answers from the other participants and included that information in the text when appropriate. The participants directly quoted are four males and one female. Two of these five are located in the United States, one from Canada, one from Australia, and one from Eastern Europe. The youngest participant quoted is 30 and the oldest is 49. These specific participants are somewhat random, but were chosen because their answers were the most representative of the data I received. There were other participants who could have been quoted instead of these five.

**Description of Participant Pool**

Age of Participants

The youngest participant in this study was 19 years old. The oldest participant was 62.

Gender of Participants

I gave participants three options with which to describe their gender:

Q3: What is your gender?
   a. Female
   b. Male
   c. Other (please specify) ____________________

One participant selected “Other; ftm post-op.” I took this to mean “female-to-male, post-operative” and this participant was categorized as a male. This participant pool had a somewhat high number of autistic females (14/38 or 37%) which reflects recent trends regarding sex/gender and diagnosis (Meng-Chuan, Baron-Cohen, and Buxbaum 2015).

National Origin and Location

I gave the participants a text box or blank space in which to describe their national origin. I had expected that some themes might arise from nation or culture-specific work practices.
However, I found that this question was not phrased clearly enough and many participants answered with their ethnic heritage. The survey software that I used collected IP addresses, which printed out on the header of each survey. An IP address can be used to show the physical location of each participant at the time they took the survey. I used this information to answer Q5 and provide national/regional locations, which I then divided into five categories: Australia, Eastern Europe, the United Kingdom, the United States, and Canada.

Table 3: Location of Participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>2</td>
</tr>
<tr>
<td>Eastern Europe</td>
<td>1</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>7</td>
</tr>
<tr>
<td>United States</td>
<td>24</td>
</tr>
<tr>
<td>Canada</td>
<td>3</td>
</tr>
</tbody>
</table>

Education

I asked participants about their education. I initially coded answers into the following categories: High School/Some College, College, and Advanced Degree. Two (2) participants had more than one advanced degree; two Masters degrees in one case, and a former veterinary surgeon now pursuing a PhD in a different field in the other case. It is estimated that 12% of people in the US have post-graduate degrees; 34% (13/38) of the participants in this study held post-graduate degrees (Bureau 2014).
Table 4: Education

<table>
<thead>
<tr>
<th>Q7: Highest Level of Education (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School/Some College</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

I then used axial coding to combine the college graduates with the advanced degree graduates to make a new category of All College Graduates. Most participants in this study (29/38 or 76%) have a college degree, which is higher than the US average of 42% (Bureau 2014).

Autism Diagnosis

Previous autism studies have only used participants who had medical diagnoses of autism or Asperger’s Syndrome (Baldwin et al. 2014; Howlin et al. 2005; Hurlbutt and Chalmers 2004). Autism is beginning to be understood as a culture and as a social minority (Davidson 2008; Orsini and Davidson 2013), which may have different forms of identification. I gave participants several options for confirmation that they were on the autism spectrum. Several participants (4) gave multiple answers, which all included a medical diagnosis. These participants were combined with the “medical diagnosis” answers, as a medical diagnosis is considered to be the acceptable form of documentation under the ADA (Anon 2010; Jones 2012). No potential participants attempted to take the survey with an E (I don’t know) or F (No) answer to Q8.
When was the participant diagnosed?

I asked this exploratory question to see if any themes emerged. I formed three categories for the resultant responses and relabeled this category:

### Table 6: Time Since Autism Diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Recent (within 5 years)</th>
<th>As an adult (more than 5 years ago)</th>
<th>As a child</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>23</td>
<td>10</td>
<td>5</td>
</tr>
</tbody>
</table>

A majority (23/38 or 61%) of the participants have been diagnosed within the last five years. This is a possible limitation of this study. Recent discovery that one is part of a minority social class could cause changes in perspective and behavior which may have an impact on participants’ responses.

### Occupations

I asked participants to list their current or past occupation. All but three participants were currently working. I sorted the responses into thematic categories.
Information Technology and Computer Systems Development

This made up the largest career category with 10 participants. Half of these participants (5/10 or 50%) were in analyst/administrator positions. Two (2) participants were project leads, two (2) were developers or designers, and one (1) was a Vlogger. Most participants in this career category were current, former, or occasional supervisors (7/10 or 70%). All participants in this career category were male. Most (8/10 or 80%) had a college education and half (5/10 or 50%) had a Master’s degree. Most (9/10 or 90%) were located in the United States. Two (2) of the participants in this group used “othering” language for their co-workers (see “Othering of Non-Autistics” on page 87). I did not see any other similarities in this group.

Business Systems and Administration

Seven (7) participants were grouped in the general category of business systems and administration. This included five participants who classified themselves as either typists, transcriptionists, data entry, or editors, as well as an accountant and a retired vice president of a financial institution. Most of these participants (6/7 or 86%) related that they were working with other people who they either knew or suspected were also on the autism spectrum. I did not see any other similarities in this group.

Customer Service and Service Industry

I grouped these two career fields together because both deal almost exclusively with the public in high pressure environments (work tasks are timed, part of the job is to deal with angry customers, there is little privacy for workers, etc). All of the five participants in this group were current or former supervisors. Most of the participants in this category (4/5 or 80%) were female. I did not notice other similarities within this group.
Education and Science Industry

This category includes professors, teachers, researchers and laboratory scientists. There were five (5) participants who fit into this general category. All five were college graduates. Three in this category (60%) held PhDs and one had a doctorate in a former career field and was completing a PhD in a new field. All of these participants admitted to passing at least some of the time. All were current or former supervisors. Two from this group (2/5 or 40%) were receiving unasked for accommodations; these were the two participants who held Bachelor’s degrees and were not working in higher education.

Social Services

Five (5) participants described working either as social workers or in high level supervisory positions in social work organizations. Most (4/5 or 80%) knew of or suspected other workers who were on the autism spectrum. Most (4/5 or 80%) of these participants were female and all were college graduates. One participant held two Master’s degrees and another was a Doctor of Medicine, despite no longer working directly in medicine. There were no other similarities within this group.

Blue Collar

Four (4) participants fit in a blue-collar, or traditional labor industry. This category consisted of a self-employed construction worker, an autobody painter, an over-the-road trucker, and a warehouse worker. Two (2) of the participants were trade school graduates and two (2) replied that they had some college experience. Two (2) participants in this category had been diagnosed as being autistic as children and the other two (2) participants were both diagnosed seven (7) years prior. This is notable as most of the participants in this study were recently
diagnosed. Three (3) in this category (75%) were not satisfied with their careers. All participants in this category were male. I did not find any other similarities in this career group.

Library Science

There were only two participants in these category, one of which was a work-study position and the other a supervisory status librarian. Both participants were female, both had disclosed at work, and had asked for and received accommodations. Both participants had recent diagnoses and knew of or suspected that they had co-workers also on the autism spectrum. Both stated that they were satisfied with their careers.

Theme from the Introduction

Presence of Autistic People in the Workforce

Howlin et al.’s 2005 study of autistic adults in a UK vocational program is often cited in an improper manner to claim that only 12% of all autistic adults are appropriately employed. I directly asked the employment status of participants in Q11 of my survey. Of the 38 participants in this study, 27 (71%) are in full-time jobs, 8 (21%) are in part-time jobs, 2 are unemployed and not seeking work and only 1 person is unemployed and seeking work.

Table 7: Employment status

<table>
<thead>
<tr>
<th>Q12: Employment status (n=38)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Full-time worker</td>
<td>27</td>
</tr>
<tr>
<td>Part-time worker</td>
<td>8</td>
</tr>
<tr>
<td>Unemployed, not seeking work</td>
<td>2</td>
</tr>
<tr>
<td>Unemployed, seeking work</td>
<td>1</td>
</tr>
</tbody>
</table>
Supervisory Status

I asked participants to tell me if they were currently or formerly an official or unofficial supervisor. I defined an unofficial supervisor as a person who sometimes leads others at work. I grouped participant answers into current/former/occasional/unofficial supervisors and those who were never supervisors.

**Table 8: Supervisory Status**

<table>
<thead>
<tr>
<th>Q12: Supervisory Status</th>
<th>(n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current supervisor</td>
<td>12</td>
</tr>
<tr>
<td>Former supervisor</td>
<td>7</td>
</tr>
<tr>
<td>Occasional/informal supervisor</td>
<td>6</td>
</tr>
<tr>
<td>Never a supervisor</td>
<td>13</td>
</tr>
</tbody>
</table>

Most participants (25/38 or 66%) were either current, former, or occasional/unofficial supervisors. No participants had autism-related job coaches or other special situations. When I looked at the data by age, a trend emerged:
I made a chart to illustrate this trend:

The older the participants were, the more likely it was that they were current, former, or occasional/unofficial supervisors. Nearly all (9/10 or 90%) of the Baby Boomer generation participants were current/former/occasional/unofficial supervisors. I did not see any other similarities within the group of participants with supervisor experience or the group without supervisor experience.

Two possible reasons occurred for me as why older autistics are more likely to be in supervisory positions. 1) Baby Boomers and Generation X are in the job market simultaneously,
despite the now older age of the Boomers. Many Boomers cannot afford to retire and many others choose not to retire, as they don’t seem to have adjusted to seeing themselves as an elderly population. This leaves less room for young workers to move up. Millennial workers, including those on the autism spectrum, are stuck in entry level positions. It is a common practice for a younger (Generation X or Millennial) worker to leave a company in order to move up in either status or pay, but Boomers do not use this strategy, as they are less marketable in the job pool. Simply by being at a company for a long period of time, they move up to senior and managerial positions.

2) Baby Boomer and Generation X autistics are both less likely to have been diagnosed as autistic or suspected to be autistic as awareness of autism was not common pre-1990s. They are more likely to have late diagnoses and so to have not had personal knowledge that they are autistic before they started their careers. Any differences in their behavior were more likely to have not noticed, attributed to something else, or been dismissed as quirks, enabling them to move up in an organization without an internalized autism stigma or a stigma from others. Their results at work may have brought more attention than their mannerisms or social skills, and so they may have achieved more had other attributes been scrutinized.

There will be no way to know if Generation X autistics will take the place of Boomers in terms of supervisory roles, and/or if Millennials will take the place of Generation X, until time goes by and everyone has a chance to get older. The reasons why this trend is occurring could unfold as the Millennial generation gets older and the new Generation Z takes its place. Further study of this phenomenon could show what generational cohorts are best suited for which working roles in autistic populations. This could be helpful for organizations who are strategizing teams of workers or tracking potential leaders.
Help in Gaining Employment

Howlin et al.’s 2005 follow-up of participants in a vocational program for autistic adults is often mis-used as a source for how many autistic adults are employed and at what level. I suspected that most autistic workers had not used a vocational or other autism-specialized service to gain employment, so I directly asked participants if they received help finding a job and if so, what kind of help (autism-specialty service, job placement service etc, colleague etc.).

Most participants (26/38 or 68%) had not used help in getting their current or most recent job. Of the remaining participants, 5/12 (42%) received help from an employment service/job placement service/recruiter and 6/12 (50%) received help from a friend/colleague/other contact. One participant in this study chose “employment service/job placement service/recruiter, but was moved to “autism-specialty employment service” because (s)he clearly stated elsewhere in the survey that the service was a vocational program that (s)he qualified for due to being on the autism spectrum. It should be noted that 37/38 (97%) of these participants had not used a vocational or autism-specialty service to gain employment.

Job Satisfaction

A slight majority of participants (20/38 or 53%) said that they were satisfied with their jobs. This was a minor theme which was only notable in a later section of axial coding (see Accommodations on page 23).

Representative Narratives

Nearly every participant gave an extensive, elaborative answer to almost every questionnaire question. I chose five participants to serve as representative narratives with quoted answers. The following five participants have elaborated upon some experiences common to
many participants in this study and serve as representative narratives for other participants. These five participants were chosen over other possible representatives due to the descriptive quality of their answers.

I coded each participant’s answer and have represented the majority result in a numbered frequency in each section. I summarized elaborative answers from the other participants and included that information in the text when appropriate. The participants directly quoted are four males and one female. Two of these five are located in the United States, one from Canada, one from Australia, and one from Eastern Europe. The youngest participant quoted is 30 and the oldest is 49.

Participant 2

Participant 2 is a 38-year-old male located in the United States. He works in an IT (information technology) environment as an authority figure or unofficial supervisor, with no employees officially reporting to him. He describes being the only person in his work environment who knows “how and why everything works” and is frequently relied upon in situations that should not be his responsibility (Participant 2). He sometimes performs work for his co-workers to avoid having to explain things to them. Participant 2 says that, “honestly, helping my co-workers with their work is extremely easy for me (even if it’s not in my direct line of work it’s like a puzzle) and it garners the favor needed [at times].” But Participant 2 said there was also an aspect of bullying going on at work.

I’ve been bullied into doing work that wasn’t mine and wasn’t my choice to do—that makes a big difference. I’ve been forced to talk to people that I didn’t need to and go to meetings and lunches I did not want to go to. Also have been on call 24/7 abused when the higher-ups on the lists didn’t answer because they knew I would (Participant 2).
He made mention several times that he believed he appeared “odd” “weird” or “creepy” to others and relied upon scripts to communicate in most casual situations, although he said he did try to present himself authentically in more personal relationships (Participant 2). He said he enjoys being around his co-workers, despite the fact that they have differing interests. “I get along with my coworkers and think they are funny to observe, like animals in a zoo- I pass time trying to figure out their motivations for doing incomprehensible stuff and take delight in how they try to impress each other” (Participant 2). Participant 2 said that his co-workers will sometimes talk to people on the phone or in-person for him during times when he is not comfortable. He told me that he is comfortable in his office and participates “fully” in conversations with co-workers; with a “decent read on their quirks” adding that “normal people are all very weird in one way or another” (Participant 2).

Participant 13

Participant 13 is a 49-year-old male located in the United States. He works in software development in an organization with matrix-style management (few managers with self-motivating production teams). He does not have any official employees but sometimes leads projects. He has noticed autism traits in other people at work and formerly had a supervisor who was on the spectrum and tried to lead him to knowledge that he was autistic as well, before the participant was diagnosed. Participant 13 has trouble recognizing “office politics” situations at work and the hidden motivations of others. He said that after he disclosed that he is on the autism spectrum, he was treated better in some ways but worse in other ways.

For many years, coinciding with the tenure of my former boss with Asperger’s, I was judged on my strengths and received top ratings, then she retired and a new boss came in, and suddenly I was being judged on my weaknesses and was almost fired. It was a harrowing, confidence-shattering experience. After I disclosed, I was coached in how to cope with my weaknesses and encouraged to work to my
strengths and things generally got much better. That was wonderful. A couple of clients who had relied on my complicated analyses suddenly began talking to me as if I was an unintelligent person. I believe my boss at that time told them about my diagnosis—but this may be paranoia on my part. I am not particularly good at interpreting some subtle signals from other people and this falls in that category. My organization treated me better, but those individuals, to whom I did not disclose, began to discount my intelligence not too long after my disclosure, so I think this was a case of being treated worse (Participant 13).

Participant 13 related some difficulty with ad-hoc social situations and said he relies heavily on scripts and simply staying silent to avoid making the wrong impression. He noted that a lot of what most people say is uninteresting and hard to follow and described work social events as “exhausting” and “draining” (Participant 13). I asked him to tell me about his confidence in his social skills.

I am confident in certain undemanding situations that don’t lead to prolonged conversations. I can meet people and greet them appropriately and so on, though I don’t always recall their names and have a hard time distinguishing faces. Any situation that requires more prolonged social engagement leaves me uncomfortable. I don’t know what kind of impression I am making. I know I can talk too much about things that I care about so I try to say little. I find a lot of what most people talk about uninteresting and hard to follow (Participant 13).

He described himself as a physically large, strong person, with a large vocabulary and strong argumentative skills, therefore not an easy target for bullying. However, one of his former bosses went to great lengths to bully and mock him, even arranging a special office viewing of the movie, “Office Space” and then publically declaring that Participant 13 was like the character “Milton” (Participant 13).

“Office Space” is a 1999 movie about disgruntled white collar workers (Carhalvo 2016). It features a character named Milton Waddams who mutters about detailed unfairness (“The ratio of people to cake is too big”) and is eventually fired but allowed to continue coming to work.
because his boss will not inform him that Milton no longer works for the company (Anon 2016; Carhalvo 2016). Milton has often been cited as being a character who is possibly autistic (King_Oni 2010; Stereokid 2008).

Participant 25

Participant 25 is a 30-year-old male located in Australia. He is the supervisor of a warehouse. He had recently received a promotion to this role when I talked to him. He described spending his entire life passing as "normal" and the attempt to reach this ideal nearly drove him to suicide. Participant 25 told me that now that he understands that he is on the autism spectrum, “I can’t go back to being the way I was before” and no longer attempts to pass. Since disclosing at work that he is autistic and making a new attempt to present himself more authentically, he has experienced negative reactions from his bosses, peers, and employees. “The people I work with have started acting like they’re scared of me and they seem to be distancing themselves from me” (Participant 25). I asked him if he thought he had been the target of derogatory jokes at work and he replied, “I think I have, but I don’t know whether what was said were meant to be jokes or insults. Sometimes I don’t even know if I’m the person being talked about” (Participant 25). He describes daily stress and frequent exhaustion at work, which he helps alleviate with stimming.

Stimming behavior that I do at work can be divided into two categories. Stuff that makes people uncomfortable and stuff that doesn’t. Things I do that don’t make people uncomfortable includes making origami swans, spinning a pen around my fingers and making pointless spreadsheets. Things I do that I believe make people uncomfortable include shaking my legs, flicking my fingers, stretching my neck from side to side, flapping my fingers onto my thumbs, alternately flexing my left and right glutes so that I sort of rock from side to side in my chair and also rubbing my feet together. Sometimes if I’m feeling overwhelmed I go to the toilet or a part of the building where no one can see me and do what I suppose you could call full body stimming; I flap my hands and then my whole arms get involved and then I
twist my torso at the hips. Sometimes I even finish that behavior by jumping from foot to foot while doing all that other stuff (Participant 25).

Participant 25 says he has a growing suspicion that he is unsuitable for his position and cannot stay at his place of employment for much longer. He followed-up his interview to tell me that he had left his place of employment and was now pursuing a graduate degree in autism studies. He expressed satisfaction and hope for the future with his new career field (Participant 25).

Participant 29

Participant 29 is a 31-year-old female, located in Canada. She works as a supervisory-level librarian. She says she is aware that she walks, talks, and acts differently from other people and that she is more “innocent” than others, but does not feel disabled by these differences (Participant 29). It was not clear if Participant 29 was not able to pass, or if she purposefully chose not to pass as non-autistic or neurotypical. She admitted sometimes modulating her voice or behavior, simply out of respect for others, to make them more comfortable. Participant 29 experienced a point in her career in a former workplace where she was severely bullied and told she “appeared weird”. She told me that experience “hurt my soul” (Participant 29).

Participant 29 repeatedly brought up her contentment in her career field and passion for her interests, which she can pursue in her career. She appeared conflicted about not advancing in her career, mentioning that she wanted to know that she could be promoted but not necessarily wanting to take that step.

I did not apply for a promotion because I love what I do and could do it forever, almost. I keep up to date with trends in [my field]. I just love doing what I do. I am terrified of trying out for a new job and going back to my previous career environments where I was so badly understood (Participant 29).
Participant 29’s current place of employment is supportive of her and of autism in general. She and her co-workers discuss autism at work and how to best serve their customers who are on the autism spectrum (Participant 29). She says that, “While I am the only person with autism here, our staff has met with and had positive interactions with customers with autism” (Participant 29).

Participant 43

Participant 43 is a 37-year-old male located in Eastern Europe. He has a lower-level clerical job in an office environment. He works with his wife, who he suspects is also on the autism spectrum. He describes his work life as very uncomfortable for both himself and his wife and says that they are in an “us vs. them” environment (Participant 43).

I have worked here for 2.5 years and literally talk to no one, save my wife…And she too talks with [only] one person who just started and has been there 1.5 years. When I say no one, I mean no one. Nothing. Not even good morning. Walk right by people like they are ghosts (Participant 43).

He is not friends with anyone at work (except for his wife) and has a lot of trouble communicating with his boss, who has a thick foreign accent (Participant 43). He says his boss rarely tries to speak with him at all (Participant 43). He told me, “It takes so much out of me just to go and stay seated for that long in a place I hate with things that bore the hell out of me” (Participant 43). I asked Participant 43 to elaborate about his stress and anxiety at work:

I think the stress of having to focus on something I don’t care about or have any interest for is driving me nuts. I get resentful of my boss simply for selling stupid [products], which is his business. But it drives me crazy all day every day. I think most people would have adapted by now. The fact that nothing is told to you directly by anyone is tough too because I like to know the exact rules and expectations…I think to many people this is an annoyance. To me it’s crippling. I get anxiety all day, get even more angry and sometimes sit there not even working at all for many hours (Participant 43).
Participant 43 sometimes needs to use marijuana in the morning before work and says that although other people might not call his musical tastes “soothing” he is able to use music to “zone out” chatter that would otherwise be intolerable. Participant 43 made a point of saying that he knows he is unapproachable and that he does not respect his co-workers. He describes himself as “unemployable” and “lucky to have a job, truth be told” (Participant 43).

Themes from the Literature Review

Using an exploratory research approach, I analyzed all participant responses first and then organized responses into themes. Some themes emerged that could be mapped directly back to the literature review.

The Workhorse: Autism as a Strength

I asked participants if they had a sense that they were performing more, less, or equivalent work to their peers, and if it was of the same quality. A total of 22/38 (58%) of participants fit a theme I am calling the “autistic workhorse.” In this workhorse situation, autistic workers are self-reporting a higher quality and/or volume of work than their co-workers. From the perspective of the worker, falling into a workhorse role may not seem to be a strength. However, from a company perspective, a worker who is a workhorse is clearly an asset. For this reason, “the autistic workhorse” is a theme that falls under “autism as a strength.” I have not seen this theme previously documented in existing autism literature.

Some participants talked about being taken advantage of for having superior abilities.

At a previous job, I did all of the work for a massive project overhauling [a] system. After giving a presentation on the new system, I was given a quick congratulations… but nothing more. Meanwhile, a friend-of-a-friend-hire who only acted as though he was working on the project received not only a raise, but also a brand new office while I was stuck in a cubicle. I chalk that one up to not understanding office politics as well as my co-workers (Participant 21).
Other participants mentioned having a sense that they were workers of high value, but little respected.

I exhibited superior workplaces skills than [my co-workers]. There was usually a slight hint of jealousy in how they treated me…Because of my desire for precision and long memory, some co-workers have blamed me for working slow or not working additional hours—even though they were doing the same thing (Participant 16).

A few participants noted that there seemed to be a systematic effort on the part of their bosses or co-workers to bully or manipulate them into doing more work.

The boss normally knew who to depend on to show up for work…[co-workers took advantage] usually by purposefully leaving work early, thereby offloading their responsibilities on me at closing time…[but], to most people, I was a nobody. No matter how hard or long I worked, it was never validated or appreciated. (Participant 30).

A few participants gave other reasons for doing more work than their co-workers. Participant 39 stated, “I feel that I need to work much harder than others because I usually can’t use verbal language to convey my ideas.” Participant 3 explained, “I think it’s a combination of wanting to do my best, [being] uncomfortable with not doing things perfectly, hating to be bored, wanting the day to go by faster, and feeling anxious when there are things that aren’t ‘finished’. I do this wherever I work, or whatever kind of work it is.”

Negative Perceptions of Autistics/Stigma of Autism

Bullying

The majority of the participants (29/38 or 76%) admitted to being victims of workplace bullying or systematic exclusion at some point in their careers. Many participants mentioned being the victims of bullying, social exclusion, and/or sexual harassment, often causing them to leave jobs to resolve the problem. Some participants in high level careers related bullying and
professional sabotage on a “nasty” level (Participant 4) from other high level co-workers and senior management. “I’m familiar with the sensation of someone using your head as a stepladder” (Participant 1). Participant 27 described a situation where a co-worker had the same job description and pay grade, but a lower skill set, which the participant guesses may have been threatening to the co-worker:

I found she was gunning for me behind my back. I figured this out when our managers called both of us into a meeting and we were told “we can’t afford to lose either of you, so you are both being asked to go to Employee Assistance.” I went, under protest, and I don’t know if the other employee ever went or not. I found this so ridiculous a way to manage, that I spent my one meeting with EA strategizing how to find a different job. I also learned she was gunning for me a different route. A manager’s wife who worked for us part-time stopped being friendly to me. I asked that manager what was wrong? He said his spouse didn’t want to get caught in between me and the co-worker who was gunning for me so she was being aloof from both of us (Participant 27).

Participants described environments where they were gossiped about, discounted, or even ridiculed. “I heard someone describe me as weird. It hurt my soul. [People] talked about me behind my back” (Participant 29). Some participants said they were unsure as to when they were being made fun of, or when another person was simply joking around. “I have a trick where I just take anything derogatory as a joke and then I can’t be accused of being petty or not being able to take a joke” (Participant 46).

Several participants complained about being bullied by extroverted bosses or co-workers in their workplace into performing “salesman” behavior that had nothing to do with their jobs. Some participants made a point to mention that although they are systematically excluded from workplace social activities or social circles, they prefer to be left out or not bothered.
Possible Theoretical Explanations

Symbolic Interactionism

A closer look into symbolic interactionism and the exact social actions being performed by autistic workers and the other people they interact with at work may offer insight into why they are being bullied by their bosses and co-workers. It could be that autistic people are giving atypical responses to social actions performed by non-autistic workers and this elicits negative responses from the non-autistics. Erving Goffman discusses “failures” of social actors and “refusals to perform” social routines, which describes what happens when anything not expected happens or an expected thing happens during social interactions (Goffman 1959, 1963a, 1967, 1974). It may be helpful to directly educate autistic adults about symbolic interactionism. An understanding of symbolic interactionism may help autistic adults give a better description of what is going on during social routines, which in turn may help sociologists better understand social interactions between autistic and non-autistic people.

Non-Autistic Predators at Work

Manipulative personalities and behaviors are often rewarded in professional organizations (Babiak and Hare 2006; Martha Stout 2005). It could be that autistics in the workplace, especially in authoritative and white-collar roles, are coming across individuals who are specifically looking for others with traits that they can pick on and/or exploit. The rate of sociopaths and psychopaths is roughly 1-3% of the US population, which matches that of autistic people ((CDC) 2014; Babiak and Hare 2006; Martha Stout 2005). Most people with a personality disorder follow the law and have careers like anyone else. Many autistic people have casually mentioned suspecting that they have fallen victim to a sociopath, psychopath, or narcissist (KevinLA 2013; Peoplesrjames 2015). It could be that sociopaths or psychopaths are coming
across autistic co-workers naturally in the workplace and bullying them, or it could be that they are purposefully seeking out people with autism traits in order to bully or exploit them. There is currently some research by Leif Ekblad, creator of the Aspie Quiz, in the area of predatory non-autistic behavior and neurodiverse reciprocal behavior, but this work has not yet been accepted for publication (Ekblad n.d.).

Stigma about Autism

Most of the participants (25/38 or 66%) described hearing others relate to autism in some kind of stigmatized fashion. I used axial coding to create several subthemes regarding the stigma of autism. Many participants complained that the people around them not only failed to understand autism, but seemed to refuse to understand. Some participants said that others would not believe that they are autistic or have stated that the participant doesn’t seem autistic. “I would sum up the attitude as ‘somebody else’s problem’” (Participant 45). One participant suspects that many people in her/is family are also autistic, but those same family members refuse to acknowledge that (s)he is on the spectrum, let alone see autism traits in themselves (Participant 40).

Other participants describe environments where their co-workers actively avoid them or discussions about autism. “There have been a few friends who have disappeared over the past couple of years because they think I’m just trying to get attention” (Participant 21). Some participants talked about working in environments where autism discussion was actively discouraged. “I’ve been told to keep quiet about it, I’ve been told that the other autistics, ignorant of their condition, deserve to maintain their ignorance” (Participant 1).
Another participant was surprised at the lack of knowledge about autism in her workplace, despite working in a disability services-related field, “[I had a co-worker] accuse me of ‘faking’ my diagnosis because I presented so differently than her son. I have even had a pregnant co-worker ask for my opinion on the safety [of] vaccines because she and her husband would be ‘devastated’ if their child ‘got autism’” (Participant 48). Many participants talked about having to listen to people in their workplace systematically say derogatory things about other people on the autism spectrum or about autism in general. “I have overheard co-workers making fun of individuals on the spectrum or using words like “odd” and “strange” when speaking about individuals on the spectrum. I have had co-workers react negatively when talking about kids on the spectrum going to college or learning to drive” (Participant 38). Sometimes these comments directly include a reference to a participant, “[Co-workers discuss autism] usually in a derogatory way toward any sort of weird or nerdish behavior- then they remember you and be like, “Oh, you know a REAL retard, not like you” (Participant 2). Participant 30 became used to co-workers attempting to cause her/im bodily harm, such as trying to lock the participant in a freezer on one occasion.

Treatment Post-Autism Disclosure

Since I ended data collection on this project, the first academic article about autism stigma and adults has been published (Johnson and Joshi 2016). Although Johnson and Joshi’s 2016 article does address autistic adults at work and the issues of devaluation and stigma attached to disclosing autism, they specifically pose this as a “future” issue that will occur as autistic youth age into adults. I believe this is an underestimation of the existing autistic adult population. It is also assumed that to withhold an autism disclosure suggests that one holds an internalized stigma against autism (Johnson and Joshi 2016). Many autistic adults may have only recently discovered
themselves that they are on the autism spectrum and may have not had a reason to share this information with others. I have not attempted to address the issue of “internalized autism stigma” in this thesis. I hope that more academic investigations follow Johnson and Joshi’s lead into this new area of research.

I asked participants if they were treated differently after they disclosed an autism status at work. Participants described post-disclosure treatment in the following ways: Acceptance, Ignored, Disbelief, Discredited.

Acceptance

Some participants found that some or all of their co-workers were more accepting of them or their needs after they disclosed that they were on the autism spectrum. Participant 13 clearly stated that her/is organization treated her/im better, although the people within the organization did not. Participant 45 also described a positive experience:

It has only been a couple of months, but I have had numerous meetings with my [bosses], was able to be exempted from a new role on the basis of reasonable adjustments and have been encouraged to work from home more often/reduce attendance at meetings. [A boss] is helping me to review my research plans and break down and prioritize my objectives more effectively. I would say that, on the whole, people have been very positive and caring (Participant 45).

Ignored

Many participants described post-disclosure environments where either they or their disclosure was actively ignored. “Left out is the simplest way to explain how I feel at work” (Participant 1). “Most people seem to have forgotten about me mentioning that I’m autistic” (Participant 32). However, a few participants said that they were thankful or grateful for an
indifferent reaction to their disclosure. “I am fortunate enough to be in a place where autism really does not matter all that much as far as how people treat you” (Participant 44).

Disbelief

A few participants disclosed to someone at work, but the person to whom they disclosed expressed doubt that they were actually autistic. “[A boss] didn’t have a proper understanding as to what autism is---she said: ‘You don’t seem like someone who is autistic’ (everybody thinks of ‘Rain Man’)” (Participant 22).

Discredited

A few participants were directly or indirectly discredited following an autism disclosure, finding that their autism disclosure had been used as a subject of gossip. “Some of the people in our [organization] used my disability to discredit my work” (Participant 39). Other participants have noticed that their co-workers seem to have less patience with them post-disclosure, or are exhibiting other obvious negativity. “I feel recently that they have been having shorter fuses with me than they used to. And a few meetings ago, they sure were vocal about how they felt about some of the things I have done and how I have acted. I feel they didn’t try to understand me at all” (Participant 5).

Passing as Neurotypical

Most participants in this study (29/38 or 76%) admitted that they attempt to present themselves as someone who is not autistic, or to “pass” at least some of the time. Some described passing as merely keeping a low profile as much as possible. Other participants described passing as more of a lifelong attempt to appear normal and less of a conscious effort to suppress or disguise autism.
Not knowing about my autism until recently has caused me to learn masking (adaptation) skills since I was a child…I spent my free time watching thousands of movies wherein I learned what was considered proper social interactions and what wasn’t (thankfully, this happened in the 1960s and 1970s where movies could be trusted to offer more mainstream representations of such interactions). My use of movies isn’t too far afield from certain video-based Cognitive Behavioral Therapies. At this point in my life, however, my masking skills are largely routine for me…for a couple hours. Beyond this limit, I revert to a more silent, introverted version of myself. It takes an hour of recharging for every hour of masking. This means that some work days were tedious and lengthy requiring me to pace myself for several hours only to collapse from exhaustion when I finally returned home. This was my normal (Participant 16).

Some participants mentioned that they have other, more distracting characteristics that seem to take precedence over autism, preventing a “normal” appearance, but perhaps enabling them to pass more effectively, such as having a distinctive physical appearance or physical disability. “I am fat and tattooed and look like a lord of the rings dwarf so it takes people a while to note my behavior” (Participant 2). This type of passing is known as “masquerade” passing, where a social actor either distracts from an identity by masquerading as something else, or plays up the main identity as its own masquerade (Siebers 2004).

Resistance/Autistic Minorities in the Non-Autistic Majority

Initially, I thought that the “Resistance” theme from the literature review was not reflected in the data I collected. However, the base of that theme was a quote from Berger and Luckmann: “[people can] refuse to be what they are supposed to be” when forming an alternate society (Berger and Luckmann 1966). Autistic people as a social minority are a subculture or an alternate society. The theme Social Relationships at Work and its subthemes arose as a picture of what really occurs with autistic workers as social actors in a work environment, at least from their own perspectives. Social Relationships at Work, when told from the autistic worker’s point of view, fits both themes from the literature review: Resistance and Autistic Minorities in the Non-Autistic Majority.
Social Relationships at Work

I asked participants what kind of relationships were present in the participants’ workplaces.

“Work-Friends”

A slight majority of the participants (22/38 or 58%) categorized their co-workers as “work-friends” who could not be referred to as true friendships. Many participants gave their co-workers various sub-classifications after selecting “work-friends” as a dominant descriptor. “I would say 30 percent peers, at least openly- sometimes they are useful to talk to people or to be sounding boards. Mostly they are background noise though, which isn’t really a bad thing at all-it makes the time pass better” (Participant 2). Work-friends were further described by participants as peers, team-mates, and/or background noise.

Mostly they are tools and background noise. The other departments are all background noise, they are doing whatever they do and I mostly ignore them until they have a problem and they need me to resolve. Then I use my agents to get it done. They have different strengths and weaknesses and I’ll give them projects based on who will do it the best and what else we have to do (Participant 17).

Friends

Many participants (12/38 or 32%) categorized some or all of their co-workers as “friends.” The majority of this group (8/12 or 67%) specified that they were friends with “one or two” people at work. A few participants further noted that in addition to being friends their co-workers were allies.

I am friends with one person who does the same job and has worked with me for seven years. He says that at first he didn’t know how to take me, but after getting to know me, we are okay. We back each other up with the boss, share about our personal lives, and [he] and I do each other favors outside of work…[however, this co-worker] seems more comfortable with other employees (Participant 24).
Not Friends

Five (5) participants (13%) selected the “not friends” with their co-workers option on Q43. Some participants described work environments where they were bullied or pointedly ignored by most of their co-workers. Other participants seemed to have low, or even non-existent opinions of their co-workers. “For the most part, they are loud, inefficient, and overly social” (Participant 38). Some participants told me that they have to make an effort to notice others around them, who simply do not seem to mean much to them, one way or another. “I don’t really pay that much attention to the people as long as they fit within my system of work” (Participant 7).

Joking

I asked participants if they joked with co-workers at work as an indirect method of determining friendship levels and general work environments. I could not find any specific literature addressing this issue, but I suspected that the presence and nature of joking in a work environment would give an overall impression of the comfort level in that workplace. I isolated two subthemes in the area of joking: Reciprocal Joking and Uneven Joking.

Reciprocal Joking

Most participants (28/38 or 74%) described a reciprocal joking environment in their workplaces, where their co-workers joke around and the participant contributes. Some participants in this group mentioned having methods of careful, or self-protective participation in office joking. Others describe having senses of humor that not everyone gets, or not always getting the humor of someone else. “I have a way for joking with others, but when non-autistics joke around I don’t have much access to it” (Participant 39).
Uneven Joking

The remaining participants (10/38 or 26%) described environments where some kind of uneven joking is taking place. Some participants said they were annoyed or distracted by co-workers who engaged in too much light-hearted behavior or asked them to take part in silliness which was uncomfortable for them. “I’ve been trying to open up a bit, but I just have a hard time doing it…Mostly they leave me alone as they’re trying to be lighthearted and fun and can probably tell I don’t really enjoy it” (Participant 17). Participant 38 echoed a similar sentiment, “I feel my co-workers spend too much time socializing and joking around…[I joke around] rarely…if I am not working for a moment.”

Rare or No Joking Environments

Several participants described more serious working environments where joking did not often occur.

Autistic Work Experiences

I did not directly ask workers what was most important to them at work or what elements take up most of their work days. Some of the responses that the participants gave about stress, anxiety, exhaustion, and depression were similar to what was found in previous studies about working autistic adults (Balfe and Tantam 2010; Hurlbut and Chalmers 2004). I was hesitant to place Stress, Anxiety, and Exhaustion, or Depression into this category of Autistic Work Experiences and am only doing so to follow up with previously published material about autistic workers. I don’t believe these experiences are representative of any autistic person’s total work experience. I did not anticipate this issue with data representation or I would have asked an open question about work experiences, such as “What experiences have you had at work?” or “What has been your most important experience at work?”
Stress, Anxiety, and Exhaustion

I asked the participants to if they experienced stress, anxiety, and exhaustion from work that they believed was related to autism. All 38 participants admitted to experiencing some mixture of stress, anxiety, and/or exhaustion related to autism or being autistic in an environment designed for non-autistic people.

Stress and Anxiety

The majority of participants (34/38 or 90%) described experiencing anxiety related to autism or being autistic. All participants who did not complain of anxiety related to autism but did admit to stress related to autism appeared to be confusing the two terms. did not give a clear definition of either term and it occurred to me that the word “stress” is commonly used in conversational English in place of the word “anxiety”. No participants described circumstances where they experienced stress that did not result in anxiety. No participants described experiencing anxiety which did not derive from a stressor. Because of these factors, I coded stress and anxiety as a single theme (stress and anxiety). When the categories of stress and anxiety were combined, all 38 participants (100%) admitted to experiencing anxiety (or “stress”) related to being autistic.

Many people mentioned that sensory-rich work environments cause them a tremendous amount of stress and anxiety during their work day. Other participants said that telephone calls, meetings, and other highly social work tasks cause an overwhelming amount of stress with resulting anxiety and dread.

Much of [my stress] is related to sensory issues, mostly auditory, that don’t seem to bother anyone else. Phone calls are stressful (one of the most stressful forms of communication). Multi-tasking is difficult when I’m on a call or in a meeting or
someone is talking to me. I can’t listen and read, or listen and write/type (Participant 35).

Ethical/moral issues also induced anxiety for several participants. Participant 31 was repetitively put in moral dilemmas as a medical professional where her/is choice of patient welfare over the social needs of her/is co-workers caused many problems at work and ultimately contributed to her/is choice to change professions.

“[A subordinate] once said to me ‘this case better not make me late finishing the shift’ because she had some social commitment. My reply was ‘on a scale of whether or not this [patient] is alive in the morning, that is not a consideration.’ I would say that I was the [medical professional] whom you would want if you were the patient” (Participant 31).

One participant suggested that stress may have a unique effect on her/im:

I think normal everyday stressors seem to take more out of me than some of my coworkers. As much as I hate to admit it, I am more sensitive than the average person in some ways. Dealing with sensory issues, interpreting social cues, etc, seems to add an extra layer of effort to everything I do (Participant 48).

Exhaustion

Most participants (35/38 or 92%) experienced exhaustion related to autism or being autistic. Some participants attributed their exhaustion after work to working too hard to ensure work quality. Other participants described exhaustion simply from being at work. Many participants mentioned sensory overload causing exhaustion after a work day. One such participant talked about sensory stress at work during the day, along with frequent interruptions, both of which caused her/im a great deal of anxiety and then exhaustion by the end of the day, “Mainly, it’s mental, not physical exhaustion. My job is not mentally demanding, but just being
at work seems to exhaust me” (Participant 33). Some describe the exhaustion as physical, “My body feels like it was hit by a truck” (Participant 38).

Depression

I did not ask participants about depression, but this emerged as a minor theme, and seemed to be related to stress, anxiety, and exhaustion. A small number of participants (5/38 or 13%) discussed depression related to being autistic. The participants in this small group seemed to associate the depression to being “outed” as autistic or being actively discouraged from talking about autism. Following a discussion with her/is boss, where Participant 29 was discouraged from discussing autism, Participant 29 attempted to pass as non-autistic:

Which led to depression. And to real desperation and a nearly suicidal evening months later. Those few events have led me to reassess how I treat others who attempt disclosure with me. The really bad disclosure has led to me discussing mental health in my current workplace and telling my staff that I care to avoid their feeling overwhelmed or burnt out, and we talk stress. Since then, five or six staff members, including people from other departments and other whom I have not disclosed to have disclosed disabilities to me (Participant 29).

The number of people in this small subgroup is too small to draw any conclusions, but I think it might be worth specific exploration with a large sample later on.

Autistic Communities

I asked participants if they worked with any known autistics or people who displayed autistic traits and could possibly be on the autism spectrum. There is very little academic or even informal, online documentation about autistics observing other autistics (Diament 2005; DigitalMelody 2014; DontASPme 2013; Edenthiel 2015; KraftieKortie 2015). I asked participants if there were other people at work who they knew or suspected were also on the autism spectrum. A slight majority of the participants (25/38 or 66%) confirmed that they either knew or believed that one or more of their co-workers were on the autism spectrum. Most of
these 25 participants did not go into further elaboration other than to state that one or more co-workers were autistic or had autistic traits. However, two (2) participants described actively supporting or protecting other autistic subordinates or co-workers and three (3) other participants described being actively supported or protected by autistic bosses. “[M]y boss and I work daily on figuring out how to support each others needs. We work out plans and schedules and systems that allow us the structure and ability to work and get stuff done” (Participant 40). Participant 40 went on to say that (s)he and her/is boss have different ways of working; supporting each other in this way helps them to capitalize on their unique strengths.

Disclosure

I asked participants a single question to determine if they disclosed and to whom they disclosed if a disclosure took place. It should be noted here that there were rare elaborations in the disclosure section. I got the impression that this was not an interest area for the participants of this study.

<table>
<thead>
<tr>
<th>Q24: Have you disclosed your autism status to anyone you work with? (n=38)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
</tr>
<tr>
<td>plunges only (HR and/or boss)</td>
</tr>
<tr>
<td>To co-workers and subordinates only</td>
</tr>
<tr>
<td>To everyone the participant works with</td>
</tr>
<tr>
<td><strong>No disclosure</strong></td>
</tr>
</tbody>
</table>
A slight majority of participants (23/38 or 61%) have disclosed their autism status to someone at work.

To Whom Disclosed

I grouped the participants’ answers into four categories: To an authority only, To co-workers and subordinates only, To everyone the participant works with, and No disclosure. Different careers have different organizational structures, so not every job has a subordinate or client. All of the participants had an authority and known peers who work for the same entities as the participants and could be referred to as co-workers. The category “everyone the participant works with” is meant to be inclusive of jobs with various organizational structures. For example, a participant with 40 direct reports could be grouped together with a participant who has no employees. Of participants who disclosed, most (17/23 or 74%) disclosed that they were on the autism status to everyone that they worked with.

Formal versus Informal

I asked participants who did disclose to specify if that disclosure was in the form of formal documentation. I purposefully phrased this question vaguely (“formal documentation” as opposed to “medical documentation” which is required for ADA benefits) because I anticipated that participants would be from different countries and I was unable to research the protected disabled worker policies for all countries globally (Anon 2010; Jones 2012).
Only three (3) participants provided formal diagnoses to all people to whom they disclosed. All three participants had a history of being bullied, which was very common in all participants, and all three passed as non-autistic sometimes or often. All three of these participants had recent diagnoses (within the last five years). I was unable to find any other similarities within this group.

Most participants (16/23 or 70%) did not provide formal documentation when they disclosed their autism status at work. Most participants in this group (10/16 or 63%) were working in the United States; under US law, these participants were not protected by the ADA (Anon 2010; Jones 2012). I was unable to find any other similarities within this group.

A few participants gave formal documentation to some people to whom they disclosed, but informally disclosed to others. All of the participants in this group had asked for some kind of accommodations. All four of these participants had recent diagnoses (within the past five years). I could not find any other similarities within this group.

<table>
<thead>
<tr>
<th>Q25: Formal versus informal disclosures (n=23)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal disclosure</td>
<td>3</td>
</tr>
<tr>
<td>Informal disclosure</td>
<td>16</td>
</tr>
<tr>
<td>Disclosed formally to some and informally to others</td>
<td>4</td>
</tr>
</tbody>
</table>
Accommodations

Worker-requested Accommodations

I asked participants if they have requested accommodations at work. Most participants gave very brief responses in this area, with very few elaborations. Like the Disclosure section, I got the impression that participants did not find this to be an important or interesting area of the survey. Under the ADA, a worker can ask Human Resources or a boss for accommodations after the worker has provided formal, medical documentation of a disability (Anon 2010; Jones 2012). I allowed participants to choose whether they have asked co-workers, subordinates, or clients for accommodations in addition to higher-ups. I reorganized the answer columns based on responses and the job title (not every job title has a client/customer/student).

Table 13: Accommodations

<table>
<thead>
<tr>
<th>Q28. Have you asked for autism-related accommodations? N=38</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Yes, I asked an authority/authorities only</td>
</tr>
<tr>
<td>Yes, I asked authorities and co-workers</td>
</tr>
<tr>
<td>Yes, I asked all people I work with</td>
</tr>
<tr>
<td>Yes, I asked authorities and clients/customers/students</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>

A small number of participants (12/38 or 32%) asked for accommodations at work. Of these, most (9/12 or 75%) were Generation X or between the ages of 32 and 50. Half of the
participants who asked for accommodations (6/12 or 50%) were female. Most (9/12 or 75%) knew or suspected a co-worker of also being on the autism spectrum. Most (9/12 or 75%) were current, former, or unofficial supervisors. Most (9/12 or 75%) pass as non-autistic often or sometimes; the remaining three (3) responded that they pass rarely or used to be in the habit of passing but are consciously no longer passing. Most (10/12 or 83%) participants in this group were diagnosed as being on the autism spectrum recently, or within the past five (5) years. Most (11/12 or 92%) reported being satisfied in their current positions at work. I could not find any other similarities within this group.

Worker-requested Informal Help

I asked participants if they were receiving unofficial or informal help because of Choi et al.’s study on workplace helping behaviors (Choi 2006). I believe that informal helping between friends and alliances can take the place of formal accommodations.

<p>| Q30. Do you receive special help that wouldn’t be considered official accommodations? |
|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|-------------------------------|</p>
<table>
<thead>
<tr>
<th>N=38</th>
<th>Often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
<th>I don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>6</td>
<td>9</td>
<td>20</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

Many participants gave answers that contradicted their selected response, especially in the “never” response category. Participants also frequently answered Q30 while giving a narrative response to another survey question. There were similar themes in accommodations and helping behaviors, which did not match the selected responses for either Q28 or Q30. I
combined Q28 and Q30 into Accommodations or Help and then isolated themes based on narrative responses.

Accommodations or Help

Most participants (26/38 or 65%) were receiving autism-related accommodations or special help. I used axial coding to isolate subthemes, or what kind of accommodations or help participants were receiving.

Social Accommodations or Help

Some participants ask a boss or co-worker for advice when dealing with social issues at work. Other participants have been excused from non-essential meetings or other social obligations at work. Two (2) participants are receiving or are scheduled to receive social skills training as part of their continuing career development. Participant 33 suspected that her/is boss is more lenient and also noted that, “Having difficulty with any type of social interactions makes it difficult to ask [for accommodations or help], and also I may feel guilty for asking for any special treatment.”

Sensory Accommodations or Help

Some participants were given a quiet space to work, either in the form of special desk placement or a private office. A few participants have had the fluorescent lighting around them changed to a different kind of lighting or turned off. Two (2) participants have been allowed to work from home at times in order to better focus on their work. Participant 2 used his co-workers as social interference, “My direct co-workers will frequently make calls and talk to people when I don’t want to, and act as intermediaries in situations where I’m not comfortable.”
Flex-Time

Some participants work non-traditional work-weeks in order to conserve energy, using four- instead of five-day weeks or taking personal time off as needed.

Planning/Paperwork/Organization Accommodations or Help

Some participants are receiving help from their bosses or co-workers in preparing paperwork or similar materials. One participant was provided with a GPS device to help with travel. Another participant asks an employee to help keep the work environment organized.

Thorough Explanations

This is arguably “special” help but has been recommended as an autism accommodation (Grandin and Duffy 2008; Smith et al. 2000). Two (2) participants mentioned receiving additional directions or explanations of job tasks as needed.

Unasked for Autism-Specific Accommodations or Help

Many participants (8/38 or 21%) are receiving accommodations or help that they did not request. Half (4/8 or 50%) were female. A majority (6/8 or 75%) were current, former, or occasional supervisors. Most (6/8 or 75%) were passing as non-autistic often or sometimes. Most (5/8 or 63%) were working with other people who they knew or suspected were also on the autism spectrum. Most (7/8 or 88%) were working in the United States. I did not find any other similarities within this group. Some in this group (4/8 or 50%) were given unasked for sensory accommodations or help. Two people (2/8 or 25%) were given unasked for emotional support or sensitivity. One participant was given unasked for social skills training as part of her/is continuing professional development. Another participant was provided with an unrequested
GPS device after her/is employer learned that the required navigation and driving for the participant’s job was stressful.

No Accommodations or Help

Some participants (12/38 or 32%) said they were not receiving accommodations or help. Half of these participants (6/12 or 50%) had disclosed that they were on the autism spectrum. Most of the participants in this category were male (10/12 or 83%); I could not find any other similarities within this group.

Received Accommodations as Requested

I asked participants who asked for accommodations if they received what they asked for.

<table>
<thead>
<tr>
<th>Table 15: Received Accommodations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q29. Did you receive accommodations? N=12</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>I received accommodations, but not what I asked for</td>
</tr>
</tbody>
</table>

Granted Accommodations

All five (5) of these participants who were granted accommodations said that they passed either often or sometimes. Most (4/5 or 80%) said they knew of or suspected a co-worker of also being on the autism spectrum. Most (4/5 or 80%) had recent diagnoses of autism; within the past five years. I did not see any other similarities within this group.
Some of the granted accommodations were:

- Sensory issues (this was not detailed)
- Leeway with travel time
- A schedule of tasks to be completed each week, in order of importance
- A mapping of strengths and weaknesses from boss
- Opting out of heavily social work tasks; tells clients not to take quietness personally
- Backed out of a highly social work role and continued with expectations more suited to strengths

Denied and Partially Denied Granted Accommodations

I combined the “no” and “I received some accommodations, but not what I asked for” categories, because the elaborations following the selected responses were similar. Most (5/7 or 71%) knew of or suspected a co-worker of being on the autism spectrum. A slight majority (4/7 or 57%) were female. Most (6/7 or 86%) had been diagnosed recently, or within the past five years. Most (6/7 or 86%) were current or unofficial supervisors. Some in this group (2/7 or 29%) were receiving unasked for accommodations. It should be noted here that “not what I asked for” could apply to being partially accommodated or being given an accommodation that is different from what a worker has requested. In the cases of these two participants, each was denied what they specifically asked for and given a separate accommodation. One participant was given a very clear denial:

“I’ve asked that my communication difficulties be taken into consideration by my staff and the management team and have been told basically I don’t have a right to ask for that. I’ve asked that others not shame things I have difficulties with and they continue to shame difference” (Participant 39).
Some of the accommodations which were denied, or only partially accommodated were:

- Direct communication styles
- Private offices or working space

Self-Accommodations

Some participants talked about creating their own accommodations by turning off fluorescent lights. I did not ask if participants took measures into their own hands by creating their own structured environment at work, so I cannot say if this was a theme.

Helping Others

I asked participants about helping others because of Choi et al.’s work about helping behaviors; reciprocal helping is common in workplaces among co-workers (Choi 2006). It would be reasonable to assume that autistic workers are helping their co-workers.

Table 16: Helping Others

| Q31: Do you help your co-workers? (n=38) |
|-------------------|-------------------|-------------------|---------------|
| Often | Sometimes | Rarely | Never |
| 14 | 17 | 3 | 4 |

As with other questions in the study, participants often answered Q31 in narrative responses to other questions. I used axial coding to combine the “often” and “sometimes” responses. Most participants (31/38 or 82%) help their co-workers often or sometimes.
Some participants reported habitually helping their co-workers for no definable reason. Some participants actively try to help others in order build a good reputation, which in turn gained tolerance, trust, and/or favors which can be called in later. Some participants participate in a helping environment; they help co-workers and are similarly helped when needed. Several participants mentioned that they help others find continuing education opportunities, or provided their own educational materials for co-workers. Two (2) participants help others because they prefer to see things done correctly. “I go out of my way to make certain they have everything they need to build it precisely how I have envisioned it. I go out of my way to help test what they implemented matches my vision” (Participant 7).

**Newly Emerged Themes**

A few unexpected themes emerged which were not addressed in the literature review or introduction: Othering of Non-Autistics, Coping, and Difficulties of Comparisons of Self to Peers. The themes of Othering of Non-Autistics and of Coping have not been addressed in academic literature about adult autistics. I did not ask any direct questions about the Othering of Non-Autistics because I did not know if or how it would relate to this study. Difficulties of Comparisons of Self to Peers could arguably be called a Theory of Mind failure (Baron-Cohen 1995; Deleau 2012). Theory of Mind is the idea that people have internal states (such as knowledge, desire, belief, etc.) and each person may have a different internal state (Baron-Cohen 1995). Autistic people have long been shown on tests to have Theory of Mind failures, which is a deficit in or the total inability to guess another person’s internal state, sometimes even scoring below animals in their abilities to guess the internal states of others (Baron-Cohen 1995; Baron-Cohen, Leslie, and Frith 1985; Premack and Woodruff 1978).
Theory of Mind failures and difficulties of Comparisons of Self to Peers could both be explained by differences in language and culture (Deleau 2012; Gernsbacher 2007; Gernsbacher and Pripas-Kapit 2012; Happe 1993). People with language deficits who are not autistic also fail Theory of Mind tests (Deleau 2012; Happe 1993) and people who are part of a minority culture score poorly on tests with references to the culture of their oppressing majority (Gernsbacher 2007; Gernsbacher and Pripas-Kapit 2012).

Theory of Mind in general has been covered in autism literature, but I am fairly sure that Theory of Mind as it relates to autistic workers has not yet been studied. Autism with language deficits has been studied exhaustively in academic literature. There is a small but growing field about autism as a culture, but as far as I have found, no academic literature about autism culture at work.

Coping

I had not been able to find any academic literature related to autistic adults and coping mechanism. I asked participants about coping mechanisms because I thought it could be potentially significant to document. I directly followed up with some participants about this issue when clarification or further elaboration seemed necessary.

Soothing Substances and Behaviors

Some participants (10/38 or 26%) reported that they require a soothing substance or behavior in order to tolerate work. Soothing substances mentioned were coffee, beer, sugary food, benzodiazepines, marijuana, and tobacco. Some participants used these substances during work and others used them directly following work to aid in recovery from anxiety.
and exhaustion. One participant has a therapy dog who accompanies her/im everywhere. Another participant mentioned both listening to music and “zoning out” as necessary.

Many participants described using exercise or stimming as a soothing behavior, either during or immediately after a work day. Some participants described using a stimming behavior either openly or when others could not see them in order to get along at work. Most participants did not go into detail about what a stim might be. Stim behaviors are unique to each person, and not everyone uses the term “stim,” which is why I did not use the term in my survey. Many participants described helpful exercise routines which they used during or immediately following work; including walks, drives, horse rides, and full body exercises.

Recovery or “Buffer” Period

Nearly all participants (37/38 or 97%) reported needing a recovery or “buffer” period after a work day. I did not go into further detail with this question because I wanted participants to provide their own detail. Prior to this study, I had never read about this in academic literature, but had casually noticed that autistic professionals seem to require quiet time to themselves, or a period where they perform a ritual (reading the paper, taking a walk, etc) immediately after work.

Most participants simply said yes, they did need a recovery or buffer period directly following a work day. Some participants described needing to be alone or in a quiet place immediately following work. Other participants have used vacation or sick time as needed in order to recover from being at work. “Sometimes I feel like I need a weekend between each day” (Participant 25). Two (2) participants described taking periodic, forced breaks in order to reset focus and avoid overstimulation.
Sometimes, I need to relax and unwind a bit before I can get focused on something for work. I have sensitivity to criticism, or I sometimes stumble upon something that upsets me, and I need to cool down before I decide how to deal with the situation (Participant 15).

Difficulties with Comparisons of Self to Peers

I asked participants to compare themselves to their peers. I expected the responses to fit either the theme of Stigma of Autism or Autistic Strengths. However, a new theme emerged, showing that comparing oneself to peers may be difficult for autistic professionals. This may be worth future study, as such an inability may be either a strength or a weakness. Participants did not elaborate in the sections of Fair Treatment from Boss and Fair Treatment from Co-Workers. When I followed up with participants asking for more information they were unable to give me more information.

Fair Treatment from Boss

I asked participants if their boss treats them differently than their co-workers.

Table 17: Treated Differently by Boss

<table>
<thead>
<tr>
<th>Q45: Does your boss treat you differently? N=38</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Better</td>
</tr>
</tbody>
</table>

I Don’t Know/Missing Data

The high number of “I don’t know” responses may warrant further study in the future. Most of the participants (7/10 or 70%) in this category were in higher level careers with supervision of other people or systems as part of their jobs. I was unable to find any other
similarities in this group. An inability to judge fair treatment from authority figures could bring effects (either positive or negative) to autistic workers.

Worse Treatment

Two (2) participants who said that their boss treated them worse than other employees noted some kind of manipulation on the part of their boss. Others said their bosses were suspicious of or intimidated by them. Only one (1) participant said that her/is boss appeared to be hyperfocused on any kind of mistakes, which the participant described as behavioral mistakes.

Better Treatment

All of the participants who have noticed better than average treatment from their bosses described treatment which rewarded their strengths, was sensitive to their weaknesses, and was friendly on a social level.

Fair Treatment from Co-Workers

I asked participants if their co-workers treated them differently than other co-workers.

<table>
<thead>
<tr>
<th>Do your co-workers treat you differently? N=38</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
</tr>
<tr>
<td>Better</td>
</tr>
<tr>
<td>2</td>
</tr>
</tbody>
</table>

I Don’t Know/Missing Data

As with Q45 (does your boss treat you differently) a large number of participants (13/38 or 34%) gave an “I don’t know” answer to Q46 (do your co-workers treat you differently). Most of the participants in this category (9/13 or 69%) were in higher level positions, supervising people or systems. I was unable to find any other similarities within this group. This finding may
warrant closer examination in the future, as being unable to judge if one is treated the same or differently as compared to other co-workers may be an advantage or a disadvantage to autistic workers.

Worse Treatment

Some participants had experience with being treated badly by their co-workers, although the problem has since resolved. Other participants described environments where they are socially excluded for being different. Some participants felt their co-workers were ableists, or held it against them that they had less social tendencies.

Possible Theoretical Explanations

A large number of participants answered with “I don’t know” when asked if they were treated differently by their boss or co-workers. I believe this issue will require deeper investigation to determine what is going on and who is benefitting from this inability to compare oneself to their peers. I reviewed some existing theory and did find some possible factors which may be contributing to this phenomenon and could be useful to explore further.

Theory of Mind Failure

It could be that autistic workers who cannot gauge whether others are treating them differently are experiencing a theory of mind failure. As previously discussed, theory of mind failures could be due to language or cultural differences (Deleau 2012; Happe 1993). Further investigation into this may be useful both in understanding if theory of mind is playing a role and if so, the practical impact of theory of mind on the lives of autistic adults.
Symbolic Interactionism

Some of Erving Goffman’s examples of persistent “failures” in social interaction or “refusals” to go along with expected social routines do result in feedback from the other social actor that is congruent with behavior by non-autistics or neurotypicals toward autistics, as reported by autistics (Goffman 1959, 1963b, 1967, 1974, 1981). For example, if one social actor has caused another social actor (whether purposely or inadvertently) to “lose face,” it is expected that the first social actor perform some action that allows the second actor to “save face;” if this never occurs, the second social actor is eventually forced to resort to either use tactless retaliation or indignant outrage to regain their lost “face” (Goffman 1967). From the perspective of an autistic person, if they are the first social actor who caused the second to lose face, the second social actor may be seen as irrational, and perhaps a bully. Symbolic interactionism may be used to take apart the actions of these autistic persons who cannot compare themselves to others. By looking at the social actions at a minute level, we may be able to gain a better picture of what goes on between autistic workers and their peers. It may be that they are either doing something that isn’t expected or not doing something that IS expected and this may be giving them an advantage or a disadvantage.

Social Comparison Theory

Leon Festinger hypothesized that people tend to compare themselves with others, but will decrease their comparisons if there is a great difference between their own opinion and experiences and those of the other person: “If the only comparison available is a very divergent one, the person will not be able to make a subjectively precise evaluation of his opinion or ability” (Festinger 1954). Further, Festinger also developed the theory of cognitive dissonance, which is a tendency for people to seek consistency with their cognitions (feelings, beliefs,
opinions, etc.); when there is inconsistency between the cognitions, the person must rationalize, or justify siding with one cognition against the other (Aronson 1972). An autistic person, inherently differently than those around her/im, would regularly come in contact with the opinions and experiences of others which do not fit in with her/is own. The autistic person would then be forced to either disregard their own opinions and experiences or the other person’s in order to move forward without an untenable feeling of cognitive dissonance. It may be reasonable to conclude that autistic people, especially those in careers requiring decision-making, may not have the energy to devote to cognitive dissonance and must disregard opinions and experiences which do not make sense before they can cause cognitive dissonance. Or it could be that autistics, like most people, are not able to adequately describe the cognitive dissonance process. It could be that constant cognitive dissonance is contributing to the “draining” feeling that autistics frequently complain about. This theory would require further research to determine if it may apply.

Othering of Non-Autistics

A few participants (4/38 or 11%) made a general statement that could be categorized as othering their non-autistic co-workers. The “other” is a representative of a population or idea who/that stands in opposition to what is considered normal; “othering” is a process of assigning a person or idea to this kind of category (DeBeauvoir 1949). Two of the four (2/4 or 50%) participants in this category were working in the computer industry (see “Customer Service and Service Industry” on page 48). Most of the participants in this category (3/4 or 75%) were male. I did not notice any other similarities, but with only four participant in this category it may be premature to make connections.
I did not specifically screen for this theme, but it has been established in autism literature that autistic people sometimes refer to themselves as a being in a normal, “non-human” state and non-autistics as “human” or something “other” (Gernsbacher 2007; Hacking 2009b). A participant urged other autistics to be polite and kind to their co-workers because, “You may not need these types of gestures from others, but others need them from you” (Participant 48). Another participant referred to co-workers in a generous fashion, but repeatedly as “they” or “these people” (Participant 17). Participant 2 referred to co-workers as “animals in a zoo.” These statements may show that some people feel empowered and self-assured in being autistic.

Possible Theoretical Explanations

While looking into this phenomenon, it became difficult to avoid my main source of information on the matter, which was personal conversations with autistic people. I have noticed that people who seem to have notably high self-esteem will slip into referring to themselves as something other than human which I have taken to mean “superhuman.” There are numerous personal posts and blogs where autistics other non-autistics and/or describe themselves or their abilities as something other or above that of a human being (JuggaspieZ2k 2012; Kim 2012; Penguin 2014; TylerPaul 2007). Academic resources make reference to dehumanizing others, mostly in conjunction with some kind of abuse. I was unable to find any resources discussing dehumanizing or othering as a method of maintaining or building one’s own self esteem. I found references to post-humanity, which is a kind of consciousness outside of human existence and bordering on artificial intelligence, but this did not seem to apply to what the participants and other autistics were describing. I have not found others to have followed up on Ian Hacking’s work about autistics as aliens (Hacking 2009b).
The only possible, previously existing theoretical material that I believe may apply is G.H. Mead’s building of a social self (Mead 1934). A social self is the “me” self that is learned after interacting with others and internalizing oneself as an actor in someone else’s world (Mead 1934). Mead allowed that it would be possible to build a social self, or to view oneself from an outside perspective, by using non-human entities, such as animals or objects as reference points (Mead 1934). Therefore, an autistic person could have varying degrees of involvement with others during early childhood and still build a social self. Because the degree with which social input by other human beings may be unique to each autistic individual, an autistic person’s social self may sometimes also be atypical. Some autistic people may have a feeling that they are not the same as other human beings. Close examination of existing observational investigations of autistic children could be compared to literature about social self-building and may confirm a link between autistic people, othering, and an atypical social self. Another approach would be to gather more information from people who use this othering terminology to find more commonalities and research leads.
CHAPTER 5: DISCUSSION AND CONCLUSION

This study was of 38 adult autistic workers located in the United States, the United Kingdom, Europe, and Canada. Most (35/38 or 92%) of these workers were employed. Discounting two participants who were retired or permanently disabled, 97% of the participants were employed. Most participants (25/38 or 66%) were either current, former, or occasional/unofficial supervisors. Further investigation into why this may be could help subsequent generations of autistic adults reach the same levels of authority and success as their predecessors. The “autistic strength” that most (22/38 or 58%) of the participants mentioned was not a talent (Gernsbacher et al. 2008; Gonzalez et al. 2013; Stevenson and Gernsbacher 2013) but a simple tendency to produce more and better quality work over their peers. This “workhorse” phenomenon has not yet been explored in academic literature about autistic adults. It would be interesting to understand when it is an advantage to work harder and better than others and when the worker is simply being taken advantage of. Further exploration into this subject could help future and current autistic workers and help organizations better recruit and retain resources.

Most participants (22/38 or 66%) related hearing others refer to autism in a stigmatized fashion and most (29/38 or 76%) reported bullying or systematic exclusion in some point over their careers. Most participants (29/38 or 76%) also admitted trying to pass as non-autistic or neurotypical at least some of the time. Current research about autism discourse is from the perspective of non-autistic authorities (Dillenburger et al. 2010; Lester and Paulus 2012). There is no academic literature directly asking autistics to provide their opinions on the way other people speak about autism and autistic people. There has been research about bullying of autistic people (Balfe and Tantam 2010). There is currently an effort to understand a possible predatory
effect that may be happening with non-autistic people toward autistic people (Ekblad n.d.). This effort should be given more support. Further research into symbolic interactionism may also help to understand bullying and stigma of autistic adults.

Most participants described their co-workers as “work-friends” (22/38 or 58%) or as “friends” (12/38 or 32%) and most (28/38 or 74%) said they worked in a reciprocal joking environment where they told and heard jokes at work. Most participants (31/38 or 82%) help or do favors for their co-workers often or sometimes. There has been some recent exploration into friendships for autistic adults (Helles et al. 2016), and into friendships at work for non-autistic people (Choi 2006), but the specific function of friendships for autistic people at work has not yet appeared in academic literature. It may be beneficial for there to be an increased public awareness that an autistic person may be present in the workplace, taking part in friendships and light-hearted interactions, and helping co-workers. Exploration of this issue may help bring awareness to autism as a state that is not necessarily unpleasant for the autistic person or those around her/im.

A notable number of participants (13/38 or 34%) were not able to gauge whether they were treated differently by co-workers at work and a smaller, but still notable number (10/38 or 26%) could not gauge whether their boss treated them differently than other workers. It could be that these workers are experiencing theory of mind failures, which could be explored with further investigation. Symbolic interactionism may be useful in unraveling what is going on during social exchanges between autistic and non-autistic workers and therefore why some autistic workers are unable to determine whether or not they are treated differently. Another possible avenue for investigating this phenomenon is a combination of Festinger’s social comparison and cognitive dissonance theories; which could explain an effect where confusing social input is
disregarded by an autistic person before it is completely cognitively registered, therefore blinding them of certain goings on around them.

A slight majority of participants (25/38 or 66%) know of or suspect a co-worker of being on the autism spectrum. A few people were actively supporting an autistic subordinate or being supported by an autistic boss, but most people who mentioned this phenomenon simply noticed the traits in others. If another person has been noted to be “possibly autistic” this lends credence to the idea that there is an “autistic look” (Lester and Paulus 2012) which is observable. These ideas of observing autism and of autism solidarity are both worth future study.

Most participants (34/38 or 90%) experience autism-related stress or anxiety at work and most (35/38 or 92%) experience autism-related exhaustion at or following work. The common sources for anxiety and exhaustion at work were stated to be: sensory-rich environments, highly-social work tasks, moral dilemmas, and “just being at work” (Participant 33). Some participants (16/38 or 42%) reported using a soothing substance or behavior (stimming or exercise) at or following work in order to tolerate work. Nearly all participants (37/38 or 97%) said they need a recovery or “buffer” period following their work day before resuming non-work activities.

The presence of autism-related stress/anxiety and exhaustion and the resulting coping mechanisms were the most interesting parts of this study for me. I believe that if these areas of stress were described in more detail, they could be avoided in many cases, thus increasing productivity for autistic workers. I would also like a more detailed analysis of the coping mechanisms, from a greater number of people. These could be offered as suggestions for other autistic people who are struggling to find their own coping mechanisms. I believe that this section is the key to greater successes for autistic adults in the workplace.
A small number of participants (4/38 or 11%) used a form of “othering” language when describing non-autistic people. This phenomenon has been documented by Ian Hacking but has not been subsequently explored in academia (Hacking 2009b). I believe that the participants used othering language as a form of expressing higher than normal self-esteem. It could be that this is a coping mechanism used as a form of resistance against autism oppression. It could also be that some autistic people form an atypical form of social self which can be expressed in this form (Mead 1934). Further exploration into this subject may lead to an alternate to the standard narrative of autistics trying to fit in; this type of narrative may lead to an accepted archetype of an autistic elite, completely comfortable being different.

Most participants (23/38 or 61%) have disclosed to someone at work, but most of these (16/23 or 70%) did not provide formal documentation. Of those who disclosed, most (17/23 or 74%) told everyone that they work with that they were on the autism spectrum. Since a good portion of the participants (14/38 or 37%) were not from the United States, ADA rules did not apply to them. Formal documentation may not have been required in non-US countries to legally ask for accommodations or to expect not to be discriminated against. It could be that participants were not informed about the nuances of the ADA, but as I did not ask them specifics about the ADA, I cannot make a judgment about what they did or did not know.

Some participants (12/38 or 32%) asked for official accommodations at work. Other participants (14/38 or 37%) were receiving help that would not be considered official accommodations. A total of 26/38 or 65% were receiving accommodations or special help. The remaining participants (12/38 or 32%) were not receiving any accommodations or special help. The kinds of accommodations or help that the participants in this study received were, social, sensory, flex-time, planning/paperwork/organizational, and thorough explanations. It would be
uncommon for a worker to receive no help at all at work (Choi 2006). The reason I asked participants if they were receiving help was to determine if informal help was taking the place of formal accommodations. I was unable to answer that question on a large scale, as some people who received formal, autism-related accommodations were also receiving informal, autism-related help, sometimes help that was not requested. It does appear that most people in this study do use either autism-related formal accommodations or autism-related informal help. I cannot say if this is unusual because I did not look at a control population. It could be that non-autistic populations use the same amount of formal accommodations and informal help for some other reason. However, this information is useful because it tells us what kind of accommodations or help are already in place for workers.

In conclusion, this study did not answer many questions due to its small sample size. This study grew from an initial focus on disclosure practices to a general overview of life at work for an autistic adult. The overview as presented by participants in many areas does not match existing literature about autism, leading one to wonder if the participants represent an invisible population. I believe this project opened some important discussions. Autistic adults are present in the workforce, functioning at a much higher level than previously described in both academic and popular literature. Stress and stigma about autism are problems which are quietly and personally dealt with by unique coping strategies. This population seems to be able to work harder and more efficiently than their peers. Issues of disclosure and accommodation may be working outside of formal disability systems.

I had two original research questions, which helped to form an initial focus for this project. My first original research question was: Do people on the autism spectrum disclose their autism status at work? The answer was: Yes, with caveats. Only a slight majority discloses, and
that disclosure is not formal. Participants had plenty of opportunity to tell me more about disclosure but most elected not to share. Disclosure seemed to become a smaller theme in this project as other themes were mentioned with more depth and frequency. The participants answered questions about disclosure with less thoroughness and enthusiasm as other questions in this study, leading me to wonder if disclosure was as important to them as other subjects they mentioned. My second original research question was: Why (do participants disclose) or why not? I should have directly asked participants why they chose to disclose or not disclose. Since I did not, I could only guess at the answer to that question. I believe the problem with most autism research is that too many researchers guess instead of directly asking their participants. It’s easy to want to fill in a blank to complete a project, but in this case, it would be unethical for me to guess. I should have asked.

In the course of pursuing my original research questions, I found the real story with this project, which is the general picture of work life that emerged from the participants’ data. There are many subjects here that have not been formally documented outside of online forums and side conversations, so the academic narrative is that the phenomenon does not exist. The autistic worker provides an important function to any organization and deserves an audience. Further study on what is already working well for autistic employees will let other workers and their companies replicate their strategies. This will improve productivity and efficiency for organizations and comfort and respect for workers.
APPENDIX

Original Research Questions

The research questions I chose seemed to be, at that time, the nexus of all other published work:

- Research Question 1: Do people on the autism spectrum disclose their autism status at work?
- Research Question 2: Why or why not?

A third question was edited out of the submitted draft of the thesis proposal for this project: Research Question 3: Do people on the autism spectrum ask for accommodations at work? This question was dropped as it was expected to be a minor point.

Purpose of Original Research Questions

The specific questions were chosen because I thought that clarification of these points would help bring deeper understanding to previously published studies about working autistics and bring opportunities for greater efficiency to future studies.

Question 1: Do people on the autism spectrum disclose their autism status at work?

Previous studies about autistic workers only use participants who have been medically diagnosed with an autism spectrum disorder and have disclosed to someone at work that they are on the autism spectrum (Baldwin et al. 2014; Hurlbutt and Chalmers 2004; Roux et al. 2013). One article about the presence of autism in academic professionals suggests that many people could be keeping their autism status a secret (Diament 2005). I thought that systematically asking a group of people who identify as autistic if they disclosed their autism at work might give us as academics a place to start in affirming the existence of a hidden autistic worker population.
Many questions on the survey exist as a caveat to this research question. Since I am allowing that participants might be “secretly autistic” at work, I gave participants the option of self-identifying as autistic from taking an online assessment test or being told by an educational professional or social worker, for example. I also asked participants questions asking them to judge if others at work were “secretly autistic.” The point behind these questions was to establish if there was a hidden population. At the time that I constructed the original research questions, I did not think “Is there a hidden, passing, autistic population in the workforce” was a useable research question. I believed that asking about workplace disclosure got at the same issue and was easier to define.

Question 2: Why or Why Not?

I had hoped that this question would give me the rest of the answers about this project. I expected that some of the already documented issues from the literature review would be mentioned by the participants, in addition to some unexpected themes. I thought that exploratory research would allow me to go back and adjust accordingly after examining the data. For example, I could explain that one expectation had little or nothing to do with the findings and then have the freedom to do more research and explain further about a new finding. I see now that I should have directly asked participants “Why/Why Not” but this was an oversight on my part.

Question 3: Do people on the autism spectrum ask for accommodations at work? (Not officially used)

Although I did not officially use this research question, as it did not appear as research question, I did include all survey questions about this topic. I had a suspicion, which was not reflected or even mentioned in the literature, that autistic workers were successful at work due to
a blend of official and unofficial accommodations. Unofficial accommodations is a casual term I am using to mean friendly helping actions between co-workers. There is some research about helping behaviors between friends and co-workers and how these behaviors occur more frequently either between people who are similar types of people or between people who are physically located next to each other (Choi 2006; Festinger et al. 1952; Rossetti 2011).

Some additional questions that were associated with this “hidden” research question were about friendships, helping, respect, and accommodations. Some of the questions I asked about “stimming” behaviors were also part of this general line of questions as stimming is a form of coping or self-accommodating.

Research Questions Post Focus Change

There were no research questions after I changed the focus in this project. I discovered that the research questions I asked addressed only a small corner of what the participants described to me as important to them. The overarching theme in their narratives seemed to be that they are working autistic people and they are a hidden, or invisible minority class. I was able to change the title of this thesis to reflect the new focus, but I did not feel it would appropriate or accurate to write new research questions. There were too many specific issues that the participants addressed with no common problem.

Restatement of the Original Research Problem

Previous studies about autistic adults at work have focused on how autistics can gain and keep employment (Hendricks 2010; Hurlbut and Chalmers 2004; Nesbitt 2000; Roux et al. 2013). Some literature about working autistics is presented as guides to help workers on the spectrum capitalize on their strengths and minimize their weaknesses (Grandin and Duffy 2008;
Smith et al. 2000). With no public narrative or architype of successful, working autistics, the existing narratives of help for autistics gives the impression that autistics need help. No academic studies have assumed that autistic workers are already present, perhaps undocumented as such.

I had two guiding research questions, but provided participants with 55 questions involving many aspects of their work life. By focusing on my initial research questions, I hoped to provide an alternate narrative to the widespread assumption that autistics are under- and unemployed in large numbers.

My first research question was: Do people on the autism spectrum disclose their autism status at work? The reason I chose this as a guiding question was because previous studies about autistic workers had made several critical assumptions which I suspect to be erroneous: 1) That working adults on the autism spectrum are all or mostly medically diagnosed with some form of autism (as opposed to having a self-diagnosis or diagnosis by an educator, for example); 2) That working adults on the autism spectrum all or mostly use a autism support service; 3) That working adults on the autism spectrum have disclosed to another person that they are on the autism spectrum. People who do not fit all three of the aforementioned criteria could be assumed to not exist in previously published academic literature about autistics and work and therefore should be considered a hidden and sensitive population. “Hidden” because they have previously been missed by academia in prior studies and “sensitive” because people who are not public with an aspect of their identities may have good reasons to conceal this information, and should be given according respect and consideration.

My second research question was: Why or why not? This general question of why/why not initially seemed to be a good way to address a large bank of exploratory questions meant to
unearth whatever phenomenon(s) lay underneath the mere existence of autistic workers who may or may not be disclosing their autism statuses at work. In retrospect, I now believe that the only way to answer why/why not would have been to directly ask participants, “Why did you disclose?/Why did you not disclose?” I had thought that the exploratory questions would answer these questions, but I did not find clear evidence connecting any explanations to disclosure. The exploratory questions instead revealed other themes about participants’ work life which may lead to new research areas in the sociology of autism. I believe this information will be useful to further both the personal comfort and productivity of workers and to help organizations capitalize on their human investments.

Revision of Research Questions and Project Focus

The original title of this thesis was “Autism Disclosure in the Workplace.” After analyzing the data, I changed the title to more accurately describe the content of the participant responses, “Autistic Workers: Invisible People”. I chose this title to evoke emotional response from the reader, who is meant to wonder in what way are autistic workers invisible. I used the subtitle Invisible People because I wanted to suggest that when autistics are working, many aspects of them as people are not recognized to academia or even to the other workers around them. I also wanted to highlight the fact that at their most base, autistics are people.

The information gained in the exploratory portion of this project overwhelmed the portion about disclosure and thus the project became more about the experiences of the human beings who generously gave narrative descriptions to each question. There was an overarching sense that they were not being listened to by the professionals around them and their experiences were not being recognized, even when those experiences were positive. I went back to the
drawing board to use a more aggressive exploratory research approach and thus changed the topic of this thesis to suit the information I was given by participants.

Survey Questions

1. Identifier Number: _____________________ (contact the research team if you have not been provided with an identifier number)
2. What is your age? __________________
3. What is your gender?
   a. Female
   b. Male
   c. Other (please specify) __________________
4. What is your race? __________________
5. What is your national origin? __________________
6. Are you fluent in English?
   a. Yes
   b. No
7. What is the highest level of education you have completed?
   a. I did not finish high school
   b. High school or equivalent
   c. Trade or technical school/Associate’s degree
   d. Some college
   e. Bachelor’s degree
   f. Master’s degree
   g. PhD or MD
   h. Other (please elaborate)
8. Are you on the Autism Spectrum? Select all that apply
   a. Yes, diagnosed by a medical professional
   b. Yes, diagnosed by an educational professional
   c. Yes, diagnosed by a counselor or social worker
   d. Yes, diagnosed by a self-administered test
   e. I don’t know (please contact the research team before continuing)
   f. No (please end this survey. Thank you for participating!)
9. At what age were you diagnosed? ______________
10. What is your current employment status? Select all that apply
    a. Full-time worker, paid
    b. Part-time worker, paid
    c. Volunteer work, unpaid
    d. Business owner/Entrepreneur
    e. Former full-time worker, paid
    f. Former part-time worker, paid
    g. Former volunteer worker, unpaid
h. Never employed or volunteered
i. Other (please elaborate)

11. What is your current or past occupation? __________________________

12. What is your supervisory level? Select all that apply
   a. I am a supervisor, manager, or teacher
   b. I oversee others unofficially
   c. I used to supervise or oversee others (please elaborate, why did this change?)
   d. I am only responsible for myself
   e. I have a job coach or mentor who helps me do my job
   f. Other (please elaborate)

13. Are you satisfied with your job?
   a. Yes
   b. No
   c. I don’t know

14. Do people close to you know that you are on the autism spectrum? Select all that apply
   a. Yes, my family knows
   b. Yes, my friends know
   c. No
   d. I don’t know
   e. Only one or two people know (please elaborate)

15. Do people in your personal life understand what autism is? Select all that apply
   a. Yes, my family understands
   b. Yes, my friends understand
   c. Only one or two people understand (please elaborate)
   d. Some people struggle to understand (please elaborate)
   e. I don’t know
   f. No

16. Do you have special abilities that others do not have?
   a. No
   b. I don’t know
   c. Yes (please elaborate)

17. Do you have special problems that others do not have?
   a. No
   b. I don’t know
   c. Yes (please elaborate)

18. Do you ever try to present yourself as someone who is not autistic?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never

       Please elaborate below

19. Did you receive any help getting your job?
a. Yes, from an autism-specialty employment service
b. Yes, from an employment service/job placement service/recruiter
c. Yes, from a friend/colleague/other contact
d. No

20. Have you ever heard people at work discuss autism? If so, what was the general opinion?
   a. No, I haven’t heard anyone discuss autism at work
   b. Yes (please elaborate)

21. What level of autism awareness is present in your work organization?
   a. My organization actively looks for and hires autistic people as a business strategy
   b. My organization sometimes seeks to hire “autistic types” but does not seem to be aware of autism
   c. My organization employs autistic people or “autistic types” but discussion about autism is discouraged
   d. My organization takes part in well meant, but offensive/misguided autism charities or movements
   e. I believe I am the only autistic person here
   f. I don’t know
   g. Other (please elaborate)

22. Are there others in your workplace who know of and disclose their autism status?
   a. Yes
   b. No
   c. I don’t know

   (please elaborate below)

23. Are there people in your workplace who you suspect of unknowingly being autistic?
   a. Yes (please elaborate)
   b. No

24. Have you disclosed your autism status to anyone you work with? Select all that apply
   a. Yes, to Human Resources (HR)
   b. Yes, to my boss
   c. Yes, to my co-workers
   d. Yes, to my employee(s)
   e. Yes, to my clients/customers/students
   f. No (skip to Work and Accommodations)

25. Was your disclosure in the form of formal documentation?
   a. Yes
   b. No
   c. I gave formal documentation to some and informally disclosed to others (please elaborate)

26. Do you think the people you disclosed to understand what autism is?
   a. Yes
   b. No
   c. I don’t know
   d. Some do (please elaborate)
27. Were you treated differently after you disclosed your autism status?
   a. Yes, I was treated better
   b. Yes, I was treated worse
   c. Some treated me better and others treated me worse
   d. No, I was treated the same

   Please elaborate below

28. Have you asked for autism-related accommodations at work? Select all that apply
   a. Yes, I have asked Human Resources (HR)
   b. Yes, I have asked my boss
   c. Yes, I have asked my co-workers
   d. Yes, I have asked my clients/customers/students
   e. No (skip to question 26)

   Please elaborate below

29. Did you receive accommodations?
   a. Yes, I received the accommodations I asked for
   b. No
   c. I received some accommodations, but not what I asked for

   Please elaborate below

30. Do you receive special help at work that would not be consider official accommodations?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

31. Do you help or do favors for co-workers, beyond what is required in your job description?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never (skip to Interacting with Co-Workers)
   e. I don’t know

   Please elaborate below

32. Do you receive anything in exchange?
   a. No
   b. Yes (please elaborate)

33. How often do you feel confident with your social skills?
34. Do your co-workers joke around at work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

35. Do you joke around with your co-workers?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

36. Have you been the target of derogatory jokes at work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

37. Have you been bullied at work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never (skip next question)
   e. I don’t know (skip next question)

   Please elaborate below

38. Who has bullied you at work? Select all that apply
   a. Boss
   b. Co-worker(s)
c. Employee
d. Customer/client/student
e. Other

Please elaborate below

39. Do your co-workers or boss take advantage of you?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

Please elaborate below

40. Do your co-workers leave you out of things?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

Please elaborate below

41. Do your co-workers put you down?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

Please elaborate below

42. Do people at work give you the information necessary for you to do your job?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

Please elaborate below

43. Are you friends with your co-workers?
   a. Yes, many of them
   b. I am friends with one or two of them
   c. I am “work friends” with them but these are not real friendships
   d. No, I am not friends with any of them
   e. I don’t know

44. Do you and your co-workers perform the same amount and quality of work?
a. Yes
b. I don’t know
c. No (please elaborate)

45. Does your boss treat you differently than your co-workers?
   a. No
   b. Yes (please elaborate)

46. Do your co-workers treat you differently than other co-workers?
   a. No
   b. Yes (please elaborate)

47. What is your general opinion of your co-workers? Select all that apply
   a. Friends
   b. Team-mates
   c. Peers/colleagues
   d. Oppressors
   e. Background noise
   f. Tools
   g. Other (please elaborate)

   Please elaborate below

48. Do you experience stress at work that you think is related to being autistic?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

49. Are you advancing in your career?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

50. Have you been denied a raise or promotion without being given a valid reason?
   a. No
   b. Yes (please elaborate)

51. Do you feel anxious at or after work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
52. Do you feel exhausted at or after work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

53. Do you need a soothing substance or behavior in order to tolerate work?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

54. Do you need a “recovery” or “buffer” period after a work day?
   a. Often
   b. Sometimes
   c. Rarely
   d. Never
   e. I don’t know

   Please elaborate below

55. May we contact you if we have a follow-up question?
   a. Yes
   b. No
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