Female Autistic Perspectives: Limits in Diagnosis and Understanding

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FEMALE AUTISTIC PERSPECTIVES:
LIMITS IN DIAGNOSIS AND UNDERSTANDING

by

ALEXANDRA HELMERS

A master’s thesis submitted to the Graduate Faculty in Liberal Studies in partial fulfillment of the requirements for the degree of Master of Arts, The City University of New York.

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FEMALE AUTISTIC PERSPECTIVES: LIMITS IN DIAGNOSIS AND UNDERSTANDING

by

Alexandra Helmers

This manuscript has been read and accepted for the Graduate Faculty in Liberal Studies in satisfaction of the thesis requirement for the degree of Master of Arts.

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THE CITY UNIVERSITY OF NEW YORK
ABSTRACT

Female Autistic Perspectives: Limits in Diagnosis and Understanding

By

Alexandra Helmers

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The diagnosis of autism spectrum disorder has increased dramatically within the last two decades, with males being diagnosed, on average, four to five times more than females. Although researchers in the medical community have searched for a biological explanation for this discrepancy, no definitive cause has been found. I argue that our understanding of autism is primarily a social and cultural construction, in addition to a diagnosable medical disorder. The gender disparity in diagnosis reflects cultural narratives surrounding social interaction and the widespread belief in two distinct gender roles. Furthermore, narratives surrounding the topic of autism tend to unintentionally highlight gender stereotypes and validate cultural, learned rules as inherent to individuals, which in turn may affect the diagnosis of autism. I explore the various reasons that we may locate autism in males more than in females, and highlight how areas that are usually thought to be objective are unintentionally biased, based on the binary gender system. A side-effect of the difference in diagnosis between males and females is that women and girls tend to be diagnosed later in life, or remain undiagnosed, which causes them to lose access to treatments and therapies from which they may have benefited. The anxiety this causes among autistic women is apparent when focusing on their memoirs and first-person accounts of their experiences. I offer an analysis of these personal narratives that highlights the embedded sexism in society leading girls and women to be underrepresented in the autistic community. Additionally, I’m looking towards a shift in the understanding of gender identity itself, and the future of diagnosis and neurodiversity.
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Introduction

Once thought of as rare, the number of individuals diagnosed as having autism spectrum disorder has dramatically increased within the last two decades. Autism has been widely discussed in the news and in popular media, corresponding with a rise in fictional portrayals of autistic characters in pop culture. The diagnosis of autism is increasingly common, and males are disproportionately diagnosed at a higher rate than females. According to the Centers for Disease Control and Prevention, “ASD occurs in all racial, ethnic, and socioeconomic groups, but is about 4.5 times more common among boys than among girls” (“Facts About ASD”). The CDC’s Autism and Developmental Disabilities Monitoring Network (ADDM) reported in 2007 that “1 in 150 children had ASD (based on 2002 data from 14 communities).” By 2014 reports showed that “about 1 in 68 children had ASD (based on 2010 data from 11 communities)” (“Autism and Developmental Disabilities.”) A 2014 article published by the Journal of the American Medical Association uses this data to point out that as the rate of autism diagnosis has increased consistently over the last two decades, “the condition remains nearly 5 times more common among boys than girls […]” (“Autism Spectrum Disorder Up by 30%”). However, this does not reflect the reality faced by many women and girls who feel underrepresented by the medical and social communities surrounding autism spectrum disorder.

Women and girls with autism have become a recent point of focus, as many high-functioning autistic women have spoken out about the difficulties in receiving a diagnosis. Some have diagnosed themselves, which they speak about in their memoirs and personal accounts. One of the questions attending this issue of diagnosis is if girls exhibit different symptoms of autism than boys do, are these symptoms being acknowledged by the medical community? An official diagnosis of autism is based on many factors, mostly focusing on a child’s social behavior, as
there is no medical test that can be used to definitively diagnose autism. The CDC states, “We do not know all of the causes of ASD. However, we have learned that there are likely many causes for multiple types of ASD. There may be many different factors that make a child more likely to have an ASD, including environmental, biologic and genetic factors” (“Facts About ASD”).

Popular organizations, such as Autism Speaks, fund studies to find the cause or causes of autism, and to discover why it seems more prevalent in boys and men than in girls and women. Because diagnosis among males is so prominent, females with autism have voiced feelings of neglect and describe the struggles involved with seeking the correct diagnosis. What then causes the discrepancy in diagnosis and why is it more widespread among boys and men?

When observed from a cultural point of view instead of a scientific one, the gender gap in autism cases indicates a socialized phenomenon, rather than a medical and biological one. The gender disparity in the diagnoses of autism reflects the cultural narratives surrounding social interaction that have been created and continue to be created by society at large. Narratives covering the topic of autism may unintentionally emphasize gender stereotypes and validate cultural, learned roles as inherent to individuals, strengthening the separation between boys and girls. Is it that more males are on the autism spectrum disorder than females, or do we look for the disorder in males rather than in females, heightening the imbalance in diagnosis? Another factor at work could be that the known symptoms of autism are based mostly on male subjects, and therefore females with autism may exhibit symptoms in ways that are not acknowledged by the medical community and therefore not recognized as indicators of autism. Throughout this work, I will discuss questions of diagnosis, focusing on how society pathologizes transgressions of social and gender norms. Social constraints help to shape and create identities, and these cultural norms tend to reflect in the otherwise “objective” world of science and medicine.
I will demonstrate that much of the current knowledge surrounding the diagnosis of autism is based on biases that do not take into account differences that may arise due to the gender of the autistic individual. By studying life writing by autistic individuals of both genders, as well as autobiographies of family members of autistic individuals, I will analyze the subtle, inherent gender expectations that may affect the diagnosis of autism, as well as possible biological reasons that females and males may exhibit different “symptoms” of autism, leaving women and girls underrepresented from the larger autistic community. Using first-person narratives by autistic female writers, I observe a strong outcry for a change in the way we diagnose autism.

I will primarily refer to two genders, male and female, as is broken down in most of the research available, though I acknowledge that the binary gender system is not “natural,” but a socially constructed phenomenon. I focus primarily on Western societies, especially the United States, and my survey yielded predominantly white perspectives. Though this study is not about race and diagnosis, the attendant gap in research and medical attention for people of color with autism suggests another avenue for thinking through problems with bias and exclusion in the medical world.

When discussing gender and autism, biological sex and gender become inescapably entwined with each other, complicating the ability to provide a simple definition of either. Within this work, I ask that readers both acknowledge that biological differences based on the sex of an individual (such as hormonal differences between males and females) as well as conditioned gender differences shaped by society can both affect the personalities, actions, well-being and diagnosis of an individual. It may be a combination of these factors that creates the lack of attention and support towards autistic girls and women. Underrepresentation of females
in the autism community works as a microcosm, highlighting the macro-issue of systematic female disenfranchisement in countless other areas of society.

**Brief History of Autism in the United States**

As disability scholar Lennard Davis states, “the ‘problem’ is not the individual with disabilities; the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (Davis 3). Individuals with autism tend to act outside the strict boundaries that create our understanding of social normalcy. This deviation is what marks these individuals as “autistic.” Autism is a disorder that exists because we live in social communities that track an individual’s growth and actions based on an unwritten list of social expectations. The given gender of an individual has a huge impact on these expectations, which dictate what is perceived as a child’s deviant behavior. Yet when it comes to the symptoms and indicators that are looked for when diagnosing a child with autism, the list of what to look out for that is available to parents and caretakers is the same for both boys and girls, and possible differences among the reactions of boys and girls is rarely mentioned. It is imperative to look at the combination of factors that lead both genders to react differently in social situations, and start acknowledging that their symptoms may vary when it comes to diagnosis, since there is no genetic test that can be used to definitively locate autism. Because gendering begins at birth and enforces many differences among boys and girls, it would be helpful to take this into account when diagnosing autism, as well as other disorders.

In the 1990s, the diagnosis of autism expanded into what is now known as autism spectrum disorder (ASD), a term first used by scholar Lorna Wing, who left behind the previous term “continuum” from her research in the 1980s (Donvan 313). The newer definition of autism as inhabiting a spectrum of behaviors means that someone with what is considered high-functioning autism can cognitively function in a very different way than someone with low-functioning autism,
yet remain under the same umbrella category. In this way, autism is a term that is used to describe many different “non-normative” ways of interacting with others, primarily defined by a lack of typical social behavior and eye contact. The CDC defines autism spectrum disorder as “a developmental disability that can cause significant social, communication and behavioral challenges […] people with ASD may communicate, interact, behave and learn in ways that are different from most other people” (“Facts About ASD”) Signs of autism have been expounded on since autism first became a recognized diagnosable disorder in the United States in 1943. At that time, child psychiatrist Leo Kanner studied children who exhibited certain traits, and created what we now know of as the diagnosis of autism. Around the same time, Hans Asperger of Austria, a pediatrician and medical theorist, also studied children with similar traits (Straus 535). Later, the term “Asperger’s” would also be coined by Lorna Wing (Donvan 315). Asperger’s syndrome is considered a form of high-functioning autism which features social impairment but no cognitive disabilities. The definition of autism spectrum disorder now encompasses Asperger’s syndrome, which was once separated from ASD in the Diagnostic and Statistical Manual of Mental Disorders (DSM) but has recently been reabsorbed as part of the autism spectrum disorder in the DSM V which was published in 2013 (“Diagnostic Criteria”). The CDC references this change on their “Facts About ASD” page: “A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS) and Asperger syndrome.” Asperger’s Syndrome is still used colloquially to describe those with high-functioning autism, particularly in the media, as well as among the “Aspie” community. Therefore, the term will be used throughout this work.
Symptoms of Autism and Male Biases

Because autism cannot be diagnosed using one definitive test, a series of symptoms and personality traits are used to determine official diagnosis of the disorder. Since the diagnosis is based on behavioral differences along a wide spectrum, diagnosis is not always obvious or correctly given. Furthermore, because a certain precedent regarding autism has already been set, diagnosis tends to follow a certain trend, specifically that it is more prevalent among males than females. A recent study in Social Science and Medicine journal studies this phenomenon, stating, “In terms of how gendered expectations might affect ASD diagnosis, the simplest and most likely scenario is that ASD, as a syndrome that is commonly and epidemiologically associated with males, would be more readily recognized in male versus female children, given equal presentation of symptoms” (Cheslack-Postava and Jordan-Young). The difference in diagnosis may also be due to the fact that symptoms themselves may be tailored to what autistic boys tend to enact, and not what autistic girls exhibit as symptoms of autism. For example, aggression may be a symptom of autism that is more prevalent in males than females, and so more males are diagnosed. Tony Attwood comments on this type of biased diagnosis in Asperger’s and Girls, stating,

We do not know whether this is a cultural or constitutional characteristic, but we recognize that children who are aggressive are more likely to be referred for a diagnostic assessment to determine if the behavior is due to a specific developmental disorder, and for advice on behavior management. Hence, boys with Asperger’s Syndrome are more often referred to a psychologist or psychiatrist because their aggression has become a concern for their parents or schoolteacher. A consequence of this referral bias is that not only are more boys referred, clinicians and academics can also have a false impression of the incidence of aggression in this population (Attwood 3)

As illustrated above, certain symptoms that tend to be more associated with males are used for diagnosis, further emphasizing these symptoms as leading to an autism diagnosis. In this way,
the repeated diagnosis of autism in males based on factors like the above-mentioned aggression reiterates already potentially biased beliefs about autism symptoms. Symptoms that may be more common in females may never have been formally considered symptoms of autism, delaying or causing missed diagnoses for autistic females.

Many studies of the differences between the male and female brain have attempted to locate a biological difference within males and females to help explain the high rate of autism among boys in particular. Simon Baron-Cohen’s idea of the “extreme-male brain theory of autism” is described in his book, *The Essential Difference: Male and Female Brains and the Truth about Autism*. Although Baron-Cohen points to several studies to provide evidence of cognitive difference in the sexes, much of this evidence is insubstantial, as a majority of the work focuses on learned, gendered behavior absorbed by children and mirrored by society at large. It also emphasizes basic gender essentialism; Baron-Cohen’s analysis focuses on his assertion that the female brain is better at empathizing (connecting with others and understanding feelings), and the male brain is better at systematizing (organizing and compartmentalizing). For Baron-Cohen, these are opposite impulses.

Although Baron-Cohen argues that the differences between traits among girls and boys are “inherent,” the evidence used to support this does not show that biological factors are responsible for children’s aesthetic choices, such as choice in toys or colors. Baron-Cohen’s work is an illustration of a larger issue in society which continuously categorizes individuals. Simultaneously, it posits that boys and girls may enact different symptoms when it comes to autism, which very well may be true. However, the cause of the difference that Baron-Cohen asserts may not be correct. Ultimately, the cause of the differences in symptoms among females and males, whether biological or socialized, is not the most relevant aspect of diagnosis, since
socialized factors won’t likely change anytime soon. The effect that gendering of individuals has on symptoms and diagnosis should be the focus at the moment, as well as recognizing these differences and working to integrate them into the medical field.

Yet integrating specific symptoms that may be different based on gender can be tricky, as it runs the risk of further emphasizing gender biases. On one hand, recognizing gender differences can provide more support and individualized therapy; on the other, it could lead to further stereotyping. Kristin Bumiller criticizes Baron-Cohen’s statements on gender in her article “Quirky Citizens: Autism, Gender, and Reimagining Disability,” stating,

> While the validity of this research is subject to a debate within the scientific community, it nevertheless promotes a view of autism that reinforces cultural stereotypes of gender. From a feminist perspective, the essentialist version of autism is a disturbing reconstruction of gender and disability stereotypes in the guise of new scientific knowledge. (973)

Bumiller adequately highlights the embedded sexism in society which is supported through research like Baron-Cohen’s, which focuses too heavily on proving biological difference between males and females, using non-scientific evidence to support the claims. As Bumiller states, “a gender-based theory of autism grossly oversimplifies the enormous complexity of the autistic condition” (973). Gender is increasingly being viewed as a spectrum, as is autism, and thus the symptoms and actions of different genders on the spectrum can yield very different results. Just as there is no medical test for autism, there is no medical test for gender or gender orientation. Even the work of looking at multiple factors that cause boys and girls to enact symptoms differently runs the risk of emphasizing the separation between boys and girls on the spectrum.

Continuing the commentary on scientific models of autism in her book, *Constructing Autism: Unravelling the ‘truth’ and understanding the social*, Majia Holmer Nadesan states,
The medical and scientific literatures represent autism as a biological facticity that must be explained using positivist methods and assumptions of the natural sciences. That is, the medical and scientific literatures often assume autism is some thing or things, some essential biogenetic condition(s), which will ultimately be unequivocally identified and known as a spatially centered genetic, neurological, or chemical abnormality through the efforts of scientists toiling in their laboratories (2).

As Nadesan emphasizes here, autism seems to be something that cannot be simply discovered and cured. Diagnosing autism is subjective--an individual matches several symptoms that point to autism as the overall cause. Therefore, each blend of factors is different for each person, and there is not one form of autism. Diagnosis of any cognitive disorder is subjective in some ways, which is perhaps why it seems many women with autism are first diagnosed with other cognitive disabilities, a fact that is illustrated in the myriad of memoirs that will be discussed shortly.

Another issue with diagnosis is the male bias within the medical community. Research on autism is performed using a majority of male patients. A 2012 study, “The Gender of Participants in Published Research Involving People with Autism Spectrum Disorders,” discusses the over-representation of males with autism. The authors reviewed over 600 articles about autism from 2010 through 2012 found in several academic journal and database sources, and found that “85.85% of the participants with ASD who took part in intervention research […] were male” (Watkins et al.). This provides evidence that research being done on autism could also be excluding a group of female autists who either don’t fit into the diagnostic criteria looked for, or are assumed to be much less likely to have autism, and therefore less desired for scientific studies. It is also a possibility that males with ASD behave differently than females with ASD and exhibit more obvious symptoms that can provide more definitive results. The authors point out, “It is noteworthy that very few studies we examined, 0.49% of the total, involved only females with ASD, and a case could be made that this population has been largely ignored by
researchers” (Watkins et al.). Although males and females may exhibit different symptoms of autism, the male body tends to be a scientific and medical default, and studies on autism may be contributing to the gender disparity by focusing on males more often than females, further amplifying an issue that they are attempting to solve. It also continues a long tradition of placing males before females in medical testing.

To further understand why the figure of the autistic male may outshine the autistic female, we need to understand the traits and symptoms that seem to go along with the diagnosis of autism and how those are affected by gender. The cultural expectation for neurotypical women often manifests in the form of the nurturer, or caretaker role, highlighting empathy. The cultural narrative surrounding the autist (who is disproportionately male) tends to hone in on the idea of lone genius or savant, with a lack of empathy or connection to others. Both cultural figures are creative forces, yet the social expectation of each role could not be more different. More representation of autism in the media has gone hand-in-hand with portrayals of the genius male. Jordynn Jack discusses this problem in her article “‘The Extreme Male Brain?’ Incrementum and the Rhetorical Gendering of Autism.” Jack states,

Since the 1980s, autism has become increasingly associated with the science, computing, hi-tech industries and, in the process, with masculinity and fathers. For one, the brains of autistic themselves are compared to computers. Diagnosing famous scientists, engineers, and computer scientists with autism has become a parlor game and cottage industry […] contemporary understandings of geek masculinity have become one of the more common, gendered terministic screens through which autism is now understood, producing scales that align people in order of technological or ‘systemizing’ skill.

It goes without saying that the scientists and engineers that Jack alludes to as being post-diagnosed are mostly, if not all, male, which adds to the cultural narrative of male genius, or savant, with autism. Larger cultural narratives are shaped by the “terministic screens” Jack refers to, a phrase which is used here to describe systems of language informing human action.
Through the dialogue surrounding the topic of autism, many of the stereotypes about gender and autism become realized and shape our own perspectives on it.

Author Michael Fitzgerald emphasizes these stereotypical beliefs that autism is inherently male while commenting on the dynamic between maleness and autism in his book, *Autism and Creativity: Is There a Link between Autism in Men and Exceptional Ability?* Fitzgerald links male creativity and genius specifically to autism, emphasizing that it is a male disorder. In this book and in his follow-up co-written with Brendan O’Brien, *Genius Genes: How Asperger Talents Changed the World*, Fitzgerald and O’Brien retroactively diagnose several famous “geniuses” as being on the autism spectrum, *all of* which are male. Of the choice to only include male examples of genius, the preface of *Genius Genes* states, “All are men because a) autism is a far more common disorder in men than in women and b) in Western culture and societal structure, the vast majority of famous historical figures are men” (Fitzgerald and O’Brien, x). It is true that history is largely written about men due to unabashed historical sexism, but reiterating this by focusing only on men of the past valorizes them and emphasizes the stereotypes discussed above. Diagnosing historical figures who are no longer alive is also a problematic topic, since the diagnoses themselves cannot be based on accurate symptoms.

Fitzgerald does briefly acknowledge females with autism in his book *Autism and Creativity*, stating,

> To date the enormous creativity of certain individuals with autism/Asperger’s syndrome and genius has been largely shown in men. Some will say this is entirely cultural, but I don’t believe that cultural factors can fully explain this. There does seem to be something unique about male creativity and autism. I believe that Temple Grandin showed autism, and not a ‘female form of autism.’ Nevertheless, males are more susceptible. (Fitzgerald 52).

Fitzgerald does not particularly explain what the “female form of autism” is, or why it seems that more men show savant-like talents. Fitzgerald seems to get close to implying that there may be
different types of autism, specifically based on gender and sex, but doesn’t engage with this idea. Instead of explaining how women may fit in with the autism narrative, he excludes them altogether, widening the gap between men and women with autism by not engaging at all with female forms of it. Fitzgerald also mentions the most famous autistic woman to date, Temple Grandin. What does it mean to say that Grandin does not show a “female form of autism”?

Grandin herself seems to align herself openly with the typical male mind rather than female mind. But this concept is problematic because it again emphasizes that there is a specific way of being autistic. If Grandin is not believed to show a female form of autism (yet is female biologically), this implies that the male individuals in Fitzgerald’s studies exhibit a “male” form of autism, which is separated from women, except for a select male-brained few. Could it be that the traits of maleness that Fitzgerald attributes to savantism are actually more in line with a lack of gender conformity in general, a gender neutrality that we label as male?

Interestingly, Temple Grandin also post-diagnoses many famous artists and scientists (all male) as being autistic in the chapter “Einstein’s Second Cousin” in her book *Thinking in Pictures and other Reports from My Life with Autism*. She does not comment on the maleness of her examples. Grandin’s work does not particularly focus on gender, but looks at what people can do to help autistic individuals as a whole. Possibly because she was diagnosed with autism at a young age, we do not see the same call for diagnosis of autism from Grandin’s writing as more contemporary female autistic writers tend to emphasize. Her early diagnosis may also be due to the fact that signs of her autism were more obvious. Grandin also associates herself with the more “male” autistic experience. In *The Way I See It*, Grandin comments on Baron-Cohen’s “extreme male brain theory,” stating:

> By looking at my own experiences, I can relate to this idea that autistic brains accentuate male traits. As a child I hated dolls and loved to build things. As an
adult, I work in the construction industry… Many activities that girls normally like, I hated. (193)

The statement “many activities that girls normally like” is inherently gendered, as Grandin has taken in what she believes are “normal” traits for neurotypical females. Grandin goes on to state, “Normal boys value competition and power more than do girls” (194). Grandin’s assertions here are based on socialized gender norms, which are assumed to be “natural.” Although this frame of thought is increasingly archaic, it is still extremely prevalent in countless aspects of our lives.

When it comes to autism diagnosis, if we expect boys to be competitive, rambunctious and act like leaders, then a boy who seems introverted and intently focused on an obsessive topic may be more obviously problematic to an adult than a quiet girl who acts in the same way. The girl can be overlooked because it is expected that girls are quiet and thoughtful, which might be another reason girls are diagnosed less often. Jeans Kearns Miller specifically addresses this issue in *Women from Another Planet?: Our Lives in the Universe of Autism*, stating: “A child who is aggressive, noisy, exhibiting lack of motor inhibition (wild, acting out) is attended to, and this behavior is characteristic of boys. A child who is well behaved, quiet, and apparently compliant will often be overlooked, sometimes despite underachievement. Such a child is quite likely to be a girl” (xxi). At first glance, this statement risks emphasizing gender stereotypes: rough boys and quiet girls. However, the issue of girls being overlooked appears repeatedly in autism literature for women, and this difference between the genders may be part of the reason for it. It must not be overlooked that girls not only tend to be quieter, but are expected to be quieter and generally more “well-behaved” than their male counterparts.

With the male savant as the default image of the most familiar Aspie/autist, the female autist is something different, perhaps largely unrecognizable until recently. Autism as primarily male is continuously confirmed by literature and media, which tends to emphasize male
geek/savant figure. Just a small sampling of autistic male characters in popular culture include Adam from the film Adam (2009), Sam in Netflix’s Atypical (2017), Will Graham in Hannibal, Shaun Murphy in The Good Doctor (2017) and even undiagnosed characters, like Sheldon Cooper of the ongoing sitcom The Big Bang Theory, emphasize this idea in mainstream culture, seeming to continue from 1988’s Rain Man which helped bring autism to mainstream media.

There are so many examples of male autist/savant figures that the topic warrants a separate study in the ways that the media portrays neurodiversity in both women and men, with more representation being given to neurodiverse men, mirroring the underrepresentation of women in all other forms of media and entertainment.

In Representing Autism: Culture, Narrative, Fascination, Stuart Murray illustrates society’s perceived understandings about what autism is and how it functions based on research and popular portrayals in film and literature. Murray states, “if current ideas about autism seem almost wholly centered on children, they also frequently involve the notion that the condition is, in some way, inherently masculine” (140). Murray argues that the perceived link between autism and masculinity is culturally produced. He states,

In accounts of Asperger’s, whether in fiction or memoir, the stress on the male figure is even more pronounced. The kind of interests and obsessions--science, mathematics, calendars, and timetables…seem to be paradigmatically male concerns, almost extensions of an idea of male personalities.” (141).

Murray is correct in asserting that the topics above are generally associated with maleness.

Working with the binary system already in place, if we accept certain topics as male, then we also accept others as female. Murray continues, remarking that

the explosion of interest in autism comes when there has been a sustained analysis the concept of the masculine in all manner of social and cultural contexts…autism is a novel explanatory category, one that potentially provides new conclusions in the ongoing debates about male status and behavior. (143)
What Murray alludes to above is the changing definition of masculinity, and how a more sensitive and socially awkward male figure is becoming embraced, especially with autism knowledge on the rise. However, it seems that there are not nearly as many portrayals of women with autism in the media, and women don’t seem to have as malleable a position in society as the autistic male. That may sound strange, but take for example that autistic males often show a lack of interest in typical “masculine” pastimes such as sports or an interest in girls (a heteronormative assumption), yet still retain maleness in society by being interested in technical, scientific and other typical “male” hobbies and interests. Female autists who do not take an interest in traditionally feminine topics are seen as androgynous and outside mainstream society, and there aren’t as many outlets for them to take advantage of as there may be for men. We are used to the figure of the male loner, skilled at computers and technical work but not skilled at social interaction. This is the figure of autism that is portrayed often in the media.

The quiet and concentrated, perhaps socially awkward female figure is not as obviously shown. Rudy Simone points to this dynamic in her popular self-help book for women on the spectrum, *Aspergirls: Empowering Females with Asperger Syndrome*. Speaking to other females on the spectrum, Simone states,

> Men may share most of our traits, but I think that their way of experiencing and manifesting them is different. For example, we all know that men with Asperger’s like to dress comfortably and may shop at thrift store to get that broken-in feel. But in the case of women, the same trait often shows up as dressing like a teen, sporting little or no makeup and having a simple hairstyle. While people with AS may share a kind of androgyny, this appears in AS men as a gentleness; Aspergirls have a tendency to be independent and wield power tools. (14)

Simone touches on an interesting and problematic issue here—traits that are portrayed by high-functioning men with Asperger’s are seen as gentle and at times endearing. On the other hand, traits that are common in women with autism are seen as less so. Simone spends the rest of her
work pointing out the particular issues that girls and women on the spectrum face, particularly social exclusion. Since women are under more scrutiny to be social in the first place, the pressures placed on women with autism can be very difficult, and autistic women are more likely to not have received assistance as early as their male counterparts due in part to late diagnosis.

The interests that children have may also lead to certain diagnosis because of gendered expectations. People tend to be exposed to certain things from childhood on, which can later affect what they engage in, emphasizing gender roles and gendered pastimes. Based on memoirs written by men with autism, there tends to be more opportunities for male savantism to occur, and this may be because of what males are generally exposed to versus what young girls are generally exposed to. In his memoir, *Born on a Blue Day*, Daniel Tammet explains how his father taught him chess (103) and Tammet immediately excels at it, exhibiting his natural “savant” like talent for mathematical and logical games. Although Tammet does not comment on gender, the introduction of chess by his father may illustrate an action specific to Tammet being male. Would he have been introduced to chess if he were a daughter instead of a son? He certainly may have, but perhaps he would have been given a doll instead. It may be worth recognizing that hobbies that are associated with autism are generally tied into things that are considered “male,” such as memorizing train time schedules, taking apart model toys and putting them back together (also commented on by Murray). Most individuals have preconceived notions about gender, affecting the observations made of even one’s own children, unintentionally enforcing certain behaviors which can later affect diagnosis.

Differences in life experience between the genders becomes apparent when comparing the life writing of male autists and female autists. In these works, it is striking how little male writers specifically focus on their gender as something that affected them throughout their lives,
yet female writers tend to repeatedly speak of their struggles with gender issues at an early age. It’s not that gender expectations do not affect males, but criticism by others or the realization that they themselves aren’t acting “normal” by society’s standards may not be as apparent. For example, in his memoir *Send in the Idiots*, Kamran Nazeer speaks of his time with his partner, in a subtle realization that they aren’t typical males: "There was a conversation lurking about the boy-style things we didn’t know how to do- whistle, rig a sail, fight- and the consequences of these incapacities. We weren't keen to have it, but the last silence had been a long one, and it did feel like a time for whistling" (134). This first mention of gender appears far into the book, and equates masculinity with stereotyped concepts. Many men do not know how to whistle, rig a sail, or fight, but these examples portray a deficit that Nazeer and his partner seem to feel, or at least acknowledge, as men with Asperger’s. Although the statement does show an awareness of certain societal deficits, Nazeer does not go any further into discussing masculinity.

John Elder Robison writes even less about gender in his memoir *Look Me in the Eye: My Life with Asperger’s*. Robison unintentionally highlights the freedoms of being male as he is able to travel much more freely and with less danger than he would as a woman in his young life, and have adventures described in detail in the book. For many people on the autism spectrum, gender becomes apparent to them when societal rules are enforced, and male memoirs tend to inadvertently show that men have less pressure to act in a particular way, though of course there are issues of typical masculinity and expectations that they too must deal with. However, it seems that in female autist self-writing, women and girls have more rigorous rules to follow, and their gender tends to eventually come to the forefront of their writing at some point, as they are constantly reminded of their roles as women. Personal safety is another factor that repeatedly appears in memoirs of autistic women and advice books for those caring for autistic girls, as their
vulnerability is heightened and their lack of understanding of social nuance puts them at a higher risk of physical and sexual assault.

**Expecting Female Compassion and Empathy**

Empathy and the ability to understand emotion and care for other peoples’ emotions is highly associated with women. Exhibiting this type of empathy is difficult for women on the spectrum. The belief that women are more empathetic may actually be part of what causes the under-diagnosis of autism in girls and women. It also seems to cause pain in particular to autistic women, some of whom feel they are deficient in it. Temple Grandin focuses a chapter of her book *Thinking in Pictures*, to “Learning Empathy,” in which she explains how difficult neurotypical understandings of empathy and emotions are for her and other autistic individuals to connect with. It is assumed that women and girls are naturally “better” at reading emotions and being emotional than their male counterparts. Furthermore, when young girls are not able to connect emotionally with others, it may be overlooked by adults who are in the position of recognizing autistic traits, particularly because of the girls’ abilities to mimic normal behavior.

Expanding on this topic, Emily Bazelon talks about autism and empathy in her 2012 TED talk (“Emily Bazelon at TEDxWomen 2012”). Bazelon states, “Showing empathy is routinely expected of [girls and women].” She continues, “the world can be a slightly more forgiving place for boys with autism because for better or for worse, awkwardness is a more acceptable male trait.” This reference ties back into the prominence of the acceptable figure of male geek or savant. While this is helping to redefine traditional masculinity tropes, women’s roles have been slower to develop, and there are fewer portrayals of positive socially awkward females. Lori Ernsperger also comments on this in her book *Girls Under the Umbrella of Autism Spectrum Disorders*. A section on puberty highlights some of the issues girls with autism face, such as
ambivalence towards personal appearance, clothing, and hygiene (164-165). As a generalization, Ernsporger muses, “As a gender, women are supposed to be motherly, docile, and passive. Men are allowed much more latitude for being self-centered and aloof” (165). As we think about gender stereotypes such as the ones portrayed in this statement, it becomes increasingly clear that the imbalanced diagnosis of autism between boys and girls may be a socialized phenomenon, rather than biological one. One might assume that autism should be diagnosed at a higher rate in females than in males, since boys are “expected” to be “aloof” and less social. However, if these traits are expected in males, then overall they are also looked for in males. As Bazelon states, “The classic image of a child with autism is a boy who has memorized the train time table[…] but girls don’t necessarily have the same obsession with numbers or store of arcane knowledge.” Traits and symptoms that indicate autism almost seem to be tailored to reflect what society views as “more male” than female--agression, anti-social behavior, savantism.

At the same time, there is a concern that girls and women on the spectrum want to connect more than autistic boys do, but aren’t able to do so, which further emphasizes gender stereotyping. Bazelon spends some time on this idea and goes on to explain “the suffering is acute for girls and women with autism because they so confound our expectations about being female. For them it’s the intersection between gender and disability that creates a real disadvantage.” How do we know if autistic girls may have a desire for social connection more than boys on the spectrum? Are boys content with being alone and not seeking out connections, or are we stereotyping both genders? It’s hard to say, and one must be careful with these views as they can risk placing males and females in their traditional stereotypical social spheres. The rhetoric used to better understand gender and autism potentially runs the risk of emphasizing problematic gender roles.
If girls with autism exhibit behaviors that show that they care more about social worlds than boys with autism do, is this evidence that there is a biological difference between the genders, or is it rather that by the time a child is in social situations, he or she has already been molded in certain ways by being socially gendered at birth? Certainly, a comparison of the memoirs by autistic men and women tend to support this idea, but these narratives are a small sampling of the number of ways autistic individuals cope with society. Donna Williams focuses greatly on her overwhelming emotions related to human connection in her book *Nobody Nowhere*, whereas Temple Grandin focuses more on her connections with animals in many of her works. There is not one particular way that either gender enacts its autistic traits. The more we try to understand the differences in the genders when it comes to symptoms and behaviors, the more we risk further reinforcing the traditional gender binary. In self-help books written specifically for girls and women on the spectrum the societal expectations on women are focused on in order to provide readers with information on how to “fit in.” Writers must acknowledge the way gender affects daily life, but also struggle with emphasizing the importance of uniqueness and diversity. This dichotomy can be noticed in much of the current literature that feature strategies for helping autistic women in social situations.

While we acknowledge that much of our gendered experience is socialized, there are actual biological differences between males and females which become more apparent as the sexes go through hormonal changes. On her website *Musings of an Aspie*, Cynthia Kim dedicates a section to adult diagnosis, and she also focuses on specific issues that arise particularly among women with autism. Kim talks about the time period when her autism finally became clear: when she was experiencing menopause. The hormonal shifts intensified her behavior, particularly when it came to socializing. In her post, “At the Intersection of Gender and Autism-Part 3,” she
explains experiencing a specific symptom of it: “Three years into perimenopause, my language processing has developed some glitches. When I write, I leave out words and make odd substitutions. Speaking is an adventure in trying to remember which noun I’m looking for.” Kim continues to explain that it wasn’t something listed as a normal symptom of menopause, so she blogged about her experience:

I was stunned to hear from dozens of autistic women in their forties and fifties who had similar experiences. Other discussions on menopause revealed more common ground. I wasn’t the only one who was suddenly tired of the effort it takes to pass for “normal.” I wasn’t the only one having more meltdowns or struggling to cope with day-to-day responsibilities. There were a lot of “me too” replies, too many for them to be a coincidence. (Kim)

Kim’s experience with menopause made her cognitive differences apparent, but it wasn’t until connecting with many other women experiencing similar symptoms that she was able to make the connection, since this specific symptom she describes above was not available in any of the sources she was consuming. Like puberty, menopause further emphasizes the biological differences between the sexes, and these hormonal and physical changes should be acknowledged as we look at the individual symptoms that autistic individuals may encounter. I too searched for scientific evidence of the symptoms Kim explained above but could not find any scholarly or scientific sources on the topic (I did find a lack of information on menopause in general). The advice book Life on the Autism Spectrum: A Guide for Girls and Women by Karen McKibbin, points this issue out explicitly, stating,

Because of the lack of research into adults on the spectrum, it can be extremely difficult to find research to show how life changes, such as menopause, impact the quality of life of a female Aspie and their ability to manage their emotions and physical symptoms in addition to everything else in their day-to-day life. (McKibbin 147)

The book also features a section called “Puberty and Menopause” which reviews the specific mood changes that may occur within female autists, attempting to fill in some of the information
that is generally lacking form most sources that offer assistance. The general lack of focus on
symptoms specific to women in medical texts surrounding autism is an example of the medical
default being a male body, not a female one.

**Passing & Coping: Female Autistic Experience**

Obsessive interests of girls may be considered normal or appropriate by onlookers only
when the item the girl might be interacting with is deemed typical of girls of that age, like dolls
or stuffed animals. Obsessive behavior is more likely to be overlooked if the focus of the
obsession is stereotypically coded feminine. Rudy Simone discusses this issue in *Aspergirls*,
stating “Another reason that autism may be overlooked is that our obsessions do usually fall
under the heading of “normal” girlhood things, like books, music, art, and animals,” (23).
Simone suggests here that, for example, if we expect girls to play with dolls or stuffed animals
(the toys she has most likely been given), this behavior may seem cognitively “neurotypical” and
not a marker of difference. However, the child may not be playing with them in a typical way,
which is more difficult to notice. Additionally, it’s recently become recognized that autistic girls
may be better at mimicking the actions of others, or adapting to social situations, which is known
as “passing.” Here, this term is an iteration of the historical practice of racial passing. Racial
passing, as described by Matthew Pratt Guterl in his book *Seeing Race*, is “the dark body
blending, without any remark or notice, into whiteness” (166). In this context, passing is now
being used to describe non-neurotypical individuals, specifically females with autism, blending
with neurotypical groups, behaviors, and practices. Passing doesn’t seem to be listed in most of
the medical literature surrounding autism, but it is discussed quite frequently in first-person
narratives of autistic women, and in informal sources that exist for parents and caretakers of
autistic girls. For example, autistic blogger Judy Endow writes on her website, “It is a lot of work
to look non-autistic, and yet, looking non-autistic is the ticket to sit at many tables. It is not right, and yet, I choose to expend a great deal of energy inhibiting my autistic ways for the sake of sitting at some of society’s tables.” Endow highlights the importance of doing this for employment reasons, and also explains her history of misdiagnosis in her early years and states that she learned to “’suck it up’ to purchase my ticket to freedom” (Endow). Endow’s experience is not unique, as many women on the spectrum have voiced similar experiences.

Passing is discussed by Jennifer O’Toole, creator of the Asperkids book and website. Maia Szalavitz interviews O’Toole in her article, “Autism-It’s Different for Girls.” Szalavitz talks of O’Toole’s obsession with compulsively arranging Barbie dolls. From afar, this behavior appeared “normal,” and the obsession wasn’t noted. Szalavitz expands on O’Toole’s experience with passing:

social life did not come at all naturally to her. She used her formidable intelligence to become an excellent mimic and actress, and the effort this took often exhausted her. From the time she started reading at three and throughout her childhood in gifted programs, O’Toole studied people the way others might study math. And then, she copied them- learning what most folks absorb naturally on the playground only through voracious novel reading and the aftermath of embarrassing gaffes. (Szalavitz)

If O’Toole’s experience is common, then it could be that many girls with autism are being overlooked during testing for autism based on their ability to portray themselves as interacting socially in a “normal” way. Since it seems that boys are more obvious in their symptoms and are more obviously acting different than their peers, they may be diagnosed more easily. They may also better fit the symptoms currently listed as indicators of autism, while many girls may not.

Because of the ability to pass as neurotypical, girls and women with high-functioning autism may elude the appropriate diagnosis of autism for years. It seems that many women and girls are diagnosed with other cognitive disorders before receiving their diagnosis of autism.
Stereotypes and expectations based on gender affect the diagnosis of autism, since social understandings of deviant and non-normative behavior are affected by gender roles, and these carry over to medical fields. Expectations regarding diagnosis are also absorbed by those who have autism themselves. Dawn Prince-Hughes discusses this issue in her memoir, *Songs of a Gorilla Nation*. Prince-Hughes struggled with being undiagnosed until adulthood and comments that the lack of diagnosis of girls who have Asperger’s syndrome was one of the defining reasons that she did not think she could be autistic herself. She states, “as I mentioned earlier in this book, Asperger’s Syndrome didn’t make it into the Diagnostic and Statistical Manual (DSM-IV) until 1994, and as I also mentioned, I developed a lifetime pattern of using my intelligence to find ways to appear normal-to “pass” (165). Prince-Hughes speaks of her struggle when wondering if she was autistic before being diagnosed, since she was aware of the stereotypes and beliefs about the autistic community:

Whenever my mind wandered in that direction, I kept coming back to certain things I had been told: only boys have Asperger’s, people with Asperger’s don’t have real emotions, they don’t have friends, they don’t have partners in life, they can’t relate to other people at all. And then there was the aggression. That was something I absolutely couldn’t relate to (170-171).

The quotation above illustrates Prince-Hughes grappling with the fact that she would rationalize herself away from the thought that she may have Asperger’s because of the knowledge that it is a primarily male disorder. She also did not match the other common beliefs about autism. The stereotypes about Asperger’s seen in the above quotation are still relevant today, as portrayed through the prevalence of the male savant figure in media. It’s hard to track how many autistic girls may currently be misdiagnosed, or have been misdiagnosed in the past partly because of this gender dynamic.
As illustrated by Prince-Hughes’ experience, the act of passing as neurotypical individual doesn’t just occur in young children, and it can continuously occur throughout adult life, delaying the diagnosis of autism further. A contributor to Women from Another Planet, Susan Golubock, shares a personal story and speaks directly about her own experience with passing:

For a long time, I got past the social aspects of work by keeping my mouth shut and a low profile. I focused on my work [...] Socially, I was considered ‘sweet’ and ‘nice,’ period… I had so succeeded in hiding the person I was in my own world and performing the role expected of me in the world, that I guess this was all there was to observe about me. It never bothered me until I overheard someone say that I had no personality. (Miller, 151)

Golubock goes on to explain that when she did show her personality, she encountered negativity and opposition in the workplace. This implies that social interaction can be especially stressful for women. Generally, women are constantly expected to have more of a social nature, to be more talkative, understanding, and emotionally empathetic than male colleagues, even in professional environments. For someone like Golubock, not being able to adhere to these unwritten social rules can cause significant anxiety, as well as affect one’s livelihood.

Passing can temporarily help autistic girls and women “fit in” and alleviate social pressures. However, as it is a constant act, many autistic women have spoken of their personal struggle with it. Liane Holliday Willey was not diagnosed with autism until well into her adult life. In her memoir, Pretending to Be Normal, Willey describes her experience with diagnosis; she was not diagnosed with Asperger’s syndrome until her daughter was diagnosed with it. Musing on her life before her diagnosis, Willey writes, “As I look at where I was thirty, twenty, ten, even five years ago, I note how much I have changed, how much I have progressed toward the standard definition of normal.” She continues:

In some ways I cannot help but be happy I have found a mostly comfortable place to rest. A point in life that sits balanced between neurologically typical and Asperger’s Syndrome. In other ways, I meet who I am with a certain amount of
sadness, for I often wonder what parts of me I had to leave behind before I came to this place in my life [...] If I had not been taught and encouraged to be as social as I now am, would I have found a different but somehow more satisfying kind of individualized lifestyle? (126-127)

In this passage, Willey directly discusses the negative aspects of socialization. Willey depicts the struggle of being molded by society against one’s will, and wonders what she might have been like if she were able to fully explore her unique capabilities. She implies that she took part in the passing discussed by so many others, and in doing so became more “normal,” but feels she may have lost something as well. Willey yearns for a past where her differences would have been celebrated instead of stifled. Perhaps this is slowly becoming a new reality, as a pro-neurodiversity movement seems to be gaining traction, with websites like Wrongplanet.net celebrating difference and not focusing on a cure for autism, but an acceptance of it.

Nonetheless, it may be more difficult for women and girls to find support groups because of late diagnosis. If an autism diagnosis is given to someone as an adult instead of as a child, then that individual may also lose many opportunities for therapies and treatments while growing up which may have helped them, as well as the foundations of a supportive community. Many autistic female writers discuss the ramifications of late diagnosis in their memoirs, speaking of their coping mechanisms before the diagnosis, such as passing. Like Liane Holliday Willey, Sophia Summers, author of Asperger’s- If You Only Knew wasn’t diagnosed with Asperger’s syndrome until her child was diagnosed with it. Summers discusses passing and her experience with trying to normalize herself. As Summers explains:

I was becoming quite skilled at imitating others, especially if their personalities impressed me [...] If I saw a scenario on television, I would practice reenacting the scene, along with the drama, and use it in situations that related to mine. I became a talented actress, and I was proud. Eventually, I was assuming other personalities; they weren’t totally real, but pieces of personalities that intrigued me. I was on my way to becoming what I thought people expected me to be: normal. (15)
Again, the description here illustrates how often girls may be overlooked in diagnosis, pushing the diagnosis farther in the future for the autistic woman, if it is given at all. Summers may have seemed neurotypical based on the personalities she was copying from television, but upon closer inspection, this “normal” behavior was not typical and took significant effort. Although Summers doesn’t often explicitly point out her gender, her description above illustrates the way girls with autism may pass by mimicking pop culture narratives as their baseline. Interestingly, *Life on the Autism Spectrum: A Guide for Girls and Women*, talks about how girls with autism may practice social scenes to prepare for interactions in every day life. It describes, “girls and teenagers also learn how to interact with others through sitcoms, movies and soap operas. These shows allow female Aspies to practice their social skills by watching them on TV and understanding how behaviors can cause certain emotional reactions in others, as well as how other social behaviors occur within their peer group” (McKibbin 33). The mimicking behavior is depicted in almost a positive way in this book, as passing is not discussed explicitly and the overall goal seems to be seamless integration into neurotypical social worlds.

As illustrated above, the personal narratives of autistic female writers highlight a pattern of passing which may cause women with autism to be diagnosed much later in life, since clinicians may not be aware in the way that girls may differ from boys in their symptoms. This issue has recently begun to be studied in the scientific community, and is pointed out in a recent article in Research in Autism Spectrum Disorders which states, “improved clinician awareness of ASD and stigma may improve healthcare through minimizing potential problems such as diagnostic overshadowing, misdiagnosis, and service avoidance by patients” (Lum, 2014). It also points to its study of females with ASD that illustrated “100% of participants had experienced frustration with uninformed clinicians” (Lum, 2014). This is particularly worrisome. It’s possible
that clinicians are uninformed about the nuances of autism symptoms because medical
knowledge is based on males as default. Just as autism is thought to be more of a male disorder
than a female one, other disorders, like anorexia and depression, are considered more
stereotypically female. Therefore, the diagnosis of both genders becomes skewed. A common
feeling of disregard by the medical community as well as society at large is voiced by many
autistic female writers. Jennifer O’Toole writes on her website, “Talk about autism and you’re
usually talking about men and boys. Too often, there is no girl talk. No from-the-inside-out
women’s perspective. The girls are barely visible. The women are afterthoughts” (O’Toole).
Unfortunately, autism is not the only area where women “are afterthoughts” and this needs to
change, immediately. There needs to be more awareness about how gender rolls at large can
affect things like diagnosis.

Although it may seem that the medical or health-care industries are able to operate
objectively from socialized gender constraints, as shown, this is not the case. Embedded beliefs
about the binary gender system seeps into nearly every aspect of social life, even seemingly
innocuous areas. Jordynn Jack comments on this issue in her book on autism, *Autism and
Gender*:

> It seems possible that the dominant characterization of autistic individuals as male
computer geeks leads researchers and practitioners to overlook females who have
autistic traits because they do not present themselves in stereotypical ways. For
example, an intense interest in ponies or princesses might not come across as
autistic in the same way that an intense interest in sports schedules or computers
might. (151)

If we give girls items that are not associated with autism, and they become obsessed with these
items, it may be overlooked as a normalized female trait, such as an attachment to a doll or a
love of ponies, as Jack references above. Neither of these examples is associated with autism.
However, a boy being obsessed with toy cars or infatuated with mechanics may be a more
obvious marker of autism. A list of symptoms of autism has been created, and continues to perpetuate these symptoms within a particular gender, leaving girls sidelined because they might not match with a certain set of limited bullet points. Although it may seem silly to focus on toys, they are a way that children are socialized into genders and gender does unconsciously affect the medical industry as well as the social sphere. Jack comments on the way that scientists will point out symptoms of autism but not recognize that the symptoms are learned based on gender:

In scientific discourse, researchers sometimes muddle sex and gender together. For example, theorists might reason from the sex ratio of autism diagnoses to theories of autism that reflect gendered norms, as is the case when autism is portrayed as somehow linked to male technological aptitude, computing or geekiness, According to this argument, the unequal sex ratio in autism diagnosis (which is usually four to one, male to female) must mean that autism is caused by some sexed difference (such as heightened testosterone levels). Yet, as evidence for this claim, scientists point to the preponderance of gendered masculine interests among autists (such as computing, engineering, and other technical interests). In this case, scientists do not distinguish between sex and gender but, rather, subsume one into the other. (13)

As Jack points out above, the stereotypes surrounding autism and Asperger’s in particular are further emphasized by the medical and scientific community, which combines sex and gender as one force instead of recognizing that they work in different ways. Many advice guides for parents and caretakers fall into this same pattern of overgeneralizing an unexamined gender dynamic, relying on non-nuanced stereotypes for gender roles and perpetuating the ongoing difficulty in diagnosis of young girls and women with autism.

A Call for Diagnosis

A significant portion of the autistic writers studied here have voiced their desire for diagnosis and spoken of the relief they experienced when the diagnosis was finally received, even if it came well into their adult lives. But what are the practical benefits of being diagnosed, and why would this serve a community of females who have not been previously acknowledged as being autistic?
Parents of children with autism generally seek the diagnosis for multiple reasons, such as legitimizing their child’s difference and to receive benefits regarding educational programs. They may also receive health insurance coverage for certain treatments, such as speech therapy. Most benefits for autistic children are only available if one has an official medical diagnosis of autism. But in addition to practical and financial benefits, a diagnosis of autism can also serve to affirm an individual’s sense of personal identity and difference, which seems to be one of the reasons autistic women continue to seek the correct diagnosis even into adulthood.

Majia Holmer Nadesan asserts that despite scientific work to find something of an autism gene, autism remains largely a socially constructed disorder and Nadesan acknowledges some of the reasons that autistic individuals may desire their diagnosis:

The unifying experience of being ‘different’ transcends the disparate narratives of individuals who self-identify as autistic. Even the most articulate individuals who claim autism describe this sense of difference as permeating their lives, particularly in relationship to their interactions with social peers and with respect to the intensity of their particular interests. Thus, the noun ‘autism’ summarizes, organizes, and articulates difference in a way that oddly depersonalizes the source of these differences by rendering the syndrome/disorder/personality style as responsible for the individual’s dislocation within the social field. Autism becomes the unifying, organizing center that explains and predicts the individual’s differences: I am different because I am autistic and autism explains my difference. (Nadesan 205)

Here, Nadesan emphasizes the experience of diagnosis desired by many individuals to legitimize their difference. While it may depersonalize the individual experience, as stated, it can emphasize a unifying one, which can be important for one’s well-being. The diagnosis can provide an explanation to others for the “abnormal” behavior the individual may exhibit, and therefore causes others to be more accepting of the behavior. For girls and women especially, who are generally under more social scrutiny than males when it comes to social situations, there has been a call for a community which includes them. Many girls and women feel that they are the minority figures in a larger group of male autists, and some seek out the autism diagnosis
themselves because of the validation that often comes with it. This struggle is discussed in *Girls Growing up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years*, one of several advice books for parents of girls on the spectrum:

Over the years we have worked and communicated with hundreds of families of girls and women with ASDs about their diagnostic journey […] for some girls, the journey was short–they demonstrated classic symptoms of autism at a young age and were diagnosed before the age of five. For other girls and women, the path has been circuitous, labyrinthine and roundabout, with many red herrings in the way. (Nichols, 37)

The chapter goes on to discuss that many women with ASD were diagnosed with previous diagnoses of other disorders, like “ADD/ADHD, anxiety, depression or mood lability, obsessive compulsive disorder, a language disorder, or an eating disorder” (37). Because on average, females are not diagnosed as early as males with autism, girls and women tend to lose opportunities for early intervention and therapies that they may have desired or benefited from.

Many parents of daughters with autism have acknowledged that they feel separated from the larger group of parents who have sons on the autistic spectrum, and feel that advice and assistance for those with autistic children is not particularly tailored to the raising of girls on the autism spectrum. In her parenting book, Eileen Riley-Hall speaks openly of the frustrations of not finding appropriate support for her autistic daughters, stating “It is difficult enough to have a child diagnosed with a lifelong developmental challenge, but then to discover you are a curiosity in that group makes life even harder” (41). She continues, “Not only had I produced two children who had to face such challenges, but somehow I had even managed to bungle that. Even specialists in the field found the fact that I had two girls on the spectrum a novelty” (41). Here, Riley-Hall’s personal anecdote illustrates what seems to be a shared experience of having daughters on the spectrum. Because girls with autism are much less common than boys with autism, they become an anomaly. (Interestingly, her comment stating that she managed to
“bungle that” implies that she herself is somewhat at fault for her daughter’s diagnoses, a problematic nod to the belief that the mother is somehow at fault when the child is disabled, another gendered stereotype.) A quick overview of the comments reviewing her book on Amazon.com provides ample examples by parents of girls with autism who feel like minorities among the larger autism community. Riley-Hall contributes this lack of diagnosis to the different ways that girls enact their autistic symptoms, and the lack of studies done on autistic females.

Riley-Hall’s daughters were able to be diagnosed as children, and although they faced difficulties with the treatment and information available being somewhat tailored for boys on the spectrum, they are still able to engage in some of the benefits of diagnosis. But for the autistic women who did not receive a diagnosis until well into their adult life, they are affected in ways they may never fully be able to understand. In her autobiographical work *Life Behind Glass: A Personal Account of Autism Spectrum Disorder*, Wendy Lawson states,

> I was 42 years old when I was appropriately diagnosed with Asperger’s Syndrome in August 1994. I had always known I was different from other people and ‘had problems’ but this had been wrongly explained by a misdiagnosis of schizophrenia as a young adult and an episode of post-natal depression after the birth of my first child at 22. (i)

Lawson’s experience is an example that represents many women who believe that they were incorrectly diagnosed in their past. Many argue this diagnosis of autism is necessary because it becomes self-actualizing, and although the diagnosis itself does not change the way autistic symptoms manifest in an individual, it can be liberating for an autistic person to finally have a “reason” behind the difference. Furthermore, Lawson was also diagnosed with several other disorders before receiving her label of Asperger’s. Misdiagnosis seems to be one of the main causes of the under-diagnosis of women with autism.
Autistic writer Donna Williams speaks of her journey towards diagnosis in her autobiography, *Nobody, Nowhere*. Williams describes being misdiagnosed with several other disorders (including schizophrenia), and finally discovering that she is on the autism spectrum as adult at 26 years of age. While researching schizophrenia to try and find an explanation and “a word to put to all of this.” As she explains, “I wanted an opinion once and for all as to why I was like this” (187). She describes the moment of realization:

Suddenly it jumped out at me from the page. It was the first time since my father had said it four years ago that I’d heard the word. “Autism,” it read, “not to be confused with schizophrenia.” My heart jumped, and I shook. Perhaps this was the answer or the beginning of finding one. I looked for a book on autism. // There upon the pages I felt both angered and found. The echoed speech, the inability to be touched, the walking on tiptoe, the painfulness of sounds, the spinning and jumping, the rocking and repetition mocked my whole life. My head swam with images of the abuse that had been my training. The necessity of creating the characters had torn me apart but saved me from being a statistic. Part of me had complied with my training, the other part had made it through twenty-six years with a private, cut-off world intact. (187)

What Williams desired throughout her autobiographical work was an explanation for the difference she felt and the different ways that she behaved. She was “both angered and found” when realizing that she had not been given the correct diagnosis, and this kind of relief and contempt for being missed in terms of diagnosis is seen repeatedly in female autobiographical works about autism diagnosis. The diagnosis is desired in part because of the stigma autistic individuals face by those in the “neurotypical” community, which can be more accepting of difference if someone has “reason” that explains it. Our society cannot yet accept that people are cognitively different, and so an obvious deviation from the norm can cause much pain to an individual. The later women are diagnosed with autism, the longer they are left without the help most appropriate to them, which leads to feelings of resentment and confusion.
Is diagnosis a positive thing, then? It’s largely necessary for medical benefits and social acceptance, but how helpful is it for society as a whole? Temple Grandin explains her personal feelings about diagnosis and labels in *The Autistic Brain: Thinking Across the Spectrums*:

I would go even further and argue that we need to think not just about smaller autism subgroups that are defined by their symptoms but about the symptoms themselves. Because thinking about individual symptoms on a symptom-by-symptom basis will eventually allow us to think about diagnosis and treatment on a patient-by-patient basis (Grandin 115).

This quotation illustrates an ideal goal of diagnosis, where diagnosis doesn’t just lump individuals into a certain label, but cares for them as individuals, with different symptoms and treatment methods. Grandin also asserts that she would like to move past diagnosis all together to what she considers as “phase-three thinking”: “Forget about the diagnosis. Forget about labels. Focus on the symptom.” (114). She describes phases one and two as including looking at the brain and realizing how “extraordinarily complex the brain is” and how there are many causes of difference” (114). Grandin continues,

Twenty years from now, I think we’re going to look back on a lot of this diagnostic stuff and say ‘That was garbage.’ So as I see it, we have a choice. We can wait twenty years and several more editions of the DSM before we start to clean up this mess. Or we can take advantage of the technological resources that are beginning to become available and start phase three right now” (116).

Perhaps the realization of Grandin’s goal is starting now, with more increasing recognition of individuals exhibiting different symptoms and signs of autism. For the time being, the diagnosis of autism is still necessary for medical care, education benefits and a social understanding and acceptance of difference by the neurotypical community. Perhaps in the future, autism won’t be a label anymore, as neurodiversity will be embraced without a diagnosable syndrome. But until that happens, the goal should be to adequately diagnose those with autism so that they may be part of a larger community of aid, and not face the many hardships that those who are diagnosed
later in life have spoken of. The diagnosis allows for much needed communities to be formed as well, for those with autism and their families.

Helping Autistic Women and Girls: Conforming vs. Celebrating Difference

Diagnosis is sought for the benefits that an individual receives from it. There are now an increasing number of resources for those with autism and their families, friends and caretakers, including many advice books which are tailored specifically for females on the spectrum. A large part of integrating autistic children into mainstream society focuses on being social, making friends, and being able to interact “normally” with others. The goal of fitting in with society includes adhering to proper gender roles. Because autism itself is characterized by difficulties in navigating the social world, being able to integrate socially is desirable not only to parents of autistic individuals, but to many autistic people themselves. The desired outcome of many of the therapies and treatments for autism is to better integrate autistic individuals into mainstream society, particularly focusing on autistic adolescents so that they do not feel separated and penalized by their peers. But this may further emphasize problematic gender roles. Girls Growing Up on the Autism Spectrum features one such example, stating,

Girls with ASDs need to learn to recognize nonverbal RA behaviors, such as eye-rolling, knowing glances, turning one’s back and giggling with a hand over one’s mouth. The social skills of girls with ASDs are rarely sophisticated enough to detect when RA is occurring, and to know how to respond, without support and teaching. (Nichols 195)

In the quotation above, RA refers to “relational aggression,” a manipulative form of aggression which involves nuance, as described above. It’s true that autistic girls should be aware of the nuanced social cues that will occur around them. However, would this specific advice be given to boys? Even the action of “giggling with a hand over one’s mouth” is gendered and this description is most likely of a peer who is female, not male. Boys with autism may not have to
learn such intricate social rules if they spend their time with other boys, since in general, male behavior tends to be more direct and less nuanced (which could be a socialized phenomenon). Passages of the book exhibit struggles specific to the female autist experience. Whether learned or biological, girls may generally act differently than boys. Is teaching autistic girls the patterns of what is considered typical female behavior helpful? The book continues,

It is also helpful for your daughter to learn about the social structure of adolescent female groups, which can be quite complex. For girls who are capable of understanding the different social roles in a group setting, it may be helpful to review them with her. Roles can include the Queen Bee, the Wannabee, the Sidekick, the Gossip, the Tagalong, the Torn Bystander, and the Floater.

After this list of problematic labels appears, the chapter then continues to list films that caretakers of autistic adolescent girls can watch together to highlight examples of neurotypical behavior. While the idea behind this type of therapy may mean well, it brings up complicated issues surrounding teaching girls to be social in specific ways. Labeling “types” of girls is detrimental because it emphasizes that individuals can be labeled and placed in a certain category, which autism itself helps to unravel and emphasizes as untrue. Much of the social therapy for individuals with autism should be carefully considered as it may work to suppress individuality and continue to perpetuate problematic social roles based on gender. Depending on where an individual is placed on the spectrum, it may also be difficult to know how much social interaction or how little interaction an autistic individual may want without making assumptions, which would most likely also be based on gender.

Is it also possible that this type of therapy contributes to autistic girls’ tendency to “mimic” and “pass”? Much of the suggestions regarding girls on the spectrum focus on this type of social normalization, grappling with the autistic individual’s desire for inclusion but also a desire to applaud uniqueness. We know that girls on the spectrum tend to have a high risk of
anxiety and depression, and receive help later in life than boys on the spectrum. Integrating with their female peers may help to alleviate that anxiety as girls develop, but it can also emphasize the importance of socially “passing.” In this case, the treatment for autism reiterates the behavior of many high-functioning autistic women and girls already exhibit, which includes normalizing their behavior to fit in with others. But the alternative of being bullied is not acceptable, and so the answer to reducing that outcome is understandably the act of social integration. Perhaps this type of general advice can be changed to be less stereotypical when talking of boys and girls, which would benefit both neuro-diverse and neuro-typical communities.

A recent article, published on the website Spectrum speaks explicitly on the problems with diagnosing women with ASD, focusing on the specific symptoms that girls exhibit. An article featured on the website, Apoorva Mandavilli’s “The Lost Girls,” chronicles the experiences of several girls and women on the autism spectrum, and points to the specific issues that females with autism face, particularly when gender is taken for granted. Mandavilla mentions a program at the University of Kansas called “Girls’ Night Out” which pairs neurotypical girls with girls with autism for an evening. Through these nights, the girls participate in social events that are typical for young women of their age to help autistic girls understand cultural norms. Examples include visiting “a hair or nail salon, a coffee shop or gym, or learn(ing) how to buy clothes appropriate for their age and the weather.” This list of examples emphasizes how gendered actions blend in with more gender-neutral actions that are important regarding the caring of oneself. Buying clothes is an important task in being self-sufficient. Visiting a nail salon may be less so, but understanding and being comfortable with a gendered task like this can help to alleviate the stress of being an outsider that many women with autism face. It can also be a fun event to help autistic girls and neurotypical girls bond with each other.
When deciding what activities would be most helpful for autistic children, gender inevitably must be acknowledged, especially towards the pre-teen and teenage years. Living in a society that accepts a primarily binary gender system immediately places expectations on individuals dependent on their biological sex. If the goal of therapy for autistic individuals is to help them fit into society and function on a specific social level, then understanding gender becomes an important part of this therapy. Yet again it emphasizes the separation between boys and girls, which is potentially detrimental on both sides. The treatment utilized when working with autistic girls and boys highlights larger issues in our society having to do with our general definitions of normality.

Some help guides emphasize normalizing girls’ behavior to help them integrate into social spheres, in turn strengthening the gender boundaries between males and females. *101 Tips for the Parents of Girls with Autism* lists among its advice, “Private conversations (i.e. talking about your period) are for private places (home) with close family (your sister and mom). Public conversations (shopping, homework, hairstyles) are okay in public places (school cafeteria) with public people (your classmates)” (Lyons, 108-109). While helpful in terms of preventing a child from being singled out, this advice again reiterates the social rules that people adhere to in social settings. Taboo subject matters are socially designed, and dependent on one’s gender.

Certain writers have emphasized that girls and women on the spectrum have a specific set of challenges, just as neurotypical women tend to have, based purely on the expectations based on their given gender. Eileen Riley-Hall specifically points out the extra difficulties that females on the spectrum may have throughout their lives based on the preexisting expectations of their surrounding communities:

From what I have seen, the special challenges for girls on the spectrum seem to arise out of the fact that they are *still girls*, and having a social communication
challenge can be even more difficult when you represent the half of humanity that is supposed to be really good at making friends, carrying on conversations, exhibiting good manners, and generally being more civilized. (42)

Riley-Hall’s choice of the word “civilized” is an interesting, if not problematic, one, which indicates that girls are less aggressive than boys and more docile. Yet, whether nature or nurture, it seems to be that a large part of the misdiagnosis of girls with autism occurs because girls are less aggressive and their outbursts are not as obvious as the symptoms in boys with autism. We do not know if there is something inherent in genes that causes this or if occurs from socialization, but it needs to be acknowledged in order for girls to receive adequate care and assistance.

Evidence of gender-based biases are clear in narratives by parents with children on the spectrum, since they had to deal first-hand with advice and treatment recommended by doctors and therapists. Roy Richard Grinker discusses autism from an anthropological view in his research-based memoir, Unstrange Minds: Remapping the World of Autism. Grinker’s daughter is autistic, which fueled Grinker to research autism treatment in other countries besides the United States. Grinker views the diagnosis of autism both as “a biological disorder but [also] as a group of symptoms that have become especially meaningful in particular times and places” (11). Of his daughter’s diagnosis, Grinker states, “The psychologist thought about recommending placement in a class for children of normal intelligence with emotional disturbances, but dismissed that idea because her classmates would then be mostly boys with attention and aggression problems- poor social models” (18). Here, Grinker makes it clear that his daughter has a hard time finding a space where she can comfortably belong in since her gender separates her from “the boys.” This point also emphasizes that boys and girls with autism tend to act differently, with boys possibly being more aggressive, evidence towards the argument that it’s
easier to locate autism in boys at an earlier age because of more direct and noticeable behavior. If girls tend to act out less, then it’s harder to associate their behavior with a disorder. Within memoirs about raising autistic children, parents often speak of markers of normalcy that are not being exhibited by their own child, markers that are dictated by gender.

Continuing in his memoir, Grinker compares his daughter to “non-autistic” teenage girls, stating, “I try not to think about what other teenage girls are like-the ones I see outside our local middle school, gossiping and talking about boys-and focus only on Isabel” (23). Although Grinker was not attempting to make a grander statement about gender in general, this statement shows how much gendered behavior is normalized. It is considered normal for women and girls to be more talkative and social than men and boys. At times in his memoir, Grinker points to moments in Isabel’s childhood that mark her difference from others. These also tend to emphasize that Isabel did not partake in normative gendered behavior:

She didn’t talk to the dolls and rarely put them together into pretend social situations, like a tea party. But she did come up with brief exchanges between characters from different stories. For example, two of her American Girl dolls, Addie, the child of a mid-nineteenth-century slave, and Kirsten, the nineteenth-century immigrant from Scandinavia, played out a short conversation she had seen take place between Woody and Buzz from the movie Toy Story. She did not generate new stories herself, though, and wouldn’t allow toys from different domains to be near each other. (184-185)

Here again we see an expectation for gendered behavior: a tea party with female dolls. Grinker’s daughter does not act like a typical girl when it comes to play. Would Grinker have expected a son to put dolls in a social situation? How would it be different if he had a son on the spectrum instead of a daughter. Would the lack of gender conformity be as obvious?

Gender bias exists and though it may seem like something that we should work to breakdown, it is also something that needs to be moderately adhered so that individuals, especially children and teenagers, can avoid being stigmatized by their peers. To help include
autistic children and teens more seamlessly into the social world, caretakers must help them follow “rules” based on their given gender. Girls and women are expected to follow more rigorous rules and portray themselves in a more refined fashion than boys and men, which can lead to further stress and stigmatization if these (sometimes superficial) expectations are not met. Dr. Temple Grandin remarks on her own experience with conformity in *Unwritten Rules of Social Relationship*:

"social conformity opens the doors to group interaction. And while we don’t want to make people with ASD into something they’re not, people with ASD have to be taught- or as adults they need to accept- this unwritten rule of social relationships: the outside package is just as important as what’s inside. Before you even get close enough for conversation, people are forming opinions of you based on what they see. (311)"

Grandin goes on to explain her specific choices of how to dress in certain situations, and the book’s coauthor, Sean Barron, also goes on to explain his difficulties with dressing appropriately as a teenager: “As I look back on those years, I realize that not only did I have no idea how my own clothing worked, I also had no idea about how other people dressed and why…also lost on me was the concept that, like certain behaviors, many types of clothing were appropriate in one setting and not okay in another” (318). Barron and Grandin both comment on the way they had to learn about appropriate appearance. Neurotypical individuals may be able to observe this type of social rule and adequately adjust their behavior, but this doesn’t come naturally to autistic individuals.

Although this issue affects both males and females, females tend to have extra rules to learn when it comes to appearance. This issue is discussed in *Girls Growing Up on the Autism Spectrum*, since this book functions as an instructional manual for parents and caretakers of autistic girls. Chapter 5 of the book, “Feeling Good Inside and Out: Self-perception and Self-confidence,” focuses on many issues particularly specific to females, such as learning about
menstruation, breast development, and appropriate attire for these situations. Although
menstruation is a more pressing issue, as it has to do with health and hygiene, the chapter also
focuses on bras, which may be uncomfortable for many autistic girls, as they tight-fitting items
of clothing. The chapter states:

For a variety of reasons, some women choose not to wear a bra. However, your
daughter will be going to school for many years of her adolescent and young adult
life. Not wearing a bra is going to draw public attention from peers and
classmates to her breasts, and it might also be in violation of her school dress
code. (144)

Although not explicitly stated, statements like this throughout the book bring attention to the
special issues that girls deal with. It also highlights the way that girls are scrutinized for their
clothing choices, and overall appearance.

Some girls come to group dressed in fashionable but somewhat inappropriate
clothing […] other girls dress in a casual, fashionable manner. Still other girls
typically wear track pants, running shoes, baggy T-shirts, and sweatshirts. Their
overall look is disheveled and they are often poorly groomed (e.g. hair not
brushed). (148)

The quotation above seeks to explain the different ways that girls on the spectrum may portray
themselves. In general, many autistic females may read as gender queer when they wear practical
clothing that is comfortable to them. Karen McKibbin dedicates a chapter of Life on the Autism
Spectrum to “Gender Labeling,” stating,

The gender labeling within our society-from toys to clothes, to the social
expectations of how we present ourselves to others- can be another set of almost
unspoken, but very visible social expectations that at times can dominate how we
judge or accept others. (128)

The section continues with descriptions of how gender identity that is portrayed to others is
shaped by things like personal style. Riley-Hall also discusses style and gender identity in her
book, encouraging parents to enforce grooming and hygiene rules with their daughters (47). As
Riley-Hall explains,
There are girls on the spectrum for whom the whole issue of gender is confusing. They know they are girls, but what that means in social terms is confusing for them, especially if their interests are more in line with the things boys like…sometimes it just takes longer for girls on the spectrum to mature enough to understand gender as a concept…finding an appropriate sense of style and grooming underlies our daughter’s greater need to be accepted by and included with their peers as much as possible. (48)

The advice reiterates the importance that appearance can have when helping children on the spectrum, but it can also be detrimental. By associating understanding gender concepts as a means being a marker of “maturity,” Riley-Hall implies that gender may be natural, when it isn’t. Advice books tend to help individuals fit in with their given social roll based on gender, grappling with retaining the preferences of an individual and conforming in certain ways to make everyday life easier.

Another issue that arises in self-help books is that when looking at possible causes for the gender difference in diagnosis of autism, the works tend to enforce stereotypes about gender to support certain arguments. For example, comments in *Girls Growing Up on the Spectrum* include, “our 18-year old can’t stand to be with her [male] aspie counterparts because they only talk about science and sports…she wants to talk about relationships, art, music, and feelings” (20). Another anonymous contributor in the book writes,

My youngest has autism and although we had her evaluated a number of times… they would say ‘Well, she is too affectionate to have autism’ even though she had so many of the characteristics…I really wish that there was a scale that was more tailored to females for diagnosing autism. Girls are innately more affectionate and compassionate than males whether they have autism or not, and this is what keeps them from being properly diagnosed.” (Nichols, 21)

It’s obvious how loaded with gender stereotyping in these comments are. Is it true that girls are innately more affectionate and compassionate than males, or is this how we are raising boys and girls to behave? It is apparent that the difference in diagnosis between the sexes is possibly due
to several factors, and so it is not just one thing that must change, but much of what we currently think about relating to autism may have to change.

Categorizing human beings in this way is not helpful, and females generally face a higher level of scrutiny when it comes to their social behavior, whether neurotypical or neurodiverse. Boys and men may be freer when it comes to social conditioning from the outside community, though of course expectations regarding traditional masculinity are an issue for males. Tony Attwood’s website on Asperger’s features a section called “Girls and women who have Asperger’s syndrome,” in which he speaks of the signs of Asperger’s in girls, particularly focusing on some of the social relationships: “There may be single but intense friendships with another girl, who may provide guidance for her in social situations, perhaps in a benevolent way and in return, the girl with Asperger’s syndrome is not interested in the ‘bitchy’ behavior or her peers and is a loyal and helpful friend” (Attwood, “Girls and women who have Asperger’s syndrome”). It is obvious that the term “bitchy” would not be used if boys with Asperger’s were being described here, and this type of rhetoric surrounding the behavior of girls in general perpetuates the same archaic stereotypes that have prevailed for decades.

Because of the stereotyping of “normal” female behavior, we repeatedly see females with autism as described as more aligned with typical male behavior than female behavior. Of a hypothetical female with Asperger’s, Attwood states,

Inevitably there will be times when she has to engage with other children and she may prefer to play with boys, whose play is more constructive than emotional and adventurous rather than conversational. Many girls and women who have Asperger’s syndrome have described to clinicians and in autobiographies how they sometimes think they have a male rather than a female brain, having a greater understanding and appreciation of the interests, thinking and humor of boys. (“Girls and women who have Asperger’s syndrome”)
Attwood’s assertions here seem to imply that traits are inherent and based on gender. He states that boys’ play is “adventurous” and “constructive” while girls’ play is “emotional” and “conversational.” Attwood doesn’t explicitly state that these aspects are inherent, however. By the time children exhibit play, they have already been trained to act in alignment with a certain gender. Again, we see the “male-brain” theory at work here, asserted by an expert in autism. It’s far more helpful to learn about the autistic female experience from women with autism. Their experiences are not simply observable by professionals, especially within a biased social sphere.

Sub-categorizations and the pathologizing of women on the spectrum are spoken of on the Autism Women’s Network blog. Under a post titled “My Personality is Not a Sub-Type Presentation,” contributor C.L. Bridge speaks of her frustration with the embedded sexist language used inadvertently by medical and psychological experts. Bridge states,

When I was first identified as autistic around 2001, very little had been written about autistic girls. There was a page or two in Tony Attwood’s book *Asperger’s Syndrome*, but there were very few books and articles that focused specifically on how girls experience autism. Today, that is changing. I wish I could be happier that more professionals are realizing autism isn’t a “male” condition. Unfortunately, there is very little “autistic girl” literature written by professionals that I can read without cringing. All too often, these books and articles combine sexism with ableism. (Bridge)

Bridge goes on to describe the way that many specialists and writers on autism topics separate autistic “symptoms” from ways that a “typical” girl would act, and sometimes place autistic girls into sub-types categories. Symptoms of autism are considered atypical because they don’t ascribe to strict pre-existing gender boundaries. As discussed earlier, much of this devious behavior has to do with simply not adhering to things like certain types of clothing or playing with certain types of toys. Bridge criticizes the pathologizing of autistic girls’ interests and compares them to interests of neurotypical girls, where their hobbies are simply seen as “personalities and interests.” Indeed, autistic girls may be pathologized in a way that
neurotypical girls are not, and I would argue that this type of categorization is also done to girls and women as a whole, as women’s health issues tend to be categorized into sections often called “women’s health” which implies male as the default body.

**Autistic Gender Identity**

As parents and the larger community try to “normalize” autistic individuals, gender becomes a major part of the normalization, dictating what behavior is considered typical, since As controversial as it is to enforce gender ideals onto children, it may help alleviate the stress and anxiety that forms when autistic individuals are viewed as outsiders, or separate from other children. Scholar Kristin Bumiller explains that autistic children may not understand that certain objects are relegated for a specific gender, and uses an example of a boy with autism becoming attached to a Barbie lunchbox “because it relieves stress to repeatedly fiddle with the latch mechanism” (977). As Bumiller states, “When professionals see such preferences as merely gender inappropriate behavior, they are disregarding the child’s own conception of gender relevance and/or attachments to objects that reduce anxiety” (977). Something as insignificant as a plastic toy then becomes a marker of non-normative gender difference, which may open the child to ridicule from other classmates. Yet it’s just a neutral object when separated from gendered ideals and can alleviate the child’s stress.

Autistic people in general seem to adhere less to gender standards than non-autistic people, and Jordynn Jack posits that language delay itself may add to a lack of understanding of social gender norms:

Although not all autistic people have language delays as children, some do. Since gender depends on rhetorical and linguistic factors, language delays may also delay a developing sense that boy and girl, blue and pink, trucks and dolls are typically linked in discourse as well as social acts. Without words for “boy” and “girl”, one might not develop a gendered sense of “appropriate” behaviors. (191)
Here, Jack attributes an autistic individual’s lack of language acuity as a young child with a lack of understanding of “normal” gendered behavior. The lack of appropriate gendered behaviors can be a source of anxiety for some autistic individuals. Bullying and ridicule based on gendered norms is sadly common even among young children of elementary school age. The policing of gender starts extremely young.

Autistic individuals, particularly female ones, tend to work against preexisting gender notions, which is highlighted in many of the personal narratives discussed later in this paper where female writers speak about their lack of interest in common gendered interests. But as autistic individuals become older, towards teenager and adulthood, it becomes more difficult to navigate the social sphere, particularly romantic relationships, without somewhat of a concept of normalized gendered behavior. Bumiller sheds some light on this discussion:

[M]any adolescents with autism may consider themselves to be gender neutral, and when confronted with the prospect of dating either withdraw socially or choose to be regarded as androgynous. In social skills training, young autistic persons are explicitly taught about the relevance of gender performance to finding sexual partners. For example, books designed to teach autistic adolescents about sexuality often list specific examples of how potential dates will perceive their appearance or behavior as masculine or feminine. These instruction manuals for entering intimate relationships explain that gender performances have social meaning and tell why they are important to rituals of dating and marriage (977-978).

Here, Bumiller aptly highlights some of the advice found in books for autistic individuals regarding the nuanced landscape of social contact and understanding. Many of these social rules are implied and understood by non-autistic individuals through social interaction; they are not explicitly stated, which is why it may be hard for autistic individuals to understand. Many high-functioning autists are aware of gender norms but may choose not to identify with the binary gender system. Rudy Simone emphasizes the gender neutrality of many Aspies in Aspergirls. For
example, in her chapter “Gender Roles and Identity,” Simone discusses her dismay of being ridiculed for not adhering to typical gender behavior. She states,

    Splitting AS traits along gender lines may seem unnecessary to many on the spectrum because we tend to be androgynous creatures—in mannerisms, behavior, and mostly, in essence…our androgyny shines through our feminine shells. Many times I’ve been accused of being either a transvestite or a lesbian and that has also happened to my Aspergirl peers (61)

The policing of gender in the statement above is obvious; Simone’s choice of the word “accused” shows that gender non-conformity (non-heteronormative) is a means of insult and control by the larger community, an example of the majority attempting to fit individuals with labels. Simone’s experience is not unique and the policing of gender and feminine ideals is repeatedly discussed in other narratives of autistic women.

    Several female autistic writers have discussed an affinity to “male” traits, claiming that they fit in with typical male behavior rather than neurotypical female behavior. Simone further complicates gender expectations by stating:

    Though we may not feel particularly womanly, others will still see us as such and measure our behavior against nonaustitic females, when in reality I feel it would be more appropriate and fair to measure our behavior against a man’s—after all, men are not expected to be socially adept, or have an abundance of nurturing feelings. This would be a much fairer standard of measure and other Aspergirls agree. (Simone, 62)

Here, Simone’s analysis touches on gender ambivalence being associated more with males than females. Problematically, Simone asserts that autistic women should be compared with neurotypical men, but does not comment on neurotypical women. Simone feels that she relates more to men than women because of her lack of total understanding of social norms. Additional rules seem to have been placed upon women in general, and autistic women have a harder time understanding those rules, thus associating with male traits more than female ones, since males seem to be given more lenience by society if they don’t necessarily fit into certain boxes. But
associating with a more “male” set of behaviors further boxes people into one of two distinct
gender categories, without blending the lines of distinction and working towards disintegrating
those gender boundaries.

As discussed earlier, Grandin also problematically asserts that she has a more “male”
centered brain than female, which seems to be based on the stereotypical notions of female and
male differences. In *Thinking in Pictures*, Grandin continues to remark on her difference as being
notable because she was not interested in normalized female pastimes, stating,

I could not participate in the social interactions of high school life… I could not
understand why clothes were so important when there were much more
interesting things to think about and do in the science lab… my peers spent hours
standing around talking about jewelry or some other topic with no real
substance… I just did not fit in (132).

It’s clear that the other peers that Grandin is speaking of here are most likely girls who are
performing their gender roles. It is most likely that not all of the girls were interested in those
things, but overwhelmingly, Grandin felt separated from her peers, as she was not able to feign
interest as a way of coping with these social rituals. Grandin often speaks about the interests that
helped her while growing up. For example, she states “electronics and experimental psychology
were much more intriguing than clothes” (132).

The idea that autistic women tend to engage in more male interests is problematic, and
seems to be something we are moving away from as a society at large, as well as becoming more
open to different sexual identities. Dawn Prince-Hughes comments on gender in her work,
stating,

I grew to realize that the two-gender system presumed in our culture and aimed at
purifying heterosexual sex ignored many complexities of biology and psychology,
as well as the nature of changing people and their political commitments… I have
since learned that most autistic people do not see gender as an external or internal
category that is important or even applicable, especially to themselves; as a result
of learning about myself, I finally unlocked the enigma of sexual desire, now
understanding it well. We should rid ourselves of the myth that autistic people simply don’t have sexuality; rather, it is different and takes more time to unravel. (Prince-Hughes 58-59)

Here, Prince-Hughes not only talks about the lack of binary gender association among the autistic community, but also speaks of sexuality itself. Autistic individuals, like much of the disabled community, are generally viewed as lacking sexuality. This is an issue with the portrayal of the disability community overall, and is particularly interesting within the autistic community, as a lack of gender conformity affects one’s sexuality, and the sexual cues given to others. Prince-Hughes discusses how her demeanor and fashion choices became signs to others of her sexuality, though she did not intend this at first:

Another component of my ‘mystique’ was my appearance: I wore leather jackets because their weight and thickness calmed me; dark glasses, sometimes even at night, because they cut out some of the stimulation to my nervous system; and heavy boots that made me feel secure and grounded as I clomped around in them. I must have looked like a perfect practiced stud with all the trimmings, when in reality I was withdrawn and armored primarily out of anxiety and confusion. (79)

Prince-Hughes goes on to explain that she was portraying herself in a way that attracted women to her sexually, but wasn’t aware of this. Attire can be a social marker of an individual’s intentions, and so because of her lack of understanding, Prince-Hughes was submitting unspoken signals to others about her sexuality. This is one of the nuances of social interaction that is focused on when working with autistic teenagers. It is not only relevant for their personal knowledge, but also for personal safety which, particularly for women, goes hand-in-hand with sexual situations.

Understanding social cues of other children and girls can be helpful to avoid bullying for young people, particularly young women, on the spectrum. Girls and women must also be made aware of the extra threats they may face and their own personal safety. Women are more likely to be targets of sexual abuse than men, and not being able to understand threats can be particularly
dangerous for women on the spectrum. While personal safety is an issue for all on the spectrum, it is much more prevalent for girls and women, particularly because they may not understand the warning signs or their own sexuality. While fashion choices may not seem as important as other issues, it can affect the safety of women and girls unintentionally. In seeking to be “normal” females with autism may put themselves in situations of danger without realizing. A recent study in *Journal of Autism and Developmental Disorders* on women with autism recorded the experiences of the women interviewed:

Fourteen women with ASC (aged 22–30 years) diagnosed in late adolescence or adulthood gave in-depth accounts of: ‘pretending to be normal’; of how their gender led various professionals to miss their ASC; and of conflicts between ASC and a traditional feminine identity. Experiences of sexual abuse were widespread in this sample, partially reflecting specific vulnerabilities from being a female with undiagnosed ASC. (Bargiela)

Although the sample is small, the study above illustrates that sexual abuse may be prevalent among women on the autism spectrum, but it may not be wholly recognized as an epidemic, though it appears in personal stories of those with autism. For example, in Mandavilli’s article “The Lost Girls,” parents of one of the autistic girls featured are constantly worried about her safety, particularly around male attendants who work at the program that she is in.

Unfortunately, violence against women is very real threat and because those on the autistic spectrum, or those with other cognitive issues may not be aware of danger they are putting themselves in, they can easily become victims of sexual or physical assault.

Temple Grandin comments on sexuality and the dangers of not being able to understand warning signs in her memoir *Thinking in Pictures*:

I’ve remained celibate because doing so helps me to avoid the many complicated social situations that are too difficult for me to handle. For most people with autism, physical closeness is as much a problem as not understanding basic social behaviors. At conventions I have talked to several women who were raped on
dates because they did not understand the subtle cues of sexual interest. Likewise, men who want to date often don’t understand how to relate to a woman. (133)

Physical abuse and safety is not usually mentioned in memoirs by male autistic writers, but it is a significant focus in female writers’ work. For example, after a suicide attempt, Sophia Summers, spent time at a psychiatric institution, where a male nurse sexually harasses and assaults her repeatedly:

If it wasn’t bad enough that I was depressed and drugged-up from all the pills in my system, the orderly was kissing and touching me. All I could do was silently cry. I was so ashamed that I said nothing. I didn’t dare tell the doctor, only to be accused of more lies. During the day, the orderly played board games with me and encouraged me to be cheerful if I wanted to be released. I played board games with him, fakes a smile, and tried to act like I was in a good mood so that I would be released. It worked. A week later, I was home. He had the nerve to call me at home, and I told him to leave me alone. He never called again. (Summers 37-38)

Issues of safety rarely appear in autistic memoirs by male autists, but they do appear in many memoirs written by women. Even without necessarily adhering to a certain gender, women are more likely to be a target for abuse. Girls with autism need to specifically be taught what actions they may unintentionally partake in that may make them targets for abuse, as terrible as the thought may be. The type of danger that women may be confronted with throughout their lives is specific to their gender, and should be acknowledged and discussed. Though we can work to eliminate socialized gendered norms as much as possible, anatomy and biology cannot be changed, which is why treatment of autism must be somewhat specific when it comes to males and females. Menstruation, menopause, and personal safety are all topics that are often excluded from books on autism, but are extremely relevant for females on the spectrum, and their caretakers.
Looking Forward

Hopefully, diagnosis will not be needed as it is now in the very near future. As Temple Grandin suggests, perhaps we can look at individual symptoms and help each person based on his or her own experiences and needs, rather than prescribing labels to lump individuals into broad categories. Autism itself is a label of individuality, a cognitive difference that is entirely unique to each autistic individual. In his article “Autism as Culture,” scholar Joseph Straus discusses this concept, stating,

[T]here will never be a cure for autism any more than there were cures for fugue or hysteria because these are not diseases. Rather, they are clusters of behaviors, abilities, and attitudes that, under the right cultural conditions, get grouped together and provided with a label. The label appears to confer coherence on the category, but this is a fiction, or rather, a contingent cultural construction. (Straus 540)

As Straus asserts above, the label of autism is a socially created term which attempts to explain, or at least encapsulate, wide spectrum of behaviors that vary from what is considered typical behavioral norms. Straus asserts that the dramatic rise in the diagnosis of autism from the 1980s onwards may very well be a marker of a shift in cultural values, making the diagnosis “a major presence in the culture of early twenty-first century America” (536). As a society, we now recognize neurodiversity in a way we may not have in the past, with an increasing trend towards a more open understanding and acceptance of difference.

Steven Silberman’s recent book on the topic, NeuroTribes: The Legacy of Autism and the Future of Neurodiversity, captures the spirit of Straus’s point. Silberman’s analysis of autism includes a focus on the history of autism, the changing diagnosis of autism, and the way the disorder has shifted within society. Silberman emphasizes neurodiversity as a central aspect of humanity, and not as a disability. There is not just one way to be, but many different ways of
understanding our sensory experiences and interactions with others. Silberman doesn’t particularly focus on gender, but he makes an important point in requesting that the neurotypical reader acknowledge that those who are diagnosed with autism may process the world around them in a different way. Silberman states,

By autistic standards, the “normal” brain is easily distractible, is obsessively social, and suffers from a deficit of attention to detail and routine. Thus people on the spectrum experience the neurotypical world as relentlessly unpredictable and chaotic, perpetually turned up too loud, and full of people who have little respect for personal space. (471)

As illustrated above, the “neurotypical” brain can be considered abnormal and “chaotic” to those with autism or other neurodiverse minds. There is no one correct or normal way to interact with our daily surroundings. All we have are our own perspectives, and they are neither normal nor abnormal. They just are.

Moving forward, women and girls need to be more included in this trend towards acceptance of neurodiversity and autistic traits. This is already happening in many ways, with perhaps a significant example being a new character introduced on PBS’s Sesame Street: Julia, a female muppet who has autism. Sesame Street’s decision to not only feature a character with autism on the show, but particularly one who reads as female, is significant, and perhaps telling that conversations surrounding the specific issues faced by women and girls on the spectrum are finally being heard. Hopefully, girls and women won’t feel left out of discussions surrounding autism in the future, as preconceived rules based on the binary gender system continue to be questioned and broken down. At the same time, differences based on sex and gender should continue to be acknowledged without being markers of exclusion. Perhaps the focus won’t have to be on the issues of diagnosis, but rather on the inclusive communities surrounding those on the
autism spectrum, leading to a celebration of neurodiversity and unique qualities of each individual person.


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