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## Journey to diagnosis for women with autism

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### Abstract

**Purpose** – The purpose of this paper is to review the barriers that girls and women face in receiving an accurate and timely autism diagnosis. The journey to late-in-life diagnosis will be explored with a focus on mental health and well-being. The aim is to improve the awareness of the female autism phenotype to provide access to early identification and appropriate supports and services.

**Design/methodology/approach** – The author's clinical experience as an individual, couple and family therapist specializing in girls and women with autism informs the paper. Research on co-occurring mental health experience and diagnoses are reviewed and combined with case examples to outline the themes leading to and obscuring autism diagnosis.

**Findings** – Females with autism are less likely to be diagnosed or are identified much later than their male counterparts. Living with unidentified autism places significant mental strain on adults, particularly females. Achieving a late-in-life diagnosis is very valuable for adults and can improve self-awareness and access to limited support.

**Practical implications** – Mental health professionals will develop a better understanding of the overlap between autism and psychiatric conditions and should consider autism in females who are seeking intervention.

**Originality/value** – This paper provides a clinical approach to working with autistic girls and women. This knowledge can complement the existing research literature and help build the foundation for a greater understanding of the female autism phenotype.

**Keywords** Women, Autism spectrum disorder, Female, Non-binary, Diagnosis, Self-diagnosis, Mental health, Suicide

**Paper type** General review

### Introduction

Gender bias in autism assessment and research is a well-established phenomenon (Lai and Baron-Cohen, 2015). Explanations for underdiagnosis and misdiagnosis include a gendered presentation of autism traits, a lack of knowledge of the female autism profile and the use of gold standard diagnostic tools that were developed and normed for a male population that are not sensitive to the female phenotype (Lai *et al.*, 2011). Sex ratios previously believed to be 4:1 male to female (Fombonne, 2009), vary when factors of age and intellectual ability are considered (Nicholas *et al.*, 2008). Girls with stronger verbal skills and higher IQ who meet the criteria for autism are much less likely to be diagnosed or are identified much later than their male counterparts (Loomes *et al.*, 2017). It has been suggested that females have greater social motivation, study the social behavior of others, get much more feedback about their behavior and interpersonal skills, mask their autism, and develop more internalizing traits (Gould and Ashton-Smith, 2011). Camouflage, which develops as a protective social quality, has the opposite effect when women are meeting with professionals who dismiss or misunderstand their needs because they “do not look the part” (Tint and Weiss, 2017). Autistic\* females without an intellectual disability (ID) are at significant risk for having their needs overlooked or identified later in life, causing them to miss crucial support that may accompany a diagnosis and alleviate some of their struggle. Further, it robs females of the opportunity to fully know themselves and adapt successfully in a

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world that was not designed with their needs in mind. Compared to autistic men, women newly diagnosed on the spectrum report significantly higher rates of depression and suicide risk. Missed misdiagnosis or late-in-life autism diagnosis can lead to a fatal outcome (Cassidy *et al.*, 2014). For the purposes of this paper, late-in-life diagnosis is defined as adulthood, 18 years of age and older. \*This paper uses person-first (woman with autism) and identity-first (autistic person) language interchangeably to reflect the diversity of client preferences.

This paper reviews the clinical experience of an individual, couple and family therapist who specializes in working with autistic teens and adults, with a focus on females in Toronto, Canada. The women's experiences featured in this paper are from the caseload of this clinical social worker's private practice setting from 2010 to 2018, and from the participants of Asperfemme Toronto, a support group for women with autism that this author founded and co-facilitates. In total, 63 women ranging in age from 18 to 72 years participated in counseling. The women sought support at different points of their autism journey. Many engaged in services prior to their diagnosis, wanting to meet with a professional who understands the female autism profile. These women wanted confirmation and support during their process of self-exploration and autism education. Others sought counseling post-diagnosis to develop a greater understanding of their unique autism profile and improve their mental health and well-being. The number of sessions varied for each client depending on the focus and goals of therapy and the complexity of the issues. Some participated in only a few sessions, while a selected few maintained an ongoing therapeutic relationship that spanned several years. Additional stories of 25 females who were known exclusively through the Asperfemme Toronto support group are incorporated into this review. All of the women were diagnosed with autism in adulthood.

This paper will explore the mental strain of undiagnosed autism, including the mental health and cognitive factors that interfere with accurate and timely diagnosis for females. Next, the varied pathways to autism identification are outlined. Challenges with autism identification will be discussed. The paper will conclude with an overview of the impact of late autism diagnosis for autistic women.

### Pre-diagnosis – the mental strain of undiagnosed autism

Prior to their autism diagnosis women have shared feeling in a perpetual state of confusion and overwhelm (Hendrickx, 2015). As one client notes, "The whole world is confusing. Everyone figured it out but me." Undiagnosed autistic women struggle to function in this sensory-social world without the knowledge that they are on the spectrum and the explanation and tools that the diagnosis can provide. They describe feeling different from others from a young age whether they escaped into their imaginary world or books, delved into interests with an intensity that peers could not relate to, or just always felt like they did not fit in. Their difficulties with social communication and information processing made it a challenge to follow and participate meaningfully in conversations and group dynamics. Their intense sensory processing experiences made life scary and unpredictable. Difficulties with emotional processing and overload led to outbursts or meltdowns invoking deep-seated embarrassment and shame.

Feeling different and being socially excluded are common for autistic women as articulated in the autobiographies of Liane Holliday Willey (1999) and Laura James (2017), and the guides *Aspergirls* by Rudy Simone (2010), and *I Think I Might Be Autistic: A Guide to Autism Spectrum Disorder Diagnosis and Self-Discovery for Adults* by Cynthia Kim (2013). Alienation and isolation have detrimental effects on self-esteem and self-worth. Many women share that they never feel good enough. These feelings are accompanied by intense shame and self-doubt. Their intelligence and level of understanding are often underestimated in social situations. One client expressed anger and despair over the constant misunderstandings; "Why doesn't anyone understand me?" Girls and women with autism are perplexed as to why they put so much effort in and yet, time and time again, struggle to achieve the outcome they aim for, whether it is to form lasting relationships, get through the day without a meltdown, cope at school or work, or communicate clearly to others what they want and need. Not knowing what is causing their differences and why they struggle creates further confusion and self-judgment.

Many women use masking, consciously or unconsciously, to attempt to hide their differences and be more socially accepted (Lai *et al.*, 2017). They choose a peer or a character from a movie or television who appears to be well liked, and using mimicry learn to copy their way of speaking, gestures and body language. Others use self-imposed rules to render themselves invisible in an attempt to avoid being noticed or ridiculed, or they repress behaviors that others think are weird. Masking can complicate social situations. If women appear socially competent and they behave in unusual ways, their behavior is harshly judged even though the issues arise from missed or misinterpreted social cues. They feel hurt and flawed knowing that they may have inadvertently offended others, but do not know why or how to make it better. Masking can be detrimental to a person's sense of self. This communicates inwardly that their true self is flawed and needs to be concealed or altered. Frequently this leads to identity crises, because after years of piling on layers of camouflage they are left wondering who they really are. As one woman notes, "I don't know what it means to be me." Years of rote learning and mimicry permits them to pass as neurotypical, but this incessant extensive posturing leads to significant fatigue and mental strain (Hull *et al.*, 2017). Their minds are full at the end of each day, trying to make sense of all of the conversations that took place and wishing they had made a different contribution. Overload can be lessened through social withdrawal and sensory deprivation, such as baths, dark quiet rooms, immersion into intense interests, deep pressure from pets or weighted blankets and soothing music.

Autistic women are at high risk for trauma exposure throughout their lifetimes. Confusing and emotionally painful events in childhood have detrimental impacts on their overall quality of life affecting sleep, agitation, distractibility, social interaction, restrictive interest use, dietary disturbance, self-care skills and educational outcomes (Mehtar and Mukaddes, 2011). Girls with autism are three times more likely to be sexually victims than their neurotypical peers (Ohlsson *et al.*, 2018). Peer victimization in the form of bullying is a regular occurrence for children with autism. Hofvander *et al.* (2009) found that autistic females without intellectual disability report significantly more experiences of bullying compared to their male counterparts. Bullying victimization is very stressful and distressing for autistic children and can lead to increased anxiety, depression, self-injurious behavior and negative self-concept (Cappadocia *et al.*, 2012). As adults, women continue to be targets as they are unable to pick up the intentions of others, they like to please, and due to information processing delays they can enter into precarious situations without becoming aware of the dangers. The cumulative effect of living with unmet social and emotional needs places significant mental strain on girls and women with unidentified autism.

### ***Co-occurring mental health and learning issues that overshadow autism***

Mental health symptoms emerge from a lifetime of struggling in a neurotypical world. Co-occurring conditions for autistics are alarmingly high, ranging from 65 to 94 percent. The most common co-existing mental health conditions are with anxiety disorders, major depressive disorder and Attention-Deficit Hyperactivity Disorder (ADHD) conditions (Haruvi-Lamdan *et al.*, 2018). Women with undiagnosed autism often seek professional help to understand and treat their mental health conditions but their autism is often missed. As Dworzynski *et al.* (2012) argue, mental health clinicians are not looking for autism when they encounter a female – autism is not on their radar.

Anxiety is the most pervasive mental health condition experienced by autistics with up to 66 percent endorsing symptoms. Anxiety is not experienced equally across genders. Lieke *et al.*'s (2018) found that autistic girls have significantly more anxiety symptoms than boys, in the areas of separation anxiety, social phobia, panic disorder and generalized anxiety disorder. The older and brighter a woman is, the more likely she is to experience anxiety. (Davis *et al.*, 2011; Van Steensel and Heeman, 2017). The increasing demands of the adult world coincide with the end of structured supportive environments such as schools and programs leaving autistic young adults feeling lost and unsupported. Changes to routine or vague instructions increase anxiety. Knowing what to expect and what is expected of them create a scaffolding where they can anchor their thoughts, choices and behavior. Challenges with central coherence or a clear narrative about oneself make it difficult to extrapolate from past situations and apply information to new or similar circumstances. Anxiety increases as extra effort is required to navigate novel and seemingly unfamiliar situations. Sensory processing challenges increase anxiety. The unpredictable sensory experience of painfully

loud, bright, smelly and crowded spaces can leave people on edge, not knowing when the next sensory assault may occur.

According to Bejerot *et al.* (2014), one in four adults with autism experiences social anxiety. Social anxiety may be rooted in social skill deficits and repeated social errors or missed opportunities, making social situations feel threatening. For women with unidentified autism, anxiety comes from knowing they are different, but not knowing exactly why or how. Although chronic anxiety is often the norm, due to alexithymia and interoception challenges, women may not be aware that they are experiencing anxiety if they are not aware of the symptoms and how they manifest. Difficulties with alexithymia, the process of identifying and expressing emotions, make it challenging for autistic women to recognize and self-report when they are struggling. They are confused about what they are feeling and why, and often do not have the emotional vocabulary to speak about and regulate these emotions (Ketelaars *et al.*, 2016). As a result, women are only accessing help when situations become dire, instead of receiving proactive and preventative mental health support that could potentially stave off crises.

Depression is experienced by up to half of all autistic adults. A study by Hedley *et al.* (2018) examined risk and protective factors for depression and suicide in autistic adults and found that 50 percent of their sample experienced depression, with women's scores significantly elevated. Being a female, like having higher intelligence is related to increased likelihood of depression. In a systematic review of over 8,000 research articles on autism and depression, Hudson *et al.* (2018) found that depression is experienced at a much higher rate by autistic individuals with above average intelligence. One possible explanation is that greater cognitive ability leads to increased self-awareness and distress over differences (Rai *et al.*, 2018). They may be depressed because they know they are different, but despite every effort they cannot seem to meet the expectations of themselves or others. Childhood bullying victimization and social exclusion often haunt women and erode their self-esteem, with lasting impacts into adulthood. Suicide is the leading cause of premature death for autistic adults with average or above IQ (Hirvikoski *et al.*, 2016). In a clinical study of adults diagnosed later in life with Asperger's syndrome, 66 percent had contemplated suicide in their lifetime, with females being the most affected (Cassidy *et al.*, 2014). Rates of suicidal ideation were highest for women 35–64 years, ranging from 75 to 89 percent of the group studied. Loneliness, perceived burdensomeness and lacking a sense of belonging all contribute to suicidal thinking across the lifespan (Pelton and Cassidy, 2017).

Bipolar affective disorder (BPAD) can co-exist with autism, but it can also be mistaken for the condition because of shared features – irritability, mood dysregulation, sleep dysfunction and quasi-manic behavior (Joshi *et al.*, 2013). A review of the literature found the mean prevalence of autism with BPAD to be 7 percent (Skokauskas and Frodl, 2015). Autistic meltdowns can appear as mood dysregulation but the underlying cause is different. Meltdowns of individuals with autism can be triggered by an overload of information, emotion or sensory input and may present as uncontrollable sobbing, anger, loss of the ability to speak and possible destructive behavior toward self or others. These behaviors can result from a build up of emotions or can happen from a sudden trigger. Intense emotional experiences have the potential to be miscategorized as mood swings and BPAD symptoms. Sleep problems such as insomnia and sleep onset issues are common in autism spectrum disorder (ASD) (Richdale and Schreck, 2009) and may be viewed as the decreased need for sleep associated with hypomania. Passionate focus on intense interests can also present like mania, if the individual has a heightened sense of excitement and grandiosity about their passions that is temporary and uncharacteristic of their typical behavior.

Substance use can become a way to cope with the intense stress, anxiety and depression that comes from camouflaging autism. Based on his Swedish longitudinal population-based study findings, Butwicka *et al.* (2017) suggested that being autistic doubles the risk of addiction, with individuals with average or above IQ at particularly high risk. For some, self-medicating is the only way to quiet the constant noise in their heads. Drugs and alcohol can facilitate connection with others by reducing crippling social anxiety by creating a common bond. Drug use can be a highly ritualistic behavior that is familiar and calming. Propensities such as adherence to routine and repetitive behavior can increase the risk of drug or alcohol use becoming habitual. The act of camouflaging is exhausting and can lead to high levels of anxiety, which increases the risk of developing substance use disorders as a way to cope and fit in.

ADHD often accompanies autism. Because of symptom overlap, the diagnosis of one may overshadow the other. In a review of existing research, Rommelse *et al.* (2010) found that 30–80 percent of children with autism also met criteria for ADHD. Many women receive a diagnosis of ADHD in childhood, years before their autism is identified. ADHD may be picked up due to impulsive or disruptive behavior. For girls with inattentive subtype, teachers may notice students daydreaming in class, becoming engrossed in a book during lessons or doodling incessantly in notebooks. Executive functioning challenges such as difficulties with attention, organization and multitasking exist with both conditions. For girls and women with autism, an ADHD label may help identify attentional, behavioral and executive functioning challenges, and lead to accommodations and support in an educational setting, but it does not capture the full range of autism traits such as narrow interests, rigidity in behavior and social skill difficulties. These girls and women continue to struggle without the proper identification of autism.

Another group of conditions that can overshadow autism is eating disorders, specifically anorexia. A longitudinal study by Anckarsäter *et al.* (2012) found that up to 30 percent of women with anorexia met criteria for autism, although not all women were identified prior to participating in the research. Autism and anorexia's shared cognitive profile includes rigidity in behavior and thinking, perfectionism, theory of mind deficits, executive functioning challenges and mood and anxiety disorders (Oldershaw *et al.*, 2011). As well, specific features of autism increase the risk of developing eating disorders. Sensory processing challenges can limit dietary preferences and environments in which they feel comfortable eating. Interoception and body awareness challenges may lead to missing hunger cues. Hyperfocusing can cause people to forget about eating. Coordination issues and longstanding clumsiness may influence women to develop an adversarial relationship with their bodies. Gastrointestinal issues can lead to chronic pain impacting dietary choices. Psychopharmacological medications to alleviate mental health symptoms often cause weight gain. Some girls and women are drawn to weight loss for social reasons, hoping to improve their status. They struggle to fit in socially and believe that if they were skinny, they would be popular and people would like them. Anorexia can also come from intense anxiety, overwhelm and a need for control. This can manifest through counting calories, restricting food or exercising obsessively. Anorexia treatment programs focused on body image may be ineffective for autistics whose disordered eating developed due to other factors.

Obsessive compulsive disorder (OCD) can mask autism due to the shared features of compulsive repetitive behaviors and obsessive thoughts. The social communication challenges inherent to autism, may not be apparent in undiagnosed autistic females as their difficulties may be camouflaged. Passionate interests, another autistic feature that could differentiate from OCD are often missed because the passions of autistic girls and women usually mirror those of their neurotypical peers, but differ in quality and intensity (Gould and Ashton-Smith, 2011). OCD typically emerges in puberty, while autism is a developmental condition that is predominantly identified in childhood. For many females, however, autism symptoms are not apparent until adolescence when social demands outweigh skills; the convergence of the two conditions causes diagnostic confusion. There is a genetic relationship between autism and OCD – OCD is twice as likely to occur in people with autism and if a parent has OCD, children have a higher risk of autism. In a cohort study in Denmark by Meier *et al.* (2015), individuals with OCD were four times as likely to go on and receive an autism diagnosis compared to individuals without. Wikramanayake *et al.* (2017) studied 73 adult outpatients with OCD and evaluated them for co-existing autism. Slightly more women participated in the study than men. Half the group had traits of autism, and 29 percent met diagnostic criteria for autism. Despite having met with multiple mental health professionals, none of those patients had been previously assessed for the condition. The over-representation of women in this OCD service may result from a failure to recognize autism in females. Instead of having their autism accurately identified in childhood through developmental services, their needs are being brought to the attention of psychiatric services later in life. This research stresses the need for clinicians to look for autism when meeting with female patients seeking OCD treatment.

Borderline personality disorder (BPD) also has shared traits with autism and can lead to confusion over the correct diagnosis. Shared issues include interpersonal difficulties, challenges with affect regulation and self-harm. Dudas *et al.* (2017) studied the presence of autistic traits in individuals with autism, BPD and controls. Rates of autistic traits were equally elevated in both groups and

individuals with BPD endorsed high rates of systemizing, the drive to analyze or construct systems. Similar to people with autism, “individuals with BPD have (a) heightened emotional sensitivity, (b) inability to regulate intense emotional responses, and (c) slow return to emotional baseline” (Crowell *et al.*, 2009). These characteristics support the theory that some females with BPD may have undiagnosed autism and that professionals should evaluate for autism when assessing for BPD. Marsha Linehan (1993), who developed dialectical behavioral therapy (DBT) for the treatment of the BPD, explained the development of the condition through a biosocial model. BPD arises from the interaction between a person with a highly sensitive temperament and an invalidating environment. Based on this theory, persons with autism, and are at risk for developing BPD because of their emotional sensitivity, reactivity and experiences with trauma and multiple invalidating environments at home, school, work or in the community where their needs are not clearly met or understood.

High incidence of trauma exposure throughout the lifespan places autistic women at risk for developing post-traumatic stress disorder (PTSD). Difficulty processing complex and highly emotional information coupled with difficulties seeking support intensifies vulnerability. Rates of reported PTSD and autism are low, ranging from 0 to 17 percent (Haruvi-Lamdan *et al.*, 2018), and do not accurately reflect the lived experience of trauma. This suggests that PTSD presents differently in persons with autism and that the tools being used to screen for PTSD are not sensitive for this population.

A woman’s cognitive profile can also mask autism. There is a significant genetic link between autism and elevated intelligence (Crespi, 2016). Autism may go undiagnosed in gifted women because their eccentricities may be falsely attributed to high IQ. Females with non-verbal learning disability (NLD) share many traits with autism. An NLD label is given to learners in North America who have average to above average intelligence and possess stronger verbal skills and weaker motor, visual-spatial and social skills. Commonalities between autism and NLD include difficulties reading visual social cues such as gestures, body language and facial expression, issues understanding tone of voice and picking up on inferences such as irony or sarcasm, coordination challenges, executive functioning difficulties and weak central coherence (Ryburn *et al.*, 2009). What differentiates the two conditions are the narrow interests and repetitive behaviors inherent to ASD. But as mentioned, the intense interests and behaviors of girls and women with autism are often missed due to the typicality of them, such as a passion for American Girl dolls or compulsive hair twirling. Social difficulties are present in both conditions, but the reasons may differ. For instance, someone with NLD may have challenges reading social cues because of visual-spatial challenges whereas, someone with autism might be aware of the gestures but not understand their meaning. The underlying cause of challenges should be investigated to identify the correct condition.

Despite the many obstacles to obtaining accurate identification of autism in females, women are coming to their diagnosis late in life, and often through their own exploration and discovery.

## Pathways to identification

There is greater identification of autism in this generation than ever before and yet still, the female profile is minimally recognized and understood. Identification of autism in women is often a long and round about journey involving years of struggle, appointments with multiple professionals and a fragmented understanding of their challenges leading to misdiagnoses and greater misunderstanding. The common pathways to identifying autism diagnosis I have encountered in my clinical practice are: having a family member receive an autism diagnosis, sensing that their partner may have autism, exposure to autism in popular culture, plateaus in development, workplace issues, mental health crises, burnout, and exposure to firsthand accounts of women with autism.

### *Family and romantic relationships*

Often women come to realize that they have autism during the process of a family member’s diagnosis. For some, this begins when a mother has a young child who is not meeting milestones and is referred for a developmental pediatric assessment. Parents relate to their son or daughter’s habits and think, “they are just like me.” Older generations can have an “aha” moment

when grandchildren receive their diagnoses. Often these family members feel deep empathy for and kinship with the younger autistic family member. While the young person's autism is accurately identified, it is often a struggle for mothers and grandmothers to find a professional who can recognize and diagnose their own autism. After years of masking autistic traits and compensating for their challenges, their external traits are often not discernable.

Women in romantic partnerships who experience communication and intimacy issues often question whether their partner is on the spectrum. As they begin to suspect their partner has autism, they research about the condition and realize that they relate to the descriptions of autism and that they themselves may be on the spectrum.

### *Mainstream popular culture*

Women with autism are starting to see themselves reflected in popular culture. This is highly significant because up until recently there was a limited and narrow portrayal of autism in the media. Autistic girls and women had no one to look up to as role models on the screen or in writing. Fictional characters such as Sheldon on the television show *The Big Bang Theory* and the narrator from the novel and stage play of *The Curious Incident of the Dog in the Night-Time* (Haddon, 2003) have both been gateways for women to identify traits of autism in themselves. Sheldon is not formally diagnosed with autism but his characteristics suggest an Asperger's profile. Women identify with his blunt and honest communication style, challenges reading social cues and rigid behavior. With *The Curious Incident* they relate to the logical narrator who is incapable of lying and has difficulty envisioning scenarios that he has not experienced. Interestingly, even though these characters are male, girls and women have found that they relate to these presentations of autism.

Overt depictions of female characters with autism in popular culture are minimal but growing. Many viewers and fans suggest that television and film characters Dr Temperance Brennan from *Bones* (Malia, 2017), Dr Jillian Holtzman from *Ghostbusters* (Kurchak, 2016), Laurie Bream from *Silicon Valley* (Aspienwild, 2018) and Detective Saga Norén from *The Bridge* (Townsend, 2015) all have autism. Girls and women are pleased to finally see aspects of themselves in these characters. The hope is that these representations continue to expand beyond a unidimensional portrayal of autism.

### *Chronic under and unemployment*

Repeated employment failures and challenges can suggest the possibility of autism. There is often a disconnect between a woman's intellectual and educational achievements versus and her work position and accomplishments. Many women excel in a job interview because of masking abilities and superficial social strengths, but then struggle to hold down a job despite being highly qualified and capable. The importance of the right fit for the individual cannot be overstated. Social skill deficits can interfere with job performance such as speaking too loudly for the environment, being too blunt or experiencing crippling anxiety so they lose their ability to speak and engage with colleagues and customers. Many women have been accused of not being team players because they do not smile enough or for being too direct and abrupt. Rigid rule following and policing others, and focusing on tasks while neglecting peer interactions can hinder relationship-building with colleagues. Ultimately, their behavior is puzzling, offensive and distracting to others, yet they rarely receive direct feedback about their performance and have an opportunity to rectify the situation.

Information processing differences can create challenges if only verbal instructions are given, when someone requires visual prompts and written instructions to remember multiple tasks. Executive function challenges can interfere with work completion due to issues with organizing time, prioritizing tasks and planning and initiating work. Sensory overload from bright and noisy fluorescent lights, loud open workspaces, offensive smells and scratchy uniforms can easily overwhelm and distract an employee. After a history of workplace challenges, these women try to understand why their performance does not match their abilities and potential. Some women seek out the support of a therapist or life coach who may recognize the common themes across failed employment and recommend an autism assessment.



## **Burnout**

Autistic burnout is the emotional, physical and mental exhaustion caused by the cumulative effect of excessive and prolonged stress from having to consciously think through every life process. After years of performing at a high level, women can suddenly hit a wall. Due to interoception difficulties, they might miss cues of fatigue, hunger or negative emotion until the issues are severe. Feelings of inadequacy push them to work their hardest to prove their worth. They become profoundly drained and fatigued and can no longer function. This experience is often first identified as severe depression, but then a thorough history can reveal underlying sensory, social and behavioral challenges. It can take years to fully recover from burnout, and most people never return to the level of activity and performance they previously sustained.

### **“Failure to launch”**

Another group of women who receive late diagnoses could be considered “failure to launch” – those who struggle to transition into adult life demands due to skill deficits and anxiety about growing up. These young adults who live at home with their parents often have had many failed attempts at securing meaningful employment or volunteer work, and spend much of their time isolated at home reading or using electronic devices. They feel stuck and yet they lack and are not learning the skills required to move forward. Executive functioning challenges, social skill deficits, anxiety, low self-esteem and difficulty setting realistic expectations all prevent forward progress. This is intensified by an inability to envision a place for themselves in the adult world where they will be accepted and their needs adequately supported. As a result, the idea of taking on responsibility and placing faith in their abilities frightens and overwhelms them. Challenges with meeting societal and family expectations can prompt an autism assessment.

### **Autobiographies, blogs and advocacy groups**

Now more than ever before, the voices of girls and women with autism are being heard. Autobiographies such as Liane Willey Holliday’s *Pretending to be Normal* and Laura James’ *Odd Girl Out*, and anthologies like Rudy Simon’s *Aspergirls* and *Spectrum Women* edited by Barb Cook and Michelle Garnett have become the go to resources to learn about what it means to be a female diagnosed with autism in adulthood. Women can see themselves and their stories reflected in print, allowing them to recognize the patterns of thinking and behavior that makes them autistic. Countless blogs and autobiographical Youtube videos showcase the adult autistic experience and give people reference points to compare to their own lives.

Once autism is identified as a possibility, the challenges remains to find a professional who can adequately recognize and diagnose the female autism phenotype.

### **Difficulties with identification – public vs private health services**

A major barrier for women to receive an autism diagnosis is the lack of professionals who are aware of the female profile. There is a wide heterogeneity of how autism presents in women, and often diagnoses are limited to those with more obvious adaptive impairments. Missed diagnosis frequently creates further depression and despair for women who are seeking acknowledgment and validation of their social difficulties only to be told, that they cannot be autistic because they make good eye contact or communicate with gestures. This phenomenon appears to be a universal experience across the globe.

In Canada, adult assessments are conducted by psychologists or psychiatrists. Only a few diagnosticians specialize in working with girls and women with autism in Canada. There is a real gap in service for women with suspected autism to be assessed in the publicly funded health service, like the in the UK. Resources are scarce and the level of awareness of the female profile is tenuous. In Toronto, the wait time for a publicly-funded adult assessment through a psychiatric hospital is one year, and the process takes a few months. Some women wait months for publicly-funded testing only to have their autism missed. Where possible, those

women then pay for a private assessment with a practitioner specializing in women. The price tag for a private autism assessment is upwards of \$3,500 Canadian dollars (£2,100). Some people have private insurance through their work that they can use toward the cost of the assessment. Others go into debt or cannot proceed with the diagnostic process because the cost is prohibitive. These circumstances are not unique to Canada and are rather universal. According to members of an international Facebook group “AsperDames” for autistic women over the age of 40, similar challenges of accessing an assessment and having their autism identified occur in Australia, the Netherlands, New Zealand, the UK (specifically mentioned were Wales and Northern Ireland) and the USA.

Self-diagnosis is sometimes the only option if they cannot access or afford a formal assessment. Others choose not to seek out a diagnosis because they are satisfied knowing for themselves. These individuals do not see a benefit to having a formal evaluation. To them, the diagnostic process will not improve their self-understanding, or provide access to any tangible financial supports or disability services.

### Life after diagnosis

Receiving an autism diagnosis can generate a confusing and conflicting responses – relief and validation, shame and self-loathing, and confusion and shock to name a few. For many women, autism becomes their intense interest and they become experts on the condition. Women who do their own research and seek the diagnosis as a confirmation of their autism express pride, relief and validation for finally being seen and understood. They wear their diagnosis as a badge of honor. They are often already a part of the autistic community on social media like Facebook and Twitter.

Already believing in their hearts they are autistic; the official diagnosis is affirming and gives them the chance to communicate their diagnosis to others with authority. Grief and loss are experienced when they look back on all of their lost opportunities. These women tend to embrace their diagnosis and may refer to themselves as “autistic.” They are more likely to disclose their autism in relationships and in the workplace.

Females who seek out an assessment based on recommendation from a family member, school official or physician may see the diagnosis as something that represents everything in them that is deficient or flawed. Instead of embracing this label like their female autistic counterparts whose diagnostic experience is self-driven, they feel deep shame and internalized stigma for being different and not good enough. Some women are able to move from devastation to acceptance by learning more about autism and getting connected to the beautiful aspects of their condition such as creativity and sensitivity. Others are unable to embrace their diagnosis and keep it hidden, living in fear that others will discover their secret or notice their autistic traits they work so desperately to hide.

For some, the diagnosis is met with confusion and overwhelm. The autism that they are familiar with may be very different from their experiences. A lot of work is needed to help integrate this new aspect of themselves into their identities. Therapy can be very useful to help women understand their unique autism profile and, learn how to thrive in a sensory-social world that was not designed for their needs in mind. At this time, there are very few services targeted to girls with autism and even fewer for autistic women. Adult women diagnosed later in life usually have higher IQ, and do not qualify for most government funding or services. Many women seek support and a sense of belonging through online communities such as Facebook and Twitter, or attend support groups in their area.

### Conclusion

#### *Summary of main findings and clinical experience*

Women are being identified with autism throughout adulthood. When they finally receive their diagnosis they are often exhausted and demoralized. Only to have their autism missed and disbelieved can be unbearably draining. Despite these challenges, the autistic woman has incredible resilience. Equipped with support and a confirmed diagnosis, she gains new self-understanding and a sense she belongs. She can now develop self-acceptance and quiet some of the anguish that she has carried throughout her life.

### *Recommendations for other clinicians in the field*

Females deserve and should be entitled to early and accurate autism diagnosis. Greater research of the lived experience of girls and women with autism needs to be conducted. Diagnostic processes need to be updated to reflect the diversity of the female autism phenotype. Clinicians working in pediatrics all the way to adult and gerontological health need to be better educated on the unique presentation of autistic females. This is especially pertinent for psychiatrists who are assessing and treating co-occurring mental health issues. As (Rai *et al.*, 2018). argues, earlier detection may reduce mental health risks such as depression, anxiety and suicidality. Accurate and timely identification could lead to relevant and effective services targeted to meet the specific needs of females with autism.

There is a generation of lost girls who are beginning to find themselves in adulthood. We need to do better for the younger generations of autistic girls. To best serve them, we should lead with hope, positivity and a focus on strengths. They need to know that they are valued and that their needs will be supported. Autistic girls and women deserve to lead full and meaningful lives and have the opportunity to thrive.

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