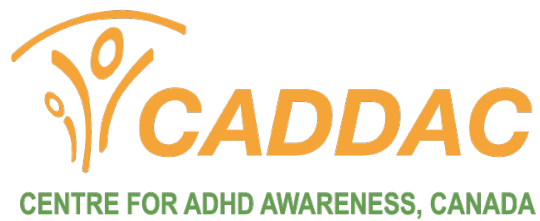


***Girls and Women with ADHD: our  
missed forgotten and most vulnerable***



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## **Girls and Women with ADHD: our missed forgotten and most vulnerable**

When most people hear the term Attention Deficit Hyperactivity Disorder, or ADHD, they usually picture young overly active boys, who have difficulty sitting still and staying focused. What they rarely picture, are bright, daydreamy, girls unable to get their school work done, or forty-year-old moms struggling to keep their families and households organized, their employers happy and their volatile emotions in check. While all of these presentations of ADHD are accurate, it is the girls and women with ADHD who remain significantly underdiagnosed and undertreated in Canada due to our lack of awareness, training and research. This is placing some of our most vulnerable Canadians at risk.

ADHD, the most common neurodevelopmental disorder in children, is a chronic, complex, disorder which affects all aspects of someone's life. Conservatively, ADHD affects 1.5 million Canadians (Manos, 2010, Statistics Canada, 2017). ADHD, especially when undiagnosed and untreated, not only impacts the lives of individuals with ADHD and their families, it also has a detrimental impact on Canadian society. The "cost of illness" associated with ADHD (using conservative incidence rates estimates), is over seven billion dollars. (CADDAC, 2013)

Research has shown that ADHD:

- can reduce life expectancy as much as 22 years, 2.5 times more than the four leading health risks, obesity, smoking, alcohol use and coronary heart disease combined; (Barkley, Fisher 2018)
- increases rates of mental health conditions such as anxiety, depression, other mood disorders, substance abuse and eating disorders; (Wilens, Biederman 1998; Lee 2011; Charach, Yeung, 2011)
- increases lifetime alcohol use disorder to (36%) for those with ADHD compared to 19% of those without ADHD and half of adults aged between 20-39 with attention deficit hyperactivity disorder (ADHD) have had a substance use disorder (SUD) in their lifetime. ((Esme Fuller-Thomson et al.,2021)
- increases the likelihood of attempting suicide (14.0% with ADHD vs. 2.7% without); (Esme Fuller-Thomson et al.,2020)
- results in fewer years of education; (Barbarese et al., 2007)
- reduces employment by 10-14%, reduces earnings by 33% and increases social assistance; (Fletcher, 2014)
- increases involvement in serious transport accidents by 45% to 47%; (Chang 2014)
- increases physician visits ten-fold in adults as well as emergency visits and hospital stays; (Katzman et al., 2017)
- increases rates seen in the correctional population are 5 times that of adults, and ten times that of youth in the general population. (Young 2015)

- results in increased rates of sexually transmitted disease and increased rates of adolescent pregnancy (24% to 38% compared to 4 to 5%) (Barkley et al, 2006; Barkley et al., 2008; Flory 2006)
- increases the rate of childhood physical abuse by four-fold; (Fuller-Thomson et al., 2014) and
- increases the risk of sexual abuse for both sexes. Rates for males with ADHD increased to 11.1% from 5.6% for those without ADHD, and rates for females with ADHD increased to 33.7% from 14% for females without ADHD. (Fuller-Thomson, Lewis 2015)

Even though ADHD is often referred to as the most easily treated mental health disorder, many adults with ADHD remain undiagnosed and untreated. (CADDRA) However in recent years, due to some increased awareness of adult ADHD, we are seeing more adults reach out to their medical professionals asking for an assessment of ADHD. With the growing numbers of adults being diagnosed an interesting, yet disturbing, trend is surfacing. In adulthood, the number of females diagnosed compared to the number of males is close to equal, (Faraone et al., 2000) yet we continue to diagnose triple the number of boys to girls in childhood. (Young et al., 2020) Since ADHD is a highly heritable disorder, this informs us that we are not effectively assessing and diagnosing our girls with ADHD, until they themselves ask for that assessment. Why is this?

### **The Presentation of ADHD in Girls and Women**

As mentioned in the opening paragraph girls with ADHD often look quite different from their male counter parts who more often present with the “classic”, or well known, look of ADHD. Although females can present with all three primary symptoms of ADHD, inattention, hyperactivity and impulsivity, their symptoms often appear less severe and less dramatic specially around hyperactivity, the symptom that is most visual. (Young et al., 2020) Rather than running and climbing, girls may exhibit their hyperactivity in less obvious and annoying ways such as twirling their hair, chewing their cuticles or being too chatty. (Littman, Girls) In addition, while girls can have the combined presentation of ADHD, a metanalysis (Arnold 1996, Quinn 2008) indicated that females present more often with the primarily inattentive presentation, which does not include hyperactivity and impulsivity. This results in girls looking more passive, day dreamy, disorganized, easily overwhelmed and sluggish rather than annoying and disruptive, which are generally the symptoms that prompt referral for assessment. (Mowlem 2018; Young et al., 2020)

Another reason why girls are less likely to be assessed for ADHD is their strong need to fit in and not be seen as different but still seen as competent. Boys seem to be less concerned with these needs. As a society we still expect girls to be neat, organized, compliant, cooperative as well as sensitive to others. (Littman, Girls) Girls with ADHD are known to exhaust themselves by spending hours on homework and assignments to hide their academic struggles. Unfortunately, the more subtle presentation of ADHD in girls along with their added need to conform, results

in girls with ADHD going unnoticed, referred less for assessments and therefore less often diagnosed, understood, treated and supported. (Young et al., 2020)

Another significant factor that interferes with the diagnosis of girls and women with ADHD is their high rate of coexisting disorders. (Fuller Thomson et al 2016) Because girls and women with ADHD tend to internalize their symptoms and impairments (Lynn, 2019) it may not be surprising that their comorbid disorders are also internalizing in nature, unlike those for males whose tend to be more externalizing. (Young et al., 2020) As stress for these girls increases in adolescence, we begin to see the common comorbid conditions of anxiety, depression and eating disorders appear. (Brewerton & Duncan 2016; Fuller Thomson et al 2016). This often leads to anxiety and depression incorrectly being diagnosed as the primary disorder (Quinn, Madoo 2014) decreasing the likelihood that ADHD will be diagnosed. (Nadeau, Quinn 2002)

A recent CADDAC survey of Canadian women with ADHD found that 46% were misdiagnosed with another disorder prior to being diagnosed with ADHD. Sixty percent of these women felt that their treatment had been delayed by two or more decades due to this misdiagnosis. Many women in this survey spoke about being diagnosed and unsuccessfully treated for anxiety and depression for years and even decades until their underlying ADHD had been diagnosed. "I wasted over a decade being prescribed antidepressants and anti-anxiety medications that did nothing or made things worse. I haven't been nearly as depressed since starting ADHD medication and I have only had occasional episodes of depression since then. Anxiety is also better with ADHD medication but it took me longer to get it fully under control because I had so many years of trauma from untreated ADHD."

Another reason why girls with ADHD are missed until later in life is that hyperactivity and impulsivity symptoms, seen more in males, present early in life, while the intense emotional reactivity problems, frustration tolerance and mood swings, the more common symptoms in females, increase in severity as estrogen enters the picture. Therefore, the symptoms we see more often in girls with ADHD present less often before the age of seven unless their ADHD is severe. In fact, premenstrual estrogen levels, can create havoc with otherwise regulated ADHD symptoms for adolescent girls and women. (Littman, Girls)

### **Barriers to Females Receiving a Diagnosis and Treatment for ADHD**

Throughout the process of obtaining an assessment and diagnosis, girls and women are at a disadvantage. Despite the fact that girls and women are found to be just as, if not more, impaired and negatively impacted as males, (Biederman, Faraone 2004; O'Callaghan 2014) teachers and parents refer girls for assessment far less often than boys. (NICE 2018) The exact reasons for this are unknown, however it makes sense that the differences in presentation, stated above, may be a contributing factor.

Once a girl or woman is referred to a clinician, these clinicians use rating scales that have been normed using studies with mostly male participants. (NICE 2018) Many of the symptoms listed on even the newest version of the Diagnostic Statistical Manual (DSM) still focus on the more

obvious presentations of ADHD and not the more subtle symptoms seen in girls. (Young et al., 2020) Therefore, many girls with ADHD can score as subthreshold on these rating scales, even though they are significantly suffering from their ADHD symptoms.

A lack of training of medical professionals impacts the diagnosis of girls and women with ADHD in two ways. Firstly, few physicians and other health care providers are trained in ADHD, which results in many girls and women with ADHD being misdiagnosed. Since family physicians and mental health workers are well trained in mood disorders, these girls symptoms look to the untrained eye as the symptoms of the more familiar disorders of anxiety and depression. A third of women in the CADDAC survey who were first misdiagnosed were diagnosed with anxiety, while another third, were misdiagnosed with depression.

Secondly, even when trained in ADHD physicians and psychologists are rarely trained in the unique presentation of females with ADHD. (Chesapeake, Women) They are also unaware of the need to take into consideration the extraordinary effort girls and women make to conform and appear competent. A recent consensus paper geared to medical professionals highlighted the need to weigh collateral information more heavily when assessing females for ADHD. (Young et al., 2020)

Women in the CADDAC survey spoke about the cost that lack of diagnosis meant to their lives. “It is complicated, multifaceted, painful to have this insight at middle age after so many years of struggle thinking there was something deeply wrong with me. No direction, immense self doubt, every decision painted with this brush. Financial problems, binge drinking, eating disorder(s), immense relationship issues and complexities. It was a huge relief to be diagnosed, but came with grief and sadness for so many years of chaos. It has taken a huge toll.”

### **Increased Vulnerabilities for Girls and Women with ADHD**

A series of Canadian studies have found females with ADHD were far more vulnerable than women without ADHD, and had increased risks over males with ADHD, in the areas of physical health, mental health and childhood adversity. (Esme Fuller-Thomson, 2014, 2016, 2020) The 2016 study, looking at data from a 2012 Canadian Community Health Survey, reported that women with ADHD had triple the prevalence of insomnia, chronic pain, suicidal ideation, childhood sexual abuse and generalized anxiety disorder and double the rate of substance use, smoking, depressive disorder, severe poverty, and childhood physical abuse compared to women without ADHD. (Esme Fuller-Thompson 2016) The 2014 study found that only women and not men with ADHD indicated significant increased rates of being exposed to parental domestic abuse during their childhood. The reason for this is unknown. (Esme Fuller-Thomson 2014)

Alarmingly, the 2020 study found that women with ADHD had a lifetime prevalence rate of suicide attempts of 24% as compared to a 3% prevalence rate for women without ADHD. Men with ADHD were also more likely to have attempted suicide compared to men without ADHD, however at far lower rates, (9% vs. 2%, respectively). This study strongly recommended that

increased screening for suicidal ideation as well as suicide prevention strategies should be put in place for women with ADHD. The paper also suggested that current levels of misdiagnosis and delayed or undertreatment of women may be fueling these higher rates of suicide. (Esme Fuller-Thomson 2020)

In addition, females with ADHD incur additional vulnerabilities just because they are female. Teenage girls with ADHD are at greater risk for pregnancy than are other teenage girls (Barkley et al, 2006; Barkley et al., 2008; Flory 2006). Perhaps due to their low self-esteem, poor impulse control, poor planning ability, and inconsistency, many of these girls are prone to have unprotected sex, use birth control inconsistently, and/or have multiple partners. (Chesapeake High School) Females with ADHD also tend to become sexually active earlier than their peers and have increased number of sexual partners resulting in increased rates of sexually transmitted infections. (Young et al., 2020) In later life, perimenopause and menopause may bring on full blown ADHD which has been at a tolerable level or even undetected in the past. (Quinn, Hormones) Several women in the CADDAC survey spoke about these experiences, "I also feel that more research needs to be done on the uniqueness of the condition in women as I have experienced changes in my symptoms according to hormonal changes experienced through puberty, pregnancy and now as someone going through perimenopause."

### **Additional Stress and Suffering for Women with ADHD**

When compared to men, women with ADHD perceive themselves as more impaired, and their experience of negative events as more painful. (Mowlem 2018). Social problems may be particularly impairing for girls with ADHD. As they reach their adolescent years many have difficulty with relationship and social rejection, becoming vulnerable to bullying, including physical and social-relational bullying, and cyberbullying. (Young et al., 2020)

Leading experts in women with ADHD frequently describe the additional complexities for women with ADHD they witness in their clinical practices. Dr. Ellen Littman believes that while women with ADHD have similar symptoms to men they appear to suffer more, possibly due to the internalizing of their symptoms, hormonal fluctuation and society's expectations. She feels that they have greater tendencies towards self-doubt and self-harm. (Littman, Women) The Chesapeake Centre speaks about girls being raised to "internalize", to take in and own negative feedback, to apologize, to accommodate, not to fight back and to take the blame on. (Chesapeake, Women) While Linda Roggli, writes about women with ADHD being more likely to blame themselves for their difficulties, feel lucky if things turn out well and be more likely to struggle with low self-esteem and shame. In general, women with ADHD are more vulnerable to their perceived failures in self-regulation than men. (Roggli, 2021)

## Summary

Due to a lack of awareness and understanding of ADHD in girls and women, as well as the lack of medical training and research in the field of female ADHD, girls and women with ADHD are more likely to be undiagnosed, diagnosed later in life, or misdiagnosed. They therefore remain untreated or treated for an incorrect diagnosis. While this lack of diagnosis and treatment would, in of itself, increase the detrimental effects of ADHD, it is not known why girls and women with ADHD have significantly increased rates of vulnerability to physical and mental health disorders as well as increased childhood adversity. Some possible reasons for this have been suggested, such as the internalizing nature of ADHD seen in women, the impact of socialization on females resulting in their need to fit in and meet expectations and the additional hormonal impact on ADHD symptoms. At this time, we have very little research explaining this phenomenon. We do however know that early diagnosis and multimodal treatments can have a significant impact on the trajectory of the lives of those with ADHD. We also know that there are ways to help rectify the continued under-referral of girls and women for assessment, improve our resources to assess females, use better strategies to mitigate the increased vulnerabilities for women with ADHD and better flag those who may be affected by these risks.

### **CADDAC is asking that the government:**

- increase awareness of ADHD in females through mental health and community health initiatives for the public, educators and medical professionals;
- fund the development and distribution of female specific ADHD screening tools to all medical, educational, employment and justice system professionals; and
- encourage the development of normed rating scales for female ADHD and additional research into the vulnerabilities for females with ADHD through funding opportunities.

### **CADDAC is asking the medical community to:**

- encourage all general practitioners and mental health providers to screen for female ADHD whenever any comorbid condition is being considered;
- provide training for medical professionals on female ADHD assessment, diagnosis and treatment and the need for screening of suicidal ideation and treatment; and
- encourage research into the added vulnerabilities for females with ADHD, normed rating scales for females, why co-existing mental health disorders drastically interfere with the diagnosis of ADHD in women, how hormonal fluctuations impact women with ADHD and the best way to disseminate this research to all medical professionals.



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