A Call to Action

The Majority of Women with ADHD are Being Left Behind by the Health System

It is Imperative that we address the lack of health services and support that is affecting women's health, family life and careers. *Take the Survey now....*Subject: https://forms.office.com/r/dqeCmgrtjy

ADHD Foundation Neurodiversity Charity

50 to 75% of the 1 million Women in the UK with ADHD are undiagnosed and may be experiencing unnecessary poor health and socioeconomic outcomes. Only an estimated 75,000 women out of an estimated 1 million women aged 18-65 with ADHD in the UK are accessing health care. This is despite many health issues continuing into adulthood, including anxiety, depression, obesity and eating disorders, employment and family life. 2021

7 Recommendations – A Call to Action

- 1. Increase capacity within the NHS to improve access to assessment, diagnosis and treatment for those who need it within 18 weeks from point of referral across the UK. This includes considering ADHD as a potential root cause for challenges such as mental health issues, eating disorders and unhealthy lifestyles.
- 2. Introduce minimum standard protocols for private providers of ADHD diagnosis and treatment so that shared care agreements enable those with a private diagnosis to be treated by their local NHS ADHD services.
- 3. A parliamentary debate and enquiry to investigate the variations and inconsistency of health provision for ADHD and specifically the health inequalities experienced by girls and women with ADHD.
- 4. NHS Digital to initiate the capture of data on diagnosis and research to identify how many girls and women are diagnosed, accessing treatment and how many have been misdiagnosed and incorrectly treated to inform future services that more accurately meet the Health needs of the estimated 750,000 women and 423,000 girls with ADHD.
- 5. Initiate a training programme for schools and early years providers to ensure early identification, referrals to clinical assessments that are not hindered by pre referral assessments that only measure impact on education, rather than both health and education.
- 6. Schools, colleges and Universities collaborate with other professionals to ensure early identification and intervention to reduce the need for health care services (e.g., Diabetes, cardiovascular disease, mental health issues) in adulthood and thus also improve the education and economic outcomes for girls and women.
- 7. Enlist the Royal Colleges and British Medical Association in ensuring that ADHD and its common presentation in women forms part of the medical training curriculum for all health care professionals, including General Psychiatry, GP's, Health Visitors and School Nurses, in line with the national autism strategy.

Angela Barnes

 There were so many years of being misdiagnosed and treated for anxiety and depression...

 "Finally, being diagnosed with ADHD made me realise that having ADHD wasn't the problem - it was not knowing I had ADHD that was the problem."



Statement by The ADHD Foundation Neurodiversity Charity on behalf of women

The majority of women with ADHD are being left behind. The scientific evidence relating to the impact of undiagnosed, untreated ADHD on physical health, psychological health, employment and economic independence is unequivocal. It is imperative that we address the lack of health services and support that is affecting women's health, family life and careers now.

The social and economic impact of undiagnosed untreated ADHD is currently immeasurable but likely to be very significant. Accurate data from NHS on the number of girls and women who are diagnosed – and accessing treatment and those who are misdiagnosed is critical. We must address this systemic bias so that women & girls can get the support they need when it can have its biggest impact.

Zina Alfa

• "I was diagnosed last year with ADHD, and it was a huge relief.
Although I was 27 when formally diagnosed, I sometimes wonder to myself why this wasn't picked up earlier?"



The evidence women with ADHD are being left behind

- Research suggests that women with ADHD are significantly underdiagnosed in the UK [1].
- Women with ADHD present with symptoms that are different from men and because of this, they are frequently missed or misdiagnosed with other health conditions and given the wrong treatment [2, 3].
- There is genetic overlap between ADHD and Autism which is widely misunderstood by health care professionals in the UK, creating greater challenges to girls and women with dual presentation of ADHD & Autism [4].
- World Federation of ADHD Consensus statement 2021 states the prevalence of ADHD is 5.8% (World Health Organisation states Global Prevalence is 5.26%) or 847,000 of the 14.6 million children & young women aged under 18 in the UK children. Some research suggests childhood prevalence in the UK is 7.1%.
- In adulthood the NHS data implies that only 2.9% 1.5 million UK citizens with ADHD will continue to experience significant impairments across the lifespan, but with current trends showing we are diagnosing as many men as we are women [1].
- NHS data suggests that less than only 1% 200,000 adults with ADHD out of 2 million are what NHS describe as 'still symptomatic' and accessing health care for ADHD. ADHD is however a lifespan condition and the exact number of adults with ADHD accessing care is not known.
- The majority of under 18's diagnosed are male who are three times more likely to be diagnosed and treated than women [5,6].

We diagnose and support three times as many boys as we do girls...

...with serious implications for their education, careers, economic independence, and their mental and physical health.

ADHD affects 5.26% to 5.8% of the population according to the World Health Organisation. Out of 14.6 million UK children under 18 years, it is estimated that 423,000 girls in the UK under age 18 have ADHD but are three times less likely than boys to be diagnosed and supported [1, 5].

Girls who are diagnosed tend to be diagnosed by 17 years of age – on average 9 years later than boys, resulting in underachievement in education and increased risk of mental health problems.

We diagnose as many adult women as we do males, suggesting girls and young women are neglected by health services and in adulthood misdiagnosed and incorrectly treated for other conditions. This is both a waste of health care resources and a source of additional costs arising out of educational underachievement and socio economic outcomes for women [1].

The Evidence – Why women with ADHD are less likely to be identified and supported.

- Females present with both the <u>hyperactive</u> and <u>non hyperactive inattentive type</u> of ADHD and therefore more likely to be overlooked in childhood because they are not noticed as much as hyperactive boys [7, 8].
- Masking happens: Young females mature sooner than males and are therefore better able to mask their emotional dysregulation, poor concentration and memory and impulsivity [1, 9].
- They are more likely to be perceived in childhood and adolescence as overly talkative, daydreamers and behaviourally compliant. Cultural misrepresentations of ADHD may prevent girls and women from self identifying as having ADHD due to historic stigmatising stereotypes about boys with ADHD [1].
- There is a lack of awareness and training for health professionals including in general psychiatry, about ADHD and its impact on physical and psychological health. This is true for both males and females but especially females who are more likely to be identified late or misdiagnosed and given the wrong medical treatment [2, 3, 10].

The changing perceptions of women with ADHD...

"Being diagnosed with ADHD at 35 has transformed my life. Getting the diagnosis has allowed me to get the right support at work and to make peace with a part of myself I spent years trying to hide. The damage ADHD causes does not come from the condition itself, which can be managed quite easily, but from a lack of proper treatment and diagnosis. Left untreated, ADHD can destroy lives."

Kate Lister – University Lecturer, Author and Journalist



The evidence of late diagnosis of girls

- Adult studies report similar numbers of men and women are now being diagnosed with ADHD in the UK [11].
- While ADHD under-diagnosis does also affect boys, it is especially a concern in girls. When recognised ADHD tends to be diagnosed on average later in girls than in boys: ADHD diagnosis peaks at age 8 in boys and age 17 in girls.
- This suggests that there is a delay as well as failure to recognise ADHD in girls with significant implications for their education, physical and psychological health.
- Research evidence is influenced by gender bias due to males being 3 to 4 times as likely to be diagnosed and treated in childhood [1].



Jennifer Barton

Journalist

- "As someone who loves words, I can remember all too clearly the ones used to describe me throughout my life. Dreamy. Intense. Energetic. Forgetful. "Always late." Creative. Chaotic. Hypersensitive. Hysterical. Lost. Disorganised. Impulsive. Messy. Moody. Talkative. Loud. "A total ditz." Some of these descriptors stung – and still do. Others I wear with pride. These words, both positive and negative, have helped shape my understanding of my personality. Assemble them and they reflect more than simple personality quirks: these words and phrases make up the elaborate jigsaw puzzle of my mind. They're emotions I've known to be my reality across a lifetime.
- Only recently did they start to make sense as something else: a diagnosis. I'm neurodivergent; I have ADHD and I've only just found out, at the age of 39. I've always felt different, out of place, like I'm inhabiting my own separate planet... now I have proof that this is indeed the case. Simply knowing this has given me some power of it. I know what I am dealing with now."



The consequences of late diagnosis for girls and women

- Many girls meet the criteria for Mental Health problems, which can be more confusing for untrained clinicians who do not understand ADHD.
- With Combined Type ADHD in girls, there are higher rates of mental health problems and self harm [12].
- Interviews with girls with ADHD show that they perceive difficulties as personality traits, leading to increased risk of low self esteem, self blame, anxiety and internalising [13].
- Given the genetic overlap and prevalence of co=occurrence in symptomology, girls with a diagnosis of Autism should also be considered and screened for ADHD.
- Research suggests an increase in symptoms during puberty [14].
- Undiagnosed, untreated ADHD in women and girls increases the risk of failing in education, resulting in reduced employability and economic independence and prosperity.

The consequences of late diagnosis for girls and women

Undiagnosed, untreated ADHD in women and girls increases the risk of:

- Post partum depression
- Difficulties with low mood and emotional regulation are more common and more severe in girls and women with ADHD
- More vulnerable to bullying and social isolation
- Greater risk of unplanned pregnancy
- Hospitalisation for mental health problems
- Hormonal fluctuations resulting in reduced cognitive functioning and emotional dysregulation during menstrual cycle and menopause

"When asked by women about seeking diagnosis, I can't recommend the NHS because of the waiting time of up to 5 years. I, myself, a well-educated middle class professional, found three years' delay and countless referrals to general psychiatrists and ADHD nurses difficult to navigate. The Adult ADHD services to which I was referred now no longer exists — so no doubt sufferers would have to travel further to find help on the NHS. Meanwhile private diagnoses are not always accepted by NHS Trusts so women are may not be able to afford to pay for their medication.

Treatment when it comes is transformative. I would not have been able to retrain as a secondary school teacher, aged 52, without medication and the additional learning support offered by my university. I have been working in the classroom for four years now and I see girls with undiagnosed ADHD every day, with little hope of getting help for it when it is still seen as a "boys' problem", and only a 1/3rd of girls compared to boys will have a diagnosis.

In 16 schools and dozens of classrooms that I have taught in over the past 5 years, I have only seen two female pupils on my register with a formal diagnosis, where teachers are obliged to differentiate and the school to support them. This is for a condition that affects one in 20 children, one in every class. Instead the girls are simply removed from classes and stuck in "Reflection rooms" often for days at a time, or written off by Senior Leaders as "naughty" or "chatterboxes" without any knowledge of underlying causes. It's a shocking waste of potential, because many of these adolescents are the brightest in the class, and because ADHD does not affect intelligence – just learning ability, and a diagnosis could mean a brighter academic future.

For adult women, the misdiagnosis and wrong treatment for other conditions such as bipolar disorder, depression and anxiety shows partly the complexity of the problem as it continues into adult life undiagnosed. It also shows the ignorance of general psychiatry, where it should be firmly on the curriculum. No other mental health issue can be treated so successfully as ADHD, and offer the potential to transform women's lives for the better. That it is so woefully overlooked is a travesty".



Catherine Millan

Works as a Participation Co-ordinator at Manchester University

"I always knew I struggled with some things at school and because I was a 'good student' and the School 'Head Girl', the idea that there was something 'wrong' with me never occurred to me or my teachers. I was just told repeatedly to 'try harder' as my exam results never reflected my predicted grades.

I have learned to play to my strengths at work and used strategies to compensate for my poor concentration, planning and organising skills. I have a very healthy lifestyle, but despite this, I always felt constantly tired, worrying and experiencing constant low mood. It was my Line Manager who told me to get assessed for ADHD and dyslexia which often occur together. Being diagnosed at 33, was actually a relief. I know what I am dealing with now, in one sense I have always known, but I just couldn't identify with the stereotype of the fidgety disruptive child and learning how to deal with it more effectively."



Appendices



What is ADHD?

World Federation for ADHD Guide 2019: https://www.adhdfoundation.org.uk/wp-content/uploads/2019/06/The-World-Fedaration-of-ADHD-Guide-2019.pdf

ADHD is a neurodevelopmental condition comprising of three main diagnostic criteria: Hyperactivity, Inattention & Impulsivity.

These characteristics occur naturally in all human beings, especially in childhood when the brain is underdeveloped. For a diagnosis of ADHD, these naturally occurring behavioural presentations must appear in a more extreme form to such an extent that they impair daily functioning. Competencies required of children at a prescribed chronological age are especially difficult for children with ADHD in a classroom context. The inability to learn in a certain way and at a required level of progress is often misunderstood and children can be wrongly labelled as lazy or badly behaved for not doing as they are instructed. The confusion arises because adults do not know whether the child is choosing not to follow instructions, or because they are not able to process the information and reason appropriately. The developmental delay can present as 'immaturity' which has also led to ADHD being misrepresented as a 'behavioural disorder' when in fact it is a neurodevelopmental condition affecting brain function, which in children will inevitably be expressed behaviourally in the form of low frustration tolerance, emotional dysregulation, poor concentration, low inhibitory control and in some, hyperactivity.

ADHD is a lifespan condition, however as the brain reaches maturity in early twenties, most people will have learned strategies to manage the impairments they experience and chosen lifestyles and careers that support their well being and socio-economic goals. Many people however, continue to struggle with ADHD, requiring medical and psychological support.

ADHD is genetic in origin, though in rare cases, it can be caused by traumatic brain injury. Genetic potential for ADHD may also be triggered by pre term birth. ADHD frequently co-occurs with autism, dyslexia, developmental co-ordination disorder (dyspraxia) Tourette's, Tics, dyscalculia and sensory processing disorder. ADHD is also known to correlate with other physical health conditions such as migraines, allergies and inflammatory conditions.

Undiagnosed, unmanaged ADHD can increase the risk of anxiety, depression, eating disorders, obesity, PTSD, OCD, addictions and other mental health concerns. Well managed, those with ADHD can and do lead healthy, successful lives.

Women experience unique impairments related to ADHD, internalisation of anxiety resulting in more susceptibility to depression, greater emotional dysregulation at certain points in the menstrual cycle and difficulties with cognitive impairment during menopause. [15]

What is ADHD?

A neurodevelopmental condition that delays development in some brain functions until late teens Inattention

Impulsivity

Emotional
Dysregulation
– inhibitory
control

What is ADHD?

3 Subtypes Inattentive Hyperactive impulsive Combined Hyperactivity physical and psychological

ADHDT FOUNDATION The Neurodiversity Charity

Memory impairment (Working memory) Executive Functioning skills- including planning, organising, time management &

Women and ADHD

An article by:

Professor Amanda Kirby MRCGP MBBS PhD

Professor Emeritus Cardiff University Chair of ADHD Foundation Neurodiversity Charity and CEO of Do-IT Solutions Ltd.



I am very interested in this topic as ADHD with a number of family members with diagnoses. Despite having a number of ADHD traits myself this was not considered as a child at all. I was fidgety, a doodler, but not disruptive. I was chatty, enthusiastic, and impulsively volunteered to help with everything. I was anxious and a ruminator and had a 'busy brain' that often ended up trying lots of different hobbies because I was curious but gave them up if they bored me. I also seemed to work much harder than others to achieve what others seemed to do with less effort. As a student, I put in endless hours when others were 'playing'. I look back and think now was that about inefficiency, or uncertainty about being good enough? I have always had 'imposter syndrome' and never really believing I was good enough even when I won awards from others... I always thought it was not for me! I never thought that I had ADHD.... till in my 60s... despite diagnosing and recognizing it in others.

Adults talk about feelings of 'inner restlessness', and I find this is very real for me. I find it very hard to do one thing only. If I am listening to a lecture, I need to make notes or doodle at the same time. If I am watching TV, I often do something else at the same time like being on my laptop writing something while listening to it in the background. The thought of sitting still doing only one thing is hard for me. I think this is why I prefer to be lecturing as I am the one doing something and can move around. As the chair of the ADHD Foundation, I feel passionate about raising awareness of ADHD and neurodiversity in all sectors of society but especially in females as so many girls have been completely missed in childhood. Many of us are emerging now at different stages of our lives, and some are looking back and thinking how much easier could it have been if I had known...

What is it all about?

The term neurodiversity recognizes diverse and varying brains and it is becoming associated with both positive traits and characteristics associated in some people with Dyslexia, Dyscalculia, Attention Deficit Hyperactivity Disorder (ADHD), autism spectrum disorder/condition (ASD/C), Developmental Coordination Disorder/Dyspraxia, and Developmental Language Disorder as well as specific challenges that some people may have.

Increasing awareness of neurodiversity means there are females self-diagnosing one or more conditions in adulthood. But there are many girls and females who still haven't had their support needs recognized and continue to have challenges in day-to-day life. For some arriving at adulthood, it can mean having years of constant feelings of anxiety and for many being or having been depressed. Cycles of burnout, with challenges with sleep, may have been their norm. Their diagnosis was missed altogether or considered as something else.

Past challenges can result in difficulties progressing in education and socially. It can include a sense of never quite fitting in. I have had many females feel both relieved and at the same time angry at gaining a diagnosis in adulthood. Some are frustrated at not achieving what they see now as their potential. Sadly, some end up with lower-level qualifications despite having wasted talents. Even sadder are some females who end up in the justice system have been both misunderstood and misdiagnosed.

Estimates for childhood ADHD range between 3% and 7%. The pathway to adulthood does not appear to be different in males or females with ADHD. A recent review has shown that about 80% of children continue to experience challenges that can impact on day to day functioning. Importantly, research on gender differences in ADHD increasingly suggests that girls may be consistently under-identified and underdiagnosed.

This has mostly been explained by some differences in the way challenges and strengths are present in females compared to males. Females (in general) with ADHD have been reported to have fewer hyperactive/impulsive symptoms and more inattentive symptoms when compared with males with ADHD. They are less likely to be disruptive and so fade somewhat into the background and so not necessarily noticed as being a 'nuisance' to others.

If they are disruptive then this may be associated with other factors in their life and ADHD not even considered. Lack of knowledge by teachers and health professionals about the presentation in females means they can be missed altogether till adulthood. Sciutto, Nolfi, and Bluhm(2004) found that teachers more often refer more boys than girls for treatment for ADHD, even when showing equal levels of impairment.

A major contributing factor to late or missed diagnoses of ADHD in females appears to be the presence of coexisting symptoms that often cloud or overshadow the diagnostic picture. As many as 75% of children with ADHD are likely to have at least one other mental health condition. In general, boys with ADHD have been found to have more externalizing disorders (noticed by others) than while females tend to show more internalizing disorders (not seen always by others) in comparison to girls without ADHD. Low mood, emotional lability, and anxiety may be especially common in females with ADHD. Substance misuse may be problematic for some people with ADHD. This often means other conditions are diagnosed before ADHD is considered.

Females who get diagnosed with ADHD generally have to be **more** <u>symptomatic than their male counterparts.</u> This means they need to have a greater impact on day-to-day life before being recognized or considered as potentially having ADHD. Often females get diagnosed because someone else in their family has a diagnosis of ADHD such as their child.

Some ADHD signs and the impacts for females

(Note: not everyone has everything and this list is not exhaustive. Some of these signs may be associated with other conditions too - this is why it is helpful to be professionally diagnosed).

- 1. Starting something and not finishing it and then feeling bad because of this
- 2. Working much harder to achieve because not sure of how hard you need to work ... burn out cycles
- 3. Chatty, enthusiastic, overly engaged (and then not!)
- 4. Losing your day drifting off down a rabbit hole of interest- seen sometimes as 'daydreaming'.
- 5. Distracted by other people's conversations around you and drifting off when talking to someone unless the topic is of high interest and then fully engaged.
- 6. Impulsive (enthusiastic) decision making saying yes before saying no and then regretting it because of too many yes's
- 7. Not being able to sit still/stay quiet for long/fidgety/toe-tapping/doodling/hair twirling
- 8. Sleep disturbance, busy brain, and rumination and feelings of disappointment when it hasn't gone right (again). Feeling anxious.

- 9. Losing possessions even though you are sure you put them in one place, disorganised.
- 10. Loads of information/knowledge... but a brain that has an inconsistent filing system.
- 11. Poorer concepts of time passing
- 12. Other people's perceptions of you thinking that you are less capable than you really are or overly direct or rude because of interrupting (I often find it hard to stay quiet for long!).
- 13. Compensating to camouflage by working even harder to cover up mistakes/driving anxiety and obsessional actions to do so putting the pressure on yourself.
- 14. Prevarication ends up with you doing the things you like doing and avoiding the tedious things we still all have to do as much as possible even though we know they often won't take us long in reality.
- 15. The impact for females may result in having greater social problems in school and it may result in having been more vulnerable to bullying, including physical and social-relational bullying, and cyberbullying.
- 16. Like males, there is an increased school dropout, academic under-achievement, and more accidents with females. Not surprisingly there is an impact on self-esteem and self-concept.

Living with ADHD

The challenge for many females who have not been diagnosed is they may have learned a whole range of (not always positive) compensatory strategies such as using alcohol or cannabis to slow them down. Social interaction may be achieved with higher-risk activities. Coping strategies may be less overtly noticed, such as avoiding specific events, settings, or people, not facing up to problems, spending too much time online, or not seeking out help when needed. Women with ADHD may experience challenges in the workplace, such as disorganization, inattention, difficulty accepting constructive criticism and appraisal, and difficulties managing interpersonal relationships with colleagues. Working longer hours (but often hidden from others) to complete tasks because of time management/focus challenges can also be exhausting. Cycles of burnout may also be more common but may not be recognized or seen as something else.

We start to see increasing numbers of highly skilled females with ADHD talking about what it is like for them. Some of them are entrepreneurs using their vision of pulling things together, commitment, and passion to be successful. It will be interesting to understand more the factors at play that resulted in being more resilient and successful and what differentiates these females so we can help all with ADHD to be their personal best.

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NICE Guidelines for ADHD & Useful links

NICE Guidelines 2018 on the diagnostic criteria and treatment of ADHD in

England and Wales https://www.nice.org.uk/guidance/ng87

Scotland SIGN Guidelines for ADHD https://www.sign.ac.uk/assets/sign112.pdf

Patients Guide to NICE Guidelines: https://www.adhdfoundation.org.uk/wp-content/uploads/2019/01/ADHD-NICE-Guidelines-Patient-Booklet.pdf

http://adhd-institute.com/assessment-diagnosis/diagnosis/dsm-5/

https://www.icd10data.com/ICD10CM/Codes/F01-F99/F90-F98/F90-/F90.9

UK National Consensus Statement on Women and ADHD https://adhdfoundation.org.uk/wp-content/uploads/2021/06/ADHD-Female-consensus-2020.pdf

Failure of health care provision for people with ADHD in the UK Journal Frontiers in Psychiatry <a href="https://www.frontiersin.org/articles/10.3389/fpsyt.2021.649399/full?&utm_source=Email_to_auth_ors_&utm_medium=Email&utm_content=T1_11.5e1_author&utm_campaign=Email_publication&fie_Id=&journalName=Frontiers_in_Psychiatry&id=649399

Will The Doctor See Me Now 2019 Report on Capacity within NHS for the Treatment of Adults with ADHD. https://adhdfoundation.org.uk/wp-content/uploads/2019/07/Will-the-doctor-see-me-now-Investigating-adult-ADHD-services-in-England-v2.0-1.pdf

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