



# WOMEN AND GIRLS WITH ASD AND ADHD UNDER-IDENTIFIED, UNDER-DIAGNOSED AND UNDER-SUPPORTED

Resolution Shortlist Briefing Notes



## **Women and Girls with ASD & ADHD Under-identified, Under-diagnosed, Misdiagnosed, Under-Supported**

***Women and girls presenting with autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) are going undiagnosed. The NFWI calls on the government and funding bodies to fund research into the female presentation of ASD and ADHD, and for action to be taken to improve the diagnosis process for women and girls, to ensure that they are equipped to better manage these conditions and do not suffer in silence. The NFWI further calls on WI members to raise awareness within their WIs of the issues facing women and girls with ASD and ADHD.***

### **Proposer's position**

The proposer wants the Government and leading professionals to ring-fence funding for research into female presentation of ASD (autistic spectrum disorder) and ADHD (attention deficit hyperactivity disorder). The proposer also calls for age and gender appropriate diagnostic tools to be developed, training of healthcare and other professionals, and awareness-raising within WIs.

### **The scale of the problem**

Autistic Spectrum Disorder (ASD) is the medical name for autism. Autism is a lifelong developmental disability which affects how people communicate and interact with the world.

Attention Deficit Hyperactivity Disorder (ADHD) is a condition that affects people's behaviour.

Although the main components of ASD and ADHD are different, they can share some of the same symptoms and presenting issues.

People with ADHD can seem restless, may have trouble concentrating and may act on impulse. The symptoms of ADHD usually improve with age, but many adults who were diagnosed with the condition at a young age continue to experience problems. People with ADHD may also have additional problems such as sleep and anxiety disorders.

ASD can cause social, communication and behavioural challenges. According to NHS England, autistic people may find it hard to communicate and interact with other people, may find it hard to understand how other people think or feel, may find things like bright lights or loud noises overwhelming, stressful or uncomfortable, may get anxious or upset about unfamiliar situations and social events, may take longer to understand information or may have repetitive patterns of thinking or behaviour.

Historically ASD and ADHD have been recognised as mainly affecting men and boys resulting in women and girls being overlooked or misdiagnosed. According to the National

Autistic Society, men and boys are three times more likely than women and girls to be diagnosed as autistic.

ADHD can present differently in girls. Boys are more often described as 'hyperactive' while girls are more often described as 'inattentive' or as a combination of inattentive and hyperactive. Women and girls are often better at masking or camouflaging their difficulties. In general, they engage in more "internalizing" behaviour than boys, meaning they tend to take their problems out on themselves rather than others.

According to the National Autistic Society's Centre for Autism, professionals often don't recognise and understand the different ways autism can manifest in women and girls. Neurodevelopmental specialists and clinical psychologists highlight that ADHD symptoms in women can often be misunderstood and misdiagnosed by medical professionals, mistaking them for stress, anxiety, or another related condition.

## The current situation

According to Autistica, the amount of money UK funding organisations invested in UK autism research tripled from 2013 to 2016, shifting the investment per autistic person from £5 to £15.

In July 2021, the UK Government launched its 5 year autism strategy for England. The Strategy includes a commitment to improve public understanding of how autism can affect people differently, including the difference in how autistic women and girls present. This is the only reference to women and girls throughout the Strategy. The Strategy also commits to develop a research action plan during the first year of the strategy to identify research priorities for the next 5 years.

However, the National Autistic Society has raised concern that the 2021 Spending Review did not set out how the autism strategy will be funded beyond its first year.

The need for further investment in autism research has continued to be highlighted. In November 2021, Robert Buckland QC MP led a debate on funding for autism and neurodiversity research in the House of Commons in which he called for a 'sea change' in how autism is diagnosed and treated.

During the debate, the Minister for Care and Mental Health, Gillian Keegan, said that one of the challenges is that there are gaps in knowledge about what services and support work best for people. She went on to say, 'we need better evidence about the effects of masking and under-diagnosis of autism for women and girls'.

Research is currently underway to improve the autism diagnosis process for children, following a commitment in the 2019 NHS Long Term Plan to test and implement the most effective ways to reduce waiting times for specialist services. The Autism Diagnosis Pathway Study, led by Sussex Community NHS Foundation Trust, aims to find models to achieve this.

According to Autistica, the hope is that this study will inform updates of the existing NICE guidelines for autism diagnosis.

As part of wider work to improve the diagnosis pathway, the Minister for Children and Families, Will Quince, said in December 2021 that NHS England/Improvement is looking at ways to improve the quality of diagnosis for girls.

### How could the WI work on this issue if it was passed?

A full campaign would be developed by the NFWI if the resolution is passed, taking into account developments since then. To help inform your discussions, here are some ways the WI could consider working on this issue.

**At local and regional levels**, WIs and federations could learn about ASD and ADHD and consider how they can be inclusive to women with these conditions. WI members could also explore local volunteering opportunities with specialist charities, and look into waiting times for diagnosis in their areas.

**Nationally**, the NFWI could engage with specialist organisations that provide expert advice or support in relation to ASD and ADHD diagnoses in women and girls and contribute to existing awareness raising initiatives.

The NFWI could also call on public health bodies to run enhanced public information campaigns focussed on the signs of ASD and ADHD in women and girls.

The NFWI could also campaign for further research into ASD and ADHD in women and girls.

### Points to consider:

- This is a gender equality issue and would align well with our broader campaign and organisational work in this area, as well as our focus on inclusivity as part of our strategic vision.
- WI members are well-connected in their communities, and could use their existing networks to reach more people with the key messages on this issue.
- The resolution covers ASD and ADHD which are both neurological, but they are different conditions. Would a WI campaign targeted a single condition be more effective, or could this be an opportunity to draw attention to two important issues?

## Further information

**NHS:** [www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/](http://www.nhs.uk/conditions/attention-deficit-hyperactivity-disorder-adhd/)

**NHS:** [www.nhs.uk/conditions/autism/signs/](http://www.nhs.uk/conditions/autism/signs/)

**Autistica-** [www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Diagnosing-Autistic-Women-And-Girls.pdf](http://www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Diagnosing-Autistic-Women-And-Girls.pdf)

**BBC Futures-** [www.bbc.com/future/article/20190530-why-is-adhd-missed-in-girls](http://www.bbc.com/future/article/20190530-why-is-adhd-missed-in-girls)

## Video content

**ADHD in Women and Girls- Misconceptions:**

[www.youtube.com/watch?v=Ls3djLqwLhA](http://www.youtube.com/watch?v=Ls3djLqwLhA)

## Public Affairs Department Contacts

If you have any questions about the resolutions or the resolutions process then please get in touch with the NFWI Public Affairs department.

**Post:** National Federation of Women's Institutes, 104 New Kings Road, London, SW6 4LY

**Telephone:** 020 7371 9300

**Email:** [publicaffairs@nfwl.org.uk](mailto:publicaffairs@nfwl.org.uk)

**Website:** [thewi.org.uk](http://thewi.org.uk)