Autistica Action Briefing: Diagnosing Autistic Women and Girls

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about diagnosing autistic women and girls. It was developed in collaboration with leading researchers and autistic women as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. We know that autistic women and girls have faced diagnostic bias; diagnostic services and public policy need to ensure parity.

www.autistica.org.uk/AutismStrategy

"My GP did not believe women could 'get' autism." [1]

What we know

"Unfortunately, the stereotype is males that speak in a monotone voice and are obsessed with trains or machinery, and this needs to change." [1]

- **Thousands of autistic women and girls in the UK may be undiagnosed and overlooked.** Autism appears to be more common in males than females[2] with a recent meta-analysis estimating that the ratio is about 3:1.[3] Recent biological research has pointed towards reasons why this might be the case.[4] However, estimates of this gender gap have closed significantly over time.[4] Smaller differences in the number of men and women have been found in autistic adults,[5] suggesting that autistic women are more likely to grow up undiagnosed.[3] The gender gap also appears narrower amongst autistic people with learning disabilities,[6] which suggests more women without a learning disability are being missed.

- **Women and girls tend to be diagnosed later**[7,8] **and are less likely to receive a diagnosis than men and boys with similar levels of autistic traits.**[4,9] Research suggests autistic girls 'fly under the radar' unless they have additional difficulties.[10] Some studies have found gender-based differences in scores on commonly used autism diagnostic measures.[11,12,13] This may be due to bias in the design and/or application of these tools.[4,14]

- **Stereotypes can prevent autistic women and girls from receiving a diagnosis.** Presentations of autistic traits that are more common in women and girls[11,15] may not always be recognised by professionals.[16] Autistic women frequently report having their concerns dismissed due to misconceptions that autism is a "male" condition, that the abilities and interests of autistic people are the same between genders and that women and girls are stereotypically "quiet" and "shy".[1,15,16,17]

- **Women and girls who 'camouflage' autistic traits face further delays in diagnosis.** Research is beginning to understand that many autistic people may consciously or unconsciously mask their differences to seek acceptance, which can impact their mental health.[16,17,18] On average, autistic women and girls are more likely than autistic men and boys to camouflage, in part due to gendered cultural expectations.[4,19] One study found that while autistic people across all genders report camouflaging, autistic women were much more likely to report being denied a diagnosis on that basis.[18]

- **Autistic women and girls may be misdiagnosed with mental health conditions.**[16,20,21,22] Autism is not a mental health condition, but autistic people often do experience mental health issues and some autistic traits can be mistaken for symptoms of mental ill-health.[20] Diagnostic tools can be ineffective at accounting for these distinctions.[23]

- **Autistic women and girls face serious health inequalities.** Autistic women with a learning disability are among those at highest risk of early death in the autistic community.[24,25] Autistic women are also markedly more likely to die by suicide than non-autistic women,[24,25,26] and report lower quality of life than their male peers.[27] Initial evidence suggests that autistic women are at greater risk of abuse.[28,29,30] Investing in diagnosis could help deploy resources more effectively towards supporting those women throughout their lives.

What we need to find out

"I was misdiagnosed with mental health conditions from my early teens to my forties."[1]

Historically, autism research disproportionately focused on men and boys.[31] **We now know that many autistic women and girls went undiagnosed in the past and continue to be missed today.** Adult diagnosis is a particular research priority for the autism community,[32] and is especially significant for the many women who grew up without a diagnosis.[7,8] To ensure better recognition of autistic women and girls in future, research now needs to consider:

- Are existing diagnostic tools as sensitive to autistic traits in women compared to autistic men?

- What patterns of prior diagnosis (or misdiagnosis) are common in autistic women? Are those patterns different in men? What other characteristics or experiences are common in women and girls before receiving an autism diagnosis?

- What is the role of camouflaging in the delayed or missed diagnosis of autistic women and girls?

- Are there significant differences in wellbeing between autistic women diagnosed in childhood and those diagnosed in adulthood?

- What are the perceptions of GPs and other health professionals about autism in women and girls? To what extent does unconscious bias affect the time taken for women and girls to access diagnostic assessment?

- How can education and health professionals become more proficient at identifying possible signs of autism in girls and young women, and effectively co-ordinate assessment and support? How can clinical teams gain the skills needed to make timely valid diagnoses?

What we should do now

"Daughter was refused a diagnosis as a child because 'girls don't get autism'. Now she's trying for adult diagnosis but was told it will not help her and she does not need it." [1]

- The *"priority challenges for action"* underpinning the most recent Adult Autism Strategy in 2014[33] included: *"I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process."*[34] This should be just as true for women as for men.

> **The Department of Health and Social Care's new Strategy[35] should address the specific challenges women and girls face in autism diagnostic pathways.**

- The Long Term Plan made autism an NHS clinical priority[36] but it did not specify how adult diagnosis would be improved or how gender inequalities around autism would be addressed.[37] Improving adult diagnosis is an important step in tackling health inequalities,[38] particularly for women who tend to be diagnosed later in life than men.[7,8]

> **The NHS Long Term Plan workstream on autism should consider ways to remove barriers to diagnosis for autistic women, as part of wider work to tackle unwarranted variation in adult diagnostic pathways.**

- Women and girls often present in eating disorder or other mental health services before receiving an autism diagnosis.[39]

> **NHS England should consider auditing identified autistic women and girls in eating disorder and inpatient mental health settings to establish whether there were missed opportunities to intervene earlier, had autism been considered.**

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