

Raising the Voices of AuDHD Women and Girls: Exploring the co-occurring conditions of autism and ADHD

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This is a Current Issue because neurodivergent women and girls have been left behind, missed by the medical profession for decades. ADHD and autism have historically been considered to be male conditions, with diagnosis being 4 times more likely for males than females. The tides are changing with more women becoming aware of, diagnosed with, and seeking a diagnosis of conditions such as ADHD and autism. The media response to this surge in diagnoses has often been disparaging, although attempts to widen awareness exist (including recent BBC documentary *Unmasking My Autism*). However, women face long waiting lists, a lack of pre- and post-diagnosis support, sex biases in diagnostic criteria, and are left to deal with the trauma of a lifetime of misdiagnoses, poor mental health, and internalisation of negative messages about their character, alone. This piece explores two issues; the gendered omission of women and girls from autism and ADHD diagnoses and the theoretical and practical implications of the co-occurring conditions. When I refer to gender, I am referring to the social structure of gender which produces shared meanings about gendered behaviours, norms, roles, relations and institutions.

The neurodiversity movement asserts that difference is a naturally occurring feature of humanity and that all individuals are equal, although they might not be treated as such. It seeks to move away from a deficits-based model that positions those with neurological differences as 'abnormal' in contrast to the 'norm' – those without neurological conditions. Individuals with such differences are 'neurodivergent' (note – an individual can be neurodivergent while a group is neurodiverse) and the neuro-majority are 'neurotypical'.

Neurodivergent individuals are a neuro-minority in the general population, and thus face structural barriers living in a world designed by and for neurotypicals. These barriers are compounded by gendered structures of oppression (as well as classed and racialised, which is important to remember, along with how these axes intersect, although the focus here is on gender).

The neurodiversity umbrella covers all forms of neurological difference including mental health conditions, Tourette's, ADHD, autism, personality 'disorders', among others. Despite this, focus has tended to be on autism (which is perhaps to be expected given that the emergence of the neurodiversity movement was closely linked to the autism movement) and, increasingly, ADHD.

Autism and ADHD are most often treated separately, despite the high likelihood of their co-occurrence. It is estimated that 30-80% of individuals with ADHD are also autistic. Yet, assessments and services are conducted in isolation, with no consideration of the intersection of conditions, or of wider intersections of sex, ethnicity, class, age, and disability, that impact on individuals' experiences. Similarly, research, conferences, and events tend to focus on autism **or** ADHD.

In part, this omission can be explained by the fact that it has only been 10 years (since 2013) that a combined diagnosis has been possible, due to the diagnostic criteria. The lack of

adequate descriptive language reflects this; should I refer to ‘a person with autism and ADHD’? This option is problematic as it ignores the majority’s preference for identity-first language. Perhaps, ‘an autistic person with ADHD’? This is also problematic as it forefronts autism as part of the person while ADHD is seen as an add-on, or secondary. How about the term AuDHDer? This is gaining traction in online communities (demonstrated by the popular X [previously Twitter] hashtag #AuDHD) although not yet widely recognised. Therefore, AuDHD is perhaps the most suitable term currently available and the term I use here as an AuDHDer.

Diagnostic criteria have been criticised for their narrow focus on deficits, their basis in male presentations of conditions, and their limited applicability to the full lived experience of neurodivergent individuals. Within neurodiverse communities, there are shared understandings of key features of autism and ADHD that either are not emphasised by or are entirely missing from the diagnostic criteria. This includes the autistic community’s centring of sensory experiences, and shared features of ADHD such as Rejection Sensitivity Dysphoria, where individuals are hyper-sensitive to perceived criticism and rejection. Both of these ‘missed’ elements reflect the internal experience of neurodivergent individuals, rather than their external presentation. It is notable that women and girls tend to experience ADHD and autism more internally and mask more efficiently (because of gendered expectations of that women be sociable, uncomplaining and conforming to societal rule), which lead to a gendered failure to recognise neurodiversity.

There is a risk of discounting the disabling personal elements of conditions that occur regardless of environment, when embracing the social model of disability and celebrating difference, as the neurodiversity movement does. However, the neurodiversity movement aims to overcome this by emphasising the minority status of neurodiversity. It has been suggested that the movement reflects a paradigm shift away from ‘health as normality’ where

health is defined as ‘normal’ functioning in relation to averages, towards ‘health as democracy’ which recognises these differences in opinion, aims for representation, and challenges inequality (Chapman, 2023). However, there is still the issue here of majority rule with the risk of quieter, less popular, voices being drowned out by the louder majority. Historically, this majority has been white and male.

Theories are only relevant when they are useful, which begs the question to what extent current theories of autism and ADHD provide meaningful and useful explanations for those with both conditions, and particularly women? It is inescapable that theoretical tensions exist between the way we understand ADHD and autism. Efforts to de-medicalise autism and embrace the social model of disability have been largely successful within neurodiverse communities. Yet ADHD is still considered to be a disorder and, even if not considered a disorder, is often treated by medication. This theoretical tension, as well as diagnostic contradictions, are evident in the descriptions provided by AuDHDers. For example, a presentation at the National Autistic Society’s 2023 conference by neurodivergent influencer and advocate Purple Ella was titled ‘Autism and ADHD: Living the paradox’. There is a risk of trying to compartmentalise lived experience into separate boxes of ‘autistic’ and ‘ADHD’, as the diagnostic criteria does, which can result in individuals feeling they do not fully belong or ‘fit’ anywhere, and prevents the development of a holistic understanding of ourselves.

It seems that the experience of having both autism and ADHD is distinct. In this respect, we might imagine autism as the colour red, ADHD as the colour blue, and AuDHD as purple – more than a sum of its parts; a thing in and of itself. Of course, neurodivergent individuals are likely to have more than two colours, presenting the challenge of being truly intersectional, taking into account all of the colours and shades that make up an individual. The result of this is that some colours get ignored or bracketed so that others can be focused on. I myself am guilty of doing so; I also have dyspraxia, yet rarely refer to myself as a dyspraxic AuDHDer.

What influences the conditions we focus on or that we perceive to disable us the most? How can we be fully intersectional and take into account not just different facets of neurodiversity but the interplay between neurodiversity and ethnicity, sex, class, age, other disabilities, and so on?

Research needs to be done with and by, not on, neurodivergent individuals and especially those whose voices have been missing from research. The autistic community have made strides here, with research increasingly being conducted by autistic researchers and guidance provided for conducting participatory autism research (Gowen et al. 2019). I am currently conducting research about late-diagnosed women's experiences of autism and ADHD, as a late-diagnosed woman who struggled to find any research or information about living with both conditions post-diagnosis.

However, challenges remain in a research landscape that prioritises and funds research which does not reflect the needs of those who are researched. The majority of funding for autism research goes on etiology studies, with the implication that autism is a disease that needs to be eradicated. Qualitative research still holds less policy sway than quantitative research despite the fact that it is most suitable for capturing the richness and diversity of neurodivergent people's experiences, which can then feed into developing useful support. Feminist research that focuses on women's lived experiences is under-valued in the context of metrics that judge the worth of research on its generalisability. Thus, women's voices have been missing from research on autism and ADHD resulting in diagnoses based on male presentations of the conditions and women and girls being under-diagnosed.

Furthermore, the criteria of 'quality' research are inherently neurotypical; verbal communication tends to be valorised over written, which excludes non-verbal individuals and those who are more comfortable communicating in writing, and at a distance rather than in

person. Guidance on how to conduct a successful interview focuses on maintaining eye contact, which is notoriously uncomfortable for many autistic individuals. Being a successful researcher requires networking and building research partnerships, something I struggle with as an autistic individual. It is hard not to internalise the failure to meet such benchmarks as personal failings, especially against the backdrop of a lifetime of negative messages that cast AuDHDers as lazy, not trying hard enough, overly emotional and impulsive, socially awkward, dramatic, rude, and the list goes on. My previous research about anti-austerity activism revealed how women activists tended to feel guilt about not doing 'enough' of the 'right' type of activism. Despite this being a structural issue related to gendered constraints and norms, women internalised feelings of inadequacy. I wonder the extent to which the internalisation of ableist societal attitudes is also gendered?

Attitudes towards neurodivergent individuals need to change; greater awareness and understanding of the complex difficulties we face can be achieved by qualitative research with and by neurodivergent individuals. The neurodiversity movement argues for a paradigm shift that recognises difference as naturally occurring and all neurotypes as equal. To fully achieve this requires a radical overhauling of society, institutions, and behaviour to remove the privileging of neurotypical ways of thinking and being. On the road towards this ideal, we need to address and tackle these oppressive structures that disable and disadvantage neurodivergent individuals; a task which is easier said than done when the power to change things is often held by those the status quo most benefits, in this case, neurotypical people. At the same time, the impact of intersecting axes of oppression, gendered norms, roles and institutions needs to be recognised and addressed to ensure that neurodivergent women and girls are not forgotten.

As I've suggested, there are theoretical questions to grapple with, along with clinical questions about diagnosis processes. More practically, and more immediately, holistic

neurodiversity assessments that are women-centred and trauma-informed need to become a reality, with pre- and post-diagnosis personalised support provided. The counterargument is always about resourcing. However, the costs of multiple waiting lists, assessment processes, mental health treatments, economic costs of unemployment, and the human cost of suffering is much higher. It is high time that we stop ignoring, silencing, and hurting AuDHD women and girls. We have waited long enough to be heard.

References

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