The Intersectionality framework and the late diagnosis of Autism and ADHD in Women

Intersectionality can help us understand why many women with autism and ADHD are diagnosed so late in life in the UK, compared to males who are usually diagnosed as children. I use the term neurodiversity during this piece to encapsulate the complexities and co-occurrence of autism and ADHD with each other and other neurodivergent conditions. Autism and ADHD are focused on as these are diagnosed medically, which captures further complexities within healthcare such as wait times, cost of private healthcare and gender bias and inequalities within health research.

Intersectionality framework

Crenshaw first coined intersectionality in the 1980s to help explain the oppression faced by black women in America. It explains how being black and a woman comes with multiple layers of oppression that cannot be understood through standard white feminist thought (Crenshaw, 1991). The social movement of feminism cannot 'fix' the complexities of the oppression of black women. Today, it is used as a tool to explain the multiple dimensions or layers of oppression experienced by individuals through their race, gender, disability, etc. These categories are intertwined and are the make-up of a person; they cannot be separated in analysis. Crenshaw (2015) describes intersectionality as an analytical sensibility, a way of thinking about the relationships between power and identity. It is a tool for examining the overlaps of different forms of oppression and can help us understand the social world's complexities; as such, it has been increasingly used in public discourse. It is also a way of orientating our research to think about different social problems, particularly those marginalised in multiple facets whose experiences can be overlooked.

Collins is another critical thinker around intersectionality. She talks about four 'guiding premises' (2019): systems of power (race, gender, class, etc.) are interdependent; intersecting power relations produce complex social inequalities; social location within intersecting power relations shapes experiences; and intersectional analysis is needed to solve social problems. Power and inequality are crucial to understanding and using intersectionality. Just like social categories, power dynamics are intertwined and construct each other, and these dynamics change within social locations. Within complex social location arrangements, inequality is produced. We, therefore, end up with individuals' social positions shifting and contradicting each other within systems of power, not just top-down but throughout the social world. There will always be some interaction or situation where one will have more or less power depending on their categories or intersections and how they are placed or viewed in their context.

Similarly, Crenshaw (2015) claims intersectionality is a way of thinking about identity and how this can change within time and space. What being a woman means and feels like changes depending on where and when we are because gender is socially, historically and culturally constructed. It is the same for what being black, disabled, and poor means. Identity is intersectional and multidimensional in this way of thinking. Our identities are not fixed or permanent; our categories can change over time and in different contexts; for example, you can acquire a disability or a neuro-difference during your life. The meaning of our social categories are not contained inside us but they are fluid and experienced differently everywhere and across intersectional categories (Gibson, 2013).

The concepts of manliness, femininity, gender norms, and their history can also be helpful in our understanding of intersectionality and how it affects power and identity. Bederman (1995) discusses the advancement of civilisation that co-occurred with the emergence of manliness and manhood, representing authority and power, meaning the white man; this, therefore, is where gender and race intersect, whereby the white man is seen as the highest power. Still today, anyone who deviates from the dominant form of 'man' or the 'norm', whether that be by race, gender, class, etc, their intersections and the inter-relationships between these deviations may be policed, legislated, understood, lived and felt differently and in different social locations and institutions.

Collins and Bilge (2016) discuss the six ideas that guide the analysis of a problem using intersectionality: social inequality, power, relationality, social context, complexity and social justice. A single source of oppression rarely causes social inequality; intersectionality gives us the tools to understand the layers of social inequality that make up the oppression of an individual. As aforementioned, power is mutually constructed through social identities, and social categories become 'systems of power' that intersect and give meaning to each other. They also discuss the four domains of power (structural, disciplinary, cultural and interpersonal), another way of analysing power relations through social categories or 'intersections'. Collins and Bilge describe relationality as the 'both/and frame'; we cannot look at social categories in isolation; they are interconnected. Going back to power and power *relations*, "power constitutes a relationship" (p.28); this is crucial to understand when using intersectionality. Our analysis must be contextualised. Differences in social contexts can determine how intersections are experienced and perceived. The social world is complex, intersectionality is complex, and the problems it tries to address are complex. The final idea, social justice, is not a "requirement" (p.30) for intersectionality, but they go hand in hand for most issues.

Late diagnosis of Autism and ADHD in Women

Neurodiversity is an umbrella term that describes differences in how people's brains work. Attention Deficit Hyperactivity Disorder (ADHD) and autism are two 'types' of neurodivergence I will focus on. It is common for these conditions to co-occur with dyslexia and dyspraxia, among other conditions. These conditions tend to be misunderstood and stigmatised, and there are many stereotypes around them, especially for women.

In the past couple of years, there has been a significant rise in ADHD diagnoses and increased waiting lists, with the NHS being unable to meet demand. This is likely due to an increased change in social attitudes and a growing awareness of neurodivergent conditions, particularly on social media (BBC, 2024). Since 2019, there has been a 51% increase in ADHD medication prescriptions and people waiting to see an autism specialist has increased by five times (Morris, 2024). This increase has also led to an ADHD medication shortage, partly due to increased demand, which is having significant consequences, such as some people losing their jobs (Gordon, 2024). Research by University College London (UCL) found that the relative increase in ADHD diagnoses was largest amongst adults and was also higher in the most deprived areas compared to the least deprived areas (UCL, 2023). This highlights the inequalities surrounding diagnosis as those who can afford private healthcare will be assessed quicker, which results in those in the most deprived areas having to suffer from symptoms and lack of support for longer.

ADHD and autism are more common in males. However, it is more common for women to get diagnosed later in life or misdiagnosed. It has been estimated that for women, it is most common to be diagnosed with ADHD in their late 30s to early 40s, whereas for males, it is age 7 (Quintal, 2022). Almost 80% of women with autism were initially misdiagnosed with mental health conditions like anxiety, depression or eating disorders. This is because autism and ADHD are typically typed according to the male standard, and there is still gender bias within diagnostic tools and amongst the medical profession, with particularly ADHD being seen as a 'little boys' condition (Kelly et al., 2022). Autism and ADHD present themselves differently in women, but this is not accounted for in diagnosis and, therefore, gets missed or misdiagnosed as mental health conditions. There are many case studies where this has had extremely adverse effects on these women's lives.

Another primary reason why diagnosis gets missed in women is 'masking' or 'camouflaging'. This is where neurodivergent traits are concealed to 'pass' as neurotypical, learnt over time by observing what is 'socially acceptable' by neurotypicals around them (Radulski, 2022). This constant hiding of who they are leads to women going unnoticed as they internalise their symptoms, which can cause stress, mental illness and identity loss. Neurodivergence is also related to other health conditions, such as hypermobility and fibromyalgia, as they have similar symptoms to autistic overwhelm and burnout. It is, therefore, common for women to get diagnosed with these conditions instead of neurodivergence, highlighting the lack of understanding of co-occurrence with these conditions and neurodiversity in women, especially by the medical profession (Neurodiversity Week, 2024).

There is a lack of research on women with autism, particularly women's health and how autism affects menstruation and menopause. However, the evidence that does exist has found that autistic women experience hormonal changes differently from non-autistic women; for example, autistic people may have an increased risk of experiencing PMDD (premenstrual dysphoric disorder) (Groenman, 2022). People with autism already struggle with physical and mental health, emotional regulation and coping skills; menopause only heightens these struggles. Moseley et al., (2020) found that menopause not only amplified pre-existing "cognitive, social, emotional and sensory difficulties" (p.1423) but created new ones. This amplification of symptoms has led to women discovering they are autistic during menopause or perimenopause, and some autistic people who have ADHD said that their ADHD traits were also heightened (National Autistic Society). This suggests that it would be beneficial for autistic people to know they are autistic before getting to this life stage. Menopause can be an already daunting and isolating time for women, but with the added layer of being neurodivergent, mental illness and suicide risks are greater (Moseley et al., 2021). The lack of research in this area means there is also a lack of support, understanding and professional knowledge around the intersections of autism, women and health for this group to navigate this significant life transition.

Intersectionality and late diagnosis in Women

The intersectionality framework is important for us to use when looking at the issue of late diagnosis of neurodivergence in women, as it helps us understand how these categories intersect and impact each other and why the oppression experienced through these categories has led to this issue. Intersectionality can help us to understand why women are commonly diagnosed with autism and ADHD as adults rather than being picked up in childhood, like more commonly in males. As well as the gender bias in diagnosis, gender norms are partly to

blame for this issue as women are more likely to mask neurodivergent traits or behaviours to appear neurotypical and ‘fit in’ with peers (Kelly et al., 2022). Women already have societal ‘feminine standards’ to adhere to, but autistic women find this more challenging to reach despite being expected to meet these standards (Sedar, 2023).

Identity is a salient concept concerning neurodivergent individuals, especially around diagnosis, and intersectionality helps us explore this. Mutually constructing social identities impacts individuals' experiences of oppression, and these change with social location; for example, autistic women may feel empowered talking about their struggles with other autistic women but less so discussing this with a manager in the workplace. Kelly et al.’s (2022) research found from a systematic review of qualitative research on late-diagnosed autistic women that they reframed experiences of social exclusion and feeling misunderstood into ‘sense-making experiences’ and developed “neurodiverse-affirming autistic identities” (p.1). They did not feel supported by health and social care professionals but found support through meeting others who identified the same on social media. Sedar (2023) highlights the representation of autism in the media; male autistic characters in television shows and films are predominantly depicted as male and either a genius or someone who needs much support, which does not represent how autism is experienced in real life or by women, which can further give meaning to how autistic women view themselves or how others see them. Autistic women can find it challenging to construct their own identities as they do not connect with the male autistic identity or the neurotypical women normative.

Thinking about this issue through an intersectional lens highlights the broader issue of inequalities in health care as the diagnostic tools were designed by and made for males. Bederman’s (1995) work on manliness and the white man being the highest power aids our understanding of this as the system of power of gender means men have historically controlled research, data and the design of our healthcare system, resulting in women not being included in research despite their complex healthcare needs. We are now seeing the consequences of this power imbalance as women who were overlooked throughout their lives are being diagnosed with autism and ADHD as adults. Adding the additional category of race to this intersection, the effects of this system of power can mean further inequalities in diagnosis as neurodivergent traits can also present differently with race and culture. For example, fidgeting, a sign of autism, would look different for a black woman from a white man (BBC, 2023). Furthermore, a study by Lovelace et al. (2021) found that the experiences of black autistic women are missing from medical and educational research, and across 77 years, three studies discussed black autistic women, and none spoke to intersectionality.

There is a lack of research on the experiences of neurodivergent women, but the research that exists has shown that their experiences are complex. The very premise of women being diagnosed late is intersectional. Therefore, intersectionality gives us the tools to answer questions about the late diagnosis of women as it can help us understand how their other layers impact their neurodivergent experiences. One of these experiences is the menopause. Women already experience a stigma and isolation during menopause, and a lot of women's health is misunderstood. Interrelationships of health, gender and neurodiversity mean neurodivergent women going through menopause lack the proper support and information to be able to deal with this major life transition (Neurodiversity Week, 2024).

The issue of late diagnosis and the menopause is rarely talked about or researched. Looking at this through an intersectional lens can help us explore barriers to receiving help, experiences of autistic discovery after going through menopause or perimenopause, and other

linkages to hormones and autism in women. It could also help us investigate how the autistic menopause experience may differ from the norm. An intersectional framework would offer insight into this to assess the impact of mutually constructing categories on adult autistic identification and hormonal experiences. Hormones impact our brain, which therefore impacts the experience of being neurodivergent/neurodivergent identity and the experience of hormonal changes. We could also investigate other systems of power, not just gender, but race and sexuality and how these intersect with neurodiversity as these groups are often ignored. A suggested methodology for this study would be a constructionist stance with qualitative methods.

I found no studies that involved women, menopause, autism or ADHD (or neurodiversity) and intersectionality in the UK. However, Moseley et al., (2020 and 2022) found through qualitative study that there is a lack of support, knowledge, understanding, and communication for autistic people on menopause from professionals and in general. Experiences of menopause varied but included the deterioration of mental health and daily function and the heightening of and development of new cognitive, social and sensory difficulties. Other research and educational work in the field is commonly carried out by women who are neurodivergent themselves, as lived experience lends itself to this effort (Neurodiversity Week, 2024). This is something that Collins and Bilge (2019) discuss in relation to social justice, “people who are engaged in using intersectionality as an analytical tool and people who see social justice as central rather than peripheral to their lives are often one and the same” (p.30). Using intersectionality, we can better understand the unique experiences of neurodivergent women and examine the manifestation of inequalities produced in healthcare in the UK.

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Mark: 74

You have done an excellent with this assessment. You have understood the intended mission of applying and exploring an investigative framework. The way you have thought through the various dimensions of women, diagnosis, neurodiversity and menopause shows a lot of sociological imagination and originality.

The first part of the essay where you discuss the framework needs a bit more care with the way you engage with texts. The ideas are there but I think you could have a bit more direct quotation/reflection for greater depth. The referencing could also be more careful.

But overall really great work!