



Understanding late diagnosis

a quick-reference resource

Late diagnosis

As our understanding of neurodiversity deepens, an increasing number of individuals are undergoing diagnoses later in life. It is not uncommon for adults to receive such diagnoses after years of experiencing challenges that were not previously recognised as neurodivergent traits.

This delayed recognition may be due to a variety of factors, including limited access to diagnostic services, societal stigma, a lack of awareness, and insufficient funding for assessments. When diagnostic criteria are developed based on a narrow subgroup, those outside of it with certain characteristics such as gender, race, and sexuality may face misdiagnoses or delayed diagnoses, highlighting the need for more inclusive and comprehensive approaches.

Did you know?

Until recently, research primarily centred on predominantly young, white, middle-class, cisgender boys, thereby **influencing diagnostic criteria** and introducing biases

Around **80%** of autistic girls remain undiagnosed by the age of 18

Access to diagnoses is often **limited for marginalised groups**, exacerbating disparities in recognition and support

Adults who receive late diagnoses often report feeling **relieved** and **validated**, finally understanding themselves better

Boys are diagnosed with ADHD **5x** more frequently than girls, though case numbers for men and women later in life are roughly comparable

The impact

Educational and occupational challenges often arise due to the lack of timely support. Without the right support, individuals may struggle to understand their strengths and challenges, hindering individuals from reaching their full potential.

A delayed diagnosis can lead to mental health implications, as misdiagnosis prolongs the journey towards receiving appropriate support, exacerbating stress and anxiety.

Socially, individuals may experience isolation, bullying, or difficulties in forming relationships as they may struggle with social cues and communication, leading to misunderstandings and challenges in building and maintaining connections with others.

How to support late diagnosis at work

Support becomes essential in navigating a newfound understanding and addresses the challenges associated with delayed recognition.

Following a diagnosis, it is common for adults to receive minimal to no support from medical professionals, leaving them to navigate their condition largely on their own.

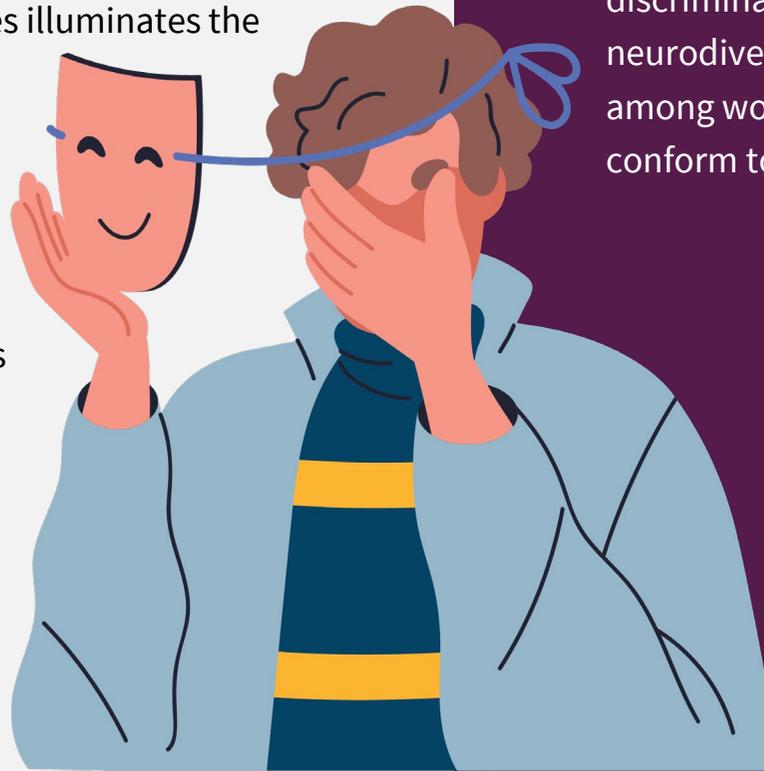
- Facilitate therapy for diagnosis comprehension and trauma healing
- Guide in maintaining work-life balance to avoid burnout
- Cultivate inclusive environments valuing diversity
- Implement support tools to ease self-advocacy
- Recognise intersectionality's impact on experiences
- Extend support to undiagnosed individuals
- Offer educational resources for understanding neurodiversity
- Provide access to support groups for shared experiences
- Ensure accessibility accommodations are available and utilised
- Advocate for workplace policies that accommodate neurodivergent individuals

Past Experiences

Understanding past experiences are crucial as growing up undiagnosed, individuals have likely encountered significant challenges, including criticism and difficulty understanding themselves.

This may have been exacerbated by experiences of manipulation, ostracism, and feeling misunderstood. The lack of support systems further compounds these struggles, leaving individuals to navigate their neurodivergent traits alone.

Reflecting on these past experiences illuminates the profound impact they have on an individual's journey towards self-awareness and acceptance, highlighting the importance of providing support and validation to those undergoing late diagnoses for neurodivergent conditions.



Masking

Masking is prevalent among individuals with late diagnoses, this involves consciously or unconsciously concealing neurodivergent traits to align with societal expectations.

This masking behaviour often arises from a complex interplay of factors such as the desire for safety and security within social contexts, fear of stigmatisation or discrimination. This tendency to camouflage one's neurodivergent characteristics can be particularly common among women, who may feel additional pressure to conform to societal norms and expectations.

Consequently, the act of masking can inadvertently delay the recognition and diagnosis of neurodivergence, as individuals may internalise the need to suppress or downplay their true selves, hindering the identification of their unique neurocognitive profile.

Cultural expectations

The cultural expectations surrounding late diagnosis for neurodiversity are profound. As Ellie Middleton, a neurodiversity advocate, aptly states, "Societal perceptions can play a major role in how people present and understand their differences."

This sentiment underscores the significant influence of societal norms on individuals' self-perception and the interpretation of their neurodivergent traits. Particularly within marginalised communities, there exists a pervasive sense of needing to overachieve and project an idealised self-image to navigate societal expectations.

Many individuals feel compelled to conceal traits that may be perceived as less acceptable, further complicating the process of recognising and acknowledging neurodiversity.

Wellbeing

A late diagnosis and recognition of neurodivergent traits can lead to feelings of confusion, isolation, and self-doubt. This can lead to individuals seeking support from peers, online communities, and mental health professionals to cope with the challenges.

Connecting with others who share similar experiences can provide validation and a sense of belonging, while professional guidance offers strategies for managing challenges.

The benefits of understanding one's neurodivergence can lead to feelings of validation, self-acceptance, and the relief of having access to appropriate accommodations and support services.

REFERENCES AND RESOURCES

1. [Making Sense of the Past as a Late-Diagnosed Autistic Adult | Psychology Today](#)
2. [UNMASKED by Ellie Middleton | Waterstones](#)
3. [Women and Autism \(neurodivergentinsights.com\)](#)
4. Hull et al. 2020 [The Female Autism Phenotype and Camouflaging: a Narrative Review \(autismeexpertise.nl\)](#)
5. [Missed diagnoses and misdiagnoses of adults with autism spectrum disorder - PMC \(nih.gov\)](#)
6. [Spotlight On: Racial and Ethnic Differences in Children Identified with Autism Spectrum Disorder \(ASD\) | Autism | NCBDDD | CDC](#)
7. [Autism and BAME people](#)
8. [Trans and Autism \(neurodivergentinsights.com\)](#)
9. [Women and ADHD](#)

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