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Women’s and girls’ ADHD diagnosis journeys: a mother-daughter autoethnography

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ABSTRACT

Attention-deficit/hyperactivity disorder (ADHD) remains underidentified, underdiagnosed and undertreated in women and girls. Research exploring their diagnostic experiences across national contexts is limited, despite an urgent need for experience-based knowledge to address epistemic injustices in healthcare. Using a collaborative autoethnographic approach, this study examines the diagnosis journeys of a mother and daughter, both with ADHD. We focus on critical incidents in the daughter’s ADHD/dyslexia diagnosis journey over a decade, spanning childhood to adulthood and two health systems: England and Aotearoa New Zealand. Findings reveal how limited understanding of ADHD in girls/women, combined with co-occurring conditions, contributed to repeated missed or misdiagnoses by teachers, education psychologists, psychiatrists, paediatricians and general practitioners. A network of professionals across health and education settings acted as gatekeepers, often unintentionally hindering access to support. Moreover, the experiential knowledge of both women was frequently sidelined, perpetuating epistemic injustice. We discuss implications for policy and practice and highlight the value of lived experience in addressing systemic barriers to ADHD diagnosis, recognition and understanding for women and girls.

INTRODUCTION

Attention-deficit/hyperactivity disorder (ADHD) has long been stereotypically associated with young boys who are restless and disruptive in classrooms. The media has reinforced misconceptions that ADHD is a ‘fake disease,’ overdiagnosed and overmedicated. However, decades of research show that ADHD is a complex neurodevelopmental condition that persists across the lifespan, affecting 2%–6% of the global population and occurring across all genders, cultures and ethnic groups. [1–3] Recognition of ADHD’s persistence into adulthood has contributed to rising diagnosis rates among adults worldwide. Despite this trend, research, including in England and Aotearoa New Zealand (hereafter NZ)—the two national contexts central to our study—shows that ADHD remains ‘underidentified, underdiagnosed and undertreated[1] p2. For example, England’s 2025 Adult Mental Health and Wellbeing Survey reported that 13.9% of adults met clinical criteria for ADHD, with prevalence higher in women (14.9%) than men (12.4%); yet only 1.8% of adults had a formal diagnosis.[4] Similarly, in NZ, just 0.72% of the population received ADHD medication in 2021 (1.63% children and 0.45% adults), highlighting a ‘large treatment gap’[5(p32), 6]. Inequities in assessment and care are evident across socioeconomic status, ethnicity, gender and co-existing neurodevelopmental and mental health conditions.[7–9] Researchers and stakeholders emphasise the urgent need to address the inequities in diagnosis and treatment contributing to this ‘gap’.[5 6 8 10–12]

Timely and appropriate treatment is critical. Untreated ADHD and its common psychiatric and physical comorbidities (eg, anxiety, depression, substance use disorders, oppositional defiant disorder, metabolic disorders) are associated with a 7–13-year reduction in life expectancy,[2 13] with significant impacts on psychological, social and health-related quality of life across the lifespan.[1 14–18] ADHD increases the risk of educational and occupational failure, accidents and injuries, criminality and addiction, risks that intensify when diagnosis and treatment are delayed.[1 16 19–22] Evidence consistently shows that medication and/or psychological interventions improve health, well-being and educational and employment outcomes for individuals, families and communities.[1 23 24] Yet, individuals with ADHD often experience stigma and discrimination, which undermine health and well-being, treatment effectiveness and life opportunities.[25 26] The societal burden of ADHD is substantial,[23] with wide-ranging implications for public health[23 27] and disproportionate impacts on low-income groups, girls/women, BIPOC and LGBTQI+ communities.[10 28–31]

For women and girls, this situation is particularly concerning. A 2023 international review shows that girls are underdiagnosed, leaving women and girls ‘suffering in silence’[30] p653, with far-reaching negative impacts across all life stages.[27] The author argues that ‘accurate and timely diagnosis can profoundly change the lives of women and girls with ADHD’[30] p653. Generations of women overlooked in childhood have contributed to global surges in adult women seeking diagnosis.[30 32] Scholars stress the urgent need to better understand the challenges women and girls face in obtaining diagnosis,[27 33–35] including those of diverse ages, ethnicities and gender identities, and across different locales. While research on women’s lived experiences has grown, particularly in the past 2 years, in comparison to boys/men, there is ‘still a dearth of research on ADHD in girls/women’[27] p3. Existing studies have focused on specific national contexts (eg, UK,[27 33 36–39] Scandinavia[26 32 40]); when we began our research, adult women’s experiences in NZ were limited to one master’s thesis.[41] Given differences in health systems and diagnostic procedures, research across national contexts is needed

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to inform public health policy and improve access to diagnosis for girls and women, to help mitigate the damaging impacts of missed diagnosis.[27]

Our auto-ethnographic research contributes to this knowledge gap by focusing on two women in one family—a mother (Belinda) and daughter (Poppy)—both diagnosed with ADHD in the past decade. As awareness of ADHD's highly hereditary nature has grown, families have become an important context for self-recognition.[42] We examine Poppy's ADHD/neurodiversity diagnosis journey over a 10-year period, from early childhood to adulthood, and across two countries, England and NZ. Our study explores the individual and systemic challenges she faced in seeking diagnosis; how girls' and women's ADHD and neurodiversity diagnoses are made sense of; and the different and fluctuating impacts across different contexts including the family, school and health settings over time.

The following literature review contextualises our research and identifies key gaps in understanding. We then outline our research objectives.

Literature review

First, we explain shifts in understanding of ADHD from the dominant biomedical model framing it as a disorder to being understood as neurodiversity.[43] We consider the role of diagnoses, highlighting the need to consider the views of individuals diagnosed with ADHD and how they engage with, interpret and make meaning within the diagnosis process. Then we highlight research focused on women's experiences of ADHD diagnosis and underline the interrelated factors that have contributed to women's ADHD being 'hidden,'[44] trivialised and stigmatised,[26] creating 'epistemic injustices'.[45]

Understanding ADHD: from biomedical models to neurodiversity

From a medical perspective, ADHD is characterised by 'a persistent pattern of inattention and/or hyperactivity-impulsivity that has a direct negative impact on academic, occupational, or social functioning'.[46] Once regarded mainly as a childhood disorder, predominantly affecting boys, ADHD is now understood as a neurodevelopmental condition linked to brain function differences emerging during development. Advances in neuroscience, genetics and epigenetics reveal ADHD's complex causes and outcomes, marked by heterogeneity and high heritability.[47]

Dominant discourse frames ADHD through a pathological biomedical lens, classifying it as a disorder or dysfunction.[47–49] Diagnosis follows DSM-5 criteria (2013), identifying three subtypes; hyperactive, inattentive and combined, though symptoms, such as emotional regulation issues, are now recognised.[47] Given its mental health impacts, ADHD is often described as a 'mental health' issue or disorder[38] and is also categorised under disability legislation as a cognitive or neurodevelopmental disability.

This deficit-based model has been criticised through the social model of disability[50] and the Neurodiversity Movement,[51] which frames neurological differences as 'neurodivergent (ND),' emphasising diversity. The neurodiversity 'umbrella' includes autism, ADHD and dyslexia. Emerging in the 1990s, neurodiversity research, particularly Critical Autism Studies (CAS), challenged deficit narratives and knowledge production that overlooked neurodiverse people's interests.[52–54] New methodologies were proposed reconsidering the intersection of culture and biology in constructing 'autism as disability'[49] p3520. Subsequently, Neurodiversity Studies evolved, extending progress from autism studies to other areas of neurodivergence, with neurodiverse individuals actively shaping the discourse.[49 55]

Neurodiversity approaches critique the assumption that neurotypical functioning (neuro-normativity) is normal and superior, which creates harm and exclusion for neurodiverse people. This approach aligns with the concept of 'cognition-based ableism' in the social model of disability[56] p253. Ableism refers to entrenched beliefs, stereotypes and practices that privilege ability and normality, devaluing and discriminating against people with disabilities.[56] Internalised ableism occurs when ideals of intelligence, excellence and normalcy shape self-narratives, leading to critical self-judgement and long-term harm.[57] Neurodiverse individuals often imitate neurotypical behaviours, or mask their ND behaviours, to appear 'normal'.[58] Masking negatively impacts identity and self-concept, contributing to cumulative mental health issues including low self-esteem, exhaustion, burnout, anxiety and depression.[35 36]

Critical ADHD studies

Recognition that ADHD has similarities and differences with other forms of neurodivergence, and the complexity of ADHD's position at the 'intersection of psychiatry and culture'[49] p3523, has led to the emergence of Critical ADHD Studies (CADS).[43 49 59] While medication has been described as transformational by many ADHDers,[41 42 60] some neurodiversity perspectives critique medication as a means to 'fix' ADHD[38] p.3, reinforcing 'the medical hold' on ADHD's narrative[49] p3251.

CADS proponents Jackson-Perry, Bertilsdotter, Rosqvist and Brown describe it as a 'loosely bound framework' [49] p.3523 for centring and de-pathologising ADHD lived experience. CADS embraces various 'epistemological, methodological and theoretical positions,[59] prioritising ADHD voices and meaningful participation to reflect the diversity and complexity of experiences[49] p 3521. However, CADS remains a developing field with challenges and points of discord,[37] including contradictions around ADHD diagnosis and validity.[49]

Recent work identifies CADS ongoing foci and absences[49] which are relevant to our study and its objectives. First, CADS advocates 're-storying' ADHD[49] p3525 to acknowledge strengths such as hyper-focus, creativity and cognitive flexibility,[61] while emphasising that ADHD is 'complex, contextual and relational,' and experiences vary across time and settings[49] p3522. Thus, strengths-based accounts must not ignore disabling aspects in different contexts.[36 49] Second, as ADHD spans 'cultural and medical worlds'[49] p3522, interdisciplinary approaches are required to ensure discussions of diagnosis and medication extend beyond psychiatry or medical sociology.[36] Third, research on multiple neurodivergences is needed, particularly given the heterogeneity and overlap.[62] Craddock's research[36–38] examines women's experiences of combined ADHD and autism diagnoses (AuDHDers), noting that while 30%–80% of ADHDers are also autistic, DSM-5 only permitted dual diagnoses from 2013.[50] Fourth, these authors—and others—highlight the importance of intersectional research, including considering the whiteness of neurotypicality,[59] and impacts for BIPOC ADHDers.[12]

The role of diagnoses: centring 'patient' voices

Medical sociology shows diagnostic categories are socially constructed, reflecting societal knowledge and treatment norms.[63] Foucauldian perspectives view psychiatric diagnoses such as ADHD as regulatory tools that distinguish 'normal' from 'abnormal',[63] often linked to exclusion and blame,with medical professionals acting as 'gatekeepers'.[50]

Recent ADHD research, including CADS, critiques diagnosis for its cultural relativism, gender and ethnic bias, disconnect from lived experience and reliance on DSM's deficit-based classifications.[35 40 43] Craddock argues the DSM 'fixes the status of conditions' creating an illusion of stability and scientific certainty, and sanctioning 'medical authority'[38] p3. However, the DSM's ADHD's criteria have changed over time, including through recognition of ADHD's persistence into adulthood and of combined ADHD-ASD (autism spectrum disorder) diagnoses, revealing the DSM's instability.[38] Some therefore advocate self-diagnosis as equally valid.[64] Other 'diagnosis-critical' approaches deem ADHD diagnoses invalid, framing ADHDers as 'victims of diagnostic excess', a stance that can reinforce deficit paradigms[49] p3520.

While acknowledging these tensions, diagnosis is important in the ways it enables access to medication, support and accommodations (eg, in school/work), and legal rights, such as disability support.[32] In line with many CADS/ND scholars, we argue for 'room for the medical without losing sight of the cultural'[49(p3520)]. Furthermore, contradictions also emerge in ADHDers' experiences. Nielsen's ethnographic study of adults with ADHD in Denmark highlights diagnosis as multifaceted, shaping treatment, institutions and ADHDers' behaviours and emotions.[32] She shows diagnosis responses vary: some conceal them due to stigma; others reject them as misrepresentative.[32] Yet, for many, diagnosis validates struggles and reframes perceived character flaws as a legitimate medical condition.[32] Reclaiming a pathologised identity becomes a means to secure resources, representation and recognition.[64] Similar findings across qualitative research with women ADHDers also show diagnosis helps women make sense of life experiences, often generating new practices and identities.[32 33 36 61] Our study builds on these insights exploring ADHD/ND diagnostic experiences for girls/women, their variable functions across place and contexts including the family, school and health settings, and over time.

Diagnosis also reflects systemic constraints.[32] In England and NZ, policy gaps, workforce shortages and underfunding create barriers to timely diagnosis and treatment.[6 65] Challenges include long waits, costly private assessments and medication shortages.[8 11] ADHD NZ reported that 90% of parents struggle to access help for children, while adults often rely on expensive private assessments, disadvantaging low-income and Māori/Pacific communities.[8] In England, the National Health Service (NHS) faces record demand and severe mental health pressures,[66] prompting the launch of an ADHD Task Force in 2024 to improve timely diagnosis and support.[65] The NZ health system has also acknowledged systemic flaws, with recent efforts focused on medication access.[67 68] These concerns highlight the importance of understanding the inequities and diagnosis barriers for women and girls in NZ and England.

Women, ADHD diagnosis and epistemic injustice

International research, historically dominated by quantitative and mixed-methods studies, has identified inter-related factors contributing to ADHD in women being 'hidden'. More recent work incorporates ADHDers' voices, including girls and women across life stages, and those with ADHD and ASD.[26 34–36 39 41 60 61]

First, diagnostic criteria and research have largely reflected male and white ADHD presentations.[30 31] Women have been under-represented in research; one review found 81% of participants were male.[30] This absence was reinforced by assumptions that hormonal fluctuations made women unreliable research subjects. Only recently has women's health become a priority, with growing attention to ADHD's relationship with sex hormones,[69] showing hormonal changes can exacerbate ADHD symptoms, with important implications during puberty, pregnancy, menopause and for oral contraceptive use.[70]

Second, referral research reveals persistent bias toward male ADHD presentations in diagnostic criteria and clinical practice.[30] Women more often exhibit inattentive symptoms (distraction, disorganisation, forgetfulness), rather than hyperactivity or disruptive behaviours.[30] Disruptive behaviours are less tolerated in girls, increasing judgement and stigma.[22] Individuals 'do' or 'perform' gender by conforming to societal norms and expectations associated with social constructions of masculinity or femininity.[71] Hence, gender, as well as class and 'race',[3] shape stigma and its impacts.[25 26] As Craddock outlines, expectations that women are nurturing, sociable and compliant contribute to failures to recognise neurodivergence.[36] Consequently, many girls and women mask symptoms to avoid rejection and discrimination, a practice that erodes identity, lowers self-esteem and worsens mental health, further contributing to their neurodivergence being missed.[25–27 30 36]

Misdiagnosis and underdiagnosis are further compounded by co-occurring conditions.[30] Women with ADHD are more likely than men (with and without ADHD) to experience anxiety, depression, bipolar disorder, self-harm, eating disorders (EDs), autism and learning difficulties (LDs) (eg, dyslexia).[72–75] Women's anxiety and depression often occur earlier and more severely.[72 76] Comorbidities increase ADHD impacts and pose clinical challenges—for example, anxiety can significantly alter the manifestation of ADHD symptoms—worsening outcomes.[75] Physicians frequently treat these conditions first, delaying ADHD diagnosis and care.[44 76]

Stigma also plays a critical role: ADHDers are at risk of experiencing discrimination and stigma across the lifespan, impacting their mental well-being, treatment effectiveness and life opportunities.[25 26] Visser *et al* found widespread ignorance and scepticism among children, parents, teachers and health professionals, framing ADHD as a 'fashion phenomenon' or 'fabrication'.[25] Participants reported discriminatory treatment and lack of support in education, work and healthcare,[21] showing stigma as a reinforcing cycle shaped by gender norms. Like Nielsen,[32] these findings underscore systemic misunderstanding.

In sum, gendered symptom expressions, biased diagnostic frameworks and entrenched societal stereotypes and stigma have contributed to ADHD in women being unrecognised, misdiagnosed or 'dismissed' by themselves, their families and professionals.[25 30 36] These barriers are not just individual or social struggles; as Craddock argues, ADHD being unrecognised and misdiagnosed constitutes epistemic injustice' given its preventable, lifelong harms[36] p1453.

Epistemic injustice, coined by Fricker,[45] refers to systemic discrimination denying marginalised groups full status as 'epistemic agents', or creators of knowledge. It has two main types, testimonial and hermeneutical, while in practice they interconnect.[51] Testimonial injustice occurs when stereotypes undermine credibility, such as dismissing ADHD as 'fabricated' or discounting women's symptom reports, leading to delayed care.[25 36 77] Hermeneutical injustice arises when individuals lack interpretive resources to understand their experiences, while professionals hold interpretive power.[36 77] This injustice occurs in healthcare when 'patients' lived experience is undervalued and professional knowledge is deemed more credible. CADS and ND research aim to challenge these injustices rooted in the medical model of healthcare and research,[43] advocating for neurodiverse people to reclaim their status as 'credible creators of knowledge'[78] p448 about their lives.

Research objectives

Building on these literatures, our research addresses the following questions:

1. What barriers do girls and women encounter in seeking ADHD diagnosis, recognition and understanding?
2. How do environments and institutions shape girls and women's experiences with and (mis)diagnoses of neurodivergences?
3. To what extent were our experiences and experiential knowledge as ADHDers acknowledged or sidelined by professionals across institutional settings, and with what impacts?

Our study makes five key contributions to ND/ADHD research: First, we add to the literature on women's ADHD diagnosis from the perspective of neurodiverse individuals, spanning England and NZ, countries where diagnosis inequities have been recognised. Second, recognising diagnosis as a process with evolving meanings,[32] we examine experiences across contexts and over time. Our mother-daughter longitudinal approach explores Poppy's neurodiversity awakening as a 10-year journey across different life stages from childhood to adulthood, revealing the diverse contexts where ADHD was recognised, missed or dismissed. This multicontext perspective is critical for policy as ADHDers often navigate multiple systems beyond healthcare and face intersecting forms of discrimination.[79] Third, we contribute to research on neurodiversity within families, an underexplored context for ND self-recognition.[32] Fourth, we address the need for research on multiple neurodivergences[38 62] by considering diagnostic challenges for individuals with ADHD and dyslexia. Lastly, as detailed in our methodology, we respond to CADS/ND calls for research by neurodiverse scholars,[43 80] expanding collaborative autoethnographic approaches, including family participation.[40]

Next, we introduce ourselves and outline our collaborative autoethnographic methodology. Our findings and discussion of Poppy's diagnostic journey follow.

The authors

Belinda, the lead author, is a cis, heterosexual, white woman who grew up in England. She has worked as an academic since 1997, initially in England and for the past decade or so in NZ. Belinda was diagnosed (privately) with 'mild/moderate combined hyperactive/inattentive ADHD' (Psychiatrist report, 2019) at age 54 in NZ. This followed the diagnosis of her son, then aged 13. With growing awareness that ADHD is highly hereditary, mothers being late-diagnosed after recognising their children's ADHD is an increasingly common storyline in the ADHD community.[42] In the lead-up to getting her son diagnosed, Belinda did a lot of research and reading; descriptions about ADHDer's lives resonated with her. Belinda's ADHD self-awakening led to considerable reflection and feelings of both relief and confusion.

> I'd 'successfully' navigated life for the past 50 years; I was healthy [mostly], had a good job, stable income, friends, a lifelong partner and family. School hadn't been easy, and I'd flunked my A levels. But I went to university aged 21, thrived and a PhD followed. From there I had navigated my way as an academic for over 25 years. I knew some colleagues and friends found my inability to sit still, and turning up late frustrating; so did I. My "big mouth" and inability not to "speak out" about issues that mattered to me, had often got me in hot water. But I also had an ability to think 'out of the box, was creative, and passionate. I didn't feel like I had a disorder or a disability.

Over time, Belinda recognised she had underestimated the impact of her ADHD, likely because she had a lifetime learning to compensate. She had learnt to mask, but maintaining the appearance of normalcy expended large amounts of energy, contributing to anxiety, depression, overwhelm and burnout:

> Anxiety had plagued me through my life. I'd get overwhelmed, keep going, but eventually just crash. The doctors prescribed antidepressants, beta blockers, sleeping pills, and some counselling; but these didn't really help.

Poppy, also a cis heterosexual white woman, was born and brought up in England, moving to NZ with her family aged 12. She was diagnosed with dyslexia aged 8 in England. Poppy returned to England without her parents, aged 16 (2018), where she completed high school. This move was precipitated by her poor mental health, including developing Anorexia Nervosa (AN) as an early teen. Poppy received her 'combined hyperactive/inattentive' ADHD diagnosis by the NHS England Child and Adolescent Mental Health Services (CAMHS) in 2020 aged almost 18. Poppy returned to NZ in 2021 and later completed her Bachelor's degree in design. She still lives in NZ, where she works as a freelance designer and lives with her partner; she continues to struggle with various mental and physical health challenges related to her neurodiversity. Poppy describes herself (2025) as 'focused and likes to dive deep; creative; fun-loving and adrenaline seeking, but also scattered, restless, impulsive and while outwards confident, often seeks approval from others.' She is an avid reader, loves animals and the outdoors.

Methodology

To achieve a better understanding of neurodiverse peoples' lived experiences, interpretivist qualitative research with, and by, ND individuals is advocated.[43 49 55 80] Aligning with these objectives—and feminist and disability research advocating for situated knowledge from marginalised positions[81]—we employed a collaborative autoethnographic methodology.[82]

Collaborative autoethnography

Autoethnography is a method that connects the autobiographical to the cultural and social.[83] Researchers use storytelling, rich description and self-reflection to expose their personal histories, relationships and embodied and emotional experiences, showing how these narratives relate to the social phenomena and wider contexts.[84] Our study aligns with 'analytic autoethnography'[85] which connects researchers' stories to wider research findings and theories, demonstrating their transferability beyond the researcher's context. The researcher is usually an 'insider' to the group or setting being studied, and visible as such in the researcher's published texts.[85]

Autoethnography can also be collaborative. Duo ethnography involves two or more co-researchers juxtaposing their experiences; their 'dialogic narratives' help create multiple understandings of a phenomenon[86] p9. Researchers have demonstrated the value of duo ethnography for understanding mental health experiences, and ADHD specifically.[40 62 87]

The' doing' of duo ethnography

There is no single approach to 'doing' duo ethnography,[88] and like autoethnography, different views exist on which criteria should be used for evaluating this research.[89] Sawyer and Norris[86 90] outline strategies to enhance the ethics, rigour (credibility and trustworthiness), and transferability of duo ethnography which we adopted. Rigour across methods and interpretation is shown through the depth of the researcher's involvement and the transferability of the research.[86] Researchers therefore provide clear documentation of the methodology process; rich description; explaining how their experiences connect to the cultural phenomena, showing reflexivity, positionality and self-awareness. Importantly, 'critical introspection' is not something 'packaged into a few sentences within a section of a manuscript labelled 'reflexivity'[88] p 3. Throughout the process, we saw ourselves as sites of inquiry, prompting self-examination, dialogue and reflection, using our critical reflexivity to assist ourselves and others to better understand the lived experiences of neurodiversity and ADHD. As Ellis and Bochner[84] argue, autoethnographic rigour is demonstrated by showing the research has 'verisimilitude; that is, 'it evokes in readers a feeling that the experience described is lifelike, believable and possible' p 751.

We used positional awareness to help ensure the analysis connected the personal to wider social/cultural/political contexts.[91] Accordingly, we reflected on our shared social locations as ADHDers and white women with socioeconomic privilege and unpacked our differences, such as in age/life stage. Despite our shared inattentive/hyperactive diagnosis, ADHD manifests itself heterogeneously, and we too have different struggles and strengths. We also brought different assumptions and biases to our project. For example, Belinda has become increasingly frustrated about the lack of understanding and trivialisation of the challenges for ADHDers, even for those like herself with the material resources and abilities to advocate for her family. Poppy's experiences of poor mental health as a teenager have motivated her to speak out and advocate for young women.[92] Recognising these motives is important because they shape how we tell our story.

Core ethical practices also need to be implemented in autoethnographic research; namely informed consent principles; doing no harm, anonymity and confidentiality; integrity; and ensuring the findings are used appropriately to benefit society without causing harm to the individuals or communities studied.[93] Yet despite this, the ethical challenges in autoethnographic research are complex, leading to a divergence and conflict between the lived experience of doing autoethnography and formal ethical guidelines.[93 94] We engaged in thoughtful reflective practice' in applying the core ethical practices to our autoethnography, recognising that the ethics autoethnography's adopt 'in practice' needs to be 'anticipatory and situated,' and that the relational nature of ethnography can make absolute anonymity difficult to guarantee,[93] p.17. Gibbs' who also conducted autoethnographic research involving family members, reflects on these unique ethical considerations, which helped inform our decisions around consent, inclusion, respect and relational ethics.[93] First, following Gibbs, we decided that retrospectively applying for formal ethics approval had little value for our research based on recollections of our past experiences. Second, after much debate, and seeking wider counsel, we decided that we did not want to publish under a nom de plume. While this strategy would have ensured full anonymity for us, family members and others in our narratives, both authors felt the need to 'own' this narrative, particularly as their involvement was driven by their desires and wider activities for social justice and advocacy for ADHD and mental health.[92 95] As Poppy reasoned (discussion 2025), 'if we are anonymous, it seems we are ashamed of story—of our ADHD'. In line with Gibbs, we were committed to ensuring the research is used to benefit society without causing harm (psychological, social) to the individuals or communities studied.[93]

We therefore obtained verbal consent from all close family members and invited them to read, give feedback and approve the final text. We ensured that we had adequately concealed the identities of other people in the narrative, particularly the professionals across health and education settings. To safeguard this anonymity, any documents which might identify people and places were used sparingly in our paper, and the contextual detail removed, even for those who appear indirectly in our narrative. We also took advice from colleagues who read the developing narrative,[93] which resulted in us omitting parts that they saw as overly emotive or revealing of individuals or places.

Researcher relationships: mother-daughter

Rather than positioning the researched as 'other', duo ethnography emphasises their status as equals in dialogue.[86] Acknowledging that 'this was not just my story to tell' (Belinda) and required Poppy's involvement led to the collaborative nature of this project. However, our research relationship needed further reflection.

Hultman and Hultman, two ADHDers, also engaged in collaborative research as mother-daughter.[40] They highlight the challenges of co-creation with another ADHDer and the advantages of being 'bonded' through shared experiences[40] p.200. However, whereas both these authors were researchers, only Belinda was a salaried academic, creating a different relationship with a potential power asymmetry. As Poppy was not an academic, it was important that she chose to participate and felt able to withdraw at any point. Poppy's agreed commitment was to write her narrative and engage in the collaborative discussion. However, while not an expectation, she chose to read and comment on the developing manuscript. We also had regular check-ins to ensure Poppy was still comfortable with the developing research and paper. While our methodological intent was to conduct research 'with' and not 'on' another[90] p21, the responsibility for the project, and for the academic writing, was Belinda's alone. Given this dynamic, we use the term 'collaborative auto-ethnography'[82 91] which felt more fitting than duo-ethnography.

Our collaboration required trust and a willingness for us both to be vulnerable and to listen. Belinda appreciated from her past 'insider researcher'[91 96] that it often has an emotional toll, especially when revisiting and revealing difficult and traumatic experiences publicly.[97] Like Hultman and Hultman, these emotions were managed through ongoing communication and reflection.[40] To some extent, however, engaging in this research and the writing of this paper has been a cathartic process for us both.

Data and analysis

Several different data types contributed to our research which were collated in an online shared notebook (in Onenote). First, both authors wrote self-narratives (Belinda's was around 6000 words, Poppy's 2000) over a period of several months. We did not discuss the focus of these or share them until after they had been independently written. Second, both authors had diaries. Poppy kept a daily diary from age 13, and Belinda wrote a diary throughout Poppy's hospitalisation for her ED in 2016, constituting 21 entries between 8 March and 3 May. These sources were added to our project notebook. We subsequently engaged in written back-and-forth and oral conversations, such as both reflecting on a particular incident, and how we felt; or asking each other (in the shared notebook) further questions or points of clarification. For example:

> Poppy: When I was first sick with anorexia I didn't want anyone to know—I think I didn't want people to know how badly I had fallen or make them feel bad.

> Belinda: When you say how far you had fallen, what do you mean? And who didn't you want to feel bad?

This process enabled us to gain deeper insights into events, how they impacted us in similar and different ways, and their wider significance.

Third, we collated the various reports and correspondences from different professionals, including teachers, educational psychologists, consultants, general practitioners (GPs), counsellors and psychiatrists that were involved in Poppy's dyslexia, ED, depression and ADHD diagnosis and care (14 documents). Participation in online forums, podcasts and blogs about ADHD from 2018 also offered wider insights into the different spaces where ADHD is articulated, negotiated and managed,[32] providing background context in helping to situate our experiences. Belinda took screenshots of these, which were also added to the project notebook.

Within duo ethnographic approaches, 'data and meaning making' are interconnected throughout the research process with ongoing dialogue providing new insights[98] p. 643. We engaged in a back-and-forth between our 'data', academic literatures and other women's autobiographic accounts, to help make meaning of, and contextualise our experiences. We found Denzin's[99] focus on 'epiphanies'—significant, life-altering events that have transformative significance in a person's life—useful in identifying key or 'critical' incidents' in these narratives. Critical incidents have been used and defined in a variety of ways in qualitative research.[100] In line with Denzin,[99] we conceptualised these as transformative events or turning points, where we gained deep insights that promoted reflection. Nonetheless, we recognise that it is our 'interpretation of the significance of an event that makes it critical'[100] p.450 and therefore used these to help identify the underlying circumstance and structures that produced the event.

Our findings section titled 'Poppy's journey' is structured chronologically corresponding to the critical incidents in Poppy's neurodiversity identification journey when her neurodiversity/ADHD was missed, from her early childhood dyslexia diagnosis, ED as a teenager, to eventual ADHD diagnosis. We interweave our data (ie, vignettes from our autoethnographic narratives, diaries and reports) with wider literatures, showing the findings' transferability beyond this context.[85]

Poppy's diagnosis journey

Childhood and school

Poppy was diagnosed with dyslexia at the age of 8 by an Educational Psychologist (2011). From a medical perspective, dyslexia is described as a 'specific LD' associated with 'differences in reading, writing and spelling, despite a 'normal intelligence', intact sensory abilities and adequate education'[78] p444. However, dyslexia is now considered as neurodivergence, affecting individuals' day-to-day lives differently, including across different environments and contexts.[78] There is a strong bidirectional co-occurrence between ADHD and dyslexia, estimated that 25%–40% of people with ADHD also have dyslexia.[101 102]

Belinda's narrative outlined the circumstances leading to recognition of Poppy's dyslexia, highlighting that while dyslexia was largely unidentified during Belinda's childhood, over subsequent decades, Belinda had suspected she had some sort of LD.

> Belinda: In primary school Poppy became an avid reader. She wouldn't let not knowing or misreading words stop her. She had a very vivid imagination and was able to piece together a story. Around age 7 Poppy was struggling with writing. Written homework was torture as she just sat there looking at the page. She hated the weekly spelling lists. …It brought back memories of my childhood. My mum would help me practice, but I still got the spellings wrong and felt so stupid. By secondary I had developed a deliberate semi-illegible writing style to try and hide my poor spelling. I hated to see Poppy struggle in the same way.
> Poppy was also finding maths hard. She was clearly frustrated, so I spoke to her teachers. They assured me it was quite usual to find writing hard at first, even as a good reader.
> I raised my concerns again the following year, however, the teacher felt my worries were unwarranted.

As the school wouldn't refer Poppy for a LD assessment, a decision was made to get Poppy assessed privately.

> Belinda: I felt like a pushy mother, but I just felt something was not quite right.

Parental concern has often been a feature in the identification of dyslexia in middle-class children.[103] Belinda wanted to protect Poppy from experiencing the shame and inadequacy she had felt.

The educational psychologist report following her assessment identified that 'Poppy is a bright child, generally working at levels above the national average' but confirmed she 'experiences a LD'. They explained that Poppy's profile of 'spikes' and 'dips'—abilities from the 97th percentile to below the 10th percentile in other areas—was very typical of children with dyslexia/LDs. The report identified the 'executive function (EF) challenges' Poppy experienced, including poor 'organisational skills', 'time blindness' and 'short-term memory deficits'. EF is the term given to skills that help individuals plan, focus attention, organise, remember instructions, and manage their own emotions and actions to achieve goals. They are essential for self-regulation and navigating daily life, with core components including working memory, inhibition or self-control; selective attention and cognitive flexibility, such as creative thinking 'outside the box,' and seeing things from different perspectives.[104] The report highlighted 'when Poppy was absorbed in an activity, she did not always hear what was said to her', and her 'disorganisation' and being 'easily overwhelmed by tasks'.

> Poppy: When I was young, simple things like taking things upstairs to my room seemed impossible. There always seemed to be a pile of stuff, which never seemed to go down… It made me feel a bit ridiculous that I 'couldn't do' something so simple. I do remember wondering if this was something everyone had to deal with living on two floors, or if I was different. It felt very overwhelming. I would try and do it when the pile was emptier, but as soon as more stuff piled up, it would become something I would avoid as it became more overwhelming—creating a sort of cycle.

In hindsight, these behaviours were also flags for Poppy's ADHD. Although ADHD and dyslexia are separate 'conditions', they can share symptoms, including difficulties with attention, organisation and memory,[105] and a 'spiky cognitive profile'.[36] The neurodiversity movement has critiqued the concept of executive dysfunction which promotes the medical 'deficit model' and fails to account for natural variations in brain wiring, arguing ND individuals navigate challenges and strengths related to executive functioning.[106] However, our understanding of dyslexia was as an LD that needed to be fixed. Even at this young age, Poppy was frustrated and discouraged by her struggles, so we organised tutoring to help Poppy with her EF skills, writing and maths, while also trying not to put pressure on her and embrace her strengths.

Self-comparisons with her neurotypical friends led Poppy to articulate and internalise ableist dominant moral values like 'not trying hard enough', attributing self-blame and seeing herself as 'different' and 'stupid'.

> Poppy: I remember being nervous before and during the [dyslexia] test and that I was going to give the 'wrong' answers… afterwards I remember feeling relieved. I wasn't just an idiot.
> It did make me feel inadequate at times. Why did I need the extra help and support? I Remember my brother being called the 'smart one' and I was the one who 'worked hard'. … It made me feel a bit annoyed as I was mostly always trying hard, whereas it seemed like it just came easy to him. I also think being surrounded by girl friends who were very academically smart made me subconsciously think I was the 'stupid' one.

As Poppy was a bright child, (her scores on the General Abilities Index met the threshold used to classify children as intellectually gifted), who worked hard at school and had the privilege of support paid for by her parents, she was able to maintain 'average' or above academic work and had glowing school reports. However, reflecting wider research, Poppy's academic and gendered performances 'masked' her internal struggles including procrastination, tiredness due to intense focus and frustration.[58] In Holthe and Langvik's research, 'inconsistencies' in girls' schoolwork were explained by teachers as individual shortcomings, leading to 'self-blame and low self-esteem' among the girls[26]; this was also the case for Poppy. Research also suggests the ability to mask is positively correlated with intelligence[107]; bright girls like Poppy are particularly likely to go under teachers' and parents' radar, contributing to keeping their ADHD hidden for years.[26]

Research now shows girls' ADHD often becomes prominent at puberty, not early childhood.[26] For Poppy too, her struggles impacted her schoolwork more markedly in high school, as confirmed by two further educational assessments (in 2017 and 2019).[i] Poppy was now 'underachieving' in several areas, 'significantly below expected for her intellectual ability and age' (report 2017). The 2019 report also highlighted indicators of inattentiveness, such as 'careless mistakes', reading in a 'rushed style' making errors; and noted 'organisational' deficits in her writing structure', common ADHD EF 'flags'.

Poppy had continued to mask and internalise ableist beliefs about herself, which led her to embrace a toxic 'perfectionism', driving herself to exhaustion trying to fulfil unrealistic expectations. For example, due to changing school, Poppy had to repeat a year, so expected she would be put in the 'smart class'. When this did not eventuate, she felt disappointed and ashamed.

> Poppy: Everyone thought I was going to be in the 'smart' class. I remember feeling let down and disappointed as I had technically already done the year.
> Belinda: Who was everyone? Mum and dad? Friends?
> Poppy: No one in particular… I think it was something family had spoken about as I had already done the year. Looking back, it was most likely more my perception of what people would think - I thought I was letting everyone down because in my head that was what was expected of me. …I'd always being a people pleaser.

In summary, from primary school, Poppy had exhibited and experienced many behaviours now recognised as 'typical' of ADHD in girls, including appearing withdrawn, anxious, being a pleaser, disorganised and messy, forgetful, making careless mistakes in schoolwork, a chatterbox and verbally impulsive.[42] Poppy learnt to mask her differences from an early age, and her dyslexia and ADHD traits were mistakenly observed as her 'personality' by teachers, tutors and teaching aids, both in primary and beyond. Poppy's advanced intellectual abilities, hard work and targeted support enabled her to compensate and complete high school with little institutional support for her differences beyond extra time in assessments. Although Poppy's three educational psychologists' reports indicated EF challenges and inattention, these were explained as dyslexia. Healthcare professionals now recommend screening for both ADHD and dyslexia when an individual presents with symptoms of either one, to ensure appropriate support.[105]

The invisible nature of ND 'impairments' contributes to destructive internalised ableism,[36] and the onus is placed on the individual to articulate their struggles and seek help, creating further barriers and inequities. When ADHD remains unidentified, repeated experiences of 'failure, alienation and inadequacy' increase the risk of developing 'comorbid disorders', including depressive symptoms, anxiety, sleep disorders, EDs, substance use and low self-esteem[26] p3. As we detail, Poppy's masking and internalised ableism fuelled her perfectionism and anxiety, leading to harmful coping mechanisms, particularly as an adolescent, including alcohol, risk-taking, self-harm and not eating.

Neurodivergence and EDs

In the following discussion, we reflect on Poppy's care experiences when, at the age of 13 (2016) living in NZ, she developed an ED, AN. AN is considered a 'psychiatric disorder'[108] where 'patients' show a pervasive 'drive for thinness' and distorted body image with a 'false perception of being fat'[109] p.870. AN is acknowledged to be complex, associated with serious health impacts, and high remission and mortality rates.[108 110] The links between ADHD and EDs have been established for some years,[111 112] with mounting evidence that EDs grow in severity alongside ADHD.[113] Yet recent research in Australia shows that awareness of the links between EDs and neurodiversity is still lacking among clinicians, warning that a 'hegemonic discourse of pathology' still underpins ED care protocols and practices[114] p35, which can be detrimental for neurodiverse individuals. When Poppy developed AN (2016), we were not aware of her ADHD, nor that dyslexia was neurodivergence; had we known, it is unlikely to have prevented AN developing. Our focus here is on showing that ED treatment protocols at the time focused on restoring physiological health, but not the potential causes or triggers for her ED. Due to the biomedical and siloed nature of her ED treatment, once Poppy was considered 'well' from a biomedical perspective, she did not receive the further care she needed, with ongoing mental health impacts. This is concerning; statistics show even individuals like Poppy who have received 'successful' inpatient AN treatment have high remission and mortality rates,[108 110] with elevated risks for a range of mental 'disorders' including suicidality[108] p526. Furthermore, although a psychiatric assessment was undertaken following the protocols used to guide AN care throughout NZ,[ii] the guidance at that time included

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[i] These reports conducted in 2017 when Poppy was aged 15 years 6 months in NZ, and then England, 2019 aged 16 years 9 months, were required for Poppy to continue to receive accommodations [extra time] by examination boards.

[ii] The Starship protocols from 2016 are not available online, however it was explained to us that the NZ protocols were based on the NHS England recommendations i.e. RCPsych [2012]. We cite the more recent Starship 2021 protocols, however we are not inferring that Poppy was based at Starship.

consideration of depression, obsessive-compulsive disorder (OCD) and autism, but not ADHD.[115]

Belinda's narrative outlined the lead-up to Poppy 'becoming sick' (Belinda's diary). Towards the end of 2015, 'Poppy seemed quite low in her mood and spent more time at home: somewhat withdrawn and not her usual bubbly self' (Belinda). Poppy started restricting what she ate, cutting out certain foods (eg, fats, high calories), and was visibly losing weight. We visited a GP, where Belinda raised her worries about Poppy's poor mood and explained a family history of depression. Poppy was subsequently monitored via weight checks and blood tests and referred to CAMHS. Over the following 2 months her weight loss accelerated, and she was also self-harming in other ways. One morning, we discovered she was not even drinking water and, because she was so weak, had collapsed trying to get to the bathroom, so we drove her to hospital. As Poppy had lost 30% of her body mass (the Starship admission criteria was weight loss of 15%–20% in 3 months), and refused any food offered, she was admitted, and a nasogastric tube was inserted. The paediatrician told us Poppy was 'medically unstable', and her physical condition was 'life-threatening' (Belinda's diary).

National guidelines for adolescents advise most AN patients stay in hospital for 2–3 weeks[115]; Poppy's was hospitalised for several months, initially with cardiac monitoring and a 24-hour suicide watch. The care team explained that her treatment would follow the national AN guidelines, which specified, 'medical and nutritional stabilisation' is the 'first and most important goal of inpatient treatment', usually necessary 'before psychological therapy can be effective'[115][[iii]] Also following the guidelines,[115 116] Poppy's care team involved psychiatrists, counsellors, nutritionists and family therapists, overseen by a paediatrician. Posthospitalisation, the whole family attended weekly family therapy where the focus was supporting Poppy to eat, but did not elicit further consideration of her self-harm, anxiety or OCD tendencies.

These protocols were undoubtedly effective in restoring her physical health, and Poppy received excellent care from the staff. Nonetheless, Belinda repeatedly raised her concerns about Poppy being withdrawn and depressed before the AN developed and asked the psychiatric team to consider antidepressants. It was explained that significant weight loss 'leads to impaired cognitive function' which can manifest as 'mood disturbance', but these improve as nutrition and body weight increase.[102]

Some months later, just before Poppy returned home, it was agreed for Poppy to trial an antidepressant. Belinda recounted that a few weeks later, 'we saw the first glimpse of our old Poppy' (diary).

> Poppy was fooling around with her dad and the dogs… we saw a smile… then laughter followed. From then on, her mood improved. It was slow but over the following months we gradually saw the old Poppy return. She also stopped her OCD like behaviours such as obsessively lining up her colouring pens and following routines such as plaiting her hair in the same way every day.

Aged 15, Poppy wrote an article about her anorexia journey in which she explained she did not see herself as a 'typical' anorexic, but a 'bubbly and happy kid, always ready to give anything a go and never over-obsessed with my body'.[92] She felt she had got sick 'seemingly out of the blue', and 'quickly hit rock bottom'.[92] In our family therapy at CAMHS, they often stated that Poppy's progression was 'unusual', her very fast decline and fast 'recovery' (ie, weight gain) once home did not fit their 'typical patient' profile. However, Poppy's depression and OCD-like behaviours did not lead to any further investigation or follow-up beyond antidepressants.

Poppy continued to take antidepressants; when she tried to stop, she became withdrawn and moody. In private counselling a year or so after her hospitalisation, Poppy explained that at the time of the AN developing, she did not feel she 'fitted in' (living in NZ) and mourned her life and friends in England. The counsellor felt Poppy had experienced 'trauma'. Poppy had not disclosed the depth of her feelings to her parents as she did not want to upset them:

> Poppy: I used to war in my own head about pleasing everyone not wanting to let them down. It was the same about eating, or not.

Over the following years, Poppy experienced a range of significant physical and mental health issues. As noted, Belinda was surprised that Poppy's ED did not elicit any further follow-up from CAMHS or her GP about Poppy's mental health. In hindsight, had Poppy's psychiatric assessment included ADHD screening, as some now recommend for all ED patients,[114] and more dialogue between her health providers, Poppy's ADHD might have been diagnosed 5 years earlier, potentially mitigating a range of mental health challenges through adolescence.

ADHD awakenings: Poppy's formal diagnosis

As explained, girls' ADHD often becomes visible in adolescence, not early childhood,[36] which can lead to difficulties for teenage girls seeking ADHD evaluation.[26] Similarly, Belinda struggled to get Poppy an appointment with CAMHS in England where Poppy was living. She persisted, with help from a friend who worked at CAMHS.

> Belinda: Following my ADHD diagnosis, I began avidly reading about women ADHDers which was emerging on the internet, including the links with eating disorders. I realised many of Poppy's 'issues' fitted; her anxiety, mood swings, her dyslexia attributed EF traits, 'unusual' ED, disorganisation, and creativity. Also, between ages 14-16 Poppy had displayed other ADHD- like 'risk' taking and impulsive behaviours. There was one period where she spent a lot of money online shopping …she just seemed totally out of control.

Poppy's comprehensive NHS assessment included a QB test which is a computer-based ADHD diagnostic screening tool that measures the ability to regulate activity, attention and impulsivity (qbtech.com). This test indicated Poppy was on the 99th percentile in both hyperactivity and inattention, helping to confirm her 'combined ADHD diagnosis'. We were both surprised by Poppy's high hyperactive scores.

> Poppy: Doing the QB tests and seeing the results was a real eye opener. I never imagined myself as being hyperactive; I think of young boys running around, or not being able to sit down in a chair. It really highlighted to me the misinformation or stereotypes around ADHD.

The report explained that Poppy's hyperactivity was evident in her micro movements, including darting eyes, hair twiddling, body picking and also being talkative. Girls displaying their hyperactive symptoms in these less visible ways are being recognised as a key factor contributing to their ADHD diagnoses being dismissed.[26 30]

[iii] The ethics and rationale for such force-feeding treatments remain contentious and widely debated.

Postdiagnosis, Poppy reflected on wanting to share her diagnosis with her friends. However, she found:

> Poppy: Some of my friends didn't believe me…'you don't have ADHD'. I remember trying to explain to them and feeling a bit disheartened when people were talking about ADHD as a trend, or just putting a label on my personality.

Such experiences of ADHD stigma from friends and family who believe ADHD is a 'fake disease' are prevalent across recent lived experience-based research,[25–27 35 36] impacting credibility and causing testimonial injustice. Poppy decided to trial stimulant medication which she found very helpful, even life changing; 'with them I can do so much better, and achieve more, live better' (Poppy, 2024). Her narrative detailed that it was 'the first time I could sit down and focus on doing work for greater periods of time, and not only just as a one off' (Poppy). She also recalled talking with 'workmates', who

> all noticed I was different. They said I could have a conversation without going on a massive tangent, and we could have deeper discussions. This was not something I realised other people noticed, or even that I did (Poppy).

However, reflecting previous research, being diagnosed is not just about access to medications or accommodations, but self-understanding.[26 32 36 41] For both Poppy and Belinda, the diagnosis provided 'validation' of their struggles, confirmation that something was 'different,' and an explanation for our experiences and difficulties. This was vividly illustrated in Belinda's narrative about first recognising she had ADHD:

> Belinda: While I knew I was a bit 'different' and that feeling had started at school, I was so like my dad: being a 'bit different' felt normal. All the research I did in when getting my son diagnosed resonated with me: 'Brain like a motor, unable to turn off'. 'Orchestra without a conductor'. 'Ferrari without breaks'. My short attention span, hyperfocus, creativity, non-linear thinking, forgetfulness, obsession with keeping lists, persistent lateness, constant chatter, thrill seeking, and many other 'symptoms' all fitted. A lifetime of insomnia and what my dad had called my 'granny's belly'—to describe how she felt sick in her tummy when she was anxious—were likely ADHD related.

Diagnosis offered a vocabulary and narrative for us to re-interpret our life's through and develop self-understandings.[32]

> Poppy: For me it made so much sense looking back… and understanding why I had struggled with the things I did.

As Nielsen[32] also found, rather than continuing to blame our struggles on perceived personal flaws, we developed better self-understanding; diagnosis contributed to a re-evaluation of our biographies and identities.[32] It also facilitated better relationships within our family, as we were able to understand why we behaved in particular ways.[35]

In summary, our narrative shows key incidents when Poppy's dyslexia and ADHD were missed the impacts on her and her family, and the different settings in which her ADHD was made meaningful, including the home, family, school and health settings. Both Poppy's and Belinda's narratives show that receiving an ADHD diagnosis is not a single event but a process over many years, involving a network of interacting people, events, contexts and contradictory knowledges, with multiple and changing implications for the individual. Within this, the family was an important context for self-recognition, particularly once Belinda became aware of ADHD's hereditary nature, and how ADHD and dyslexia interlink. Yet as Belinda's narrative illustrates, as a child she attributed her feelings of being 'different 'at school to being like her father; in a family of (then undiagnosed) intergenerational ADHDers, being different was 'normal'. Further research is needed to better understand how neurodiversity is experienced in families, including the impacts of stigma and misunderstanding, particularly when multiple family members are neurodiverse.

DISCUSSION: EPISTEMIC INJUSTICES IN WOMEN/GIRLS ADHD DIAGNOSIS

Research highlights epistemic injustice's prevalence in healthcare, particularly psychiatry, mental health and disability,[77] where deficit-based models systematically stifle voices, testimonies and interpretive tools of marginalised groups.[51] Women being missed or dismissed as ND constitutes epistemic injustice due to the 'enduring negative consequences of this oversight'[36] p1450, including chronic anxiety and depression,[26] poor mental health and trauma.[35] Our experiences also illustrate these harms and show how epistemic injustices operated within ADHD diagnosis in NZ and England, underscoring the structural and interpersonal dimensions of epistemic injustice, where credibility deficits and interpretive gaps perpetuate harm.

Like Belinda and Poppy, women ADHDers frequently struggle to be heard by clinicians; 68% of the women in Holden and Kobayashi-Wood's research reported being dismissed by medical professionals when trying to get ADHD recognition,[27] also resulting in delayed or inadequate care and more complex and severe health outcomes.[72] Experiences of misinformed and even ADHD-denying GPs are reported in Morgan's UK-based research[35] and are widespread in online ADHD communities. For example,

> let's not pretend it's rare. It's 2025, and there are still doctors who don't believe ADHD is real… Not all doctors, of course. But it only takes one to do serious damage (ADHD International Alliance, 2025).

Our research also shows systemic issues in ADHD care in both NZ and England that shaped diagnostic experience, alongside widespread denial of ADHD as a legitimate condition, undermining the credibility of ADHDers' lived experience. While professionals we encountered in education and health settings did not explicitly deny ADHD and were often highly committed—innovative teachers and compassionate medical teams—they lacked adequate ADHD/neurodiversity knowledge, contributing (although unintentionally) to oversights and misdiagnoses.

GPs are typically the first point of contact for ADHD, anxiety, depression and EDs, yet they are rarely specialists. As Belinda reflected in 2024:

> Belinda: I've had multiple conversations with GPs in NZ and England, excellent doctors, but who still have many misconceptions about the experiences of having ADHD. I find this really concerning.

None of the GPs or counsellors we consulted in either country linked our overwhelm, anxiety or depression to ADHD.[35] Informal conversations also confirmed most health professionals were unaware of ADHD's association with EDs; one GP in NZ admitted their ADHD training was 'perhaps one half-day' and 'probably very out of date' (Belinda's narrative). Similarly, limited attention to Poppy's mental health during and after ED treatment is concerning, as teenage girls with combined ADHD face high self-harm risk.[117] Reflecting mental health research, epistemic injustices often stemmed from systemic factors beyond professionals' control, particularly inadequate training and resources.[118]

In NZ, only psychiatrists can diagnose and prescribe ADHD medication for adults, and their perspectives are prioritised in policy,[119] reinforcing their status as holders of privileged knowledge.[63] Yet Belinda's experiences as a patient, support person and attendee at ADHD workshops revealed that psychiatrists' knowledge was inconsistent and sometimes outdated:

> Belinda: ADHD doesn't seem core to psychiatrists' work. One who claimed expertise was completely out of touch with current research—even what's available via podcasts.

Despite this, health professionals are perceived as having the authority to interpret patients' experiences, their perspective regarded as 'not only authoritative' but often 'exclusive of other perspectives'[118] p.349. Belinda felt her insights were repeatedly disregarded across institutional settings, that is, schools, primary care, hospitals, CAMHS. When individuals lack interpretive resources to understand their experiences, while others hold interpretive power, hermeneutical injustice occurs.[36 77] Belinda recognised Poppy's struggles early because they mirrored her own, yet without 'objective' evidence, her concerns were dismissed. Teachers labelled her a 'pushy mother,' and clinicians ignored her belief that depression had underlined Poppy's ED, or that although she was eating again, she was not 'fixed'.

Belinda's frustration and sense of being misunderstood echo sentiments across ADHD communities[33]: For example,

> It's the refusal to believe anyone who doesn't fit the mould. … And it's always the same story: someone knew something was wrong, but no one would listen [ADHD International Alliance, 2025].

Over time, Belinda acquired knowledge about neurodiversity and ADHD, including academic research she could access. She became better able to legitimise her lived experiences, positioning herself as an authoritative voice, a 'knower' through citing academic research and using medical discourse (eg, comorbidities, executive dysfunction). Yet, Belinda recognised, this was a privilege unavailable to many ADHDers.

In summary, epistemic injustices in our ADHD journeys arose from systemic barriers in the NZ and England health systems; entrenched societal stereotypes and the unquestioned authority of medical professionals,[63] compounded by structural constraints such as inadequate training and resources.[118]

Implications for policy and practice

While our research is based on just one family, and two health systems, our findings highlight a range of barriers for girls and women seeking ADHD diagnosis, operating from the micro to macro level in both England and NZ. Widespread lack of knowledge about how ADHD presents in girls/women, and ADHD's prevalent coexisting conditions, was a key factor in Poppy's narrative across education and health professionals including psychiatrists, paediatricians, GPs and counsellors. These professionals unwittingly acted as gatekeepers. Lacking sufficient knowledge about ADHD's gendered manifestations, they created significant barriers. Improving clinician and health workers' education and training programmes is vital.[1]

However, to address the systemic barriers across health and education settings that exacerbate misdiagnosis requires a more systemic, societal response.[118] Our findings support recent recommendations made by the NHS taskforce and Australian Federal Inquiry that a multifaceted and multisectoral approach to ADHD care reform is needed with better communication between the different ADHD stakeholders in the health system and beyond.[79 120] Screening at risk groups is also proposed. Australian researchers recommend all young women presenting with anxiety or depression are screened for ADHD due to the high prevalence of 'comorbidities'.[121] Similarly, because dyslexia and ADHD share many symptoms, it is important for healthcare and education professionals to consider both conditions when evaluating individuals who exhibit symptoms of either one.[105] While EDs like anorexia are rarer, more effective treatments are urgently needed.[110] Incorporating ADHD/neurodiversity screening in ED assessment processes and care pathways, and integrating ED screening into ADHD care, would facilitate early identification and support.[114] This report also details the various ways in which pathology-based ED treatment can be harmful for neurodiverse individuals with extensive guidelines for treatment. More widely, it is suggested that all ED stakeholders need to rethink how EDs are approached, adopting a more 'holistic, intersectional and lived experience-led lens'[111] p9.

CONCLUSIONS

This research sought to address key questions focused on the lived experiences of ADHD diagnosis in girls and women, and contribute methodologically to the growing body of lived experience-led research in ADHD research emphasising the value of ND people as researchers and research participants. The findings show how lack of knowledge about ADHD in women and girls by key professional gatekeepers contributed to Poppy's ADHD being repeatedly missed or misdiagnosed, and how her multiple neurodivergences (dyslexia/ADHD) and coexisting conditions (anxiety, depression, self-harm) contributed to Poppy's ADHD being missed for over a decade. Examining how different contexts influenced our understandings and experiences of ADHD gave greater insights into the lived experience of diagnosis as a multifaceted process, and of the ways institutions and professionals within them can regulate ADHD diagnosis and understanding. Findings support Nielsen's research in highlighting that receiving an ADHD diagnosis is not a single event but a process, with multiple and changing implications for the individual and their family.[32] For some women—including Belinda and Poppy—diagnosis can help gain understanding and self-acceptance, helping them to stop blaming themselves and start to live more fulfilling lives.[122] Further research is needed to better understand how neurodiversity is experienced in families, and the diverse contexts where ADHD is enacted and made visible, such as education, work, leisure and health.

Regarding our question about 'patients' experiential knowledges and lived experiences, our research revealed that despite the unquestioned privileged status of health workers as 'knowers', they often lacked sufficient knowledge, leading to misdiagnosis or diagnosis delays, and more significant health issues. ADHDers and their families' experiences and knowledges were consistently undervalued or ignored in these different institutional settings, creating testimonial injustice. Our research, therefore, supports the objectives of CADs and ND epistemologies in seeking to gain better legitimacy for experience-based knowledge. The need to disrupt the knowledge production hierarchies that marginalise qualitative research and experiential knowledge is not unique to ADHD, but impacts mental health and disabilities more widely.[123]

Recognising our positionality as white women with socioeconomic privilege that enabled us to pay for diagnoses and support, we echo appeals for more intersectional ADHD knowledge.[12 43 49 59] Considerations of racialised as well as gendered and age-based inequities in accessing ADHD healthcare are essential,[35] as is understanding the impacts of these barriers for BIPOC and other marginalised communities including LGBTQIA+.[12 28 29 124] Rangiwai's[124] research in NZ from a Māori perspective demonstrates how Eurocentric language and concepts have dominated ADHD understanding.[49] Neurodiversity researchers need to problematise ADHD's colonialising histories and practices.[64 124] The relationship between ND identities and other marginalised identities is complex, with significant impacts on how mental health symptoms are experienced; hence these considerations need to be considered in tailoring an individual's treatment.[12]

Methodologically, we show that epistemic insiders' collaborative autoethnography is valuable for reframing the story of ND conditions, enabling researchers to 'think and speak differently' about our embodied experiences in contexts mainly defined by medicalised practitioners and discourses. Our mother-daughter longitudinal autoethnographic approach enabled us to explore how and why ADHD was missed or ignored across different life stages from early childhood to adulthood, and across different institutional settings over time. This multicontext approach is important as ADHD is relational and contextual, and cultural norms impact appropriate behaviour, including in gendered ways. Additionally, as people with ADHD are often at the intersections of several government systems, not just healthcare, they can experience multiple forms of exclusion and discrimination. Lastly, like other countries, societal understanding of ADHD in girls/women in NZ and England has been slow to shift, and ableist attitudes continue to contribute to misunderstanding, stigma and internalised ableism with lifelong impacts.[25–27]

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