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Mental Health Diagnoses and Treatment before Receiving a Diagnosis of Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder

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Submitted in partial fulfilment of the requirements for the degree of
Doctorate in Clinical Psychology

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Chapter 1: Systematic Review

Mental Health Diagnoses before Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorders: A Systematic Review

Prepared in accordance with the author requirements for Review Journal
of Autism and Developmental Disorders;

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Abstract

Growing evidence suggests that individuals often receive mental health diagnoses before being diagnosed with autism spectrum disorders (ASD) or attention deficit hyperactivity disorder (ADHD) (Martin et al., 2024; Martini et al., 2025; Rocco et al., 2021; Russell et al., 2025). However, common diagnostic patterns and the quality of supporting evidence remain unclear. This review systematically examined the research base to determine which mental health diagnoses are most frequently reported before ASD or ADHD diagnosis, and evaluated the evidence base using the Crowe Critical Appraisal Tool and GRADE approach to assess certainty. A Synthesis Without Meta-Analysis (SWiM) approach was utilised in response to the substantial heterogeneous data produced by the 17 studies analysed.

Anxiety and depressive disorders were the most reported diagnoses preceding both ASD and ADHD, while psychotic and personality disorders were additionally frequently experienced before ASD. Females demonstrated higher rates of prior mental health conditions than male in both ASD and ADHD groups. Findings were limited by substantial heterogeneity and imprecision. A clinical implication of this review may be for clinicians to consider whether ASD or ADHD have been overlooked or potentially overshadowed when patients (particularly those who are female), present with persistent, treatment-resistant, recurrent anxiety and depression, psychotic or personality disorders. In such cases clinicians may find it helpful to screen for ADHD and/or ASD to reduce diagnostic delay and the harms associated with this.

Introduction

Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) are lifelong neurodevelopmental disorders (NDDs). ASD is characterised by difficulties with social communication, reciprocal social interaction and the presence of restricted, repetitive activities, behaviours and interests (WHO, 2019). ASD is inclusive of historical terms like autistic disorder, childhood autism, atypical autism, Asperger's syndrome, Pervasive developmental disorder-Not otherwise specified (PDD-NOS), or 'high-functioning autism' (WHO, 2019). Although awareness of ASD has increased over recent decades, and prevalence rates vary across studies, research estimates ASD impacts approximately 1.5% of the population with a median male-to-female ratio of 4.2 (Ekvan et al., 2026; Zeidan et al., 2022).

Attention deficit hyperactivity disorder (ADHD) involves persistent patterns of inattention and/or hyperactivity-impulsivity which have a direct negative impact on academic, occupational, or social functioning (WHO, 2019). ADHD affects approximately 1.6% to 5% of the general population and has a more balanced gender ratio than ASD, with estimates suggesting approximately one to two males for every female diagnosed (Faheem et al., 2022; Popit et al., 2024).

There is a growing body of research suggesting that many autistic people are not diagnosed until later in life (Russell et al., 2025). This is also the case in ADHD, where the mean age of diagnosis has been found to range between 6 to 18 years of age (Rocco et al., 2021). In ADHD, potential late onset has been a suggested reason for this,

however this concept requires further exploration (Bayard et al., 2026). Presentations of ADHD and/or ASD (henceforth known as ADHD/ASD) are felt to be different between females and males, and some suggest that the less well-known female presentation may contribute to a delay in diagnosis of both NDDs (Faheem et al., 2022; Mao et al., 2024; Marques et al., 2025; Skoglund et al., 2024). For example, autistic females have been found to have higher rates of internalising behaviours like social withdrawal, anxiety and emotional dysregulation than males, as well as social camouflaging behaviours which complicate timely diagnosis (Mao et al., 2024). Autistic males on the other hand exhibit higher rates of externalising behaviours like hyperactivity, repetitive behaviours and speech delays, which may help their autism to be more easily recognised than females (Mao et al., 2024). In ADHD, research suggests that females are substantially more likely than males to present with predominantly inattentive ADHD and less likely than males to present with combined or hyperactive-impulsive type ADHD (Siddiqui et al., 2024). Siddiqui et al. (2024) also found that females with ADHD are also twice as likely or more to have diagnoses or treatment for anxiety or depression than males. Such differences in presentations are relevant to consider in the current review, because the most common mental health diagnoses of people with ADHD/ASD may vary by gender.

Research indicates that individuals diagnosed with ADHD/ASD later in life are given mental health diagnoses prior to these NDD diagnoses (Martin et al., 2024; Martini et al., 2025). The role of these mental health diagnoses is particularly discussed in relation to autism where researchers query whether they are experienced as a misdiagnosis or a comorbidity (Fusar-poli et al., 2022; Kentrou et al., 2024). Misdiagnoses are difficult

to determine; however, mental health conditions are higher in ADHD/ASD compared to the general population (Hossain et al., 2020; Njardvik et al., 2025; Steel et al., 2014). Prevalence rates vary greatly across ADHD/ASD comorbidity studies, though anxiety, depressive, psychotic and behavioural disorders (including conduct disorders [CD] and oppositional-defiant disorder [ODD]), are among the most common co-occurring mental health diagnoses (Hossain et al., 2020; Njardvik et al., 2025). This suggests considerable overlap between the mental health diagnoses associated with ADHD and ASD.

Whether the mental health diagnoses experienced by people with ADHD/ASD are comorbidities or misdiagnoses, consideration should be given to the possibility of these diagnoses overshadowing ADHD/ASD and potentially delaying their diagnosis (Estrin et al., 2021; Jadav & Bal, 2022). A psychological theory which may explain this phenomenon is confirmation bias, where clinician's may look out for and favour information about a patient's difficulty based on their belief in their existing mental health diagnosis, while ignoring information which may challenge this (Nickerson, 1998). Presence of such bias has been evidenced in research about both medical and allied health professionals, and highlight the negative impact confirmation bias can have on diagnostic accuracy (Featherston et al., 2020; Saposnik et al., 2016).

Having unrecognised ADHD/ASD is reported to have a significant impact on mental wellbeing of this population, leading to higher rates of depression and anxiety in both, and greater emotional difficulties, suicide attempts and substance abuse in ADHD (French et al., 2023). French et al. (2023) point out that given the strong relationship

ADHD/ASD have with mental health conditions, such as anxiety and depression, clinicians working in psychiatric settings should routinely consider screening for these NDDs. However, their research did not focus specifically on mental health conditions prior to ADHD/ASD, and comorbidity research outlines other mental health conditions are also prevalent in this group.

Therefore, it remains unclear if there is a pattern of common mental health diagnoses received before a diagnosis of ASD/ADHD, which could better prompt clinicians to screen for these NDDs. It is also unclear what the quality of the evidence is of individuals being given other mental health diagnoses before ADHD/ASD. To the researcher's knowledge no systematic review has been conducted on this topic before, therefore the aim of this review is to assess the quality of evidence that identifies the mental health diagnoses received prior to an ADHD/ASD diagnosis, and to explore the most common mental health diagnoses that are reported.

Review question

What are the most common mental health diagnoses received prior to an autism or ADHD diagnosis?

Methods

Protocol and Registration

This systematic review was conducted and reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) 2020 guidelines ([Appendix 1.1](#) on page 106 and Fig. 1). The protocol for this systematic review was registered with PROSPERO (REF No. [CRD420251231847](#)) on 14th November 2025. The protocol was updated to reflect changes in database access; refinements to the search strategy following pilot testing and database-specific adaptations; and clarification of the exclusion criteria to ensure studies using purposive sampling of specific mental health conditions were excluded.

Eligibility Criteria

The eligibility criteria and search strategy for this review were developed and guided by the PICOS (Patient/Population/Problem, Intervention, Comparison/Control, Outcome, Study Design; Richardson, 1995; Amir-Behghadami & Janati, 2020) framework (see [Appendix 1.2](#) page 110). Eligibility criteria are described in detail below.

Inclusion Criteria

1. Participants have a diagnosis of ADHD/ASD using ICD or DSM criteria (any version).
2. Participants given a mental health diagnosis *before* ADHD/ASD.
3. Where data on mental health diagnoses is not separated by timing before and after ASD/ADHD diagnosis, over 60% of the total sample must be diagnosed before ASD/ADHD to be included.

4. Studies reporting quantitative data on the mental health diagnoses received before ADHD/ASD diagnosis.
5. Full text paper available in English

Exclusion criteria

1. Studies focusing on people with an intellectual disability (ID). Participants with ID can be included in the data, but focus must be on mental health diagnoses prior to ADHD/ASD.
2. Studies where mental health diagnoses are given at the same time or after an ADHD/ASD diagnosis or where timing of diagnoses cannot be determined.
3. Non-empirical studies (e.g. reviews, case reports/series) and qualitative studies.
4. Studies using purposive sampling to specific mental health conditions.

Search Strategy and Screening

The following databases were searched: Embase, PsycInfo, Medline, Cinahl, Web of Science, Google Scholar (first 100 results), University of Glasgow Enlighten Theses and ProQuest Dissertations and Theses Global. The search terms were developed using the PICOS framework (see [Appendix 1.2](#), page 110). The search strategy for each database is detailed in [Appendix 1.3](#) (pages 111-112). The systematic search was completed on 22nd May 2026.

Piloting searches were carried out in the initial scoping phase to develop the search terms. The results were reviewed to ensure key studies were produced and the search terms were refined accordingly. Keywords and database-specific subject headings were

utilised along with Boolean operators (e.g. OR/AND/NEAR), synonyms and truncation to maximise sensitivity and specificity. Minor database-specific modifications were subsequently made to accommodate differences in indexing and search functionality, particularly regarding diagnostic sequencing and the term misdiagnosis, while maintaining overall consistency in the search strategy. Specific mental health diagnoses were not labelled within the search strategy to avoid predetermining which conditions would be identified. Grey literature searches required additional refinement to maximise retrieval of relevant records with separate searches conducted for ADHD and ASD. The search strategy and selected databases were reviewed in consultation with the University of Glasgow college librarian to ensure effectiveness and adherence to best practice.

All search references were exported into EndNote where EndNote's duplicate reference removal tool was used, followed by manual de-duplication. References were subsequently exported to Rayyan where remaining duplicates were identified, checked individually by the lead researcher and removed. Using the eligibility criteria, 10% (n=785) of titles and abstracts were independently screened by the lead researcher and a second reviewer (TS). Inter-reviewer agreement was 98.3% with 13 discrepancies resolved through discussion. As agreement exceeded the 80% threshold recommended for accelerated screening approaches in rapid reviews, the remaining records were screened by the lead researcher (Nussbaumer-Streit et al. (2023)). Full-text screening was conducted using the same approach, with 10% (n=6) independently screened by the second reviewer (TS). Inter-reviewer agreement was 83.4% with one discrepancy resolved through discussion.

Data Extraction

A data extraction tool was developed and piloted on Microsoft Excel through consultation with the research team prior to running the search strategy to refine the extraction fields and ensure all relevant data could be captured effectively and consistently. Data extracted included study characteristics, participant demographics, diagnostic procedures, prior mental health diagnosis (PMHD) outcomes and prevalence estimates (see [Appendix 1.4](#), page 113, for further detail). To ensure extraction accuracy, the second reviewer (TS) independently extracted data from 20% (n=4) of the included studies, no discrepancies were identified.

Quality Assessment

The Crowe Critical Appraisal Tool (CCAT) form (v1.4) (Crowe, 2013a) alongside the CCAT user guide Version 1.4 (Crowe, 2013b) was used to evaluate the methodological quality and risk of bias of the included studies in this review. The CCAT was chosen for high construct validity across different research designs allowing the lead researcher to easily compare different types of studies and utilise a standardised scoring system (Crowe and Sheppard, 2011). The CCAT is divided into eight sections: Preliminaries, Introduction, Design, Sampling, Data Collection, Ethical Matters, Results and Discussion with prompt descriptors in each section. Each section can be scored on a six-point scale from 0 (no evidence) to 5 (excellent) creating a possible maximum total of 40. To establish study rigor, total scores were divided into the quality categories developed by Shumba et al. (2020), namely: high (total score >30 or a mean score of 3.8-5 across sections), medium (total score 25-30/mean score 3-3.8) and low (total score <25/mean

score <3). To ensure application accuracy, the second reviewer (TS) independently evaluated 20% (n=4) of the included studies. The assessment and scoring were discussed between the reviewers with any discrepancies addressed to reduce bias and refine application of the criteria.

Certainty of Evidence

The certainty of the evidence was assessed using the GRADE (Grading of Recommendations Assessment, Development, and Evaluation) approach (Schünemann et al., 2013). GRADE evaluates the certainty of the evidence across five domains: risk of bias, inconsistency, indirectness, imprecision and publication bias. Overall certainty of the evidence can be classified as high, moderate, low or very low. Certainty in observational designs can be downgraded if concerns are identified within any of the GRADE domains and can be upgraded where observational studies demonstrated particularly strong evidence, such as a large magnitude of effect, evidence of a dose-response relationship, or where plausible confounding would strengthen confidence in the observed findings (Schünemann et al., 2013).

Synthesis of Findings

Studies varied substantially in how PMHD diagnoses were described, measured, and reported. They also varied in diagnostic criteria used to determine ASD and ADHD, which may mean that autistic participants identified in a more modern study where criteria is broader and more inclusive, may not have been recognised if an older study's diagnostic criteria was utilised. Heterogeneity was also found across cross-sectional, longitudinal and retrospective study designs. Given this heterogeneity, statistical meta-

analysis was not considered appropriate as comparing such data was unlikely to be meaningful. Findings were therefore synthesised narratively in accordance with the Synthesis without Meta-analysis (SWiM) guidelines to promote transparency and best practice reporting (Campbell et al., 2020). Studies were grouped according to ADHD/ASD, and findings were compared across studies to identify patterns, similarities, and differences in outcomes. To reduce the influence of outliers which may skew the data, medians and interquartile range (IQR) were calculated. Where studies reported prevalence of PMHD only by sex or age group, overall prevalence estimates were calculated using weighted averages based on subgroup sample sizes.

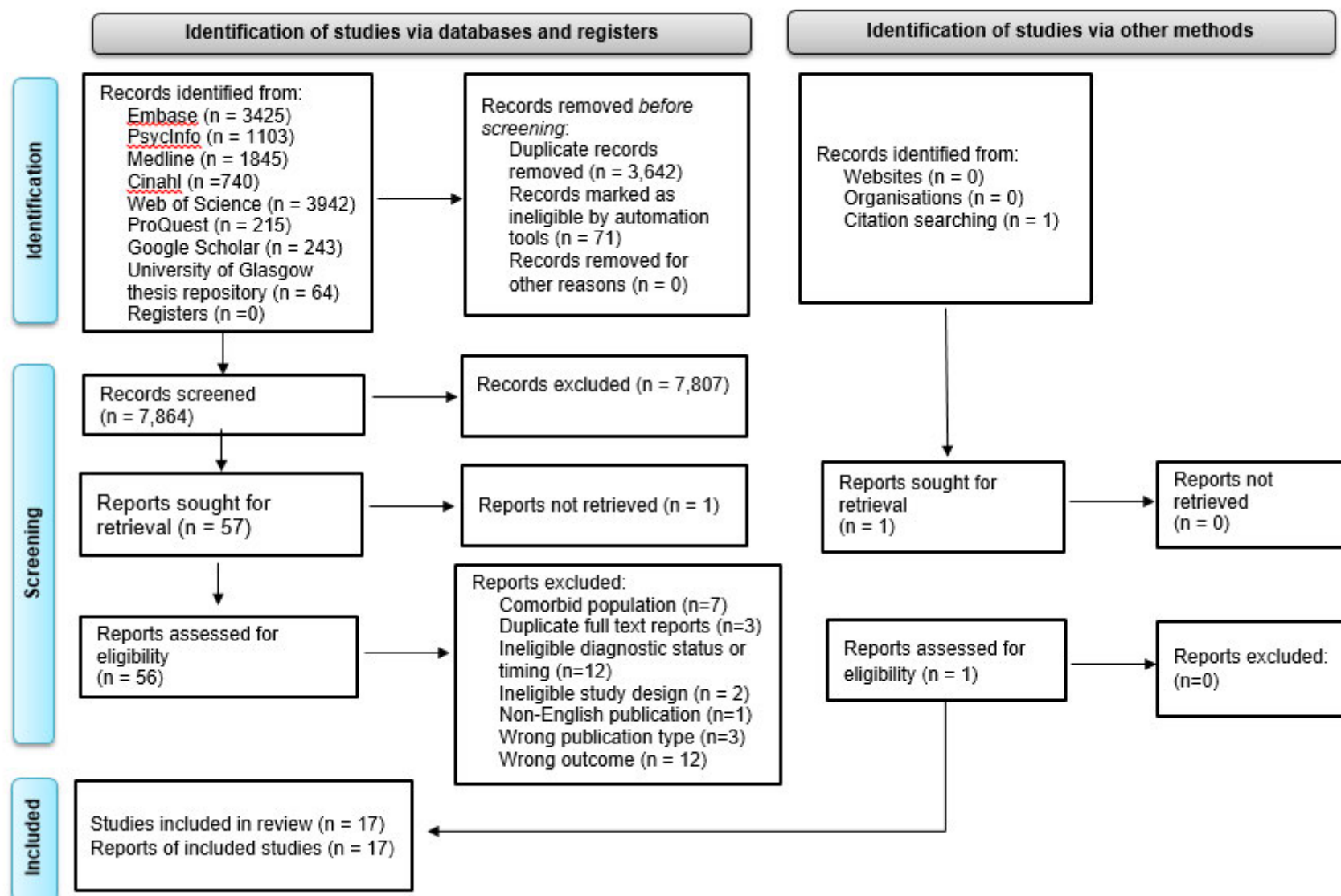
The direction and consistency of findings were examined, with sources of heterogeneity, including differences in participant characteristics, study design, diagnostic criteria, and outcome measures considered when interpreting findings. Based on the proportion of studies reporting each PMHD, a descriptive classification system was used to assess reporting consistency as “high” (>75%), “moderate” (50–75%) or “low” (<50%). Prevalence consistency was assessed based on the width of the IQR as “extremely high” (<5 percentage points), “high” (5–10), “moderate” (11–20), “low” (20–30) or “extremely low” (>30) consistency. Graphs were used as a descriptive tool to facilitate comparison of prevalence estimates and variability across diagnostic categories. Quality appraisal using the CCAT was integrated into the synthesis to contextualise the strength and trustworthiness of the evidence, with methodological limitations considered when drawing overall conclusions.

Results

Study Selection and Screening

The PRISMA flow chart (Fig. [1](#)) illustrates the study selection process. A total of 11,577 records were identified across all database searches. Automatic deduplication in EndNote removed 2,770 records, and manual checking identified a further 872 duplicates. After importation to Rayyan 71 additional duplicates were identified and removed through Rayyan's automated processes, resulting in 7,864 records for title and abstract screening. Following screening, 57 records were sought for retrieval. One redacted report could not be accessed and was excluded after attempts to contact the author were unsuccessful. Sixteen of 56 full-text articles assessed against the eligibility criteria met the inclusion criteria. Within the PRISMA diagram, studies classified as having as an ineligible study design included those which used purposive sampling to a particular mental health condition/s. Forward and backward citation searching of the included studies identified one further eligible study, making a final sample of 17 studies.

Fig. 1 PRISMA Flow Diagram on Study Selection Process



Study Characteristics

The characteristics of the included studies and participants are presented in Table [1](#) along with the key findings relevant to this review. Studies were conducted in Sweden (n=5), Netherlands (n=2) and the USA (n=2), and one in each Denmark, Italy, Iceland, Brazil, Wales, Japan and India. Ten studies focused on ASD, and seven on ADHD. Collectively, they involved 76,012 autistic people and 117,869 individuals with ADHD whose ADHD/ASD diagnosis occurred after the mental health diagnoses investigated. Publication dates ranged from 1992 to 2025, although most studies were published after 2008. Sample sizes varied considerably, ranging from small research cohorts to large national registry studies involving more than 70,000 autistic people, and 85,000 individuals with ADHD. Studies predominantly utilised retrospective observational designs gathering data from clinical records, population-based databases and national registers, alongside a smaller number of studies with descriptive cross-sectional and longitudinal designs using research samples. The age of participants, and the age of ADHD/ASD diagnosis ranged from childhood to adulthood, though studies frequently did not report the age which ADHD/ASD diagnoses were given (n=8). There was considerable variation in the diagnostic criteria used for ASD, with five different sets of criteria utilised across the 10 studies. Due to the changes in criteria this meant several different diagnostic terms were used for ASD. The ADHD studies demonstrated slightly greater consistency in ADHD diagnostic classification, with only three different sets of criteria used across the seven studies. Across both groups of studies, participant samples were predominantly male, with only three studies including more than 50% female participants.

Table 1 Characteristics of Included Studies

Author/s (publication year), Country	Study design	Data source, sampling period	Population ADHD/ASD, (specific ASD diagnosis), criteria defined by.	Sample characteristics (Total sample size, mean/median age [SD where reported; range], sample size examined for PMHD if different, mean age at ADHD/ASD diagnosis [Dx], % female ADHD/ASD)	Key findings: Mental health conditions preceding ADHD/ASD (as described by authors) *grouping of disorders where breakdown is provided.	Criteria used to define PMHD	Other NDD/ psychiatric conditions reported % (n)
Fusar-Poli et al. (2022), Italy	Retrospective	Clinical records, patients diagnosed between 2013- 2019	ASD (ASD), DSM-V	N=161 Median age: 23 (18-55) Age ASD Dx: adulthood. 29.2%	Depressive disorders, anxiety disorders, Psychoses*, PDs, OCD, Bipolar, Eating disorders, emotional and CDs, gender identity disorder, other psychiatric disorders*	ICD-10	ADHD (6.8%, n=11), ID (21.7%, n=35), language disorder (2.5%, n=4).
Geurts and Jansen, (2011), Netherlands	Retrospective	Clinical records, patients seen between 1994 and 2006.	ASD (Autistic disorder, AS, PDD-NOS), DSM-IV-(TR)	N=125 Median age: 31.0 (18-64) N=105. Age ASD Dx: 18-82. 24%	Mood, anxiety, psychotic characteristics*, PDs*, attachment problems, sexually impulsive, eating disorder, adaption disorders, addiction/substance dependency.	DSM-IV-(TR)	ID=34% (n=36), learning disorder (1%, n=1), paedophilia (2%, n=2).
Ghaziuddin & Zafar (2008), USA	Retrospective	Clinical records, December 2001-December 2006	ASD (ASD), DSM-IV	N=38 Mean age: 26.5 (11.3; 18- 57 years) N=28 (14 AS, 8 PDD-NOS, 6 autism) Age ASD Dx: NR. 35.7%	Depression*, anxiety disorders*, psychosis, OCD, catatonia.	DSM-IV	ADHD (17.86%, n=5), Tourette syndrome (3.57%, n=1).

Jónsdóttir (2022), Iceland	Retrospective	Clinical Records, 2013 & 2021	ADHD, ICD-10	N=1001 Mean age: 30.8 years (9.2; range 18-64). Age ADHD Dx: NR. 47.8%	Depression, anxiety, other disorders (unexplained).	NR (diagnosed by GP, psychologist or self-report)	NR
Kentrou et al. (2021), Netherlands	Cross-sectional	Population Register (Netherlands Autism Register), sampling period NR	ASD (PDD, ASD), ICD-10	N=1019 Mean age: 45.84 (13.23; 20.35-84.35) Mean age ASD Dx: 34.2. 51.5%	Mood disorders, anxiety disorders, trauma related disorders, PDs, burnout/chronic fatigue, eating disorders, ODD/CD, SUD.	NR (self-report)	ADHD: 10.5% (n=107). Males: 7.7% (n=38), females: 13.1% (n=69)
Manfro et al. (2024), Brazil	Prospective longitudinal cohort	Research sample, sampling period NR, but follow up was three years later.	ADHD, DSM-IV	N=2,511. Mean baseline age: 9.82 (1.06; NR) Mean follow up age: 13.14 (1.04; NR). N=28 (Youth-Onset group) Age of ADHD Dx: NR but Dx by follow up. 64.3%	Any depression disorder, any anxiety disorder, any CD/ODD.	NR (utilised 'psychiatric instruments')	NR
Martin et al. (2024), Wales	Retrospective cohort	Population register (Secure Anonymised Information Linkage databank). 01.01.2000 and 31.12.2019	ADHD, ICD-10	N=16,458 Age: NR, (3-30). Mean age ADHD Dx: Males: 10.9; Females: 12.6. 20.3%	Depression, anxiety, other mental health condition (unexplained).	ICD-10	NR
Martini et al. (2025), Sweden	Longitudinal cohort	Three population registers. Born in Sweden between 1990-2015. ASD Dx	ASD (autism, childhood autism, atypical	N=72,331 Mean age: NR Mean age ASD Dx: 13.01 (6.00, 1.0-30.9).	Depressive disorders, anxiety disorders, psychotic disorders borderline PD, bipolar, AN, other eating disorders, sleep disorders.	NR (diagnosed on records)	ADHD: 26.5% (n=19,133). Females: 24.5% (n=5,907);

		examined 2010-2020.	autism, AS, PDD-NOS, Other PDD), ICD-9	33.3%			Males: 27.4% (n=13,226). ID: 14.3% (n=10,331), females: 12.7% (n=3054), males: 15.1% (n=7277).
Mazefsky et al. (2012), USA	Cross sectional	Research sample, sampling period NR	ASD (autistic disorder, AS, PDD-NOS), DSM-IV-TR	N=35 Mean age: 12.11 (2; 10–17) Mean age ASD Dx: 10.89 years (3.0; range; 3-16) 20%	Depressive disorder, anxiety disorder, OCD, bipolar disorder, ODD, internalising disorders, externalising disorder (ADHD, ODD).	NR (parent report)	Externalising disorder (ADHD, ODD) 62.9% (n=22)
Nahar et al. (2019), India	Retrospective	Clinical records, 2000 - 2016	ASD (High-functioning autism [HFA] AS, PDD-NOS), ICD-10.	N=33 Mean age: 22.76 (4.8; 17-37) Mean age of ASD Dx: same as above. 21.2%	Depression, psychotic spectrum disorder, OCD, bipolar affective disorder, behavioural addiction, SUD.	ICD-10	12% ADHD (n=4)
Nylander & Gillberg (2001), Sweden	Cross-sectional	Research Sample, screening from 1996 census.	ASD (Atypical autism, Childhood autism assessed by ICD-10, AS - no criteria used)	N=1,323. 66 screened. Mean age: NR N=17 no pre-dx ASD (Total ASD=19) Mean age ASD Dx: NR. NR for target sample, but 26.3% of 19 with ASD.	Neurotic depression, anxiety neurosis, Schizophrenia paranoid type, schizoaffective type & NOS, PD, bipolar affective psychosis, crisis reaction, phobia.	ICD-9	ID ('Mental retardation') 11.76% (n=2)
Nylander et al. (2009), Sweden	Cross-sectional	Research Sample, April-June 2001	ADHD, DSM-IV	N=141 (completed screening tool) N=47 assessed.	Affective disorders*, anxiety disorders*, PDs*, maladaptive reactions*, alcohol/drug dependence*.	NR (taken from records)	Organic syndromes 2.7% (n=1), childhood disorders F70-F98

				Mean age: 39 (13.19; NR).			(n=6), unclear diagnosis (n=2).
				N=24 no pre-Dx ADHD (Total ADHD=30) Mean age ADHD Dx: NR. 70% with ADHD			
Okada et al. (2024), Japan	Mixed method observational retrospective cohort (data relevant to this review) and cross-sectional.	Nationwide Insurance Claims Database, 2005-2021. Enrolment period for retrospective cohort: 2017-2019.	ADHD, ICD-10	N=14,940. Mean age: NR (0-57) Mean age ADHD Dx: NR. NR	Recurrent depressive disorder, anxiety disorders, schizophrenia, schizotypal disorder, mood disorders, OCD, bipolar affective disorder, eating disorders, CD (excluding ODD), Reaction to severe stress and adjustment disorders, SUD, dissociative disorders, somatoform disorders, tic disorder, sleep disorder.	NR (taken from records)	ASD: Child: 33.9%, Adult: 14.1%, ID: Child: 5.3%, Adult: 1%.
Ratey et al. (1992), USA	Cross-sectional retrospective	Clinical records, NR.	ADHD, DSM-III-R	N=60 Median age: 34 (NR; 22-65). Mean age ADHD Dx: NR. 25%	Mood disorders*, anxiety, OCD, other (eating disorders sleep disorders, somatization), drug abuse, antisocial behaviour.	NR	NR
Rødgaard et al. (2021), Denmark	Retrospective cohort	Population register (Danish National Patient Registry), 1994-2018	ASD (Autistic disorder, atypical autism, AS, PDD-NOS, Other PDD-NOS), ICD-10	N=2,199. Mean age: NR. Mean age ASD Dx: NR. 40.3%	Affective (mood) disorders, anxiety disorders, psychotic disorders, stress disorders, OCD, CD, dissociative and conversion disorders, eating disorders, selective mutism, sleep disorders, somatoform disorders, tic disorders.	ICD-10	ADHD: 9.3% (n=205); disorders of scholastic skills: 1.1%, (n=24); disorders of social functioning: 3.26% (n=72); disorders of speech and

							language: 1.85% (n=40); ID: 4.44% (n=98).
Ryden & Bejerot (2008), Sweden	Cross-sectional controlled	Research sample, January 2001-December 2006	ASD (ASD), DSM-IV	N=84 Mean age: 30 (10; NR) Mean age ASD Dx: NR. 46.4%	Major depressive disorder, generalized anxiety disorder, psychotic disorders, borderline PD, OCD, bipolar disorder, AN, post-traumatic stress disorder (PTSD), panic disorder, and social phobia.	DSM-IV	NR
Skoglund et al. (2024), Sweden	Population-based cross-sectional	Population register (Regional Healthcare Data Warehouse of Region Stockholm), 2011-2021	ADHD, ICD-10	N=85,330 Mean age: NR Mean age ADHD Dx: Females: 23.5 (13.8; NR); males: 19.6 (13.9; NR). 44.1%	Mood (affective) disorders, anxiety disorders*, psychotic disorders, PDs, eating disorders, CD, sleep disorders, SUD	ICD-10	ASD: 11.4% (n=9,687); Tics/Tourette: 1.3% (n=1,102); ID ('Mental retardation'): 1.2% (n=999).

NR Not reported, AN anorexia nervosa, AS Asperger's syndrome, CD conduct disorder, ID Intellectual Disability, OCD Obsessive compulsive disorder, ODD oppositional defiant disorder, PD personality disorder, SUD substance use disorder.

Prior Mental Health Diagnoses (PMHD)

The included studies reported a broad range of mental health diagnoses received prior to ADHD/ASD diagnosis. These included depressive (including mood) disorders (n=17), anxiety disorders (n=16), psychotic disorders (n=10), personality disorders (PDs) (n=8), OCD (n=9), bipolar disorder (n=7), eating disorders (n=9), trauma- and stress-related disorders (n=4), substance use disorders (SUD) (n=8), behavioural disorders (e.g., ODD/CD) (n=8) and sleep disorders (n=4). Several less commonly reported conditions were also identified, including catatonia (n=1), selective mutism (n=1), dissociative/conversion disorders (n=2), maladaptive reactions (n=1), antisocial behaviour (n=1), tic disorders (n=2), attachment disorders (n=1) and gender identity disorder (n=1).

There was considerable variation in how PMHDs were defined and classified across studies. Among the ASD studies, four different diagnostic criteria were used, while three studies did not report the criteria used to define PMHDs (Kentrou et al., 2021; Martini et al., 2025; Mazefsky et al., 2012). Reporting was further reduced among the ADHD studies, with only two out of seven studies specifying the diagnostic criteria used to define PMHDs (Martin et al. 2024; Skoglund et al., 2024). Where justification was provided, PMHD diagnoses originated from healthcare professional, self- or parent-report, or psychiatric instruments.

Several studies reported additional, non-mental health diagnoses prior to ADHD/ASD, such as intellectual disability (ID), Tourette syndrome, organic syndromes, and vague categories like 'childhood disorders' among others. ADHD was reported as a diagnosis

preceding ASD in seven of the ASD studies (Fusar-Poli et al., 2022; Ghaziuddin & Zafar, 2008; Kentrou et al., 2021; Martini et al., 2025; Mazefsky et al., 2012; Nahar et al., 2019; Rødgaard et al., 2021), and ASD was reported as a prior diagnosis in two of the ADHD studies (Okada et al., 2024, Skoglund et al., 2024).

Methodological Quality

Table [2](#) illustrates the methodological assessment of the included studies by study type (ADHD/ASD). Asterisks indicate studies independently assessed by the second reviewer (TS). CCAT scores ranged from 18 to 38, with most studies classified as high quality. One study in each group was rated as low quality (Geurts & Jansen, 2011; Ratey et al., 1992), while Ghaziuddin and Zafar (2008) and Nahar et al. (2019) were classified as medium quality. Applying the alternative mean-score classification resulted in Nylander and Gillberg (2001) and Nylander et al. (2009) being categorised as medium quality despite achieving overall scores within the high-quality range, highlighting limitations of the CCAT classification system proposed by Shumba et al. (2020).

Across studies, the introduction domain received the highest ratings, with all studies scoring at least four points. Ethical considerations received the lowest ratings, with two studies scoring zero due to a lack of reporting on ethical approval, consent procedures, funding, conflicts of interest or participant confidentiality, contributing substantially to their low overall quality ratings (Geurts & Jansen, 2011; Ratey et al., 1992). Lower scores were also common in sampling, study design and data collection domains, reflecting limited reporting of sampling strategies, design rationale, data collection methods,

potential sources of bias, study variables, effect modifiers, participant withdrawal, and missing data.

Four studies did not report a sampling period (Kentrou et al., 2021; Mazefsky et al., 2012; Manfro et al., 2024; Ratey et al.; 1992), and no study reported conducting a priori power analysis. However, several studies used large population-based or national registry data sets, reducing concerns regarding statistical power. Ten studies reported both inclusion and exclusion criteria, while the remainder reported at least one. Despite referring to diagnostic criteria to assess ADHD/ASD, many provided limited information regarding assessment procedures. Reporting of PMHD measurement was also inconsistent, with substantial variation in methods across studies; limiting comparability of prevalence estimates across studies.

Table 2 Quality Assessment of Studies using the CCAT

ASD Studies	Authors	Preliminaries	Introduction	Design	Sampling	Data collection	Ethical matters	Results	Discussion	Total	Percentage	Quality Category ^a	Mean
	Fusar-Poli et al. (2022)*	4	5	4	3	4	4	4	4	32	80.00%	High	4.00
	Geurts & Jansen (2011)	4	4	3	4	3	0	3	3	24	60.00%	Low	3.00
	Ghaziuddin & Zafar (2008)*	3	4	3	3	3	2	3	4	25	62.50%	Medium	3.13
	Kentrou et al. (2021)	4	5	4	4	4	4	4	4	33	82.50%	High	4.13
	Martini et al. (2025)	5	5	4	5	4	5	4	5	37	92.50%	High	4.63
	Mazefsky et al. (2012)	4	5	4	3	4	4	4	5	33	82.50%	High	4.13
	Nahar et al. (2019)*	4	4	3	3	3	3	3	4	27	67.50%	Medium	3.38
	Nylander & Gillberg (2001)	4	5	3	3	3	4	4	4	30	75.00%	High	3.75
	Rodgaard et al. (2021)	5	5	4	5	4	5	4	4	36	90.00%	High	4.50
	Ryden & Bejerot (2008)	5	5	4	4	4	4	4	5	35	87.50%	High	4.38
	Total score for domain	42	47	36	37	35	35	37	42				
	Mean score per domain	4.2	4.7	3.6	3.7	3.5	3.5	3.7	4.2				

Authors	Preliminaries	Introduction	Design	Sampling	Data collection	Ethical matters	Results	Discussion	Total	Percentage	Quality Category ^a	Mean
Jónsdóttir (2022)	4	5	4	4	4	3	4	4	32	80.00%	High	4.00
Manfro et al. (2024)	5	5	4	4	4	4	4	4	34	85.00%	High	4.25
Martin et al. (2024)*	5	5	4	5	4	5	5	5	38	95.00%	High	4.75
Nylander et al. (2009)	4	5	3	3	4	4	3	4	30	75.00%	High	3.75
Okada et al. (2024)	5	5	4	3	3	4	4	5	33	82.50%	High	4.13
Ratey et al. (1992)	3	4	2	2	2	0	2	3	18	45.00%	Low	2.25
Skoglund et al. (2024)	5	5	4	4	4	4	5	4	35	87.50%	High	4.38
Total per domain	31	34	25	25	25	24	27	29				
Mean score per domain	4.4	4.9	3.5	3.5	3.5	3.4	3.9	4.1				

^aHigh (green): total score >30 or mean score of 3.8-5, medium (orange): total score 25-30 or mean score 3.0-3.8, low (red): total score <25 or mean score <3.0.

*Appraised by second reviewer (TS).

PMHD Outcomes

A broad range of PMHDs were reported across the 17 studies. The findings for PMHD per study can be seen in Supplementary Table [1](#) and [2](#) (Appendix 1.5, pages 114-118). Depressive disorders were reported in all studies, while anxiety disorders were reported in all ADHD studies and nine of 10 ASD studies. Prevalence estimates varied substantially across studies for both depressive and anxiety disorders, indicating considerable heterogeneity in PMHD prevalence across ASD and ADHD samples. Substantial heterogeneity was also evident in how the PMHDs were categorised. Several studies combined related diagnoses (e.g. mood, anxiety and psychotic disorders), whereas others reported specific diagnoses separately (e.g. SUD). Nine ASD studies and two ADHD studies (Manfro et al., 2024; Ratey et al., 1992) reported on the number of PMHD experienced by participants (Supplementary Table [3](#), Appendix 1.5, page 119). However, substantial variability was observed across studies. Across ASD studies, between 34% and 100% of participants had at least one PMHD, with prevalence decreasing as the number of PMHDs increased. The limited data available for ADHD precluded meaningful comparison between diagnostic groups.

Synthesis of PMHDs

In line with the SWiM approach, the data for the ASD/ADHD studies were synthesised separately. The PMHD experienced before ADHD/ASD were grouped into diagnostic categories to facilitate comparison across studies.

ASD Studies

Table 3 and Fig. 2 show that anxiety, depressive and psychotic disorders were the most frequently reported diagnoses prior to ASD, thus demonstrating the highest reporting consistency. However, prevalence consistency was lower, with depressive disorders demonstrating low consistency and anxiety and psychotic disorders showing moderate consistency. Despite using median and IQR values to reduce the influence of extreme values, substantial variability remained in prevalence estimates for four out of nine of the diagnostic categories analysed. Conversely, several of those with less frequently reported PMHDs, such as SUD and PDs, demonstrated narrower IQRs and therefore greater prevalence consistency. Fig. 3 shows that PDs demonstrated the highest median prevalence (14.95%), whereas depressive disorders exhibited the greatest variability in prevalence estimates.

Table 3 PMHDs in ASD Studies

PMHD	No. of ASD studies reporting each diagnosis	Prevalence range	Median	Q1-Q3	IQR (Q1-Q3)	Reporting consistency	Prevalence Consistency
Depressive disorders	10	3.00-50.00%	13.55%	12.07-36.53	24.46%	High	Low
Anxiety/anxiety disorders	9	5.40-42.00%	8.75%	5.84-17.14	11.30%	High	Moderate
Psychotic disorders	8	1.00-29.40%	9.20%	6.07-18.88	12.81%	High	Moderate
Bipolar Disorder	7	1.30-39.30%	3.70%	2.50-14.30	11.80%	Moderate	Moderate
OCD	7	2.17-48.40%	5.54%	3.14-10.43	7.28%	Moderate	High
Eating disorders	6	1.90-13.20%	2.44%	2.10-4.67	2.58%	Moderate	Extremely High
PD	6	11.76-19.60%	14.95%	11.93-16.15	4.23%	Moderate	Extremely High
CD/ODD/Emotional disorders	5	2.40-28.60%	3.00%	2.71-7.50	4.79%	Moderate	Extremely High
SUD	3	2.00-3.40%	3.00%	2.50-3.20	0.70%	Low	Extremely High

Fig 2. Number of ASD studies reporting each PMHD

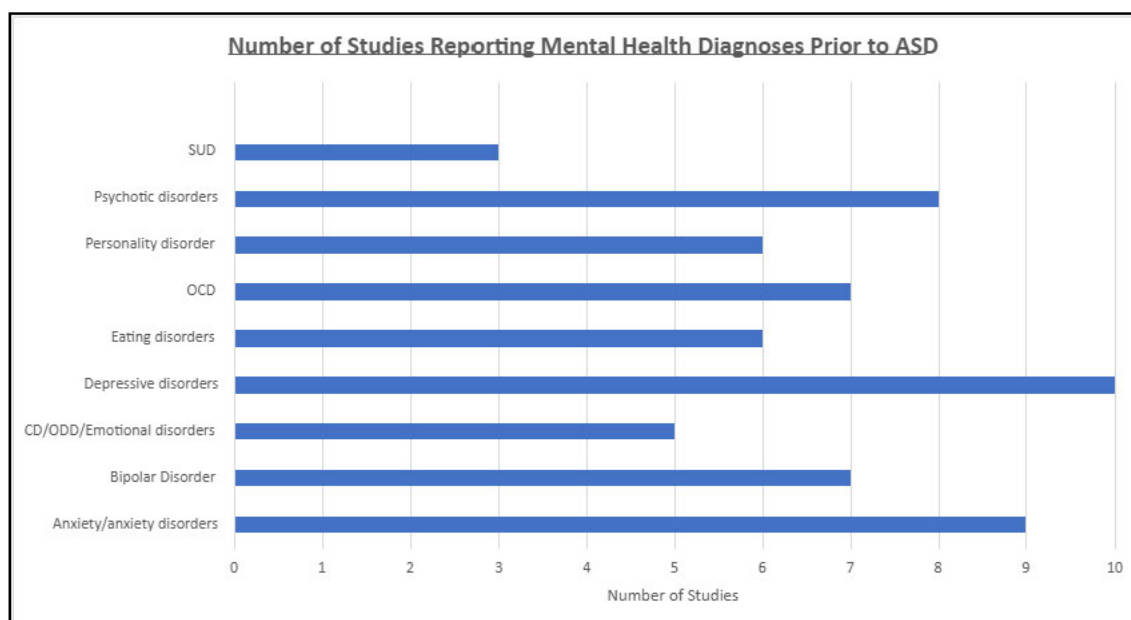
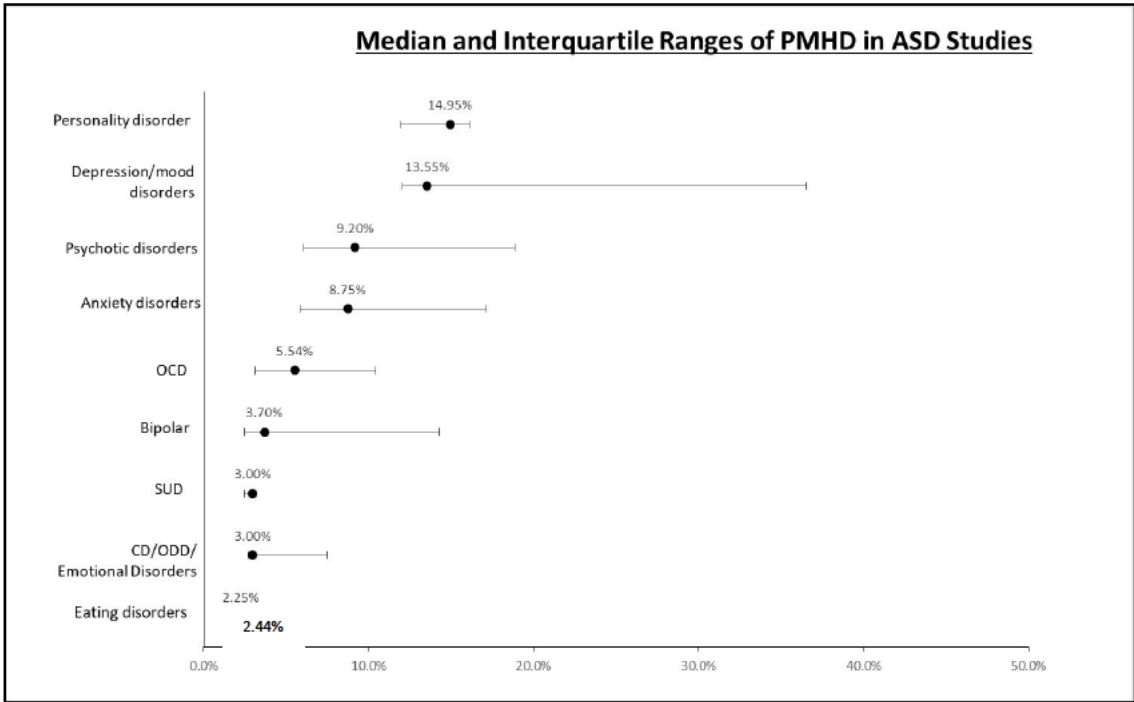


Fig. 3 Median and IQRs of PMHD in ASD studies



Although prevalence by sex is not the primary focus of this review, four of the ASD studies presented prevalence rates of PMHD by sex. This data is illustrated in Supplementary Table 4 and Supplementary Fig. 1 (Appendix 1.5, pages 120-121). Across the PMHD categories reported, median prevalence estimates were generally higher in females than males except for CD/ODD/emotional disorders. The highest median prevalence estimates among females were observed for depressive, PDs, and anxiety disorders, although prevalence estimates for these categories demonstrated only moderate consistency, compared to the other PMHDs reported. In males, PDs showed the highest median prevalence, followed by depressive and anxiety disorders; the latter two diagnoses demonstrated “extremely high” consistency of prevalence estimates. However, this sex-stratified data was only available from two to four studies per diagnostic category.

ADHD Studies

Similarly to the ASD studies, anxiety and depressive disorders were the most consistently reported diagnoses prior to ADHD diagnosis (see Table 4 and Fig 4). However, prevalence estimates were less consistent for both diagnoses, demonstrating only moderate IQR widths. All other diagnostic categories scored low reporting consistency, reflecting the smaller number of contributing studies. Nevertheless, most PMHD reported by only two or three studies demonstrated narrow IQRs, demonstrating “extremely high” consistency in prevalence estimates across studies.

Table 4 PMHDs in ADHD Studies

PMHD	No. of ADHD studies reporting PMHD	Prevalence range	Median	Q1-Q3	IQR (Q1-Q3)	Reporting consistency	Prevalence Consistency
Depressive disorders	7	3.60-48.80%	27.40%	24.40-35.00%	10.60%	High	Moderate
Anxiety disorders	7	0-54.60%	15.00%	10.80-21.90%	11.10%	High	Moderate
Sleep disorders	2	6-12.80%	9.40%	7.70-11.10%	3.40%	Low	Extremely High
CD/ODD	3	0.20-11.00%	7.10%	5.30-8.90%	3.60%	Low	Extremely High
PDs	2	3.90-8.00%	5.95%	4.93-6.98%	2.05%	Low	Extremely High
Psychotic disorders	2	1.20-5.60%	3.40%	2.30-4.50%	2.20%	Low	Extremely High
OCD	2	0.80-5.00%	2.90%	1.85-3.95%	2.10%	Low	Extremely High
SUD	3	0.60-12.30%	2.70%	1.65-7.50%	5.85%	Low	High
Eating disorders	2	0.50-2.80	1.65%	1.08-2.23%	1.15%	Low	Extremely High

Fig. 4 Number of ADHD studies reporting each PMHD

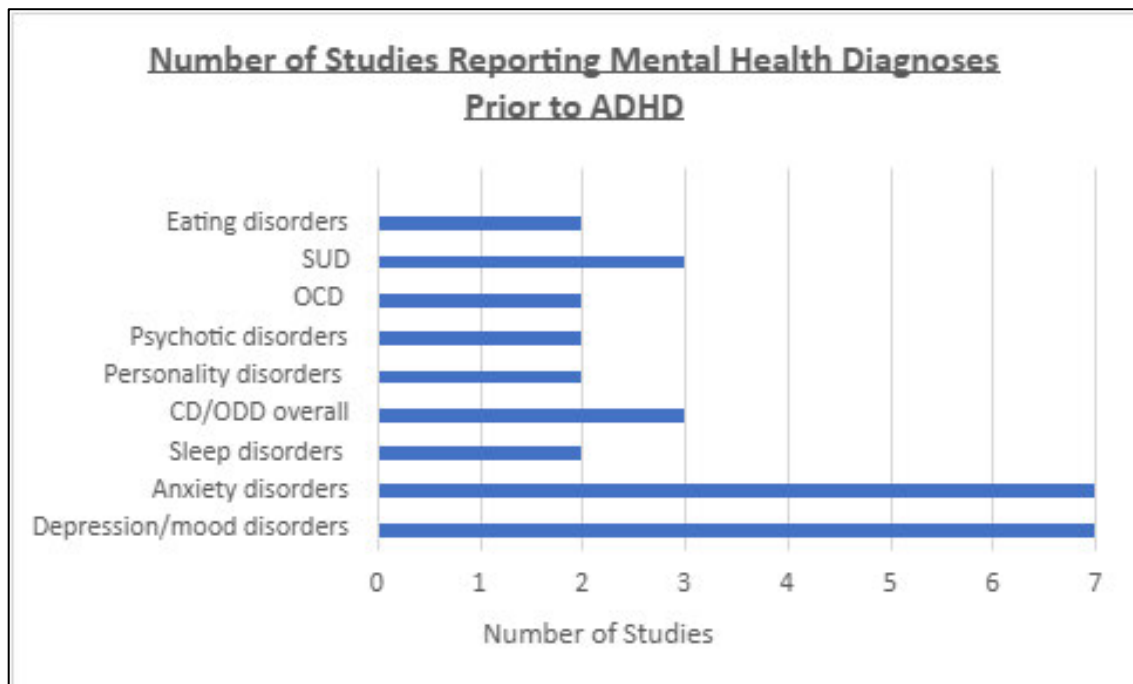
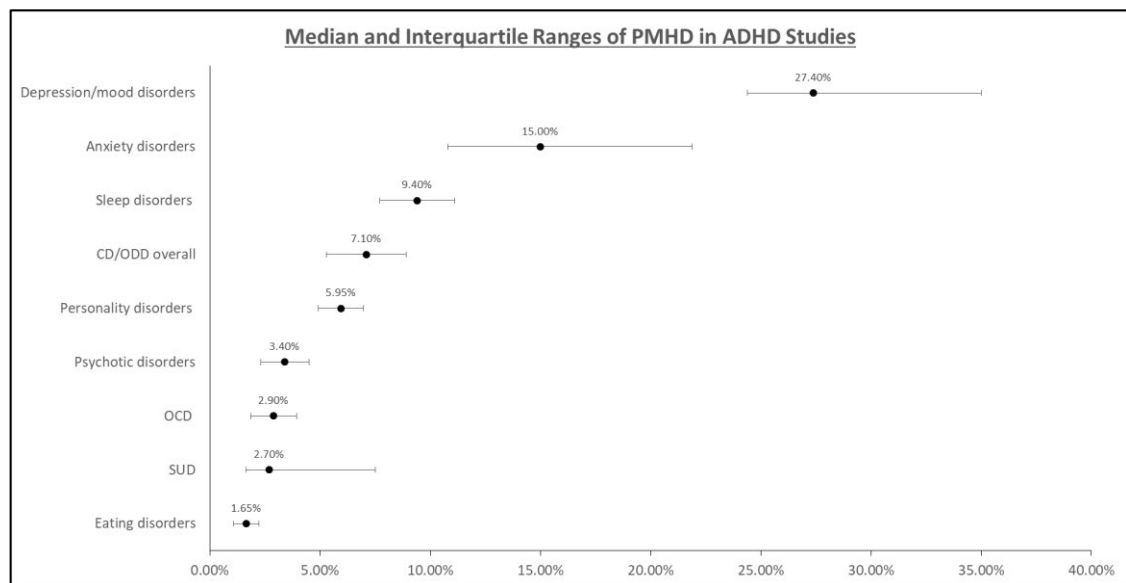


Fig. 5 Median and IQRs of PMHD in ADHD Studies



As well as being the most frequently reported PMHD categories, Fig. 5 illustrates that anxiety and depressive/mood disorders (27.4%) also had the highest median prevalence estimate prior to ADHD diagnosis. However, these categories also demonstrated the greatest variability in prevalence estimates across studies. SUD also appears to

demonstrate relatively high prevalence estimates compared with other PMHD categories; however, Table [4](#) indicates that this observation is largely relative to the lower prevalence estimates reported for the remaining diagnostic categories.

Only three ADHD studies reported sex-stratified prevalence estimates across two or more PMHD categories, and these were limited to anxiety and depressive disorders (see Supplementary Table [5](#) and Supplementary Fig. [2](#) in Appendix 1.5, pages 122-123). As in the ASD studies, females demonstrated higher median prevalence estimates than males for both anxiety and depressive disorders. Anxiety disorders were the most prevalent PMHD among both females and male. The consistency of these prevalence estimates ranged from “high” to “moderate” across disorders and sexes.

Certainty of Evidence

GRADE ratings are presented in Supplementary Table [6](#) (Appendix 1.5, page 124). As all included studies were observational, certainty of the evidence was initially rated as low. No evidence was eligible for upgrading as this review focused on prevalence estimates rather than intervention effects or causal associations. Although several methodological limitations were identified during CCAT appraisal, average domain scores were generally high and risk of bias was not considered sufficiently serious to warrant downgrading. Likewise, all studies provided data relevant to the review question and publication bias could not be adequately assessed. Precision was supported in both groups due to the large, combined sample sizes across ASD (77,318 participants) and ADHD (120,441 participants) studies. However, the ASD findings were rated “very low” due to substantial inconsistency and variability in prevalence estimates across studies.

The ADHD findings however demonstrated greater overall consistency, resulting in a “low” certainty rating. Sex-stratified findings were also downgraded to “very low” for both groups due to imprecision, because few studies contributed data.

Discussion

This review sought to determine the most common mental health diagnoses received prior to an ADHD/ASD diagnosis. Alongside this, we aimed to assess the quality of this evidence to determine if there is enough reliable data to illustrate a specific pattern of PMHD which may prompt clinicians to screen for ADHD/ASD. Seventeen studies were included in this review, 10 ASD studies and seven ADHD studies. The mental health diagnoses most often reported across studies prior to ADHD/ASD were anxiety and depressive disorders. In the ADHD studies, these diagnostic groups also demonstrated the highest median prevalence estimates, whereas in the ASD studies, PDs were found to have the highest median prevalence, followed by depressive and psychotic disorders. Psychotic disorders were also highly reported, with eight out of 10 ASD studies reporting this diagnostic category. Sex stratified data revealed that females across ADHD/ASD studies displayed higher median rates of PMHDs compared to males, aside from the single category of CD, ODD or emotional disorders in the ASD studies. The highest PMHD median rate for females in the ASD studies was depressive disorders, followed by anxiety and PDs, whereas in males PDs were highest, followed by depressive and anxiety disorders. In the ADHD studies, sex-stratified data was only comparable for depressive and anxiety disorders and found that both sexes had a higher median prevalence estimate for anxiety over depressive disorders. Furthermore, it appeared common for participants across ADHD/ASD studies to experience at least one PMHD (34-100%) if not more, though selection bias and study design must be considered carefully when interpreting this finding.

These findings support the review question. However, the interpretation becomes less clear when the most frequently reported PMHDs differ from those with the highest median prevalence estimates, as observed in the ASD studies. This inconsistency, alongside the substantial variability in prevalence estimates across the ASD studies, considerably limits confidence in these findings, as reflected in the very low GRADE certainty rating. This also demonstrates that frequent reporting does not necessarily reveal the most consistent prevalence estimates. In contrast, findings for ADHD demonstrated greater consistency, with the most frequently reported PMHDs also showing the highest median prevalence estimates. Accordingly, confidence in these findings is somewhat greater, although the evidence was still rated as low certainty according to GRADE. Confidence in the sex-stratified findings for both groups was further limited by the small number of contributing studies, resulting in very low certainty ratings. Consequently, although the findings provide preliminary support for the review question, they should be interpreted with caution given the low to very low certainty of the evidence and the methodological concerns identified across the included studies.

The high rates of anxiety and depressive disorders prior to ADHD diagnosis, are also among the most prevalent mental health diagnoses within the general population (Steel et al., 2014). It should be considered therefore if mental health studies are skewed to search for these diagnoses. However, prevalence estimates in the current review (anxiety disorders: 15%, depressive disorders 27.4%) were generally higher than general population estimates (6.7% and 5.4% respectively) (Steel et al., 2014), and broadly comparable to ADHD comorbidity estimates, especially for comorbid anxiety disorders

(18.4%) (Njardvik et al., 2025). Comorbidity prevalence estimates for depressive disorders however seem to be much lower (8.3%) (Njardvik et al., 2025), compared to this study's finding prior to ADHD. One possible explanation is that living with unrecognised ADHD contributes to poor mental wellbeing, lower self-esteem, anxiety and depression, and that diagnosis can provide a sense of relief lifting feelings of low mood (Alarachi et al., 2026; French et al., 2023). Yet, diagnosis does not necessarily equate to adequate support, which could explain why anxiety may remain high following diagnosis (Alarachi et al., 2026). However, the included studies were not designed to examine causal mechanisms and these findings should therefore be interpreted cautiously.

Anxiety, depressive and psychotic disorders are some of the most common comorbid mental health disorders in ASD, making the high reporting rates of these diagnoses in this review unsurprising (Hossain et al., 2020). The median prevalence estimates for these diagnostic groups in this review (anxiety disorders 8.75%; depressive disorders 13.55%, psychotic disorders 9.20%) fall within the prevalence ranges reported in Hossain et al.'s (2020) umbrella review of comorbid psychiatric disorders in ASD (anxiety disorders 1.47-54%, depressive disorders 2.5-47.1%; psychotic disorders 4-67%), lending support to the consistency of these findings. Anxiety, depressive, and psychotic disorders therefore seem to be present before and after ASD diagnosis, which makes sense as research indicates approximately 54-94% of autistic people experience mental health difficulties for a range of reasons. One such reason could potentially be the negative impact neurotypical society has on autistic people's mental health and the use of camouflaging strategies to cope with this even after autism diagnosis (Field et al.,

2024). Although fewer ASD studies reported PD in the current review, this was also consistent with Hossain et al.'s findings, who only found one study to report a prevalence estimate for PD (12.6%) which was comparable to the median prevalence estimate found in this study (14.95%) prior to ASD diagnosis. This slightly higher prevalence estimate of PD prior to ASD diagnosis could also support research suggesting PD may be misdiagnosed prior to ASD (Fusar-Poli et al., 2022; Kentrou et al., 2024).

Although based on a limited number of studies, females generally showed higher PMHD prevalence than males prior to ADHD/ASD diagnosis. This is consistent with existing evidence that females experience higher rates of internalizing disorders, including anxiety, depression and eating disorders, both in ASD comorbidity research and among individuals newly diagnosed with ADHD (Mao et al., 2024; Siddiqui et al., 2024). Sex differences were also more pronounced in the ASD studies than the ADHD studies, particularly for depression, anxiety, PD and eating disorders. Delayed identification may contribute to these differences, as females are often diagnosed with ADHD/ASD later than males, and may therefore spend longer without appropriate support (Marques et al., 2025; Siddiqui et al., 2024). More broadly, females in the general population are more likely to present with internalizing difficulties, while males more commonly exhibit externalising problems such as SUD or CD, suggesting these findings reflect wider sex differences in mental health presentations (Fusar-Poli et al., 2022; Otten et al., 2021; Steel et al., 2014). This may also explain why CD was the only PMHD with a higher median prevalence in males than females within the ASD studies. However, it does not account for PD having the highest median prevalence for among males in this review. While misdiagnosis could be a contributing factor; existing evidence suggests

misdiagnosis is more often perceived by females than males (Kentrou et al., 2024). Another alternative is that this sex-stratified data lacks precision given that only three studies contributed to it.

A key consideration when interpreting the findings of this review is the substantial heterogeneity across studies. Although medians and IQRs were used to minimise the influence of outliers, prevalence estimates for several PMHDs, particularly depressive and anxiety disorders, and psychotic disorders in the ASD studies, remained highly variable, suggesting substantial disagreement between studies. This variability may partly reflect differences in sample composition, diagnostic procedures and study design, alongside marked variation in study sample sizes, which ranged from fewer than 30 participants in some studies to over 70,000 in others. Smaller studies are more likely to produce unstable prevalence estimates, further contributing to variability. In addition, evidence for some PMHDs was sparse, and diagnostic categories were often defined inconsistently across studies, making it difficult to determine the accuracy of the reported prevalence rates. However, these challenges are not unique to this review (Hossain et al., 2020).

Although most studies were rated as high quality, limitations within the design, sampling and data collection domains may have introduced bias. This was reflected in the CCAT findings, where sampling data collection and study design were among the weakest scoring domains across both ADHD/ASD evidence bases. Furthermore, several PMHD categories were informed by only a small number of studies, and potential sampling bias was identified within at least one study (e.g. Okada et al., 2024). These factors may have limited generalisability of some findings despite the generally high

methodological quality observed overall. In addition, several ASD studies did not report using gold standard assessment measures or multidisciplinary diagnostic procedures, potentially increasing risk of diagnostic bias (National Institute for Health and Care Excellence, 2021). Several studies provided limited discussion of bias or generalisability; a recognised limitation of registry-based datasets where detailed procedures are often unavailable (Rødgaard et al., 2021).

These methodological limitations, alongside the substantial heterogeneity across studies, reduce confidence in the findings of this review. Consistent with the GRADE assessment, the ASD findings and sex-stratified analyses across studies were judged to provide very low certainty evidence, indicating that the true prevalence rates are likely to differ substantially from those reported here. The ADHD findings were rated as low certainty evidence, suggesting that confidence in the estimates remains limited and that the true prevalence may also differ meaningfully from the reported values. These ratings reflect limitations within the overall evidence base rather than poor-quality individual studies.

Clinical Implications

The aim of this review was to highlight whether a pattern of PMHDs exists that may prompt clinicians to consider ADHD/ASD assessment and consequently reduce delayed diagnosis. Although anxiety and depressive disorders are common within the general population, understanding that people with undiagnosed ADHD/ASD have a higher prevalence of depressive and anxiety disorders compared to the general population, may support clinicians to consider screening for ADHD/ASD when anxiety and

depressive disorders are persistent, treatment-resistant, recurrent, or accompanied by lifelong functional difficulties. The higher prevalence of PDs and psychotic disorders should also be noted by mental health professionals who work with these populations, and consider if ASD has been overlooked or potentially overshadowed by their mental health condition.

Another pertinent finding is that females demonstrated a higher PMHD prevalence and are often diagnosed with ADHD/ASD later than males. Clinicians should be aware that delayed identification may contribute to poor mental health outcomes in some individuals, and thus clinicians should consider screening for NDD to reduce the diagnostic delay, which could impact the individual's mental health further.

Strengths, Limitations and Future Directions

There are several strengths and limitations to note regarding this review. First, a key strength is the high overall sample sizes that these findings are drawn from across a range of different countries, improving external validity and confidence in the findings. Secondly, most studies were rated as high quality and findings were evaluated using both the CCAT and GRADE, enhancing confidence in the overall assessment of evidence quality. Third, the search strategy was comprehensive, utilising multiple databases and grey literature. Lastly, this appears to be one of the first reviews synthesising evidence on PMHDs preceding ADHD/ASD identification, with implications for supporting earlier recognition and support.

However, several limitations must also be considered. Although the CCAT provides a comprehensive framework for appraisal, its application requires subjective judgement

which may introduce reviewer bias. Variability in how information is reported across studies may result in different scoring decisions between reviewers. Whilst a consistent approach focusing on content rather than information placement was adopted, and agreement between reviewers was high, some subjectivity in quality ratings cannot be entirely excluded. Additionally, although the CCAT categorical classification system is useful to rapidly communicate to readers the quality of each study, the overlap between high and median quality scores creates ambiguity, and thus must be used with caution. Another key limitation of this review, as noted, is the substantial heterogeneity observed across prevalence estimates. These may reflect differences in study design, sampling strategies, diagnostic criteria, categorisation and methods used to identify PMHDs. Consequently, the reported prevalence rates should be interpreted cautiously, as they may not represent the true prevalence rates of PMHDs in ADHD/ASD. The feasibility of conducting a meta-analysis and therefore necessitating the use of SWiM methodology was also limited by the substantial heterogeneity observed across prevalence rates. Finally, the dual examination of PMHD in both ADHD and ASD may have made this review overly complex due to the high level of ADHD-ASD comorbidity. Seven ASD studies reported prior diagnoses of ADHD before ASD was identified, while two ADHD studies reported prior diagnoses of ASD. This pattern is consistent with existing comorbidity research demonstrating substantial comorbidity between the conditions (Hossain et al, 2020; Njardvik et al., 2025). However, this finding presents a conceptual challenge for the current review, which aimed to examine PMHD as conditions occurring before the recognition of ADHD/ASD. Yet, in cases of ADHD-ASD comorbidity, it is unclear if a PMHD came before their comorbid NDD or not, limiting the extent to which the findings in this review can be considered as prior to ADHD/ASD.

This issue may reflect a broader limitation within the evidence base rather than solely a limitation of this review, as studies rarely account for the temporal relationships between PMHDs and co-occurring NDDs.

To improve confidence in this review's findings, future reviews could examine studies where no other NDD has been diagnosed prior to the target diagnosis of the review. Alternatively, future studies could explicitly account for ADHD-ASD comorbidity, and only examine PMHDs prior to this dual diagnosis. Further research using longitudinal designs would be particularly valuable in clarifying temporal relationships between PMHDs and subsequent ADHD/ASD identification to further develop the evidence base. Future studies could also seek to utilise greater consistency in diagnostic procedures, and further explore gender differences, which is likely to be especially relevant given the gender differences in mental health prevalence rates in the general population, ADHD/ASD comorbidity and in relation to delays in ADHD/ASD diagnosis.

Conclusion

This systematic literature review examined mental health diagnoses occurring prior to ADHD/ASD identification. Anxiety and depressive disorders emerged as the most consistently reported PMHDs, while evidence also suggested elevated rates of psychotic and personality disorders prior to ASD diagnosis. Although overall study quality was high, substantial heterogeneity and imprecision limited certainty in the findings. Nevertheless, these results highlight the potential importance of considering ADHD/ASD in individuals presenting with recurrent or persistent mental health

difficulties and may support efforts toward earlier recognition of these NDDs and improved diagnostic timing for ADHD/ASD.

Authors Contributions

FH developed the project, data extraction tool and analysis plan under supervision from LH. FH developed the search strategy with support from the University of Glasgow's college librarian. FH conducted the literature search, screening, data extraction and quality appraisal with support from TS. FH carried out data analysis and narrative synthesis and wrote the first draft of the manuscript for this review. FH and LH edited and approved the final version.

Disclosure Statement

The authors declare no conflict of interest.

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Chapter 2: Major Research Project

Mental Health and Treatment Experiences of Late Diagnosed Autistic Women within Adult Mental Health Services

Prepared in accordance with the author requirements for Autism in
Adulthood; <https://journals.sagepub.com/author-instructions/aua>

Plain Language Summary

Title: Mental Health and Treatment Experiences of Late Diagnosed Autistic Women within Adult Mental Health Services.

Background: Mental illness is more common in autism than in the general population, with late autism diagnosis contributing to poor mental health. Autistic women are more commonly diagnosed later in life than males and receive more psychiatric and behavioural diagnoses than males. In such situations, undiagnosed autistic women may be diagnosed with mental health conditions, but their autism can be missed. It is thought that the diagnoses autistic women are given before their autism diagnosis may hide or overshadow their autism from professionals. Yet, without an autism diagnosis, the treatments offered are unlikely to be appropriately adapted to the person's needs.

Aims: This research project aimed to look at the possible impact of other diagnoses overshadowing autism in women, and the impact of therapeutic or medical treatments which women received before being diagnosed with autism.

Research Question: What are autistic women's experiences of mental health diagnoses, and mental health treatments, prior to their autism diagnosis?

Methods: Twelve autistic women who were diagnosed in adulthood were interviewed either face-to-face or online. These interviews were recorded, transcribed and analysed

for meaning which was organised into key themes. The researcher applied a structured analysis method to understand the meanings of the autistic women who shared their stories. The list of diagnoses and treatments (medication and therapeutic) were also collated.

Findings: The autistic women in this study experienced a number of mental health diagnoses and treatments prior to their autism diagnosis. Four main themes were found through the interviews: 1. Repetitively missed, misunderstood and misattributed; 2. Treatment can bring brief relief or mismatch that erodes wellbeing; 3. Gaining an autism diagnosis: shifting from silent struggle to emotionally complex self-understanding; and 4. Gendered barriers to recognition prompt motivation for change.

Conclusions: Late diagnosed autistic women can experience a range of mental health diagnoses and treatments before their autism diagnosis, which are fraught with struggle and misunderstanding. It is possible that the mental health conditions they received overshadowed their autism, and alongside a lack of autism knowledge in professionals and the wider system; created a barrier to earlier diagnosis.

Abstract

Background: Many autistic women are not diagnosed until adulthood and often present to mental health services with difficulties prior to diagnosis. In such situations the mental health problems autistic women experience may overshadow their autism, leading them to be given mental health diagnoses and treatments which do not consider autism. There is a body of existing qualitative research exploring autistic people's experiences of late diagnosis and a smaller body looking at the experiences of autistic women. However, there is little research examining the experience of diagnostic overshadowing and treatments which may have been given before an autism diagnosis. To gain a clearer understanding of this phenomenon, the aim of this research was to explore autistic women's experiences of mental health diagnoses and treatments prior to their autism diagnosis.

Methods: This research study used an Interpretive Phenomenological Analysis (IPA) approach to explore the experiences of mental health diagnoses and treatments prior to their autism diagnosis. Twelve autistic women diagnosed in adulthood were interviewed either online or face-to-face using a semi-structured interview approach. The seven steps of IPA were applied to the qualitative data. Quantitative data of the diagnoses and treatments they received was also collated.

Results: Four superordinate themes (with 10 subordinate themes) emerged from the data: 1. Repetitively missed, misunderstood and misattributed; 2. Treatment can bring

brief relief or mismatch that erodes wellbeing; 3. Gaining an autism diagnosis: shifting from silent struggle to emotionally complex self-understanding; and, 4. Gendered barriers to recognition prompt motivation for change.

Conclusion: Late diagnosed autistic women can experience a range of mental health diagnoses and treatments before their autism diagnosis, which are fraught with struggle and misunderstanding. Diagnostic overshadowing and lack of knowledge about female autism appear to be significant factors.

Background

Autism spectrum disorder (henceforth referred to as autism) is a lifelong neurodevelopmental disorder characterised by differences in social communication and interaction, alongside restricted or repetitive patterns of behaviour (World Health Organisation [WHO], 2019). Although autism emerges in the developmental period, many individuals are not diagnosed until adulthood constituting a 'late diagnosis' (Russell et al., 2025). The broadening of the diagnostic criteria over the past two decades may partly explain this (Arvidsson et al., 2018). Consideration is now being given to a potential 'lost generation' of autistic adults born prior to these diagnostic changes, who may be undiagnosed, considered misdiagnosed or have experienced diagnostic overshadowing (Lai & Baron-Cohen, 2015; Gupta & Gupta, 2023; Stagg & Belcher, 2019; Stewart & Happé, 2025). Diagnostic overshadowing refers to one diagnosis obscuring recognition of another, such as autism being overlooked in the presence of a mental health diagnosis (Matson & Williams, 2013). This can result in neurodivergent behaviours being attributed to psychiatric disorders, leading to interventions that do not consider autism and may therefore be inappropriate or harmful (Au-Yeung et al., 2019; Dubreucq et al., 2021; Isaac et al., 2022). Although therapeutic interventions for autistic people should be adapted (National Institute for Health and Care Excellence (NICE), 2021), without an autism diagnosis appropriate adaptations are difficult to implement, particularly given evidence that mental health support for diagnosed autistic people can be inadequate (Brede et al., 2022).

Many autistic people present to services before receiving an autism diagnosis. Fusar-Poli et al. (2022) reported a median interval of 11 years between initial clinical evaluation and a formal autism diagnosis. During this period, individuals may receive multiple mental health diagnoses and corresponding treatments without autism being considered (Au-Yeung et al., 2019; Gellini & Marczak, 2024). While autistic people have a higher prevalence of mental health conditions than the general population (Hossain et al., 2020), research indicates that diagnoses given prior to autism identification are not always accurate (Fusar-Poli et al., 2022), and can be perceived by autistic people as misdiagnoses (Kentrou et al., 2024). However, most studies reporting diagnostic experiences rely on self-report and do not clinically reassess diagnosis, meaning that the distinction between comorbidity and misdiagnosis remains unclear (Gellini & Marczak, 2024; Kelly et al., 2024; Kentrou et al., 2024). The concept of misdiagnosis must therefore be considered with caution.

Although a late diagnosis has not been associated with a specific gender threshold (Russell et al., 2025), large population-based studies indicate that autistic females are more likely than males to be diagnosed later in life, with diagnosis rates increasing with age (Fyfe et al., 2025; Kavanaugh et al., 2023). Several barriers have been proposed to account for this disparity, including male-normed diagnostic criteria, limited professional understanding of female autism presentations, and a greater tendency for females to engage in masking or compensatory strategies (Cruz et al., 2025; Estrin et al., 2021). Gender differences are also evident in mental health diagnostic patterns. Autistic females receive a significantly greater number of psychiatric and behavioural conditions than males (Jadav & Bal, 2022) and are more

likely to be diagnosed with internalising conditions like anxiety, depression, eating disorders, or borderline personality disorder than males (Fusar-Poli et al., 2022; Gu et al., 2023). These patterns suggest that undiagnosed autistic females may be at particular risk of delayed identification, diagnostic overshadowing, and treatments that do not consider autism, potentially impacting mental health outcomes.

Qualitative research has sought to improve our understanding of autistic people's experiences of being diagnosed in adulthood, with several recent systematic reviews and a qualitative meta-synthesis focusing on this topic (Gellini & Marczak, 2024; Kiehl et al., 2024; Nayyar et al., 2024; Wilson et al., 2023), with one specifically focusing on autistic women (Kelly et al., 2024). Common themes include feeling different prior to diagnosis, difficulties with 'fitting in', and the costs of late diagnosis alongside positive experiences such as an increased sense of belonging, autistic identity and self-understanding. These reviews also highlighted barriers to autism recognition, including feeling dismissed, misunderstood or misdiagnosed, and connecting this to professionals' limited autism knowledge (Gellini & Marczak, 2024; Kelly et al., 2024; Wilson et al., 2023). Brede et al. (2022) similarly describe challenges autistic adults face in accessing appropriate mental health support, including systemic barriers and risks of inappropriate medications; but did not focus specifically on experiences prior to autism diagnosis, or on women's experiences.

These findings are consistent with the minority stress model, which has been adapted and applied to autism (Botha & Frost, 2020). This model proposes that autistic people experience an additional burden of chronic stress as a consequence of occupying a

stigmatised minority status. Experiences commonly reported by autistic adults, such as feeling different from others, difficulties fitting in, concealment of autistic traits through camouflaging, and expectation of rejection, may function as minority stressors that contribute to poorer mental health outcomes (Botha & Frost, 2020). Consequently, this minority stress model provides a useful theoretical framework for understanding why autistic people experience higher rates of mental health difficulties than the general population (Hossain et al., 2020). Furthermore, autistic women often report greater use of camouflaging strategies to mask autistic characteristics (Mao et al., 2024), which may represent an additional source of minority stress. This may help explain evidence suggesting that autistic women experience higher rates of anxiety, depression and other mental health difficulties than autistic males (Jadav & Bal, 2022).

The limited research that explores autistic women's experiences does not examine their mental health diagnoses and treatment prior to receiving an autism diagnosis (Gosling et al., 2023; Kelly et al., 2024; O'Connor et al., 2024). Au-Yeung et al. (2019) found that autistic participants were less likely than non-autistic participants to agree with their mental health diagnoses, attributing this to professionals confusing autism characteristics with mental health conditions. However, this study did not distinguish experiences by gender, by timing of diagnoses or explore how participants made sense of past treatments.

Taken together, the evidence highlights a gap in understanding autistic women's experiences of mental health diagnoses and treatments received prior to their autism diagnosis. The current study addresses this gap by foregrounding autistic women's

voices to explore the meanings they attach to these experiences, in line with NICE (2021) guidance emphasising the importance of understanding the impact and interaction of autism and co-existing mental conditions, and supporting more autism responsive practice.

Aim and Research Question

This study explored autistic women's experiences of mental health diagnoses and treatments prior to their autism diagnosis. The research question was: *what are autistic women's experiences and views of mental health diagnoses and treatments (including medical and therapeutic) received prior to gaining an autism diagnosis?*

Methods

Ethics

Ethical approval was obtained from South Central - Hampshire A Research Ethics Committee (REC reference 25/SC/0190; Appendix [2.4](#), pages 129-133). An amendment was approved to extend the data collection period and to add another location to facilitate interviewing a rural participant. Management approval was granted by NHS Ayrshire and Arran (AA) Research Development (Reference: 2025AA036; Appendix [2.5](#), pages 134-136).

Study Design

A qualitative research design using Interpretive Phenomenological Analysis (IPA) was employed to explore autistic women's experiences of mental health diagnoses and treatments received prior to their autism diagnosis. IPA was selected due to its focus on understanding how individuals make sense of significant life experiences and its established utility in research with autistic participants (MacLeod, 2019; Smith et al., 2022). IPA's idiographic commitment allows for detailed exploration of both shared and divergent experiential meanings, within a relatively homogeneous group.

Patient and Public Involvement

To promote an autism inclusive approach, consultation was sought from autistic people regarding study documentation. Three autistic women known to NHS AA Community

Mental Health Teams (CMHTs) provided feedback on participant documents. Feedback was incorporated into final materials (Appendix [2.6](#) & [2.7](#), pages 137-138).

Recruitment

A purposive sampling approach was used. In line with NHS AA's Information Governance procedures, adults 18+ diagnosed with autism and assessed as eligible to participate by psychologists within AA CMHTs and had previously consented to be contacted about research, were invited to participate. Preferred communication methods were used to share study information, namely the Participant Information Sheet, interview schedule, privacy notice and consent form. Those who did not initially respond were sent a follow up email two weeks later. Individuals contacted the lead researcher to arrange an initial conversation to verify whether they met the inclusion and exclusion criteria, discuss adaptations to aid comfort during the interview, and address questions.

Eligibility Criteria

Participants included in this study: identified as a woman (including cisgender and transgender women who socially transitioned prior to autism diagnosis), were aged 18 or over, had received an autism diagnosis after age 18 by AA CMHT, and had received mental health diagnoses or treatments prior to autism diagnosis. Individuals were excluded if they were male, under 18, diagnosed outside AA CMHTs, not diagnosed as autistic, or met ICD-11 criteria for intellectual disability.

Justification of Sample Size

IPA studies typically use small homogeneous samples to facilitate in-depth idiographic analysis, with 6-10 participants for professional doctorates, or 3-16 depending on study aims and complexity (Smith et al., 2009; Smith et al., 2022). Given the homogeneity of a sample of women diagnosed within one health board who had prior mental health diagnoses and treatment experiences, a slightly larger sample of 8-12 participants was sought. The aim was not to achieve breadth or representativeness, but to capture a range of experiential accounts to ensure sufficient variation within the sample to explore both convergences and divergences in participants' experiences, such as differences in diagnostic journeys, mental health histories, and experiences of healthcare services. This is consistent with IPA's commitment to examining patterns of shared meaning alongside individual variation, while maintaining an idiographic focus.

Study Sample

All participants (n=12) were white cisgender women aged between 20 and 60 years (median 43.5 years). Time since autism diagnosis ranged from under one year to two years (median under 12 months). Although all participants were diagnosed and currently supported within Scotland, three reported receiving mental health treatment earlier in England, and one in Ireland. Thirteen individuals expressed interest; one subsequently withdrew, resulting in a final sample of 12 participants.

Data Collection

Prior to the interview, all participants were required to provide an informed consent form and were reminded of confidentiality limits and their right to withdraw.

Adjustments to support comfort were also discussed, such as breaks and sensory considerations. Data was collected through semi-structured interviews, guided by a flexible interview schedule. Interviews were conducted either face-to-face or online and lasted 40-120 minutes inclusive of breaks. Participants were offered a debrief one to two weeks after the interview to reflect on the process and add any further information they wished to share. Ten participants took part in a debrief.

The interviews and debriefs were audio recorded using secure NHS equipment and transcribed verbatim. Transcripts were checked for accuracy against recordings and anonymised. In one instance where the audio recording failed, the interview notes were reviewed and supplemented by the participant to ensure accuracy of meaning. Due to time constraints and the additional burden this exercise places on participants, no other transcripts were reviewed by participants. In line with the IPA approach, the lead researcher made reflective notes throughout the study process.

Data Analysis

Data was analysed following Smith et al.'s (2022) seven step IPA analytic process. Transcripts were read and re-read to support immersion in each account before detailed exploratory notes were made focusing on descriptive content, linguistic features, experiential processes (such as expressed emotions, metaphors, tone), and conceptual reflections, where questions were asked of the data. These notes were recorded alongside each transcript to maintain proximity to the participant's voice. From the exploratory notes, experiential statements capturing the essence of the

participant's meaning were developed and clustered to form personal experiential themes for each participant. Patterns of convergence and divergence across cases were then examined to develop superordinate and subordinate themes, while retaining attention to individual nuance and idiographic depth (see Appendix [2.9](#) on page 140 for records of the data analysis process). Alongside the qualitative analysis, descriptive information regarding participants' diagnostic and treatment histories were organised into a table to provide contextual grounding.

Researcher Reflexivity

As a non-autistic female trainee clinical psychologist working in NHS AA, I view myself as an outsider to this population. However, my 15 years of working with autistic people across health and social care and repeatedly hearing accounts from autistic people who feel they have been failed by mental health services, has shaped a strong motivation to evidence barriers and advocate for more equitable care. Additionally, as a woman I am attuned to gender disparities in health care, which further informed my interest in this topic. I therefore view myself as an ally to this study's population.

I had no pre-existing relationship with participants, and I was mindful that discussing mental health care with an NHS clinician may have felt anxiety provoking. I was also aware of potential challenges related to autistic communication differences, and how these could influence the interview dynamic. I carefully considered how my long-term academic work on autism and my experience of hearing autistic people's stories of receiving diagnoses in adulthood, may have shaped how I interpreted participants' narratives and unconsciously influenced the analysis.

For these reasons, I maintained an open and reflective stance throughout this study. I used a reflective diary (Appendix [2.11](#), page 142) at each stage to monitor my expectations, emotional responses, and developing interpretations, and remained alert to alternative perspectives. In line with the IPA double hermeneutic, I continually returned to the transcripts to ensure that developing themes reflected participants' meanings, rather than my own preconceptions. This process supported a rigorous analytic approach that remained idiographic and grounded in the participant's lived experience.

Findings

Quantitative Data

The past diagnoses and treatments each participant received are documented in [Table 5](#). Pseudonyms have been used to protect their identity. Due to confidentiality, ages have not been reported next to participant names. A range of diagnoses and treatments were reported between the ages of 11 to 60 years. [Table 6](#) illustrates the frequency of each diagnosis given. Anxiety (n=8) and depression (n=8) were the most common diagnoses received. Where a formal diagnosis was unclear, this was noted. All participants received a form of therapeutic input, though some were short-lived. Ten received medicinal input, one participant (Emma) reported not being offered medication, and one declined to take medication (Clara).

Table 5

Participants' Diagnoses and Treatments

Participant	Diagnosis	Treatment	
		Medicinal Intervention	Therapeutic Intervention
Arya	GAD, agoraphobia, depression, OCD, health anxiety, bipolar, CPTSD, autism.	Diazepam, Prozac, Amitriptyline, Escitalopram, Depakote, Quetiapine, Lithium (did not take), venlafaxine, Amitriptyline, Sertraline, Trazadone.	CBT (graded exposure), hypnotherapy, CBT (graded exposure), group therapy, private counselling, CP.
Barbara	Stress, dyspraxia, depression, anxiety, workplace stress, CPTSD, depression, autism.	Beta-blockers, SSRIs, declined SSRIs.	Declined group CBT, psychology input for CPTSD, CP.
Clara	Post-natal depression suggested, stress-related physical	Health visitor, offered and declined antidepressants repetitively.	SA counselling, CP.

Participant	Diagnosis	Treatment	
		Medicinal Intervention	Therapeutic Intervention
	health conditions, bipolar suggested, anxiety, PTSD, autism.		
Dorothy	Depression, autism.	Prozac, antidepressants.	Two sessions with child psychologist.
Emma	Depression discussed, OCD discussed, OCD, autism.	None offered	CAMHS, regulation support at school, private therapist, self-help, wellbeing support at university, CP.
Florence	Eating disorder, depression, anxiety, suggested bipolar but decided anxiety only, anxiety, autism.	2-3 antidepressants, mental health inpatient assessment (not admitted), Diazepam, Temazepam, Beta blockers.	Psychiatry and psychology input, CBT (graded exposure), psychology & psychiatry, graded exposure with CPN, CP.
Greta	BPD, autism.	Fluoxetine, Citalopram, Quetiapine, Sertraline, one week inpatient (no treatment), A&E for mental health.	Three experiences of therapy, STEPPS programme, MBTI introductory course, 18 months MBT, CP (CFT).
Helena	Anxiety and depression repetitively diagnosed, autism.	Medication including Sertraline, declined medication, started medication.	CBT, group therapy, online CBT, hypnotherapy.
Irena	Autism assessed, concluded not autistic in early years, ADHD assessment not concluded, depression, anxiety, autism, CPTSD.	Sertraline	School counsellor, parent declined NHS counsellor, college guidance counsellor, private therapist.
Joan	Dyslexia, anxiety discussed & diagnosed annually through adulthood. CPTSD discussed, autism.	Zopiclone, Citalopram, Mirtazapine, antidepressants, Sertraline, Melatonin, Zopiclone.	Counselling from school nurse, University counsellor, NHS CP.
Katherine	Depression, complicated grief, OCD, dyslexia, ADHD suggested but not assessed, stress-	Declined antidepressants, Sertraline, Trazadone,	Declined Cyclothymia group, CP on two occasions.

Participant	Diagnosis	Treatment	
		Medicinal Intervention	Therapeutic Intervention
	related physical health conditions, cyclothymia, CPTSD, autism.		
Lyra	Anxiety and depression, autism.	St John's Wort, Vitamin injections, Escitalopram (took once), Amitriptyline, Zopiclone, Mirtazapine.	Signed off work, SA therapy, private unqualified therapist, CP (CFT).

Note. Abbreviations: BPD, borderline personality disorder; CAMHS, Child and Adolescent Mental Health Service; CBT, Cognitive behavioral therapy; CFT, Compassion-focused therapy; CP Clinical psychology; CPTSD, Complex post-traumatic stress disorder; CPN, Community psychiatric nurse; GAD, Generalised anxiety disorder; OCD Obsessive Compulsive disorder; PTSD, Post-traumatic stress disorder; SA, sexual abuse.

Table 6

Frequency of Diagnoses Received

Diagnosis	Frequency
Agoraphobia	1
Anxiety/GAD	8
Bipolar/Cyclothymia	2 (+2 suggested)
BPD	1
CPTSD/PTSD	5 (+1 discussed)
Complicated grief	1
Depression	8 (+2 suggested)
Dyslexia	2
Dyspraxia	1
Eating Disorder	1
OCD	3
Health Anxiety	1
Stress	1
Stress- related physical health conditions	2

Qualitative Data

All participants engaged well with the interview process, appearing to share a genuine interest in the topic area and motivation to share their stories. Four superordinate themes and 10 subordinate themes emerged from the analysis ([Table 7](#)).

Table 7

Superordinate and Subordinate themes

Theme number	Superordinate theme	Subordinate theme
1	Repetitively missed, misunderstood and misattributed	1. Misattribution, misdiagnosis and reductive labelling leave needs unmet 2. Misunderstood through long-term systemic misrecognition. 3. Professional misattunement: feeling unheard and unseen
2	Treatment can bring brief relief or mismatch that erodes wellbeing	1. Medication may have a place, when it is not ineffective, unwanted and harmful. 2. Therapeutic intervention can be supportive when not limited by access, depth and connection 3. Repetitive, ill-fitting treatments have limited usefulness, reinforcing distress and pushing people away.
3	Gaining an autism diagnosis: shifting from silent struggle to emotionally complex self-understanding	1. Not knowing you are autistic means coping alone 2. Learning you are autistic is transformative, though emotionally complex
4	Gendered barriers to recognition prompt motivation for change	1. Barriers to recognition 2. Systemic misunderstanding of female autism drives a need for change

The first two themes illustrate what experiences of past diagnoses and treatment were like for these women. Themes three and four are more overarching and reflective of their overall experiences. Each of the superordinate and subordinate themes are presented below with substantiating excerpts from participant transcripts. In some extracts ‘...’ is used to indicate some text has been removed.

Throughout the analysis process it became apparent that many of the themes were highly interrelated. For example, participants described how having their autism missed contributed to feelings of coping alone, while experiences with professionals and the wider system often fostered a sense of depersonalisation. These connections were evident across participants' accounts, highlighting how the themes functioned as both distinct experiential phenomena and interconnected aspects of a broader lived experience.

1. Repetitively missed, misunderstood and misattributed

1.1. Misattribution, misdiagnosis and reductive labelling leave needs unmet

Although all participants reported experiencing mental health challenges throughout their lives, they also shared an overriding feeling that the mental health diagnoses they were given did not get 'to the root cause' (Lyra) and were 'reductive terms' (Irena). Some perceived their mental health diagnoses as inaccurate and reported having them removed from their health record since learning they were autistic: 'But they kept telling me I was depressed, and I was never depressed' (Florence).

In some cases, it was felt that these diagnoses were actively harmful, where labels were stigmatising, used against them, or impacted their mind set: 'BPD – I don't think I ever had it. It was a misdiagnosis. My autistic brain tells me this was incorrect so it was bad ... People use it as amo against you' (Greta).

Which is damaging because I think from an early, 11, it was drummed in that I have this mental illness that I have really bad anxiety, and it prevents me leaving

the house. So then you give that to an autistic person, that's your mind set, isn't it. (Arya).

There was some divergence regarding the usefulness of past diagnoses. For example, Helena found some reassurance in framing her difficulties as 'just depression' rather than her 'personal nature'. However, for the most part, feeling a diagnosis was correct was tainted by the feeling they weren't helpful because it ran the risk of all their needs being represented under one label: 'I think that whilst it was a correct diagnosis, it wasn't *the* diagnosis' (Joan). Additionally, mental health diagnoses were suggested to overshadow consideration of another reason for their difficulties: 'I also don't think it helps because they've gave you... You have a diagnosis ... So we're not looking for another one' (Arya).

1.2. Misunderstood through long-term systemic misrecognition

Being misunderstood and missed was a pervasive theme across the participants, with several explicitly attributing this to 'the system' and how it is 'structured' (Irena), rather than individual clinicians: 'so she's been really good ... I think that where clinical psychology hasn't been able to help, it's more because they've been boxed in by the broader NHS structure rather than any, like, lack of willingness or this kind of thing ...' (Barbara). Some reported this as an ongoing issue in relation to trying to access an ADHD assessment.

Several people shared a feeling that their repetitive help seeking should have been a key sign that something wasn't right. And while masking was suggested as a factor in some people's autism being missed, others felt their autism was obvious:

But I also think that autistic women do mask so much. But at the same time, when you're a repeated, basically, customer of the NHS for mental health services, I wish somebody had, you know, stepped in or said at some point, maybe she needs to be seen by a psychologist ... (Lyra).

Someone should have said, I mean, my doctor, I'd obviously been to them quite a bit for like anxiety and other things and I mean, it's so obvious that I'm not neurotypical. And yeah, someone should have noticed, especially before my late 40s. (Florence).

Some of the women tried to understand why this misrecognition had happened with suggestions including a lack of training, brief consultation times offering only a 'snapshot', and symptom overlap with mental health disorders that appeared to 'fit in' (Clara). Overall, there was a strong feeling that repetitive misrecognition contributed to poor mental wellbeing:

... nobody ever thought maybe we should look into this a bit more, or nobody wants to know why after like 10 years the Amitriptyline was not doing anything. I feel a little hard done by because, I do feel like that we're punished a lot ... And we don't know why we're on the outside all the time. (Katherine).

1.3. Professional misattunement: feeling unheard and unseen

Professional misattunement was a common theme across participants, who reported feeling unheard, unseen and disconnected from professionals. Some commented on feeling the professionals they saw had an impersonal approach where focus was on

specific things, like medication or their mental health condition rather than holistic care, potentially indicating a level of diagnostic overshadowing.

Like I wasn't broken, I wasn't depressed. ...I'll make a joke of it, but you've got the broken thumb and somehow it would wind its way round because you were depressed. No, like you're not looking at me as a whole person. You're looking at anxiety and depression first. So like I felt as if I wasn't being listened to. (Florence).

... all the psychiatrists cared about was trying to get me on some form of antidepressant, even though I wasn't exhibiting symptoms of depression ... And so...actually with the...psychiatry that damaged trust ... Because I didn't feel like I was being treated like an individual or listened to. (Barbara).

A common experience was feeling that professionals were 'dismissive' (Helena), and lacked attunement or respect for the difficulties these women experienced: 'I was referred into the system for anxiety. That was a symptom, it was all of this other stuff that was going on. And yet that was kind of peddled as the main idea' (Clara). This impacted participants' confidence in clinicians: 'they didn't know what to diagnose me with...So we'll just diagnose her with that' (Katherine), and made it difficult to ask for help:

There's a lot of kind of gasping that goes on sometimes when you go to the doctor. You know, things not getting taken seriously ... you're getting loads of kind of pushback already for other things, it's hard to go and ask for an autism assessment. (Lyra).

Many women also shared positive experiences with professionals, however, these were more prevalent after their autism diagnosis was given.

2. Treatment can bring brief relief or mismatch that erodes wellbeing

2.1. Medication may have a place, when it is not ineffective, unwanted and harmful

This theme represented a range of experiences relating to medication. Most people who had received medication reported it being repetitively ineffective and mismatched to their needs, with many experiencing ‘horrendous’ (Arya) side effects or withdrawals, leading the majority of participants to avoid medication: ‘I’ve got a fear of the medication now. Like I don’t want it. It doesn’t work. I don’t want it, so I’ve probably refused it for about the past...probably last five years’ (Arya).

And I kind of felt like a sort of like medical guinea pig of like, ‘oh, we’ll try this one on you, see if this one works or this one and this one’. And I’d be coming back all like, ‘no, this is making me an insomniac ...’ (Helena).

However, some people, like Katherine found benefits from medication: ‘So I get put on Trazodone tablets and it was like somebody switched a light bulb on in my head. Fantastic. Excellent. Totally clicked with my mental health. I could focus better. I sleep better’. While others felt it had ‘a place’, even if it also made certain experiences worse:

Mirtazapine helped a lot in terms of just being able to get from day-to-day ...

So it made my anxiety worse. And then the depression that came, like, with it

was just worse ... But I think the medication only has a place as well when it's the right time to give it. (Joan).

Another prevalent theme was the feeling that medication was more accessible than therapeutic intervention, with some being advised 'it's your only option' (Dorothy). Medication also appeared to be actively encouraged by professionals, leading them to 'tussle about it' (Clara) when it wasn't wanted, feeding into the theme that some interventions felt mismatched or ill-fitting: 'I said, "I don't need drugs". I said, "I need psychological intervention". "Well, we don't do that. We don't do it".' (Clara).

2.2. Therapeutic intervention can be supportive when not limited by access, depth and connection

The term 'therapeutic intervention' (TI) groups the variety of different therapeutic input the women experienced, as seen in [Table 5](#). It should be kept in mind that while some women may reference 'therapy' it is not always clear what this referred to or which professional this was delivered by. A range of views were shared about TI. Sometimes TI was felt to be useful and support growth. Other times it was much less helpful due to a range of barriers, such as the intervention not being adapted for autism: 'These therapies did help with some specific things, but as they were formulated around BPD certain things will have gone counter to how an autistic brain has the capability of operating' (Greta). Other reported difficulties in connecting with their clinician:

I was a bit suspicious of her because, *haha*, she would like take notes. And I thought that was weird. Also, she would like ask me what the difference between a blog and a vlog was. *Haha*. And she also spoke about like how well her grandkids are doing and stuff. I'm like struggling so much. (Emma).

Some were able to highlight this sense of TI being 'surface level' (Joan) or limited in its usefulness, feeling 'stuck' and 'broken' even when progress had been made (Arya). However, most participants found at least some elements of TI useful, whether it was validation: 'the fact that she saw things as being difficult' (Emma), someone to model strategies: 'She was probably the most helpful person, because she did it with me rather than telling me to go home and do it.' (Florence), or developing a psychological understanding of oneself which aided them on their journey to self-understanding by helping them 'realize that there was something else there' (Joan).

I was quite like, oh, it was useless or whatever. But see, when it comes to just at the very base level of thinking, of patterns of thinking, it's helpful, like just beliefs about yourself when you have specific words about yourself that you use. (Irena).

2.3. Repetitive, ill-fitting treatments have limited usefulness, reinforcing distress and pushing people away.

This subtheme summed up the feeling and consequence of treatment that didn't meet their needs and appeared ill-fitting or mismatched. Most women seemed to share a

view that when treatment wasn't effective, gave them negative experiences, or felt like 'endless circles' (Arya); it reinforced a negative view of themselves and discouraged them from returning for further support: So for a long time I was like, oh, no, any kind of counselling and all that, it's not for me. (Dorothy).

... if therapy's not going to help me, like if I'm relapsing again after having been in like full blown therapy with like a real psychologist, then I'm not, like I'm not going to get better. There's no point in going to the doctor. So I let it get like pretty bad again before going back. (Joan).

3. Gaining an autism diagnosis: shifting from silent struggle to emotionally complex self-understanding

3.1. Not knowing you are autistic means coping alone

In line with the exclusion criteria, all participants reported difficulties with their mental health prior to their autism diagnosis. There was a strong feeling across the women that this was an extremely difficult time, with most connecting their experience of being misunderstood to being 'left to figure things out on your own' (Irena). Some also masked this experience, 'feeling like an utter failure because you're not coping ... you're pretending that you are' (Clara); leading them to suffer in silence: 'And then for all these years, you're just suffering in silence because you're hiding it' (Katherine).

There was slight divergence within this theme, where some women spoke about using their observation skills and masking to help them cope, for example 'I was all right at school because I had a really good memory I was determined that I was going to

watch what people did to get friends' (Clara). However, this did not always equate to coping. In fact, the resonant message from these women was that their awareness of being different but not understanding why, negatively impacted their mental wellbeing: '...as there is no explanation and only punishment for stepping outside the lines you develop shame' (Greta).

I was constantly told, 'you don't have any self-esteem, you've got really low self-worth' and all of this. And I'm like, that, that I attribute to not being diagnosed as autistic because I was constantly looking at myself and my peers and feeling different or being seen differently. (Joan).

Several women also highlighted the juxtaposition of being different enough to be vulnerable to bullying and abuse, but not different enough for their difficulties to be recognised appropriately:

It has made them very susceptible to dangerous people. And that lifetime has been undiagnosed and not being aware that you're vulnerable. You could never even pay somebody an amount of money that would cover the damage that's done between the day they're born until they find out. (Lyra).

3.2. Learning you are autistic is transformative, though emotionally complex

All participants agreed that gaining an autism diagnosis was life changing: 'It's so helpful, massively helpful. I mean, I would probably say at this point it has saved my life. So,

absolutely. Definitely worth the time'. (Helena). Many felt their autism diagnosis helped them find the acceptance and self-understanding they had been looking for:

The things that were put down to kind of like failures of character, or just being shit at life, you know, those things projected onto me, are now no longer things that I accept about myself. And I'm much happier, and go like, nope. I have the diagnosis. I know that is the 'tism'. (Barbara).

It's like, it's totally fundamental. Like, I was diagnosed and nothing changed. But everything changed at the same time because it was how I see myself and how I move in the world, changed ... And I wasn't able to diagnose myself. I wasn't able to, give myself that. They could have given that to me. (Joan).

However, they also highlighted how emotionally complex and even 'destabilising' (Clara) gaining a diagnosis was given their past experiences. Some expressed anger, bitterness and sadness at not being diagnosed sooner: 'I think at the time that I was pretty upset because I feel like I struggled like so much and I didn't really have to. And people just saw me as like bad all the time' (Emma). While others focused more on the 'relief' and 'luck' (Dorothy) or positives of getting a diagnosis: 'There's definitely a grief, but there's also like a freedom that comes because you finally feel free of all these other mental health diagnoses they've gave you and an acceptance of who you are and that's all right' (Arya).

4. Gendered barriers to recognition prompt motivation for change

4.1. Barriers to recognition

All the women in this study suggested that barriers to recognition of autism revolved around them being a woman, with some linking this to limited knowledge of female autism when they were younger: 'if I'd perhaps been a boy and it had been 20 years later, then I'd perhaps got a diagnosis a lot younger' (Dorothy). Others suggested masking may have played a role:

I have to be able to do that to protect myself, to be able to mask, to ... be normal or to be like, accepted, So ... that's probably how it went so long, because I'm just not traditionally autistic in the way that, in the harmful way that they're perceived in media, or in news or whatever. (Joan).

Emma did not feel she masked: 'masking, what is that? Like I feel I've never done that'; leaning more towards stereotype and a lack of understanding of autism and to explain her late diagnosis. Barbara explored this phenomenon in more depth, sharing the impossible nature of trying to separate mental health, womanhood and autism, indicating these inextricably linked experiences overshadow one another:

I'm not sure to what extent autism and mental health is wrapped up in the experiences of just being a woman ... so it's difficult for me to tease out what is specific to the autism, which is just bog standard misogyny, internalised misogyny, administrative misogyny and patriarchy.

A comment that crosses over with the professional's theme adds to this, where Greta indicates diagnostic overshadowing presenting a barrier to her autism being recognised:

We need more professionals looking out for it (autism). They pick BPD and hammer it. I think they specialise in their one thing and neglect to think holistically, they assume the system works and that the wrong people will have been filtered out before they reach them. 'Well of course you have BPD, you're seeing me aren't you, I specialise in BPD'.

4.2. Systemic misunderstanding of female autism drives a need for change

Many of the women shared their feelings on wanting to improve the experiences of future autistic women and girls. Several discussed the benefit they gained from seeing autistic women in the media and being able to identify with them. Others felt passionately about sharing their experiences to try and improve knowledge within their own circles: 'You just have to sort of live with the climate and the attitudes that people have towards it and be that one autistic person that they know that ... isn't like a naturally autistic person ...' (Dorothy). Overall, there was a shared sense that improved knowledge of autism in women was needed across professionals and society: 'I think also there's probably societal change and societal attitudes that need to change as well' (Helena).

Discussion

This study explored how autistic women experienced the mental health diagnoses and treatments they received prior to their autism diagnosis. While some existing research examines late autism diagnosis in women (Kelly et al., 2024), the current study specifically focuses on experiences of past diagnoses and treatments which have previously received limited empirical attention.

Four themes emerged, illuminating difficult experiences of past diagnoses and treatments, shaped by barriers to care that left them coping alone, before finally understanding themselves and advocating for change. These themes echo existing literature on late diagnosed autistic people, such as feeling misunderstood and misdiagnosed prior to diagnosis (Gellini & Marczak, 2024; Kelly et al., 2024), while extending this work to include women's diagnostic and treatment specific histories. Several past mental health diagnoses and treatments were experienced, mirroring those Fusar-Poli et al. (2022) found as most common in females prior to autism diagnosis and further supporting evidence that women often experience prolonged engagement with mental health services before autism is diagnosed.

These women characterised their past diagnoses by feeling misunderstood and at times misdiagnosed, while their autism was missed and often misattributed to something else by professionals or 'the system'. Some explicitly stated that certain diagnoses were inaccurate and have since had them removed from their records, hence the use of

‘misdiagnosis’ in the theme heading. Existing qualitative research supports this experience of autistic people feeling misdiagnosed, mislabelled and misunderstood throughout their lives (Gellini & Marczak, 2024; Kelly et al., 2024; Wilson et al., 2023). However, it is possible that unrecognised autism contributed to valid mental health difficulties which subsequently overshadowed autism itself; a pattern reflected in participants’ reports of accurate yet reductive diagnoses (Au-Yeung et al., 2019). This supports Wilson et al.’s (2023) interpretation that professionals with a reductionist view holds the potential for diagnostic overshadowing. Additionally, some participants in this study felt their symptoms of distress mirrored other disorders, reflecting Au-Yeung et al.’s (2019) findings that autistic characteristics are mistaken as symptoms of a mental health condition, even when autism is diagnosed. Diagnostic overshadowing may therefore be a key mechanism in autistic women’s autism being missed or misattributed.

Treatment experiences were closely linked to systemic processes and professional interactions. Many reported ineffective or poorly tolerated medication and limited access to TI due to systemic barriers which steered them towards seemingly mismatched treatments that didn’t address their underlying needs. On critical reflection, it is possible that some treatments may have been matched appropriately but were experienced as ill-fitting because their autism was not accounted for. These experiences are comparable to research describing limited treatment options resulting in long-term inappropriate and ineffective medication use, dissatisfaction with repetitive treatments, and perceived inappropriate support negatively impacting autistic people’s self-view and motivation to seek further support (Brede et al., 2022;

Camm-Crosbie et al., 2019). Participants' accounts suggest that diagnostic overshadowing played a central role, where clinicians focused on existing diagnoses or symptoms interpreted as a mental health condition, guiding treatment plans which did not meet their needs and diverting attention away from autism. This left many feeling unheard and misunderstood, particularly in the context of limited professional knowledge of female autism, which likely reinforced diagnostic overshadowing. This supports existing research highlighting diagnostic overshadowing in delayed autism diagnosis for women (Gupta and Gupta, 2023). It is also consistent with literature describing a reliance on stereotypes, lack of understanding of the female autism presentation, poor listening, a focus on treatments that overlook core difficulties and greater distrust of health professionals among women (Au-Yeung et al., 2019; Gellini & Marczak, 2024; Huang et al., 2020; Kelly et al., 2024).

These cumulative experiences contributed to a sense of coping in isolation, with many masking their differences while lacking a framework for self-understanding. Consistent with existing literature, masking and prolonged misrecognition were associated with shame, emotional distress, and reduced help-seeking (Gellini & Marczak, 2024; Kelly et al., 2024). Several women also described heightened vulnerability, echoing research on the intersection between autism and vulnerability to abuse (Gosling et al. 2023; O'Connor et al., 2024).

The final themes captured how participants made sense of life after diagnosis, while still holding their earlier experiences in mind. All described the diagnosis as profoundly impactful; deepening their self-understanding and acceptance, yet emotionally

complex considering their previous struggles. Such experiences of gaining an autism diagnosis align with a wealth of existing research on late diagnosis (Gellini & Marczak, 2024; Nayyar et al., 2025; O'Connor et al., 2024; Wilson et al., 2023). Some also expressed a need for change to improve experiences for future autistic women and girls, often thinking specifically of their own children.

The themes that emerged from this study illustrate the interconnected nature of diagnosis, treatment and professional interactions across these women's pre- and post-diagnostic journeys. Together, these themes offer a novel interpretive lens through which to understand autistic women's lived experiences and contribute meaningfully to the existing research base.

Strengths and Limitations

The insights in this study must be interpreted carefully as the participants represent a specific group of women who may have particularly wished to share their stories. A corresponding limitation is that, due to the size of dataset, only a proportion of the available idiographic detail can be presented within the constraints of a thesis. A strength of the study is that the larger IPA sample enabled richer exploration of both convergence and divergence.

Implications and future research

This study highlights that women's diagnostic and treatment experiences prior to an autism diagnosis are often fraught with difficulty, with diagnostic overshadowing and lack of understanding of female autism acting as barriers to autism being considered.

This has implications for clinical practice, where professionals working with female patients should keep autism and diagnostic overshadowing of mental health difficulties in mind, so autistic women are recognised sooner. These findings also have implications for policy, supporting the need to address barriers to diagnosis, which the Scottish Government has been urged to include in the proposed Learning Disabilities, Autism and Neurodivergence Bill (Scottish Government, 2024).

As the women in this study emphasised, furthering knowledge and understanding of autism in women is also critical. Future research exploring how professionals and systems can achieve this may therefore be particularly valuable.

Conclusion

This study extends the research base regarding the experiences of autistic women by adding specific insights into their pre-autism diagnosis encounters with services, diagnosis and treatment. While related elements have been noted in other studies, to the researcher's knowledge no previous work has examined this particular phase with comparable depth. By centring the complex realities of women who, as Katherine put it, are 'just trying to survive,' this study highlights the need for more nuanced, timely and compassionate diagnostic practices.

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Appendices

Appendix 1: Appendices for the Systematic Review

Appendix 1.1: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported (page)
TITLE			
Title	1	Identify the report as a systematic review.	8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	9
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	10-11
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	11
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	12
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	13
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	13 & Appendix C
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	15-17 & 21.

Section and Topic	Item #	Checklist item	Location where item is reported (page)
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	18
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	18-19
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	19-20
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	

Section and Topic	Item #	Checklist item	Location where item is reported (page)
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not conducted
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	18
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	19
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	21-22
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	24-28
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	30-33
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	34
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	34-40
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported (page)
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	34-40
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	40-41
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	42-47
	23b	Discuss any limitations of the evidence included in the review.	48
	23c	Discuss any limitations of the review processes used.	
	23d	Discuss implications of the results for practice, policy, and future research.	47
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	15
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	51
Competing interests	26	Declare any competing interests of review authors.	
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. This work is licensed under CC BY 4.0. To view a copy of this license, visit <https://creativecommons.org/licenses/by/4.0/>

Appendix 1.2: PICOS framework for Systematic Review

PICOS Element	Inclusion	Exclusion
Participants	BOTH: - Have a diagnosis of ASD or ADHD diagnosed by ICD or DSM criteria. AND - Have been given a formal mental health disorder <i>diagnosis</i> which was <i>prior</i> to their autism or ADHD.	- No ASD or ADHD diagnosis - No prior mental health diagnosis. - Majority of sample (>60%) have an intellectual disability (ID). People with ID can be included in the data, but the focus must be on mental health diagnoses prior to ADHD/ASD.
Intervention	N/A	
Comparison	N/A	
Outcomes	BOTH: - Mental health diagnoses received prior to an ASD or ADHD diagnosis. AND - Presented as diagnostic names and quantities (frequencies/proportions). Where data includes both mental health diagnoses received before and after ADHD/ASD and the data is not separated by this timing, over 60% of the total sample population need to have been diagnosed before their ADHD/ASD to be included.	- Does not provide quantities of mental health diagnoses. - Mental health diagnoses only perceived as misdiagnosed (rather than their previous diagnoses regardless of perception) - Mental health conditions not diagnosed (e.g. those described as 'symptoms') - Mental health conditions diagnosed at the same time or after ADHD/ASD diagnosis, or described to 'co-occur' without evidence of being diagnosed before ADHD/ASD. - Mental health conditions where timing of diagnosis cannot be determined in relation to ADHD/ASD.
Study Design	- Published quantitative studies, including any of the following: longitudinal or cross-sectional studies, observational or retrospective studies, experimental or intervention studies. - Mixed method studies with quantitative data stating which diagnoses people are most often given before their autism or ADHD diagnosis. - Research from both clinical and research settings. - Studies with full-text papers in English	- Studies which use purposive sampling of people with a specific mental health condition/s who later receive an ADHD/ASD diagnosis. - Review studies or case reports/series. - Studies with only qualitative research data

Appendix 1.3: Search Strategy

Ran on 22nd May 2026

Database	Terms
Embase 1974-2026 April 06	1. exp autism/ 2. exp Asperger syndrome/ 3. exp attention deficit hyperactivity disorder/ 4. (autis* or ASD or Asperger* or ADHD).ti,ab,kw. 5. neurodevelopmental disorder*.ti,ab,kw. 6. pervasive developmental disorder*.ti,ab,kw. 7. Neurodiversity/ 8. Or/1-7 9. prior diagnos*.ti,ab,kw. 10. exp diagnostic error/ 11. Missed diagnosis/ 12. Missed diagnos*.ti,ab,kw. 13. misdiagnos*.ti,ab,kw. 14. mental health diagnos*.ti,ab,kw. 15. (previous diagnos* or earlier diagnos*).ti,ab,kw. 16. (late diagnos* OR delayed diagnos*).ti,ab,kw. 17. or/9-16 18. 8 and 17
PsycInfo 1806 to March 2026 week 5	1. exp Autism Spectrum Disorders/ 2. exp Attention Deficit Disorder with Hyperactivity/ 3. (autis* or ASD or Asperger* or ADHD).ti,ab,id. 4. neurodevelopmental disorder*.ti,ab,id. 5. Exp Neurodiversity/ 6. Or/1-5 7. prior diagnos*.ti,ab,id. 8. diagnostic error.ti,ab,id. 9. exp Misdiagnosis/ or missed diagnos*.ti,ab,id. 10. misdiagnos*.ti,ab,id. 11. mental health diagnos*.ti,ab,id. 12. (late diagnos* or delayed diagnos*).ti,ab,id. 13. (previous diagnos* or earlier diagnos*).ti,ab,id. 14. Or/7-13 15. 6 and 14
Medline	1. exp autism spectrum disorder/ 2. exp Attention Deficit Disorder with Hyperactivity/ 3. (autis* or ASD or Asperger* or ADHD).ti,ab. 4. neurodevelopmental disorder*.ti,ab. 5. pervasive developmental disorder*.ti,ab. 6. neurodiversity.ti,ab. 7. 1 or 2 or 3 or 4 or 5 or 6 8. (prior diagnos* or previous diagnos* or earlier diagnos*).ti,ab. 9. (late diagnos* or delayed diagnos*).ti,ab. 10. (misdiagnos* or missed diagnos*).ti,ab. 11. mental health diagnos*.ti,ab. 12. exp Diagnostic Errors/

	13. 8 or 9 or 10 or 11 or 12 14. 7 and 13
Cinahl	1. (MH "Autism Spectrum Disorder") 2. (MH "Attention Deficit Hyperactivity Disorder") 3. XB (autis* OR ASD OR Asperger* or ADHD) 4. TX neurodevelopmental disorder* 5. S1 OR S2 OR S3 OR S4 6. (MH "Diagnostic Errors+") 7. XB (prior diagnos* OR previous diagnos* OR earlier diagnos*) 8. XB (late diagnos* OR delayed diagnos*) 9. XB mental health diagnos* 10. XB (missed diagnos* OR misdiagnos*) 11. S6 OR S7 OR S8 OR S9 OR S10 12. S5 AND S11
Web of Science	Filters: 1. SSCI - Social Science Citation Index 2. Science Citation Index Expanded (ECIE) 3. Emerging Sources Citation Index (ESCI) 4. Conference Proceedings Citation Index - Science 5. Conference Proceedings Citation Index - Social Science and Humanities. (autis* OR ASD OR Asperger* OR ADHD OR "autism spectrum disorder" OR "attention deficit hyperactivity disorder" OR "neurodevelopmental disorder*" OR "pervasive developmental disorder*") AND (misdiagnos* OR missed diagnos* OR ("mental health" NEAR/3 diagnos*) OR ("psychiatric" NEAR/3 diagnos*))
Google Scholar	1. "autism" AND (misdiagnosis OR "missed diagnosis" OR "mental health diagnosis") 2. "Mental health" "before ADHD diagnosis" 3. "ADHD" "diagnostic delay" "mental health"
University of Glasgow Enlighten Theses	Keywords: 1. Autism 2. ADHD
ProQuest - Dissertations & Theses Global	(autis* OR ADHD OR "attention deficit hyperactivity disorder") AND (misdiagnos* OR "delayed diagnosis" OR "late diagnosis" OR "prior diagnosis") AND ("psychiatric diagnos*" OR "mental diagnos*")

Appendix 1.4: Data Extraction Framework

Domain	Specific details/Prompt
Study Identification	- Title - Author(s) - Publication year - Journal name - Location of study (country and/or region) - Setting
Study Characteristics	- Study design - Study aim - Sampling period - Sample size - Recruitment - Consent procedures - Eligibility criteria
Participant Information	- Mean/median age (SD; range) - Age group - Sex ratio - Target population (ADHD/ASD)
Outcomes	- Definition of ASD/ADHD used (e.g. criteria) - ADHD/ASD assessment procedures - Age ADHD/ASD assessed - Nature of past mental health data (self-report/diagnosed) - PMHD assessment procedures - Evidence MH was diagnosed before ADHD/ASD
Prior Mental Health Diagnoses	- Name of mental health condition - Percentage (n) overall - Percentage (n) female - Percentage (n) male - Other previous psychiatric disorders (not mental health) - Frequency of people with at least one previous psychiatric condition - Frequency of people with only one previous psychiatric condition - Frequency of people with two previous psychiatric conditions - Frequency of people with three previous psychiatric conditions - Frequency of people with four previous psychiatric conditions - Frequency of people with five/more previous psychiatric conditions - Frequency of people with no previous psychiatric conditions

Appendix 1.5: Supplementary Information

Supplementary Table 1: Prevalence of PMHD in ASD Studies

ASD Studies										
PMHD % (n), female % (n), male % (n)	Fusar-Poli et al. (2022)	Geurts and Jansen, (2011)	Ghaziuddin & Zafar (2008)	Kentrou et al. (2021)	Martini et al. (2025)	Mazefsky et al. (2012)	Nahar et al. (2019)	Nylander & Gillberg (2001)	Rodgaard et al. (2021)	Ryden & Bejerot (2008)
Anxiety	Anxiety disorders: 10% (n=10) 7.5% (n=12); F 12.8% (n=6); M 5.4% (n=6)		Social phobia Anxiety & GAD: 17.85% (n=172); (n=5)* F: 23.0% (n=121); M: 10.3% (n=51)	Anxiety disorders: 16.9% (n=11,181); F: 27.0% (n=6,512); M: 9.7% (n=4,669)	Anxiety disorders: 15.5% (n=15) F: 27.0% (n=6,512); M: 9.7% (n=4,669)	42.0% (n=15)	NR	Anxiety neurosis 300.A: 5.88% (n=1) Phobia: 5.88% (n=1)	Anxiety disorders: 5.4% (n=119); F: 8.2%; M: 3.5%	GAD: 5.7% (n=3) Panic disorder: 9.4% (n=5) Social phobia: 17% (n=9)
Bipolar Disorder	2.5% (n=4); F 4.3% (n=2); M 1.8% (n=2)	NR	Reported with depression	NR	1.3% (n=915); F: 2.2% (n=536); M: 0.8% (n=379)	14.3% (n=5)	39.3% (n=10)	Bipolar affective psychosis 296.C, 296.X: 11.76% (n=2)	NR	3.7% (n=2)
CD/ODD/Emotional disorders	7.5% (n=12); F 2.1% (n=1); M 9.6% (n=11)	3% (n=3)	NR	2.4% (n=24); F: 1.5% (n=8); M: 3.2% (n=16)	NR	28.6% (n=10)	NR	NR	CD: 2.71% (n=59); F: 1.4%; M: 3.6%	NR
Depressive disorders	13.7% (n=22); F 27.7% (n=13); M 7.9% (n=9)	13% (n=14)	Includes bipolar: 50% (n=14) ^a	26.1% (n=266); F: 36.0% (n=189); M: 15.7% (n=77)	13.4% (n=9,671); F: 21.4% (n=5,160); M: 9.4% (n=4,511)	40.0% (n=14)	3% (n=1)	11.76% (n=2)	Affective (mood) disorders: 8.71% (n=191); F: 13.9%; M: 5.2%	Major Depressive disorder: 49% (n=26)
Eating disorders	1.9% (n=3); F 6.4% (n=3);	2% (n=2)	NR	5.4% (n=55); F: 9.0% (n=47);	2.38% ^B	NR	NR	NR	2.49% (n=55); F: 5.0%;	AN: 13.2% (n=7)

	M 0% (n=0)			M: 1.6% (n=8)	AN: 0.8% (n=570); F: 2.1% (n=497); M: 0.2% (n=73) Other ED: 1.6% (n=1,150); F: 3.9% (n=952); M: 0.4% (n=198)			M: 0.8%		BN: 0% (n=0)
OCD	7.5% (n=12); F 6.4% (n=3); M 7.9% (n=9)	NR	3.57% (n=1)	NR	3.0% (n=2,143); F: 4.2% (n=1,013); M: 2.3 (n=1,130)	11.4% (n=4)	48.4% (n=16)	NR	2.17% (n=47); F: 3.3%; M: 1.4%	23% (n=12)
Personality disorders	14.9% (n=24); F 23.4% (n=11); M 11.4% (n=13)	15% (n=16)	NR	19.6% (n=200); F: 27.8% (n=146); M: 10.9% (n=54)	3.0% (n=2,143); F: 4.2% (n=1,013); M: 2.3%(n=1,130) Borderline PD: 0 .7% (n=474); F: 1.7% (n=418); M: 0.1% (n=56)	NR	NR	11.76% (n=2)	NR	Borderline PD: 13.5% (n=7)
Psychotic disorders: psychosis, Schizophrenia, dissociative and other psychotic disorders	16.1% (n=26); F 12.8% (n=6), M 17.5% (n=20)	9% (n=9)	First episode: 7.14% (n=2)		1.0% (n=754); F: 1.3% (n=307); M: 0.9% (n=447)		27.2% (n=9)	29.4% (n=5)	2.86% (n=63); F: 3.4%; M: 2.5% Paranoid Schizoaffective and conversion disorders: 11.76% (n=2) : 5.88% (n =1) NOS: 11.76% (n=2).	9.4% (n=5)
SUD	NR	2% (n=2)	NR	3.4% (n=35); F: 3.0% (n=16); M: 3.8% (n=19)	NR	NR	Cannabis: 3% (n=1)	NR	NR	NR

Other psychiatric disorders	SUD, Tourette, mixed developmental disorder, selective mutism: 4.3%) Gender identity disorder: 3.1% (n=5); F 6.4% (n=3), M 1.8% (n=2)	Attachment problems: 1% (n=1) Sexually impulsive: 1% (n=1) Adaption disorders: 3% (n=3)	Catatonia: 3.57% (n=1)	Trauma-related disorders: 5.3% (n=54); F: 8.2% (n=43); M: 2.2% (n=11) Burnout/chronic fatigue: 8.0% (n=82); F: 11.4% (n=60); M: 4.5% (n=22)	Sleep disorder: 8.9% (n=6,409); F: 12.5% (n=3,006); M: 7.1% (n=3,403)	Internalising disorders (anxiety, depression, bipolar, OCD): 57.1% (n=20)	Behavioural addiction: 9% (n=3)	Crisis reaction 309.A: 5.88% (n=1),	Stress disorders: 10.77% (n=237); F: 16.5%; M: 6.9%	PTSD: 1.9% (n=1)
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AN anorexia nervosa, BN Bulimia nervosa, CD conduct disorder, ODD oppositional defiant disorder, GAD Generalised anxiety disorder, NOS Not-otherwise specified, OCD Obsessive compulsive disorder, PD Personality Disorder, PTSD post-traumatic stress disorder, SUD substance use disorder.

^A anxiety disorders include OCD, however, also reports OCD data separately (n=1) so recalculated to reflect this and OCD reported separately.

^B Overall eating disorder prevalence rate calculated by lead researcher

Supplementary Table 2: Prevalence of PMHD in ADHD

ADHD Studies							
PMHD % (n), Female % (n), male % (n)	Jónsdóttir (2022)*	Manfro et al. (2024)	Martin et al. (2024)*	Nylander et al. (2009)	Okada et al. (2024)* Child and adolescent (C&A), Adult (A)	Ratey et al. (1992)	Skoglund et al. (2024)
Anxiety	54.6% F: 61.7% (n=295), M: 45.9% (n=240)	0% (n=0)	21.9% F: 29.8%; M: 19.9%	Anxiety disorders F40.0-F42.9: 10.8% (n=4)	Anxiety disorders; 9.9% C&A: 5.8%; A: 17.9%	15% (n=9)	Including stress F40-F48: 36.7% (n=31,291); F: 50.4% (n=18,932); M: 25.9% (n=12,359)
CD/ODD (any)	NR	10.7% (n=3)	NR	NR	CD (excluding ODD): 0.2% C&A: 0.3%; A: 0.0% ODD: 0.4%, C&A: 0.6%; A: 0.0%	NR	CD: 3.5% (n=2,995); F: 2.6% (n=994); M: 4.2% (n=2,001)
Depression	48.9%* F: 53.6% (n=256), M: 43.8% (n=229)	Any depression disorder: 3.6% (n=1)	24.4%* F: 35.5%; M: 21.6%	Affective disorders F32-F33.9, F34.1-F39.9, F53.0: 35% (n=13)	Depressive episode: 13.9% C&A: 4.1%; A: 33.0% C&A: 0.0%; A: 0.3% Recurrent depression: 0.1% C&A: 0.0%; A: 0.3% Mood disorders: 15.9% C&A: 5.2%; A: 36.9% Bipolar: 3.9% C&A: 1.2%; A: 9.2%	Mood disorders (includes depression, dysthymia and cyclothymia): 46.6% (n=28)	Mood (affective) disorders: 27.4% (n=23,399); F: 37.5% (n=14,103); M: 19.5% (n=9,296)
Eating disorders	NR	NR	NR	NR	0.5% C&A: 0.4%; A: 0.6%	NR	2.8% (n=2,367); F: 5.6% (n=2,094); M: 0.6% (n=273)
OCD	NR	NR	NR	NR	0.8% C&A: 0.6%; A: 1.1%	5% (n=3)	NR
Personality disorders	NR	NR	NR	8% (n=3)	NR	NR	3.9% (n=3,358); F: 6.3% (n=2,357); M: 2.1% (n=1,001)

Psychotic disorders	NR	NR	NR	NR	Schizophrenia and schizotypal disorder: 5.6%; C&A: 3.7%; A: 9.2% Other psychotic disorders: 1.4%, C&A: 0.6%; A: 2.9%	NR	F20-F29 (Schizophrenia, schizotypal, delusional, and other non-mood psychotic disorders): 1.2% (n=1,046); F: 1.2% (n=443); M: 1.3% (n=603)
Sleep disorders					12.8% C&A: 7.1%; A: 23.8%		6.0% (n=5,112); F: 7.5% (n=2,812); M: 4.8% (n=2,300)
SUD				2.7% (n=1)	0.6% C&A: 0.1%; A: 1.6%	13% (n=8)	12.3% (n=10,537); F: 12.9% (n=4,834); M: 12.0% (n=5,703)
Other psychiatric disorders	Other disorders: F: 18.6% (n=89), M: 14.3% (n=75)	Other PMHD: F: 46.9%; M: 35.3%	Maladaptive reactions: 18.9% (n=7)		Dissociative disorders: 1.0%; C&A: 0.4%; A: 2.1% Reaction to severe stress and adjustment disorders: 8.1%; C&A: 6.4%; A: 11.5% Somatoform disorders: 5.7%; C&A: 5.5%; A: 6.0% Tic disorders: 1.2%; C&A: 1.8%; A: 0.1%	Eating disorders, sleep disorder or somatization: 15% (n=9) Antisocial behaviour disorder 5% (n=3) "Other": 15% (n=9)	NR

CD conduct disorder, ODD oppositional defiant disorder, OCD Obsessive compulsive disorder, SUD substance use disorder.

*No overall prevalence provided, lead researcher calculated these.

Supplementary Table 3: Frequency of PMHD per participant across Studies

Frequency of PMHD	0	At least 1	1	2	3	4	5	6/more
Fusar-Poli et al. (2022)	33.5%	NR	36.6% (n=59)	2/3: 24.84% (n=40)		4/5: 7.7% (n=6)		1.2% (n=2) 6/7/8 PMHD
Geurts and Jansen, (2011)^a	(62.9% (n=66))	39.05% (n=41)	21.0% (n=22)	13.3% (n=14)	4.8% (n=5)	NR	NR	NR
Ghaziuddin & Zafar (2008)	25.0% (n=7)	75% (n=21)	NR	NR	NR	NR	NR	NR
Kentrou et al. (2021)	51.9% (n=529)	50.2% (n=512) ^b	18.8% (n=192)	14.8% (n=151)	7% (n=71%)	4.5% (n=46)		5+: 3% (n=30)
Manfro et al. (2024)	89.3–85.7% (n=25–24) ^c	10.7–14.3% (n=3–4)	NR	NR	NR	NR	NR	NR
Martini et al. (2025)	54.7% (n=39,557)	45.3% (n=32,774)	27.2% (n=19,693)	10.3% (n=7,470)	4.6% (n=3,336)	1.9% (n=1,357)	0.8% (n=546)	6: 0.3% (n=224) 7+: PMHD: 0.2% (n=148)
Mazefsky et al. (2012)	22.9% (n=8)	77% (n=27)	17.1% ^d (n=6)	2/more: 60.0% (n=21)	3/more: 28.6% (n=10)	NR	NR	NR
Nahar et al. (2019)	6% (n=2)	94% (n=31)	NR	45% (n=15)	NR	NR	NR	NR
Nylander & Gillberg (2001)	NR	NR	NR	NR	NR	NR	NR	NR
Ratey et al. (1992)	0	100% (n=60) ^d	NR	NR	NR	NR	NR	NR
Rodgaard et al. (2021)	F: 61.2% M: 69.3%	34% (n=747)	NR	NR	NR	NR	NR	NR
Ryden & Bejerot (2008)	37% (n=31)	63% (N=53)	NR	NR	NR	NR	NR	NR

^a Axis 1 disorders only. Author's Table 1 and text reported discrepant estimates for Axis I disorders (39.0% vs 32.0%). Table 1 values were extracted because frequency counts for 0, 1, 2 and >2 disorders were provided.

^b At least one PMHD or co-occurring diagnosis.

^c Derived from reported baseline diagnosis, not explicitly stated by authors.

^d Derived from reported cumulative frequencies.

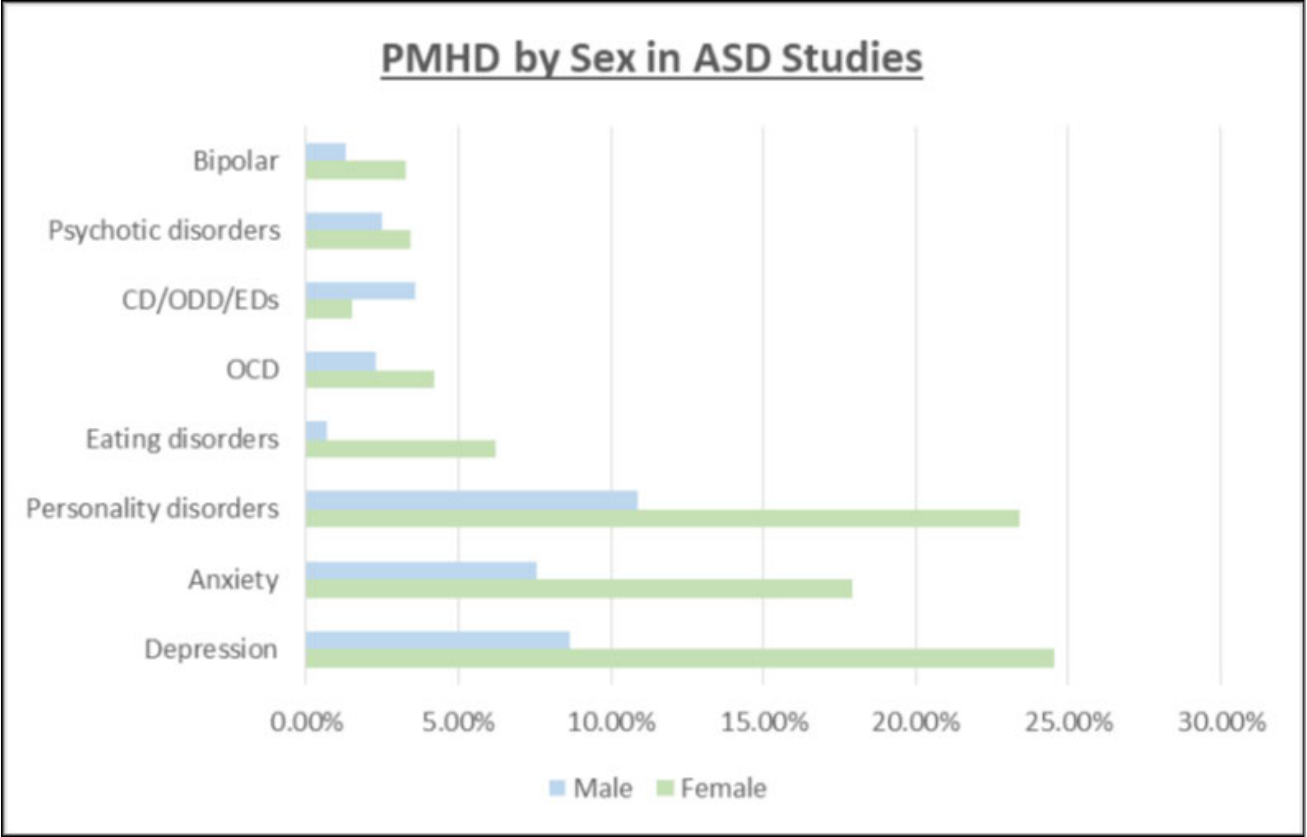
^e Derived from total counts.

Supplementary Table 4: PMHD by Sex in ASD Studies

PMHD in ASD Studies	Female median (Q1-Q3)	IQR	Prevalence consistency	Male median (Q1-Q3; IQR)	IQR	Prevalence consistency	Number of studies
Depressive disorders	24.55% (19.53-29.78)	10.75%	Moderate	8.65% (7.24-10.96)	3.74%	Extremely High	4
Anxiety disorders	17.90% (11.65-24.00)	12.35%	Moderate	7.55% (4.93-9.85)	4.93%	Extremely High	4
Personality disorders	23.40% (12.55-25.60)	13.05%	Moderate	10.90% (5.50-11.15)	5.65%	High	3
Eating disorders	6.20% (5.75–7.05)	1.30%	Extremely High	0.70% (0.45–1.00)	0.55%	Extremely High	4
OCD	4.20% (3.75–5.30)	1.55%	Extremely High	2.30% (1.85–5.10)	3.25%	Extremely High	3
CD/ODD/Emotional Disorders	1.50% (1.45–1.80)	0.35%	Extremely High	3.60% (3.40–6.60)	3.20%	Extremely High	3
Psychotic disorders	3.40% (2.35–8.10)	5.75%	High	2.50% (1.70–10.00)	8.30%	High	3
Bipolar	3.25% (2.73–3.78)	1.05%	Extremely High	1.30% (1.05–1.55)	0.50%	Extremely High	2

Prevalence consistency: <5 percentage points indicated “extremely high” consistency, 5–10 “high” consistency, 11–20 “moderate” consistency, 20–30 “low” consistency, >30 “extremely low” consistency.

Supplementary Fig. 1: PMHD by Sex in ASD Studies

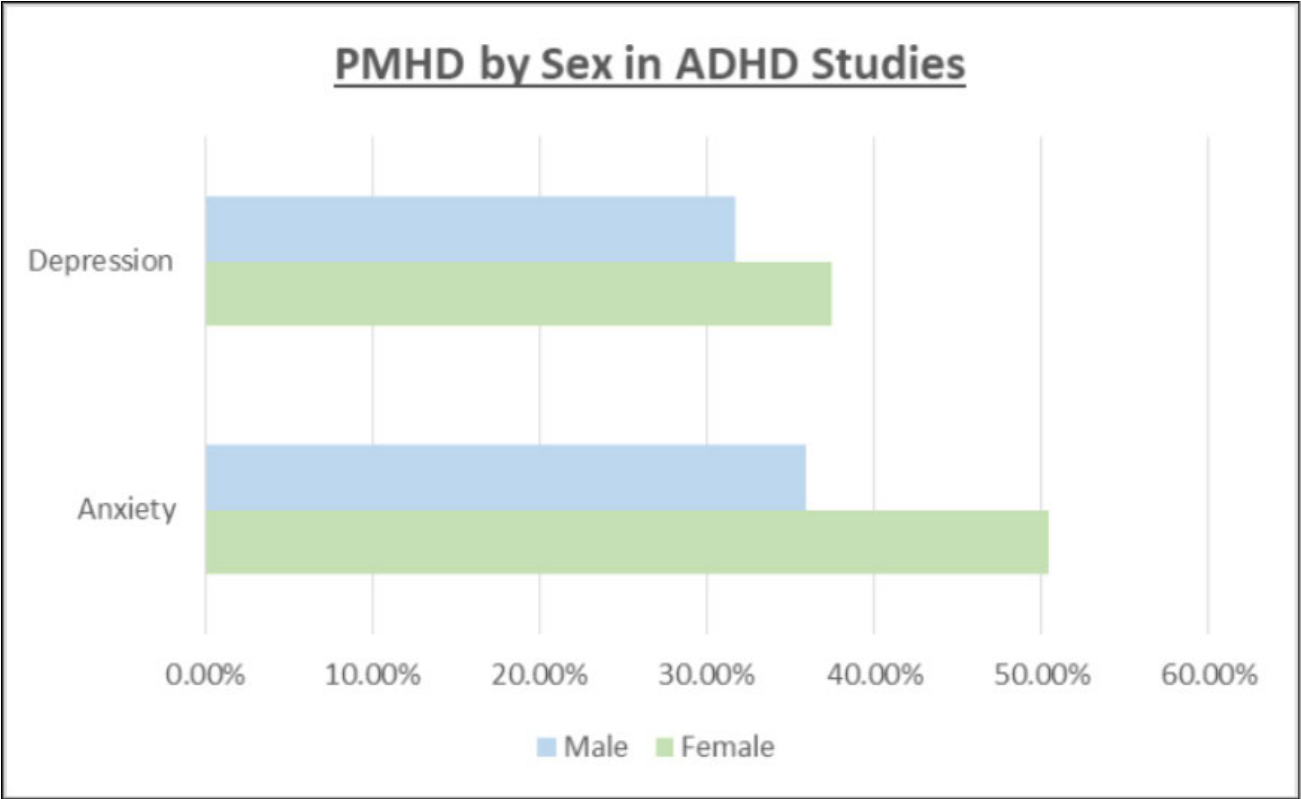


Supplementary Table 5: PMHD by Sex in ADHD Studies

PMHD in ADHD Studies	Female median (Q1-Q3)	IQR	Prevalence consistency	Male median (IQR)	IQR	Prevalence consistency	Number of studies
Anxiety	50.40% (40.10–56.05)	15.95%	Moderate	35.90% (30.90–40.90)	10.00%	High	3
Depression	37.50% (36.50–45.55)	9.05%	High	31.65% (25.58–37.73)	12.15%	Moderate	3

Prevalence consistency: <5 percentage points indicated “extremely high” consistency, 5–10 “high” consistency, 11–20 “moderate” consistency, 20–30 “low” consistency, >30 “extremely low” consistency.

Supplementary Fig. 2: PMHD by Sex in ADHD Studies



Supplementary Table 6: GRADE Certainty Ratings

Studies assessed	GRADE Certainty level
ASD study findings	Very low
Sex-stratified ASD findings	Very low
ADHD study findings	Low
Sex-stratified ADHD findings	Very low

Appendix 2: Appendices for Major Research Project (MRP)

Appendix 2.1: Standard Reporting Qualitative Research Checklist

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study, identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	62
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	65
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	66-68
Purpose or research question - Purpose of the study and specific objectives or questions	68
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale**	69
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	72
Context - Setting/site and salient contextual factors; rationale**	69
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	69-70
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	118
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	71
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	71

Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	73-75
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	71-72
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	71-72
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	71

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	75-77
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	78-86

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	87-89
Limitations - Trustworthiness and limitations of findings	89

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	90
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	90

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

Appendix 2.2: Final Approved MRP Proposal

Available at: <https://osf.io/yzcwg/files/a4tx9>

Appendix 2.3: Proceed to Ethics Letter



School of Health
& Wellbeing



HM/PR

9th December 2024

Frances Holborn

f.holborn@student.gla.ac.uk

Dear Fran,

Major Research Project Proposal

Mental Health and Treatment Experiences of Late Diagnosed Autistic Women Within Adult Mental Health Services

The above project has been reviewed by your University Research Supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely

Prof Hamish McLeod
Professor of Clinical Psychology
DClinPsy Research Director

School of Health & Wellbeing
College of Medical, Veterinary and Life Sciences
University of Glasgow
Mental Health and Wellbeing, Clarice Pears Building
90 Byres Road, Glasgow G12 8TB
Email: dcclinpsy@glasgow.ac.uk

The University of Glasgow, charity number SC004401



Appendix 2.4: Ethical Approval Letter



Health Research Authority

South Central - Hampshire A Research Ethics Committee

Health Research Authority
2 Redman Place
Stratford
London
E20 1JQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

07 July 2025

Dr Laura Hughes
Clarice Pears, University of Glasgow
90 Byres Rd
Glasgow
G12 8TB

Dear Dr Hughes

Study title:	Mental Health and Treatment Experiences of Late Diagnosed Autistic Women within Adult Mental Health Services
REC reference:	25/SC/0190
IRAS project ID:	350933

Thank you for your letter of 24 June 2025, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The [UK Policy Framework for Health and Social Care Research](#) sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of [research transparency](#):

1. [registering research studies](#)
2. [reporting results](#)
3. [informing participants](#)
4. [sharing study data and tissue](#)

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device

- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: [Research registration and research project identifiers](#)).

Where a deferral is agreed we expect the sponsor to publish a [minimal record](#) on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, [a minimum research summary](#) will still be published in [the research summaries database](#). At the end of the deferral period, we will publish the [full research summary](#).

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: [Research summaries - Health Research Authority \(hra.nhs.uk\)](#)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at [Managing your approval - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Consent to be Contacted form]	1	23 May 2025
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1	23 May 2025
Interview schedules or topic guides for participants [Topic Guide]	2	23 June 2025
IRAS Application Form [IRAS_Form_23062025]		23 June 2025
Letters of invitation to participant [Letter of invitation]	2	02 May 2025
Other [Privacy Notice]	4	02 May 2025
Other [Provisional Opinion from REC -]	1	23 June 2025
Participant consent form [Participant consent form]	4	12 May 2025
Participant information sheet (PIS) [Participant Information Sheet]	6	23 June 2025
Research protocol or project proposal [Mental Health and Treatment Experiences of Late Diagnosed Autistic Women within Adult Mental Health Services]	9	23 June 2025
Summary CV for Chief Investigator (CI) [Cv for Dr Laura Hughes CI]	2	23 May 2025
Summary CV for student [Lead researchers CV]	2	12 May 2025
Summary CV for supervisor (student research) [Field supervisor/Principal investigator's CV]	2	12 May 2025

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: [Quality assurance - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/quality-assurance)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: [Learning - Health Research Authority \(hra.nhs.uk\)](https://www.hra.nhs.uk/learning)

IRAS project ID: 350933 Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project.

Yours sincerely

pp.

Mrs Vivienne Laurie
Chair

Email: hampshirea.rec@hra.nhs.uk

Copy to: Dr Alastair Wilson

Appendix 2.5: Research Development Approval letter



Research, Development & Innovation
56a Lister Street
University Hospital Crosshouse
Kilmarnock
KA2 0BB

Dr Paula Killean
Senior Principal Clinical Psychologist
NHS Ayrshire and Arran

Date 25th July 2025
Your Ref
Our Ref CM/CBNW/MF RDI No 2025AA036
Enquiries to Dr Carolina Borda-Niño-Wildman
Head of RDI
Email carolina.borda@aapct.scot.nhs.uk

Dear Dr Killean

Mental Health and Treatment Experiences in Autistic Women

I confirm that NHS Ayrshire and Arran have reviewed the undemoted documents and grant RDI Management approval for the above study.

Documents received:

Document	Version	Date
Localised OID	4	02/06/25
IRAS form	6.4.1	23/06/25
MRP Proposal	9.0	23/06/25
Opportunity to Participate in Autism Research	None	None
Letter of invitation by email or post	2	02/05/25
P.I.S.	6	23/06/25
Consent Form	4	12/05/25
Privacy Notice	4	02/05/25
Interview schedule	2	23/06/25

The terms of approval state that the investigator authorised to undertake this study within NHS Ayrshire & Arran is: -

- Dr Paula Killean, Senior Principal Clinical Psychologist, NHS Ayrshire and Arran

With additional investigators:-

- Frances Holburn, Trainee Clinical Psychologist, NHS Ayrshire and Arran

The sponsors for this study are University of Glasgow.

This approval letter is valid until 30th September 2026.

A final report should be submitted to the Research, Development & Innovation generic mailbox randdprojectteam@aapct.scot.nhs.uk when the study is completed.

Please note that as a requirement of this type of study your name, designation, work address, work telephone number, work e-mail address, work related qualifications and whole time equivalent will be held on the Scottish National Research Database so that NHS RDI staff in Scotland can access this information for purposes related to project management and report monitoring.

In addition approval is granted subject to the following conditions: -

- All research activity must comply with the standards detailed in the UK Policy Framework for Health and Social Care Research <http://beta.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research> and appropriate statutory legislation. It is your responsibility to ensure that you are familiar with these, however please do not hesitate to seek further advice if you are unsure.
- Recruitment figures must be submitted to RDI on a monthly basis. If recruitment figures are not received timeously you will be contacted by a member of the RDI team to provide this data.
- You are required to comply with Good Clinical Practice (ICH-GCP guidelines may be found at www.ich.org/LOB/media/MEDIA482.pdf), Ethics Guidelines, Health & Safety Act 1999, General Data Protection Regulation (GDPR) and Data Protection Act 2018.
- If any amendments are to be made to the study protocol and or the Research Team the Researcher must seek Ethical and Management Approval for the changes before they can be implemented.
- The Researcher and NHS Ayrshire and Arran must permit and assist with any monitoring, auditing or inspection of the project by the relevant authorities.
- The NHS Ayrshire and Arran Complaints Department should be informed if any complaints arise regarding the project and the RDI Department must be copied into this correspondence.
- The outcome and lessons learnt from complaints must be communicated to funders, sponsors and other partners associated with the project.
- As custodian of the information collated during this research project you are responsible at all times for ensuring the security of all personal information collated in line with NHS Scotland policies on information assurance and security, until the secure destruction of these data. The retention time periods for such data should comply with the requirements of the Scottish Government Records Management: NHS Code Of Practice. Under no circumstances should personal data be stored on any unencrypted removable media e.g. laptop, USB or mobile device (for further information and

guidance please contact the Information Governance Team based at University Hospital Crosshouse 01563 825831 or 826813).

You should inform the RDI Team if your contract with NHS Ayrshire & Arran comes to an end and provide an alternative contact / PI for the study within NHS Ayrshire and Arran. This is necessary for continued oversight of the study and archiving and destruction purposes.

If I can be of any further assistance please do not hesitate to contact me. On behalf of the department, I wish you every success with the project.

Yours sincerely

Dr Crawford McGuffie
Medical Director

c.c. Alistair Wilson, University of Glasgow (Sponsor contact)
Dr Laura Hughes, University of Glasgow (CI)
Hugh Bunyan, Finance, NHS Ayrshire & Arran
Information Governance, NHS Ayrshire & Arran
Frances Holburn, Trainee Clinical Psychologist
Wendy Van Riet, Director of Psychological Services

www.nhsaaa.net



Appendix 2.6: Participant Information Sheet and Consent form

Participant Information Sheet: <https://osf.io/yzcwg/files/egtu3>

Consent form: <https://osf.io/yzcwg/files/65vzg>

Appendix 2.7: Copies of Non-Standard Research Materials

Topic Guide: <https://osf.io/yzcwg/files/txz8y>

Interview Schedule: <https://osf.io/yzcwg/files/umrqm>

Letter of invitation: <https://osf.io/yzcwg/files/u58jr>

Privacy Notice: <https://osf.io/yzcwg/files/9ntup>

Appendix 2.8: Detailed Data Analysis Plan

Available at: <https://osf.io/yzcwg/files/kj7zx>

Appendix 2.9: Records of Data Analysis Process

Available at: <https://osf.io/yzcwg/files/hz2s5>

Appendix 2.10: Data Availability Statement

Data for this study is not made publicly available due to the highly confidential and personal nature of the information shared by the participants in this study. For this reason, the data shared in Appendix 2.9 has been redacted and edited to protect the identity of the participants.

Personal data is stored until the end of the study, prior to submitting the End of Study form when it is permanently erased. The pseudo-anonymised data presented in chapter 2 will be stored on the University of Glasgow's Enlighten Library Thesis and Dissertations Repository for 10 years, in line with the data management plan and agreement from Research and Development in Ayrshire and Arran.

Appendix 2.11: Excerpt from Reflective Journal

17/01/2026

Listened to and cleaned my third interview. It was only 38 mins so this only took a few hours!

I noticed some low feelings when listening to this again. And remembering this woman's presentation. She has been through so much, been so distressed and to make it worse she had lost her job the same day as the interview – but wanted to do it anyway. No one picked up on her autism until adulthood (as per the study criteria) but she showed so many signs in childhood, it's frustrating to hear she wasn't given the right help sooner. And hard to hear about her self-harm. This is what a lack of support does! Frustration and anger on her behalf. She laughs at various points – seems like nervous/ironic laughter – usually when talking about things that aren't good. Very quick interview. She doesn't go off on tangents. Very to the point and direct. The audio wasn't as good on this one so there are a few occasions I cannot decipher what she has said. Thankfully my notes are very tidy for this one as I typed them up (it was an online interview), so they have helped me clarify a few bits.

Step 1-3 complete! Delighted I have managed to do this in a day. Granted, it was short and the participant was direct. She also had nothing to add from her debrief so there was nothing even to add to the analysis for that. Next steps – conduct step 4 for the 3 interviews I have analysed!

18/01

Took a lot longer to do step 4 than I thought - tricky to get a feeling all the themes are right - great when you sense that they fit. I expected to have some outliers but at risk of wanting to have as few as possible I don't want to force them into a theme that isn't right. Or miss one that is.

19/01

For some reason I thought step 4 would be straightforward and quite quick – it is not! Sometimes it's really tricky to decide if you have the right themes or not. I was able to hold the participants in mind and found it helpful to recall what exactly they meant by the statements so that I could gain a feel for if they were in the right theme/subtheme.

I found it helpful to do the first one twice. I feel like it was reassuring to get almost the same things come out.

I have also learnt that I should make my ES more specific to singular points. Otherwise, it makes it tricky to put them into themes/subthemes. However, they are meant to be more summative, and less than ENs so there needs to be balance here.