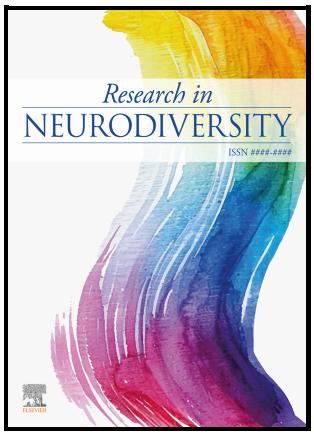

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PII: S3050-5798(26)00044-6

DOI: https://doi.org/10.1016/j.rin.2026.100058

Reference: RIN100058

To appear in: *Research in Neurodiversity*

Received date: 2 July 2026
Revised date: 5 August 2026
Accepted date: 8 August 2026

Please cite this article as: Valeria Khudiakova, Jacqueline Sin, Piyali Bhattacharya and Kirsten Barnicot, Who is receiving an adult autism diagnosis and included in research? A systematic review and meta-analysis, *Research in Neurodiversity,* (2026) doi:https://doi.org/10.1016/j.rin.2026.100058

Who is receiving an adult autism diagnosis and included in research? A systematic review and meta-analysis

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Author contributions: VK: Conceptualization, Methodology, Formal analysis, Writing – original draft; JS: Conceptualization, Methodology, Writing – review & editing; PB: Formal analysis, Writing – review & editing; KB: Conceptualization, Methodology, Writing – review & editing.

Abstract

An increasing number of adults have been receiving an autism diagnosis in recent years, due to changes in diagnostic criteria and increased awareness. It is unclear whether certain groups are more likely to face disparities when seeking a diagnostic assessment. As diagnostic criteria and tools are shaped by research, research samples should reflect the diversity of the autistic population.

This systematic review examined the demographics of adult-diagnosed autistic people represented in quantitative research. We searched Web of Science, PsycINFO, Embase, Medline, and ProQuest Dissertations & Theses for eligible studies and conducted citation searching, identifying 108 eligible studies. We used a

random-effects proportional meta-analysis to estimate the pooled proportions of participants reported as female, women-identifying participants, gender-diverse, and ethnically and racially minoritised participants, and participants with ten common co-occurring psychiatric diagnoses, i.e. anxiety, depression, ADHD, OCD, intellectual disability, bipolar disorder, psychotic disorders, substance use disorders, and personality disorders.

The pooled proportion of participants reported as female was 35.51%. Only five studies reported on gender-diverse participants, who comprised an estimated 10.50%. Twelve studies included data on race/ethnicity with a pooled proportion of ethnically and racially minoritised participants of 10.45%. The pooled proportions of participants with co-occurring conditions ranged from 5.94% for substance use disorders to 33.56% for depression.

We identified high heterogeneity levels and gaps in demographic reporting across studies, especially regarding gender identity, race/ethnicity, and intellectual disability. We discuss the implications of these gaps in representation and reporting and differences between sample sources for the generalisability of research findings people.

Keywords: adult diagnosis, representation, equity, gender, ethnicity, mental health

Background

The number of people receiving an autism diagnosis has risen dramatically in recent years, attributed to broadened diagnostic criteria and increased awareness (Harrop et al., 2024; G. Russell et al., 2022). This means that individuals previously not considered autistic are now being recognised and diagnosed, including in adulthood. Emerging research on children indicates that some disparities persist, with female, socioeconomically disadvantaged, and, often, children from ethnically[1] and racially minoritised backgrounds less likely to receive an autism diagnosis (Kelly et al., 2019; Pham & Charles, 2023; Yuan et al., 2021). However, it is currently unclear what, if any, diagnostic disparities apply to adults. The context of seeking a diagnosis in adulthood is distinct, as seeking an adult diagnosis is frequently self-initiated, and opportunities for autism recognition and access to specialist services are more limited (Khudiakova et al., 2026; Lewis, 2017; Murphy et al., 2023), which may shape who has the opportunity to receive a diagnosis and to be included in research.

Because diagnostic criteria, tools, and practices are shaped by research, it is imperative that research samples reflect the full diversity of the autistic population (J. Davies et al., 2024; G. Russell et al., 2019). Systemic underrepresentation in research may reinforce the same barriers, such as clinician expectations, screening thresholds, and behavioural norms, that have led to many autistic people remaining unrecognised or receiving inappropriate supports in routine clinical settings (Davies et al., 2024). Accordingly, in this review, we focus on who is represented in research on autistic people diagnosed in adulthood.

[1] We acknowledge that ‘race’ and ‘ethnicity’ are socially defined and contested concepts that nonetheless remain crucial in describing injustices faced by some communities (Garcia et al., 2022). A more detailed discussion on language is provided further in the introduction.

Sex, Gender Identity, and Adult Diagnosis

Sex and gender identity (i.e., internal sense of gender which may or may not align with sex assigned at birth) have long been linked to unrecognised autism, in particular amongst women and people assigned female at birth (women/AFAB) whose presentations of autistic traits may not align with male-based conceptions of autism (Bargiela et al., 2016). The use of diagnostic tools and criteria developed mainly based on presentations more typical of men and those assigned male at birth (men/AMAB) and therefore lacking sensitivity in women/AFAB may contribute to these disparities (Diemer et al., 2025; D'Mello et al., 2022; Lai et al., 2011; G. Russell et al., 2011). While the recent rise in adult diagnoses is partly driven by a growing number of women/AFAB receiving a diagnosis each year (Harrop et al., 2024; G. Russell et al., 2022), significant disparities persist, and a substantial proportion of autistic women and female individuals remain undiagnosed across the lifespan (O'Nions et al., 2024) and underrepresented in research (D'Mello et al., 2022).

Gender-diverse[2] people are a particularly important group to examine within the context of this review. Although gender-diverse people are more likely to receive an autism diagnosis than their cisgender peers (Warrier et al., 2020), they may encounter distinct barriers when seeking one in adulthood. For instance, fears of being denied gender affirming care or perceptions of diagnostic criteria as biased (Ardeleanu et al., 2024; Tien et al., 2025) may deter gender-diverse people from seeking an autism diagnosis, in addition to past experiences of stigmatisation and perceived lack of skilled and trustworthy professionals (Lovejoy et al., 2023).

[2] Including people whose gender identity does not align with their sex assigned at birth, such as transgender, nonbinary, and agender individuals. We also recognise that 'gender identity' may also be a contentious term. We use it to refer to an inner sense of gender, which may or may not align with a person's sex assigned at birth, for clarity and consistency with past literature (McQuaid et al., 2024).

Gender-diverse people are often underrepresented in mental health and autism research, and gender identity, as distinct from sex, may not be explored and recorded appropriately (Strang et al., 2020). Given these challenges and the known overlap between gender diversity and autism, and the aforementioned barriers faced by gender-diverse people when seeking care, it is important to examine their representation in research on adult-diagnosed autistic people.

Race/Ethnicity and Adult Diagnosis

Any discussion of race/ethnicity requires a justification of the terms used. Autism research has historically been conducted in Western contexts, implicitly or explicitly positioning white[3] individuals as a default (Divan et al., 2025; Kostet, 2026b). 'Race' and 'ethnicity' are socially constructed and contested terms whose definitions vary globally; yet they remain vital in describing both the inequities and community-derived strengths experienced by communities racialised as 'minorities' (Garcia et al., 2022). There is no universally accepted collective term to refer to groups experiencing minoritisation, and all such terms have their limitations (NHS Race & Health Observatory, 2021). For example, terms such as 'ethnic minority' have been criticised as being imprecise, with highly context-dependent definitions (Jackson-Preece, 2014), and, more broadly, for positioning white individuals as the default while 'othering' the groups they refer to (Campbell-Stephens, 2020).

This review uses the term 'ethnically and racially minoritised' to highlight the social and structural processes of racialisation and minoritisation that result in disadvantage in Western contexts (Centre for Mental Health, 2026; Kostet, 2026a,

[3] As with many terms related to racial/ethnic categories, there is no consensus as to whether the category 'white' should be capitalised. We have chosen not to capitalise this term in line with the Associated Press (2020) convention. The term remains capitalised when used in direct quotations or where required by sentence or title case.

2026b). As with all collective terms, the term ‘ethnically and racially minoritised’ is imperfect, as it groups together highly diverse populations who may experience racialisation and minoritisation differently (Kostet, 2026b), and does not capture how individuals so categorised may experience intersecting challenges beyond those linked to race and ethnicity (Esmene et al., 2024). We acknowledge other preferences and terminologies in this rapidly evolving field.

Little is known about racial/ethnic disparities in accessing an autism diagnosis in adulthood. Cohort data previously showed that white children were more likely to receive an autism diagnosis compared to ethnically and racially minoritised children in the US and the UK, yet emerging evidence suggests that the trend has since reversed in some groups, potentially indicating improved access to services (Roman-Urrestarazu et al., 2021; Yuan et al., 2021). However, whether similar changes apply to adults is unknown. Adult diagnostic pathways rely on self-advocacy and self-initiation to a great extent (Lewis, 2017), which might particularly disadvantage ethnically and racially minoritised adults; recognition of autism may be hindered by stigma or lack of representation or awareness across ethnically and racially minoritised communities (Ardeleanu et al., 2024; J. Davies et al., 2024). Some adults describe a perception of autism as “this White thing that has nothing to do with us” (Jones et al., 2020), or perceive adult diagnostic services as white-dominated and therefore ‘not for them’ (Ardeleanu et al., 2024). Kostet (2026a, 2026b) further draws attention to broader societal constructions of autism and autistic identity as inherently linked to whiteness, therefore resulting in a limited understanding of the intersections of ethnic and racial minoritisation and autism recognition.

More broadly, ethnically and racially minoritised communities face intersecting barriers in accessing mental health services, including socioeconomic barriers,

systemic discrimination, and mistrust of clinicians (Lowther-Payne et al., 2023; Lu et al., 2021), which likely extend to adult autism diagnosis and compound the distinct barriers mentioned earlier. Researchers and adult-diagnosed autistic people have also raised concerns about ethnic bias in diagnostic tools, though empirical evidence is scarce (Malone et al., 2022). Evidence suggests that autism screening and diagnostic tools may under-detect autism in children from non-Western countries, likely reflecting cultural differences in behavioural expectations and the perception or expression of autistic traits (Huda et al., 2024; Tafla et al., 2024). Similarly, a small degree of bias has been identified in the gold-standard Autism Diagnostic Observation Schedule such that certain items may underestimate autistic traits in Black American compared to white children, though these effects were concluded to be small and unlikely to be clinically significant (Harrison et al., 2017; Kalb et al., 2022). To our knowledge, no such empirical research has been undertaken in adults, and it is unclear how such biases may affect adult assessments or to what extent current practices are appropriate for ethnically and racially minoritised groups. Examining the reporting and representation of ethnically and racially minoritised participants in research is therefore a vital first step.

Co-Occurring Conditions and Adult Diagnosis

A significant proportion of adult-diagnosed autistic people have previously received other diagnoses, and frequently perceive these as having overshadowed timely recognition of autism (Au-Yeung et al., 2019; Jadav & Bal, 2022; Kentrou et al., 2024). Co-occurring conditions—most notably, depression, anxiety, attention deficit/hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and personality and psychotic disorders—may also complicate the recognition of autism due to a degree of overlap in traits and diagnostic overshadowing (Cumin et al.,

2021; Lai & Baron-Cohen, 2015; McQuaid et al., 2024). However, prevalence estimates of co-occurring mental health conditions vary across studies, likely due to different recruitment methods capturing distinct subsets of the autistic population (Lai et al., 2019). Finally, although over half of autistic people are estimated to have intellectual disability (ID) (Loomes et al., 2017), autistic children and adults with co-occurring ID are routinely excluded from research (G. Russell et al., 2019). As a result, the barriers adults with ID face in obtaining an autism diagnosis remain less known, particularly in relation to the recognition of autistic traits as separate from ID (Thurm et al., 2019).

Importance of Research Representation

Systemic lack of representation in research may contribute to the issues described above. Aside from the ethical imperative for transparency in demographic reporting (Call et al., 2023), research findings based on inadequately representative samples—whether in terms of race/ethnicity, sex and gender identity, or co-occurring conditions—may shape the development of diagnostic criteria, tools, and practices, as well as post-diagnostic supports (Malone et al., 2022; G. Russell et al., 2019). Along with other structural barriers, this may contribute to enduring biases that disadvantage groups that are underrepresented. For instance, there is emerging evidence for (self-)selection bias in research on autistic adults, with individuals who volunteer to participate in research more likely to be female, employed, and highly educated than population estimates for autistic people (Rødgaard et al., 2022).

Across mental health research, people from ethnically and racially minoritised backgrounds report numerous barriers to participation, including distrust of research, practical and logistical barriers, and researchers' lack of consideration of their needs (Esmene et al., 2024; Farooqi et al., 2022; Woodall et al., 2010), which can also

affect research on late-identified autistic adults. For these reasons, it is imperative to examine who, among adult-diagnosed autistic people, is included in research and who remains underrepresented or underreported.

At the time of writing, no systematic reviews have explored the recorded demographic characteristics or co-occurring conditions of adult-diagnosed autistic people included in research. Several systematic reviews have synthesised data on the experiences of adult-diagnosed autistic people, without exploring their demographics in detail and being restricted to studies explicitly reporting on these issues of interest (Huang et al., 2020; Kiehl et al., 2024; Nayyar et al., 2025). Existing reviews on the prevalence of co-occurring conditions among autistic adults (Hollocks et al., 2019; Lai et al., 2019; Lugo-Marin et al., 2019) did not examine adult-diagnosed autistic people separately. G. Russell et al. (2019) investigated the representation of ID across autism research, but also did not consider adult-diagnosed participants separately. Finally, the review by A. S. Russell (2025) reported on research studies' definitions of 'late diagnosis' in relation to autism but did not examine the characteristics of participants receiving a diagnosis in adulthood.

This review directly addresses this gap by documenting the demographic characteristics and co-occurring conditions recorded for adult-diagnosed autistic people who are included in research. Examining differences in the representation of characteristics such as sex, gender identity, race/ethnicity, and co-occurring conditions, across different sample sources is another step towards establishing the representativeness of research on adult-diagnosed autistic people (Lai et al., 2019). For instance, samples based on all available clinical records may better approximate who is actually receiving a diagnosis. On the other hand, examining community samples may indicate who is likely to be reached, volunteer to participate, and be

included in research, acknowledging the complex barriers to participation faced by marginalised individuals (Call et al., 2023; Rødgaard et al., 2022). Documenting differences between these sources may thus demonstrate which subsets of the adult-diagnosed autistic population certain recruitment methods are most likely to access, and who may be left behind.

Aim

This review examines demographic and clinical characteristics of adult-diagnosed autistic people included in research to identify potential areas of underrepresentation or underreporting, across research. We additionally examine studies relying on clinical records, as they would most closely approximate who is receiving a diagnosis in practice. We chose to specifically focus on sex and gender identity, race/ethnicity, and co-occurring conditions due to the evidence discussed above suggesting that these factors are particularly likely to contribute to delayed recognition and diagnosis of autism.

Methods

We followed the Preferred Reporting Items in Systematic reviews and Meta-analyses checklist (Page et al., 2020; see Appendix A) and preregistered the review on PROSPERO (CRD42024594639). We searched Embase, Medline, PsycINFO, Web of Science, and ProQuest Dissertations & Theses on 24 October 2024, repeated on 23 March 2025 and 23 December 2025, using the following keywords:

1. autis* or asperger* or ASD or "autism spectrum disorder" or "autistic spectrum disorder" or ASC or "autism spectrum condition" or "autistic spectrum condition" or PDD or "pervasive developmental disorder"
2. (adult diagnos*) or adult-diagnos* or (late diagnos*) or (late identif*) or (adult identif*)

Following each repeated search, identified records were imported into the existing Rayyan library and used the duplicate removal function to remove previously screened articles. We also performed forward and backward citation searches on all included articles. The complete search strategies can be found in Appendix B.

Study Selection

The review eligibility criteria are included in Table 1.

Table 1

Inclusion and Exclusion Criteria

Inclusion	Exclusion
Primary, peer-reviewed research studies or examined theses and dissertations for research degrees	Reviews, editorials, conference abstracts
Quantitative cross-sectional, longitudinal, cohort, and intervention studies	Qualitative studies, case studies, or case series
Sample includes people obtaining a first clinical autism diagnosis in adulthood[1] (≥18 years old). If any other groups are included, data of interest must be reported separately for adult-diagnosed participants.	Sample includes children and adolescents <18 years old, those diagnosed with autism before age 18, self-identifying individuals, or non-autistic people; or participant age of diagnosis not reported; unclear whether a diagnosis was newly made (as opposed to a previous diagnosis being confirmed) in adulthood.
At least one of the following is reported for adult-diagnosed participants: 1. Sex and/or gender identity[2] 2. Race/ethnicity 3. Co-occurring mental health conditions 4. Co-occurring ID	No demographics of interests are reported for adult-diagnosed participants, or demographic data adult-diagnosed participants is aggregated with data on other groups.
Available in English	Not in English Duplicate sample Full-text unavailable

[1] More information on how we confirmed whether studies included adult-diagnosed samples, as well as when author contact was initiated to confirm the above, is provided in the Supplement.

[2] Sex refers to biological sex or sex assigned at birth. Gender identity refers to an inner sense of gender which may or may not match one's biological sex (NHS, 2021). In cases of ambiguity (k = 61 studies were identified as ambiguous in terms of sex or gender identity reporting), we assumed studies were referring to sex, rather than gender identity.

In line with past research (A. S. Russell et al., 2025), we chose a cutoff of age 18 for an adult diagnosis. We excluded qualitative or case studies, as they are likely

to have purposive and therefore much less representative samples (Tuckett, 2004). In addition, as the focus of this review was on adult-*diagnosed* participants, we excluded self-identified autistic individuals.

Two authors (VK and PB) carried out the title and abstract screening independently in Rayyan (Cohen's κ = 0.87, absolute agreement = 95.5%). Full texts of studies included at the title and abstract stage were then retrieved and assessed for eligibility by both reviewers (Cohen's κ = 0.77, absolute agreement = 93.4%). At all stages, disagreements were resolved by discussion with the wider research team. Examples of excluded studies appearing to meet the inclusion criteria and the rationale for their exclusion are provided in Appendix C.

Data Extraction

Extracted data included study year, region, aim, and sample source, and, for adult-diagnosed participants, sex or gender identity, mean age, race/ethnicity, and any recorded co-occurring conditions. We noted whether studies reported on sex or gender identity, and when unclear, we assumed the authors were referring to sex at birth, in line with past reviews (Khudiakova et al., 2024). This is acknowledged as a limitation of the available literature. For studies reporting both sex and gender identity, we extracted data on both.

We recorded the number of participants reported as Black, Asian, Arab, Indigenous, Hispanic/Latinx, and Mixed race/ethnicity. These participants are collectively referred to as 'ethnically and racially minoritised'. We acknowledge that the term 'ethnically and racially minoritised' would not apply in countries where these groups constitute the local majority. However, as all of the studies reporting on race/ethnicity were conducted in North America, Europe, or Australia, where these groups are ethnically and racially minoritised, we retained this term.

We chose to extract data on the following recorded co-occurring conditions a priori: depression, (generalised) anxiety[4], ADHD, OCD, bipolar disorder, psychotic disorders, personality disorders, eating disorders, and ID, as these conditions have been described as both highly prevalent in autistic people and potentially contributing to delayed diagnosis (Cumin et al., 2021; Thurm et al., 2019; Lai & Baron-Cohen, 2015). Extracting data on socio-economic status was considered but decided against, given the high levels of variation in how socio-economic data is collected and reported globally, thereby precluding meaningful comparisons. We planned to extract data on any other co-occurring conditions reported on in 10 or more studies; the only condition to reach this threshold was substance use disorder. No missing data was imputed if relevant values could not be calculated from available data; for instance, we did not impute participants' ethnicity based on study location to avoid unwarranted assumptions.

Quality Assessment

To appraise studies' recruitment and reporting strategies, we used the following items of the Appraisal Tool for Cross-Sectional Studies (AXIS; Downes et al., 2016) to generate a score out of 5: item 3 ('Was the sample size justified'?), 4 ('Was the target/reference population clearly defined? (Is it clear who the research was about?)'), 5 ('Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?'), 6 ('Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?'), and 7 ('Were measures undertaken to address and categorise non-responders?'). Other items

[4] We extracted data on co-occurring generalised anxiety disorder or unspecified anxiety disorders (e.g., reported solely as 'anxiety'); social anxiety disorder did not reach the $k = 10$ threshold.

were omitted as they pertained to measurement, statistical tools, and conclusions which were irrelevant to the quality of the data needed for our review objectives.

Formal assessment for publication bias was not undertaken. The Joanna Briggs Institute cautions against using funnel plots and statistical tests for publication bias in proportional meta-analyses, as there is no clear way to determine what a 'positive' outcome (which would be more likely to be published, as such methods assume) would constitute (Barker et al., 2021). As our analysis is concerned with the descriptive reporting and representation of a range of identities and co-occurring conditions, it would not necessarily be expected that studies with certain proportions would be less likely to be published. We therefore deemed that an analysis of publication bias would not be particularly meaningful in this context.

Analysis

All analyses were performed in R. The meta-analyses were performed in the *meta* (Balduzzi et al., 2019) package, using a random-effects model with a logit transformation of proportions and restricted maximum likelihood and inverse-variance weighting. Using studies with available data, we calculated pooled proportions of the following identities: female participants across studies reporting, or assumed to report, on sex; woman-identifying participants across studies explicitly reporting on gender identity; gender-diverse (transgender and nonbinary) participants; ethnically and racially minoritised participants; and participants with co-occurring depression, (generalised) anxiety, ADHD, OCD, psychotic disorders, ID, bipolar disorder, personality disorders, substance use disorders, and eating disorders. For the purposes of this review, we combined all autism diagnoses as per different diagnostic manuals (e.g., autism spectrum disorder, Asperger syndrome, etc.).

Because of regional differences in the reporting of race/ethnicity, and the very small numbers of studies reporting on specific ethnically and racially minoritised groups, we combined all ethnically and racially minoritised participants for the meta-analysis but summarised the representation of specific groups in the Study Characteristics section. Any categorisations are based on the primary studies.

We performed meta-regressions by recruitment source, publication year, and quality assessment score for all meta-analyses including at least 10 studies (Deeks et al., 2024). A Holm adjustment was performed on the *p*-values from the omnibus tests for all three meta-regressions for each outcome, with the tests for each outcome treated as a separate family. When a meta-regression was not conducted due to the small number of studies, we reported pooled percentages of identities of interest specifically for clinical record studies, as they best approximate who is receiving a diagnosis in practice. For meta-regressions by sample source where the omnibus test was significant post-adjustment, we conducted pairwise post-hoc comparisons with a Holm adjustment using the *metafor* package (Viechtbauer, 2010).

In addition, we tested whether study quality scores differed by sample source using a Kruskal-Wallis test and subsequently performed pairwise Dunn's post-hoc tests with a Holm adjustment using the rstatix package (Kassambara, 2026). All data and code are available on the Open Science Framework: https://osf.io/x2u3a/?view_only=0d8c7425aca143e586fe8867f495a9fc

Several studies excluded women/female participants or participants with ID, and, conversely, some studies only recruited participants with ID. As these are methodological choices, such studies cannot be assumed to address the same underlying proportions as studies with no restrictions on sex/gender or co-occurring

conditions. We excluded such studies from the respective meta-analyses but summarised them in-text. Studies with reported zero counts that were not stated to be part of study eligibility criteria were included in meta-analyses.

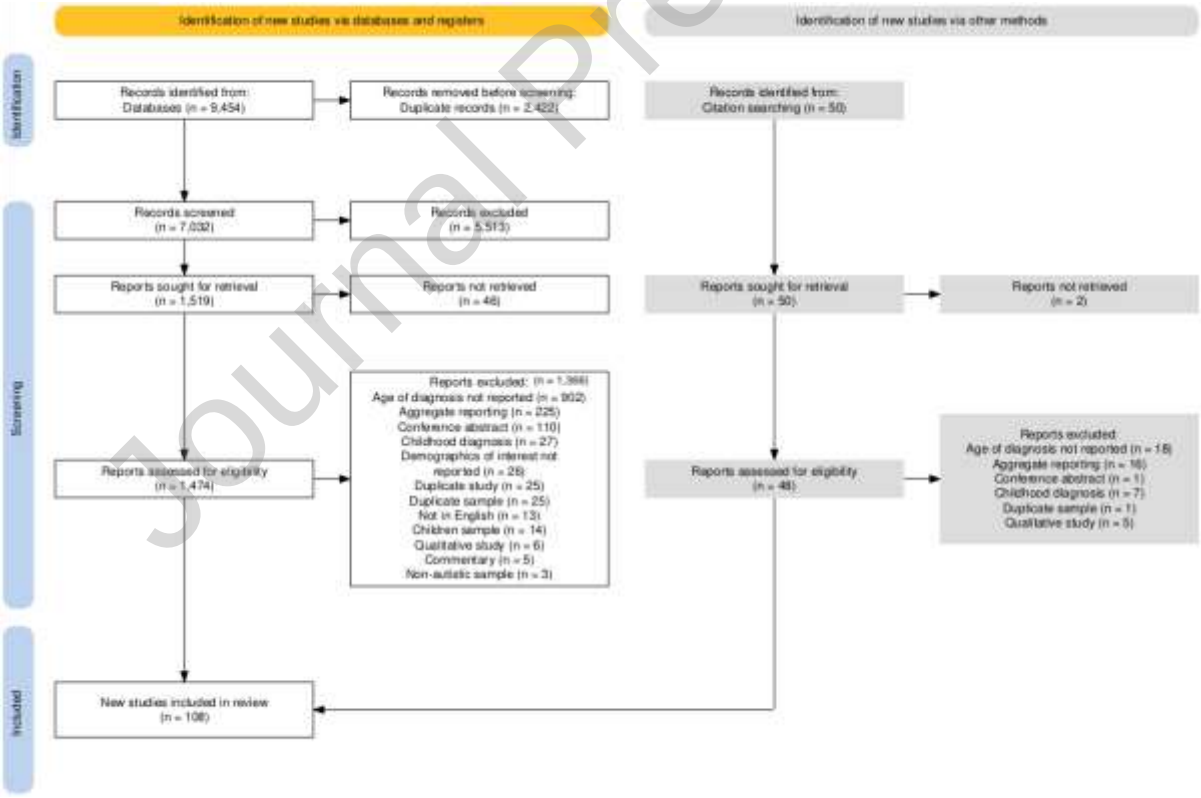
Results

Study Characteristics

The database search identified a total of 9454 studies, supplemented by 50 from citation searching. We assessed 1522 full texts for eligibility, of which 108 (109 samples) were included in this review, as demonstrated in the PRISMA flowchart in Figure 1 (Haddaway et al., 2020).

Figure 1

PRISMA Flowchart



Aggregate characteristics of all included studies are reported in Table 2 below, and due to the very large number of studies, characteristics of each individual

study are provided in Table C.1 in Appendix C. A total of 29,846 adult-diagnosed participants were included.

Table 2

Characteristics of Included Studies

Reported characteristic	Number of eligible participants (*n*)	Number of studies reporting this characteristic
Adult-diagnosed participants[1]	29,846	*k* = 108
Study region		
Europe	13,668	*k* = 86
North America	15,724	*k* = 16
Australia	265	*k* = 3
Asia	189	*k* = 3
Sex[2]		
Female	6920	*k* = 100
Male	11,040	*k* = 100
Reported gender identity		
Woman	698	*k* = 9
Man	742	*k* = 9
Gender-diverse	70	*k* = 5
Race/ethnicity[3]		
White	1644	*k* = 12
Ethnically and racially minoritised	240	*k* = 12
Arab	1	*k* = 1
Asian	39	*k* = 6
Black	33	*k* = 6
Hispanic/Latinx	61	*k* = 3
Mixed	35	*k* = 5
Indigenous	1	*k* = 1
Other	22	*k* = 3
Unspecified[4]	28	*k* = 2
Recruitment source		
Clinical records[5]	8140	*k* = 53
Clinical volunteer[6]	1021	*k* = 28
Research registries	4413	*k* = 10
Population cohorts	15,400	*k* = 8
Community[7]	439	*k* = 4
Online[8]	320	*k* = 3
Clinical volunteer and community	100	*k* = 2
Clinical volunteer and research registry	13	k = 1

[1]Several studies (*k* = 18) also included child-diagnosed participants who are not included in this review; [2]Three studies reported on both sex and gender identity (Leung et al., 2025; McKenzie et al., 2015; Taylor et al., 2019). Another three studies did not report sex or gender identity for adult-diagnosed participants (Ashwood et al., 2016; Diemer et al., 2025; Shoaib et al., 2022). Five studies (Ecker et al., 2016; Geurts et al., 2020; Kliemann et al., 2012; K. Murray et al., 2017; Vuijk et al., 2018) recruited only male participants (total n = 203) and were excluded from meta-analyses based on sex; [3]The study by Diemer et al. (2025) allowed participants to select multiple race/ethnicity categories. It was thus impossible to thus separate participants of Mixed ethnicity with white heritage (who we would otherwise include under our definition of ethnically and racially minoritised). We excluded this study from race/ethnicity analyses; [4]Refers to participants who were reported as part of racial/ethnic groups other than white without further specification (i.e., 'non-Caucasian' in Huang et al., 2024 and 'non-white' in Leung et al., 2025). [5]Defined as studies using retrospective chart reviews with consecutive inclusion of charts with no formal recruitment/consenting process; [6]Defined as studies recruiting and consenting participants from clinical settings; [7]Defined as studies recruiting via social media, word of mouth, and charity or other community organisations; [8]Defined as studies using established online recruitment platforms (e.g., Prolific, Amazon MTurk).

Only 16 studies included participants with ID (*n* = 5948), of which four, all validating ID-specific autism diagnostic measures (Bergmann et al., 2019; Heinrich et al., 2018; Mutsaerts et al., 2016; Sappok et al., 2014), exclusively included those who had ID (*n* = 328, n_{female} = 131, n_{male} = 196). Forty-one studies (*n* = 2183, n_{female} = 624, n_{male} = 1524) excluded participants with ID.

Quality Assessment

The full results of the quality assessment are provided in Appendix D. Overall, the median score on the abridged AXIS assessment was 4/5 (IQR = 2), indicating that most studies had appropriate sample selection and reporting processes. The median quality score was 5/5 (IQR = 0) for population cohort samples, 5/5 (IQR = 1) for studies using clinical record samples, 4/5 (IQR = 1) for research registry samples, 3/5 (IQR = 0) for clinical volunteer samples, 3/5 (IQR = 0) for studies recruiting from multiple sources, 3/5 (IQR = 0.25) for community samples, and 2/5 (IQR = 1.5) for

online samples. Only 66 (61.11%) of studies justified their sample size (or used all available records), and only 65 (59.26%) characterised non-responders.

The quality assessment scores varied significantly by sample source ($\chi^2(6) = 64.42$, $p < .001$, $\eta^2 = 0.57$). Post-hoc comparisons revealed that clinical record studies had significantly higher quality scores than all other recruitment methods at $p_{adj} < .050$, aside from population cohorts ($p_{adj} > .999$). Cohort studies also had significantly higher quality scores than the remaining recruitment methods. All other comparisons were not significant. The full results of the comparisons are reported in the Supplement.

Meta-Analysis 1: Gender and Sex at Birth

Female Sex

Across the 94 studies (95 samples) that provided data on sex and included female participants, the meta-analysis showed a pooled estimate of 35.51% female participants, 95% CI [32.43%, 38.71%]. Heterogeneity was high ($I^2 = 93.2\%$). The forest plot is provided in the Supplement due to the very large number of studies.

A meta-regression revealed that the proportion of female participants varied significantly based on the sample source ($F(6, 88) = 3.41$, $p_{adj} = .014$, $\tau^2 = 0.2767$), with pooled proportions for each source shown in Table 3. Clinical record studies, which may most closely approximate who is receiving a diagnosis in practice, showed a pooled estimate of 31.84% female participants, 95% CI [28.22%, 35.70%]. Post-hoc pairwise comparisons revealed no significant differences between the sample sources, aside from clinical record studies including significantly lower proportions of female participants compared to online samples ($p_{adj} = .045$) and community samples ($p_{adj} = .037$).

Table 3

Pooled Proportions of Female Participants by Sample Source

Source	*k*	Estimated % Female	95% CI	τ^2
Clinical (Records)	48	31.84%	28.22%, 35.70%	0.2707
Clinic (Volunteer)	24	36.16%	30.02%, 42.78%	0.1984
Online	2	61.71%	36.84%, 81.66%	0
Research	8	40.32%	24.14%, 58.93%	0.7290
Community	3	59.23%	21.28%, 88.64%	0.3786
Cohort	7	38.80%	30.65%, 47.62%	0.1145
Multiple	3	33.01%	19.47%, 50.09%	0

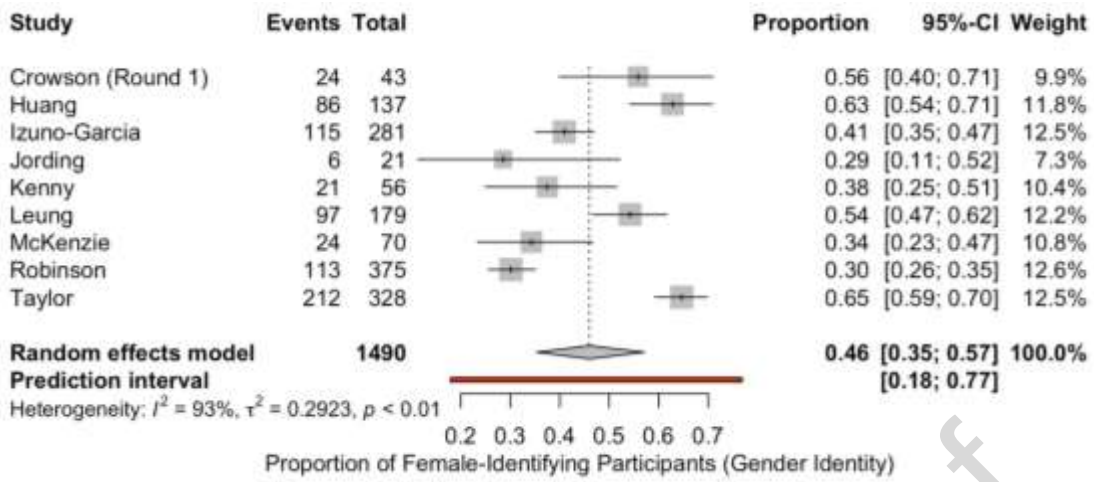
Meta-regressions by publication year (β = 0.028, *SE* = 0.014, p_{adj} = .054, τ^2 = 0.3355) and quality assessment scores (β = -0.162, *SE* = 0.072, p_{adj} = .054, τ^2 = 0.3198) were not significant following a Holm adjustment.

Women-Identifying Participants

Among the nine studies reporting on gender identity, the pooled proportion of participants identifying as women was 46.00%, 95% CI [35.26%, 57.12%], with substantial heterogeneity (I^2 = 92.8%). The four clinical record studies reporting on gender-identity – which may most closely approximate who is receiving a diagnosis in practice – showed a pooled estimate of 35.42% women-identifying participants, 95% CI [27.58%, 44.13%]. The forest plot can be found in Figure 2. The small number of studies (*k* < 10) precluded any meta-regressions.

Figure 2

Forest Plot of the Pooled Proportion of Female-Identifying Participants

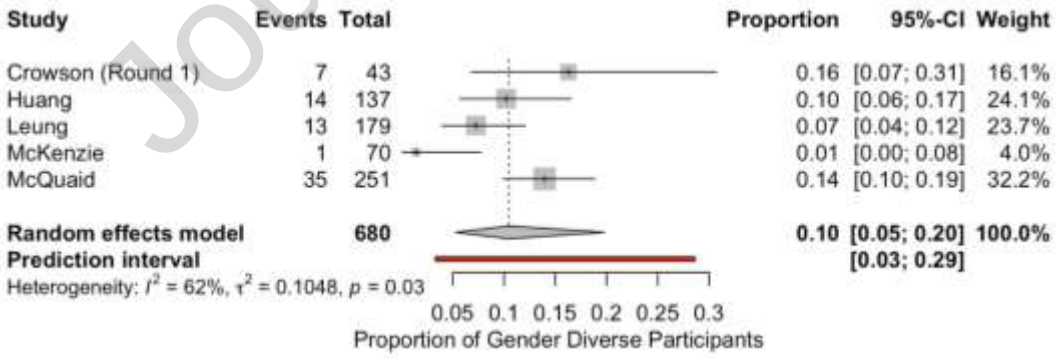


Gender-Diverse Identity

The pooled proportion of gender-diverse participants was 10.50% (95% CI: 5.28%, 19.79%) across five studies, with moderate heterogeneity (I^2 = 61.8%). Only one clinical record study included gender-diverse participants (Mackenzie et al., 2015), with a percentage of 1.43%, 95% CI [0.04%, 7.70%]. The forest plot is provided in Figure 3. Meta-regressions were precluded by the small number of studies.

Figure 3

Forest Plot of the Pooled Proportion of Gender-Diverse Participants

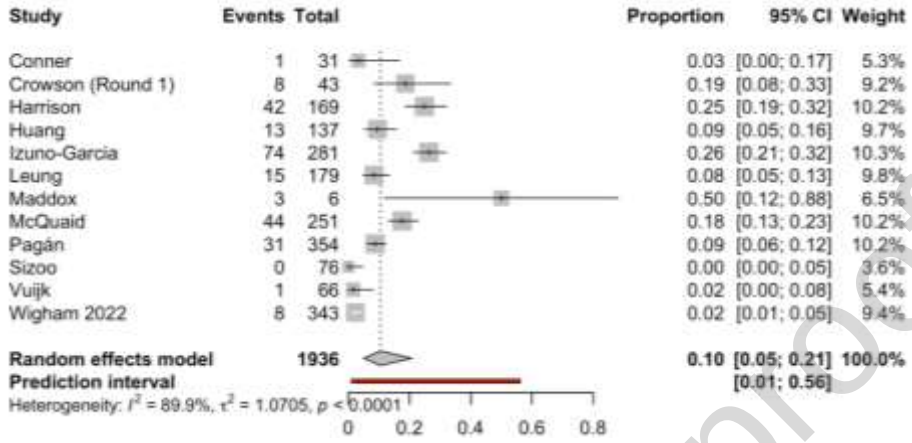


Meta-Analysis 2: Race/Ethnicity

Overall, the pooled proportion of ethnically and racially minoritised participants was 10.45%, 95% CI [4.95%, 20.70%] across twelve studies, with substantial heterogeneity (I^2 = 89.9%). The corresponding forest plot is provided in Figure 4.

Figure 4

Forest Plot of the Pooled Proportion of Ethnically and Racially Minoritised Participants



Meta-regressions revealed no significant differences between estimated pooled proportions of ethnically and racially minoritised participants across sample sources, by publication year, and by study quality. The seven available clinical record studies showed a pooled estimate of 10.33% of ethnically and racially minoritised participants, 95% CI [2.33%, 35.75%]. The results of these meta-regressions are provided in the Supplement.

Co-Occurring Conditions

The pooled estimates for the percentage of participants with co-occurring depression, anxiety, ADHD, OCD, psychotic disorders, ID, bipolar disorder, eating disorders, substance use disorders, and personality disorders, along with the results of meta-regressions by sample source are provided in Table 4. The pooled estimates for clinical record studies may most closely approximate who is receiving a diagnosis in practice. Depression was the most highly represented comorbidity, with a pooled estimate of 33.56%, 95% CI [24.77%, 43.67%]. All corresponding forest plots are provided in the Supplement.

Table 4

Pooled Proportions of Participants with Select Co-Occurring Conditions by Sample Source

Condition	Sample Source	*k*	Pooled % [95% CI]	I^2	τ^2	Test statistic	p_{adj}
Anxiety	Overall	29	24.22% [15.18%, 36.35%]	99.0%			
						$F(3,25) = 5.19$	.012
	Clinical records	15	18.60% [11.49%, 28.69%]	97.0%	1.3852		
	Clinical volunteer	7	11.28% [2.47%, 38.97%]	82.6%	2.3321		
	Registry	5	65.62% [50.13%, 78.38%]	93.3%	0.2304		
	Cohort	2	11.05% [0.00%, 100.00%]	99.7%	1.7417		
ADHD	Overall	27*	21.09% [14.61%, 29.44%]	97.9%			
						$F(3,22) = 0.28$	>.999
	Clinical records	16	19.90% [11.63%, 31.93%]	96.2%	1.2003		
	Clinical volunteer	3	16.49% [0.54%, 87.82%]	72.5%	1.4199		
	Registry	5	27.85% [9.86%, 57.66%]	97.1%	0.9982		
	Cohort	2	16.88% [0.01%, 99.73%]	99.6%	0.6946		
Bipolar disorder	Overall	14	6.01% [2.76%, 12.57%]	89.2%			
						$F(2,11) = 0.64$	>.999
	Clinical records	7	4.05% [0.79%, 18.24%]	90.8%	2.6288		
	Clinical volunteers	4	4.89% [0.21%, 56.01%]	36.8%	0.5894		
	Registry	3	10.56% [3.46%, 28.03%]	91.7%	0.5164		
Depression	Overall	26	33.56% [24.77%, 43.67%]	97.5%			
						$F(2,23) = 10.75$	.002
	Clinical records	15	25.42% [17.54%, 35.32%]	92.4%	0.5620		
	Clinical volunteer	6	29.02% [15.24%, 48.18%]	62.7%	0.3404		
	Registry	5	66.11% [50.45%, 78.90%]	87.9%	0.2315		
Eating disorders	Overall	12	6.60% [4.13%, 10.40%]	95.1%			
						$F(3,8) = 5.21$	.083
	Clinical records	3	6.98% [4.05%, 1,77%]	0.0%	0		
	Clinical volunteers	4	2.59% [1.00%, 6.55%]	0.0%	0		
	Registry	4	10.82% [4.55%, 23.61%]	93.8%	0.3141		
	Cohort	1	2.73% [2.12%, 3.50%]	-	-		
ID	Overall	12	13.21% [6.51%, 24.95%]	98.5%			
						$F(3,8) = 0.29$	.834
	Clinical records	7	15.40% [4.59%, 40.49%]	98.4%	1.8876		
	Clinical volunteers	1	5.88% [0.82%, 32.03%]	-	-		
	Registry	1	5.84% [2.95%, 11.24%]	-	-		
	Cohort	3	13.32% [1.01%, 69.80%]	99.4%	1.1815		
OCD	Overall	20	9.26% [5.75%, 14.58%]	95.8%			

						$F(3,16) = 2.21$	.379
	Clinical records	11	8.45% [4.35%, 15.77%]	84.8%	0.8675		
	Clinical volunteer	4	6.01% [0.69%, 37.00%]	77.5%	1.5880		
	Registry	4	19.40% [10.27%, 33.62%]	91.0%	0.1997		
	Cohort	1	2.27% [1.73%, 2.99%]	-	-		
Personality disorders	Overall	21	7.60% [4.82%, 11.79%]	87.2%			
						$F(2,18) = 0.23$	>.999
	Clinical records	14	6.68% [3.51%, 12.38%]	86.9%	0.8454		
	Clinical volunteer	4	8.21% [1.31%, 37.65%]	60.2%	0.9839		
	Registry	3	10.35% [1.90%, 40.81%]	80.3%	0.3604		
Psychotic disorders	Overall	20	7.87% [4.58%, 13.18%]	93.6%			
						$F(3,16) = 1.42$	.548
	Clinical records	14	10.83% [5.78%, 19.39%]	93.4%	1.1601		
	Clinical volunteer	1	7.50% [2.44%, 20.82%]	-	-		
	Registry	4	3.73% [0.54%, 21.49%]	87.5%	1.2041		
	Cohort	1	2.50% [1.93%, 3.24%]	-	-		
Substance use disorders	Overall	15	5.94% [3.23%, 10.67%]	81.6%			
						$F(2,12) = 0.34$	>.999
	Clinical records	10	5.69% [2.52%, 12.34 %]	81.9%	0.9121		
	Clinical volunteers	3	5.60% [0.07%, 84.52%]	72.3%	2.2982		
	Registry	2	6.01% [0.00%, 99.54%]	93.1%	0.7781		

**The study by Walter et al. (2023) was excluded from this meta-analysis, as all autistic participants had co-occurring ADHD by design. The study by Nakagawa et al. (2021) was also excluded from this meta-analysis as autistic participants with co-occurring ADHD were excluded from that study.*

Depression and anxiety were the only conditions for which the pooled estimate was moderated by sample source. Significantly higher rates of anxiety and depression were estimated in research registry samples compared to clinical and cohort samples (all $p_{adj} < .050$).

We conducted meta-regressions to examine whether publication year and study quality moderated the pooled estimates. Full results are provided in the

Supplement. More recent studies reported significantly higher pooled proportions of anxiety (β = 0.17, *SE* = 0.06, $F(1, 27) = 7.48$, p_{adj} = .022), and lower pooled proportions of psychotic disorders (β = -0.15, *SE* = 0.05, $F(1, 18) = 9.15$, p_{adj} = .022), while the remaining pooled proportions did not significantly differ by publication year. The results of meta-regressions by study quality were not significant for any co-occurring conditions.

Discussion

This review explores the representativeness of adult-diagnosed autistic people in research, given the documented inequities in access to adult diagnosis, as well as the wider lack of representation and reporting in the field. We synthesised demographic data on autistic people receiving a diagnosis in adulthood from 109 quantitative studies, focussing on the proportion of female, women-identifying, gender-diverse, ethnically and racially minoritised participants, and participants with ten co-occurring conditions. Heterogeneity across analyses was very high, though this is expected in proportional meta-analyses in health research (Barker et al., 2021).

Sex and Gender Identity

Across recruitment methods, people reported as female constituted a pooled proportion of 35.51% of adult-diagnosed autistic participants. However, when studies reporting on gender identity were considered, the estimated proportion rose to 46.00%. Clinical record studies, which may most closely approximate who is receiving a diagnosis in practice, showed a pooled estimate of 31.84% female participants (approximately 2.14:1 male-to-female) and 35.42% women-identifying participants (approximately 1.82:1). These proportions are higher than suggested by child-based estimates, such as the widely cited 3:1 male-to-female ratio in Loomes

et al. (2016). Recent findings, however, indicate that the preponderance of autistic males may be less pronounced in adults; for instance, Posserud et al. (2021) reported a ratio of 2.57:1, which is nonetheless higher than what is suggested by both of our estimates. Interestingly, one reviewed study found that the majority of adults receiving a diagnosis within their sample were female (Maciver et al., 2025).

The meta-analysis demonstrated that samples recruited online and from the community included *more* female than male participants and significantly higher proportions of female participants than clinical records. A likely explanation is self-selection. Indeed, some research suggests that female individuals are more likely to participate in both autism (Rødgaard et al., 2021) and mental health research (Ellis et al., 2014), but may be disadvantaged by confirmatory diagnostic assessments which are often required for inclusion in research registries and may be less sensitive in women/AFAB (D'Mello et al., 2022). G. Russell et al. (2022) propose that recent widespread discourse may encourage more women/AFAB individuals to seek a diagnosis and share their experiences, which could account for their increased likelihood of being included in research where, presumably, there is an opportunity to volunteer.

Unheard Groups: Gender-Diverse and Ethnically and Racially Minoritised Participants

Very few studies reported on the number of gender-diverse (k = 5) or for ethnically and racially minoritised (k = 12) adult-diagnosed participants, providing estimates of 10.50% and 10.45% respectively. To approximate who may be receiving a diagnosis in practice, we additionally explored the representation of these identities across studies using clinical records, yielding proportions of 1.43% (k = 1) for gender-diverse participants and 10.33% (pooled, k = 7) for ethnically and racially

minoritised participants. To contextualise these proportions, Mackenzie et al. (2015) was the only clinical record study reporting on gender-diverse participants and was conducted in Scotland, where the 2022 Census identified a percentage of 0.44% gender-diverse adults (Scotland's Census, 2024). Of the seven clinical record studies reporting on race/ethnicity, five were conducted in the United States, where the estimated proportion of ethnically and racially minoritised residents (i.e., groups other than non-Hispanic white) is 42.2% as of the 2020 Census (National Census Bureau, 2021).

The relatively small number of studies providing data on participants' race/ethnicity and gender identity separate from sex (in particular within clinical record studies), and the large number of studies using ambiguous or unclear wording, is consistent with other reviews of demographic reporting in mental health research (Kirvin-Quamme et al., 2024; Pedersen et al., 2022). In addition, the methods of ascertaining and recording sex or gender identity should also be considered; in research and clinical record-keeping, gender identity may be conflated with sex or recorded inaccurately (Gogovor et al., 2021; Proumen et al., 2023), and informant reports of gender diversity in autistic people may not always agree with self-reports (Corbett et al., 2023). It must also be acknowledged that our understanding of gender diversity in autistic individuals is predominantly based on individuals without ID, with the intersection of gender diversity and ID remaining unexplored (Dewinter et al., 2024); those with ID, as well as those who do not communicate using spoken language, may understand and communicate gender diversity differently. Our findings therefore reinforce the importance of robust and transparent reporting of sex and gender identity, such as 'two-step' questions

inquiring about sex at birth and gender identity separately (demonstrated to increase ascertainment in Tordoff et al., 2019), while avoiding assumptions.

We acknowledge that the decision to pool ethnically and racially minoritised participants obscures crucial differences between these groups that may shape their experiences of accessing an autism diagnosis and participating in research (Ardeleanu et al., 2024; Farooqi et al., 2022). Grouping these participants is not intended to 'essentialise' them as inherently 'other', or attribute any observed disparities solely to race/ethnicity, rather than to the effects of social structures that exclude ethnically and racially minoritised individuals (Kostet, 2026b). This approach was adopted to contextualise the demographic composition of existing research on adult-diagnosed autistic people and reflects the limited and heterogenous reporting of race/ethnicity across studies. Notably, two of the studies that reported on race/ethnicity did not specify categories beyond 'non-Caucasian' or 'non-white', further illustrating how the use of umbrella terms can obscure heterogeneity within ethnically and racially minoritised groups.

The observed lack of demographic reporting[5] raises two major concerns. First, this may reflect an assumption that certain demographic variables are irrelevant to study aims and thus not collected or reported (Call et al., 2023). Second, our findings highlight the well-documented issue of research samples failing to reflect the populations they aim to represent (Malone et al., 2022; Pedersen et al., 2022). Both have consequences for diagnostic tools and practices, which, in turn, shape who can access a diagnosis and who misses out. Current diagnostic tools have been developed and normed on predominantly white or unreported race/ethnicity samples

[5] We acknowledge that obtaining race/ethnicity data may not be possible in some cases – for instance, some healthcare services may not routinely include race/ethnicity in patient records, thus disadvantaging clinical record studies; but the lack of explanation is concerning.

(Pham & Charles, 2023; Woodbury-Smith et al., 2005), leading to their underperformance in more diverse populations despite assumptions of their ethnic or cultural ‘neutrality’ (Huda et al., 2024; Fernandes et al., 2022).

The lack of demographic reporting limits our ability to understand the disparities faced by gender-diverse and ethnically and racially minoritised adults seeking an autism diagnosis on a population level, despite emerging evidence indicating compounded barriers (Ardeleanu et al., 2024; Diemer et al., 2022; Malone et al., 2022; Tien et al., 2025). Moreover, as all reviewed studies reporting on race/ethnicity were conducted in Western countries (namely, Australia, the Netherlands, the United States, and the United Kingdom), this review is unable to make any claims regarding adult-diagnosed autistic people from other countries, including the Global South, beyond highlighting their under-representation in the literature. This, in itself, was not an unexpected finding, given that autism research is dominated by studies conducted in Western, high-income countries (Divan et al., 2025), even though most autistic people live in low- and middle-income countries (Global Research on Developmental Disabilities Collaborators, 2018). This lack of representation further highlights that research findings concerning adults from ethnically and racially minoritised groups in Western countries should not be assumed to be directly transferrable to other contexts, particularly given the differences between diaspora communities and communities in their countries of origin, as well as differences between and within ethnically and racially minoritised groups in Western countries (Kostet, 2026b).

Further, understanding the inequities faced by ethnically and racially minoritised autistic adults necessitates an examination of not only the disaggregated experiences of specific groups but how they are simultaneously shaped by

intersections with factors such as class, (generational) migration history, and education level (Botha & Gillespie-Lynch, 2022; Kostet, 2026a, 2026b). We were unable to include these variables in our meta-analysis due to the dearth of available data, which represents a crucial gap in the evidence base.

Co-Occurring Mental Health Conditions

Echoing previous findings that a concerning number of autistic adults face mental health challenges (Au-Yeung et al., 2019; Lai et al., 2019), with those diagnosed as adults particularly vulnerable to poor mental health (Jadav & Bal, 2022; Kentrou et al., 2024), our meta-analysis found high pooled estimates for most of the co-occurring conditions reviewed. However, there were several differences in their representation between sample sources, in particular, between clinical record, clinical volunteer, and research registry samples, which warrant further examination. Contrary to Lai et al. (2019), we found that clinical record samples had significantly lower pooled proportions of anxiety and depression.

This seemingly counterintuitive pattern (as, presumably, both registry and clinical volunteer samples are affected by self-selection) may be explained by differences in recording patterns. Co-occurring diagnoses in clinical samples may reflect the individual's most prominent presenting difficulties, as determined by clinical judgement, and may therefore not capture all of their previous or current diagnoses. In contrast, research registry participants may provide a more complete account of their diagnostic history if asked to self-report, as was the case in Jadav & Bal (2022). However, this also introduces a risk of over-reporting due to subjective distress (M. R. Davies et al., 2022). Alternatively, among recently diagnosed adults, those with more significant mental health challenges may be less likely to volunteer to partake in research (Haapea et al., 2007), which is also supported by the

descriptive finding that clinical volunteer and registry samples had lower rates of psychotic disorders than clinical record samples. Interestingly, Kaźmierczak et al. (2023) found that individuals volunteering to participate in psychology research report significantly higher symptoms of anxiety and depression than non-volunteers. This review's finding that *clinical* volunteers showed lower rates of these conditions compared to clinical record studies (which presumably reflect who is receiving a diagnosis) and research registry members suggests that the effects of self-selection bias might be context-dependent, which should be followed up on in future research. Therefore, neither volunteer source may reproduce the same profile that is actually receiving a diagnosis, and thus, different recruitment methods likely represent different subgroups of the adult-diagnosed autistic population.

Intellectual Disability

The pooled estimate of adult-diagnosed participants who had ID was 13.21%, which is far below findings showing that at least half of autistic people have ID (Loomes et al., 2016). Strikingly, this pooled estimate was nearly entirely driven by clinical record and cohort studies, with only one clinical volunteer study and one research registry study including participants with ID. Although only studies with no recruitment restrictions on intellectual functioning were included in the meta-analysis, the inclusion rates were very low even for studies that did not explicitly exclude participants with ID.

Although concerning, these findings are unsurprising given the systemic exclusion of autistic people with ID from autism research (G. Russell et al., 2019), though less is known about research on those diagnosed as adults. ID may facilitate a childhood diagnosis, as associated developmental challenges in those with ID might be perceived more readily and thus prompt an earlier diagnosis of autism

(Posserud et al., 2021; Thurm et al., 2019). As such, it is possible that *adult-diagnosed* autistic people may be less likely to have ID compared to the wider autistic population. Conversely, research also details the challenges in recognising potential autistic traits in people with ID due to potential overlap and diagnostic overshadowing, contributing to delayed autism identification (Heinrich et al., 2018; Moss & Howlin, 2009). The lack of representation of adult-diagnosed autistic people with ID means that the reasons why some people with ID remain undiagnosed until adulthood, and whether they are disadvantaged by current adult diagnostic systems, remain underexplored. Further, most screening and diagnostic tools are designed for non-ID adults and may therefore lack sensitivity in those with ID (Thurm et al., 2019). Stereotypes that adult diagnoses are largely pursued by highly educated (cisgender) women might reinforce exclusion, rendering adults with ID invisible in both research and care (G. Russell et al., 2022).

Limitations of this Review

We aimed to examine the demographics of adult-diagnosed autistic people as represented in quantitative research. Accordingly, we only included studies that reported on this group's demographics separately or had an entirely adult-diagnosed sample. Our inclusion criteria were thus conservative. In cases of ambiguity, we contacted authors to verify whether studies truly included adult-diagnosed participants, but the possibility of missing some relevant studies remains.

For the purposes of this review, we did not distinguish between conditions self-reported by participants and conditions reported through other sources (e.g., clinical records or determined by assessment as part of the study). We recognise that researchers recruiting online or from the community may find it difficult to independently verify participants' diagnoses of autism or co-occurring conditions. As

discussed above, these factors, as well as differences in reporting, may explain some observed differences between sample sources. Consequently, it was impossible to determine the accuracy of co-occurring conditions reported in the included studies. The possibility of some of the reported co-occurring conditions being misdiagnoses remains, and a substantial body of research documents the risks of diagnostic overshadowing and the misattribution of autistic traits to mental health conditions in adults (Au-Yeung et al., 2019; Kentrou et al., 2024). Therefore, our findings should be interpreted as indicative of patterns in the recording of other mental health or neurodevelopmental conditions across research, rather than prevalence estimates for the adult-diagnosed population.

Finally, while appropriate for the purposes of this review, the quality assessment with the adapted AXIS tool was closely tied to the sample source and placed studies using clinical record or cohort samples at an advantage (e.g., if all available records were used) over studies recruiting online or from the community, which may not always be able to report on non-participants. This approach nonetheless allowed us to consistently identify the most frequent issues in sample recruitment and reporting, thus highlighting limitations in the evidence base..

Limitations of Included Studies

Overall, reporting of our characteristics of interest was uneven across sample source categories. For instance, no studies recruiting from the community reported race/ethnicity or any co-occurring conditions, which therefore represents a gap in the literature. In addition, there was a considerable imbalance between the number of included studies in different sample source categories, with most of the included studies relying on clinical record and clinical volunteer samples. This imbalance likely resulted in extremely wide confidence intervals for some pooled proportions in the

meta-regressions for less represented sample sources. These pooled proportions must thus be interpreted with caution. Further, very few studies reported stratified characteristics of interest (such as race/ethnicity or co-occurring conditions stratified by sex or gender identity, or co-occurring conditions by race/ethnicity), which limits our ability to understand intersecting disparities among adult-diagnosed autistic people.

As we sought to examine the representation of key groups, this review included studies with a variety of designs and from a wide range of settings, which likely accounts for the high heterogeneity estimates, even after examining sample source as a potential source of variability. This is, however, expected; within clinical record samples, which are less likely to be affected by volunteer bias, it is known that referral criteria and diagnostic outcomes vary tremendously between adult diagnostic services even under the same healthcare systems (e.g., Hayes et al., 2018; Beresford et al., 2020). We reiterate that all of the pooled proportions should be interpreted with due caution and as descriptive of the characteristics of adult-diagnosed samples within specific study contexts.

Implications and Future Directions

This review shows that current autism research, particularly studies relying on volunteer samples or existing research registries, appears to predominantly capture a subset of the adult-diagnosed population—namely, white (or unreported race/ethnicity) individuals reported as female with co-occurring anxiety or depression. Consequently, research findings may not sufficiently reflect the experiences of autistic people who are from ethnically and racially minoritised backgrounds or are gender-diverse, and autistic people with serious mental illness or ID, thereby deepening existing disparities.

Although we showed that research representation seems to have increased among adult-diagnosed individuals reported as female, it remains unclear how many go unrecognised (O'Nions et al., 2024). Additionally, the overrepresentation of participants reported as female in volunteer samples, despite lower diagnostic rates compared to participants reported as male, suggests that recruitment methods relying on self-selection do not reach a significant portion of the adult-diagnosed population. Differences in co-occurring conditions across clinical, research, and online/community samples also indicate that these may reflect distinct populations. The causes and effects of these differences warrant further investigation.

The under-reporting of race/ethnicity and gender identity is similarly concerning. It remains unknown to what extent adult diagnostic services currently meet the needs of ethnically and racially minoritised and gender-diverse communities, and whether there are differences in how autism is recognised in previously undiagnosed adults with these intersecting identities (Botha & Gillespie-Lynch, 2022; Malone et al., 2022). Researchers should therefore strive to report the full, disaggregated racial/ethnic and gender composition of their samples. For instance, the Enhancing the QUAlity and Transparency Of health Research (EQUATOR) network (EQUATOR, n.d.) provides a set of reporting guidelines for various study designs to aid transparent demographic reporting. Additionally, Call et al. (2023) propose a social justice framework for reflexivity at all stages of research, including sampling and recruitment decision-making. Recruitment strategies targeting underrepresenting groups, including ethnically and racially minoritised communities and gender-diverse people (e.g., as used online in subsequent rounds of Crowson et al., 2024 or in the community by Carter et al., 2023) should also be explored. Such research must be undertaken in close collaboration with the

communities concerned, as research inclusion is not a tick-box exercise; when done insincerely and in ways that centre white perspectives, purported inclusion can cause further harm to ethnically and racially minoritised autistic people (Benedetto, 2024; Kostet, 2025). Simply increasing the number of research participants from ethnically and racially minoritised communities is unlikely to result in a meaningful understanding of their experiences (Esmene et al., 2024). Therefore, care must be taken to ensure that research samples reflect the communities they aim to represent, not just in terms of racial/ethnic and gender composition, but also in metrics such as education level and socioeconomic status (Rowan et al., 2010), and are documented appropriately, to avoid creating new disparities.

Conclusion

Despite greater clinical and public awareness, many autistic adults still face barriers to receiving a clinical diagnosis. This review synthesised the representation of specific demographics and identities across research, revealing disparities across 109 studies with 29,929 adult-diagnosed autistic participants. Despite being less likely to receive an autism diagnosis than men, as seen in studies of clinical records, adult-diagnosed individuals reported as female appeared to be more likely to volunteer to participate in research, just as in mental health research in general. We also found significantly higher prevalence of depression and anxiety in research samples compared to those drawn from clinics. Ethnically and racially minoritised and gender-diverse participants were frequently underrepresented or not reported on, and those with ID were often excluded. These findings underscore the need for transparent demographic reporting and improved sampling to ensure research reflects the true diversity of adult-diagnosed autistic people.

Funding: This review was funded by a doctoral studentship from the Economic and Social Research Council awarded to the first author (2931118).

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Declaration of interests

☒ The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Highlights

- We reviewed the characteristics of adult-diagnosed autistic people, as reported in current research.
- Women made up just over a third of adult-diagnosed participants across sample sources.
- Gender-diverse and racially and ethnically minority participants were reported on in few studies, or underrepresented.
- Depression and anxiety were the most common co-occurring conditions.
- Only 13.21% of participants had intellectual disability, much lower than expected.