Received: 13 August 2024 | Accepted: 13 November 2024

DOI: 10.1002/aur.3278

REVIEW ARTICLE

Who, when, where, and why: A systematic review of "late diagnosis" in autism

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Funding information
Eunice Kennedy Shriver National Institute of Child Health and Human Development; Royster Fellowship; U.S. Department of Education, Office of Special Education Programs

Abstract

An autism diagnosis can be a critical milestone toward effective and affirming support. Despite the sharp increase in the number of studies focused on late diagnosis over the last 15 years, there remains no consensus as to what constitutes a late diagnosis of autism, with cutoffs ranging from infancy to middle adulthood. This preregistered systematic review evaluated (a) the field's current quantification of late diagnosis in autism, (b) how the threshold for late diagnosis varies as a function of demographic and population factors, and (c) trends over time. Of the 11,697 records retrieved, $N = 420$ articles met inclusion criteria and were extracted. Articles spanned 35 years (1989–2024) and included participants from every continent except Antarctica. Only 34.7% of included studies provided a clear threshold for "late diagnosis" ($n = 146/420$). Late diagnosis cutoffs averaged 11.53 years (range = 2–55 years; median = 6.5 years) with a bimodal distribution (3 and 18 years). The threshold for late diagnosis varied by participant location, $F(5,140) = 10.4$, $p < 0.0001$, and sample age, $F(5,140) = 20.1$, $p < 0.0001$. Several key rationales for age determinations emerged, including access to services, considerations for adult diagnoses, and data driven approaches. What authors consider to be a "late" diagnosis of autism varies greatly according to research context. Justifications for a specific late-diagnosis age cutoff varied, underscoring the need for authors to contextualize their conceptualizations.

Lay Summary

In a review of "late diagnosis" in autism papers, the average late diagnosis cutoff was 11.5 years (range: 2–55 years) with 3 and 18 years tied for most common cutoffs. Location and age of the sample affected the threshold for late diagnosis. Studies gave different reasons for their age cutoffs, including access to early intervention and services, adult diagnoses, and data-driven reasons.

KEYWORDS
age at diagnosis, ASD, autism, diagnosis, late diagnosis

INTRODUCTION

Despite the increase in autism prevalence, the global average age of diagnosis remains consistent and around the age of 5 years (Baio et al., 2018; Maenner et al., 2023; van't Hof et al., 2021). A timely diagnosis of autism has been associated in some literature with greater improvement across a wide array of domains, including, independence in daily living, cognitive functioning, and other developmental outcomes, though this body of work warrants further investigation (Gabbay-Dizdar et al., 2022; Okoye et al., 2023; Vivanti et al., 2014). Further, an autism diagnosis can be pivotal in the development of one's self-identity, with the community connection and sense of belonging that accompanies a diagnosis yielding positive outcomes in adulthood

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(Bargiela et al., 2016; Leedham et al., 2020; Oredipe et al., 2023; Seers & Hogg, 2023). Concurrent with the field's emphasis on early diagnosis and care, there is a growing number of individuals diagnosed later than early childhood, broadly termed "late-diagnosed" in the literature (Atherton et al., 2022; Bargiela et al., 2016; Leedham et al., 2020; Mandy et al., 2022). Despite the pressing need to support individuals diagnosed in adolescence and adulthood, there is no current consensus as to what constitutes a "late diagnosis" in autism. The focus of this review is to synthesize and summarize the field's current conceptualizations of "late" diagnosis in autism research.

Autism research has focused on lowering the age of diagnosis and reducing the age between initial parental concerns and eventual diagnostic decision (Gordon-Lipkin et al., 2016). While considering the benefits of early recognition, diagnosis, intervention, and support of autism in individuals (French & Kennedy, 2018; Howlin & Charman, 2011; Margolies, 1977; Ramondo & Schwartz, 1981; Ward, 1970; Zwaigenbaum et al., 2015), it is also imperative to recognize how the focus on *early* diagnosis has impacted individuals diagnosed later. The vast majority of prevalence studies focus on individuals diagnosed in childhood (Maenner et al., 2023; Zeidan et al., 2022), thus neglecting those diagnosed outside of childhood. Individuals diagnosed late not only miss out on the benefits of early understanding and support—they often also experience negative outcomes exacerbated by their delayed diagnosis (Atherton et al., 2022; Bargiela et al., 2016). The nuance of the autism diagnostic criteria, which can miss those without language delays, or those described as having a "milder presentation" of autism (Hus & Segal, 2021), has led to generations of autistic individuals who were diagnosed later in life, sometimes termed a "lost generation" (Lai & Baron-Cohen, 2015). The prevalence of adult autism diagnoses has increased in the last two decades (Jariwala-Parikh et al., 2019), and has foregrounded the disparities that late-diagnosed individuals face. Individuals diagnosed in adulthood have described their experiences being an undiagnosed autistic including: a reduced ability to access care in adulthood (Gotham et al., 2015), poor mental health outcomes that are exacerbated by not understanding reasons for childhood peer rejection (Bargiela et al., 2016), and the deleterious effects of masking (e.g., emotional exhaustion, emotional dysregulation, and a loss of self-identity; Bargiela et al., 2016; Leedham et al., 2020). Late-diagnosed women have described their delayed diagnosis exposing them to an extended period of marginalization, causing them to habitually mask at an early age (Seers & Hogg, 2023). Late diagnosis may also delay the formation of positive self-identity, as a formal diagnosis can increase a sense of belonging (Bargiela et al., 2016; Leedham et al., 2020).

Research varies considerably in what is considered as "late diagnosis," with studies quantifying late diagnosis as a diagnosis in adulthood (Dubreucq et al., 2023; Fombonne et al., 2022; Frank et al., 2018; Ghanouni & Seaker, 2023; Lehnhardt et al., 2016), adolescence (Bargiela et al., 2016; Mirkovic & Gérardin, 2019), older childhood (Reindal et al., 2023), school-aged youth (Davidovitch et al., 2015), and in some cases as young as 3 or 4 years (Denis et al., 2022; Ozonoff, 2018). It is worth noting that neither the International Classification of Diseases nor the Diagnostic Statistical Manual provide a clinical threshold for a late diagnosis despite insurance, school systems, and healthcare systems prioritizing a timely diagnosis (American Psychiatric Association, 2022; World Health Organization, 2019). A later diagnosis of autism is more common in some demographic groups due to inequities and related barriers to care; diagnosed inequities have been documented among racial and ethnic minorities (Goldblum et al., 2024; Mandell et al., 2009; Travers & Krezmien, 2018), individuals living in rural communities (Antezana et al., 2017; Mandell et al., 2005), families who live below the federal poverty level (Liptak et al., 2008), individuals assigned female at birth, women, and gender diverse individuals (Bargiela et al., 2016; Giarelli et al., 2010; Harrop et al., 2024; Lai et al., 2015; McQuaid et al., 2024). Although the focus on late diagnosis in autism has gained attention, there remains no consensus as to what constitutes a late diagnosis. To support the advancement of research in this area, an understanding of operational thresholds for late diagnosis has the potential to scaffold a more meaningful, precise literature that can benefit those who are diagnosed with autism later in life. Evolving literature on late diagnosis could leverage operationalized thresholds to increase continuity across studies, compare across samples, and draw clinical conclusions specific to subgroups of those late diagnosed. The current study seeks to systematically (a) evaluate the field's current cutoff(s) of late diagnosis in autism and justifications for cutoffs, (b) determine how thresholds vary as a function of demographic and population factors, and (c) to evaluate trends over time.

METHOD

Transparency and openness

This review was preregistered on PROSPERO (CRD42023430095): https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=430095. Research materials, including coding manuals, analysis scripts, and preregistration information are available on Open Science Framework: https://osf.io/vck9r/?view_only=988513dd00a44668b476a8afa07508e2. We adhered to the PRISMA 2020 guidelines for systematic reviews (Page et al., 2021). Data were analyzed and modeled using RStudio version 2023.06.2 (RStudio Team, 2023).

Eligibility criteria

Study exclusion criteria included nonhuman subjects, nonautistic subjects, an emphasis on a condition other than autism, corrections or errata, genetic studies without accompanying behavioral data, and case studies not specific to autism. Inclusion criteria included full text availability and use of "late" or "delayed diagnosis" terminology. Papers did not need to have a focus on late diagnosis or late-diagnosed individuals to be included. Importantly, our quantitative results focused on papers that provided a threshold for *late* diagnoses or *delayed* diagnoses, as opposed to diagnoses in some groups made *later* than other groups, or a *delay in diagnosis* from age of first concerns to age of diagnosis. Papers needed to operationalize a late or delayed diagnosis and were not included as a having a threshold if they did not provide a cutoff and merely mentioned the term. Both descriptive cutoffs ("adulthood," coded numerically as 18) and numerical cutoffs were included. All papers which mentioned the term late or delayed diagnosis ($n = 420$) were included in the analysis of late diagnosis term use by publication year. Studies that provided a threshold for late diagnosis ($n = 146$) were analyzed further.

Search strategy

The search strategy was developed by authors TCM and CH. Electronic searches for publications in English were conducted in Embase, ERIC, CINAHL, PsycINFO, and PubMed. The query string used was:

> ("late" OR "delay") AND ("Child Development Disorders, Pervasive" OR asperger OR asperger's OR autism OR autistic OR autis* OR asd OR ASC OR "pervasive development disorder" OR "pervasive development disorders" OR "pervasive child development disorders" OR PDD OR OR "semantic-pragmatic disorder") AND (diagnos*).

Mesh terms were used for PubMed searches. English language was included as a search specifier. Search results were exported into Covidence (Covidence Systematic Review Software, 2023) where duplicates were automatically removed. Titles and abstracts were screened by authors SR, CH, TCM, MM, and KL based on inclusion and exclusion criteria. All conflicts were resolved by consensus of a coder who did not make a first-round vote. Full texts of all studies that passed title/abstract review were hand-screened by authors SR, TCM, CH, MM, SB, and KL with consensus completed by authors SR and TCM. This searching and screening process was conducted twice; first in May 2023 and again in January 2024; the second phase was conducted only searching for articles published May 2023–Jan 2024 to capture any articles that may have been published during the initial coding phase. For poster abstracts, corresponding authors were contacted to acquire the poster as full text. Additionally, authors TCM and CH emailed psychological listservs, contacted researchers in the field, and posted on autism-related social media seeking gray literature. Finally, citations of all papers that quantified late or delayed diagnosis were hand searched by SR and TCM to capture any relevant papers not captured in the searches.

Coding

Authors SR, CH, and TCM developed coding guidelines and a training process for extraction. The extraction procedure was piloted using three articles accompanied by discussion, after which the extraction template was edited for concision. Authors SR, TCM, CH, MM, KL, and SB completed extraction training and extraction. For all full texts where late or delayed diagnosis was mentioned but not quantified, no further information was extracted. For full texts which provided a threshold for late diagnosis, data extracted included study characteristics, participant characteristics, and quantifications(s) of and rationale for late diagnosis. Consensus for extraction was reached by agreement between TCM and SR.

RESULTS

Study selection

Figure 1 shows the study selection results using the PRISMA flowchart (Page et al., 2021). Searches conducted using databases retrieved 11,619 records; of those records, 4273 were removed as duplicates. Of the remaining 7345 records, 5259 were excluded based on title and abstract review, leaving 2086 records that entered the full-text review process. Of these, 38 studies could not be retrieved (e.g., posters and conference proceedings). The remaining 2048 articles were assessed for extraction; 1628 were excluded due based on our exclusion criteria (see Figure 1 for further details). After the full-text review process, 420 articles were extracted. The interrater agreement at each level of the decision-making process was excellent (Norcini, 1999): interrater proportion agreement ranged from 86% to 97% (title and abstract screening) and 90% to 100% (full text review) for each reviewer pair ($n = 12$).

Study characteristics

Study features

The 420 extracted studies reflected participants (or authors, for reviews) from six continents: North

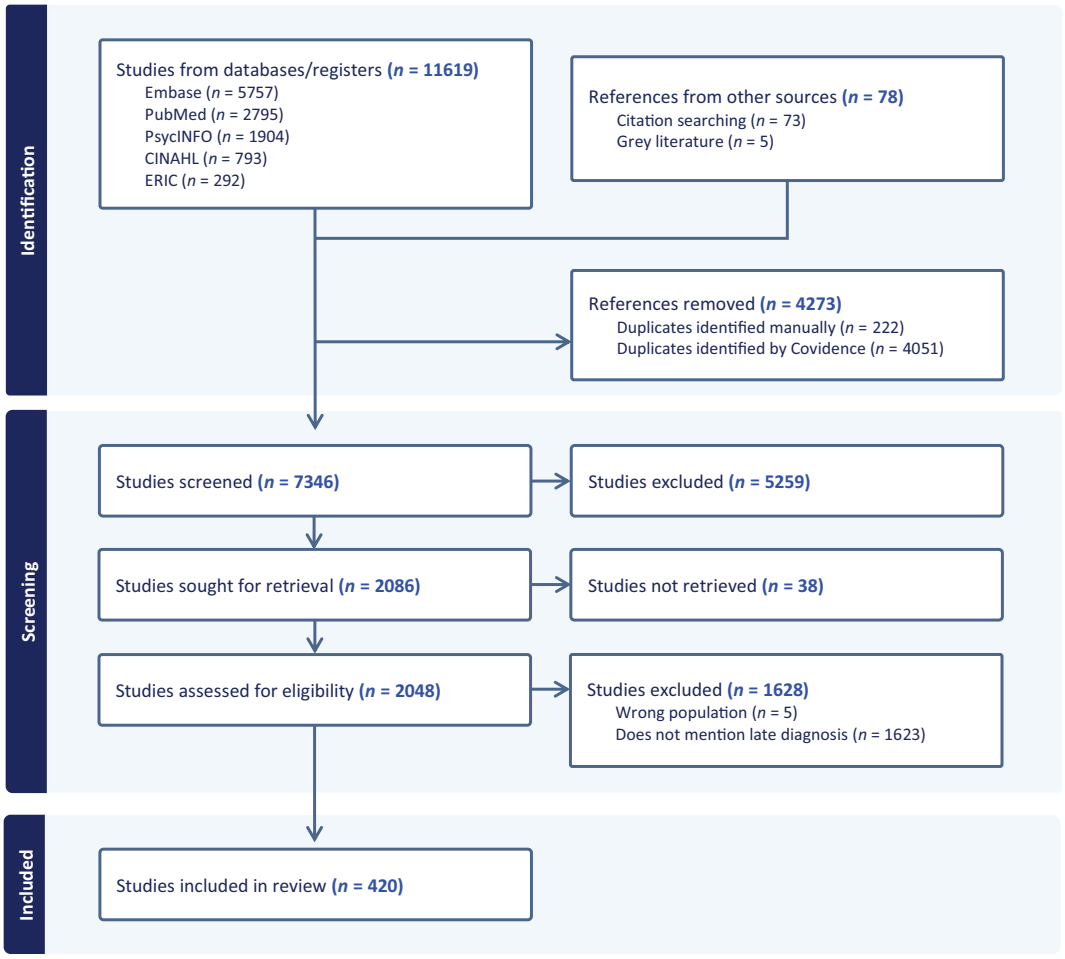

FIGURE 1 PRISMA flowchart for included and excluded studies.

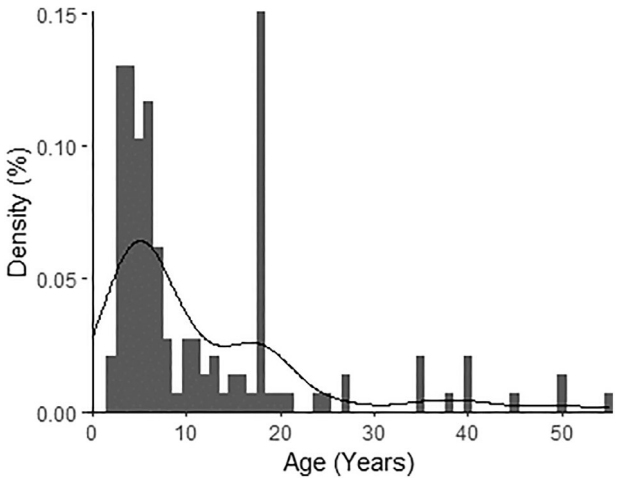

FIGURE 2 Histogram density plot visualizing frequency of late diagnosis threshold.

America ($n = 174$), Europe ($n = 132$), Asia ($n = 50$), Australia/Oceania ($n = 27$), South America ($n = 4$), and a combination ($n = 33$). The publication dates spanned 35 years (1989–2024). Forty-six papers actively recruited late diagnosed individuals (definitions of late diagnosis varied by study). One hundred and thirty-four papers reported no autistic community involvement in the design, execution, or interpretation of the study; 12 reported on community involvement from at least one autistic individual. Of the 420 studies that mentioned a late diagnosis of autism, only 34.7% provided a clear threshold ($n = 146/420$). The average cutoff for late diagnosis was 11.53 years (range = 2–55 years; median = 6.5 years). Visual inspection of the data revealed a bimodal distribution (Figure 2), of which the two modes were 3 and 18 years. Finally, the majority of papers that provided a threshold for late diagnosis utilized quantitative methods ($n = 97$), followed by qualitative studies ($n = 19$), theoretical papers ($n = 14$), reviews ($n = 8$), mixed methods ($n = 4$), and case studies ($n = 4$; Table 1). Justifications for late diagnosis cutoffs provided by researchers are discussed below.

Participant features

Of the papers that quantified late diagnosis ($n = 146$), the majority included only clinically diagnosed individuals ($n = 128$) as opposed to self-diagnosed only ($n = 1$), a

TABLE 1 Descriptives of papers that quantified late diagnosis.

Descriptives	*n*	%
Total papers	420	
Papers that quantified late diagnosis	146	34.8
Year of publication		
Mean	2018	
Mode	2023	
Range	1989–2024	
Overall PRM:PRF ratio	2.29:1	
Continent		
North America	55	37.7
South America	N/A	N/A
Europe	55	37.7
Asia	19	13.0
Africa	5	3.4
Australia/Oceania	9	6.2
Multiple	3	2.0
Youngest age group		
Infants	34	23.3
Toddlers	32	22.9
School age	16	11.0
Adolescents	5	3.4
Adults	39	26.7
No age group—reviews	20	13.7
Recruitment method		
Did recruit late diagnosed	46	31.5
Did not recruit late diagnosed	100	68.5
Diagnosis type		
Clinical diagnosis	128	87.7
Missing	10	6.8
Clinical and self-diagnosis	7	4.8
Self-diagnosis	1	0.7
Paper type		
Case study	4	2.7
Mixed methods	4	2.7
Qualitative	19	13.0
Quantitative	97	66.5
Review	8	5.5
Theoretical	14	9.6
Advocate involvement		
Advocate involvement	12	8.2
No advocate involvement	134	91.8

Note: N/A, not applicable; PRF, people referred to as female; PRM, people referred to as male.

combination ($n = 7$), or studies that were missing data on diagnosis type ($n = 10$). When assigned sex or gender of late-diagnosed individuals were reported, across studies there were 2767 late-diagnosed people referred to as female (PRF) and 6345 late-diagnosed people referred to as male (PRM), which is a 2.29:1 PRM:PRF ratio. For coding sex of participants, literature used varying sex and gender terminology, often using gender and assigned sex interchangeably. Based on limited information from papers about whether and how gender identity was characterized, we grouped participants as people referred to as female (PRF) and people referred to as male (PRM) in line with recent studies (McQuaid et al., 2024; Thomas et al., 2024).

LATE DIAGNOSIS THRESHOLDS: STUDY DIFFERENCES

Descriptives for the 146 studies that quantified late diagnosis are reported in Table 1. To test whether the mean age of late diagnosis differed between (a) participant location (i.e., continent), and (b) age groups of participants, we conducted two, one-way analyses of variance. Statistical results are available in Table 2. Results of the two-tailed tests indicated a significant omnibus difference in cutoff age as a function of publication location, $F(5,140) = 10.4$, $p < 0.0001$, and participant age group, $F(5,140) = 20.1$, $p < 0.0001$. Continent post hoc analyses revealed the following pattern of results: N. America < Europe = Australia > Asia (Figure 3b). Age post hoc analyses indicated the following pattern: Infants < Reviews; Infants = Toddlers = School age < Adults (Figure 3a). For research groups working with infants, a "late" diagnosis was often described as anything later than the first-identifiable behavioral diagnosis at 18–24 months, with late thresholds often around 2–3 years (Cox et al., 1999; Mishaal et al., 2014; Nitzan et al., 2023). For children, more cutoffs emerged around school-age entry, such as 5–6 years (Berg et al., 2018; Johnson-Taylor, 1987; Jónsdóttir et al., 2011; Santos et al., 2017). In adolescence, many thresholds set by researchers centered around access to individualized education programming and aging out of those resources, which centered around 12–13 years of age (Harrop et al., 2024). As research participants aged, so did the consideration of a "late" diagnosis, with adult studies frequently reporting an adult diagnosis (at 18 years) as the cutoff for a late diagnosis (Fombonne et al., 2022; Frank et al., 2018; Ghanouni & Seaker, 2023). In tandem with this trend, we evaluated whether mean definition age differed between the recruitment groups. Results of a two-tailed, independent samples *t*-test indicated that studies which had actively recruited late diagnosed individuals had significantly higher thresholds ($M = 16.9$, $SD = 12.8$) than those that did not actively recruit late-diagnosed individuals ($M = 9.1$, $SD = 8.8$), $t(144) = 4$, $p < 0.0001$.

The overall assigned sex/gender ratio of PRM to PRF who received a late diagnosis was 2.29:1, lower

TABLE 2 Threshold for late diagnosis by variables of interest.

Descriptives	Age cutoff for late diagnosis (years)		$F(5,140)$ or $t(144)$	Direction of findings in posthoc analyses
	Central tendency	SD		
All papers				
Mean	11.5	10.8		
Range	2–55			
Modes	3, 18			
Threshold by continent			10.4****	NA < Europe = Australia > Asia***
North America	7.5	5.1		
South America	N/A			
Europe	16.7	12.7		
Asia	4.2	1.9		
Africa	8.7	5.6		
Australia/Oceania	22.9	15.6		
Multiple	8	8.7		
Threshold by youngest age group			20.1****	Infants < reviews; infants = toddlers = S.A. < adults***
Infants	5.3	3.7		
Toddlers	6.6	3.6		
School age	5.6	2.4		
Adolescents	15.3	1.6		
Adults	22.0	12.0		
No age group	13.5	13.6		
Reviews				
Threshold by recruitment method			4, $p < 0.0001$	
Actively recruited late-diagnosed participants	16.9	12.8		
Did not actively recruited late-diagnosed participants	9.1	8.8		

Abbreviation: NA, not applicable.
***$p < 0.01$.
****$p < 0.0001$.

than the estimated overall assigned sex ratio of 3.8:1 (Maenner et al., 2023). Two linear regression analyses revealed that assigned sex/gender ratio (both PRM:PRF and PRF:PRM to account for studies eliminated when the denominator was zero) was not significantly associated with the late diagnosis threshold. Linear regression and estimates of best fit were used to evaluate trends over time. The number of publications discussing late diagnosis significantly increased over time through 2023 in an exponential fashion, Y (publications) = $1.1E{-}113e^{0.13(year)}$, Adj. $R^2 = 0.89$, $p < 0.0001$ (Figure 4). Only years with complete data were included in regression analysis. As only publications from January, 2024 were included, 2024 data was not representative of an entire year. Interestingly, the threshold for late diagnosis did not significantly change over time, though the model suggests a slight positive linear slope, Y (age) = $-639.8 + 0.32$ (year), Adj. $R^2 = 0.02$, $p = 0.056$ (Figure 5).

Studies' rationale for late diagnosis thresholds

Researchers provided several types of justifications for selecting a threshold for late diagnosis. Broadly, late diagnoses were defined in two overarching themes: later than what is possible and later than what is considered optimal. Within these, four primary rationales were identified, including: (1) access to early intervention signaling a late diagnosis, (2) data-driven approaches to justifying a cut-point, (3) ineligibility for medical/educational services as a definition of a late diagnosis, and (4) the onset of adulthood determining a late diagnosis. These rationales may fall into any justifications, though rationales related to ineligibility for services tend to be more closely aligned with optimality, and data driven approaches frequently align with possibility, as comparison to national averages and milestones were central to many of the rationales provided. Additionally, a given study may fall into multiple rationales, as these rationales inform each

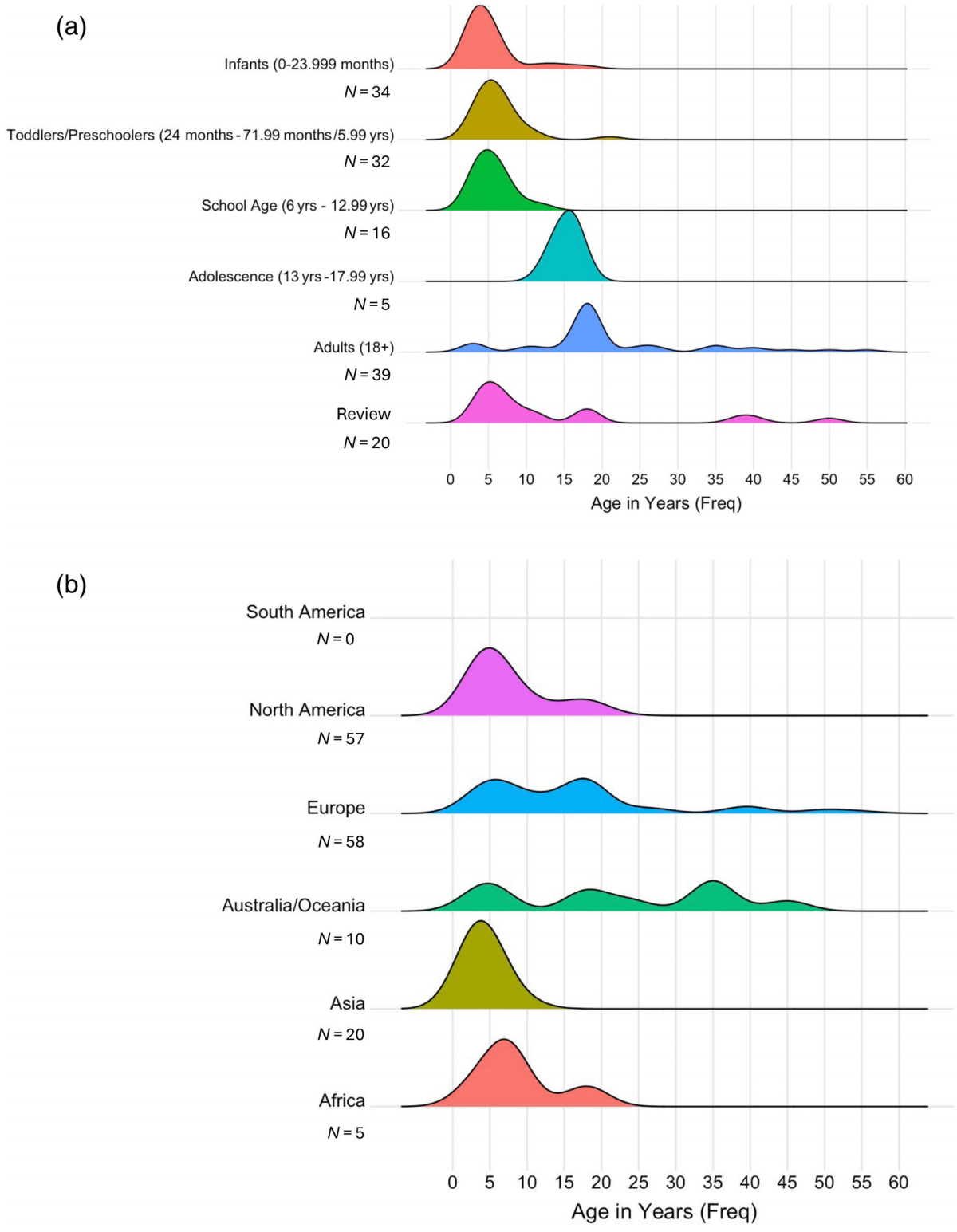

FIGURE 3 Ridge plot of late diagnosis thresholds as a function of (a) age group of participants and (b) continent of authors. Each plot contains histogram distributions emphasizing the range and mode of late diagnosis cutoff per study type (e.g., continent or age group). The *x* axis is identical, which affords visual comparison across *y* axis domains.

and are not mutually exclusive. The overlap of justification and rationale further underscores the need for authors to contextualize their conceptualization of late diagnosis. Each rationale is described below, with additional quotes from published studies for each type of justification provided in Table 3.

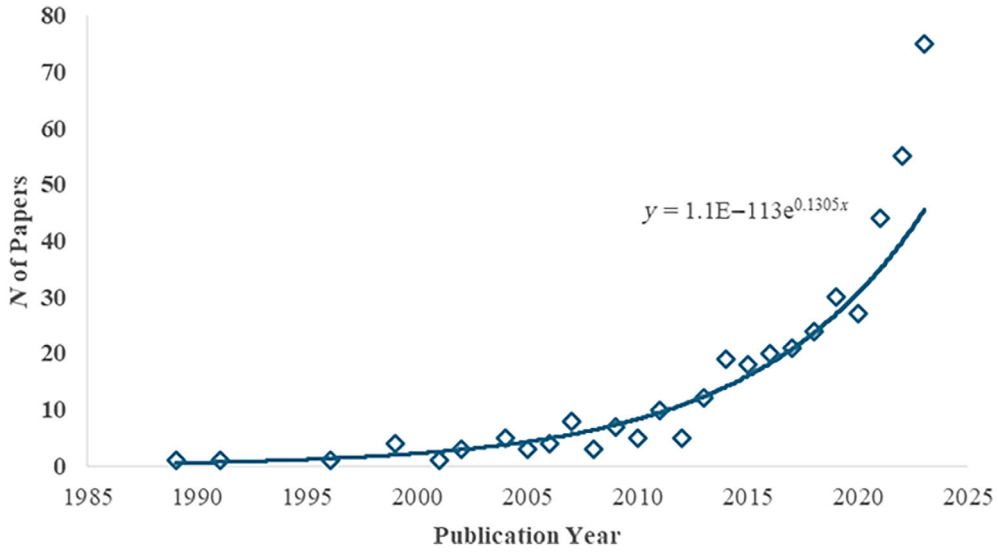

FIGURE 4 Histogram density plot of publications that mention late or delayed diagnosis as a function of publication year.

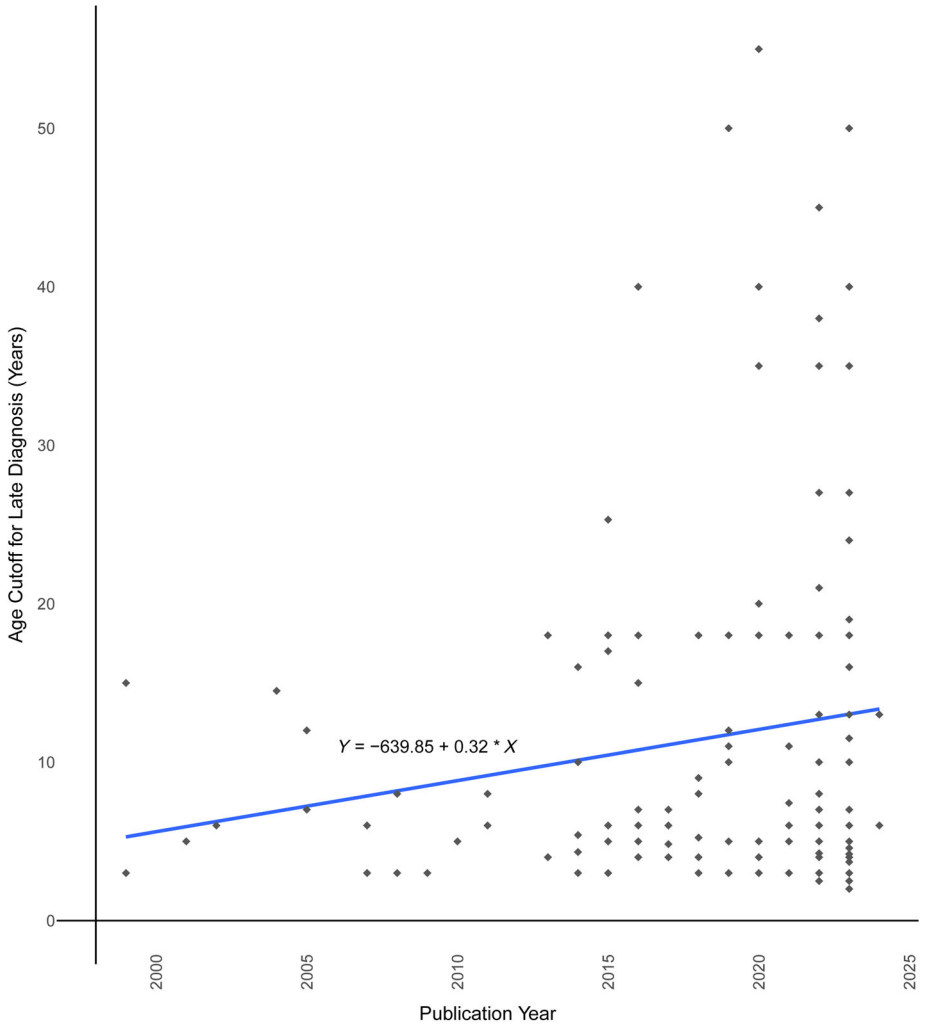

FIGURE 5 Scatter plot of late diagnosis thresholds as a function of publication year.

Early intervention

Many research studies cited the age of 3 years as a "late" diagnosis, citing evidence-based recommendations for early intervention. These definitions indicated that diagnoses made after the age of three are inherently late, as they are made after the age at which autism diagnoses are considered stable at a high level of specificity and

TABLE 3 Example rationale for late diagnosis thresholds.

Study	Rationale	Example quote
Ghanouni and Seaker (2023)	Adulthood	"…individuals with high functioning ASD had to be diagnosed with ASD after the age of 18 as to be considered a late diagnosis…In this project, late diagnosis was operationally defined as 18 years or older, which is linked to an age after adolescence." p. 2
Mishaal et al. (2014)	Data driven	"The signs of ASD usually appear prior to the age of three years (Levy et al., 2009). Nonetheless, the diagnosis of ASD is commonly delayed, with a mean age of diagnosis ranging from three to six years according to different studies." p. 874
Scholtz et al. (2021)	Early intervention	"This finding is also important as early intervention in autism makes a difference. Children with this condition are still identified often too late after the age of three years." p. 209
Habayeb et al. (2022)	Eligibility for services	"We selected the age cut-off at 6 as meaningful because it represents the timepoint during which children have aged out of early intervention programs and transitioned to school-age programming." p. 2

sensitivity (Lord et al., 2006). However, many groups also highlighted North American early intervention services, which are available for ages 0–3 years, as rationale for any age after 3 years being suboptimal, and thus a "late" diagnosis, due to missed early intervention services and opportunities. For example, one group, Nitzan et al. (2023) justified a late diagnosis cutoff of 30 months (2.5 years): "This cutoff was selected because it corresponds to the upper age limit of early screening recommendations by the American Academy of Pediatrics (Hyman et al., 2020) and because children diagnosed and treated before 30 months of age are three times more likely to exhibit improvements in social symptoms than children diagnosed at later ages (Gabbay-Dizdar et al., 2022)" (p. 4539). Access to early intervention services served as a defining anchor for many of the decisions to quantify 3 years of age as a "late" diagnosis.

Data-driven approaches

A second justification quantifying late diagnosis was data-driven approaches. This approach aligned with the "later than possible" theme, indicating that any diagnosis made after the average age of diagnosis was inherently late. In several studies, researchers used the mean or median age of diagnosis of their sample to split groups into "early" or "late" diagnosed groups. For example, Rattaz et al. (2022) grouped participants into "early" (<3), "average" (3–6), and "late" diagnoses (>7 years). Another data-driven approach included comparing the average age of diagnosis to the earliest age of possible diagnosis, as described by Delgado et al. (2023): "Although ASD can be accurately diagnosed by 14 months (Pierce et al., 2019), the median age for diagnosis is developmentally quite late, at 4 years of age (Baio et al., 2018; Brett et al., 2016)" (p. 783). The latter example is a clear demonstration that "late" in this context meant relative to what is achievable, not necessarily relative to what is optimal. Taken together, in the absence of consensus-derived thresholds, data-driven decision points based on sample means were a popular approach to differentiating early from late diagnoses.

Eligibility for services

A third rationale for late diagnosis was related to eligibility or ineligibility for accessing medical and educational services. Many researchers, citing Davidovitch et al. (2015), assigned age six as the cutoff for a late diagnosis due to (a) change in eligibility status for medical care, and (b) the start of school-related services internationally. Davidovitch et al. (2023) stated:

> While there are no established criteria for defining a late ASD diagnosis, in the Israeli context where healthcare is easily accessible at the community level and where children are seen and evaluated frequently by their healthcare team through age 6 for developmental delays, we defined children who managed to get through age 6 without raising any suspicions of autism as late diagnosed cases. (p. 295).

Jónsdóttir et al. (2011) defended their choice of the age of 6 years: "The age of 6 years was chosen because children in Iceland start elementary school at that age, and the period of early intervention then normally fades out or terminates" (p. 177). These quotes demonstrate the role of intersectionality of research context, including participants nested within their medical and educational system, and how differences in these systems may also drive differences in characterizations of "late" diagnosis. Importantly, this conceptualization overlapped thematically with access to early intervention services, but differed by paper nationality, as service inclusion/exclusion differs significantly as a function of country of origin.

Adult diagnoses

The fourth rationale emerged in the context of adult diagnoses. More than a third of the papers identified in this review detailed adult diagnoses of autism. It is clear that

a diagnosis in adulthood of a developmental disorder is inherently late, which is underscored by the breadth of available research suggesting an adulthood diagnosis of autism is later than optimal, with associations to poorer to quality of life (Atherton et al., 2022; Bargiela et al., 2016; Ghanouni & Seaker, 2023; Leedham et al., 2020; Lupindo et al., 2022; Oredipe et al., 2023). For example, Lupindo et al. (2022) stated, "For the purpose of this study, the terms delayed, and/or late diagnosis will be used interchangeably to refer to an adulthood diagnosis of autism that occurs after the South African legal age of 18" (p. 3). In the adult literature, it was not uncommon for authors to add qualifiers to their "late" cutoffs, and include "very late," or diagnoses made "much later in life" to describe late diagnosis as a diagnosis after 18 years of age (e.g., Wylie et al., 2015). There were a handful of papers who evaluated middle-to-older adulthood diagnoses of autism, ranging from 35 to 55 years (Geurts et al., 2020; Lilley et al., 2022; Stagg & Belcher, 2019), which reflects a wider trend in recent increases in publications evaluating autism in older adulthood (Mason et al., 2022). In these adult studies, the sample was described as "late diagnosed" by simply reporting the mean age of diagnosis, not necessarily defining what their cut-point would have been for a late diagnosis per se. For example, Belcher et al. (2023), stated, "…it is important to acknowledge that the diagnosed women in our sample received their autism diagnosis at a relatively late age (i.e., 27–28 years on average) …" (p. 3127).

DISCUSSION

The aim of this systematic review was to evaluate the ways in which researchers have quantified "late" or "delayed" diagnoses of autism spectrum disorder. A total of 420 articles spanning six continents and 35 years specifically mentioned late or delayed diagnoses of autism; however, only 146 (<35%) provided a clear threshold. These results indicate many research groups are examining implications of late diagnosis without providing clear cutoffs as to what age constitutes a *late* diagnosis. When quantified, late diagnosis ranged from 2 to 55 years, with a mean age of ~12 years. However, an average does not account for the wide range and bimodal distribution of cutoffs. The two most prevalent cutoffs were 3 and 18 years, suggesting there may be two competing theories driving what constitutes "late" diagnosis: (1) any diagnosis made outside toddlerhood and early intervention opportunities is "late," and (2) any diagnosis made in adulthood is "late." Though these two peaks were highly represented in the literature, they may also be viewed as the extremes of a late diagnosis cutoff; in line with authors qualifying a late diagnosis cutoff, perhaps the cutoff of three can best be considered as "late for early diagnosis" and 18 can be considered "late for a timely diagnosis."

We also evaluated whether the thresholds provided by research for late diagnosis changed over time, given the exponential increase in papers mentioning late diagnosis (Figure 4). Our results suggested a nonsignificant linear trajectory wherein the age of late diagnosis has remained stable over time or increased slightly. These findings may reflect greater attention to adult-diagnosed individuals in more recent years.

Importantly, our findings varied as a function of several contextual factors, including where the research took place, with whom the research took place, and why ages were considered "late" (e.g., project-specific rationale). Each of these patterns is discussed below.

Late in what context? The role of geography

The first research context we evaluated was geographic region of publication. Late diagnosis was most commonly addressed in papers from North American and European countries (Table 1). As seen in Figure 3b, North America, Australia, Africa, and Europe presented with bimodal distributions of late quantifications, each with a modal response early in childhood (e.g., 3–5 years) and in adulthood (18 years). Articles from Asian countries stood out as the exception to the bimodal distribution, with a tight, normal distribution and an average cutoff of 3 years. Research from European and Australian nations also stood out as having long, positively skewed distributions, suggesting a greater density of research quantifying late diagnosis into later adulthood. Indeed, the oldest ages of cutoff evaluated (35 years+) emerged from research studies from Europe and Australia. As evidenced from the current search, research on late diagnosis of autism in South American countries was absent, which represents an area for future research and funding. While beyond the scope of this review, it is likely that local considerations, such as healthcare provision, culture, and population, also impact the threshold for late diagnosis as many papers sampled from a small geographic location.

Late relative to what? How late diagnosis thresholds were decided

Understanding *why* researchers have selected various thresholds yields insight into key features of late diagnosis. Several key justifications emerged, including access to early intervention and services, considerations of adult diagnoses, and data driven definitions; these justifications could be grouped into diagnoses made later than *possible* and diagnoses made later than *optimal*. Although a paucity of strong research indicates what is the most optimal

age of diagnosis, researchers cited access to early interventions, medical care, educational resources, and quality of life implications as rationales for optimal outcomes. Across these factors, justifications intersected with country and location, with papers citing national averages, nation-based considerations regarding access to care, and legal age cutoffs (Davidovitch et al., 2023; Hodkinson et al., 2023; Klin et al., 2020; Li et al., 2023; Lupindo et al., 2022). For example, while Li and colleagues considered autism diagnosis to be late worldwide, they compared national differences in average age of diagnosis in tandem with the effect of clinical presentation:

> …the age of diagnosis of ASD is late worldwide. In the United States, the age of diagnosis of severe ASD is 3.7–4.5 years, whereas mild ASD is diagnosed at school age (5.6–8.6 years), and delayed diagnosis of ASD is more common in other less developed countries or regions, with data from Venezuela in Latin America showing an age of diagnosis of ASD of 54.38 months and Nigeria in Africa reporting an average age of diagnosis of 9 years (p. 959).

As discussed above, some papers provided an average age of diagnosis for a whole sample who were classified as "late" diagnosed, without providing a clear threshold, which may have skewed our data. Additionally, though only eight reviews were included in analysis, there is a possibility that the articles were represented twice if recurrent in a review. To address this, our team coded citations for the provided thresholds, and no papers were disproportionally represented. Additionally, publication year for reviews ranged from 2011 to 2023, with cutoffs ranging from 4 to 18, mirroring the larger dataset. This suggests that reviews were representative of the field's thresholds and did not significantly skew our data. Similarly, several cutoffs were driven by case studies or studies that considered a single person's age at diagnosis as late, often in adulthood, which may have contributed to a higher average age (Petković et al., 2015; Secci et al., 2023; Wainwright, 2023). Thus, future work should provide clearer rationale for what is selected as the cutoff for a late diagnosis.

Studies that actively recruited late-diagnosed individuals comprised almost a third of the papers that provided a cutoff for late diagnosis (46/146) and had statistically higher cut points (16.9 years, on average) compared to those which did not actively recruit late-diagnosed individuals (9.1 years, on average). Over half of studies that recruited late-diagnosed individuals (63%) included exclusively adults in their sample, suggesting that literature focused on late diagnosis of autism may have more skewed quantifications of late diagnosis. This trend, and therefore the literature focused on late diagnosis, may have driven the peak of thresholds at age 18 (Figure 2). Coding the aims of each study was beyond the scope of this project, however we acknowledge that project focus likely impacts the conceptualization of late diagnosis. Studies that, for instance, examine factors impacting the timeliness of an autism diagnosis may be grounded in different theoretical standpoints compared with studies relating late diagnosis to mental health outcomes. Though contextual factors such as location, age of participants, and recruitment of late diagnosed individuals were quantitatively analyzed regarding impact on threshold, future projects may wish to extend this to more thoroughly parse how the aims of a study and sample constraints impact late diagnosis thresholds.

CONCLUSION AND FUTURE RECOMMENDATIONS

Research discussing "late diagnosis" of autism has increased exponentially from 1989 through 2023. The age the field considers a late diagnosis has not significantly changed in this time. A bimodal distribution of cutoffs with modes at 3 and 18 and an average of 11.5 years suggests multiple critical periods for support. Often, the age authors choose as *late* reflected a crucial change in access to or desire for care. The medical and cultural context greatly informed the age at which authors quantified late diagnosis. Differences in cutoff age as a function of publication location and sample age suggest this effect is significant. Thus, just as the needs and desires of autistic individuals evolve across lifespan, so does the threshold for a "late" diagnosis. Researchers cited varied, yet equally relevant, justifications for their thresholds, underscoring the need for authors to further the contextualize their conceptualizations of late diagnosis. Taken together, these results situate the threshold for a "late diagnosis" within the context of the participants: for families pursuing early intervention services, a "late" diagnosis may range between 3 and 6 years, depending on the care being requested and accessed. In contrast, for adults seeking late-in-life identity validation through diagnosis, 18 may be a more appropriate cutoff. Expanding upon an intersectional approach to autism research, future work should also consider how participants' racial, ethnic, and gender identity impact the cutoff of late diagnosis. Additionally, this review is limited to academic articles and as such the cutoffs may differ from how the term "late diagnosed" is used in the community. Future efforts would greatly benefit from integrating community perspectives into discourse around late diagnosis. Future work may also consider how study aims impacted thresholds, and conversely how the thresholds chosen by researchers impacted samples, especially for studies which specifically recruited late-diagnosed individuals. Lastly, it is important to note that late diagnoses in "adulthood" is a descriptive range that spans tens of years. Future research may wish to evaluate the relation

between age (18–99+) of diagnosis and quality of life outcomes to investigate whether there may be meaningful profiles or sub-groups subsumed in "adulthood."

ACKNOWLEDGMENTS

This review was preregistered on PROSPERO (CRD42023430095): https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=430095. Research materials, including coding manuals, analysis scripts, and preregistration information are available on Open Science Framework: https://osf.io/vck9r/?view_only=988513dd00a44668b476a8afa07508e2. We adhered to the PRISMA 2020 guidelines for systematic reviews (Page et al., 2021). CH and JFS were supported by R01HD103895. TCM was supported by a training fellowship from NICHD (T32HD040127). MM was supported by a U.S. Department of Education OSEP training grant and a Royster Fellowship.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research materials, including coding manuals, analysis scripts, and preregistration information are available on Open Science Framework: https://osf.io/vck9r/?view_only=988513dd00a44668b476a8afa07508e2.

ETHICS STATEMENT

Since this current review relied solely upon group-level secondary data, we did not seek institutional ethics approval.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Russell, A. S., McFayden, T. C., McAllister, M., Liles, K., Bittner, S., Strang, J. F., & Harrop, C. (2024). Who, when, where, and why: A systematic review of "late diagnosis" in autism. *Autism Research*, 1–15. https://doi.org/10.1002/aur.3278