

Are the diagnostic rates of autistic females increasing? An examination of state-wide trends

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Background: Autism has been considered a ‘male-dominant’ condition. However, recent research suggests that autistic females are underdiagnosed, misdiagnosed, and later diagnosed. Females may also have different and more nuanced behavioral profiles. To examine diagnosis rates of females, we used 20 years of state-wide data to characterize historical trends in the diagnosis of autism in females to determine whether the proportion of females diagnosed with autism has changed over time. **Methods:** Data were drawn from 10,247 participants (males = 8,319, females = 1928) who received an autism diagnosis between 2000 and 2021 from state-wide autism centers associated with the University of North Carolina TEACCH Autism Program. **Results:** The rates of females diagnosed with autism increased at a greater rate compared with males. Age of diagnosis remained consistently higher for females. Late diagnosis (defined as 13+) increased over time across both males and females, however, was more commonly associated with females, particularly those with co-occurring intellectual disability. **Conclusions:** Our results indicate that the proportion of females diagnosed with autism has increased steadily over a 20-year period, which likely reflects greater societal knowledge of how autism may manifest differentially in females. **Keywords:** Autism; diagnosis; females; sex differences; late diagnosis.

Historically, autism has been considered a ‘male dominant’ condition (Baio et al., 2018; Christensen et al., 2016; Fombonne, 2009; Maenner et al., 2020, 2023). Early depictions of autism described the condition as a ‘variant of male intelligence’ (Asperger, 1944). Autism has been characterized in scientific and popular culture as through the lens of an ‘extreme male brain’ (Baron-Cohen, 2012; Baron-Cohen Simon, 2002) and has been considered a predominantly male diagnosis for many years, with a 2023 Center for Disease Control (CDC) estimate of a 3.8:1 ratio weighted in favor of males (Maenner et al., 2023) – a reduction from 4.2:1 in both 2016 and 2018 (Maenner et al., 2020, 2021). However, there is consensus that autistic females are underdiagnosed and misdiagnosed, with an estimated sex ratio closer to 3:1 based on recent meta-analytic studies (Loomes, Hull, & Mandy, 2017) and a greater number of late-diagnosed females (Green, Travers, Howe, & McDougle, 2019; Lehnhardt et al., 2016; Russell et al., 2021). Variation in diagnostic rates

between males and females may be due to the presence or absence of co-occurring intellectual disability (ID), such that females diagnosed with autism in childhood have been found to have higher rates of ID compared with males (Dworzynski, Ronald, Bolton, & Happé, 2012; Frazier, Georgiades, Bishop, & Hardan, 2014; Ratto et al., 2018).

Furthermore, there has been debate as to whether our current diagnostic practices and assessments, which have been normed for decades on mostly male samples, are suitable for females and their potentially different phenotype (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015), though other studies suggest diagnostic tools perform equally across males and females (Kaat et al., 2021). The goal of this study is to examine sex and age-related diagnostic trends using over 20 years of state-wide data from the University of North Carolina TEACCH Autism Program (UNC TEACCH) diagnostic clinics to address whether the rates of females diagnosed with autism have increased over the past two decades and whether the age of diagnosis for females has changed during this period.

It is still widely accepted that autism is diagnosed at higher rates in males, however in individuals diagnosed with autism, key sex differences in core characteristics of autism have been reported, which may contribute to the disparities and delays in diagnoses. While individual studies have been inconsistent, systematic reviews and meta-analyses suggest that autistic males have greater restricted and repetitive behaviors compared to females, with

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We have used identity first language through this manuscript in keeping with recent commentaries in the field (Bottema-Beutel, Kapp, & Lester, 2021; Kenny et al., 2016); however, we recognize there is great variation in the terminology preferred dependent on factors such as country of origin and positionality within the autism community (Buijsman, Begeer, & Scheeren, 2023; Singer, Lutz, & Escher, 2023). We also use the umbrella term ‘autism’ to summarize the various diagnostic labels that have been used throughout the timespan of this dataset and various versions of DSM.

this difference becoming significant after the age of six (Van Wijngaarden-Cremers et al., 2014) and concentrated on restricted interests and stereotyped behaviors (Edwards, Wright, Sargeant, Cortese, & Wood-Downie, 2024). Autistic females have also been reported, across studies, to have better social interaction and communication skills than autistic males (McFayden, Putnam, Grzadinski, & Harrop, 2023; Wood-Downie, Wong, Kovshoff, Cortese, & Hadwin, 2021). Given these behaviors are core aspects of the autism phenotype, it is plausible that autistic females go undetected or misdiagnosed as they do not fit with the ‘male phenotype’ of autism formed over 60 years of research.

An autism diagnosis is vital for accessing services and supports. An early community diagnosis has been associated with improvement in social communication behaviors within one to 2 years (Gabbay-Dizdar et al., 2022). An autism diagnosis can also provide a sense of belonging and identity; many late-diagnosed individuals, particularly females, report a poor sense of belonging until they receive a diagnosis that explains their challenges and experiences (Bargiela, Steward, & Mandy, 2016; Leedham, Thompson, Smith, & Freeth, 2020; Seers & Hogg, 2023). While the diagnosis of autistic females has steadily increased over the past decade (Loomes et al., 2017; Russell et al., 2021), autistic females are diagnosed, on average, 2 years later than their male peers, particularly when they present with minimal language delays (Begeer et al., 2013; Duvekot et al., 2017; Harrop et al., 2021; McCormick et al., 2020; Salomone, Charman, McConachie, & Warreyn, 2015). An increasing number of females are also being diagnosed outside of early childhood, with diagnostic rates increasing in adolescence and adulthood (Giarelli et al., 2010; Russell et al., 2021). In recent studies, parents of autistic females and adult autistic females themselves have expressed frustration in accessing a timely autism diagnosis (Bargiela et al., 2016; Freeman & Paradis, 2023; Leedham et al., 2020; Navot, Jorgenson, & Webb, 2017).

The current study seeks to understand the impact of these research trends on the timing and overall rate of autism diagnoses in females. This study replicates and extends research from the United Kingdom that analyzed 20-year trends in diagnosis (Russell et al., 2021), reporting an increase in the number of females receiving an autism diagnosis, particularly at older ages. We also sought to determine whether the shift from DSM-IV and DSM-5 in 2013 resulted in greater recognition of autistic females. Briefly summarized, major changes included the creation of a single diagnostic category, autism spectrum disorder, combining autistic disorder, Asperger syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and child disintegrative disorder. The three DSM-IV domains (reciprocal social interaction, communication, and

restricted and repetitive behaviors and interests) were collapsed into two domains in DSM-5, combining social interaction and communication. In this study, we utilized a standardized and comprehensive state-wide database, which spans over 20 years of diagnostic evaluations and includes nearly 2000 autistic females, to address the following questions:

- 1 Are more autistic females being identified over time and between DSM-IV and DSM-5?
- 2 Has the age of diagnosis lowered over time for females relative to males?
- 3 Have the numbers of *late-diagnosed* females increased over time?

Due to the increase in awareness surrounding autism in females and the removal of a language delay requirement in the change from DSM-IV to DSM-5 criteria (American Psychiatric Association, 2013), we hypothesized that the number of females being diagnosed would increase over time and with DSM-5 diagnoses. We also predicted that the age of diagnosis for both males and females would decrease over time, but at a greater rate in females. We predicted that the proportion of late-diagnosed individuals (i.e. diagnosed at 13 years or later) would increase over time in the whole sample, but at a greater rate in females.

Methods

Participants

Data for this study were drawn from diagnostic evaluations conducted across state-wide outpatient clinics operated by the UNC TEACCH. UNC TEACCH is a university-based system of regional centers that support clinical, training, and research needs of autistic individuals, their families and professionals and has been serving the state of North Carolina since the late 1960s. There are currently seven community clinics across the state serving both urban and rural communities. Across the state, clinics serve clients from all 100 counties in North Carolina. Notably for this study, UNC TEACCH provides clinical services, including diagnostic evaluations, parent support groups, and intervention services across the age range, including adults. Until 2012, UNC TEACCH provided free diagnostic assessments and since that time has accepted Medicaid, private insurance, and self-pay for services. Currently, approximately 50% of clients served at UNC TEACCH are covered by Medicaid (federally and state-funded public health insurance for individuals with low income). All individuals, or their caregivers, are asked if their diagnostic assessment data can be used for research purposes. To evaluate historic trends in diagnosis, we used data from January 2000 to December 2021. Data from 13,080 participants who provided consent for their clinical data to be used for research purposes were included in the initial analyses.

Procedures

Participants included in this study were drawn from the UNC TEACCH database, which includes 20 years of diagnostic and characterization data, spanning January 2000 to December 2021. Participants were included in the database if: (a) they were evaluated for autism at one of the UNC TEACCH clinics and (b) consented to have their data included in the database

Table 1 Characteristics of individuals who received an autism diagnosis between 2000 and 2021

	Overall	Males	Females
<i>N</i>	10,247	8,319	1928
%		81.2	18.8
Race %			
White	66.0	66.1	65.7
Black or African American	15.6	15.7	15.1
Asian	2.3	2.1	3.0
American Indian/Alaska Native	0.7	0.6	0.8
Native Hawaiian or Other Pacific Islander	0.1	0.1	0.1
More than one	2.1	2.1	2.4
Other	4.1	4.0	4.5
Missing	9.2	9.4	8.5
Ethnicity			
Hispanic or Latino	7.5	7.7	6.9
Not Hispanic or Latino	21.9	20.8	26.9
Missing	70.6	71.6	66.2
Age of diagnosis in months (Mean/ <i>SD</i> /Range/ <i>IQR</i> /Median)	100.66 (92.50)	97.04 (86.41)	116.28 (113.83)
	18.07–861.96	18.07–861.96	18.92–820.99
	77.73	74.25	96.05
	73.39	72.61	78.11
Late diagnosis (13 years+) %	15.4	14.1	20.9
Co-occurring intellectual disability % ^a	15.54%	14.30%	20.83%

^aData from 7,972 individuals.

for research purposes. The study was reviewed and approved for exemption by the University of North Carolina at Chapel Hill Institutional Review Board.

Diagnostic evaluations were completed by teams led by a licensed psychologist. Evaluations included a caregiver interview to gather developmental history and information on autism symptoms and a standardized evaluation of autism symptoms, followed by scoring of the Childhood Autism Rating Scale (CARS; Schopler, Reichler, DeVellis, & Daly, 1980; Schopler, Reichler, & Renner, 1988; Schopler, van Bourgondien, Wellman, & Love, 2010), and a behavioral observation. In the early 1990s prior to the publication of the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000; Luyster et al., 2009), UNC TEACCH used the Psychoeducational Profile (PEP; Schopler & Reichler, 1979) to provide a standardized context to capture responses to social presses, behaviors characteristic of autism, and language. As versions of the ADOS were developed at UNC TEACCH and published [e.g. the original ADOS for school-age children in 1989; the PL-ADOS for preschoolers in 1995; see Lord (2010) for a description of the evolution of the ADOS and roots in the PEP (Lord, 2010)], UNC TEACCH implemented the ADOS (Lord et al., 2000) as the standardized behavioral evaluation as it became available. Based on the parent interview and behavioral assessment (PEP or ADOS), clinicians completed a CARS diagnosis rating and a DSM rating to determine a diagnosis. During the 20-year period, versions of the CARS and ADOS changed, as well as the DSM. During the study period, the CARS (Schopler et al., 1980, 1988) and CARS2 (Schopler et al., 2010; CARS2-ST – standard form – and CARS2-HF – high functioning) were used, ADOS (Lord et al., 2000) and ADOS-2 (Lord et al., 2012) were administered, and individuals were diagnosed using DSM-IV (American Psychiatric Association, 1994), DSM-IV-TR (American Psychiatric Association, 2000) and DSM-5 criteria (American Psychiatric Association, 2013). Research on the CARS2 has determined stability of an indicated autism diagnosis between DSM-IV and DSM-5 criteria (Dawkins, Meyer, & Van Bourgondien, 2016). The database includes individuals who received an autism diagnosis and those who did not receive an autism diagnosis based on DSM criteria at the time of their evaluation if they consented to have their data available for research purposes. Individuals were considered to have an autism diagnosis if they

received a diagnosis of autism, autism spectrum disorder, Asperger syndrome, or PDD-NOS based on the DSM criteria in place during their initial diagnostic evaluation at UNC TEACCH.

Dependent variables

The goal of this study was to characterize state-wide trends in diagnosis by assigned sex at birth (our independent variable). Our dependent variables were drawn from the UNC TEACCH database and were collected at the time of evaluation. Participant characteristics are reported in Table 1.

Year of official diagnosis. Year of diagnosis (2000 to 2021) was used as a continuous variable and drawn from the date of diagnostic evaluation in the database. It is important to acknowledge that diagnostics were conducted virtually during 9 months of 2020 due to the COVID-19 pandemic, therefore referrals and evaluations during this time were reduced.

DSM version at time of diagnosis. Given the shift between DSM versions during the time of record collection, we sought to understand how changes in DSM diagnostic criteria for autism from DSM-IV to DSM-5 impacted the number of females diagnosed and age of diagnosis. Due to a staggered implementation of the DSM-5 at UNC TEACCH clinics in 2013, for this analysis we excluded all individuals diagnosed during that year ($N = 514$). We also had a number of cases which were missing or had unclear DSM diagnosis records across the wider data set ($N = 486$).

Age of official diagnosis. To characterize trends in the age of diagnosis over time, age of diagnosis, in months, was calculated for each participant using the date of birth and date of evaluation. To characterize trends in late diagnosis, we created an additional variable for individuals diagnosed age 13 and above. While research has increasingly focused on *late-diagnosed* autistic individuals (Bargiela et al., 2016; Leedham et al., 2020; Lehnhardt et al., 2016; Seers & Hogg, 2023) to our knowledge there is no current consensus definition of this term. For the current study, we defined a late-diagnosed

individual as someone who was diagnosed with autism on or after their thirteenth birthday. This age was selected as children diagnosed before the age of 13 in the United States are eligible for an individualized education program in elementary school, resulting in services and supports not made available to late-diagnosed individuals during this critical period.

Intellectual disability status. To determine who ID interacted with sex to predict diagnosis, we included (where possible) data on whether individuals were classified as having co-occurring ID or not. This was derived from individuals who had valid IQ or adaptive behavior data ($N = 7,972$). The most common developmental and cognitive measures included the Wechsler family of tests (Wechsler, 2008, 2012, 2014), Differential Ability Scales (Elliot, 2007), Bayley Scales of Infant and Toddler Development (Bayley, 2006), Mullen Scales of Early Learning (Mullen, 1995), and the Stanford-Binet Intelligence Scales (Roid, 2003). Adaptive behavior measures primarily included the Vineland Scales (Sparrow, Cicchetti, & Saulnier, 2016) and the Adaptive Behavior Assessment System (Harrison & Oakland, 2015). We categorized individuals into the ID group based on an IQ of 70 or below or an adaptive behavior T -score of 70 or below. This resulted in 1239 individuals classified as having co-occurring ID and 6,733 without.

Analytic approach

Data were cleaned and checked prior to analysis. 13,080 initial cases were identified. 412 cases were removed due to errors in dates (date of diagnosis prior to date of birth), age of diagnoses seeming too young (<18 months of age) based on practices in UNC TEACCH clinics at the time of evaluation, assigned sex listed as 'other', and evaluations occurring prior to 2000. This left a final sample of 12,668 individuals with evaluation data for analysis (Table S1). The final sample included 10,247 individuals who received an autism diagnosis (based on the DSM criteria in place at the time of their evaluation) and 2,421 individuals who did not receive an autism diagnosis. Of the 10,247 individuals who received an autism diagnosis, 1,000 were excluded from the DSM analysis (see "DSM version at time of diagnosis" section for details). To address Question 1 (Are more autistic females being identified over time?), we calculated an index number following the procedures of Russell et al. (2021), whereby we calculated the incidence at the baseline year to be 100%. Index numbers were calculated for the number of new diagnoses by year to examine the overall shape of incidence rate and separately by sex for each year to reflect number of males and females being diagnosed each year. Index numbers reflect the percent rise or decrease in incidence from 2000 and is used to capture time trends (Office for National Statistics, 2016). We plotted the incidence index number by sex and year and checked model fit to ascertain the shape that best described the trend of diagnosis incidence over time by sex. We fit a regression model with year as predictor and sex index number to ascertain the speed of increase. To examine the impact of the DSM on diagnostic rates and time we conducted a polynomial spline model examining the change in incidence rates between males and females from 2000 to 2012 (DSM-IV) and 2014–2021 (DSM-5). To address Question 2 (Has the age of diagnosis lowered over time for females relative to males?) and Question 3 (Have the numbers of late-diagnosed females increased over time?), we examined descriptive patterns over time and used multivariable regression to test moderating effects of late diagnoses and age of diagnosis on the relationship between year (predictor) and sex index number (rate of change in incidence by sex over time) and interaction terms between time, sex, and moderators (late diagnosis and age of diagnosis). To model potential sex by ID interactions, we examined whether the log odds of a late diagnosis differed by sex and ID status.

Results

Research Question 1: Are more autistic females being identified over time?

The proportion of males:females receiving a clinical diagnosis of autism decreased over time from 5.64:1 to 3.07:1, with more females receiving a diagnosis of autism over the past 20 years (Table 1; Figure 1; Table S2).

The overall time trend of new cases of autism showed a non-linear trend, with the largest increase in the overall rate of diagnosis in 2007. The polynomial trend to the fourth power with log-transformed outcome best fit the data, $F(4,17) = 29.82$, $p < .001$, $R^2 = .88$, exponentiated coefficient = 1.0, $SE = 1.0$, $t(17) = 2.93$, $p = .009$. For the time trend by sex incidence rate, the polynomial trend to the fifth power best fit the data, $F(11,32) = 17.76$, $p < .001$, $R^2 = .84$. There was a significant interaction between sex and time, estimate = 1.82, $SE = 0.81$, $t(37) = 2.26$, $p = .03$, suggesting that female incidence rates were significantly higher than male incidence rates and had differential incidence rates over time (Figure 1).

The polynomial spline model was statistically significant, $F(9,32) = 18.34$, $p < .001$, $R^2 = .84$. There was a higher percentage increase in incidence rate from 2000 to 2012 (DSM-IV), Estimate = 758.02, $SE = 179.02$, $t(32) = 4.23$, $p < .001$, compared with 2014–2021 (DSM-5). There was no interaction between year (time) and sex, suggesting that the overall average patterns of incidence rate were similar for males and females during the two DSM periods.

Research Question 2: Has the age of diagnosis lowered over time for females relative to males?

Across the whole dataset, the average age of diagnosis for males was 97.04 months (8.08 years) compared with 116.28 months (9.69 years) for females (Table 1). When examining the moderating effect of age of diagnosis between time and incidence rate, there was not a significant three-way interaction between sex, age of diagnosis, and time. There was a significant two-way interaction between sex and age of diagnosis, estimate = -62.0, $SE = 29.0$, $t(81) = 2.14$, $p = .03$. These results suggest that females had later ages of diagnosis across all study years.

Research Question 3: Have the numbers of late-diagnosed females increased over time?

To examine the number of late-diagnosed females in our dataset, we calculated the proportion of males and females who received a diagnosis at age 13 or above. Across the whole dataset, 15.4% of individuals received a late diagnosis. A logistic regression was performed to determine how sex predicted late diagnosis. There was a 38% decreased chance of males having a late diagnosis compared to females

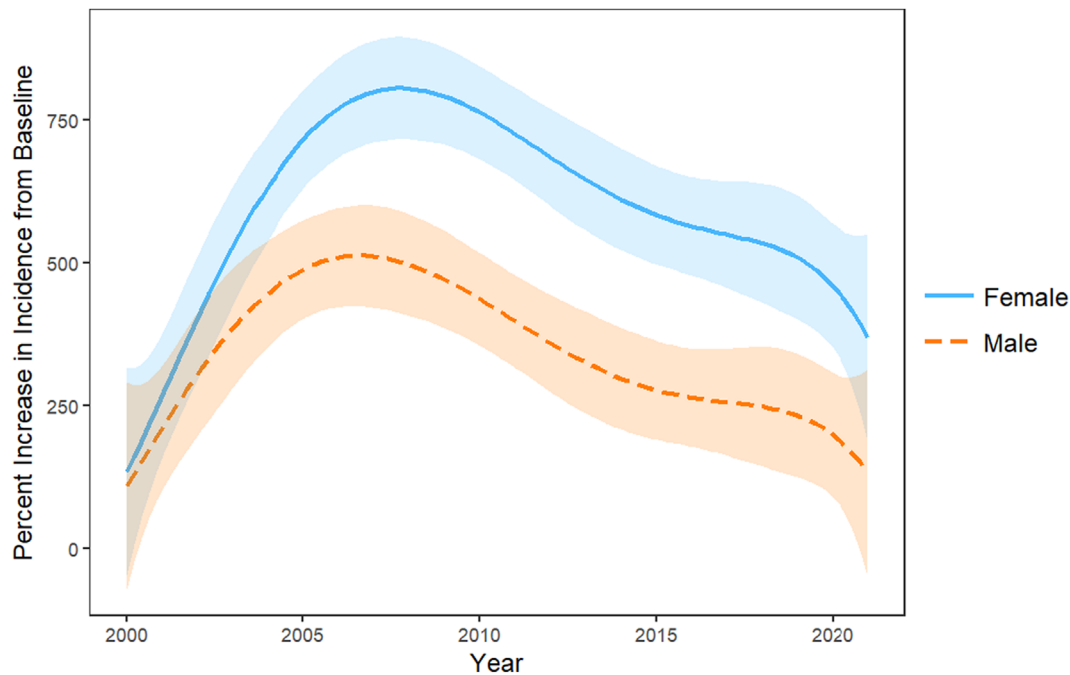


Figure 1 Percentage increase in incidence of autism diagnosis from 2000 to 2021 by sex

[OR = .62, 95% CI 0.55, 0.71], $est = .48$, $SE = .06$, $t(10246) = 7.37$, $p < .001$. Time also impacted the number of late diagnoses. The proportion of individuals receiving a late diagnosis increased over time across the whole dataset. For every year increase, individuals were 1.01 times more likely to receive a late diagnosis [OR 95% 1.00, 1.01], $est = .01$, $SE = .00$, $t(10254) = 8.12$, $p < .001$. When examining the moderating effect of late diagnosis between time and incidence rate, there was not a significant three-way interaction between sex, late diagnosis, and time. There was a significant two-way interaction between sex and late diagnosis, estimate = $-.50$, $SE = 0.21$, $t(76) = 2.32$, $p = .02$. Independent of time, late diagnosis was associated with being female. The interaction of sex by ID Status was statistically significant, $Est = 0.40$, $SE = 0.19$, $F(5694) = 2.10$, $p = .04$. Females without ID were more likely to have a late diagnosis than males with ID (Supplemental Analysis S1; Figure S1; Table S3).

Discussion

The current study aimed to understand the rate and timing of female autism diagnoses in the context of recent research trends. The sex ratio of males: females diagnosed at state-wide autism outpatient clinics steadily decreased over a 20-year period from 5.64:1 to 3.07:1, with more females receiving an autism diagnosis in the state of North Carolina over time. Despite this increase, the age of diagnosis remained later for females across all years, with an average age of diagnosis 18 months later than males. Furthermore, while the rate of late diagnoses (defined as age 13 and above) increased across the

whole dataset, late diagnosis was consistently associated with females.

In line with recent CDC estimates (Maenner et al., 2023), our data suggest that more females are being diagnosed with autism, with rates steadily increasing overtime and at a faster rate than for males (Figure 1). As age of diagnosis did not reduce for females, it is possible that females were missed or misdiagnosed at an earlier age or did not enter the diagnostic system until later than males. While the increase in diagnostic rates for females is encouraging and suggests an increase in both societal and clinician knowledge of autism in females, younger females are consistently not diagnosed at the same rate as males indicating an area of improvement within clinical services.

Despite the general increase in females identified over time, there was no impact of DSM version on the rate of diagnosis. This is despite changes to DSM-5 to receive an autism diagnosis, including the removal of a language delay requirement, meeting historic and current diagnostic criteria, and the inclusion of sensory behaviors, suggesting that DSM-IV and DSM-5 identified both males and females.

Female sex was consistently associated with a later age of diagnosis in our dataset, aligning with previous studies spanning childhood through to adulthood (Harrop et al., 2021; McCormick et al., 2020; Russell et al., 2021). While there was no three-way interaction between age of diagnosis, sex, and year, Figure 2 displays an increase in incidence rate across age of diagnosis from baseline (2000) for females, compared with a relative decrease for males (see Table S2). When there was a higher

incidence rate of autism, females were more likely to be diagnosed at later ages, whereas this relationship was reverse for males. This likely reflects the lower proportion of males diagnosed in the later ages. Late diagnosis was also more common over time and in females (Figure 3), suggesting that while rates of autism diagnoses for females are increasing, providers may continue to struggle to identify autism in younger females resulting in an older age of diagnosis. Females without co-occurring ID were more likely to be classified as late diagnosed compared to males without ID (Figure S4). It has been hypothesized that autistic females without co-occurring ID are more susceptible to a late diagnosis than males due to their autism traits presenting differently and during different developmental periods, leading to increased diagnosis in adolescence and adulthood. For example, friendships and other aspects of the social landscape change dramatically for females in adolescence, presenting new challenges and stressors that may lead to an autism diagnosis during this period (Cridland, Jones, Caputi, & Magee, 2014; Sedgewick, Hill, & Pellicano, 2019).

Taken together with the findings of Russell et al. (2021), these results highlight the increased numbers of autistic females receiving a diagnosis later in childhood and often beyond despite differences in diagnostic practices between the United Kingdom and United States. Increased rates of female diagnoses have been attributed to an increased awareness of autism in general and in females specifically and greater demand for autism diagnostic services (Crane, Chester, Goddard, Henry, & Hill, 2016; Kanne & Bishop, 2021; Lappé et al., 2018; Wiggins, Baio, & Rice, 2006; World Health Organization, 2013; Zwaigenbaum &

Warren, 2021). Alternatively, this increase in rates of female diagnosis may be due to: (a) greater recognition of *how* autism may manifest differentially across males and females, and/or (b) cultural and clinician biases about male and females. For example, Whitlock, Fulton, Lai, Pellicano, and Mandy (2020) reported that elementary school teachers in the United Kingdom under-recognized autism traits in vignettes describing autistic girls relative to boys. While our data suggest that clinical recognition of autism in females is steadily increasing, there are likely more undiagnosed or misdiagnosed females in the community compared with males.

While these state-wide trends, alongside national trends (Maenner et al., 2023), are encouraging in suggesting that females are being diagnosed more accurately across time, efforts must be made to identify autistic females earlier to improve their access to appropriate supports and to provide a sense of identity (Bargiela et al., 2016; Zener, 2019). Lai, Lin, and Ameis (2022) recently discussed the nuanced female phenotype of autism, including greater motivation for friendships and social stimuli, as well as potential differences in language use. However, the authors argue against the notion of a specific ‘female autism phenotype’, instead applying the lens of sex and gender to understand how these factors may modulate autism presentations, such as *gendered* restricted interests and differences in the use of language.

Given that females are consistently diagnosed later, this has implications for the types and suitability of services available to them. The majority of treatment approaches have been designed based on a male conceptualization of autism and therefore

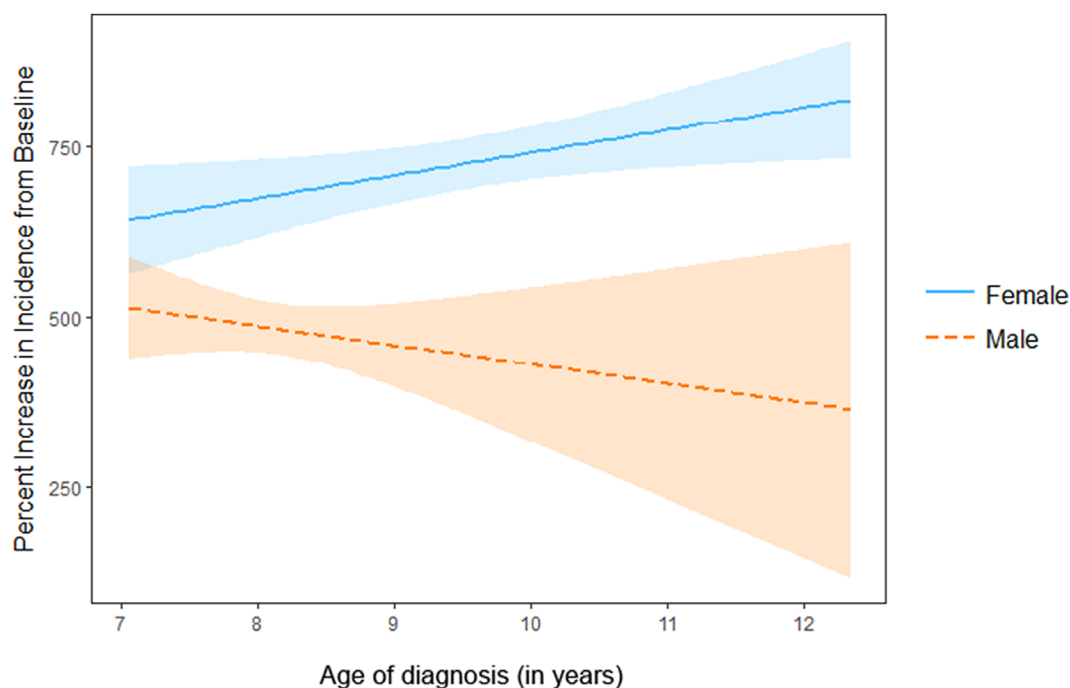


Figure 2 Percent increase in incidence of autism diagnosis by sex from baseline by age of diagnosis

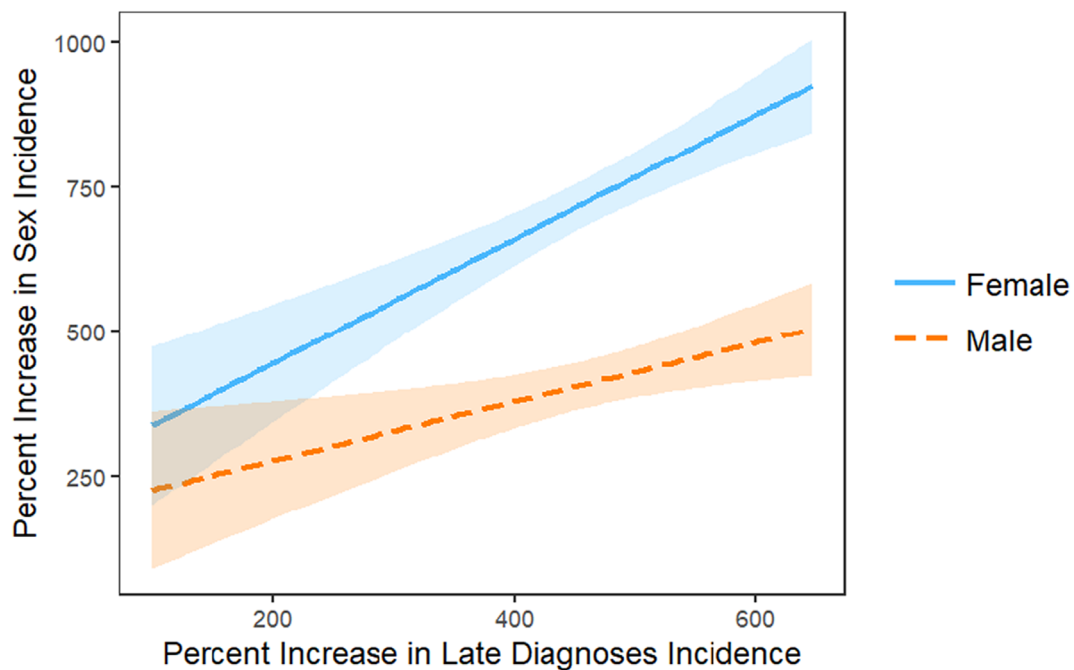


Figure 3 Percent increase in late diagnosis incidence relative to percent increase in sex incidence

may not consider the nuanced profile and needs of females. A handful of studies have examined sex differences in adolescent interventions with mixed results. McVey and colleagues reported that autistic adolescent and adult females ($N = 27$) responded similarly to a social skills intervention (PEERS©) when they pooled data across three trials (McVey et al., 2017). Ko and colleagues also examined how 10 females responded to a socialization program for adolescents relative to males (Ko, Schuck, Jimenez-Muñoz, Penner-Baiden, & Vernon, 2021). Autistic females reported a steeper increase in social competency at exit compared to autistic males. Further research is required to determine whether and how interventions may need tailoring towards females.

Additional research is also needed to understand *why* females are diagnosed so much later than their male counterparts. One possibility not explored within our data is the other diagnoses females may have received prior to their autism diagnosis. Kentrou, de Veld, Mataw, and Begeer (2019) reported that a diagnosis of ADHD delayed an autism diagnosis in females more than males. Furthermore, females are more likely to be misdiagnosed (Gesl et al., 2021) and also ‘drop’ their other diagnoses once they receive an autism one (Kentrou, Oostervink, Scheeren, & Begeer, 2021). Therefore, it is plausible that females in our sample received additional diagnoses prior to their autism diagnosis and experience more diagnostic overshadowing.

Limitations

Our study had a handful of limitations worthy of discussion. First, diagnostic evaluations were disrupted during the COVID-19 pandemic, particularly

in 2020. While the majority of data was collected prior to this time period, fewer diagnostic evaluations were completed during these 9 months across both sexes. However, we performed a sensitivity analysis to examine if trends differed between the dataset with 2020 and 2021 removed compared with the whole dataset. No differences were found in the results from this analysis compared with those reported utilizing all available data (Supplemental Analysis S2). It is important to note that changes in the model of services (free to insurance/Medicaid) at UNC TEACCH in 2012 overlapped somewhat with the switch from DSM-IV to DSM-5 and it is not possible to disentangle these two factors. While most individuals enter the UNC TEACCH system as their first point of contact for diagnostic services, it is plausible that some individuals in our dataset received an autism diagnosis elsewhere (such as school) before being referred to UNC TEACCH for a medical diagnosis. Furthermore, the number of individuals referred for an autism diagnosis at UNC TEACCH varied across the span of the dataset, with a *bump* in overall referrals, and therefore diagnoses, resulting in a non-linear trend in our data (Figure 1).

While not the focus of this study, we did not explore potential sex disparities by race, and ethnicity. Data on ethnicity were not routinely collected prior to 2016 and thus we only have complete ethnicity data from this date onwards. We recognize this is a limitation of our dataset and one that requires further investigation given race and ethnicity disparities in receiving a timely autism diagnosis (Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Magaña, Parish, & Son, 2015; Mandell et al., 2010; Mandell, Ittenbach, Levy, &

Pinto-Martin, 2007; Mandell, Listerud, Levy, & Pinto-Martin, 2002).

It is also worth noting that there is no standard definition as to what constitutes late diagnosis in autism, with some researchers focusing on diagnosis in adulthood (Lupindo, Maw, & Shabalala, 2022; Zener, 2019) and others defining late diagnosis as outside of toddlerhood and preschool (Davidovitch, Levit-Binnun, Golan, & Manning-Courtney, 2015; Ozonoff et al., 2018). What constitutes late diagnosis may also vary by state in the United States and by country. While we opted to define late diagnosis as age 13 and above based on the higher likelihood of accessing an individualized education plan during elementary school and specific services, such as early intervention, different approaches to defining late diagnosis may yield different trends over time and are worthy of further exploration. Furthermore, while UNC TEACCH does provide state-wide services, the final sample only includes families who consented to have their diagnostic data used for research purposes, thus might not be truly representative of state demographics. It is important to recognize that the demographics of North Carolina are not fully representative of the wider United States, with the second largest rural population in the country (33% vs. 14% overall), a greater Black or African American population than the United States overall (22.2% vs. 13.6%), and a smaller Hispanic or Latino population (10.5% vs. 19.1%).

Conclusions

Using over 20 years of state-wide diagnostic data, rates of autistic females diagnosed increased over time. Mirroring trends in the United Kingdom (Russell et al., 2021), more females, particularly those without co-occurring ID, received a diagnosis in adolescence and adulthood compared to males. Along with more females being identified however was the concerning pattern of their age of diagnosis remaining constantly higher and potentially increasing over time. Clinicians should be mindful of considering gendered norms and expectations when

assessing females referred for an autism diagnosis. Future directions include further probing this data to understand if the behavioral profile of females receiving a diagnosis has changed over time.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Table S1. Participant Characteristics by Autism versus No-Autism Diagnosis.

Table S2. Breakdown by Year: Percentage of Males and Females Receiving an Autism Diagnosis and Age of Diagnosis by Sex.

Data S1. Supporting Information.

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Data availability statement

All study authors had full access to all the data in the study. The lead author, C.H., takes responsibility for the integrity of the data and B.T., the study statistician, for the data analysis.

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Key points

- Autism has historically been considered a male-dominant condition, with more males receiving a diagnosis than females. However, in recent years more females have been identified and the ratio of four males to one female has been called into question.
- Using 20 years of state-wide data, this study shows a steady increase in the proportion of females receiving an autism diagnosis, with a faster rate of increase for females relative to males over the same time period.
- Females were consistently diagnosed, on average, 18 months later than males and more likely to be 'late diagnosed' (defined as 13 years and older).
- While the increasing numbers of females diagnosed with autism is encouraging, further attention should be paid to the nuanced presentation of females.

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