



Original Investigation | Psychiatry

Autism Spectrum Disorder Incidence by Age and Sex in a US Health Care System, 2016 to 2024

Erick Messias, MD, MPH, PhD; Emily Casanova, PhD; Regina Huang, MS; Siri Battula, BS; Rachel Loftin, PhD; McKenna Walsh, PhD; Ping-I Lin, MD, PhD

Abstract

IMPORTANCE Despite the increasing prevalence of autism spectrum disorder (ASD) in the US, underlying temporal trends in newly recorded diagnoses remain poorly understood.

OBJECTIVE To evaluate age- and sex-specific incidence trends of ASD from 2016 to 2024 and quantify the temporal patterns before and after the COVID-19 pandemic and diagnostic substitution.

DESIGN, SETTING, AND PARTICIPANTS This retrospective cohort study used electronic health record data from a large US health care system. Analyses were conducted from October to December, 2025. The study population included 171 134 participants (stratified as children [0-9] years, adolescents [10-18] years, and adults [≥ 19] years) who maintained continuous engagement with the health care system, defined as having at least 1 clinical encounter annually from 2016 to 2024.

MAIN OUTCOMES AND MEASURES The primary outcome was the annual incidence of newly recorded diagnoses of *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* codes F84.0 and F84.5. Temporal trends were analyzed using joinpoint regression to calculate annual percentage changes (APCs) and identify significant inflection points.

RESULTS Among 171 134 participants (mean [SD] age, 26.78 [16.38], 63.8% female), females received autism diagnoses a mean (SD) of 3.4 years later than males (age at diagnosis, 15.7 years for female individuals vs 12.3 years for male individuals; $P < .001$). Male autism incidence remained stable or declined 2016 to 2024; female incidence increased significantly post-2020 (APC, 19.0%; 95% CI, 12.1% to 33.4%). In the pediatric cohort, decreasing annual incidence among males (APC, -2.0%; 95% CI, -3.7% to -0.3%; to APC, -2.0%, 95% CI, -3.7% to -0.3%) alongside increasing incidence for females since 2020 (APC, 17.4; 95% CI, 9.0% to 45.3%). In adolescent males, incidence declined from 2016 to 2018 (APC, -29.6%; 95% CI, -48.9% to -1.2%), and stabilized from 2018 to 2024. In adolescent females, autism incidence increased significantly between 2020 and 2024 (APC, 22.3%; 95% CI, 6.1% to 62.8%). In adult males, autism incidence showed a downward trend in the 2016 to 2024 period, while in adult females, the APC from 2016 to 2024 was positive, but the finding was not statistically significant (APC, 8.0%; 95% CI, -0.9% to 20.0%).

CONCLUSIONS AND RELEVANCE In this cohort study, ASD diagnoses increased disproportionately among females after 2020 while remaining stable or declining among males. These patterns suggested that increasing ASD prevalence reflected improved identification of historically underrecognized presentations rather than a uniform population-level increase. These findings highlight the need for screening strategies that address sex-specific presentations.

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Key Points

Question How did age- and sex-specific incidence of newly recorded autism spectrum disorder diagnoses change from 2016 to 2024, including before and after the onset of the COVID-19 pandemic, within a large US health care system?

Findings This cohort study of first recorded diagnoses of autism spectrum disorder across 171 134 participants—between 2016 and 2024—found an overall increase in case identification since 2020. This increase was associated with first diagnoses among females, with male trends remaining stable over this period.

Meaning These findings suggest that the reported increases in first autism spectrum disorder diagnoses postpandemic are due to increased recognition of females with autism spectrum disorder rather than a uniform population level increase.

+ Supplemental content

Author affiliations and article information are listed at the end of this article.

Introduction

Over the past decade, considerable attention has been devoted to the rising incidence and prevalence of autism spectrum disorder (ASD) diagnoses in the US. According to the Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network, prevalence among children aged 8 years rose from 18.5 per 1000 children (approximately 1 in 54) in the 2016 surveillance year (birth year 2008) to 32.2 per 1000 (1 in 31) by 2022 (birth year 2014), reflecting a 74% increase.^{1,2} These trends are likely related to a combination of broadened diagnostic criteria, enhanced awareness, increased recognition of ASD in specific groups—racial and ethnic minoritized groups and females in particular—and expanded screening practices in early childhood. Another key driver of change is the adoption of *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition) and its consolidation of previous diagnostic categories—autistic disorder, Asperger disorder, and pervasive developmental disorder—into a single ASD diagnosis.³

In adolescents and school-aged youths (ages 3-17), national survey data similarly underscore persistent growth in ASD diagnoses. A large-scale analysis of the National Health Interview Survey for 2021 to 2022 reported weighted prevalences of 3.05% in 2021 and 3.79% in 2022, with an overall prevalence of 3.42% among US children and adolescents aged 3 to 17 years. Importantly, researchers observed a statistically significant upward trend in ASD prevalence over the past decade, even after demographic adjustments.⁴ These findings suggest that increased case ascertainment extends beyond early childhood and persists through adolescence, reinforcing the need for sustained service availability and educational accommodations throughout this developmental window.

Emerging evidence indicates a parallel yet historically underrecognized rise in ASD diagnoses among adults. Analysis of administrative health records across Kaiser Permanente sites, spanning 2011 to 2022, documents increasing autism diagnosis rates for both children and adults, suggesting that adult-onset or late-identified ASD is becoming more commonly recognized in clinical settings.⁵

Complementing these findings, Medicaid claims data (2011-2019) reveal a more than 2-fold increase in ASD prevalence among adults (≥ 18 years), rising from 4.2 to 9.5 per 1000 enrollees, with the most pronounced increase observed among individuals aged 25 to 34 years.⁶ Moreover, the proportion of adults with ASD concurrently diagnosed with intellectual disability declined over the same period, consistent with heightened awareness of ASD presentations across the intelligence spectrum.⁶

Despite well-documented variation in ASD prevalence by demographic characteristics, few studies have examined sex-specific ASD incidence trends longitudinally across childhood, adolescence, and adulthood within a single health care system. In particular, limited evidence exists on how these trends changed before and after COVID-19–related disruptions to routine health care or on the concurrent decline in legacy diagnoses such as Asperger disorder. Characterizing these patterns will help clarify the factors contributing to contemporary increases in ASD prevalence and inform health care planning and service provision.

This study aimed to evaluate age- and sex-specific incidence trends of newly recorded with *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision* (ICD-10) codes F83.0 and F84.5 diagnoses from 2016 to 2024 within a large, multistate US health care system and to assess how these trends differed before and after the onset of the COVID-19 pandemic. A secondary objective was to examine the decline in legacy Asperger disorder diagnoses in the context of *DSM-5* diagnostic consolidation and potential diagnostic substitution. Clarifying these patterns can help distinguish true changes in risk from evolving diagnostic and coding practices and inform health system planning for diagnostic and support services across the life course.

Methods

Study Design and Data Source

This retrospective cohort study used electronic health record (EHR) data from the Sisters of Saint Mary Health system's virtual data warehouse (VDW). The VDW is maintained in accordance with

Health Care Systems Research Network specifications and captures clinical encounters—including ambulatory, inpatient, pharmacy, and laboratory data—from over 5 million patients across Illinois, Missouri, Oklahoma, and Wisconsin. The system includes primary care practices and specialty services such as neurology, psychiatry, developmental pediatrics, and dedicated neurodevelopmental clinics, and ASD diagnoses in this study may therefore have been recorded in primary care, behavioral health, or specialty settings. The health care system covers rural and urban locations from the southern half of Wisconsin, southern Illinois, the St Louis, Missouri, metropolitan area, mid-Missouri, and the Oklahoma City, Oklahoma, metropolitan areas.

The VDW's utility for examining longitudinal incidence trends in neurodevelopmental disorders has been previously established in a similar cohort study of the same patient population examining attention-deficit/hyperactivity disorder in both children and adults.⁷ The study protocol was reviewed by the Saint Louis University Institutional Review Board and given exempt status as nonhuman participants research; a waiver of informed consent was granted for the use of deidentified EHR data. Additionally this study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline for cohort studies.

Study Population

The study identified 3 distinct cohorts based on age as of January 1, 2016: adults aged 19 to 50 years ($n = 109\,590$); adolescents aged 10 to 18 years ($n = 21\,341$), reflecting clinical and developmental distinctions, including the typical timing of high school completion and transition to adult services; and children aged 0 to 9 years ($n = 40\,203$). To ensure consistent engagement with the health care system, eligible participants were required to have at least one documented clinical encounter in every calendar year from January 1, 2016, through December 31, 2024, including 2020, thereby minimizing loss to follow-up; individuals with missing race, sex, zip code, or visit dates were excluded. Analyses were conducted from October to December of 2025.

We excluded individuals with missing demographic data (race, sex, zip code) or visit dates. To calculate the incidence of new diagnoses, individuals with any recorded diagnosis of ASD prior to January 1, 2016, were excluded from the analysis.

Measures and Outcomes

The primary outcome was a newly recorded diagnosis of ASD or Asperger disorder, identified using *ICD-10* codes F84.0 and F84.5 between January 1, 2016, and December 31, 2024. Incident ASD-related diagnoses were defined as the first recorded ASD-related diagnosis in the VDW during this period among patients with no recorded ASD-related diagnosis (*International Classification of Diseases, Ninth Revision* code 299.00 or *ICD-10* codes F84.0 or F84.5) prior to January 1, 2016. Thus, incident cases represent first recorded diagnoses within this health system rather than confirmed first lifetime diagnoses. Due to *ICD-10* retention of the Asperger disorder code (F84.5) despite its removal from *DSM-5* in 2013, some recorded Asperger diagnoses during the study period may reflect legacy coding practices rather than true incident diagnoses. Race and ethnicity were obtained from VDW demographic fields populated from EHRs, which primarily reflect patient self-report at the time of registration. Race and ethnicity were included as standard demographic characteristics to describe the study population and inform interpretation and generalizability of the findings. These variables were not used as analytic exposures or outcomes in the present study. Race categories and ethnicity were defined using Health Care Systems Research Network specifications and are presented in alphabetical order with other listed last. Demographic stratification by age group and sex derived from VDW variables defined by Health Care Systems Research Network specifications.

Statistical Analysis

Temporal trends in annual incidence were assessed using joinpoint regression (Joinpoint regression program version 5.1.0.0; National Cancer Institute)—which identifies statistically significant changes

in linear trends at data-driven inflection points without requiring prespecification of break points—to estimate annual percentage change (APC) with 95% CIs. Given the limited number of annual observations, models were restricted to a maximum of 1 joinpoint to avoid overfitting, and the final number and timing of joinpoints were selected by the program based on model fit. The continuous engagement criterion was adopted here to prioritize internal validity of analyses as Joinpoint analyses are sensitive to denominator drift. Separate models were fit for children, adolescents, and adults combined and stratified by age group and sex. To continue to evaluate the association of the COVID-19 pandemic with newly recorded diagnoses, we also conducted an analysis without 2020 data. Descriptive and bivariate analyses were conducted in SAS version 9.4 (SAS Institute). We compared demographic characteristics between age groups using χ^2 tests for categorical variables and Kruskal-Wallis tests for age; standardized mean differences are reported to summarize the magnitude of group differences.

Standardized mean differences are reported to assess the magnitude of group differences. All statistical tests were 2-sided, and a *P* value less than .05 was considered statistically significant.

Results

Sample Characteristics

The final total cohort included 171 134 continuously health care-engaged individuals (mean [SD] age in 2016, 26.78 [16.38] years; 109 187 [63.8%] female; 139 461 [81.5%] White), of whom 40 203 were children, 21 341 adolescents, and 109 590 adults. Because continuous annual health care engagement was required for inclusion, there was no loss to follow-up within the analytic cohort. At inception, children (*n* = 40 203) had a mean (SD) age of 4.27 (2.90) years, while adolescents (*n* = 21 341) had a mean (SD) age of 13.40 (2.59) years, and adults (*n* = 109 590) had a mean (SD) age of 37.64 (8.71) years. There were significant differences in sex distributions between the groups (*P* < .001). There was a higher proportion of males in the children group (20 836 [51.8%]) compared with the adolescent (7609 [35.7%]) and adult (33 502 [30.6%]) groups, and this predominantly female adult cohort likely resulted from the health care use–based inclusion criteria. The study sample included participants identifying as Black (21 733 [12.7%]), other (9940 [5.8%]), and White (139 461 [81.5%]). Other included Other Pacific Islander, multiracial, and individuals who recorded their race as other in the EHR. In these groups, 5977 (3.5%) identified as having Hispanic ethnicity and 165 147 (96.5%) as non-Hispanic. (Table 1).

Table 1. Summary of Sample Characteristics

Characteristic	Participants, No. (%)				Maximum SMD, %
	Overall (N = 171 134)	Children (n = 40 203)	Adolescents (n = 21 341)	Adults (n = 109 590)	
Age in 2016, median (IQR), y	30 (10-42)	4 (2-7)	13 (11-16)	39 (31-45)	NA
Sex					
Male	61 947 (36.2)	20 836 (51.8)	7609 (35.7)	33 502 (30.6)	44.2
Female	109 187 (63.8)	19 367 (48.2)	13 732 (64.3)	76 088 (69.4)	
Race					
Black	21 733 (12.7)	5587 (13.9)	2279 (10.7)	13 867 (12.7)	22.8
White	139 461 (81.5)	30 759 (76.5)	17 453 (81.8)	91 249 (83.3)	
Other ^a	9940 (5.8)	3857 (9.6)	1609 (7.5)	4474 (4.1)	
Hispanic ethnicity	5977 (3.5)	2245 (5.6)	1087 (5.1)	2645 (2.4)	16.3
Cumulative incidence of F84.0 ^b	2781 (1.6)	1827 (4.5)	545 (2.6)	409 (0.4)	27.2
Cumulative incidence of F84.5 ^c	299 (0.2)	46 (0.1)	102 (0.5)	151 (0.1)	6.7

Abbreviations: NA, not applicable; SMD, standardized mean difference.

^a Other race includes Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, multiracial, and individuals whose race was recorded as other in the electronic health record.

^b F84.0 indicates the *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* code for autism spectrum disorder.

^c F84.5 indicates the *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10)* code for legacy Asperger disorder diagnoses.

Cumulative Incidence of ICD-10 F84.0 and F84.5 Diagnoses: Overall Cohort and Age Groups

Over the study period (2016-2024) 2781 individuals (1.6%) received a new diagnosis with code F84.0, and 299 (0.2%) received a new diagnosis with code F84.5. Children had the highest cumulative incidence of autism (1827 [4.5%]), followed by adolescents (545 [2.6%]) then adults (409 [0.4%]) ($P < .001$). New diagnoses with ICD-10 code F84.5 were highest among adolescents (102 [0.5%]) followed by adults (151 [0.1%]) and children (46 [0.1%])—for all groups diagnoses of ICD-10 code F84.5 decreased over time due to changes in diagnostic practices (Table 1). New diagnoses with ICD-10 code F84.5 were rare overall (299 [0.2%] cumulative incidence) and declined steadily over time across age groups, as illustrated in eFigures 1 to 3 in Supplement 1.

Temporal Trends by Sex

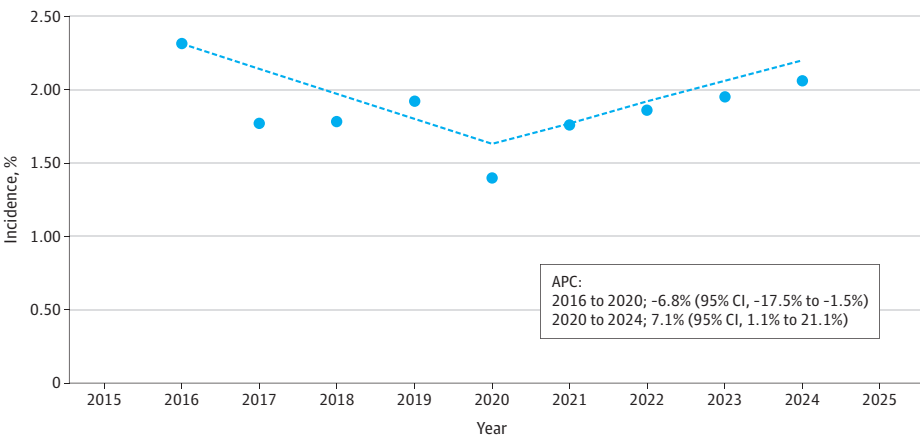
The annual incidence of ASD diagnosis decreased from 2016 to 2020 (APC, -6.8; 95% CI, -17.5 to -1.5) then increased from 2020 to 2024 (APC, 7.1; 95% CI, 1.1 to 21.1) (Figure 1). Among males, there was a decrease in annual incidence of ASD throughout the study period (APC, -3.8; 95% CI, -7.2 to -0.6) (Figure 2), while for females there was no significant change from 2016 to 2020, followed by a significant increase (APC, 19.0; 95% CI, 12.1 to 33.4). For the overall cohort, the joinpoint model identified a single inflection point in 2020, coinciding with the onset of the COVID-19 pandemic; similar 2020 joinpoints were observed in sex-stratified models for children and adolescents, whereas adult models did not include statistically significant joinpoints. Removing 2020 data showed a similar pattern: decreasing nonsignificant change for males, while for females, there was 1 joinpoint in 2018, after which there was a significant increase in newly recorded ASD diagnoses (eFigure 3C in Supplement 1).

Over the study period male annual incidence remained high but relatively stable (ranging from approximately 390 [0.63%] to approximately 514 [0.83%] annually) while female annual incidence nearly doubled, increasing from 284 (0.26%) in 2016 to 513 (0.47%) in 2024. Diagnoses with ICD-10 code F84.5 followed a downward trajectory from 2016 onwards in the total population and in all age groups (see eFigures 1, 2, 3 and 4 in Supplement 1).

Temporal Trends in Age Groups by Sex

In the pediatric cohort, there was a decreasing annual incidence among males (APC, -2.0%; 95% CI, -3.7% to -0.3%) with a rising annual incidence for females since 2020 (APC, 17.4; 95% CI, 9.0% to 45.3%) (Figure 3). In adolescent males, there was a significant early decline during the 2016 to 2018 period (APC, -29.6%; 95% CI, -48.9% to -1.2%), followed by a nonsignificant (stable) trend in 2018

Figure 1. Line Chart of Annual Incidence of Autism in the Total Population (N = 171 134)



APC indicates annual percentage change.

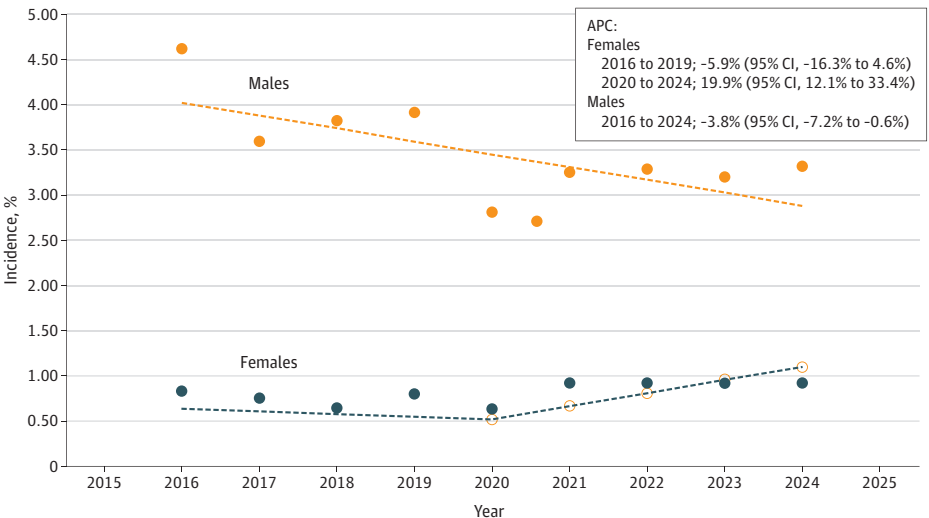
to 2024 (APC, -4.4%; 95% CI, -41.7% to 52.3%) (Figure 3). In adolescent females, autism incidence increased significantly between 2020 and 2024 (APC, 22.3%; 95% CI, 6.1% to 62.8%) (Figure 3). In adult males, autism incidence suggested a nonsignificant downward trend in the 2016 to 2024 period (APC, -3.2%; 95% CI, -14.2% to 8.4%); in adult females, a nonsignificant upward trend from 2016 to 2024 (APC, 8.0%; 95% CI, -0.9% to 20.0%) was observed (Figure 3). Although 95% CIs were wide in some strata, directionality and timing were consistent across groups.

The mean age at ASD diagnosis was lower in males (12.3 years [SD, 10.0; 95% CI, 11.8-12.7]) than in females (15.7 years [SD, 11.0; 95% CI, 15.0-16.4]) ($P < .001$). The age of ASD diagnosis by age group is presented on **Table 2**. The age of diagnoses with *ICD-10* code F84.5 by age group is presented on the eTable in [Supplement 1](#).

Discussion

In this large retrospective cohort study spanning 2016 to 2024, we observed distinct, divergent trends in the incidence of newly recorded ASD diagnoses across age and sex. While the overall incidence of new ASD diagnoses rose among children and adolescents—particularly in the post-2020 period—this aggregate growth masked a significant sex disparity. Among adolescents and adults, incidence rates for females increased significantly or trended upward, whereas rates for males remained stable or declined. Also, the age of diagnosis was significantly older for females. Additionally, we documented the rapid obsolescence of the *ICD-10* F84.5 diagnosis, reflecting steady clinical adoption of *DSM-5* criteria within administrative coding practices.³ These findings suggest that the continued rise in documented ASD incidence in clinical practice is increasingly related to the recognition of historically overlooked phenotypes—specifically females and older children—rather than a uniform increase across all demographic groups.^{1,4} Because individuals with ASD diagnoses prior to 2016 were excluded and the cohort was defined by continuous engagement from 2016 to 2024, we could not directly estimate baseline ASD prevalence within the health system at cohort inception. Nonetheless, the observed cumulative incidence among children (4.5%) and adolescents (2.6%) is consistent in magnitude with national prevalence estimates for comparable age groups during this period, suggesting that the health-system trends broadly track population-level patterns while reflecting the particular composition of a continuously engaged cohort.

Figure 2. Line Chart of Annual Incidence of Autism in the Total Population by Sex (N = 171 134)

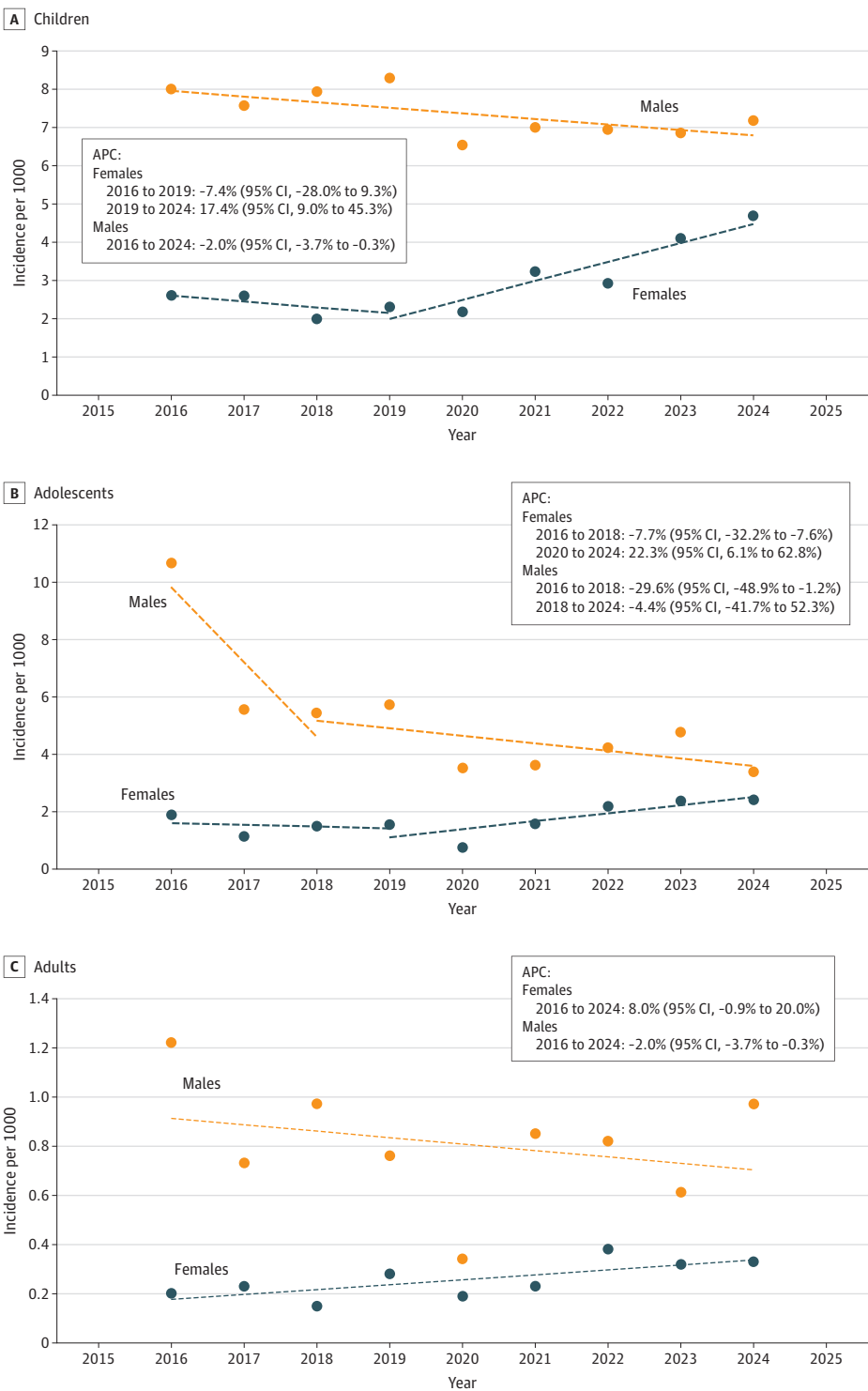


APC indicates annual percentage change.

Divergent Trends by Sex

The most clinically significant finding of this study is the disproportionate increase in newly recorded diagnoses among females in all age groups. While male incidence in these groups plateaued or declined, females experienced a significant annual percentage increase of 19% between 2020 and 2024. Furthermore, females were diagnosed on average 3.4 years later compared with males. This

Figure 3. Line Chart of Annual Incidence of Autism in Child, Adolescent, and Adult Populations



A, Annual incidence of autism in the child population by sex (n = 42 203). B, Annual incidence of autism in the adolescent population by sex (n = 21 341). C, Annual incidence of autism in the adult population by sex (n = 109 590). APC indicates annual percentage change.

aligns with a growing body of literature suggesting that females with ASD often present with distinct behavioral phenotypes—including higher social motivation and camouflaging strategies—that may evade detection by standard early-childhood screening tools designed primarily around male presentations.^{8,9} The catch-up in adolescent diagnoses likely represents late identification of these individuals as social demands exceed their compensatory capacities in secondary school settings.¹⁰ The data challenges the historical 4 to 1 male-to-female diagnostic ratio, supporting recent estimates that the true ratio may be closer to 3 to 1 or even lower when ascertainment biases are removed.¹¹ Finally, we did not examine patterns of co-occurring diagnoses (eg, attention-deficit/hyperactivity disorder, anxiety, depression) or the temporal sequence of diagnoses within individuals. Understanding whether females are more likely to receive other diagnoses prior to autism recognition could illuminate the pathways contributing to diagnostic delay and inform clinical decision-making. Future research using longitudinal diagnostic trajectories within EHR data could address these questions.

The decline in male incidence (APC −3.8%; 95% CI, −7.2 to −0.6) suggests that aggregate rising incidence reflects redistribution of case ascertainment toward females, within a health care-engaged population, rather than uniform population-level increase. Whether declining male rates reflect diagnostic saturation within a health care-engaged population, changing diagnostic thresholds, or health care use patterns cannot be determined from these data but warrants investigation.

Removing 2020 data led to a similar overall pattern except that the joinpoint for the trend in newly recorded diagnoses among females would occur in 2018, not in 2020. Qualitative analyses indicate that women with ASD use online social media platforms to share diagnostic experiences, engage in community discourse, and facilitate self-recognition.¹² Notably, the rapid global expansion of TikTok, beginning in the 2017 to 2018 period coincides temporally with the increase in adult female diagnoses observed in the present study, suggesting a potential pathway by which increased awareness and help-seeking may occur among previously underidentified individuals.

Diagnostic Trends and the Pandemic Effect

Among young children (0-9 years), incidence trends revealed a biphasic pattern: a modest decline or stability prior to 2020, followed by a significant surge (APC 5.2%) from 2020 through 2024. This inflection point likely reflects the disruptive impact of the COVID-19 pandemic on pediatric care and developmental screening.¹³ The initial dip corresponds to the suspension of in-person schooling and routine well-child visits during the early pandemic, while the subsequent sharp rise suggests a rebound or catch-up associations as deferred evaluations were completed.¹⁴ Although 2020 marked a clear disruption in pediatric incidence, sensitivity analyses excluding 2020 indicated that the postpandemic increase in female diagnoses and the relative stability or decline in male diagnoses persisted, arguing against a transient pandemic artifact as the sole driver of observed trends.

Table 2. Age of Diagnosis of Autism Spectrum Disorder by Age Group and Sex

Age group and sex	Age of autism diagnosis by age group and sex	
	No., (%)	Age at diagnosis, median (IQR), y
Children		
F	495 (27.1)	8.5 (5.6-12.0)
M	1332 (72.9)	7.1 (4.6-9.9)
Adolescent		
F	202 (37.1)	17.6 (14.9-19.6)
M	343 (62.9)	15.8 (13.2-17.9)
Adult		
F	171 (41.8)	32 (26.8-40.6)
M	238 (58.2)	31.3 (26.1-41.3)

Abbreviations: F, female; M, male.

Sensitivity analyses excluding 2020 from joinpoint models yielded similar qualitative patterns, with increasing incidence among females and stable or declining incidence among males across age groups, suggesting that the observed trends were not related solely to the anomalous first pandemic year. Furthermore, the persistence of this rise through 2024 may reflect the increased sensitivity of developmental surveillance systems, including the acceptability of telehealth for ASD assessment,¹⁵ and the broadening of diagnostic criteria to include milder neurodevelopmental differences, consistent with recent CDC Autism and Developmental Disabilities Monitoring Network findings.^{1,16}

Diagnostic Substitution and the End of Asperger Disorder

Our analysis suggests that diagnostic substitution remains a relevant factor in administrative health data. The steep decline in *ICD-10* F84.5 diagnoses (APC ~ -23% across groups) occurred inversely to the rise in autism diagnoses. Although the *DSM-5* eliminated Asperger as a distinct category in 2013, *ICD-10* codes (used for US billing) retained the label.³ Our data demonstrate that clinicians have largely abandoned the specific F84.5 code in favor of the broader ASD category, likely to ensure alignment with current diagnostic standards and service eligibility requirements. This mirrors historical trends observed when diagnostic criteria shift, where administrative prevalence is artificially modulated by coding practices rather than biological incidence.¹⁷ Researchers utilizing administrative data must strictly aggregate these codes to avoid spurious conclusions regarding prevalence trends.

Adult Incidence and Healthcare Use

Incidence among adults was lower (0.4% cumulative) than in younger cohorts, yet the demographic composition of our adult cohort warrants careful interpretation. Unlike the general population, our adult sample was predominantly female (approximately 70%). This likely reflects the specific inclusion criteria requiring annual health care encounters, which selects for a population with more consistent health care use—often women of reproductive age interacting with the health system. Consequently, while we observed a rising trend in adult female diagnoses, this may partially reflect greater opportunity for ascertainment in this group compared with adult males, who are less likely to seek routine care. The findings nevertheless corroborate recent Medicaid analyses suggesting that adults are an expanding demographic for *de novo* ASD diagnosis, highlighting an urgent need for adult-oriented diagnostic services and support infrastructure.¹⁸ Adult sex-specific trends should be interpreted cautiously, as the continuously engaged adult cohort was predominantly female, reflecting health care use patterns rather than population structure.

Limitations

This study has several limitations. First, reliance on *ICD-10* billing codes may introduce misclassification bias; we did not validate diagnoses via medical record review or standardized instruments. Second, the requirement for continuous annual health care engagement conditions the cohort on health care use, which may differentially affect diagnostic opportunity by sex and age. This continuous-engagement criterion also excludes individuals who temporarily disengaged from care during the early COVID-19 pandemic, which may have attenuated the apparent association of the 2020 service disruption on incidence estimates. Because inclusion required continuous annual health care engagement within a single health system over 9 years, the cohort likely overrepresents individuals with stable insurance coverage and regular access to care and underrepresents those with lower socioeconomic status or fragmented health care use. Combined with the predominantly non-Hispanic White composition of the sample, these features limit generalizability and may lead to underestimation of ASD incidence among racially, ethnically, and socioeconomically minoritized groups. As such, findings should be interpreted as reflecting trends in diagnostic recording within a health care-engaged population rather than population-based incidence, and this design may have underestimated ASD diagnoses among individuals with less consistent access to care, particularly adult males. This may have underestimated the true incidence of ASD in adult males. Third,

standardized measures of intellectual functioning were not consistently available in the VDW, precluding adjustment for intelligence quotient or related cognitive variables. Additionally some F84.5 codes recorded between 2016 and 2024 may reflect legacy or migrated historical diagnoses rather than new onsets, incidence estimates for this code should be interpreted cautiously; this potential misclassification underscores the importance of aggregating ASD-related codes in administrative trend analyses. Fourth, we did not model race or ethnicity-specific incidence trends, which may obscure important intersectional differences in diagnostic patterns. The cohort was predominantly White and non-Hispanic or Latino, reflecting the demographic composition and catchment of this Midwestern health system and the requirement for continuous engagement. As a result, incidence estimates may not generalize to more racially and ethnically diverse populations or to individuals with intermittent access to care, and the findings likely underrepresent ASD diagnoses among racially and ethnically minoritized groups who face structural barriers to sustained health care engagement. Additionally, as data were drawn from a single large Midwestern health care system, findings may not be fully generalizable to populations with different insurance structures or demographic profiles.

Conclusions

In this cohort study, the incidence of newly recognized ASD continued to rise, but the drivers of this increase differed across sexes and age groups. The modern expansion of the autism spectrum was characterized by the identification of females and adolescents—groups historically marginalized by male and child-centric diagnostic models—and a postpandemic rebound in detection. For clinicians, these data underscore the necessity of adapting screening practices to detect the subtler presentations of ASD in females and ensuring that diagnostic capacity extends beyond early childhood into adolescence and adulthood. The delay of 3.4 years in diagnosis for women has concrete consequences: later access to support, accommodations, and community connection during formative developmental periods. The data also suggest several priorities for policy makers and researchers. First, diagnostic capacity must extend beyond early childhood. The significant increase in adolescent female diagnoses from 2020 to 2024 (APC, 22.3%) likely reflects ongoing catch-up identification of individuals missed by childhood screening. Second, research is needed to understand mechanisms of delay as our data cannot determine whether delays stem from inadequate screening tools, practitioner knowledge gaps, or other factors. Third, screening protocols warrant re-examination, particularly given the 1.3-year delay when screening is most intensive (ie, ages 0-9 years).

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Corresponding Author: McKenna Walsh, PhD, St Louis University School of Medicine, 1402 S Grand Blvd, St Louis, MO 63104 (mckenna.walsh@health.slu.edu).

Author Affiliations: Department of Psychiatry and Human Neuroscience, School of Medicine, St Louis University, St Louis, Missouri (Messias, Lin); Department of Neurology, School of Medicine, St Louis University, St Louis, Missouri (Casanova); Advanced HEalth Data (AHEAD) Institute, St Louis University, St Louis, Missouri (Huang); University of Missouri-Kansas City, Kansas City (Battula); Prosper Health, Weston, Florida (Loftin); Department of Family and Community, School of Medicine, St Louis University, St Louis, Missouri (Walsh).

Author Contributions: Dr Messias and Ms Huang had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Concept and design: Messias, Battula.

Acquisition, analysis, or interpretation of data: Messias, Casanova, Huang, Battula, Loftin, Walsh, Lin.

Drafting of the manuscript: Messias.

Critical review of the manuscript for important intellectual content: All authors.

Statistical analysis: Messias, Huang.

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Administrative, technical, or material support: Messias, Walsh, Lin.

Supervision: Casanova.

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REFERENCES

1. Shaw KA, Williams S, Patrick ME, et al. Prevalence and early identification of autism spectrum disorder among children aged 4 and 8 years - autism and Developmental Disabilities Monitoring Network, 16 sites, United States, 2022. *MMWR Surveill Summ*. 2025;74(2):1-22. doi:10.15585/mmwr.ss7402a1
2. Maenner MJ, Shaw KA, Baio J, et al; EdS1; PhD-7. Prevalence of Autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2016. *MMWR Surveill Summ*. 2020;69(4):1-12. doi:10.15585/mmwr.ss6904a1
3. American Psychiatric Association. *DSM-5-TR® Classification*. American Psychiatric Association Publishing; 2022.
4. Yan X, Li Y, Li Q, et al. Prevalence of autism spectrum disorder among children and adolescents in the United States from 2021 to 2022. *J Autism Dev Disord*. Published online May 22, 2024. doi:10.1007/s10803-024-06390-7
5. Grosvenor LP, Croen LA, Lynch FL, et al. Autism diagnosis among US children and adults, 2011-2022. *JAMA Netw Open*. 2024;7(10):e2442218. doi:10.1001/jamanetworkopen.2024.42218
6. Rubenstein E, Tewolde S, Michals A, Fox M, Wang N. Prevalence of autism among Medicaid-enrolled adults. *JAMA Psychiatry*. 2023;80(12):1284-1287. doi:10.1001/jamapsychiatry.2023.3708
7. Paul ML, Sheth P, Davis R, Chrusciel T, Messias E. Incidence of attention-deficit/hyperactivity disorder between 2016 and 2023: A retrospective cohort. *Psychiatr Res Clin Pract*. 2025;7(1):18-24. doi:10.1176/appi.prcp.20240121
8. Dean M, Harwood R, Kasari C. The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. *Autism*. 2017;21(6):678-689. doi:10.1177/1362361316671845
9. Lai MC, Lombardo MV, Ruigrok AN, et al; MRC AIMS Consortium. Quantifying and exploring camouflaging in men and women with autism. *Autism*. 2017;21(6):690-702. doi:10.1177/1362361316671012
10. Hull L, Petrides KV, Allison C, et al. "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *J Autism Dev Disord*. 2017;47(8):2519-2534. doi:10.1007/s10803-017-3166-5
11. Loomes R, Hull L, Mandy WPL. What is the male-to-female ratio in autism spectrum disorder? a systematic review and meta-analysis. *J Am Acad Child Adolesc Psychiatry*. 2017;56(6):466-474. doi:10.1016/j.jaac.2017.03.013
12. Bellon-Harn ML, Saar KW, Santhanam SP, Heydari S. The diagnostic journey of autistic women as shared on TikTok. *Res Autism*. Published online February 22, 2025. doi:10.1016/j.reia.2025.202529
13. Wallis KE, Nekrasova E, Bennett AE, et al. Autism spectrum disorder screening during the COVID-19 pandemic in a large primary care network. *Acad Pediatr*. 2022;22(8):1384-1389. doi:10.1016/j.acap.2022.04.005
14. Wong CA, Ming D, Maslow G, Gifford EJ. Mitigating the impacts of the COVID-19 pandemic response on at-risk children. *Pediatrics*. 2020;146(1):e20200973. doi:10.1542/peds.2020-0973
15. Matthews NL, Skepnek E, Mammen MA, et al. Feasibility and acceptability of a telehealth model for autism diagnostic evaluations in children, adolescents, and adults. *Autism Res*. 2021;14(12):2564-2579. doi:10.1002/aur.2591

16. Li C, He WQ. Prevalence and treatment of autism spectrum disorder in the United States, 2016-2022. *Autism Res.* 2024;17(9):1916-1927. doi:10.1002/aur.3228

17. King M, Bearman P. Diagnostic change and the increased prevalence of autism. *Int J Epidemiol.* 2009;38(5):1224-1234. doi:10.1093/ije/dyp261

18. Murphy CM, Wilson CE, Robertson DM, et al. Autism spectrum disorder in adults: diagnosis, management, and health services development. *Neuropsychiatr Dis Treat.* 2016;12:1669-1686. doi:10.2147/NDT.S65455

SUPPLEMENT 1.

- eFigure 1. Annual Incidence of Asperger in the Total Population (N = 171 134)
- eFigure 2. Annual Incidence of Asperger in the Total Adult Population
- eFigure 3. Annual Incidence of Asperger in the Total Adolescent Population
- eFigure 4. Annual Incidence of Asperger in the Total Child Population
- eTable. Age of Diagnosis of Asperger by Age Group and Sex

SUPPLEMENT 2.

Data Sharing Statement