




The social patterning of autism diagnoses reversed in California between 1992 and 2018

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Contributed by Peter S. Bearman, October 8, 2020 (sent for review July 27, 2020; reviewed by Maureen Durkin and Bruce Link)

As rates of autism diagnosis increased dramatically over the past number of decades, prevalence rates were generally highest among Whites and among those of higher socioeconomic status (SES). Using a unique, population-level dataset, we find that rates of autism diagnosis continued to be on the rise in recent years, but who is diagnosed changed during the study period. Our data consist of birth records of all 13,272,573 children born in the state of California in 1992 through 2016 linked to autism caseload records for January 1992 through November 2019 from California's Department of Developmental Services. California's diagnosed autism incidence rate rose from 0.49 per 1,000 3–6 y olds in 1998 to 3.49 per 1,000 3–6 y olds in 2018, a 612% increase. However, diagnosed incidence rates did not rise uniformly across sociodemographic groups. By 2018, children of Black and Asian mothers were diagnosed at higher rates than children of non-Hispanic White mothers. Furthermore, among children of non-Hispanic White and Asian mothers, children of lower SES were diagnosed at higher rates than children of higher SES. These changes align with sociological theories of health disparities and contain important clues for more fully understanding the autism epidemic.

autism | prevalence | epidemiology | socio-economic status

Autism is a neurodevelopmental disorder defined by deficits in social interaction and communication and restricted, repetitive patterns of behavior. Without definitive biological markers, autism diagnosis relies on symptom detection and access to diagnostic services. Autism diagnosis is important, because it unlocks access to special education services through the US Individuals with Disabilities Education Act as well as additional support services in some states. Tracking autism incidence and prevalence rates—overall and by sociodemographic subgroups—is, therefore, crucial for appropriate resource allocation as well as identifying trends that may shed light on autism's etiology. Using unique, population data from California, the most populous state in the United States, that captures clinical autism diagnoses and spans more than a quarter-century, we show that the dramatic ascent of diagnosed autism incidence (1) continued through 2018, but the social patterning of diagnosis changed considerably.

Estimates of autism prevalence rates for the United States vary, likely because none rely on a biological marker. Instead, they rely on special education data (2, 3), parent report (4–6), or diagnostic assessments contained in medical and/or education records (7). The Centers for Disease Control and Prevention's (CDC) national autism prevalence rates rely on the latter, most recently reporting a prevalence rate of 18.5 per 1,000 children aged 8 y in 2016 (7). The CDC's prevalence rates arise out of data from a small number of Autism and Developmental Disabilities Monitoring (ADDM) Network sites, the number of which fluctuates over time between 6 and 14 and for which education records are not always available. The available national data as well as local estimates from numerous places within the United States, such as Atlanta and its surrounding metropolitan region (8), Olmsted County, Minnesota (9), and the state of California (10), among others, show marked increases in rates of autism since the 1980s. However, other locales, such as Alabama

(11), report significantly fewer autism cases over time. Like health and disease more broadly, autism is not uniformly distributed across the United States population.

For children born through the mid-2000s, autism prevalence rates were lower among Hispanic children relative to White children (2, 12, 13). The relationship between the prevalence rates for Black and White children in these same cohorts, however, varies depending on the data examined; prevalence is higher among Black relative to White children with clinical diagnoses in California (14), comparable in a nationally representative sample that relies on parent report (12), and lower based on national special education data (2). Differential ascertainment, at least in some places, likely contributes to the disparity between Hispanic and White children and the conflicting results in relation to Black and White children. For example, autism was less likely to be ascertained among both Black and Hispanic children relative to White children at ADDM Network sites among the 1994 birth cohort (15).

With respect to socioeconomic status (SES), the pattern of reported prevalence has been more consistent. SES refers to one's class position within the structure of society and is often measured in the United States by educational attainment and/or income. For children born through the early 2000s, autism prevalence is higher among children born to higher SES parents relative to children born to lower SES parents (12, 16–18). This SES gradient is likely at least partially attributable to differential ascertainment (19), and findings from outside of the United States confirm that this may be the case. In Sweden, where healthcare and developmental

Significance

Rates of autism diagnosis in the United States have historically been higher among more advantaged social groups—Whites and those of higher socioeconomic status (SES). Using data from all births in the state of California in 1992 through 2016, we find that these trends reversed during our study period. By 2018, diagnosed autism incidence rates for 3- to 6-y-old children were higher for children of Black and Asian mothers than children of non-Hispanic White mothers and were higher for children of lower SES than of higher SES parents. These reversals point to the fundamental role that access to knowledge and resources plays in driving increased autism prevalence and shifting patterns of autism cases over the past quarter-century.

Author contributions: A.S.W., C.F., and P.S.B. designed research; A.S.W. performed research; A.S.W., C.F., K.C.-P., and P.S.B. analyzed data; and A.S.W., C.F., and P.S.B. wrote the paper.

Reviewers: M.D., University of Wisconsin–Madison; and B.L., University of California, Riverside.

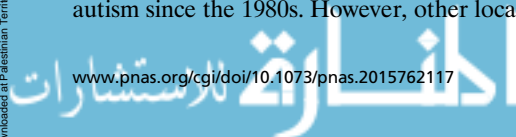
The authors declare no competing interest.

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This article contains supporting information online at <https://www.pnas.org/lookup/suppl/doi:10.1073/pnas.2015762117/-DCSupplemental>.

First published November 16, 2020.



screenings are universal and free, children born to lower SES parents are at higher risk of autism relative to children of higher SES parents (20); similarly, diagnostic rates of childhood autism are similar across SES groups in Finland (21).

The racial/ethnic and SES disparities in autism diagnosis in the United States just described are the opposite of health disparities that are observed across almost all other health outcomes (22, 23). In general, those of lower SES and racial minorities experience worse health and shorter life expectancies relative to those of higher SES and Whites, respectively (24–27). However, these patterns in autism diagnosis make sense in light of the importance of access to information for recognizing symptoms and navigating the complex processes of obtaining an autism diagnosis, especially before the year 2000 when prevalence was rising but lower (28). Information and the resources required to utilize it were more likely available to more advantaged—higher SES and White—parents (29, 30). More recently, however, as knowledge of autism and its expression has become more widespread, information about how to secure a diagnosis more evenly diffused, and state ascertainment regimes more robust, there is evidence that these longstanding racial/ethnic and socioeconomic trends in diagnosis are changing (18). In national special education data, in which autism prevalence was historically highest among White children, prevalence among Black and Hispanic children caught up to that of White children by the 2008 and 2013 birth cohorts, respectively (2). Among children with clinical diagnoses in California, there is evidence that autism prevalence plateaued or declined among White children born in 2000 through 2013 and living in high income counties but continued to increase among White children living in lower income counties and among Hispanic children in all counties analyzed (31).

While suggestive, county-level observations tell us little about if and how the SES composition of children clinically diagnosed with autism has changed (31). Extant research shows that the relationships between individual-level measures of SES and autism diagnosis and between community-level measures of SES and autism diagnosis do not always align (18). One cannot make inferences to individuals from data collected at the county level. Because of its reliance on county-level data and California's smaller Black population, the aforementioned, county-level study is unable to reliably examine trends for Black children by SES (31). We fill these gaps. In doing so, we also report diagnosed autism prevalence rates for birth cohorts 1992 through 2016 and diagnosed incidence rates for children in 1998 through 2018 using the largest available dataset of clinical autism diagnoses.* Examining trends in autism incidence rates reveals real-time diagnostic patterns that are masked by the cumulated prevalence rates described above and allows for insight into how period-based phenomena, changes in diagnostic practices or economic downturns, for example, impact rates of autism diagnosis.

Materials and Methods

We calculate diagnosed autism incidence and prevalence rates for the state of California using a linked dataset of autism caseload records from California's Department of Developmental Services (DDS) and birth records from California's birth master files. The DDS provides services to children and adults living in California with developmental disabilities, including autism. Autism diagnoses are confirmed or determined by qualified professionals at the DDS' 21 regional centers throughout the state. Until 2014, the DDS provided services to individuals with autistic disorder but not to those with other disorders on the autism spectrum. In 2014, the DDS adapted the recently published Diagnostic and Statistical Manual, Fifth Edition's (DSM-5) diagnostic criteria for Autism Spectrum Disorder (ASD) and began providing

services to individuals diagnosed with ASD. ASD encompasses what were previously considered separate disorders on the autism spectrum, including autistic disorder, Asperger's disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS). Although enrollment with the DDS is voluntary, the DDS provides services without financial stipulations, and most individuals with autism in California are enrolled (10). We use DDS caseload records from January 1992 through November 2019. Along with autism diagnosis, these records tell us date of diagnosis, age of diagnosis, and whether the individual has a comorbid diagnosis of intellectual disability.

We matched these DDS records with the birth records of all 13,272,573 children born in California in 1992 through 2016. Linking these datasets allows us to know which children born in California have been diagnosed with autism. We used Stata's user-written `dtalink` command (32) to match the records probabilistically on individuals' first name, last name, birthdate, sex, and race/ethnicity. Uncertain matches were manually reviewed. Overall, 83.9% of DDS records were matched to a birth record, with match rates ranging from 78.2% for DDS clients born in 1995 to 91.8% for clients born in 2016. DDS clients whose records did not match to a birth record were likely born outside of California, and we exclude them from the present analyses. In addition to information about the newborns, the birth records include indicators of maternal race, ethnicity, education level, and whether the delivery was expected to be paid for by Medi-Cal, California's Medicaid program.[†] As shown in the *SI Appendix*, among all children born in California in 1992 through 2016, 47% of their mothers were Hispanic White, 31% were non-Hispanic White, 12% were Asian, and 6% were Black (*SI Appendix, Table S1*). About 45% of deliveries were expected to be paid for by Medi-Cal.

Using this linked dataset, we calculate diagnosed autism incidence rates for children aged 3 through 6 y in 1998 through 2018 by dividing the number of children newly diagnosed at ages 3 through 6 y in each calendar year by the total number of children born in the California cohorts 3 through 6 y prior. Most autism diagnoses—in our data and more broadly—are made within this age range (7, 33). We also calculate diagnosed autism prevalence rates for each birth cohort, 1992 through 2016, by dividing the number of children in each cohort diagnosed with autism by November 2019 by the total number of children born in California in the corresponding cohort. We calculate these rates overall as well as by intellectual disability status, sex, maternal race/ethnicity, and two measures of maternal SES, Medi-Cal receipt and education level. Given the intersecting nature of social processes, including those surrounding health and disease (25), related to sex, race/ethnicity, and class (34, 35), we further consider diagnosed autism incidence and prevalence rates by sex and maternal race/ethnicity simultaneously and by Medi-Cal receipt and maternal race/ethnicity simultaneously. For all diagnosed incidence and prevalence rates as well as sex ratios, we calculate 95% CIs using the Wilson score method (7). This research was approved by Columbia University's Institutional Review Board and the State of California Committee for the Protection of Human Subjects.

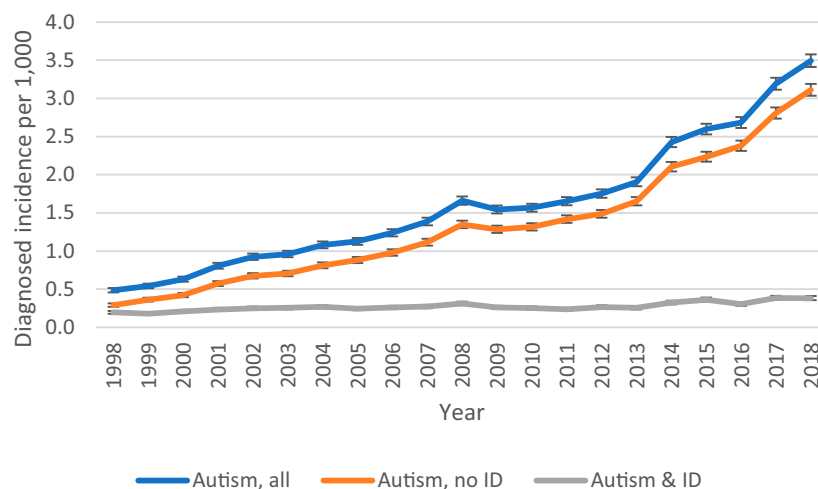
Results

Diagnosed autism incidence rates in California rose from 0.49 per 1,000 3–6 y olds in 1998 to 3.49 per 1,000 3–6 y olds in 2018 (Fig. 1A and *SI Appendix, Table S2*), a 612% increase. However, diagnosed incidence rates did not rise uniformly across this period. Rather, they rose relatively steadily from 1998 to 2008, declined and then plateaued between 2008 and 2010, and then once again increased between 2010 and 2018, with especially large increases after 2013, when the DSM-5 was published with revised diagnostic criteria for ASD. Examining diagnosed prevalence rates reveals similar but less pronounced trends. From the 1992–2013 birth cohorts, diagnosed autism prevalence rose from 3.51 per 1,000 people to 14.48 per 1,000 people (Fig. 1B and *SI Appendix, Table S2*), a 313% increase. The 2013 birth cohort is the last birth cohort for which we have complete diagnostic information through 6 y of age. Diagnosed prevalence rates in Fig. 1B flatten and then decline for the last few birth cohorts shown, because these birth cohorts have yet to live through all of the critical ages during which autism is most commonly diagnosed. Fig. 1 also reveals that the vast majority of increased

*The labels “diagnosed autism prevalence rates” and “diagnosed autism incidence rates” capture the fact that not all children with clinical autism symptoms have been diagnosed.

[†]California expanded Medi-Cal in response to the 2010 Affordable Care Act, but this expansion did not affect the eligibility criteria for our study population of new mothers and children.

A Diagnosed incidence



B Diagnosed prevalence

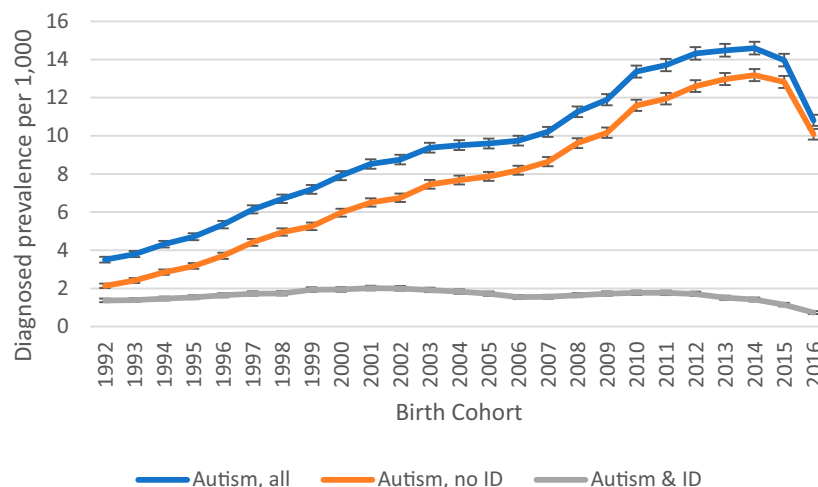


Fig. 1. Diagnosed autism incidence (A) and prevalence (B) rates with 95% CIs in California, by intellectual disability (ID) status.

autism incidence and prevalence during this period was driven by autism diagnoses among individuals who did not also have diagnoses of intellectual disability.

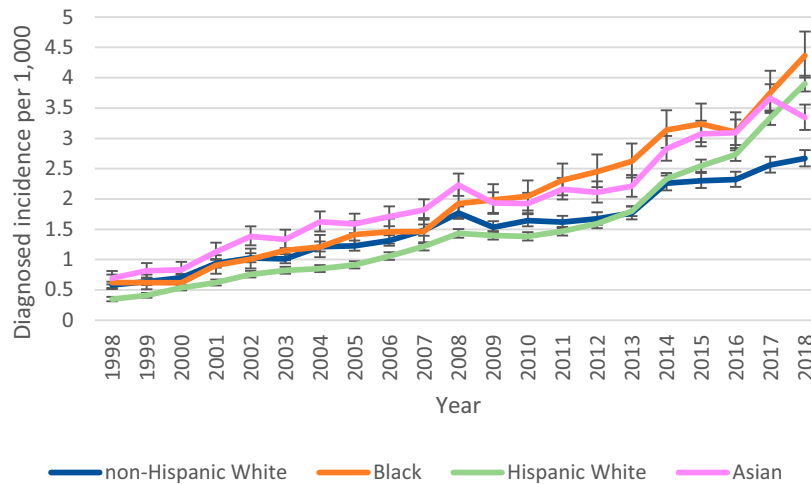
It is well established that autism diagnosis is more prevalent among boys than girls (e.g., refs. 36–38), and recent years provide no exception. Although boys continued to be diagnosed at higher rates than girls, the gap exhibits a small decline, with the male-to-female ratio of autism incidence rates decreasing from 4.66 in 1998 to 3.57 in 2018 (*SI Appendix, Fig. S1 and Table S3*). Whereas patterns of autism diagnosis by sex remained relatively stable across the 25 y we examine, patterns of autism diagnosis by maternal race/ethnicity and SES transformed considerably. Children of non-Hispanic White, Black, and Asian mothers once had relatively similar diagnosed autism incidence and prevalence rates, while children of Hispanic White mothers tended to lag behind (Fig. 2 and *SI Appendix, Table S4*). However, beginning in 2009, autism diagnosis among children of non-Hispanic White mothers slowed, and during the four most recent years of our data, 2014 through 2018, children of non-Hispanic White mothers exhibited the lowest diagnosed autism incidence rates of the racial/ethnic groups examined. Meanwhile, diagnosed autism incidence among children of Hispanic White mothers rose

sharply beginning in 2013, and, by 2018, children of Black, rather than Asian, mothers had the highest diagnosed incidence rate.

Non-Hispanic Whites are the most advantaged racial/ethnic group in the United States. A similar, if not more dramatic, reversal can be seen in relation to SES. Until the mid-2000s, autism diagnosis rates were higher among those of higher SES as measured by Medi-Cal receipt (Fig. 3 and *SI Appendix, Table S5*) or maternal education level (Fig. 4 and *SI Appendix, Table S6*). By 2018, the gradient had reversed, with those who did not receive Medi-Cal and those whose mothers had at least a college degree exhibiting the lowest diagnosed autism incidence rates relative to those who did receive Medi-Cal and those whose mothers had less education, respectively. As these reversals are also apparent when considering diagnosed autism prevalence rates across birth cohorts, they are not artifacts of changing trends in age of diagnosis.

Perceptions of behavior, responses to behavior, and access to resources vary by race/ethnicity, SES, and sex in an intersecting manner (34, 35). We, therefore, also examine patterns of autism diagnosis by race/ethnicity and sex simultaneously and by race/ethnicity and SES simultaneously. *SI Appendix, Figs. S2 and S3* show that, by the end of the period for which we have data, the

A Diagnosed incidence



B Diagnosed prevalence

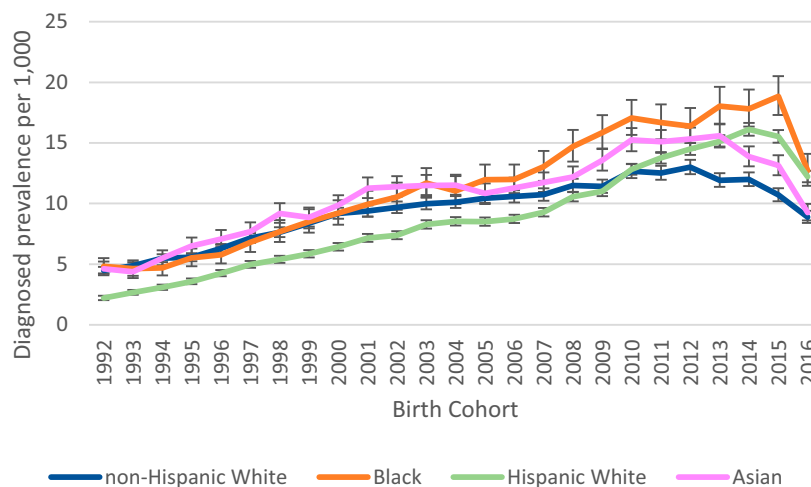


Fig. 2. Diagnosed autism incidence (A) and prevalence (B) rates with 95% CIs in California, by maternal race/ethnicity.

male-to-female ratios of diagnosed autism incidence and prevalence rates were similar across racial/ethnic groups (also see *SI Appendix, Table S7*). Additionally, in 2018, diagnosed autism incidence rates were highest for children of Black mothers among both boys and girls.

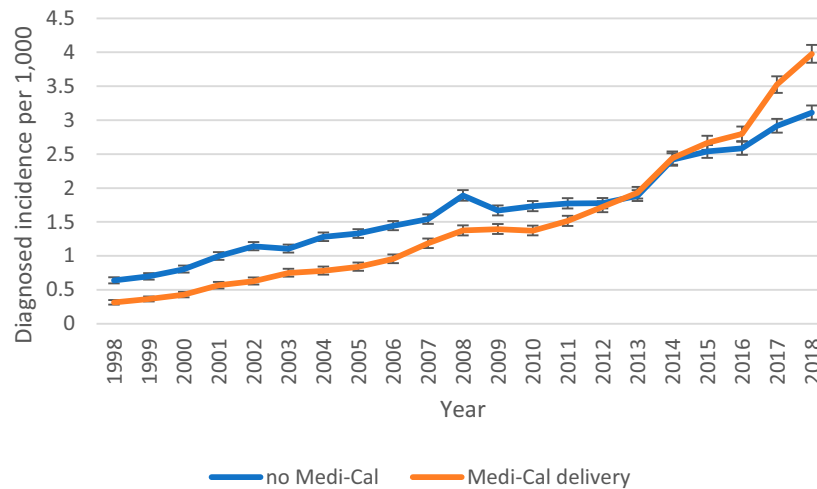
Looking at autism diagnosis by race/ethnicity and SES tells a more complicated story and reveals that the trends we have observed thus far mask important differences. From 1998 through 2008, diagnosed autism incidence rose for all racial/ethnic groups, regardless of SES as measured by Medi-Cal receipt (Fig. 5 and also see *SI Appendix, Fig. S4 and Table S8*). However, after 2008, diagnosed autism incidence rates among children of higher SES, non-Hispanic White mothers decreased and then went on to rise at a slower rate, while incidence rates among children of lower SES, non-Hispanic White mothers increased steadily throughout the period. This resulted in a reversing SES gradient among children of non-Hispanic White mothers, similar to that which we observed in Fig. 3. Children of Asian mothers exhibit a similar, albeit less pronounced, SES gradient reversal. Among children of Hispanic White and Black mothers, however, diagnosed incidence rates among those of higher SES either did not plateau (children of Black mothers) or

plateaued and then resumed their increase at a faster rate (children of Hispanic White mothers). For these children, therefore, diagnosed autism's SES gradient did not reverse during our study period. Rather, among children of Hispanic White mothers, diagnosed autism incidence rates at the end of our study period are similar irrespective of Medi-Cal receipt. Among children of Black mothers, diagnosed autism incidence rates generally remain higher among those without Medi-Cal throughout most of the period.

Discussion

In the first decades of radically increasing autism prevalence in the United States, White children were more likely to be diagnosed with autism than Hispanic, Black, or Asian children. Similarly, poorer children were less likely to be diagnosed with autism than wealthier children, even when accounting for known drivers of increased autism risk, such as maternal and paternal age (18). Health disparities in the United States mirror socioeconomic and racial disparities, with poorer, non-Whites bearing the brunt of the burden. A key driver of these health inequalities in the United States is differential access to information and resources (22, 29). Those with information and resources are

A Diagnosed incidence



B Diagnosed prevalence

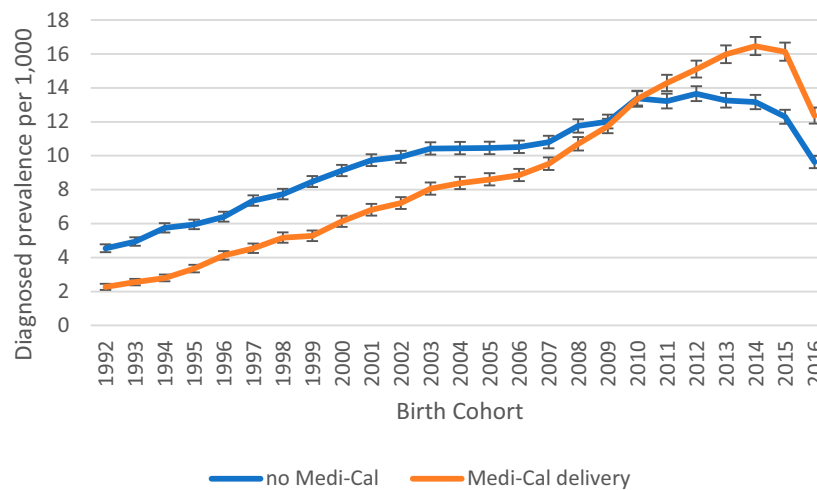


Fig. 3. Diagnosed autism incidence (A) and prevalence (B) rates with 95% CIs in California, by maternal Medi-Cal status.

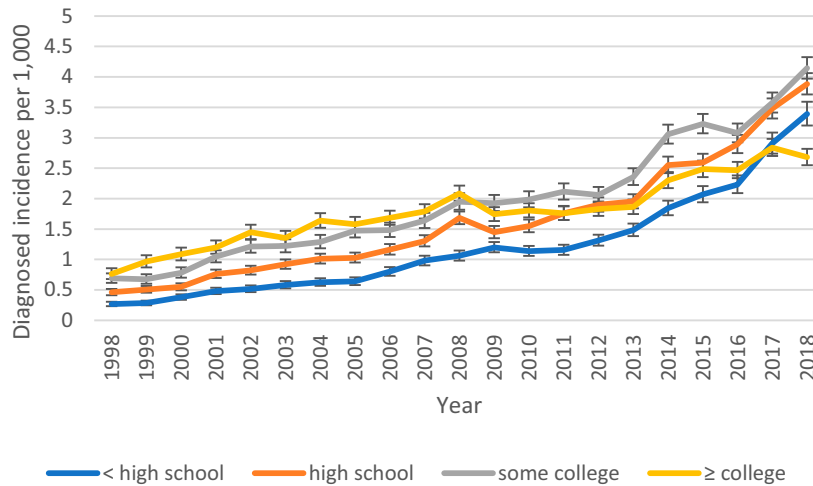
better able to secure services and treatments, and early ascertainment and early intervention make a significant impact on later outcomes (39). In the case of an autism diagnosis in California, diagnosis confers not only special education services in school, but also access to support services through the DDS that might include in-home respite services, transportation, or out-of-home day programs. It is not surprising, then, that wealthier, White parents exhibit an advantage over others in securing an autism diagnosis—and hence services—for their children during the first portion of our study period.

Using the largest available dataset of clinical autism diagnoses within the United States or globally, our results show that diagnosed autism incidence and prevalence rates have, on average, continued to increase in recent years through 2018. The size of our dataset means that we can reliably examine these trends among subpopulations, and doing so illustrates that the increase in autism diagnoses we document has not been uniform. Between 2008 and 2018, diagnosed autism incidence rates among children of lower SES, White and Asian mothers outpaced incidence rates among children of higher SES, White and Asian mothers, with children of higher SES, White mothers, in particular, being diagnosed in lower numbers. This marks a stark

reversal of well-established socioeconomic gradients in autism diagnosis in the United States, a reversal that aligns autism prevalence patterns with sociological theories of the social distribution and diffusion of new medical knowledge (29). Meanwhile, rates of autism diagnosis among children of Black and Hispanic mothers continued to rise, irrespective of SES.

Multiple factors likely help account for the recent rise of autism diagnoses among children of lower SES parents and parents of color. In 2006, the American Academy of Pediatrics recommended universal screening for autism during well-child visits at 18 mo of age (40), a recommendation that, if implemented, decouples autism diagnosis from parents' access to knowledge. Additionally, autism has strong advocacy in the United States (41) and in California specifically. As of 2009, California's state Senate includes the Senate Select Committee on Autism and Related Disorders, which has spearheaded legislation to improve linguistic and cultural competency at the DDS' regional centers and among DDS vendors. The Committee has also held hearings on "ensuring fair and equal access to regional center services for Autism Spectrum Disorders," among other topics (42). Collectively, these and other advocacy efforts have likely contributed to the deconcentration of autism diagnoses from children of high

A Diagnosed incidence



B Diagnosed prevalence

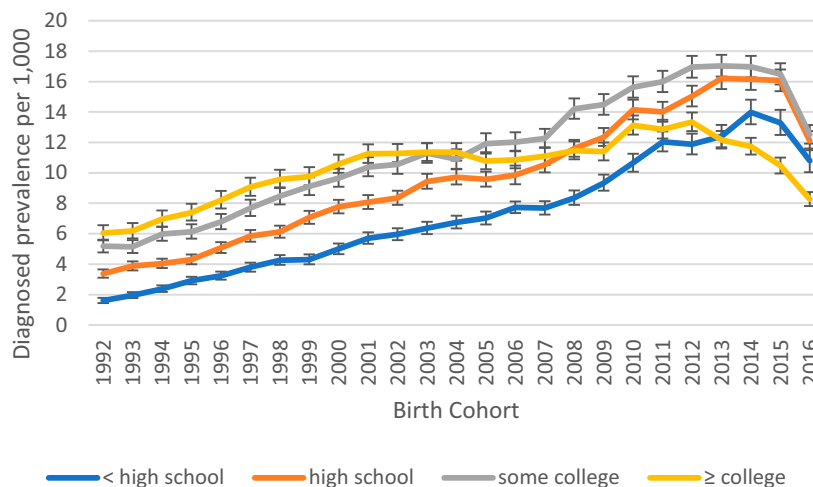


Fig. 4. Diagnosed autism incidence (A) and prevalence (B) rates with 95% CIs in California, by maternal education level.

SES, White parents, in turn, broadening access to the services that an autism diagnosis unlocks.

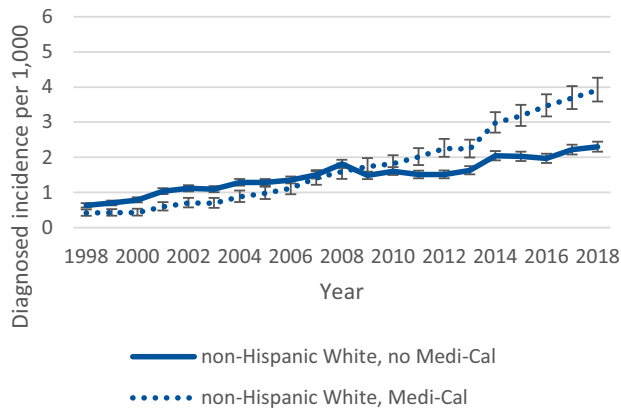
A few limitations to our results should be noted. First, we rely on birth records to construct the denominators of the incidence and prevalence rates we calculate. Our results should, therefore, be interpreted as the diagnosed autism incidence and prevalence rates for children born in California, not for children living in California. Second, since our numerators come from California's DDS, they do not include children who were born in California, moved out of the state, and were subsequently diagnosed with autism. Because California has one of the best service provision systems for children with autism in the United States, our expectation is that most parents who believe that their child may benefit from such services will not leave. Third, not all children with autism are diagnosed by 6 y of age (43, 44). However, the fact that our results are similar whether we consider diagnosed autism incidence or prevalence rates gives us confidence that the social patterning we document is not an artifact of age of diagnosis.

Our results expose important questions. While the SES gradient of autism diagnosis reversed among children of White and Asian mothers, it did not reverse among children of Black and

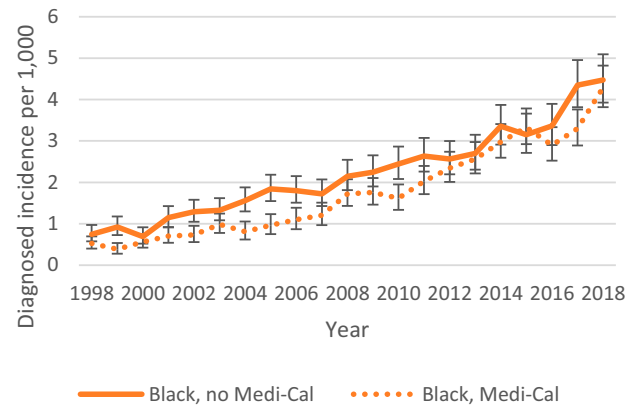
Hispanic mothers. What accounts for these differential trends? It is possible that children of high SES, White parents were close to full ascertainment, while ascertainment among children of lower SES parents and parents of color remained uneven, systematically undercounting the poorest members of those communities. This is an important target of further investigation. Meanwhile, most of the sociodemographic groups we consider exhibit declines and/or plateaus in their autism incidence rates between 2008 and 2010. Future research should examine the roles of the Great Recession (45) and related payment reductions to the DDS in 2009–2010 (46) in these drops in diagnosis. Additionally, as previously described, the DDS implemented the DSM-5's diagnostic criteria for Autism Spectrum Disorder in 2014, a diagnosis that encompasses people previously diagnosed with Asperger's disorder and PDD-NOS. Future research should examine the extent to which the rise in autism incidence we observe after 2013 is attributable to this diagnostic expansion or the end of Recession-driven payment reductions.

Taken together, our findings reveal that autism diagnosis continued to be on the rise through 2018, but who was being diagnosed was changing. These changes point to the importance of the social systems that shape ascertainment and speak more

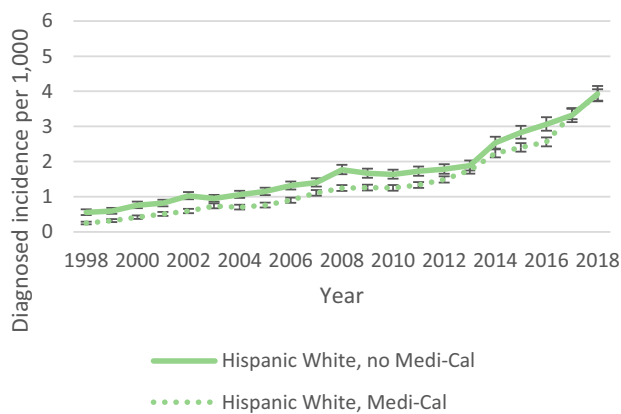
A Non-Hispanic White



B Black



C Hispanic White



D Asian

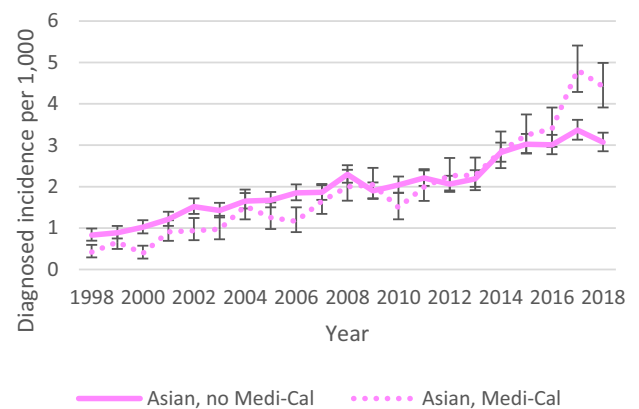


Fig. 5. Diagnosed autism incidence rates with 95% CIs in California, by maternal race/ethnicity (non-Hispanic White [A], Black [B], Hispanic White [C], and Asian [D]) and Medi-Cal status.

broadly to the ways in which social class and race continue to fundamentally shape health outcomes in our country.

Data Availability. The data cannot be shared.

ACKNOWLEDGMENTS. We thank Ka-Yuet Liu, the Interdisciplinary Center for Innovative Theory and Empirics community at Columbia University, and the reviewers. This research was supported by National Institutes of Child Health and Human Development Grant R01HD091205.

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