

# Autism incidence and spatial analysis in more than 7 million pupils in English schools: a retrospective, longitudinal, school registry study



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## Summary

**Background** Understanding how certain factors affect autism incidence can help to identify inequities in diagnostic access. We aimed to investigate the incidence of autism in England as a function of geography and sociodemographics, examining spatial distribution across health service boundaries.

**Methods** In this retrospective, longitudinal, school registry study, we sourced data for the years 2014–17 from the summer school census, which is a component of the National Pupil Database, a government registry of pupils under state education in England. Our main outcome was the incidence of autism in the English state-funded education system, defined by the amount of new autism-specific Education, Health and Care Plans or autism-specific special education needs and disability support recorded during each summer school census year since the 2014 baseline. After excluding prevalent cases in 2014, we calculated unadjusted incidence and age-adjusted, sex-adjusted incidence per 100 000 person-years per subsequent school year and by various sociodemographic categories and local authority districts. We report spatial effects using local indicators of spatial association. We used a three-level mixed-effects logistic regression model with two random intercepts (lower-layer super output area [a geographical area in England containing 1000–3000 residents] and pupil identifier) to calculate odds ratios (ORs) for autism incidence, adjusting for age, sex, ethnicity, claimed eligibility for free school meals, ethnic density quintile, Index of Multiple Deprivation quintile, first language spoken at home, and year, with our reference category being White girls without claimed eligibility for free school meals who speak English as their first language.

**Findings** Between 2014 and 2017, our total sample included 31 580 512 person-years and 102 338 newly diagnosed autistic pupils, corresponding to an unadjusted annual autism incidence of 429·1 cases per 100 000 person-years (95% CI 426·4–431·7) and an age-adjusted, sex-adjusted annual incidence of 426·9 cases per 100 000 person-years (423·5–430·4). The adjusted incidence of autism was slightly higher in 2014–15 than in 2015–16 or 2016–17, and, of the age groups, pupils aged 1–3 years, 4–6 years, and 10–12 years had the highest incidence of autism. Adjusted autism incidence in boys was 3·9-times the incidence in girls (668·6 cases per 100 000 person-years [95% CI 662·5–674·6] vs 173·2 cases per 100 000 person-years [170·1–176·3]). Across ethnic groups, adjusted incidence was highest in pupils who had an unclassified ethnicity (599·4 cases per 100 000 person-years [574·5–624·3]) or were Black (466·9 cases per 100 000 person-years [450·8–483·0]). However, in our fully adjusted mixed-effects logistic regression model, we observed lower odds of autism among Asian (OR 0·65 [0·59–0·71]), Black (0·84 [0·77–0·92]), and Chinese (0·62 [0·42–0·92]) girls compared with White girls when these groups had not claimed free school meals and spoke English as a first language. Boys from all ethnicities irrespective of first language spoken and free school meals status had increased odds of autism compared with White girls with no claimed eligibility for free school meals who spoke English as their first language. We also found that claimed free school meal eligibility, first language spoken, sex, and ethnicity differentially impacted the odds of autism. Our spatial analysis showed significant spatial autocorrelation across lower-layer super output areas in England, with 2338 hotspots (high-incidence areas surrounded by other high-incidence areas).

**Interpretation** The incidence of autism varies across sex, age, ethnicity, and geographical location. Environmental and social factors might interact with autism aetiology. Speaking a language other than English and economic hardship might increase access barriers to autism diagnostic services, autism-specific Education, Health and Care Plans, and school-level support.

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## Introduction

Autism is a group of neurodevelopmental conditions characterised by persistent difficulties in social communication and interaction, alongside unusually restricted, repetitive behavioural patterns, interests, or activities.<sup>1</sup> The prevalence of autism in the English school system is 1.8%,<sup>2</sup> although it is unclear how health service access influences current estimations and whether incidence varies across the epidemiological dimensions of time, place, and person.<sup>3</sup> Nevertheless, there is a broad consensus that the incidence of autism has increased in high-income countries because of expansions in diagnostic criteria that embrace the concept of the autism spectrum, increased awareness, and improved recognition of autism behaviours.<sup>1</sup> However, factors such as low socioeconomic status, language spoken at home, and minority racial and ethnic background might affect access to diagnostic services,<sup>1</sup> with considerable variability in incidence existing across different countries, geographical areas, and communities.<sup>3-5</sup>

Most incidence studies have focused on time as the primary variable of interest and have centred on how autism has evolved from a relatively narrow diagnosis to a condition defined within a spectrum.<sup>6</sup> Others have interpreted prevalence and incidence evidence as heterogeneous across different contexts,<sup>7</sup> with uncertainty about the reasons for this variation. Understanding causes of variation is crucial for investigating possible factors contributing to differences in diagnosis in marginalised social groups. Until the last decade, many epidemiological studies focused on incidence at the national level, ignoring potential local differences. Several studies reported an increased likelihood of autism in urban versus rural areas, supporting the hypothesis that urban environments might impact diagnostic pathways,<sup>8,9</sup> affecting minority ethnic people living in these settings.<sup>10</sup> The relationship between environmental factors and health service access and their socioeconomic dimensions across ethnic groups is essential to understand and identify factors affecting expression of the autistic

## Research in context

### Evidence before this study

We searched PubMed, Google Scholar, and PsychINFO for articles published in English between Jan 1, 2000, and Aug 5, 2022, on the incidence and prevalence of autism using the search terms (autis\* OR ASC OR ASD) AND (prevalen\* OR inciden\* OR epidemiolog\*). We found that existing research has shown that the diagnostic pathways for autism are highly influenced by social determinants and demographic variables, such as age, sex, ethnicity, and socioeconomic disadvantage. To our knowledge, our 2021 study on the prevalence of autism in the UK is the largest autism epidemiology study to include minority ethnic people and we found that autism was more prevalent among particular ethnic groups, including Black, school-age children. Understanding the relationship between environmental factors, health service access, and socioeconomic adversity across ethnic groups is essential to identify possible inequities in diagnostic access that can influence autism incidence in the English state-funded school system.

### Added value of this study

We conducted a large, retrospective, longitudinal, school registry study to investigate variation in autism incidence in England across different population strata (age, sex at birth, and ethnicity) and measures of family-level and area-level socioeconomic adversity. We found an annual crude autism incidence of 429.1 cases per 100 000 person-years (95% CI 426.4–431.7) and an age-adjusted, sex-adjusted annual incidence of 426.9 cases per 100 000 person-years (423.5–430.4). The adjusted incidence of autism in boys was about four-times the incidence in girls. Adjusted incidence was highest in pupils who had an unclassified ethnicity or were

Black. In our fully adjusted logistic regression model, we observed reduced odds of autism among Asian, Black, and Chinese girls compared with White girls if all groups had no claimed eligibility for free school meals and spoke English as a first language, after adjusting for area-level socioeconomic disadvantage, year, and ethnic density. Boys from all ethnic groups (any other ethnic group, unclassified ethnicity, White, Black, Asian, Chinese, and mixed race), had no claimed eligibility for free school meals, and spoke English as their first language had increased odds of autism compared with White girls without claimed eligibility for free school meals and who spoke English as their first language. In this model, pupils who were eligible for free school meals or lived in ethnically diverse or deprived areas had increased odds of having a recognised autism status. Our spatial analysis showed significant spatial autocorrelation across lower-layer super output areas in England. We found that the region with the largest proportion of hotspots was the South-East and the clinical commissioning group with the largest proportion of hotspots was National Health Service (NHS) Rotherham (now part of NHS South Yorkshire Integrated Care Board).

### Implications of all the available evidence

The incidence of autism varies for pupils across different ethnic groups. For public health and autism-specific policies, it is crucial to reassess assumptions of uniform autism incidence and prevalence. Our results challenge us to better understand the process of receiving an autism diagnosis and autism-specific school-level support, and how social determinants, such as ethnicity and area deprivation, affect autism status in the English educational system.

phenotype and possible inequities in diagnostic access that can influence reported incidence.<sup>1,11–15</sup>

To assess geographical, socioeconomic, and ethnic determinants of autism status in England, we present results from a large, longitudinal study of individuals with registered Special Education Needs and Disability (SEND). We investigate variations in autism incidence in England across different population strata (age, sex at birth, and ethnicity) and measures of family-level and area-level socioeconomic adversity. We examine health service access in the form of SEND support and official educational recognition of autism in the English state-funded education system (ie, autism-specific Education, Health and Care Plans and SEND support), using the geographical boundaries of different health-care commissioning services to measure the spatial clustering of autism incidence across health service areas. Our main objective was to identify whether local variation in the incidence of autism is based on area-level and family-level social determinants of health and, therefore, is dependent on health service access and should be framed through an ecological framework. This study is an extension of previously published work by our research group.<sup>2</sup>

## Methods

### Study design and data source

In this retrospective, longitudinal, school registry study, we sourced data from the National Pupil Database, which is a government registry that collects information about all pupils under state education in England (approximately 93% of all schools in the English education system; appendix p 3). We used data from one of its main components, the summer school census (collected annually in May–June, for the years 2014–17. The school census collects information from primary schools, secondary schools, special educational needs schools, maintained nurseries and academies, and pupil referral units three times per year. Data access to the National Pupil Database was granted by the Department for Education of the UK Government in March 2018 (approval number DR170622.01) and this study was approved by the ethics committee (approval number PRE.2017076) of the Department of Psychology, University of Cambridge, Cambridge, UK. Reporting of this study follows the Strengthening of Reporting of Observational Studies in Epidemiology guideline.

### Outcome and procedures

The incidence of autism in the English state-funded school system was our main outcome. Autism in the school system was defined as pupils in English state-funded schools having either a documented autism diagnosis in the form of an autism-specific Education, Health and Care Plan, which is an official recognition of SEND in England and requires attending an autism diagnostic assessment, or school-administered autism-specific SEND

support (appendix pp 3–4).<sup>2</sup> We assumed that this composite variable was the most representative estimate of formally recognised autism in the English state school system.<sup>2</sup>

From the census, we extracted the anonymised pupil identifier, SEND support and Education, Health and Care Plan status, age, sex, ethnicity, claimed eligibility for free school meals, first language spoken at home, home address census output area, and school year. Age was categorised into six groups (1–3 years, 4–6 years, 7–9 years, 10–12 years, 13–15 years, and 16–18 years). Sex assigned at birth was binarily coded (male or female) according to National Pupil Database classifications. The National Pupil Database contains seven self-reported major classifications of ethnicity: Black; White; Chinese; Asian (refers mainly to South Asian pupils); mixed; unclassified (for those who do not answer); and any other ethnic group (more information in appendix [p 4]). First language spoken (ie, the language the pupil was exposed to during early development [usually before 3 years of age]) was coded as English or other, with those without data labelled as unclassified. We used lifetime claimed eligibility for free school meals, meaning a claim for a school meal has been made on a child's behalf and their eligibility has been verified by the school at any time during the child's school years (coded as yes or no), as a family-level proxy of socioeconomic disadvantage. We used the English Index of Multiple Deprivation 2019 (available from the Office for National Statistics), divided into quintiles, as an area-level deprivation measure, allowing us to integrate family and ecological indicators of socioeconomic disadvantage,<sup>16</sup> defined as a paucity of material resources, economic adversity, or both, into our analysis. Further definitions of the seven major classifications of ethnicity, information on the Index of Multiple Deprivation, and eligibility criteria for free school meals can be found in the appendix (pp 4–5).

With 2014 as our baseline year, autism incidence data were reported for each of the 326 local authority districts in the 2011 English census (the census closest to our selected years), which represent English municipalities (appendix p 5). To respect anonymity and avoid disclosure, the Department for Education of the UK Government matched pupils' home addresses to output areas (the lowest level of census area), which we then matched to lower-layer super output area polygons (n=32844 in England). The lower-layer super output area is the next level of English hierarchical geographical area and contains 1000–3000 residents (mean 1500) from 400–1200 households (mean 650). Lower-layer super output area polygons were retrieved from Edinburgh DataShare.

### Statistical analysis

The incidence of autism was calculated as the amount of new autism-specific Education, Health and Care

For the Office for National Statistics see <https://www.ons.gov.uk>

See Online for appendix

For Edinburgh DataShare polygons see <https://datashare.ed.ac.uk/handle/10283/2546>

	New autism diagnoses	Total population	Unadjusted yearly incidence per 100 000 person-years (95% CI)	Adjusted* yearly incidence per 100 000 person-years (95% CI)
Overall (excluding 2014)	102 338	23 851 455	429.1 (426.4–431.7)	426.9 (423.5–430.4)
Year of census				
2014	..	7 729 057	1 (ref)	1 (ref)
2014–15	35 878	7 831 981	458.1 (453.3–462.8)	450.9 (444.8–457.0)
2015–16	32 727	7 954 153	411.4 (406.9–428.6)	411.9 (406.0–417.8)
2016–17	33 733	8 065 321	418.2 (413.8–449.3)	418.0 (412.0–423.9)
Age group				
1–3 years	5859	1 058 070	553.7 (539.6–567.9)	555.8 (541.6–570.0)
4–6 years	29 789	5 861 974	508.2 (502.4–513.9)	508.1 (502.3–513.8)
7–9 years	20 784	5 569 352	373.2 (368.1–378.6)	373.4 (368.4–378.5)
10–12 years	25 118	5 124 375	490.2 (485.5–496.2)	490.5 (484.4–496.5)
13–15 years	17 321	4 895 821	353.8 (348.5–359.1)	354.0 (348.7–359.2)
16–18 years	3467	1 341 863	258.4 (249.8–266.9)	267.6 (258.7–276.5)
Sex				
Female	20 177	11 684 110	172.7 (170.3–175.1)	173.2 (170.1–176.3)
Male	82 161	12 167 345	675.3 (670.6–679.9)	668.6 (662.5–674.6)
Ethnicity				
White	79 552	17 777 813	447.5 (444.4–450.6)	431.0 (426.8–435.1)
2014–15	28 269	5 857 359	482.6 (476.9–488.3)	459.9 (452.5–467.4)
2015–16	25 170	5 911 742	425.8 (420.5–431.0)	408.2 (401.1–415.2)
2016–17	26 113	6 008 712	434.6 (429.3–439.9)	422.5 (415.5–429.5)
Any other ethnic group	1 312	4 145 531	316.5 (299.4–333.6)	314.3 (293.0–335.7)
2014–15	380	1 292 297	293.9 (264.4–323.5)	272.2 (238.0–306.4)
2015–16	427	1 372 283	311.0 (281.5–340.5)	282.8 (249.4–316.2)
2016–17	505	1 479 951	341.3 (311.6–371.1)	371.2 (331.2–411.2)
Asian	6 436	2 513 441	256.1 (249.8–262.3)	276.9 (268.3–285.5)
2014–15	1 999	802 652	249.0 (238.1–259.9)	254.4 (240.1–268.7)
2015–16	1 955	832 256	234.9 (224.5–245.3)	257.6 (242.8–272.4)
2016–17	2 482	878 533	282.5 (271.4–293.6)	311.0 (296.0–326.1)
Black	5 740	1 320 654	434.6 (423.4–445.9)	466.9 (450.8–483.0)
2014–15	1 951	426 908	457.0 (436.7–477.3)	473.8 (445.7–501.8)
2015–16	1 832	437 695	418.6 (399.4–437.7)	455.8 (427.2–484.4)
2016–17	1 957	456 051	429.1 (410.1–448.1)	467.9 (441.1–494.6)
Chinese	349	1 013 57	344.3 (308.2–380.5)	327.1 (284.4–369.7)
2014–15	116	32 285	359.3 (293.9–424.7)	346.7 (267.8–425.7)
2015–16	109	33 720	323.3 (262.6–383.9)	306.4 (235.6–377.1)
2016–17	124	35 352	350.8 (289.0–412.5)	327.1 (255.4–398.8)
Mixed race	5 725	1 266 818	451.9 (440.2–463.6)	436.7 (421.6–451.8)
2014–15	1 846	396 320	465.8 (444.5–487.0)	443.8 (416.9–470.7)
2015–16	1 785	418 746	426.3 (421.0–460.6)	403.9 (378.6–429.2)
2016–17	2 094	451 752	463.5 (443.7–483.4)	454.8 (429.2–480.4)
Unclassified (no answer)	3 224	456 841	705.7 (685.7–730.1)	599.4 (574.5–624.3)
2014–15	1 317	187 160	703.7 (665.7–741.7)	615.9 (571.4–660.3)
2015–16	1 449	182 711	793.1 (752.2–833.9)	635.9 (593.3–678.4)
2016–17	458	86 970	526.6 (478.4–574.9)	523.0 (465.2–580.7)

(Table continues on next page)

Plans or autism SEND support recorded during each summer school census year since the baseline year (2014). After excluding prevalent cases in 2014, we calculated unadjusted and age-adjusted and sex-adjusted incidence per 100 000 person-years per subsequent school year (2014–15, 2015–16, and 2016–17) and the total incidence by age, ethnicity, sex, and local authority district. Direct standardisation was used to compare incidence between local authority districts by use of the 2011 English census projections for 2014.

In our spatial analysis, the spatial effects of new autism cases across clinical commissioning groups, which were, until July 2022, the way that local health services were funded and commissioned (appendix p 6), were assessed by use of global Moran's I statistic between lower-layer super output areas in R (version 4.2.0). We analysed the aggregate number during 2014–17 of new cases and whether they showed spatial autocorrelation (ie, the tendency of adjacent areas to have similar or opposing incidences) by lower-layer super output area using population-weighted centroids running 1000 Monte Carlo simulations; data for population-weighting were obtained from the Office for National Statistics. This calculation was done for the total population and then for boys and girls separately. We computed local indicators of spatial association<sup>17</sup> and structured the associations with neighbouring lower-layer super output areas through a spatial weight matrix. Using local Moran's I, we aimed to identify statistically significant spatial autocorrelation in the incidence across lower-layer super output areas and to determine whether any spatial co-location was of particularly high or low value relative to the mean autocorrelation value, plotting spatial autocorrelation across lower-layer super output area and clinical commissioning group boundaries.<sup>18,19</sup> We identified high-incidence areas surrounded by other high-incidence areas (hotspots) and low-incidence areas surrounded by other low-incidence areas (cold spots), as well spatial outliers (ie, high-incidence areas surrounded by low-incidence areas or vice versa). We selected the hotspots as regions of interest. Clusters obtained in our local indicators of spatial association analysis were located across nine English regions so we could assess cluster density within them.

We subsequently applied a hierarchical three-level mixed-effects logistic regression model with two random-effects equations using a Bernoulli distribution and modelling autism status as the primary binary outcome, with its probability determined by the logistic cumulative distribution function. We used this model because of the panel structure of the English school census, with random effects being beneficial for modelling intracluster correlations.<sup>20</sup> In the mixed-effects logistic regression model, we included predictor variables of interest: a pupil-level ethnic density score, defined as the proportion of the population in the local



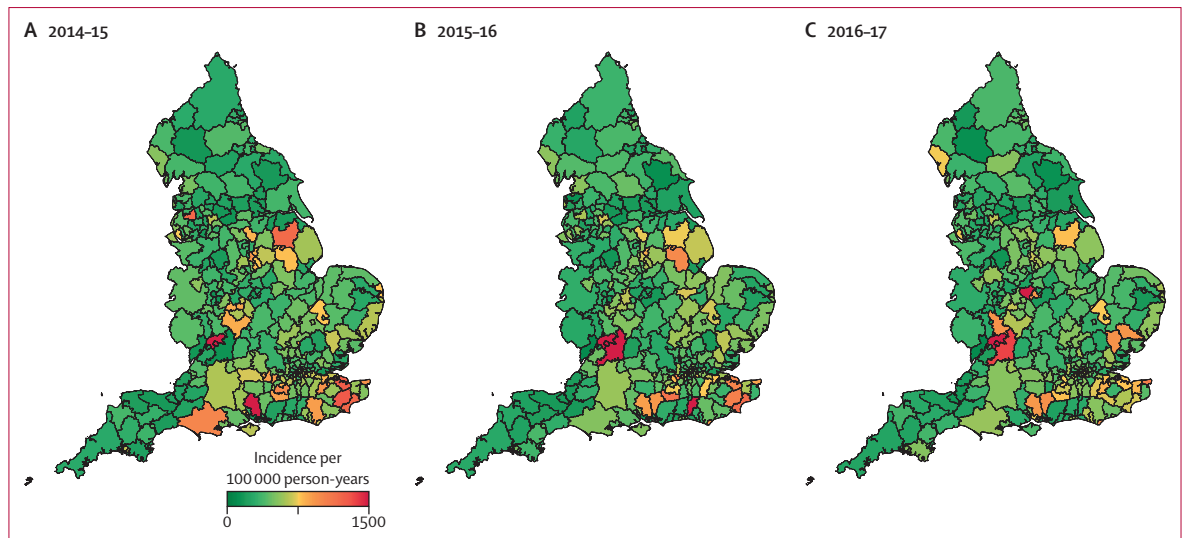
authority district in the same ethnic group as the pupil, divided into quintiles; sex (binarily coded); age (in age categories); ethnicity; eligibility for free school meals; Index of Multiple Deprivation 2019 quintiles; first language spoken; and year (excluding our baseline year of 2014). We used family-level determinants (eligibility for free school meals) and area-level determinants (ethnic density and Index of Multiple Deprivation) of socioeconomic disadvantage, looking at their effects in explaining sociodemographic differences in autism incidence across our clusters. On the basis of previous work,<sup>2</sup> we also included two-way interactions between ethnicity and sex, ethnicity and free school meals, and ethnicity and first language spoken, due to a hypothesised intersectional effect. For the purpose of these interactions, we considered White girls without an eligibility claim for free school meals who spoke English as their first language as our reference category from which we report the interactions. For completeness, we also report the effects of using White boys who had no claimed eligibility for free school meals and spoke English as their first language as our reference category. We report two intraclass correlations for this three-level nested model. The first is the intraclass correlation at the lower-layer super output area level, or the correlation between incident autism values across lower-layer super output areas. The second is the intraclass correlation at the level of the pupil identifier nested within the lower-layer super output area, or the correlation between incident autism by pupil identifier and across lower-layer super output areas. The log-odds of the outcome were modelled as a linear combination of the predictor variables to control for possible geographical data clustering on the basis of two random nested intercepts: an anonymised pupil identifier nested within lower-layer super output area. Optimisation was done by use of the original metric of variance components, with seven integration points for quadrature using a Gauss–Hermite quadrature for each level of the random effects. Consequently, we allowed for random variation across pupils, unrestricted substitution patterns across variables, and the correlation of unobserved factors with time to account for any pattern of longitudinal covariance.

We also ran our hierarchical three-level mixed-effects logistic regression model in our region of interest (hotspots) clusters to assess any possible differences with our global model. We did three sensitivity analyses: a two-level panel (nested by pupils' anonymous identifier and year) fixed-effects model without area-level nesting but with interactions; a replication of our mixed-effects three-level logistic regression model, but with only two interactions (ethnicity *vs* free school meals and ethnicity *vs* sex), using the same reference category; and a replication of our mixed-effects three-level logistic regression model without interactions, using the same reference category. We report model fit statistics

	New autism diagnoses	Total population	Unadjusted yearly incidence per 100 000 person-years (95% CI)	Adjusted* yearly incidence per 100 000 person-years (95% CI)
(Continued from previous page)				
Local authority districts with the highest incidence				
2014–15				
North Dorset	77	8900	865.2 (671.9–1058.4)	9862.0 (9712.5–10011.6)
Cheltenham	23	14 007	164.2 (97.1–231.3)	3877.7 (70.3–7685.0)
West Dorset	125	12 551	995.9 (821.3–1170.5)	3848.0 (0.0–8768.4)
Tewkesbury	31	11 860	261.4 (169.4–353.4)	1741.0 (0.0–4491.5)
Winchester	71	13 968	508.3 (390.1–626.5)	1727.7 (904.4–2551.0)
2015–16				
Tewkesbury	29	12 152	238.6 (151.8–325.5)	6327.4 (1408.6–1246.3)
Cheltenham	35	14 231	245.9 (164.5–327.4)	4937.5 (311.9–9563.1)
Mid Sussex	69	18 997	363.2 (277.5–448.9)	3315.9 (0.0–8234.5)
Cotswold†	19	10 279	184.8 (101.7–267.9)	3198.6 (0.0–8117.1)
Folkestone and Hythe	143	15 438	926.3 (774.5–1078.1)	1213.0 (835.6–1590.4)
2016–17				
Tewkesbury	28	12 436	225.2 (141.8–308.6)	6328.0 (1409.2–11246.9)
Hinckley and Bosworth	54	15 037	359.1 (263.3–454.9)	2425.8 (148.6–4703.0)
Cheltenham	19	14 425	131.7 (72.5–190.9)	2402.4 (0.0–6315.2)
Cotswold†	18	10 377	173.5 (93.3–253.6)	1452.4 (0.0–3843.5)
North Dorset	89	8917	998.1 (790.7–1205.5)	1119.8 (336.6–1903.0)
Local authority districts with the lowest incidence				
2014–15				
Taunton Deane	28	13 933	201.0 (126.5–275.4)	135.4 (85.3–185.5)
Wolverhampton	65	43 085	150.9 (114.2–187.5)	136.1 (99.7–172.6)
Cotswold†	18	10 255	175.5 (94.4–256.6)	138.2 (69.3–207.0)
Sandwell	83	57 142	145.3 (114.0–176.5)	140.3 (103.2–177.5)
Kirklees	100	67 727	147.7 (118.7–176.6)	140.4 (103.7–177.1)
2015–16				
Forest of Dean	..‡	10 385	96.3 (36.6–155.9)	92.5 (18.8–166.1)
Ryedale	..‡	6718	148.9 (56.6–241.1)	110.4 (42.0–178.7)
Wyre	26	13 249	196.2 (120.8–271.7)	133.1 (81.9–184.2)
Sandwell	88	58 625	150.1 (118.7–181.5)	136.7 (103.4–170.0)
West Somerset	..‡	3608	194.0 (50.3–337.7)	141.6 (36.9–246.3)
2016–17				
Forest of Dean	..‡	10 422	134.3 (63.9–204.7)	92.1 (43.9–140.3)
Eden	..‡	6835	146.3 (55.7–236.9)	109.5 (41.4–177.6)
Christchurch	..‡	6229	160.5 (61.0–260.0)	113.4 (43.2–183.6)
Kirklees	87	69 462	125.2 (98.9–151.6)	117.9 (82.0–153.7)
Ryedale	..‡	6661	60.1 (1.2–118.9)	126.9 (0.0–260.0)

After the reference category, ethnicities are listed in alphabetical order. \*Adjusted for age and sex. †The low and high incidence observed in the Cotswolds could be due to the low population of school-age children in state-funded schools and the impact that extra autistic children might have in such low numbers and the relatively older population within this local authority district, with children (aged <18 years) making up only 11% of the population, which is unusual for local authority districts across England. ‡No data due to the Office for National Statistics disclosure threshold and means of 15 or less.

**Table: Unadjusted and adjusted incidence of autism**



**Figure 1:** Autism incidence per 100 000 person-years by English local authority district  
Autism incidence per 100 000 person-years in England in 2014–15 (A), 2015–16 (B), and 2016–17 (C).

(Bayesian information criterion and Akaike information criterion), likelihood ratios, and intracluster correlation values for all models. All models were run by use of Stata/MP (version 17). To correct for multiple comparisons, we use a *p* value of less than 0.01 as our threshold for statistical significance.

#### Role of the funding source

The funders of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report.

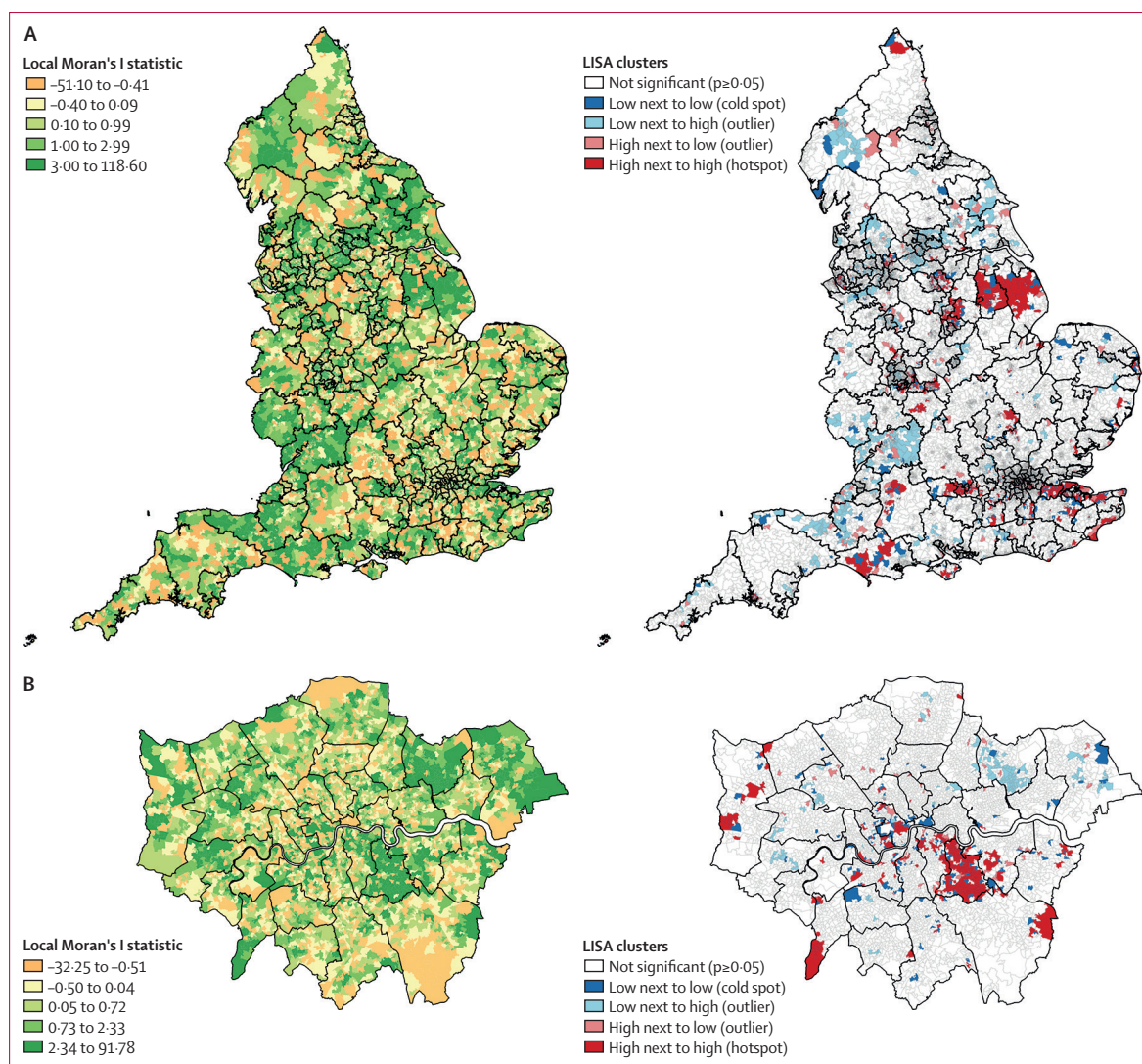
#### Results

Between 2014 and 2017, our total sample included 31 580 512 person-years and 102 338 newly diagnosed autistic pupils, corresponding to an unadjusted annual incidence of 429.1 cases per 100 000 person-years (95% CI 426.4–431.7) and an age-adjusted and sex-adjusted annual incidence of 426.9 cases per 100 000 person-years (423.5–430.4). The incidence of autism was slightly higher in 2014–15 than in 2015–16 or 2016–17 (table). Of the age groups, pupils aged 1–3 years, 4–6 years, and 10–12 years had the highest incidence of autism (table). The incidence of autism in boys was approximately quadruple the incidence in girls for the total period 2014–17, and was highest in pupils who were Black, mixed race, or had an unclassified race (table). Geographically, the incidence of autism was highest in the local authority district of Tewkesbury and lowest in the Forest of Dean almost every year (table; figure 1).

Our spatial analysis showed significant spatial autocorrelation across lower-layer super output areas in England (global Moran's  $I=0.279$ ;  $p<0.0001$ ). The local indicators of spatial association cluster maps depict the global Moran's  $I$  statistic by lower-layer super output

area with clinical commissioning group boundaries, showing 2338 hotspots and 881 cold spots (figure 2). The English regions with the largest proportion of hotspots were the South East (10.98%), the West Midlands (10.95%), the East Midlands (10.56%), and London (7.16%), with most hotspot clusters located in east or south-east districts (figure 2; appendix pp 28–29). The three largest hotspot clusters among clinical commissioning groups were found in National Health Service (NHS) Rotherham (45.51%), NHS Heywood, Middleton and Rochdale (38.81%), and NHS Liverpool (36.91% [appendix pp 31–33]). Spatial autocorrelation was more pronounced for autism incidence in boys than in girls (global Moran's  $I=0.238$ ;  $p<0.0001$  vs  $I=0.105$ ;  $p<0.0001$ ; appendix pp 28–29, 34). Additionally, we found a similar proportion of hotspots for boys (2156 [70.7%] hotspots and 892 [29.3%] cold spots) compared with our total sample (2338 hotspots [72.6%] and 881 [27.4%]; appendix pp 28–29, 34). Girls had a larger proportion of cold spots than did boys (881 [41.5%] cold spots; appendix p 34).

The three-level mixed-effects logistic regression model with two random-intercepts showed that, after adjusting for cultural factors (ie, first language spoken and ethnic density quintile), family-level deprivation (claimed eligibility for free school meals), area-level deprivation (Index of Multiple Deprivation quintile), ethnicity, sex, year, and age, White boys without claimed eligibility for free school meals and who spoke English as their first language had approximately 5-times the odds of being autistic compared with White girls without claimed eligibility for free school meals and who spoke English as their first language (appendix pp 19–22; figure 3A). All age groups showed significantly reduced odds compared with pupils aged 1–3 years. We explored the interactions between ethnicity and sex, free school meals, and first

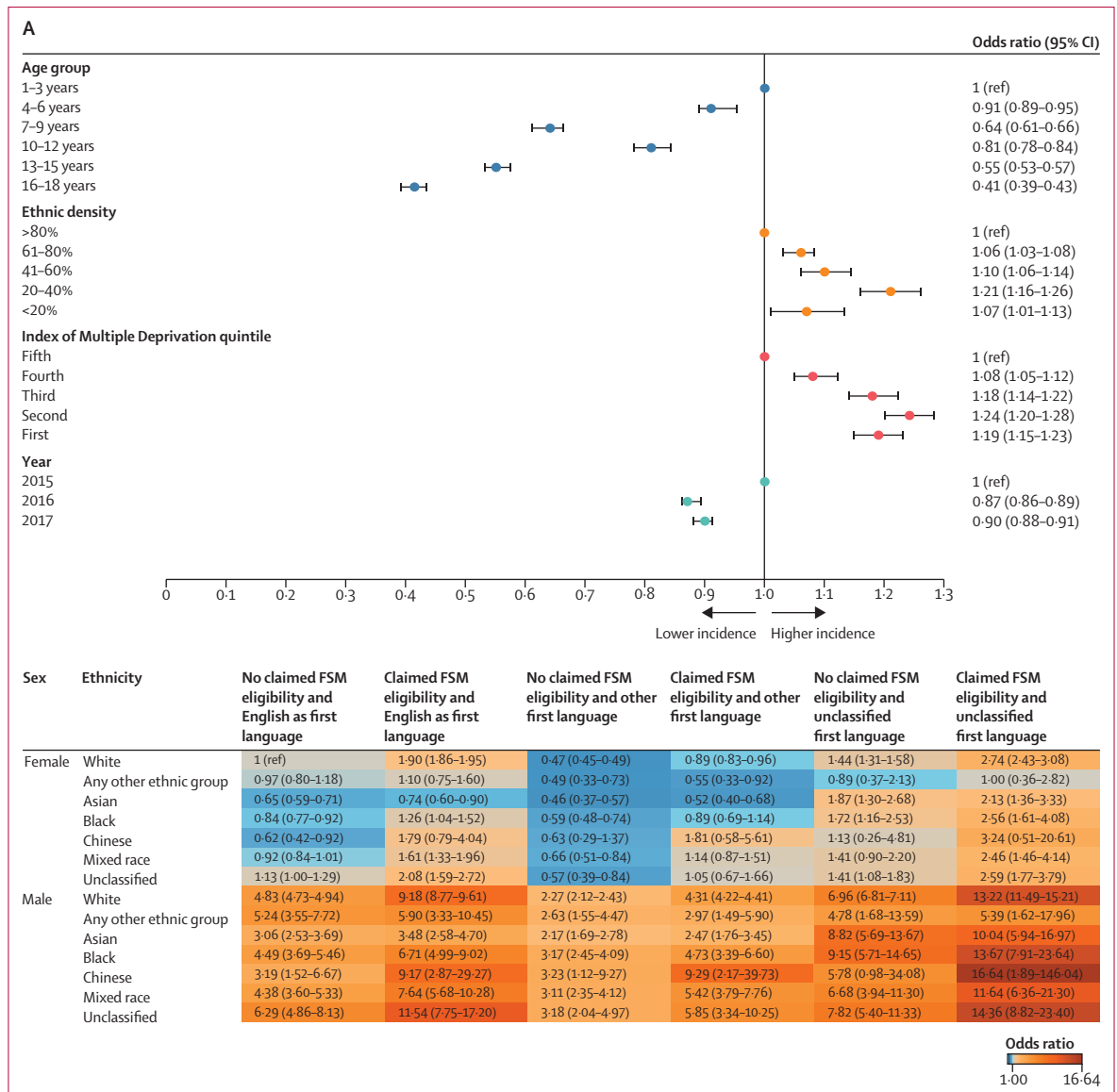


**Figure 2: Cluster maps of LISAs for the total population**

Spatial analysis in England (A) and London, UK (B). High-high regions have high autism incidence and are surrounded by other regions with high autism incidence. Low-low regions have low autism incidence and are surrounded by other regions with low autism incidence. These regions contribute positively to spatial autocorrelation. High-low regions have high autism incidence and are surrounded by regions with low autism incidence, whereas low-high regions have low autism incidence and are surrounded by regions with high autism incidence. These regions contribute negatively to spatial autocorrelation. LISA=local indicator of spatial association.

language spoken. We observed significantly lower odds of having an autism diagnosis among Asian, Black, and Chinese girls without claimed eligibility of free school meals and who spoke English as their first language compared with the reference category. Boys from all ethnic groups without claimed eligibility for free school meals and who spoke English as their first language showed increased odds of autism compared with White girls without claimed eligibility for free school meals and who spoke English as their first language (figure 3A). When White girls spoke English as their first language, then those who claimed free school meals were at increased odds of autism compared with those who did not (figure 3A). When White girls did not claim free

school meal eligibility, they were at lower odds of having a recognised autism status if they spoke a language other than English as their first language (figure 3A). Boys from all ethnic groups, but especially White boys and boys with an unclassified ethnicity, with claimed free school meal eligibility showed increased odds of autism compared with White girls without claimed free school meal eligibility if both groups spoke English as their first language (figure 3A). If boys of any ethnicity spoke other languages as their first language, they showed increased odds of autism compared with White girls without claimed free school meal eligibility who spoke English as their first language (figure 3A). Claimed eligibility for free school meals increased the odds of



(Figure 3 continues on next page)

being diagnosed with autism across all ethnic groups, whereas speaking a first language other than English decreased the odds of autism (figure 3). These effects were particularly apparent among boys, in whom the baseline odds of autism were already higher than in girls. Unadjusted and adjusted incidence rates per lower-layer super output area are provided in the appendix (pp 7–18). The results of our three sensitivity analyses are in the appendix and confirm the findings of our main analysis (pp 23–24). The results of using White boys with no claimed eligibility for free school meals and who spoke English as their first language as our reference category can be found in the appendix (pp 25–27).

All likelihood ratios for all our models were significant ( $p < 0.0001$ ), showing that our mixed-effects logistic

regression model with three-level random intercepts was an improvement over a simple logistic random intercept model (appendix p 24). Pupil panel identifier explained 2.60% of the variance and the three-level mixed-effects logistic model explained 69.02% of the variance, supporting the use of nesting. When introducing interaction terms, the Bayesian information criterion score for the main three-level model (1189700) improved by 271 points compared with the score for the mixed-effects three-level model without interactions (1189971; appendix pp 23–24), justifying their inclusion.

When we ran our model in our regions of interest, the odds of autism were significantly increased among pupils aged 4–6 years and 10–12 years and significantly decreased



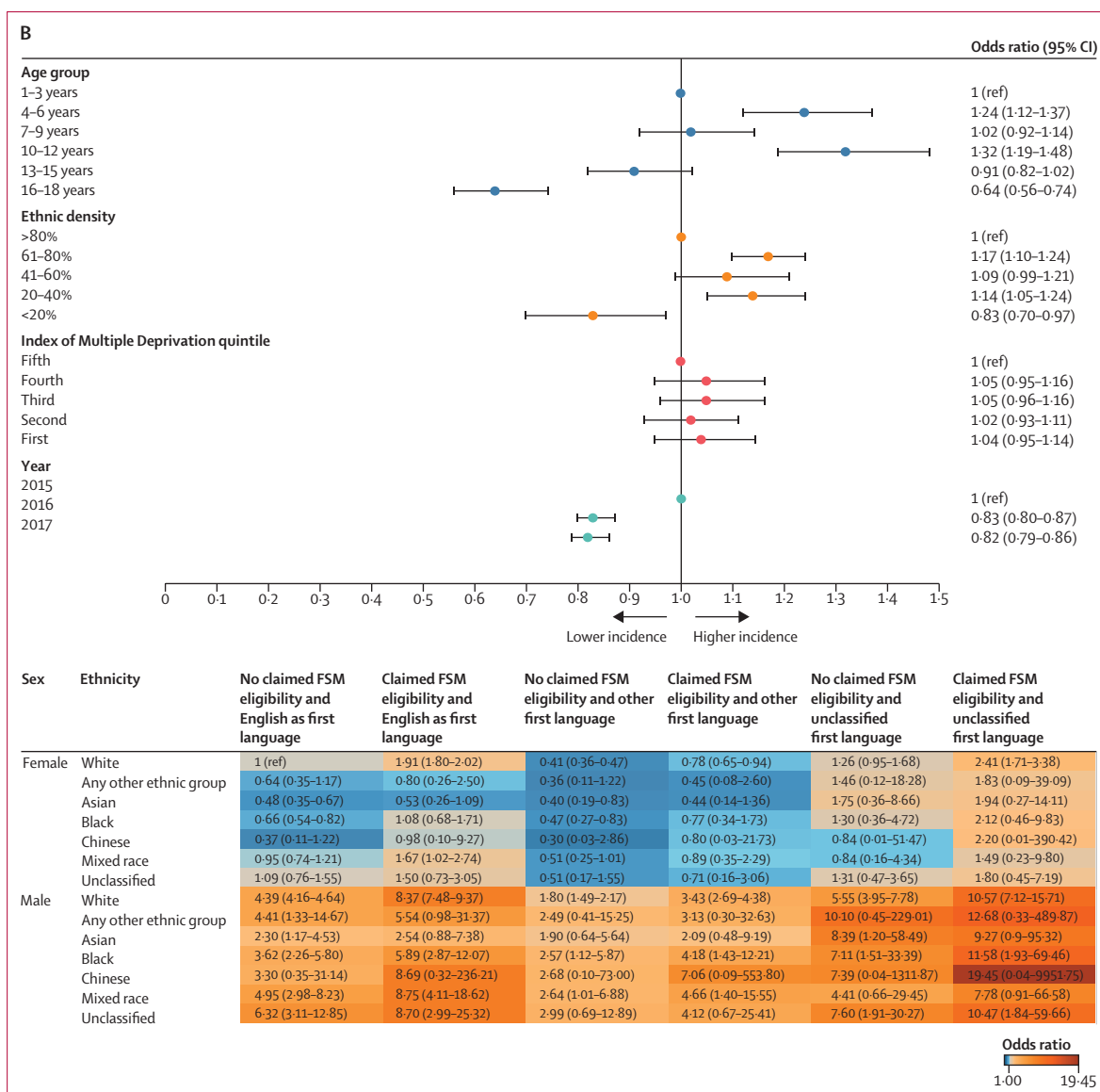


Figure 3: Model outputs

(A) Output of the multi-level mixed-effects logistic regression model nested by lower-layer super output area and yearly individual-level data. (B) Output of the multi-level mixed-effects logistic regression model nested by lower-layer super output area and yearly individual-level data using only hotspots. After the reference category, ethnicities are listed in alphabetical order. FSM=free school meal.

among those aged 16–18 years (vs those aged 1–3 years; figure 3B). The odds of autism were lower among Asian and Black girls compared with White girls, if none of them had claimed eligibility for free school meals and spoke English as their first language (figure 3B).

**Discussion**

In this study, we calculated the incidence of autism among pupils aged 1–18 years in England using national school data for the years 2014–17. We determined a crude incidence of 429.1 cases per 100 000 person-years and an age-adjusted, sex-adjusted incidence of 426.9 cases per 100 000 person-years. The incidence of autism was

slightly higher in 2014–15 than in 2015–16 or 2016–17, which could be attributed to new diagnostic criteria being adopted in 2013 (ie, the Diagnostic and Statistical Manual of Mental Disorders-5). Of the age groups, pupils aged 1–3 years, 4–6 years, and 10–12 years had the highest incidence of autism. This finding aligns with possible delays in neurodevelopmental milestones at 1–3 years and school transition stages in England, with primary education beginning between age 4 years and 5 years and secondary education starting at age 11 years, during which children are more likely to be assessed for possible special education needs. The incidence of autism in boys was approximately four-times the incidence in

girls, contrasting the previously estimated 120 cases per 100 000 person-years for boys and 20 cases per 100 000 person-years for girls.<sup>3</sup> Additionally, we found a similar number of hotspots for boys only as we did in our global analysis. Cold spots were more prevalent for girls than for boys, which could be attributed to existing disparities between sexes within the diagnostic pathways of autism. Incidence was particularly high in Black pupils and in pupils with an unclassified race. However, in our three-level mixed-effects logistic regression, we observed a reduced odds of autism among Asian, Black, and Chinese girls who spoke English as their first language and had no claimed eligibility for free school meals compared with our reference category of White girls without claimed eligibility for free-school meals and who spoke English as their first language. The inclusion of area-level and family-level socioeconomic cofounders, together with ethnic density and our hypothesised interactions, in our model might explain why we found a high incidence but reduced odds of autism in Black girls and might show that service access is an influencing factor in determining autism status in minority ethnic groups. Socially disadvantaged pupils had increased odds of autism, as did pupils from ethnically diverse and deprived areas, compared with pupils from ethnically homogenous and less deprived areas.

Among girls who spoke English as their first language and claimed eligibility for free school meals, most ethnic groups under study had higher odds of autism than our reference group, except for Asian girls. This interaction between ethnicity and sex, combined with area-level effects on autism incidence, provides further evidence that minority ethnic pupils are faced with access barriers to autism diagnostic services, Education, Health and Care Plans, and school-level support.<sup>2</sup> The complex interrelations between ethnicity, sex, socioeconomic disadvantage, and first language spoken, combined with area-level effects on autism incidence, provide further evidence about why pupils speaking a first language other than English might face access barriers to autism diagnostic services, Education, Health and Care Plans, and school-level support.<sup>2</sup> We also hypothesise that language difficulties might have some level of diagnostic overshadowing as autism.<sup>12,21</sup> Language difficulties could be even more important in multilingual and multicultural settings where diagnosticians and families do not share a similar linguistic background.<sup>12</sup> Likewise, although Chinese boys and girls with eligibility for free school meals both had a higher odds of autism than our reference group, this finding was not reflected in adjusted incidence or in previously reported prevalence data,<sup>2</sup> which might imply that Chinese pupils are less likely to experience family-level and area-level socioeconomic disadvantages, but those who do experience these disadvantages face substantial barriers to accessing health services.

To our knowledge, this study is the first to investigate the incidence of autism using a total population sample

spanning multiple years, assessing distribution across health service boundaries in high-incidence and highly spatially autocorrelated areas. This design minimalises the under-representation of minority ethnic groups that is common in autism research. However, measures relating to family-level deprivation and English as a first language should be interpreted carefully because they might capture more complex and nuanced effects in autism epidemiology. Additionally, the association between exposure and outcome in Black pupils, with high incidence and reduced odds in a fully confounder-adjusted model, could be due to Simpson's paradox, in which a third factor reverses the effect first observed.<sup>22</sup>

Our study has limitations. First, of pupils aged 1–18 years, we did not include the 7% who are enrolled in independent schools or have alternative educational arrangements like homeschooling (as the school census only includes state-funded schools).<sup>23</sup> Although complex challenges exist in interpreting incidence estimates with administrative data, we assessed educational system use and, indirectly, health service use, and our findings reflect actual numbers of individuals receiving autism-specific services in schools by locality.<sup>24</sup> Second, we were unable to assess ethnic density at the lower-layer super output area level due to possible disclosure risk, so ethnic density was assessed at the local authority district level. We tried to account for this limitation by reporting incidence by local authority district because most school and health services in the UK are provided at the local authority district level. Third, the National Pupil Database does not account for pupils with subclinical autism or those who do not meet service thresholds to receive SEND or Education, Health and Care Plans support at school. Finally, this study is observational in nature, meaning no causal inferences can be derived from our findings, which need to be further examined in future research. Ultimately, we believe that these limitations do not substantially affect the conclusions drawn from our results.

The incidence of autism in England varied from 2014 to 2017. There are many potential reasons for this variation, ranging from disparate awareness in the general population and within schools to heterogeneous use of autism diagnostic instruments, tools, or protocols in health and social services across geographies and services. Furthermore, variability in the provision of education and special educational support across different years in England has been previously observed.<sup>2</sup> This variability could partially explain the rising autism incidence found in previous work;<sup>25</sup> however, we could also infer that a higher incidence of autism in certain minority ethnic groups was not health service-dependent but rather part of the autism phenotype and its diversity. We substantiated our findings and described higher incidence in these minority ethnic groups after showing higher prevalence in our previous work.<sup>2</sup> Additionally, the incidence of autism in this study was influenced by neighbouring

areas. This finding might be explained by cultural and contextual factors that can affect identification, help-seeking, and diagnosis or by differences in local schooling and health services. Health professionals in some regions might also be more sensitive to the signs and traits of autism in diverse ethnic groups.<sup>12</sup> Future research into the local factors that contribute to spatial associations is warranted to further describe local-level factors relevant to diagnostic pathways for autism. For example, a cluster of hotspots was clearly confined within the clinical commissioning group boundary (NHS South East London Clinical Commissioning Group) serviced by the South London and Maudsley NHS Foundation Trust, which is a renowned centre for mental health and autism research, and did not spill over to neighbouring districts outside of its catchment area, such as Bromley. This finding possibly alludes to a service-driven incidence effect.

Our results provide further support that being at a socioeconomic disadvantage or a member of a minority ethnic group are key determinants in the autism diagnostic process.<sup>12</sup> We found that pupils who were eligible for free school meals or lived in an area with high deprivation had increased odds of autism. We believe that future research should take these findings into account when reporting on autism incidence or prevalence. Our model belongs to the quasiexperimental research family and, because of its longitudinal nature, we can observe that effects on autism status are particular to the families involved but might not be generalisable to the deprivation of the area they live in due to possible reverse causation or unknown cofounders. Similarly, people living in ethnically diverse environments have increased odds of autism compared with people living in ethnically homogenous environments, which supports our thesis that, even when adjusting for these variables, important differences are present in different ethnic groups.<sup>21,22</sup>

Our findings highlight the requirement to conduct community-level health needs assessments, to uncover the mechanisms that contribute to the geospatial and demographic differences we observed in this study. Community-level assessments will aid in understanding the relationship between currently competing theories about ethnic differences in autism, namely whether they are a product of environmental or health system factors.<sup>2,12,26,27</sup> Clinically, our findings add to a body of research that highlights the volatility of accessing health services for autistic communities of different ethnic backgrounds and the high incidence of autism in Black and mixed race pupils.<sup>2,11,12,26</sup> In terms of policy, our findings emphasise that more attention should be paid to disadvantaged minority groups given their high incidence of autism. Simultaneously, policy initiatives should be mindful of the intricate interactions between ethnic disparities and broader sociodemographic and geographical factors, as well as how easily minority

groups can be excluded from the benefits of large-scale policy initiatives.

The results from this work highlight how the incidence of autism differs between ethnic groups, aligning our work with existing literature on autism incidence in England,<sup>13</sup> the USA,<sup>28</sup> and Nordic countries.<sup>14,15</sup> A relationship between an increased likelihood of other neurodevelopmental conditions (eg, schizophrenia) and minority ethnic status has been extensively described, yet was absent in the autism literature.<sup>29,30</sup> The overlap between neurodevelopmental conditions should be considered when investigating possible links between deprivation, ethnicity, migrant status, and autism status, which might lead us to common causal pathways.<sup>29</sup> For public health and autism-specific policies, it is crucial to reassess assumptions of uniform autism incidence and prevalence, which might not be the case for minority ethnic groups and other socially vulnerable populations.<sup>11,31</sup> Our results challenge researchers to better understand the process of receiving an autism diagnosis and to what degree social determinants, ethnicity and level of deprivation in particular, affect autism status in the English educational system, while considering the proper support that should be available throughout this process to autistic people.

#### Contributors

AR-U, JCY, and RvK conceptualised the study, did the formal analysis, and contributed to the investigation, obtaining funding, software coding, and data curation. AR-U, JCY, and FEM contributed to the methodology. AR-U, JCY, RvK, VW, GD, HJ, GG-B, FEM, CB, CA, and SB-C accessed and verified the underlying data. AR-U, JCY, RvK, VW, GD, HJ, GG-B, FEM, CB, CA, and SB-C wrote the original draft of the manuscript. AR-U, RvK, VW, GD, HJ, GG-B, FEM, CB, CA, and SB-C reviewed and edited the manuscript. AR-U supervised, acquired funding, and did project administration. JCY and RvK contributed to creating the figures. All authors had full access to all the data in the study and had final responsibility for the decision to submit for publication.

#### Declaration of interests

We declare no competing interests.

#### Data sharing

All data used are owned by the Department for Education of the UK Government and require an application to access. We will not be able to share these data or grant access for this reason. A list of all the variables in the National Pupil Database can be found online (<https://find-npd-data.education.gov.uk>). We recommend that interested parties contact the Department for Education to discuss data access (<https://www.gov.uk/guidance/apply-for-department-for-education-dfe-personal-data>). We will be happy to share our statistical analysis plan and analytical code upon request to the corresponding author.

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