

Autism Data Sources

October 2023

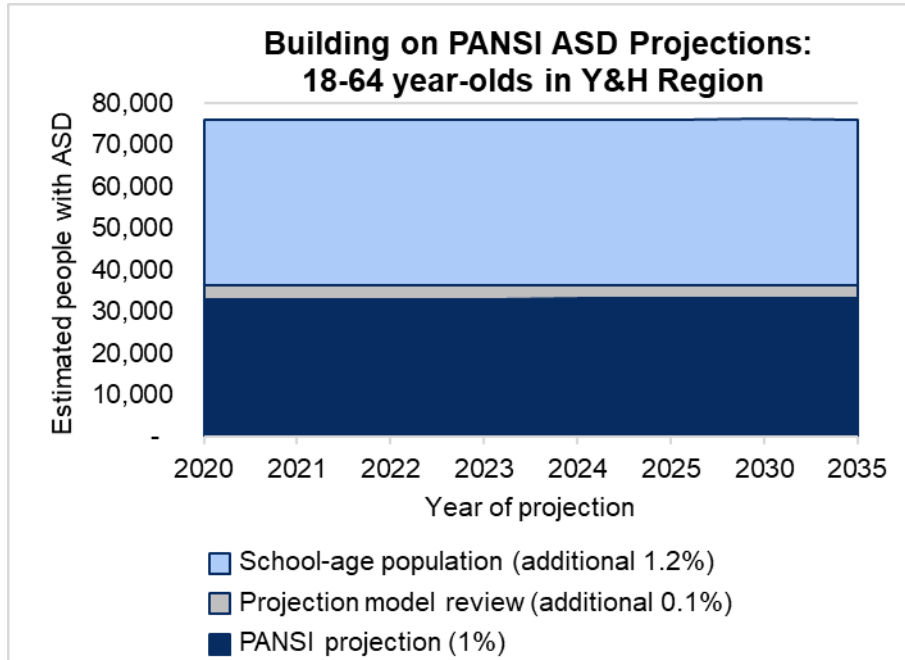
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Autistic Spectrum Disorder (ASD) Population Estimates

There have been a range of population estimates for the autistic population, which use different methodologies, these estimates are summarised below:

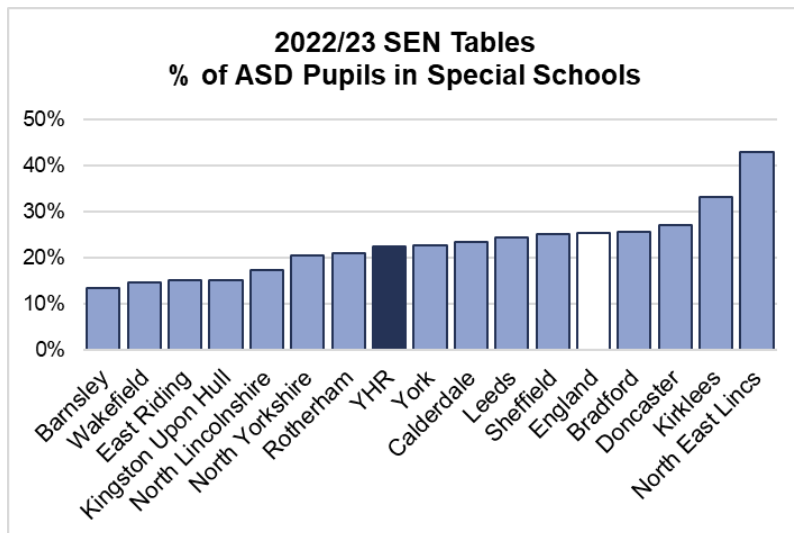
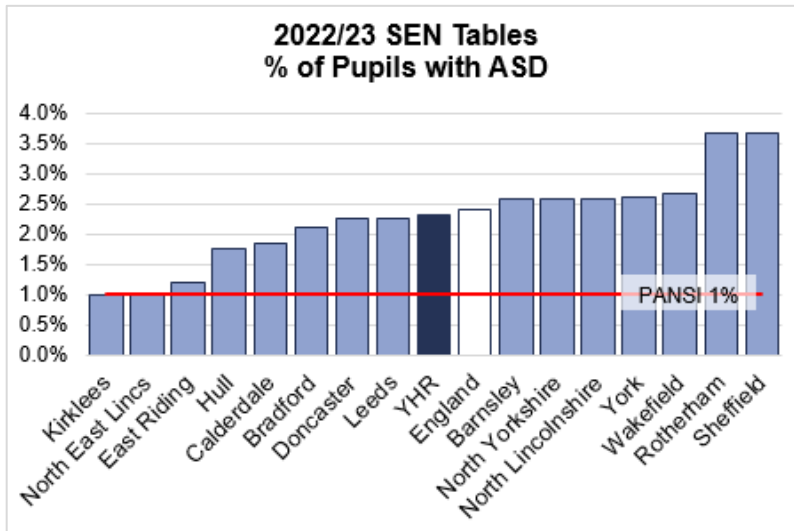
- The 2007 Adult Psychiatric Morbidity Survey (APMS) (1.0%) appears to be the key driver for population estimates and sits behind POPPI and PANSI's 1% figure and the significant variation across gender - 1.8% for men and 0.2% for women.
- An NHS-IC research project in 2012 extended the APMS to include people with learning disabilities, raising the population rate to 1.1%. The National Autistic Society use this for their estimate of 700,000 people in the UK.
- Annual school census data for 2022/23 indicates 2.4% of pupils nationally have autism identified as a primary need, which falls to 2.3% for YHR with a range at local authority level from 1.0% to 3.7%.
- The Learning Disability Profiles convert this to a rate of 16.0 per 1,000 pupils for autistic children known to schools across the Yorkshire & Humber Region (YHR) in 2020.
- The 2017 update of the periodic report on trends in the Mental Health of Children and Young People in England, indicated that 1.5% of 5-10 year-olds and 1.2% of 11-15 year-olds were identified as having Asperger's or autistic, reflecting the upward trend in younger age groups.

Prevalence Projections



- Projecting Adult Needs and Service Information (PANSI) estimates of the autism population are based on 1% of the ONS population projections. The populations projections indicate a 2% reduction in the age-group across YHR 2020 to 2035.
- Underlying 2007 research extended in 2012 to include people with learning disabilities which indicated a revised prevalence rate of 1.1% (additional 0.1%).
- Annual school census data for 2022/23 indicated a prevalence rate across all age groups of 2.3% for YHR (additional 1.2%).
- The original research included a higher prevalence amongst men - 2% compared with women 0.3%. POPPI and PANSI extend that difference to 9:1.
- In the school-based data, the gender split reduces to 3:1, with boys having the higher prevalence.

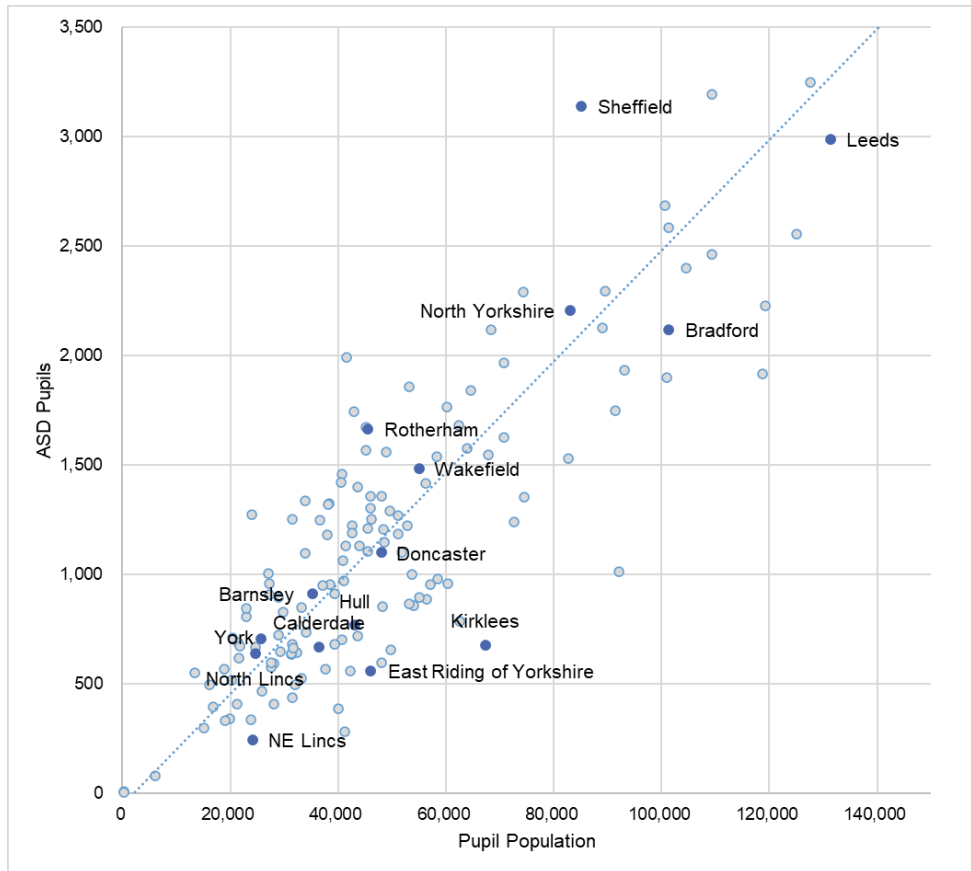
School-age Prevalence



- Annual school census is taken in January each year.
- SEN tables focus only on primary need. Children may have a secondary need of autism which is not included in the SEN data.
- Yorkshire and Humber Region at 2.3% overall compared with 2.4% for England, substantially higher than the 1% rate used for PANSI population projections.
- Education, Health and Care (EHC) plan levels increase from 1.2% at age 5 to 1.5% by age 12 but then decline to 1.0% by age 17.
- Small step change at secondary school entry for other SEN support – total of autistic pupils at 2.5% at the end of primary, 2.8% in Y7-Y8 before declining to 1.8% by Y13.

School-age Prevalence

2022/23



As expected, LAs with higher pupil populations tend to have more pupils with ASD. However there is considerable variation between different local authorities, e.g.:

Local Authority	Pupils with ASD	Total Pupils
Kirklees	678	67,374
North Yorkshire	2,206	83,133
Sheffield	3,138	85,194

Further work is needed to understand the reasons for these variations, e.g. possible links to deprivation, or differences in the capacity to diagnose pupils in different areas.

School-age Prevalence

There are variations between boys and girls and level of need nationally. While prevalence among boys remains much higher, possibly due to more successful 'masking' by girls, the gap continues to narrow.

Autistic Spectrum Disorder - Primary SEN Need (2022/23)

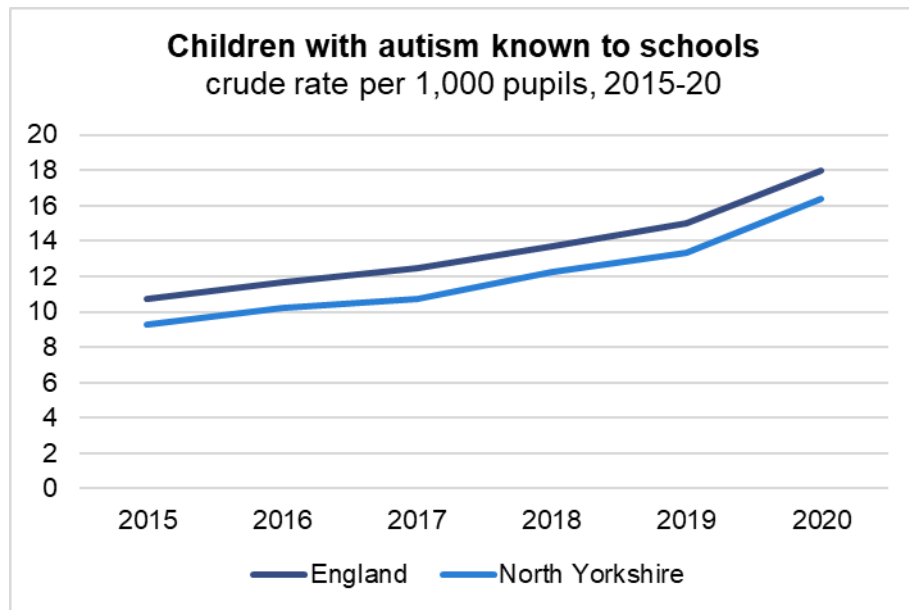
	Boys		Girls		All Pupils
Pupils on SEN support	63,854	70%	26,924	30%	90,778
Pupils with SEN with statements or EHC plan	91,730	79%	24,251	21%	115,981
Total	155,584	75%	51,175	25%	206,759

ASD Identified as Primary or Secondary Need (2022/23)

	Primary Need	Secondary Need	Total	Primary Need	Secondary Need	Total
Pupils on SEN support	90,779	16,497	107,276	1.0%	0.2%	1.2%
Pupils with SEN with statements or EHC plan	115,984	23,577	139,561	1.3%	0.3%	1.5%
Total	206,763	40,074	246,837	2.3%	0.4%	2.7%

Source: <https://explore-education-statistics.service.gov.uk/>

Trends in Autistic Spectrum Disorder Diagnoses



There has been a consistent increase in the proportion of children with autism known to schools. North Yorkshire rates have remained broadly in line with the national average.

Source: [Learning Disability Profiles](#), OHID Fingertips

This is in line with wider diagnosis trends, for example, a study by [Russell et al. 2021](#), showed that between 1998 and 2018 there was a 787% exponential increase in the incidence of autism diagnosis. This increase was largest in adults and in females compared to children and males respectively.

Reasons for increasing rates

Research including a 2021 study published in *The Journal of Child Physiology and Psychiatry* have found that:

- There has been a strong policy directive to provide earlier recognition and diagnosis.
- Autism symptom thresholds for diagnosis had dropped.
- There is a greater public awareness of autism and increased recognition of it among some minority ethnic groups.
- De-stigmatisation of the label, due to work by the neurodiversity movement and parent-led lobby groups, may have contributed to rising demand for diagnosis in order to access support.
- There have been concerted campaigns to raise awareness of autism among females and adults which may have led to increases in diagnosis in these cohorts.
- Some studies have suggested that an increase in 'autistic burnout', driven by long-term 'masking', may have driven a growth in demand for diagnosis, particularly amongst girls.
- Long waiting times for NHS diagnosis has led some families to seek assessment from private practitioners. Diagnoses made by private services are not routinely fed back to GPs, so the Clinical Practice Research Datalink (CPRD) is likely to underreport autism diagnoses. The actual increase in diagnosis may be even higher than is reported.

Source: [The Journal of Child Physiology and Psychiatry](#) and [UK Parliament](#)

Carers Survey

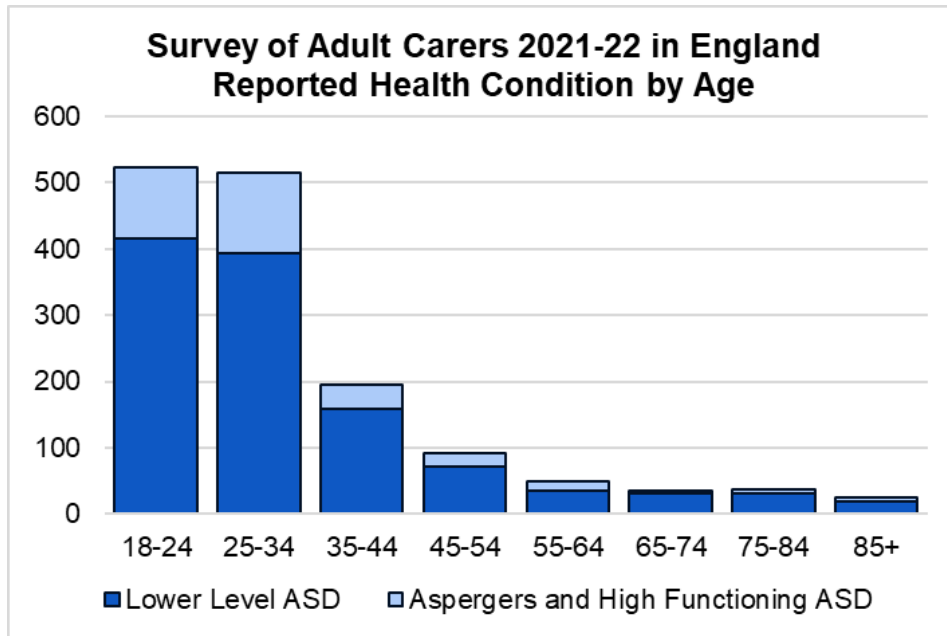


Table 2a of the Carers Survey provides a profile of answers for all questions by demographic group, based on two reported health conditions. It is not available at LA or region levels.

- It indicates 5.4% of cared for people have an ASD condition – 4.2% with lower level ASD and 1.0% with Asperger's or high functioning ASD.
- 'High-functioning' refers to those with autism who can generally function well in society. 'Lower level' refers to those who cannot generally function well in society and may need more support.
- The Carers Survey includes a table that extrapolates these survey figures to the number of carers identified in the Short and Long-Term care report (SALT), which gives 9.7% with lower level ASD and 5.7% with Asperger's or high functioning ASD.

Autism Waiting Times

(March 2023)

Sub ICB	Aged under 10	Aged 10 to 17	Aged 18 and over
NHS Barnsley	0%	16%	11%
NHS Bradford District & Craven	25%	25%	0%
NHS Calderdale	15%	14%	19%
NHS Doncaster	52%	54%	29%
NHS East Riding of Yorkshire	0%	5%	0%
NHS Hull	12%	9%	0%
NHS Kirklees	22%	23%	0%
NHS Leeds	22%	21%	43%
NHS North East Lincolnshire	15%	13%	0%
NHS North Lincolnshire	17%	15%	0%
NHS North Yorkshire	9%	11%	0%
NHS Rotherham	10%	11%	31%
NHS Sheffield	31%	40%	32%
NHS Vale of York	21%	22%	0%
NHS Wakefield	0%	0%	22%

- Proportion of patients with an open "suspected autism" referral in the month, that has been open for at least 13 weeks, receiving a first appointment after more than 13 weeks, March 2023.
- Guidance from NICE – nobody should wait for more than 13 weeks between being referred and first being seen.
- Data for England has not been released, due to a cyber attack.

Source: [Autism Waiting Time Statistics, NHS Digital](#)

Health Outcomes for Autistic People

Autistic people are more likely to have higher rates of physical and mental health conditions and additionally are more likely to receive poorer quality healthcare.

Some of these differences relate to the nature of autism, for example, autistic people may struggle to communicate symptoms. Additionally barriers may also arise from healthcare settings not sufficiently accounting for the needs of autistic patients.

- Chapter 6 of the government's autism strategy 2021-26 focuses on [Tackling Health and Care Inequalities for Autistic People](#)
- [Autistic adults have poorer quality healthcare and worse health based on self-report data - Weir et al. 2022](#)
- [A public health approach to reducing health inequalities among adults with autism – Sharpe et al. 2019](#)

Physical & primary health inequalities for autistic people:

- Most medical conditions are more prevalent in the autistic population including diabetes, hypertension and obesity. Autistic people experience premature mortality with life expectancy potentially reduced by 16–30 years. In-hospital mortality is also increased. Autistic people are over two times as likely to use A&E departments and to die after attending emergency care and three times as likely to require inpatient admission. (Doherty et al (2022))
- Autistic people were far less likely than non-autistic people to say that they could describe how their symptoms feel in their body, describe how bad their pain feels, explain what their symptoms are, and understand what their healthcare professional means when they discuss their health. Autistic people were also less likely to know what is expected of them when they go to see their healthcare professional, and to feel they are provided with appropriate support. (Weir et al (2022))
- Links between autism and poor health outcomes are well known with up to 30 years shorter life expectancy. GPs have limited training on autism and only a minority feel confident when treating autistic patients. Telephone triage has long been part of primary care delivery and the proportion of consultations offered by telephone increased markedly during the pandemic and continues to play a significant role in the delivery of health care. This can be challenging for autistic patients and affect access to care. Autistic adults report that barriers to primary care lead to poorer health outcomes, identifying predictability, sensory processing, and communication as key domains under which such barriers fall. Johnson, Doherty and Shaw (2022)

Mental health inequalities for autistic people:

Mental health inequalities:

- Almost 8 out of 10 autistic people without a learning disability experience mental health difficulties, more than 3 out of 10 autistic adults have attempted suicide (UK data) Cassidy and Rogers (2017)
- Autism and autistic traits are risk factors for suicidal behaviour – this study showed that evidence of autism was significantly higher in those who died by suicide (11.8%) than the 1.1% prevalence of autism in the UK and when autistic traits were taken into account this rose to 41%. Cassidy (2022)
- Mental health assessments and interventions developed for the general population often do not meet the unique needs of autistic people; for example, differences in social communication and camouflaging one's autistic traits, in order to “fit in” in social situations. Therefore, interventions need to be adapted in order to meet their needs. Camm-Crosbie et al (2018)
- the % of autistic people with mental health problems is 4 x higher (51%) than people without (11%), more than 25% of autistic people receive two or more diagnoses of mental health problems and around 15% of autistic people (compares to 2.8% of non autistic people) are hospitalised due to a mental health problem. Taylor (2021)

Autism and Mental Health

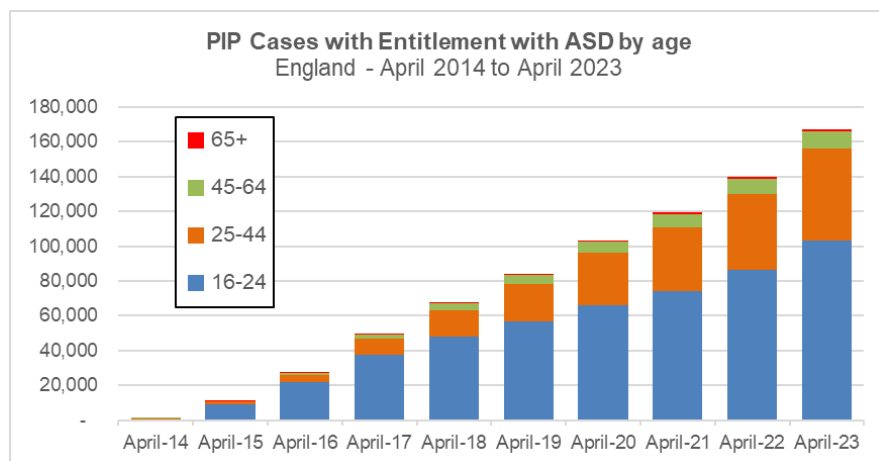
Whilst autism is not a mental health condition, autistic people are more likely to suffer from poor mental health. There is also evidence that autistic adults have higher rates of suicidal ideation and attempted suicide.

- Cassidy S, Rodgers J. Understanding and prevention of suicide in autism. *Lancet Psychiatry*. 2017 June 4(6)
- Mental health problems in autistic people Taylor (2021) MQ Mental Health Research
- Mona Johnson, Mary Doherty, Sebastian CK Shaw Overcoming barriers to autistic health care: towards autism-friendly practices *British Journal of General Practice* 2022; 72 (719): 255-256.
- Department of Health and Social Care: Suicide prevention strategy for England: 2023 to 2028 (Sept 2023)
- Arnold et al. 2019 Cohort profile: the Australian Longitudinal Study of Adults with Autism (ALSAA)

Benefits Data

- 4.9% of Personal Independence Payments (PIP) recipients nationally had an autistic spectrum disorder recorded as their main condition (October 2022).
- 75% of PIP claimants with an autistic spectrum disorder as their main condition were male.
- The specific disabilities recorded for these claimants were Autism (79%); Asperger syndrome (21%); and Retts disorder (0.3%)
- These figures above include only those for whom an autistic spectrum disorder was recorded as their main condition on their PIP claim. Other PIP claimants may have an autistic spectrum disorder in addition to their main recorded condition.

Source: [Autism: overview of policy and services, House of Commons Library, April 2023](#)



- Between April 2014 and April 2023 the number of PIP cases with entitlement who had ASD increased year on year from 802 to 167,064 nationally.
- In April 2023 cases for those aged 16-24 made up 62% of all cases with ASD whilst those aged 45-64 made up a further 32%.

Source: PIP data: Stat-Xplore

Rates across minority groups

Findings from University of Newcastle research published in March 2021:

- 1.76% of children in the UK were on the autistic spectrum.
- Black and Chinese pupils were 26% and 38% more likely to be autistic respectively.
- Prevalence was highest in pupils of black ethnicity (2.1%) and lowest in Roma/Irish Travellers (0.85%).
- Pupils with a record of autism in schools were 60% more likely to also be socially disadvantaged, and 36% less likely to speak English than pupils overall.
- 18.1% of pupils with a diagnosis of autism also had learning difficulties.
- Boys showed a prevalence of autism of 2.8% and girls showed a prevalence of 0.65%, with a boy-to-girl ratio of 4.3:1.

Source: [University of Newcastle](#)

Limitations of data sources

There are wide variations between the data sources on autism. This makes it difficult to accurately estimate the size and characteristics of the population within the community that have autism. However, a common factor across most data sources is increasing prevalence over time. This reflects improved recognition and diagnosis, particularly among children and younger people.

Long waiting times for assessments are thought to contribute to continued underdiagnosis, including for those in younger age groups. This means that levels of autism may still be underreported. Together with low levels of historic diagnosis, particularly for females and minority groups, this suggests that the actual number of people living with autism is likely to be far higher than is reflected in the data.

Conclusions

- Key projection tools have not kept up with improving data sets that better reflect whole-population prevalence and established trends amongst young people. Consider the wider range of data that is readily available for needs assessment and strategy development work.
- Data from schools census show rates of autism are higher in boy compared to girls (ratio of 4.3 to 1) and are highest in people of black and Chinese ethnicity.
- Rates of autism diagnosis are increasing, especially in adults and in women and girls.
- School data shows substantial variation in the proportion of pupils with ASD by local authority.
- Wait times show that across the Y&H an average of 16% of people with a suspected autism referral wait more than 13 weeks for their first appointment
- Data on prevalence in the adult population is limited and where it is collected it is not made available in useful formats. Discussions have begun with NHS Digital around this point. Consider identifying key data items for NHS Digital to make available at local authority and/or regional levels.
- Consider sharing data items held by individual authorities to extend this summary analysis – e.g. Survey of Adult Carers in England (SACE) reported health conditions, which could also be shared in future, each time the survey is submitted.