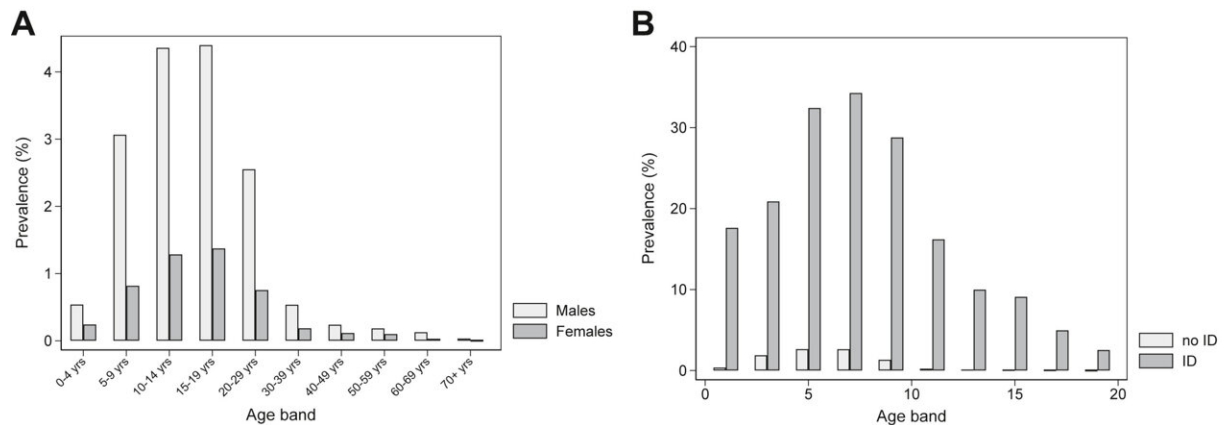


Number of autistic people in England may be twice as high as previously thought

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Percentage of individuals diagnosed autistic as of 2018: (A) stratified by sex and age-band; (B) stratified by co-occurring intellectual disability (ID) and age band. Credit: *The Lancet Regional Health - Europe* (2023). DOI: 10.1016/j.lanepe.2023.100626

The true number of autistic people in England may be more than double the number often cited in national health policy documents, suggests a new study by UCL researchers.

The first-of-its-kind research, published in *The Lancet Regional Health—Europe*, estimated how many adults in England may have undiagnosed autism.

To do this, the researchers calculated the number of people who had received an [autism diagnosis](#), from anonymized data from more than 5 million individuals registered at GP practices in England between 2000 and 2018.

They then compared these figures with a lower (c.1%) and upper (c.3%) estimate of how common autism really is in the population.

The lower estimate was based on the widely stated figure that around 1% of people in England are autistic. This came from [epidemiological research](#) published in 2011, before changes to the [diagnostic criteria](#) for autism that made them more inclusive.

Meanwhile, the upper estimate was based on rates of diagnosed autism in [young people](#) (aged 10–19) in the researchers' dataset. This is because young people are most likely to have had their autism recognized since providers are now very aware of autism in young people.

The team's estimates suggest that between 150,000 and 500,000 people aged 20 to 49 years old may be autistic but undiagnosed. Meanwhile, between 250,000 and 600,000 autistic people over the age of 50 may be undiagnosed—more than nine in 10 of all autistic people.

The midpoint of these figures translates to approximately 750,000 undiagnosed autistic people aged 20 and above, in England. This brings the total autistic population to over 1.2 million—approaching double the figure of 700,000 cited by the government for the entirety of the U.K.

Now researchers are calling for better access to diagnostic services for adults, and better support after diagnosis.

They also want to encourage greater acceptance and understanding of neurodiversity in society.

Lead researcher, post-doctoral researcher Elizabeth O'Nions (UCL Psychology & Language Sciences), said, "Historically, autism has been considered as a condition of childhood. But recently, awareness has been growing that it is present across the lifespan—in adults as well as young people.

"Nevertheless, autism is still under-recognized in adults. Our estimates suggest that about 180,000 people aged 20-plus had an autism diagnosis as of 2018, meaning that most autistic adults in England were undiagnosed.

"This matters because autistic people often experience discrimination and exploitation in society. They may have unmet support needs, even when they appear to be coping with life.

"Having a diagnosis means that someone can advocate for their right to reasonable adjustments and the support they need. Recognizing that someone with an [intellectual disability](#) is autistic can also help people to understand and support them better."

Autistic people may exhibit signs such as differences in their social communication and [social interaction](#), alongside restricted and repetitive patterns of behaviors, interests and activities.

Many [autistic people](#) require adjustments to be made to ensure equal access healthcare, employment, and local authority support.

Dr. O'Nions added, "Our findings indicate that there is still a substantial diagnostic gap in adults compared to children and young people when it comes to autism in England.

"This may partly reflect a lack of awareness and understanding of autism in adults on the part of healthcare professionals. Older adults may also

be less likely to self-identify as autistic, meaning that they do not come to the attention of services.

"Meanwhile, providers may be hesitant to raise the issue of [autism](#) given the uncertainty around waiting times for a diagnosis and the availability of support or specialist services post-diagnosis."

Study limitations

Primary care records are not directly linked to secondary care records, which could mean that some diagnoses are not represented in the study.

Meanwhile, the data does not cover all English GP practices, meaning that it wasn't possible to map local variation in diagnostic rates at a granular level.

More information: Elizabeth O'Nions et al, Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data, *The Lancet Regional Health—Europe* (2023). [DOI: 10.1016/j.lanepe.2023.100626](https://doi.org/10.1016/j.lanepe.2023.100626)

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