

One in every 64 children could have autism, Cambridge researchers find

Hundreds of thousands of children with autism have not been diagnosed, Cambridge University scientists have found.

*by Rebecca Smith, Medical Editor
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A study of schoolchildren in Cambridge has found that for every three children who have been diagnosed with autism spectrum disorder there are around two who have the condition but have not been given a formal diagnosis.

It is estimated that around one in 100 children between five-years-old and nine-years-old have autism, meaning there are around 500,000 in the UK. But when researchers carried out more detailed assessments of 11,700 children, they found the true prevalence could be as high as one in 64.

One in 10 children with autism overcome condition by age nine, study finds

This would mean that there are an additional 300,000 children in Britain with autism spectrum disorder but who have not yet been identified.

The study was led by Professor Simon Baron-Cohen at the Autism Research Centre and is published in the British Journal of Psychiatry.

Autism is a spectrum disorder with cases ranging from relatively mild problems with social interaction to more severe difficulties in behaviour such as not speaking, copying, rigid routines and social isolation.

Prof Baron-Cohen said: "We shouldn't assume that what we are currently

diagnosing is the full picture, there is no room for complacency. But equally we shouldn't be alarmist and say we should be going out and actively looking for these cases. We should wait until those people want help. It is always better if the patient or their family is looking for help rather than it being thrust upon them."

He said the undiagnosed cases are likely to be at the mild end of the spectrum, are coping well with their families and may not need a diagnosis.



Prof Baron-Cohen said that for some families the autism label may 'raise anxieties' and be intrusive, rather than helpful.

The researchers used the Special Educational Needs (SEN) registers in schools, covering 8,824 children attending 79 schools and found 83 cases of autism-spectrum conditions giving a prevalence of one in 106 children.

Then they sent a diagnosis survey to the parents of 11,700 children in Cambridgeshire. From the 3,373 completed surveys, 41 cases were reported corresponding to a prevalence of one in 101.

Finally, the team sent the Childhood Autism Screening Test (CAST) to parents of the same 11,700 children to help identify any undiagnosed cases of autism-spectrum conditions.

All children who scored highly, along with a selection of medium and low scorers, were called in for further assessment.

Excluding the 41 cases already known about, the team found an additional 11 children who met research diagnostic criteria for an autism spectrum

condition but had not yet been diagnosed.

The research said this could mean that for every three cases of autism spectrum that are diagnosed, there may be another two that are undiagnosed, giving a ratio of known to unknown cases of 3:2.

Prof Baron-Cohen said: "The two independent sources of information – the SEN register and diagnosis survey – provide converging evidence on the prevalence of autism spectrum conditions as being around one per cent of primary school-age children. This is about 12 times higher than 30 years ago; including the previously undiagnosed cases, this means that one in 64 children may at some point in their lives require support and services."

The increase in the prevalence of autism is probably due to better recognition of the condition by both parents and doctors, wider diagnostic criteria and more diagnostic services.

Prof Tony Charman, chairman in Autism Education, Institute of Education, London, said: "This study confirms findings from other recent work, including our own, that around one per cent of school age children have an autism spectrum disorder. The study also shows that in a significant proportion of cases children meeting research criteria for an autism spectrum disorder were unrecognised by schools and local health services. Accurate figures for the prevalence of autism spectrum disorders are important for planning health, social and education services."

Mark Lever, Chief Executive of the National Autistic Society, said: "This is important research, which for the first time gives us an estimate of the number of people who don't have an autism diagnosis but may be in need of support. Getting the right support at the right time is vitally important and access to appropriate diagnostic services is crucial."

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