

Autism diagnosis taking too long, experts say

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Medical experts in Newcastle, UK, say that children with autism spectrum disorder (ASD) are still being diagnosed later than they should be, meaning they are not getting access to specialist services early enough.

Their comments come as they publish a study which found that the age of diagnosis has not decreased in a decade - still averaging 4-and-a-half years (55 months).

In the biggest study undertaken in the UK of children with autism, the team analysed data between 2004 and 2014. Over this period, they found that even those classed as being diagnosed early - under the age of three - were identified at age 30 months, the same as a decade before.

The results are published today in the *Journal of Autism and Developmental Disorders*.

Early support needed

Lead author, <u>Dr Jeremy Parr</u>, who is a Clinical Senior Lecturer at Newcastle University and Honorary Consultant within Newcastle Hospitals said: "There's a growing body of evidence showing that early intervention can improve social and communication skills in children with <u>autism spectrum disorder</u>.

"Many children receive a diagnosis later than they could have done, this means that they and their parents have to struggle on longer than



necessary without suitable support or understanding of their child's difficulties.

"We need to improve awareness of the signs of autism spectrum disorder in very <u>young children</u>. We need health visitors and GPs to have the training and support to help them identify young children with ASD.

"Some children with autism are very difficult to diagnose as their difficulties are less obvious, and they won't be picked up until they're five or older. But for most children there are early signs of autism that could be picked up in the second or third year of life, if not before - signs such as limited social interaction, speech delay or loss of speech."

Autism database

The study, the largest of its kind involving 2,134 children and families, was made possible thanks to the <u>ASD-UK</u> database which gives accurate data about children with an ASD, as well as facilitating research and providing families with the opportunity to take part in research studies.

Boys, who as expected make up 82.7% of the database, were identified as getting an earlier diagnosis than girls and those with Asperger syndrome were diagnosed later. The team also found that children who were non-verbal or whose language repertoire included only single words or echoing sounds were diagnosed earlier.

This research was made possible because Dr Parr and team work as part of Newcastle Academic Health Partners, a collaboration involving Newcastle Upon Tyne Hospitals NHS Foundation Trust, Northumberland, Tyne and Wear NHS Foundation Trust and Newcastle University. This partnership harnesses world-class expertise to ensure patients benefit sooner from new treatments, diagnostics and prevention strategies.



Dr Parr adds: "We need to make more progress with education about the early signs of autism. To reduce the age at diagnosis we need early referrals to child health teams and then those teams need the resources to be able to see children in a timely fashion.

"We know that the waiting times to see an autism diagnosis specialist team can be vary greatly - between a few months and two years."

The research was funded by Autistica, the UK's leading autism research charity which funds and campaigns for research to understand the causes of autism, improve diagnosis, and develop evidence-based interventions.

Jon Spiers, chief executive of Autistica, said: "This research shows that the age of diagnosis for children with autism remains as unacceptably high as it was ten years ago.

"We need research to find ways to speed up diagnosis and to help identify those left isolated for too long, such as girls with autism.

"A diagnosis is a key milestone for children and their families: an opportunity to provide them with understanding and access to high quality services and support."

It is estimated that there are around 700,000 people in the UK living with autism - that's more than 1 in 100.

Carol Povey, Director of the National Autistic Society's Centre for Autism, said: "This important study shows that professionals still aren't picking up the signs of autism early enough.

"An early diagnosis can be life-changing for families. It can help them understand their son or daughter, give them essential information about what might help and unlock professional advice and support.



"Growing up with autism can be difficult but we've seen again and again how understanding and support can make a huge difference."

Provided by Newcastle University

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