

## New UK report reveals autism assessment and support crisis

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A report published today (Friday 2 February) by the Child of the North initiative—led by the N8 Research Partnership and former Children's Commissioner Anne Longfield's new Center for Young Lives think tank,



reveals a crisis in children's autism assessment.

<u>The report</u> warns that thousands of <u>autistic children</u> and young people are waiting months—or even years—for health and education support.

With the number of children accessing autism services now at a record high, the report, A country that works for all children and young people: An evidence-based plan for addressing the autism <u>assessment</u> and support crisis shows how most parents are being left to navigate a complex support system for their autistic child that is hampered by processing delays and waiting lists.

The University of Liverpool's Professor Melissa Gladstone, a co-author of the report, said, "The number of children accessing autism services is at a record high with the majority of children waiting for as long as two or three years for assessments. If we want to ensure an inclusive society that respects the rights of all children, we need to move away from a 'diagnosis-led' system to one where we can promote inclusion and well-being from a needs-led approach from as early as possible. This report tackles some of these issues and provides recommendations about how we can move forward to addressing these huge inequalities in care for children."

The report sets out a number of key recommendations for tackling the assessment crisis, calling for a "needs-led" approach instead of relying on a "diagnosis-led" system, where early identification becomes the norm and faster effective support is offered without relying on a diagnosis. It argues that children and young people with autism and conditions such as ADHD can thrive in mainstream education if their needs are supported in a timely way. Early identification and support can mitigate the negative and costly effects on autistic children's physical health.



It highlights how since COVID-19 there has been a 306% increase in the number of children waiting for an autism assessment. Just 1 in 10 children are receiving an appointment within 13 weeks of being referred, while more than 1 in 4 parents have waited over three years to receive support for their child.

The report warns that the failure to provide the right autism support can lead to poor long-term outcomes for autistic children, including an increased prevalence of connected conditions such as mental ill health and a greater risk of school exclusion or not attending school. Data from the Connected Bradford database included in the report reveals that children who had been referred but were still waiting for an assessment were at greatest risk of being excluded from secondary school.

Autistic children who had a diagnosis were less likely to be excluded from school, compared to those awaiting an assessment, suggesting a diagnosis and subsequent support has a protective effect. With waiting times increasing, there is a growing risk to education outcomes, with evidence suggesting that many autistic children are ending up in expensive Alternative Provision.

The report also describes how a major barrier to existing systems is the perceived need for a medical diagnosis of autism before any child can receive support, with the perception among schools that this is a requirement, preventing some children from accessing support. Given the long waiting lists, many autistic children are not receiving the support they need because they do not have a formal diagnosis.

The report also argues that planning and resourcing for diverse needs should be baked into the school system, rather than seeing both as an optional extra. This could include relaxing individual school uniform policies to support autistic pupils with sensory issues who can't tolerate wearing a uniform, removing the sounding of a bell between classes to



generate a calmer atmosphere, and a consistently structured school day with calm transitions between lessons and lunch time.

Anne Longfield, Executive Chair of the Center for Young Lives, said, "The number of autistic children seeking support is at a record high and the number waiting for an assessment has rocketed since COVID. The autism assessment crisis is leaving thousands of children without the support they need and parents having to battle their way through a nightmare process that can take years to resolve.

"The pressure and stress this is putting on families and children can have terrible and damaging consequences for mental health and for children's education chances. Autistic children with a referral who are waiting for an assessment are at significantly greater risk of exclusion from school, with all the further risks that can bring. If waiting times continue to increase, so can the risk of increased exclusion and poorer educational outcomes for autistic children.

"The evidence shows the need to move to a system of support that responds to the needs of autistic children, rather than waiting for diagnosis before any help appears. The <u>education sector</u> and <u>health</u> <u>services</u> should be working together, sharing data and information, and building local partnerships that can transform the <u>support</u> autistic children receive.

"Without urgent reform, we cannot hope to improve the life chances of the next generation. As this report highlights, change is possible—and it is happening in some schools and local areas already. What is needed now is the determination from the Government and others to make it happen everywhere."

**More information:** An evidence-based plan for addressing the autism assessment and support crisis. <a href="www.n8research.org.uk/media/CotN-">www.n8research.org.uk/media/CotN-</a>



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