

Autistica Action Briefing: Children and Young People's Mental Health

AUTISTICA

Harper G, Smith E, Simonoff E, Cawley L, Maxwell-Scott C, Davie M.

March 2019

Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about mental health problems among autistic children. It was developed in collaboration with leading researchers, autistic people and families with lived experience as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, health services, schools and public research funders to act on this information. We know more about the mental health problems young autistic people face than ever; services and policies need to catch up.

"My 10yr old son was referred to CAMHS because he kept saying he wished he was dead and talked about stabbing himself in the chest. A month later we received a letter to say that there was nothing they could do at this time and that 'Mum should keep sharp objects out of reach'" ¹

What we know

"My daughter had been rejected by CAMHS three times and had a suicide attempt aged 11" ¹

- **7 in 10 autistic children** have a mental health condition. 4 in 10 autistic children have more than one.²
- **Anxiety disorders are the most common type of mental health problem for autistic children to develop, affecting more than 4 in 10.**² Whilst we still need to understand more about the underlying cases, research shows that anxiety in autistic children is strongly associated with uncertainty,^{3,4,5} sensory differences,^{4,6,7} and social and communication difficulties.⁸
- **Autistic children are routinely denied access to mental health support for arbitrary reasons.** Some children's mental health problems are dismissed as untreatable after being confused with autistic traits.^{1,9} Others have been refused help from CAMHS who did not feel equipped to support them or told that CAMHS are not commissioned or funded to see autistic children. There are rarely any other services for those families to turn to, frequently leading to no professional mental health support being given.^{1,10,11,12}
- **Young autistic people with suicidal thoughts have been denied access to CAMHS.**^{1,13,14} Some overstretched services are forced to use risk assessment tools to determine who to support with restricted capacity. This practice is explicitly criticised in NICE guidelines,¹⁵ has been a repeated theme in inquests¹⁶ and is particularly dangerous for autistic children, especially girls, whose suicide risk is even less likely to be predicted by these tools.¹⁷ One small study found that autistic children are 28 times more likely to consider or attempt suicide than their non-autistic peers.¹⁸
- **Mental health treatments may need to be adapted to meet the needs of autistic people.** For example, there is a developing body of evidence around the need to adapt therapies such as CBT^{19,20}, and the increased effectiveness of these therapies when adaptations are made.^{21,22,23}

What we need to find out

"My daughter went through CAMHS at around 14 with severe anxiety at school. We were told there would be no treatment, because 'autistic people ARE anxious'" ¹

The **number one research priority** for autistic people, families and researchers is finding and adapting interventions to improve mental health in autistic people.²⁴ Most mental health interventions are tested only with adults, and autistic children are particularly likely to be excluded. This exacerbates the knowledge gap on what works for autistic children. Key research questions include:

- What are the environmental and biological causes of anxiety disorders in autistic children, and how do these vary from non-autistic children?
- Do autistic children respond differently to mental health therapies? How does this compare to their non-autistic peers? How can we personalise therapies of autistic people?
- What clinical indicators should health professionals look for to identify mental health problems in young autistic people?²⁵

- Are healthcare professionals in CAMHS confident in supporting autistic children with mental health problems? Are they confident in identifying and supporting co-occurring neurodevelopmental conditions like ADHD which may influence the treatment of these mental health problems?
- What non-pharmacological mental health interventions are effective in helping autistic children and young people with learning disabilities?²⁵

What we should do now

“When he was 8, my son would say that he didn’t see the point in living. When he was 13, he would ask if I thought he could cope in the world when he grew up. Three years later he has grown lonely, depressed and reclusive”

- The Government has announced that the review of its Autism Strategy²⁶ will consider the needs of children as well as adults.²⁷ Mental health problems are the community’s top research priority,²⁴ as well as one of the most common and difficult challenges a young autistic person is likely to face.

The new sections for children within the Autism Strategy should focus on improving access to effective and consistent mental health support.

- Mental health problems like anxiety are the norm, not the exception for autistic children.² Local CAMHS systems should therefore be prepared and resourced to support autistic children as an explicit part of the commissioning process.

NHS England should work with local Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) to ensure that every area has prepared clear pathways for young autistic people to access mental health support.

- The disparity between the demand for and funding of CAMHS is forcing services to make impossible decisions about who to support. Some services are using suicide risk assessment tools to set those access thresholds. Using these tools with such a limited evidence base is dangerous, particularly for young autistic people whose risk of suicidal behaviour is both higher and less likely to be predicted by those tools.^{17,18}

The Long Term Plan promises investment in specialist community teams to support autistic children and their families.²⁸ Investment in those community teams must be sufficient for CAMHS to dismantle the arbitrary thresholds that prevent families from accessing support before autistic people reach a crisis.

- The NHS Long Term Plan includes commitments to develop support packages for autistic children throughout the diagnostic process and to provide designated keyworker support to those with the most complex needs.²⁸

These programmes should focus on identifying mental health difficulties like anxiety earlier and supporting families with adjustments and coping mechanisms to prevent problems from escalating.

1 Autistica (Unpublished). A survey of the autism community’s experiences with mental health services, conducted during Mental Health Awareness Week 2018.

2 Simonoff E, et al. (2008) Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample. Journal of the American Academy of Child and Adolescent Psychiatry 47(8), 921. <[ncbi.nlm.nih.gov/pubmed/18645422](https://doi.org/10.1097/00004583-200808000-00012)>

3 Rodgers J, et al. (2017) Towards a Treatment for Intolerance of Uncertainty in Young People with Autism Spectrum Disorder: Development of the Coping with Uncertainty in Everyday Situations (CUES) Programme. J Autism Dev Disord 47(12), 3959-3966. <[ncbi.nlm.nih.gov/pubmed/29415558](https://doi.org/10.1007/s11867-017-0966-2)>

4 South M & Rodgers J (2017). Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders. Frontiers in Human Neuroscience 11, 20. <[ncbi.nlm.nih.gov/pubmed/29415558](https://doi.org/10.3389/fnhum.2017.00120)>

5 Autistica (2018). Research projects: Coping with uncertainty. <[autistica.org.uk/our-research/research-projects/coping-with-uncertainty](https://www.autistica.org.uk/our-research/research-projects/coping-with-uncertainty)>

6 Green S & Ben-Sasson A (2010) Anxiety Disorders and Sensory Over-Responsivity in Children with Autism Spectrum Disorders: Is There A Causal Relationship? J Autism Dev Disord 40(12), 1495-1504. <[ncbi.nlm.nih.gov/pubmed/20980623](https://doi.org/10.1007/s11867-010-0623-2)>

7 Autistica (2018). Research projects: Sensory reactivity and anxiety. <[autistica.org.uk/our-research/research-projects/sensory-reactivity-and-anxiety](https://www.autistica.org.uk/our-research/research-projects/sensory-reactivity-and-anxiety)>

8 Pickard H, et al. (2017) Are Social and Communication Difficulties a Risk Factor for the Development of Social Anxiety? J Am Acad Child Adolesc Psychiatry 56(5), 344-351. <[jaacp.org/article/S0890-8567\(17\)30020-5/fulltext](https://doi.org/10.1097/00004583-201705000-00012)>

9 Matson J & Williams L (2013) Differential diagnosis and comorbidity: distinguishing autism from other mental health issues. Neuropsychiatry 3(2), 233-243 <[bit.ly/2EQZ78L](https://doi.org/10.1080/14747360.2013.778171)>

10 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters. October 2018.

11 Crane L, et al. (2018) ‘Something needs to change’: Mental health experiences of young autistic adults in England. Autism. <[ncbi.nlm.nih.gov/pubmed/29415558](https://doi.org/10.1177/1063426918771555)>

12 National Autistic Society (2010). You Need To Know. <[autism.org.uk/~media/NAS/Documents/Campaigns/You-Need-To-Know/You-Need-To-Know-Campaign-report-ashx?abc=pdf](https://www.autism.org.uk/media/NAS/Documents/Campaigns/You-Need-To-Know/You-Need-To-Know-Campaign-report-ashx?abc=pdf)>

13 Health Committee, Oral Evidence: Child and adolescent mental health services: access and funding, HC 522, 21 November 2017. <[bit.ly/2E9k1c1](https://www.parliament.uk/business/committees/committees-a-z/commons-oral-evidence/written-evidence/2017-18/child-and-adolescent-mental-health-services-access-and-funding)>

14 Education Policy Institute (2018). Access to children and young people’s mental health services – 2018. <[epi.org.uk/wp-content/uploads/2018/10/EPI-Access-to-CAMHS-2018.pdf](https://www.eppi.org.uk/wp-content/uploads/2018/10/EPI-Access-to-CAMHS-2018.pdf)>

15 NICE (2011). Do Not Do Recommendation – Risk assessment tools <[nice.org.uk/donotdo/do-not-use-risk-assessment-tools-and-scales-to-determine-who-should-and-should-not-be-offered-treatment-or-who-should-be-discharged](https://www.nice.org.uk/donotdo/do-not-use-risk-assessment-tools-and-scales-to-determine-who-should-and-should-not-be-offered-treatment-or-who-should-be-discharged)>

16 Wilcox F (2018). Regulation 28 Report To Prevent Future Deaths re: Maximillien Conrad Kohler. <[bit.ly/2Ezvh7r](https://www.regulation28.gov.uk/reports/2018/01/wilcox-f-2018)>

17 Cassidy S, et al. (2018) Measurement properties of tools used to assess suicidality in autistic and general population adults: A systematic review. Clinical Psychology Review 62:56-70. <[bit.ly/2HqJ7LL](https://doi.org/10.1016/j.cpr.2018.04.001)>

18 Mayes SD (2013) Suicide ideation and attempts in children with autism. Research in Autism Spectrum Disorders. 7 (1), 109-119. <[sciencedirect.com/science/article/pii/S1750946712000931](https://doi.org/10.1016/j.rasd.2012.09.001)>

19 Cooper K, et al. (2018) Adapting psychological therapies for autism. Research in Autism Spectrum Disorders 45, 43-50. <[ncbi.nlm.nih.gov/pubmed/29415558](https://doi.org/10.1016/j.rasd.2017.11.001)>

20 NICE Clinical Guideline [CG170] Autism spectrum disorder in under 19s: support and management. <[nice.org.uk/guidance/CG170](https://www.nice.org.uk/guidance/CG170)>

21 Rodgers J & Ofield A (2018) Understanding, Recognising and Treating Co-occurring Anxiety in Autism. Curr Dev Disord Rep 5(1), 58-64. <[link.springer.com/article/10.1007/s40474-018-0132-7](https://doi.org/10.1007/s40474-018-0132-7)>

22 Zaboski B & Storch E (2018) Comorbid autism spectrum disorder and anxiety disorders: a brief review. Future Neurology 13(1). <[ncbi.nlm.nih.gov/pubmed/29415558](https://doi.org/10.1586/1547-0274.2018.13.1.1)>

23 Van Steensel FJA and Bögels SM (2015) CBT for anxiety disorders in children with and without autism spectrum disorders. J Consult Clin Psychol 83(3), 512-523. <[ncbi.nlm.nih.gov/pubmed/25894668](https://doi.org/10.1037/xap0000068)>

24 Autistica (2016). Your questions: shaping future autism research. <[autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf](https://www.autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf)>

25 Autistica (2018). National research funders prioritise mental health of autistic people. <[autistica.org.uk/news/5-ways-the-government-can-transform-mental-health-in-autism](https://www.autistica.org.uk/news/5-ways-the-government-can-transform-mental-health-in-autism)>

26 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <[bit.ly/2RPp0LZ](https://www.parliament.uk/business/committees/committees-a-z/commons-oral-evidence/written-evidence/2019-20/health-and-social-care-oral-questions-on-15th-jan-2019)>

27 GOV.UK (2018). Government review to improve the lives of autistic children. Available: <[gov.uk/government/news/government-review-to-improve-the-lives-of-autistic-children](https://www.gov.uk/government/news/government-review-to-improve-the-lives-of-autistic-children)>

28 NHS (2019). The NHS Long Term Plan. <[longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf](https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf)>