

Autistica Action Briefing: Suicide Prevention

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about suicide in the autistic community. It was developed in collaboration with leading researchers, autistic people and bereaved family members as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, local authorities, services and public research funders to act on this information. The evidence about suicide in the autistic community has evolved rapidly in recent years; prevention efforts must now do so as well.

"You go to the professionals thinking these people have trained for years and years and years and they will know. Someone will know... Charlotte died on 25th January 2016, on her own, locked in her room, mobile phone switched off." ¹

What we know

"Both my sons were refused assistance because they had not attempted suicide and were therefore 'not severe enough' despite self-harming."¹⁶

- **A disproportionate number of people who die by suicide are autistic.** Ongoing research suggests that up to 11% of people who die by suicide in the UK may be autistic², even though only 1% of the population is on the spectrum.³ Those UK numbers are preliminary but fall within the range found by a Swedish population-level study^{4,5} and are supported by a rapidly growing international evidence base around suicidality and autism.^{6,7,8,9}
- **Suicide is a leading cause of early death within the autistic community.** Autistic people are substantially more likely to consider, attempt, and die by suicide than other groups.^{4,5,10,11,12,13} In 2018, NICE guidance on suicide prevention recognised autistic people as being among those at highest risk.¹⁴
- **Autistic women are markedly more likely to die by suicide than non-autistic women.**^{4,5,11} It appears that an even greater proportion of women who die by suicide are autistic, compared to men.
- **Young autistic people with suicidal thoughts have been denied access to CAMHS.**^{15,16,17,18} Some overstretched services are forced to use risk assessment tools to determine who to support with limited capacity. This practice is explicitly criticised in NICE guidelines¹⁹, has been a repeated theme in inquests²⁰ and is particularly dangerous for autistic children, especially girls, whose suicide risk is even less likely to be predicted by those tools.²¹ One small study found that autistic children are 28 times more likely to consider or attempt suicide than their non-autistic peers.¹³
- **Factors known to increase people's risk of suicide are more common in the autistic community**, including social isolation, unemployment, trauma, abuse and other social and biological factors that increase the likelihood of mental health problems.^{22,23,24,25,26} However, autistic people are still more likely to have suicidal thoughts in studies where both they and non-autistic people have the same rates of these risk factors.⁷ It's also likely that autistic people face other issues that make them more likely to consider ending their own lives.^{27,28}
- **Autistic people struggle to access appropriate support for mental health problems or suicidal thoughts.**^{15,16,21,29} Some suicide prevention organisations are now exploring ways to make their services more accessible to autistic people.^{30,31}

"I was discharged from adult mental health services on two occasions while suicidal. On one of those occasions I was discharged directly after a suicide attempt. The reasoning was that the services didn't feel equipped to offer psychological support to me due to my ASD."¹⁵

What we need to find out

“With the words ‘help me’ screaming in my head, I was too afraid to pick up the phone”¹⁶

Mental health is the autism community’s top priority for research,³² yet research into autism and suicidality remains under-developed. This represents failure to listen to autistic people and families and lack of strategic direction within autism science.

Autistica, the International Society for Autism Research and the James Lind Alliance are supporting researchers from the Universities of Nottingham, Newcastle and Coventry to work with the autistic community in identifying the next steps for research.³³ Their **recommendations are due in 2019 and should become the basis of an international collaboration** to prevent suicides in the autistic community. Priorities will likely include:

- What adjustments help autistic people at risk of suicide access support when they are at crisis point?³⁴
- How does social camouflaging²⁷ influence suicidality amongst autistic people?
- Which life events and environmental, behavioural or biological risk factors affect the onset of mental health problems or suicidality in autistic people?
- What is the developmental trajectory of suicidal thoughts and behaviours in autistic people?
- Why are autistic women so much more likely to die by suicide than non-autistic women? Do the methods used for suicide attempts differ between these groups?
- Does help-seeking behaviour differ between autistic people and non-autistic people?

What we should do now

- A connection had barely begun to be made between suicide and autism when the Autism Act (2009)³⁵ and Think Autism Strategy (2014)³⁶ were published. The Government recently made reducing early death the primary aim of the Autism Strategy^{37,38} and have now launched a review of the Strategy for the future.³⁹

To reduce early death, the Department of Health and Social Care must ensure that suicide prevention becomes a “priority challenge for action”,⁴⁰ as part of a wider theme on reducing morbidity and mortality following their review.

- In the Government’s Fourth Progress Report on Preventing Suicide in England, the Minister for Suicide Prevention made a welcome commitment to exploring what more can be done to meet the specific needs of autistic people at risk of suicide.⁴¹

We invite the Minister to join the collaboration between researchers and charities looking at research priorities in this area. Her Department and the National Institute for Health Research should consider what they can do to help close the most pressing evidence gaps around prevention.³³

- 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.^{13,21}

The Long Term Plan promises investment in specialist community teams to support autistic children and their families.⁴² 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.

- Autistic people are almost never mentioned in local suicide prevention plans. The guidance informing local authorities about suicide prevention planning is currently being reviewed.

Public Health England should take this opportunity to update that guidance and encourage local authorities to consider the autistic community in their prevention plans.

- The lack of recorded diagnoses amongst autistic adults and the manner in which suicide datasets are currently collated means they are unlikely to reliably represent the deaths of autistic people. The Health and Wellbeing Alliance⁴³ are currently developing a pro-forma to support coroners in identifying relevant factors surrounding deaths by suicide.

This pro-forma should allow for recognition of an autism diagnosis in order to better record the true scale of deaths by suicide in the autistic community.

- 1 Autistica (2017). One Size Doesn't Fit All Campaign. For more information: <autistica.org.uk/get-involved/lets-work-together/one-size-doesnt-fit-all-campaign>
- 2 Autistica (2017). Our current research projects – understanding suicide in autism. <autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism>
- 3 Brugha T, et al. (2011). Epidemiology of Autism Spectrum Disorders in Adults in the Community in England. Archives of General Psychiatry. 68 (5), 459-66. <ncbi.nlm.nih.gov/pubmed/21536975>
- 4 Hirvikoski T, et al. (2016). Premature mortality in autism spectrum disorder. The British Journal of Psychiatry, 207(5), 232-8. <ncbi.nlm.nih.gov/pubmed/26541693>
- 5 Autistica (2016). Personal tragedies, public crisis: The urgent need for a national response to early death in Autism. <autistica.org.uk/downloads/files/Personal-tragedies-public-crisis-ONLINE.pdf>
- 6 Segers M & Rawana J (2014) What do we know about suicidality in autism spectrum disorders? A systematic review. Autism Res. 5;7(4):507-21 <ncbi.nlm.nih.gov/pubmed/24798640>
- 7 Chen MH, et al. (2017). Risk of Suicide Attempts Among Adolescents and Young Adults With Autism Spectrum Disorder: A Nationwide Longitudinal Follow-Up Study. J Clin Psychiatry. 78(9):e1174-e1179. <ncbi.nlm.nih.gov/pubmed/28872268>
- 8 Kirby A, et al. (2019). A 20-year study of suicide death in a statewide autism population. Autism Research. <onlinelibrary.wiley.com/doi/full/10.1002/aur.2076>
- 9 Hedley D and Ulljarević M. (2018) Systematic Review of Suicide in Autism Spectrum Disorder: Current Trends and Implications. Current Developmental Disorders Reports 5(1), 65-76. <link.springer.com/article/10.1007%2Fs40474-018-0133-6>
- 10 Balfe M, et al. (2010). A descriptive social and health profile of a community sample of adults and adolescents with Asperger syndrome. BMC Research Notes, 3: 300. <bmcr.esnotes.biomedcentral.com/articles/10.1186/1756-0500-3-300>
- 11 Cassidy S, et al. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. Lancet Psychiatry 1, 2, 142-7. <docs.autismresearchcentre.com/papers/2014_Cassidy_et_al_Suicidality_LancetPsychiatry.pdf>
- 12 Raja M (2014) Suicide risk in adults with Asperger's syndrome. Lancet Psychiatry. 1(2), 99-101. <[thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366\(14\)70257-3.pdf](http://thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(14)70257-3.pdf)>
- 13 Mayes SD (2013) Suicide ideation and attempts in children with autism. Research in Autism Spectrum Disorders. 7 (1), 109-19. <sciencedirect.com/science/article/pii/S1750946712000931>
- 14 NICE guideline [NG105] Preventing suicide in community and custodial settings. <nice.org.uk/guidance/ng105>
- 15 Autistica (Unpublished). What would a more inclusive and supportive society look like? Online consultation of autistic people and supporters, conducted in October 2018.
- 16 Autistica (Unpublished). A survey of the autism community's experiences with mental health services, conducted during Mental Health Awareness Week 2018.
- 17 Health Committee, Oral Evidence: Child and adolescent mental health services: access and funding, HC 522, 21 November 2017. <bit.ly/2E9klc1>
- 18 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>
- 19 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>
- 20 Wilcox F (2018). Regulation 28 Report To Prevent Future Deaths re: Maximilien Conrad Kohler. <bit.ly/2Ezvh7r>
- 21 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. <sciencedirect.com/science/article/pii/S0272735818300692?via%3DIihub>
- 22 Serretti A & Fabbri C (2013) Shared genetics among major psychiatric disorders. The Lancet 381(9875), 1339-1341. <ncbi.nlm.nih.gov/pubmed/23453886>
- 23 Lever A & Geurts H (2016) Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. J Autism Dev Disord 46(6), 1916-1930. <ncbi.nlm.nih.gov/pubmed/26861713>
- 24 Orsmond G, et al. (2004) Peer Relationships and Social and Recreational Activities Among Adolescents and Adults with Autism. J Autism Dev Disord 34(3), 245-256. <ncbi.nlm.nih.gov/pubmed/15264493>
- 25 National Autistic Society (2016). The autism employment gap: Too Much Information in the workplace. <autism.org.uk/get-involved/tmi/employment.aspx>
- 26 Autistica (2016). Our current research projects – Why are autistic people more vulnerable? <autistica.org.uk/our-research/research-projects/why-are-autistic-people-more-vulnerable>
- 27 Cassidy S, et al. (2018) Risk markers for suicidality in autistic adults. Molecular autism, 9:42. <molecularautism.biomedcentral.com/articles/10.1186/s13229-018-0226-4>
- 28 Pelton MK & Cassidy S (2017). Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample. Autism Res. 10(11):1891-1904. <onlinelibrary.wiley.com/doi/full/10.1002/aur.1828>
- 29 Camm-Crosbie L, et al. (2018) 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. Autism. <journals.sagepub.com/doi/full/10.1177/1362361318816053>
- 30 National Suicide Prevention Alliance (2018). Personal experience: Designing support services with autistic people. <nspa.org.uk/home/our-work/world-suicide-prevention-day-2018/bereavement-and-personal-experience/#autistic-people>
- 31 Morgan L, American Association of Suicidology & Common Ground (2018). Crisis Supports for the Autism Community. <[suicidology.org/Portals/14/Autism%20Crisis%20Supports%20\(FINAL\).pdf?ver=2018-10-22-120024-940](http://suicidology.org/Portals/14/Autism%20Crisis%20Supports%20(FINAL).pdf?ver=2018-10-22-120024-940)>
- 32 Autistica (2016). Your questions: shaping future autism research. <autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf>
- 33 Mental Health in Autism (2018). INSAR Policy Briefing. <sites.google.com/view/mentalhealthinautism/projects/insar-policy-briefing>
- 34 Autistica (2018). National research funders priorities mental health of autistic people. <autistica.org.uk/news/5-ways-the-government-can-transform-mental-health-in-autism>
- 35 HM Government (2009). Autism Act 2009. <legislation.gov.uk/ukpga/2009/15/pdfs/ukpga_20090015_en.pdf>
- 36 DHSC (2015). 'Think Autism': an update to the government adult autism strategy. <gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
- 37 DHSC (2018). Think Autism strategy: governance refresh 2018. <gov.uk/government/publications/think-autism-strategy-governance-refresh-2018>
- 38 Autistica (2018). Government to make early death top priority for autism policy. <autistica.org.uk/news/government-make-early-death-the-top-priority-for-autism-policy>
- 39 Hansard (2019). Minister of State for Care, responding to Health and Social Care Oral Questions on 15th Jan 2019. <bit.ly/2RPoolZ>
- 40 DHSC (2015). Think autism: updating the 2010 adult autism strategy. <webarchive.nationalarchives.gov.uk/20150601164549/http://autismstrategy.dh.gov.uk/15-priority-challenges>
- 41 HM Government (2019). Preventing suicide in England: Fourth progress report of the cross-government outcomes strategy to save lives. <bit.ly/21vqOZ>
- 42 NHS (2019). The NHS Long Term Plan. <longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan.pdf>
- 43 NHS England. Partnerships and relationships. <england.nhs.uk/ourwork/part-rel/>