

AUTISTICA

Building brighter futures through autism research

**The latest evidence about suicide
in the autistic community**

The key messages:

1. This is **not a niche issue**.
2. There are **implications for suicide prevention**.
3. Stuff is happening. **You can help**.

1. This is **not a niche issue.**



1%

of the population
is autistic

11%

of people who die by
suicide may be autistic*

Please note these are the **preliminary results of a Psychological Autopsies study being conducted at Nottingham University. This closely matches the results found in a large international epidemiological study but has not yet been peer reviewed.*

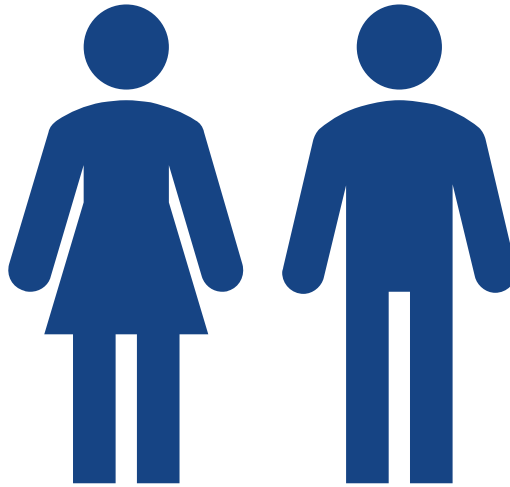
www.autistica.org.uk/our-research/research-projects/understanding-suicide-in-autism



28

Autistic children may be up to 28 times more likely to consider or attempt suicide

- 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](https://www.sciencedirect.com/science/article/pii/S1750946712000931)>



Autistic women are significantly more likely to die by suicide than non-autistic women

- 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>
- 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>
- 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>

Further research into deaths by suicide amongst autistic women and men is currently underway in Sweden.



Known risk factors for suicide are more common in the autistic community



There may also be unique risk factors in the autistic community

- 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](https://pubmed.ncbi.nlm.nih.gov/26861713/)>
- 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](https://pubmed.ncbi.nlm.nih.gov/15264493/)>
- National Autistic Society (2016). The autism employment gap: Too Much Information in the workplace. <autism.org.uk/get-involved/tmi/employment.aspx>
- 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>
- 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>
- 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>

2. There are **implications for suicide prevention.**



Autistic people rarely appear in local suicide datasets or prevention action plans

Because the majority of autistic adults do not have a recorded diagnosis

In the middle of those crisis moments, with the words "help me" screaming in my head, I was too afraid to pick up the phone

I went to my GP when I was about 16 with suicidal thoughts.... She just said go home and call my mum...she thought I wasn't emotional enough to mean what I was saying

I was discharged from adult mental health services on two occasions while suicidal.... The reasoning was the services didn't feel equipped to offer psychological support to me due to my ASD

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

Try having a meltdown because the noise in your head will not go away, whilst trying to look and act normal, whilst trying to hide from suicide

Having being turned away last time I do not now feel able to ask

*"It took my daughter's attempted suicide at the age of 14 to get her **the help she truly needed**. It is a shame that sometimes one has to sink to the very depths before being able to rise from the ashes."*

*I want mh professionals to listen to my words... **My appearance may not match what you expect**, but I'm a frank and truthful person. Listen to my words.*

*I can't talk when I'm distressed. I don't even know what would happen if I did call. A phone number you can't access isn't a service for you. **I need timely, non-verbal, crisis options to keep me safe and I need them now"***

*I do not want to end my life but I am repeatedly driven into crisis by **a bewildering system**.*

*I have constantly fought the part of myself that wants to die. **I brutally punished myself even for thinking about it**. I could not understand that 'fighting suicidal ideation' didn't mean 'punching the person who had suicidal ideation in the face'.*

When I'm suicidal, I am completely alone.



Some autistic people struggle to talk over the phone. Do you have services available online or by text?



Autistic people in distress may not look the way you expect. Don't make assumptions about why an autistic person feels or has decided something. Start by believing them and asking them why.

one size doesn't fit ALL



Autistic people with alexythmia may struggle to identify or communicate their feelings. Try using logical language rather than emotional words. Some autistic people may find it easier to compare how they feel to another occasion or a personal scale.



Autistic people may struggle with metaphors or colloquial language like “are you feeling down”. Try to be direct when communicating with them and avoid euphemisms. Give people extra time to process and respond to questions.

3. Stuff is happening
You can help by...

...Informing research / policy



- ✓ Everyone: **Complete this survey on research / policy priorities**
www.tinyurl.com/y75k5p3q
- ✓ Policy-makers & service providers: **Prioritisation workshop, Nottingham Uni, 4th-5th April (World Autism Awareness Week)**
- ✓ Everyone: **Keeping up to date with what's going on in autism research and policy** www.autistica.org.uk/take-part

...Test adapted prevention methods



- ✓ Crisis lines & other services: **Make some tweaks / adjustments. Do some basic training (ask your teams!) Google “American Association of Suicidology” + “autism” for their guide**
- ✓ Service providers, local authorities, etc: **Test new services, tools, prevention methods with autistic people. Insight Group, Mental Health Study Group & Discover Network**

...Ensuring autistic deaths don't remain hidden



- ✓ Local Suicide Prevention Groups: **Do local audits.** Tools from the Psychological Autopsies study may be adapted soon to help areas identify autistic people in their local records.
- ✓ Local Suicide Prevention Groups: **Are autistic people mentioned in your suicide prevention plans?**