

Inquiry into Suicide Prevention
 Ymchwiliad i Atal Hunanladdiad
 Ymateb gan Autistica
 Response from Autistica

**Written evidence from Autistica to the Health, Social Care and Sport Committee:
 Suicide in autism**

Autistica is the UK's autism research charity. We exist to ensure everyone affected by autism has the chance of a long, happy, healthy life.

Autistica funds ground-breaking research into the issues which matter most to autistic people and their families, including mental health in autism, ageing and autism, and early intervention. In March 2016, we published *Personal tragedies, public crisis*, a policy report bringing together evidence on premature death in autism from multiple studies, reviewed by scientists, clinicians and autistic adults. The full report can be found online [here](#).

Executive Summary

- Ongoing research, funded by Autistica, is increasing finding that the autism community many account for a *significant* proportion of total suicides in the UK. **The preliminary results of our psychological autopsies study suggests that 11% of people who die by suicide in the UK may be autistic** (please note that this exact figure is provisional). In contrast, only 1% of the population are autistic.
- After heart disease, suicide is now the leading cause of early death in autistic adults with no learning disability: this group are over nine times more likely to take their own lives than the general population. 14% of children with autism and 66% of autistic adults report having experienced suicidal thoughts.
- Autistic women are more likely to take their own lives than autistic men – a very unusual finding in the context of suicide.
- There is evidence that autistic people are more likely to choose violent methods of suicide, increasing their likelihood of taking their own life.
- Autistic people may not be diagnosed with depression prior to suicidal ideation, presenting major challenges in preventing suicide in this group.
- Because most autistic adults are undiagnosed and awareness of the links between autism and suicide is low, data on autistic suicides remains very limited.
- The Welsh Government's *Talk to me 2* strategy currently makes no mention of autism. We strongly urge the Government to establish a priority work-stream to identify and implement short- and medium-term actions to begin supporting this particular at risk group. Unless specific measures are introduced to address the needs of the autistic community, a significant number of suicides in Wales will not be prevented.
- The *Together for Mental Health* strategy includes provisions (Goal 8.1) to improve the assessment and post-diagnostic support available to people with neurodevelopmental conditions like autism. It's essential that this work addresses the distinct nature of mental health in the autism community.
- NHS Wales, the Local Health Boards, GPs and mental health services should consider autistic people with no learning disability as a high risk group for deaths from suicide. Health professionals should also be aware that often unsuspected groups (such as women and children) may be at significantly increased risk of suicide within the autistic community.
- NHS Wales should consider implementing NICE's recommendation to the NHS in England: that GP practices should establish and maintain confidential local registers of their autistic patients. Similar registers have commonly been used to improve care for people with learning disabilities and also provide the basis for targeted health promotion programmes, like annual health checks which Autistica will pilot to support the physical and mental health of autistic people.
- Suicide prevention and other mental health services should ensure their staff are trained in autism-appropriate communication techniques and building resilience in autistic people. Services should ensure frontline workers are aware of the high and distinctive lifetime risk of suicidal ideation and suicide plans or attempts, especially in individuals receiving a late diagnosis of autism.

- There are currently no evidence-based autism-appropriate suicide prevention tools or treatment programmes. Prevention and treatment methods such as helplines or talking therapies may not be suitable for autistic people who often have challenges with communication, group situations and awareness of their own and others' emotions. Research piloting these tools is essential.

Suicide in autism

1. From the very start in childhood and through to adulthood, mental health in autism is an enormous issue: 70% of children and 79% of adults meet clinical criteria for a mental health disorder, such as bipolar disorder, depression, anxiety, obsessive compulsive disorder and schizophrenia (Simonoff et al. 2008; Lever and Geurts. 2016). Research suggests a genetic link between autism and mental health problems, but mental health problems may also be triggered or influenced by environmental factors, such as social exclusion, bullying, and experiencing stigma.
2. Emerging UK research also indicates very high rates of suicidality in autistic people. 66% of newly diagnosed adults with Asperger Syndrome have considered suicide, significantly higher than the UK general population (17%) and patients with psychosis (59%); 35% have planned or attempted suicide (Cassidy et al. 2014).
3. In children with autism, suicidal thoughts are much more common than in the typical population, with 14% talking about or attempting suicide compared to 0.5% of non-autistic children (Mayes et al, 2013).
4. The largest global study of premature mortality in autism highlights suicide as a leading cause of early death in people with autism and no learning disability who make up approximately two third of autistic people (Hirvikoski et al. 2015).
5. This study also found that women with autism and no co-morbid learning disability were most at risk of death from suicide. In contrast, 87% of suicides in the UK were by males (ONS, 2015). The reasons for this increased risk in women are unclear but it may be a combination of two factors: women are typically more likely than men to attempt suicide but less likely to be successful; however autistic people may be more likely to choose more lethal methods of attempting suicide, increasing the likelihood of successfully taking their own life (Takara & Kondo, 2014)
6. The characteristics of suicide in autism may be very different to the general population, and thus require tailored prevention strategies. For example, research showed that more adults with Asperger Syndrome experienced suicidal ideation (66%) than were depressed (32%) (Cassidy et al. 2014), suggesting a different route to suicidal ideation than found in the general population.
7. There are no suicide prevention tools or treatments which have been tested in autistic populations. Given that many autistic people have challenges with communication, group situations and awareness of their own emotions, it is likely that traditional services such as telephone helplines or group cognitive behavioural therapy may not be effective in autism.
8. Despite widespread use of anti-depressants and anti-psychotics to treat mental health problems in autistic children and adults, there is very limited evidence of efficacy or safety. A diagnosis of autism is generally an exclusion factor in pharmaceutical trials, meaning that most mental health medications have never been clinically tested in autistic people.

Data on suicide in autism

9. Data on suicide in autism remains frustratingly limited for several reasons including: most autistic adults are undiagnosed; even following a diagnosis, autism is poorly recorded in health records; and coroners are unaware of the links between autism and suicide so are unlikely to include autism in a coroner's report.

10. Better data at national and local level, including local case reviews, would be a significant step forwards. Researchers at Nottingham University are creating a Suicide in Autism Research Database (SIARD) and working with Autistica and others to explore how best to understand risk factors leading to suicide in autism and how to prevent and treat suicidality.

Recommendations for action

11. **Autistic people should be considered a priority group in suicide prevention policy.** There is increasing evidence that autistic people account for a significant and disproportionate portion of total deaths by suicide. Furthermore the characteristics of suicide – along with the measures that will be best suited for prevention – appear different within the autism community than amongst the rest of the population. Unless specific measures are introduced to address the needs of the autistic community, a significant number of suicides in Wales will not be prevented.
12. **Health professionals in mental health, crisis and other NHS services must be informed about the unique risk of suicide amongst previously unsuspected groups.** The groups at risk within the autism community may not be those that health professionals expect; for example suicidal thoughts and attempts are much more common amongst autistic women and children than in the rest of the population. Similarly, autistic people at risk of taking their own lives may not present in the way that health professionals may be used to seeing. Processes such as masking – which is a common practice amongst autistic people without a learning disability (who are at highest risk) – may mean that an individual does not appear to be struggling when they are in crisis. Many autistic people report not being believed or understood by health professionals when they disclose feeling suicidal. Services should ensure frontline workers are aware of the high and distinctive lifetime risk of suicidal ideation and suicide plans or attempts, especially in individuals receiving a late diagnosis of autism.
13. **Crisis interventions need to be made accessible for autistic people.** Autistic people are unlikely to call a helpline to talk to a stranger about their feelings at the best of times, let alone when they are in crisis. Alternative methods, such as instant messaging services, should be trialled amongst this community.
14. **Mental health pathways need to be designed for autistic people's needs.** Autistic people are usually among those having the worst time within the mental health system. Mental health problems can present differently for autistic people and so are often missed or misdiagnosed. Even though a third and a half of autistic adults report having had depression, a surprisingly low number of autistic people who die by suicide have a recorded clinical history of depression. Furthermore some mental health interventions do not work for autistic people in the same way that they do for neurotypical individuals. Group therapies, for example, are less likely to be appropriate whilst common interventions – like CBT, DBT or anti-depressants – may need adjustments to work for autistic people.
15. **The Assembly should ensure that the NICE-recommended indicator on autism GP registers is included in the Quality and Outcomes Framework (QOF) and any successor programme(s).** GP registers are a tried and tested measure for addressing health inequalities – they are already used to support people with conditions like asthma, diabetes and learning disabilities. Whilst many of the general population approach their GP as a first port of call for mental health problems, the environment in a GP practices may make that difficult for an autistic person. Locally, the registers would enable GPs to make tailored reasonable adjustments (for example by offering a double appointment at a quieter time of day) based on each individual's needs. Nationally, the registers would help to begin addressing the lack of data available on autism, within the NHS.

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