## Suicide and Autism, a National Crisis.

Sue Willgoss, Advisor for Suicide Prevention with Lived Experience, Norfolk and Suffolk NHS Foundation Trust Founder #LiftLoudForDanny, Lived Experience Influencer for National Suicide Prevention Alliance

> Daniel Willgoss, 03/10/92 – 17/06/2018 #onetoomany #LiftLoudForDanny



#### The statistics that Autistica provide are horrific

- Autistic adults with no learning Disability are 9 X more likely to die by suicide than the general population
- It is the second leading cause of death for autistic people. Average life expectancy for autistic people is just 54 years old. (Swedish study of over 27,000 cases)
- Up to 66% of autistic adults have considered suicide
- Adult autistics significantly more likely to die by suicide than the general population.
- Suicide attempts tend to be more aggressive and lethal
- Autistic children are 28 X more likely to think about or try suicide
- One study showed that 15% of autistic children had suicidal thoughts compared to 0.5% of typically developing children
- In the 86 days leading up to the first Lockdown and up to the 56 days after ¼ of young people who died by suicide were autistic or had ADHD.

Autistic people make up approximately 1% of the population but 11% of suicides. Every suicide is a tragedy but these statistics of the mortality rate for autistic people is a national crisis

### Autism Community Priorities for Suicide Prevention, an International Society for Autism Research Policy Brief, April 2021

# 'Suicide in Autism is a hidden crisis...'

....overlooked by policy makers, clinicians and researchers worldwide.

Population-wide studies in the US, Sweden and Taiwan show that autistic people are up to

#### seven times more likely to die by suicide1-2 and

six times more likely to attempt suicide than the general population.<sup>3</sup>

The risk of death by suicide is even greater for autistic people without intellectual disability.

It is also greater among autistic women, who are

13 times more likely than non-autistic women to die by suicide.1

Despite these powerful statistics, numerous barriers prevent autistic people at risk for suicide from getting the attention, treatment and support they need.

Almost 80% of adults and 70% of children with ASD will experience a mental health difficulty, 40% will have at least two. Mental health difficulties are more common in those with ASD. (Autistica)

We must work with autistic people and those who support them to identify stopgap solutions to implement now and develop carefully designed and well-researched solutions over the longer term.

Following the policy brief the paper "Where do we go from here?", Autism Community priorities for future suicide research was published in June 2021.

PRIORITY RECOMMENDATIONS: WHAT YOU CAN DO RIGHT NOW ("Where do we go from here?" report) Removing barriers to mental health services is the most important issue that autistic people and those who support them have identified. We can help remove these barriers by:

- Explicitly identifying autistic people and those with elevated autistic traits as high-risk groups in suicide prevention policy and clinical guidelines;
- **Developing research and clinical partnerships** with autistic people and those who support them to ensure that future training, intervention and prevention strategies are appropriate;
- Passing legislation requiring mental health services to provide autistic people, with or without
  intellectual disabilities, with services for a range of co-occurring conditions, including suicidality screening
  and prevention;
- Improving systems of autism identification and diagnosis for older children, adolescents and adults, including appropriate post-diagnostic mental health assessment and treatment;
- **Developing guidelines to ensure that service providers recognize** the high risk for suicide in autistic people and having the necessary knowledge and skills to provide appropriate treatment for them (e.g., more and longer therapy sessions, continuity of care, appropriate sensory environments, alternative formats for making emergency appointments that do not involve using a phone or meeting someone face to face);
- **Developing new ways** of delivering accessible and personalized support and treatment; and
- Developing accreditation to recognize mental health service providers who excel in the successful support of autistic people.

Autistic people and those who support them identified a number of issues and recommended numerous ways to improve their experiences of assessment and treatment:

- **1. Believe** the autistic person who tells you that they feel suicidal, even if such information comes in a different or unexpected manner.
- 2. Listen to what the autistic person is saying.
- **3.** Ask specific and clear questions. Autistic people can have difficulty identifying and describing their feelings, understanding metaphor or reading between the lines.
- 4. Give time for the autistic person to process what you are asking. Processing speed can vary widely among autistic people, particularly when in crisis.
- 5. Check that the autistic person has interpreted and responded to your questions in the way you expect. Autistic people can interpret assessment tools differently than intended.8-9
- 6. Utilize freely available guidelines and tools (links below)<sup>24</sup> to support autistic young people and adults, and monitor and report on their mental health.
- 7. Provide support that is flexible, personalizable and tailored to meet an autistic person's unique needs.
- 8. Promote feelings of belonging, connectedness and self-worth, which could prevent suicidal thoughts and behaviours in autistic people. **Social support** is associated with reduced risk of suicidal thoughts in this population.<sub>13,15</sub> Those who report feeling that they do not belong in the world or are a burden to others are more likely than others to feel suicidal.<sub>14</sub> These are important warning signs.

## THE TOP 10 COMMUNITY PRIORITIES

In addition to implementing the stopgap measures above, think carefully about addressing the following community priorities over the long term. It is crucial that **future policy, clinical practice and research**:

- 1. Identify barriers that autistic people encounter when seeking help, which may increase their risk for suicide;
- 2. Identify the risk and protective factors for suicide in autism across the lifespan;
- 3. Examine the extent to which autistic people are not believed when reporting the severity of their distress;
- 4. Examine the development of suicidality that is not associated with other mental health symptoms across the lifespan;
- 5. Identify the best ways of assessing suicidal thoughts and behaviours in autistic people in clinical practice and research;
- 6. Identify how interventions could be adapted for autistic people and individual presentations;
- 7. Understand the experience of suicidality in autistic people, and determine if it is different from that of the general population;
- 8. Examine how autistic people seek help when they are in crisis;
- 9. Examine how well existing models for understanding suicide apply to autistic people; and
- 10. Study the impact of poor sleep on suicide risk in autistic people.

Autistic people have told us that when they are feeling suicidal, they may not show signs that people typically expect. This is because:

- they have differences communicating and interacting with other people
- they find it difficult to communicate their thoughts
- they might not want to talk about it

Remember that suicidal feelings and thoughts may look different in an autistic person. It is important not to make assumptions or judgements.

If any autistic person tells you that they are suicidal, you should believe them and do what you can to help.

www.autistica.org.uk

International Society for Autism Research Policy Brief (PDF) Autism community priorities for suicide prevention (researchgate.net)

"Where do we go from here?", Autism Community priorities for future suicide research

<u>0521 GW UoN collaboration Autism Suicide risk report v5</u> <u>FINAL.pdf - Google Drive</u>

MHAutism Group, a team of collaborators, working to better understand and prevent mental health problems, self injury and suicidality in autistic people <u>Sarah Cassidy's lab | University of Nottingham (Notts)</u>

(researchgate.net)

Follow them here: https://sites.google.com/view/mentalhealthinautism

Suicidal Behaviours Questionnaire - Autism Spectrum Conditions (SBQ-ASC) https://sites.google.com/view/mentalhealthinautism/resources/tools













### **b** Where do we go from here?



#### Autism Community Priorities for Suicide Prevention An International Society for Autism Research Policy Brief



ise powerful statistics, numerous barriers prevent autistic people at risk for suicide fro

ort they need. These barriers include a lack of evidence-based asses icidal thoughts and behaviors:<sup>48</sup> a lack of access to mental health sen t policies and guidelines that affect autistic people.

c women to die by suicide.

studies in the US. Sweden and Taiwan show that autistic people are up to seven times more likely to die by suicide<sup>12</sup> and six times more likely to attempt suicide than the general population.<sup>1</sup> The risk of death by suicide is even greater (

> "The lack of knowledge around Autism meant that he did not have the support he needed until his difficulties had impacted on him overwhelm

ctual disability.<sup>1</sup> It is also greater among autistic women, who are 13 times more likely that

some to others <sup>14</sup> social and communication difficulties, lack of

nd those who support them are typically excluded from research that informs the clinical

ns to implement now and develop carefully designed and well-researched solu

Notting

ple.65 Even if these tools did exist, they might not reach autistic people, who report havin