

Linking Suicide Prevention Strategies with Autism Strategies and including the Autistic Community: A lived experience perspective



Daniel Willgoss 03/10/1992 – 17/06/2018

Sue Willgoss

National Suicide Prevention Alliance Lived Experience Influencer

Founder of #LiftLoudForDanny

Advisor for Suicide Prevention with Lived Experience Norfolk and Suffolk NHS Foundation Trust

Expert by Experience Lead, Suicide Prevention, Norfolk and Waveney ICS

Chair Suffolk Parent Carer Forum

“Everything I do, I do with Daniel in my heart and mind, he is my driving force.”

Listen..... Really Listen

Listen
No the kids are not alright
And neither is the system
These self-proclaimed professionals
Don't take the time to listen
I understand work pressures
Lack of hours in a day
But it takes 30 seconds
Just to ask, "are you ok?"
They promise us the world
And then they don't deliver
And then we get forgotten
Like little slips and slivers

So when you see that closed off boy
Or that sad, lonely girl
Just think maybe you could be the one
That opens up their world
It only takes a smile
Or a firm grip of the hand
Just a little gesture
To show you understand
'Cause no the kids are not alright
And neither is the system
But maybe one day that could all change
If we took the time to listen

By a Suffolk Young Person

Why am I here? Because I want you to listen...

- Daniel, my son, died on the 17th June 2018, Father's Day, he was autistic, he was just 25 years old and going places.
- Daniel had been under mental health services since he was 3 ½ years old and was diagnosed as autistic just before his 9th birthday.
- Experienced anxiety, school refusal, his biggest struggles came after a head injury in April 2010.
- First suicide attempt in the December that year. Attempts on his life continued, serious intentional attempts.
- He died waiting for a call back from Mental Health Services. At his last appointment despite saying he was closer to the edge than ever before he was offered a phone app... and no hope.
- Daniel also had an Education, Health and Care Plan at the time of his death, he'd had absolutely no support from Education or Social Care and what he'd had from Health did not meet his needs.
- Education, Health, Care and all commissioning boards must have regard to the SEND Code of Practice 0-25.
- Everyone had their part to play to ensure Daniel achieved 'the best possible educational and other outcomes'
- At his inquest at end of 2021 the coroner gave a narrative verdict and spoke of 'missed opportunities', those missed opportunities included every service involved, NSFT, Education, Social Care, Safeguarding and Police.
- Suicide Prevention is everybody's business



The statistics 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
- 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.
- The National Child Mortality Database report Oct 21 on Suicide in Children and Young People stated that 16% of the young people that died by suicide 2019-2020 had a diagnosed Neurodevelopmental condition.



<http://www.autistica.org.uk/>

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.

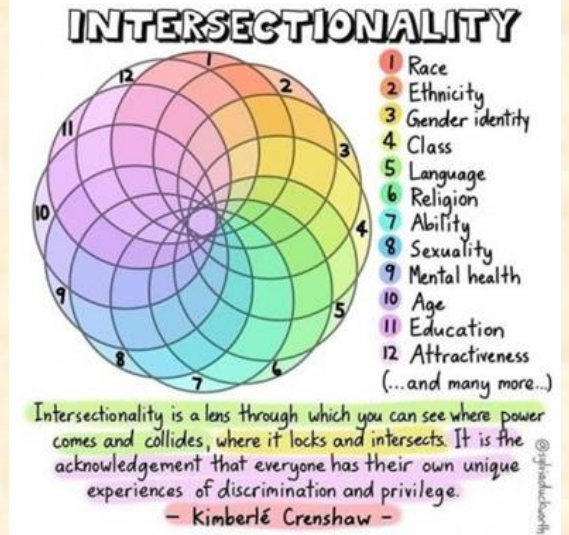
If any autistic person tells you that they are suicidal, you should believe them and do what you can to help.

Autistic people make up approximately 1-2 % 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.

www.autistica.org.uk

The statistics are worse for some of the community

- 2021 research from the University of Cambridge suggests that autistic individuals are more likely to identify with a diverse range of sexual orientations than non-autistic individuals.
- 2021 research from The Trevor Project from just under 37,000 people Autistic LGBTQ+ youth face higher levels of mental health issues.
- LGBTQ+ 13- to 24-year-olds were more likely to have seriously considered suicide in the past year if they had ever been diagnosed as Autistic or suspected they may be
- LGBTQ+ youth who have been diagnosed as autistic were over 50% more likely to attempt suicide in the past year compared to LGBTQ+ youth who have never had an autism diagnosis
- LGBTQ + and autism spectrum disorder: Experiences and challenges paper there is an urgent need to understand diverse presentations of the Neurodiverse community, gender identity, disability, race, ethnicity, and so much more, as little consideration being given to intersectionality.
- The intersectionality framework conceptualises the challenges associated with multiple stigmatized identities.



[LGBTQ + and autism spectrum disorder: Experiences and challenges - PMC \(nih.gov\)](#)

Autism Community Priorities for Suicide Prevention, an International Society for Autism Research (INSAR) Policy Brief, April 2021

‘Suicide in Autism is a hidden crisis, overlooked by policy makers, clinicians and researchers worldwide.’

The risk of death by suicide is even greater for autistic people without intellectual disability.¹

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

Almost 80% of adults and 70% of children with ASD will experience a mental health difficulty, 40% will have at least two.

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

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.

[\(PDF\) Autism community priorities for suicide prevention \(researchgate.net\)](#)

Following the policy brief, the paper **“Where do we go from here?”**, Autism Community priorities for future suicide research was published in June 2021. [0521 GW UoN collaboration Autism Suicide risk report v5 FINAL.pdf - Google Drive](#)

Their policy brief and following paper ‘Where do We Go From Here?’ has the top 10 community priorities, priority recommendations and what you can do right now, identified by Autistic people and those who support them and recommend numerous ways to improve their experiences of assessment and treatment.



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**
- **Developing research and clinical partnerships** with autistic people and those who support them
- **Passing legislation**
- **Improving systems of autism identification and diagnosis**
- **Developing guidelines to ensure that service providers recognise** the high risk for suicide in autistic people.
- **Developing new ways** of delivering accessible and personalised 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**
- 2. Listen, really listen**
- 3. Ask specific and clear questions.**
- 4. Give time for the autistic person to process what you are asking.**
- 5. Check that the autistic person has interpreted and responded to your questions.**
- 6. Utilize freely available guidelines and tools**
- 7. Provide support that is flexible, personalised and tailored.**
- 8. Promote feelings of belonging, connectedness and self-worth.**

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.

Government Policies and Risk of Suicide

- **Preventing Suicide in England: Fifth progress report** does not really address this issue.
- The **All Age Autism Strategy** talks about health inequalities, one and only mention of self harm is to those within the criminal justice system.
- There is lots of mention of mental health but no mention of suicide or suicide prevention.
- Inequalities impact on many aspects of life.
- Ambitious about Autism 2021, 50% of Autistic Children and Young People are excluded from education. That impacts on being able to achieve ‘best possible outcomes’.
- 2021 a DWP study told us that only 22% of Autistic people were in any type of employment.

Suicide in Children and Young People National Child Mortality Database Programme Thematic Report

That paper has 9 recommendations, **please implement them** (along with Autism Communities priorities), **give them strength**.

Our schools have a huge part to play as does the community to ensure our children and young people achieve their best possible educational and other outcomes.

[NCMD-Suicide-in-Children-and-Young-People-Report.pdf](#)

Preventing suicide in England: Fifth progress report of the cross-government outcomes strategy to save lives

Published 27 March 2021

Contents

Ministerial Foreword - Minister for Patient Safety, Suicide Prevention and Mental Health	3
Foreword - Chair of the National Suicide Prevention Strategy Advisory Group	6
Introduction: Suicide prevention during COVID-19	7
1. Understanding recent trends in suicide rates (2016-19)	10
Changes to the suicide rate	12
2. Pre-pandemic suicide risk factors in vulnerable groups	14
Middle-aged men	14
People who self-harm	14
Children and young people	14
People with a mental illness	15
Exacerbation of risk factors	15
3. Exacerbation of risk factors during the COVID-19 pandemic	16
Data during the pandemic	16
4. Addressing the added impact of the COVID-19 pandemic on suicide and self-harm risk	22
Addressing immediate risks of suicide and self-harm	22
5. Cross-government actions to address the wider drivers of suicide and self-harm	27
Reducing the impact on mental health in vulnerable groups	27

The national strategy for autistic children, young people and adults: 2021 to 2026

My Promise, My Hope, Your Action

World Suicide Prevention Day 2021-2023 theme

'Creating Hope Through Action'

I promised my son as I sat holding his hand the night he died that things must change, I would push for that change.

I am here today because of Daniel and my promise, for all our children, young people and their families.

Daniel's message,

"I enjoy helping. Seeing people achieve what they can is what I like. I've been at the bottom and its not nice so keeping people on the right track and pushing them to where they want to be is all I want to do. Even if it's not in the gym, helping people be the best version of themselves is what I will help do. In return it helps me be the best version of me I can be."

You can help me make that change because I believe that by all working together, we can do this. I need, we need, your pledge through action. Go out there, be the best version of you, create more hope through your action, listen, really listen and mend that broken system.

Suicide Prevention is Everybody's Business



Further Resources

Here is a list of resources that you may find useful, there will be more out there.

Dr Sarah Cassidy's Lab. [Sarah Cassidy's lab | University of Nottingham \(Notts\) \(researchgate.net\)](#)

Mental Health in Autism, Nottingham University <https://sites.google.com/view/mentalhealthinautism>

West Yorkshire (Suicide and Autism Tab) [A variety of local and national suicide prevention resources. \(suicidepreventionwestyorkshire.co.uk\)](#)

Autism learning resources and How to do a great assessment for someone who has autism. <https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/autism/Autism.aspx>

Mind Autism and Mental Health. <https://www.mind.org.uk/about-us/our-policy-work/equality-and-human-rights/mental-health-of-people-with-autism/>

Supporting people living with autism spectrum disorder and mental health problems. A guide for practitioners and providers. <https://www.mind.org.uk/media-a/4400/autism-guide-web-version.pdf>

NAS. <https://www.autism.org.uk/advice-and-guidance/topics/mental-health>

Guidelines for assessing adults with autism for self directed support (SDS). <https://hub.careinspectorate.com/media/3338/autism-initiatives.pdf>

Autism: Improving Access to social care for adults. <https://www.scie.org.uk/autism/adults/assessment-accessibility/assessment>