

Autism and Suicide: What We All Need to Know

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Our Mission

The Melisa Nellesen Center for Autism at Utah Valley University improves the quality of life for those living and working with Autism Spectrum Disorder by training professionals, providing evidence-based services and education, and fostering a community of belonging.



Hidden Crisis...

“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 **7 times** more likely to **die by suicide** and **6 times** more likely to **attempt suicide**, then the general population. 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.”

Autism....

- Social/Communication Impairments
- Restrictive/Repetitive Patterns of Behavior
- Sensory Differences
- Autistic people are more likely to have mental health problems like anxiety and depression
- On average, people on the autism spectrum die substantially earlier than people who are not autistic. (appx 16 years earlier than non-autistic people)

What does the research tell us?

- After heart disease, suicide is the leading cause of early death in adults with autism and no intellectual disability.
- Suicide risk for youth and adults with ASD is 2 to 7 times higher than those who do not have ASD.
- Autistic people with ADHD appear to be at the highest risk

Mayes et al (2013)

- Looked at 1-16 year olds with ASD
- Identified Predictors
 - Depression
 - Behavior problems
 - History of teasing/bullying
- Demographic variables
 - Age 10 or older
 - Black or Hispanic
 - Lower SES
 - Male

Widnall et al (2022)

- Retrospective cohort study done in the UK
- Records of youth aged 11-17 from 2009 to 2013
- Of 1020 youth who presented in an emergency department with self-harm, 763 (75%) had autism.
- The increased risk was identified in boys only.

Kolves et al (2021)

- Large Danish population study- 6,559,266 individuals; 32020 with ASD
- Among the ASD cohort
- Rates in autistic females 1.41-fold higher than for males
- Higher rates of attempts across all age groups
- 92.3% of the ASD sample who attempted suicide had at least 1 co-occurring psychiatric disorder
- 90.2% of those who died by suicide has at least one co-occurring psychiatric disorder

Kolves et al (cont.)

- Factors considered “protective in the general population such as older age and higher education level were not so in individuals with ASD
- Being married (cohabitating) and being employed were less protective.
- Most factors associated with suicide in the general population were not associated with suicide among those with ASD.
- Identified risk- Psychiatric comorbidity
- Possible causal mechanism- social isolation and poor access to healthcare. For women- later diagnosis and camouflaging.

O'Halloran et al (2022)

- Pooled prevalence data (meta-analysis)
 - Suicidal ideation- 25.2%
 - Suicide attempts – 8.3%
 - Death by suicide - .2%
- Estimates in self-reports were higher than in parent reports
- Adverse childhood experiences were strong risk factors
- Resilience was protective

▼ Rybczynski, et al (2022)

- Used the Ask Suicide-Screening Questions (ASQ) tool
- Screened 3800 youth visiting clinics at Kennedy-Kreiger
- ASD youth had the highest rated of suicidal thoughts (12%)
- 30% of parents declined the screening
 - Didn't believe their child was at risk
 - Believed that asking about it would be harmful

Some Risk Factors for Suicide

Universal

- Lack of support or difficulties accessing support
- Number of unmet needs
- Poor physical health
- Loneliness/Isolation
- Thwarted belonging
- Feeling burdensome to others

Autism Specific

- Late autism diagnosis
- Females
- Camouflaging/Masking
- Experiencing autism burnout
- Social and communication difficulties
- History of being bullied
- Unemployment or Underemployment
- Co-occurring conditions: Anxiety, depression, ADHD
- Gender dysphoria
- Eating disorders

Warning Signs

- Threatening to hurt or kill themselves or talking or wanting to hurt or kill themselves and/or
- Looking for ways to kill themselves by seeking access to firearms, available pills, or other means and/or
- Talking or writing about death, dying or suicide, when these actions are out of the ordinary.

These warning signs of acute suicide risk are not always communicated directly or outwardly.

*American Association of Suicidology

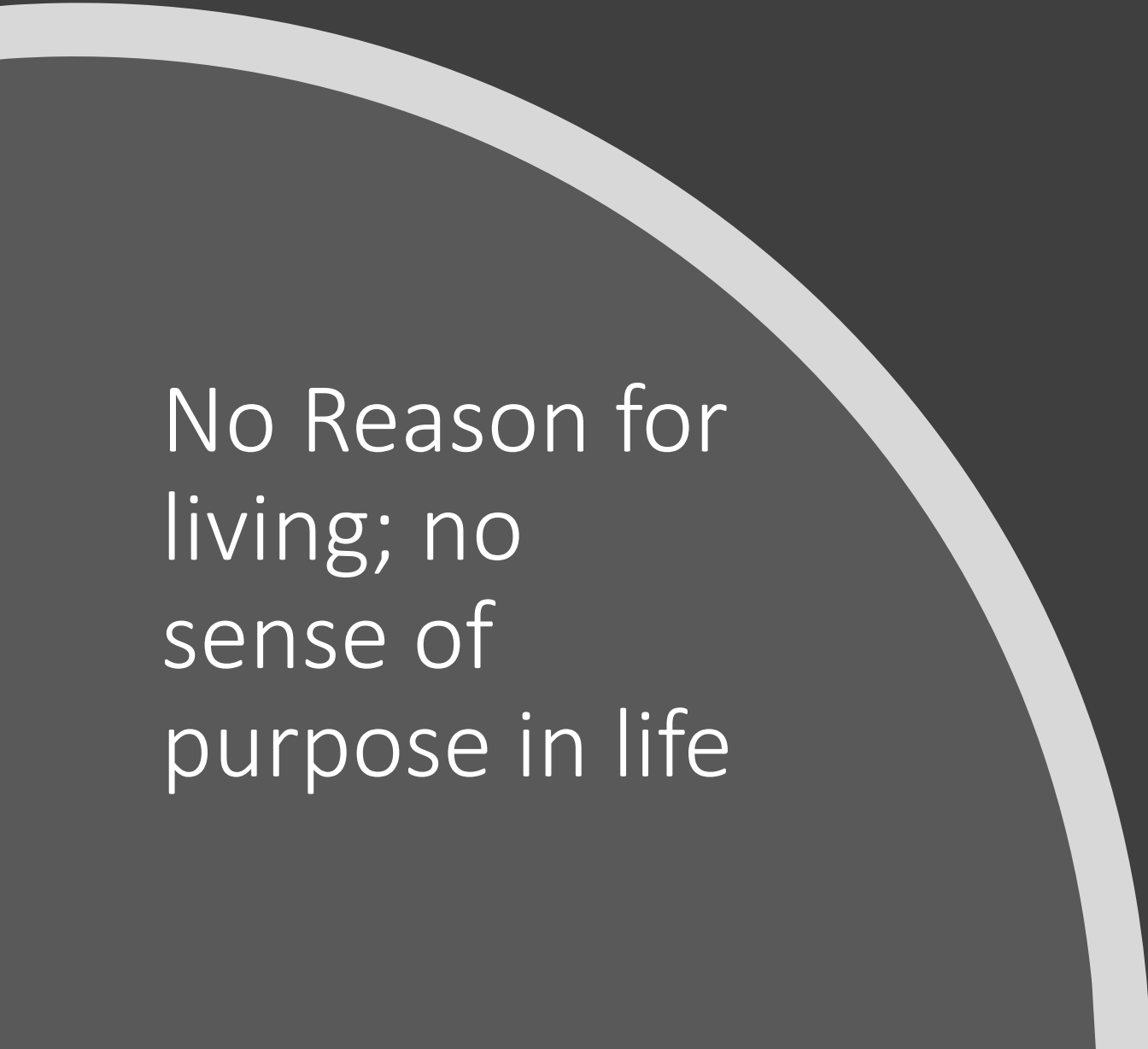
Additional Warning Signs

The following ten warning signs have additional considerations to investigate when assessing autistic people.

- Increased substance use
- No reason for living
- Anxiety, agitation, unable to sleep or sleeping all the time
- Feeling trapped
- Hopelessness
- Withdrawal
- Rage, uncontrolled anger, seeking revenge
- Acting reckless or engaging in risky activities
- Dramatic mood changes
- Giving away prized possessions or seeking long-term care for pets

Increased Substance Abuse

- Minimal studies
- Substance use minimal compared with the general population
- Is this because of the sparsity of research?



No Reason for
living; no
sense of
purpose in life

May interpret differently because of social isolation

Attention Statements:

- “I don’t belong to this world,”
- “I’ve never fit into this world,”
- “I wish I was anywhere but here,”
- “I wish I could leave here and be in a place I belong, and it’s not on this earth.”

Could be their reality if there is no sense of belonging.

Anxiety,
Agitation,
Unable to Sleep
or Sleeping All
the Time

- Lifelong struggles with anxiety
- Sleep issues common
- Changes in anxiety or sleep need to be investigated further

Feeling Trapped- Like There's No Way Out

- Cognitive inflexibility narrows options
- Can feel stuck in a negative thinking pattern or in negative circumstances.
- A crisis may cause:
 - Regression of skills
 - Deteriorated problem solving and flexible thinking
 - Diminished emotional regulation
 - Difficulty managing sensory needs

Hopelessness

- An autistic person can feel hopeless and say they feel hopeless, but that may simply be an expression of their truth.
- Hopelessness might be a word choice, not an emotion.
- The statement deserves more investigation into what is meant

Withdrawal

- **Withdrawal from friends, family, and society can be a coping mechanism for autistic people. It is needed by a majority of autistic people for self-care in staying regulating and feeling well**
- Withdrawing can also be a warning sign for autistic people.
- Is the behavior new or typical, and what are the reasons behind the withdrawal?

Rage, Uncontrolled Anger, Seeking Revenge

- Autistic meltdowns happen
- Most during childhood
- Adults can get very overwhelmed and experience them as well
- A meltdown is an overloaded sympathetic nervous system.
- When a meltdown occurs keep the person safe until it subsides. Very few, if any, autistic people can stop a meltdown from pure will or want.
- A true meltdown must run its course.

Acting Reckless or Engaging in Risky Activities, Seemingly without Thinking

- Reckless or risky behavior may be from over-thinking, perseverating, deep thinking, or just not understanding the circumstances or risks
- Look further....

Giving Away Prized Possessions or Seeking Long- Term Care for Pets

- Autistic people can become emotionally connected to their possessions or pets. Giving them away may be a warning sign.

Protective Factors

- Resilience
- Receiving mental health care from professionals trained to support autistic individuals
- Strong connections to family, caregivers, friends and other resources close by
- Life skills (problem solving, coping skills, ability to be flexible)
- Feeling good about yourself
- Beliefs that killing yourself is wrong

• *references ASERT

The Best Way to Identify Risk

- Ask the person directly
- Myth: If you talk to someone with autism about suicide, they will start thinking about suicide.
- Barrier to identification: Diagnostic Overshadowing
 - Especially common in women and girls
 - Bi-directional.

Available Resources

- Be Well, Think Well: Suicide Resources- *ASERT*
- Crisis Supports for the Autism Community (toolkit)- *American Association of Suicidology*
- Autism Community Priorities for Suicide Prevention- *INSAR*
- Personal Tragedies, Public Crisis- *Autistica*

“Three recent high-quality studies have uncovered **shockingly high rates of suicidal thoughts, behaviors and completed suicide in autistic adults**. Our recent research showed that **66% of autistic adults had contemplated suicide in their lifetime**. This was significantly higher than patients with psychosis, a high-risk group in which suicide has been extensively studied.

These results demonstrate an **urgent need** for more research to prevent suicide in autistic adults—there are no valid assessments or programmes currently available for these individuals. An absolutely imperative first step is to consistently record autism diagnoses in routinely collected government data. This will enable much-needed large-scale research into suicide risk and prevention in autism, and ultimately reduce the tragic health inequalities these individuals experience.”

– Dr. Sarah Cassidy, Coventry University



Parents

Share a time you didn't feel safe or were worried about the safety of a loved one:

- When my autistic son was suicidal and the national hotline had *no clue* how to talk to an autistic teenager.
- Fear of my son being bullied in school / P.E. locker room
- Creation of groups that are exclusive to new people.
- Social media messages for vulnerable kids.
- Concern for a family going through extreme emotional stress trying to care for a child with special needs.
- Bullying at school, not understanding

What does a safe and healthy community look like to you?

- Neighbors know each other, have good relationships and are educated about those with extra needs in the neighborhood.
- Non-judgmental
- One where all communication styles are recognized and appreciated.

What Can We Do Right Now?

- **Explicitly identify autistic people** and those with elevated autistic traits as high-risk groups in suicide prevention policy and clinical guidelines
- **Develop research and clinical partnerships** with autistic people and those who support them to ensure that future training, intervention and prevention strategies are appropriate
- **Pass 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.

• *INSAR

More of What Can We Do Right Now?

- **Improve systems of autism identification and diagnosis** for older children, adolescents and adults, including appropriate post-diagnostic mental health assessment and treatment
- **Develop 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)
- **Develop new ways** of delivering accessible and personalized support and treatment
- **Develop accreditation to recognize** mental health service providers who excel in the successful support of autistic people

• *INSAR



Charlie Garlick

Let's Work Together for a Solution

- You are invited to our team- help us:
 - Address autism and suicide in our state
 - Organize available supports and extend outreach so they are more accessible
 - Create more trainings and disperse through mental health professionals and other concerned groups
 - Work together to spread awareness
- We need you. Now that you know.....you know.

Contact Us

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