Suicide Prevention for Autistic Adults: Risk Factors, Warning Signs, and Crisis Supports

BRENNA MADDOX, PHD
LISA MORGAN, MED, CAS

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  - Shari Jager-Hyman, PhD
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  - Teal Benevides, PhD
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  - Mirabel Pelton, MSc
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Note about Language

➤ Identity-first ("autistic person") vs. person-first ("person with autism")

Avoiding Ableist Language: Suggestions for Autism Researchers

Kristen Bottema-Beutel, PhD; Steven K. Kapp, PhD; Jessica Nina Lester, PhD; Noah J. Sasson, PhD; and Brittany N. Hand, PhD, OTR/L

Overview

➤ Autism and suicide: Prevalence and risk factors
➤ Considerations for warning signs
➤ Crisis supports and resources
Suicide and Autism: What Do We Know?

Autistic Individuals and Suicide

- Suicide is a leading cause of premature death in autistic people

- Autistic individuals are significantly more likely to think about, attempt, and die by suicide than the general population

Cassidy et al., 2014; Chen et al., 2017; Croen et al., 2015; Hedley & Uljarević, 2018; Hirvikoski et al., 2016; Kirby et al., 2019; Kölves et al., 2021; Zahid & Upthegrove, 2017
Autistic Adults

- Lifetime prevalence of suicidal ideation: between 19.7% (Hedley et al., 2017) and 66% (Cassidy et al., 2014)

- Lifetime prevalence of suicidal behavior: between 1.79% (Croen et al., 2015) to 35-36% (Cassidy et al., 2014; Paquette-Smith et al., 2014)

Risk Factors

- Factors known to increase the risk of suicide in the general population are more common in autistic individuals
  - Examples: social isolation, abuse, low mood, low self-esteem, alexithymia, rumination

- We should also consider additional factors, that may be more specific to autistic individuals
Risk Factors

- Co-occurring psychiatric conditions
- Lack of social support
- Unmet support needs

Cassidy et al., 2018; Hedley et al., 2017, 2018; Kõlves et al., 2021

Unmet Support Needs

- Asking for help is a social skill.
  - May not understand who to reach out to or what to ask
- Reaching out can be a negative experience due to misunderstandings.
- Unsupported for:
  - Mental health challenges
  - Employment
  - Housing
  - Education
  - Relationships
Risk Factors

- Co-occurring psychiatric conditions
- Lack of social support
- Unmet support needs
- Camouflaging or masking

Cassidy et al., 2018; Hedley et al., 2017, 2018; Kirby et al., 2019; Kõlves et al., 2021; Raymaker et al., 2020

Camouflaging

- Strategy to fit in with others by masking their autism
- Try to look and act like everyone else
- Cost – exhaustion, lack of sense of self, lack of support, not being known
- People do not get to know the person for who they are
- Does help autistic people socialize
- Autistic people know if they show their true selves – they will be rejected
- Hinders relationships – can cause difficulty if autistic people start showing their true selves
- Leads to profound loneliness of not belonging
Risk Factors

- Co-occurring psychiatric conditions
- Lack of social support
- Unmet support needs
- Camouflaging or masking
- Late diagnosis
- Female

Cassidy et al., 2018; Hedley et al., 2017, 2018; Kirby et al., 2019; Kõlves et al., 2021
Risk Factors

- Co-occurring psychiatric conditions
- Lack of social support
- Unmet support needs
- Camouflaging or masking
- Late diagnosis
- Female
- Autistic burnout

Cassidy et al., 2018; Hedley et al., 2017, 2018; Kirby et al., 2019; Kõlves et al., 2021; Raymaker et al., 2020

Autistic Burnout

- Intense physical, mental, and/or emotional exhaustion
- Accompanied by a loss of skills
- Autistic adults who are able to live independently are especially affected
- Varies from person to person
- A result from camouflaging/masking
- Have more difficulty managing their emotions than usual
  - Prone to outburst of sadness, anger, anxiety, depression
  - Increased sensitivity to change
  - Can lead to suicide behavior

Raymaker et al., 2020
Warning Signs

- Indicate a more immediate risk of suicide (vs. risk factors)

- Less research in the autism field on warning signs, compared to risk factors
**Purpose:**

<table>
<thead>
<tr>
<th>Understand</th>
<th>Understand the need for considerations</th>
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<tbody>
<tr>
<td>Recognize</td>
<td>Recognize the differences</td>
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<tr>
<td>Support</td>
<td>Support autistic people as autistic people</td>
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Warning Signs of Suicide

- Increased substance (alcohol or drug) use
- No reason for living; no sense of purpose in life
- Anxiety, agitation, unable to sleep or sleeping all of the time
- Feeling trapped – like there’s no way out
- Hopelessness
- Withdrawal from friends, family and society
- Rage, uncontrolled anger, seeking revenge
- Acting reckless or engaging in risky activities, seemingly without thinking
- Dramatic mood changes
- Giving away prized possessions or seeking long-term care for pets

Please Note:

- Do not make any important, life-altering decisions based on the information in the following slides. All the warning signs for the general public pertain to autistic people too – with considerations about autism.

- This information is here to broaden existing knowledge about autistic people.

- Autistic people know the most about themselves. The job of professionals helping - is to make space for them communicate.
No reason for living; no sense of purpose in life

These statements could be the reality of an autistic person who feels no sense of cultural and/or social belonging.

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

Anxiety, agitation, sleep issues

These symptoms are difficulties autistic people struggle with regularly.

How might one know if they are signs of suicide?

- Use concise, specific language during the assessment or crisis call/text.
- Investigate any changes in levels of anxiety, agitation or sleep issues.
Feeling trapped

- Autistic people typically have some cognitive inflexibility, which narrows the options when feeling stuck in a negative thinking pattern or in negative circumstances.

- A crisis situation may cause a regression of skills in autistic people. Skills such as problem-solving and flexible thinking can deteriorate, diminishing autistic people’s ability to regulate their emotions and manage their sensory difficulties.

Withdrawal

- Withdrawal from friends, family, and society can be a coping mechanism for autistic people. It is needed by many autistic people for self-care in staying regulated and feeling well.

- Withdrawing can also be a warning sign for autistic people.

- The best way to differentiate is to find out what the changes are in an individual you are working with. In other words, is the behavior new or typical, and what are the reasons behind the withdrawal?
Giving away prized possessions or seeking long-term care for pets

• There are autistic people who have strong emotional connections with one or two possessions and many who are very much connected to their pets, some of whom serve as therapy pets.
• This behavior warrants further investigation.
• Closest true warning sign for autistic people – if they existed
• Remember the person you are helping. Autistic people may have other reasons for giving away prized possessions.

Other Considerations

► The thinking process of autistic people is typically very literal.

► Consider the exact meaning of what you say.

► Autistic people will often answer what they are asked in a literal way and may give a response, but not the information you are looking for to help them.
Warning Signs of Suicide for Autistic People

An autism-specific resource based on research findings and expert consensus

Morgan et al., 2021

Warning Signs

1. Sudden or increased withdrawal
2. No words to communicate acute distress
3. Current traumatic event
4. Marked increase in rate and/or severity of self-harm
5. Worsening of anxiety and/or depression
6. A new focus on death-related topics that are not a special interest
7. Perseverative suicidal thoughts and ruminations
8. Seeking means or making plans for suicide or suicide rehearsal
9. Statements about no reason for living or no sense of purpose in life
10. Hopelessness
Crisis Supports and Resources

Identifying an Autistic Person in Crisis

- Expresses difficulties with sensory issues
- May present with opposite emotions
- Difficulty identifying or verbalizing emotions
- May not know how to cope with or what to do with emotions
- Expresses difficulty or inability to make friends or sustain relationships
- May use echolalia - repeating words, sounds, and responses

Supporting Autistic People in Crisis

- Understand there may be a history of countless misunderstandings/miscommunications throughout their lives.
- Unusual patterns of speech such as odd pitch, tone, pace or robotic is part of being autistic.
- Verbal or text response time will vary according to processing speed.
- Autistic people may perseverate - ruminate on thoughts, situations, or circumstances - and find it difficult to change their perceptions.
- Autistic people can be very literal communicators.
Supporting autistic children and young people through crisis


Stakeholder Engagement
Autism Community’s Top 10 Priorities for Suicide Prevention

1. What barriers do autistic people experience when seeking help which may put them at greater risk of suicide?
2. What are the risk and protective factors for suicide in autism across the lifespan?
3. To what extent are autistic people not believed about the severity of their distress?
4. How can we further understand suicide where mental health is not a factor, across the lifespan?
5. How can we best identify and assess suicidal thoughts and suicidal behaviors in autistic people, in research and clinical practice?

Cassidy et al., 2020
Autism Community’s Top 10 Priorities for Suicide Prevention

6. How should interventions be adapted for autistic people and individual presentations?
7. What is the experience of suicidality in autistic people? Is this experience different to the general population?
8. How do autistic people seek help when they are in a crisis?
9. How well do existing models of understanding suicide apply to autistic people?
10. What is the impact of poor sleep on suicide risk in autistic people, and how can this be measured?

Cassidy et al., 2020

“Suicide is like a killer in our midst that no one wants to talk about, instead of meeting it head on.”

Morgan, 2019
Thank you!

Lisa Morgan, MEd, CAS
www.autismcrisissupport.com
lisamorganconsulting@gmail.com

Brenna Maddox, PhD
Brenna_Maddox@med.unc.edu