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Autism Community Priorities for Suicide Prevention

An International Society for Autism Research Policy Brief

April 1, 2021



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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 suicide**¹⁻² and **six times more likely to attempt suicide** than the general population.³ The risk of death by suicide is even greater for autistic people without intellectual disability.¹ 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. These barriers include a lack of evidence-based assessment tools and interventions to identify and treat suicidal thoughts and behaviors;⁴⁻⁹ a lack of access to mental health services¹⁰⁻¹¹ and exclusion from conversations about policies and guidelines that affect autistic people.

We must immediately address and remove barriers to effectively identifying, treating and supporting autistic people who are at risk for suicide in order to **save lives now.**

“The lack of knowledge around Autism meant that he did not have the support he needed until his difficulties had impacted on him overwhelmingly.”

- Family member

BACKGROUND

We do not fully understand why autistic people are disproportionately at risk for dying by suicide. However, reviews of international suicide prevention policy and research indicate that few countries identify autistic people as a high-risk group for suicide in their suicide prevention policies or clinical guidelines. This may be because autistic people do not share the familiar risk markers for suicide, including mental health problems, which commonly occur in the general population.¹² In autistic people, loneliness,¹³⁻¹⁴ feeling burdensome to others,¹⁴ social and communication difficulties, lack of support and trying to fit in by camouflaging autistic behaviors are some of the factors that increase suicide risk.^{4-5,12,15-16}

Yet, these factors and their association with suicidality are easily missed or misdiagnosed. This may be because neither clinical practice nor research offers any assessment tools that have been validated to identify suicidal thoughts and behaviors in autistic people.⁶⁻⁹ Even if these tools did exist, they might not reach autistic people, who report having difficulties accessing mental health services.¹⁰⁻¹¹ Moreover, their providers often report lack of confidence and expertise in supporting autistic clients, particularly those who feel suicidal.¹⁷ Because many autistic people camouflage their autistic behaviors to fit in, it can be difficult for practitioners to interpret their thoughts and feelings¹⁸ or recognize their true level of distress.¹⁰

Providing appropriate support to autistic people requires evidence-based policies and guidelines for clinical practice and research. But autistic people and those who support them are typically excluded from research that informs the clinical practice and policy related to the identification and mitigation of risk for suicidality. This has led to the creation of assessment tools and interventions that do not reflect or meet the unique needs and concerns of autistic people.¹⁰⁻¹¹

A “one size fits all” approach that is designed to meet the needs of non-autistic people is unlikely to work for autistic people. Fortunately, available treatments can be adapted with and for them. 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.**



THE APPROACH

- We reached these observations after conducting two systematic reviews: one of international **suicide prevention policy and the other of** the available **research on suicide in autism**.
- **We consulted with more than** 1,000 autistic people and those who support them to identify and prioritize the **top 10 issues** they agree are most important. The **James Lind Alliance**, which specializes in bringing together people who live with a medical condition, helped us to arrange this consultation (<https://www.jla.nihr.ac.uk/>).
- **We conducted** seven workshops in the UK, US and Netherlands that identified 48 priorities with and for autistic people. Participants included 788 autistic people and those who support them, who ranked 48 priority areas online to identify the top 20; an additional 30 autistic people and those who support them identified the top 10 priorities in a final workshop.

OVERALL RESULTS

Our reviews showed that no single facet of suicidality among autistic people has been extensively researched. Without such research, we cannot fully understand why they are more likely than others to die by suicide or how best to identify, support, or treat those experiencing suicidal thoughts and behaviors.

We also found that autistic people and those who support them report being excluded from services, not being believed by professionals, and receiving assessments and interventions that have been designed for other groups and therefore are inappropriate for their unique needs.¹⁰⁻¹¹

Available treatments for suicidal thoughts and behaviors should be adapted in partnership with autistic people. Such adaptable treatments include a **safety plan**—a brief, flexible and personalizable suicide prevention intervention—that has proven effectiveness in a variety of groups.⁵ One such safety plan for autistic people is publicly available,¹⁹ and researchers are exploring its usefulness.²⁰

Psychotherapy is equally effective for autistic and non-autistic people but takes longer.²¹ **Cognitive Behavioral Therapy (CBT)** can be successfully adapted for autistic people.²² Additionally, **Dialectic Behavior Therapy (DBT)** has been successfully adapted for a range of different groups, and ongoing investigations are exploring how useful adapted DBT could be for treating suicidality in autistic people.²³ Research on these adaptations may be fundamental to reducing the risk for suicidality.

PRIORITY RECOMMENDATIONS: WHAT YOU CAN DO RIGHT NOW

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.

ADDITIONAL RECOMMENDATIONS

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)²⁴ 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 behaviors in autistic people. **Social support** is associated with reduced risk of suicidal thoughts in this population.^{13,15} 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.¹⁴ These are important warning signs.



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“[Provide] what works, not what’s on offer because it’s always been done that way.”

– Autistic adult

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 behaviors 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.

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