Warning Signs of Suicide for Autistic People

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

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Six people participated in the development of this resource from July 2020-August 2021. The team covers a wide range of experiences, many with multiple experiences and roles, including autistic people, researchers, practitioners, and those with lived experience of suicide loss and suicidality.

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Purpose of this Toolkit

Warning signs of imminent suicidal behavior in the general public do not represent the unique needs of the autism community. The purpose of this resource is to inform about warning signs, indicating an immediate concern of suicidal behaviors, specific to autistic people.

Misunderstanding a suicide warning sign in an autistic individual can have devastating consequences. Reacting and intervening without fully understanding what the autistic person is experiencing can be traumatic and lead to unintentional harm.

This resource contains a proposed set of warning signs for autistic people. The warning signs are listed, followed by scenarios explaining them, emerging research findings (where available), and a One-page Summary to use in real-time. This guide is designed to enhance discussions with autistic people; it is not a substitute for professional support or risk assessment. Links to additional information about autism and suicide prevention can be found in the Additional Resources section.

In this toolkit, we use identity-first language (e.g., autistic person), given that this is the most preferred language of the autistic community (Bottema-Beutel et al. 2021; Bury et al. 2020; Kenny et al. 2016). We recognize and respect the wide range of terms and different individual preferences for describing autism, and that the language used to describe autism will continue to evolve over time. We also use a range of gender pronouns in the scenarios.

We are interested in your comments and feedback about this resource. If you would like to share feedback, please do so here: <u>https://forms.gle/8jMLZ7UftbfHfvLu7</u>

If you are thinking about suicide, please visit <u>https://findahelpline.com/i/iasp</u> to access support services.

Warning Signs

These warning signs are contingent upon a marked increase or change of specific experiences or behaviors that are different than usual for that individual. Often more than one warning sign would be present in an autistic individual at imminent risk of suicidal behavior.

- 1. Sudden or increased withdrawal
- 2. No words to communicate acute distress
- 3. Current traumatic event, reported by self or others
- 4. Marked increase in rate and/or severity of self harm
- 5. Worsening in levels of symptoms of anxiety and/or depression
- 6. A new focus on suicidal talk, ideation, or deathrelated 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

1. Sudden or increased withdrawal

Scenario

Lucia routinely withdraws for self-care. Her family and friends understand the need she has for alone time. They know Lucia will be spending time in her room for a while after school, work, and social events, and then will immerse herself in making clay animals. Suddenly, Lucia's family and friends noticed she was spending more and more time in her room. Lucia goes straight to her room when she gets home, only coming out for meals. She continues to participate in her usual activities, although she doesn't want to and takes longer to regulate afterwards. Lucia is no longer interested in making her clay animals and has not replaced that passion with another.

Research

Lucia, like many autistic people, values alone time to recover after intense social events. However, sudden or increased social withdrawal, which is unusual for Lucia, could indicate a mental health problem such as depression. It is particularly concerning that Lucia's increased social withdrawal is coupled with reduced interest and pleasure in a previously intense interest. Research suggests that together, these are unique warning signs for depression in autistic people, which could include suicidal thoughts (Cassidy, Bradley, Cogger-Ward, Graham, & Rodgers, 2021; Cassidy et al., 2018; Stewart et al., 2006). Watching out for these warning signs is important, particularly as autistic people reported that the most common reason for not telling anyone they felt suicidal is because they were not sure how to express their thoughts (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). There are tools developed with and for autistic young people and adults that could help an autistic person monitor and report on their mental health (Ambitious about Autism, 2017; Cassidy, Bradley, Cogger-Ward, Graham, & Rodgers, 2021).

No words to communicate acute distress

Scenario

Lizzie lives with suicidal ideation, PTSD, autism, and has made at least one suicide attempt to try to stop emotional pain. As a woman diagnosed with autism late in life, she has experienced numerous traumatic experiences. Lizzie can't get away from the triggers that cause her to feel like she's experiencing trauma repeatedly. The triggers come from music, conversations, touch, smells, reading, movies, and her own internal world. Most days Lizzie can work through the triggers by herself, although in a state of high anxiety, tormenting memories and tumultuous emotions leaving her exhausted. Lizzie has one person she knows she can go to for support who understands both her internal and external world. She needs to know she's not alone. Yet, when Lizzie goes to reach out for support, she finds she has lost the ability to communicate. The words she wants to say are swirling around so fast in her mind that she can't catch them. It's like they are all inside a tornado churning and turning too fast to access and there's no way to get the words from her thoughts to her mouth to speak or to her fingers to write. When Lizzie needs help the most, she can't reach out for help. She wants to connect, but it's not possible in that moment. She is not withdrawing, although it can look that way to other people. Mostly, she appears calm and in control. Words are important to Lizzie in navigating through life, and when she loses them, it frightens her. Even if nothing else troubling were going on, just losing the ability to communicate is defeating, scary, confusing, and gives her a feeling of helplessness, which triggers her and causes her to feel even more isolated and alone.

Research

Very little research exists in this area. Zisk and Dalton (2019) share information about insufficient speech and inconsistent speech, and the associated challenges for autistic adults. Autistic adults who have attempted suicide are significantly more likely to report not telling anyone because of not knowing how to communicate this to others (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). Research has identified a non-speaking way for a person to describe what happened in the lead up to self-harm using cards sorted into a timeline of thoughts, feelings, behaviors, and situations (Townsend et al., 2016).

Current traumatic event, reported by self or others

Scenario

Mateo and his family moved away from where Mateo was born. He has found it difficult to settle and has begun to act out, sing loudly, or rip up papers. His parents tried to prepare him for the move, introducing it many weeks before it happened, including him in the planning, even taking him to the new town and neighborhood before they started packing. Mateo seemed to accept the idea of the move at first, but he has demonstrated substantially higher agitation on some days and complete withdrawal on others. Since the move and with increasing frequency, Mateo has been refusing foods that he previously would eat, and he is more frequently engaging in self-harming behaviors such as hair pulling. In addition, he has refused to go into the family living room. He says that he misses being happy. Mateo reports - over and over - that the new house isn't safe. His support team tried for weeks to address the change with him in many ways, had made play dates with his best friend, invited the minister to bless the house, and even investigated whether Mateo was endangered by a helper. Nothing seemed to work, until one day Mateo's parents found him in bed with papers all around him. He had a box with the family's sheet music and was clutching many pages while humming. It finally dawned on Mateo's parents that they had no room in the new house for their old piano and so had left it behind. That piano was one of Mateo's safe objects.

Research

Like many autistic people, Mateo found changes to his routine and environment particularly challenging, and potentially traumatic. Research shows that autistic people can find different kinds of events traumatic compared to non-autistic people. For example, a majority (60%) of autistic adults identified social events as their most distressing event (compared to 20% of non-autistic people), with high levels of PTSD symptoms (Haruvi-Lamdan et al., 2020). Autistic people report a significantly higher number of potentially traumatic events over their lifetime than the general population, such as exclusion from education, homelessness, poverty, abuse and exploitation (Griffiths et al., 2019), which is associated with increased risk of suicide attempts (Pelton et al., 2020). It is important to be aware of the different types of everyday events that could be traumatic to autistic people, and like Mateo's parents, try to understand changes in behavior.

4. Marked increase in rate and/or severity of self harm

Scenarios

1. At the beginning of therapy, Andy shares that they have a history of self-cutting. They share that they currently engage in self-cutting once or twice per month. Three months later, the therapist notices cuts on Andy's arms and inquires about the frequency of self-cutting. Andy shares that they have been self-cutting at least once per week for the last month, with 4 episodes in the past week.

2. When feeling anxious or overwhelmed, Prisha often pinches herself with her fingernails, to the point that bleeding occurs, or marks remain on her skin. Prisha describes this self-harming behavior as a coping mechanism. According to Prisha, when her emotions are so overwhelming that she feels stuck or frozen, the experience of feeling the pinch and seeing the blood or physical mark is like hitting a reset button, and afterwards she can continue with her daily activities. However, after losing her job, Prisha reports that pinching herself no longer has the same calming effect, and the negative emotions feel out of control and unrelenting. She decides to try something different that she read about in an online forum - burning her skin with lit cigarettes.

Research

Like Prisha, the most common function of self-harm reported by autistic and non-autistic people is as a coping mechanism for emotional pain (Maddox et al., 2017; Moseley et al., 2019). Self-harm, regardless of intent to end life, increases risk of fatal or near fatal injury (Cassidy, 2020). Like with Prisha and Andy, a change in the rate and/or severity of self-harm can indicate an increase in intolerable distress, with or without suicidal thoughts or intent to end life. It is crucial to explore possible reasons for increases in self-harm and potential treatment options.

Worsening in levels of symptoms of anxiety and/or depression

Scenarios

1. Sophie has struggled with anxiety for as long as she can remember. She has tried different strategies to manage her anxiety over the years, with varying degrees of success. In the past two months, her anxiety has notably worsened. Her wife, Kate, has expressed concern about Sophie because she looks exhausted. Sophie explains that she is staying up too late playing video games because she cannot fall asleep when she goes to bed. Sophie tells Kate, "When I lie down on my bed, my mind races and I can't stop thinking about all of the awful things happening in the world. My mind jumps from 'What if this terrible thing happens?' to 'What if this other terrible thing happens?' I am sick of lying awake worrying, so I would rather stay up playing video games and distracting myself." Sophie has also lost weight because she feels too anxious to eat. She describes her current level of anxiety as unbearable - "it's like I have the weight of the world on my shoulders and it's about to crush me."

2. Rory arrived late to their therapy session and somewhat disheveled. They have been difficult to engage in this appointment. Their chart describes them as well groomed, cooperative, and chatty. Though mostly silent, when able to speak, Rory reported that they haven't wanted to shower or make meals. In session, Rory drew pictures with gruesome images, but could not describe why.

Research

Worsening symptoms of depression and/or anxiety could signal an approaching suicidal crisis. Depression and anxiety symptoms can be particularly challenging to spot in autistic people - these can be missed and misattributed to characteristics of autism (Au-Yeung et al., 2019). Many autistic people also have difficulties communicating their thoughts and feelings (termed "alexithymia") and may not be able to describe or report feeling depressed or anxious. Current tools developed for the general population do not include possible unique indicators of depression or anxiety in autistic people. It is important to ask about changes in common experiences of autistic people, such as increased sleep difficulties, increased withdrawal, and reduced interest in a previously intense interest (Cassidy et al., 2018; Stewart et al., 2006). Intolerance of uncertainty, and fear of violation of logical rules, are also unique indicators of anxiety in autistic people (Rodgers et al., 2020). Tools developed with and for autistic people are now available to better identify changes in mental health, depression, and anxiety in this group (Cassidy, Bradley, Cogger-Ward, Graham, & Rodgers, 2021; Crane et al., 2017; Rodgers et al., 2020).

A new focus on suicidal talk, ideation, or death-related topics that are not a special interest

Scenarios

1. Jin calmly stated he wanted to kill himself one day after school. There was no emotion; he was not agitated, but rather matter-of-fact. He could not articulate why. Jin continued to focus on suicide. He mentioned people in the news who had died, talked about people in movies dying, and discussed the 'best' ways to die. There was no known traumatic event that precipitated this subject. The words were not from a movie, a self-stimulatory behavior, or a special interest.

2. Aiyana's best friend, her dog Buddy, died after a short illness. He'd always been part of her life. He was someone she could talk to about anything. He was a good listener. Aiyana talked non-stop about going to be with Buddy. After a while, Aiyana went back to being herself. She happily participated in activities at school and home. It was as if a heavy burden had been lifted. Her friends and family were relieved until her brother overheard her talking out loud to Buddy as if she would be seeing him soon. After some investigation, her family found out her plans to kill herself to join Buddy, which was why she was so happy.

Research

Like Jin, many autistic people can report suicidal thoughts and/or behaviors without necessarily showing the same degree of distress as seen in non-autistic people (Cassidy, 2020). Because of this, many autistic people report not being believed when they report suicidal intent (Camm-Crosbie et al., 2019; Cassidy, 2020; Cassidy et al., 2021). Some people who have died by suicide, including autistic people, have been found to have extensively researched suicide methods, or to have shown a sudden increase in mood before a suicide attempt.

7. Perseverative suicidal thoughts and ruminations

Scenario

After hearing about suicide, Jamie became fascinated by the topic. She perseverated on it until suicide became a focused interest. Jamie talked about issues of suicide a lot to her family. She brought it up at dinner, on family walks, and during car rides with family. Jamie always talked about suicide as a subject she was mesmerized by, until her conversation transitioned into a more personal account. Her parents noticed she was talking more about herself when she brought up the topic of suicide. They discussed her interest, and, upon reflection, Jamie realized she had started thinking of suicide as a means to an end of the extremely challenging parts of her life. She realized she had started to personalize suicide to her circumstances and was experiencing suicidal ideation. Thoughts of suicide had become a comfort for Jamie.

Research

Autistic people with a history of suicidal thoughts were significantly more likely to report an episode lasting 8 hours or more compared to non-autistic people, who reported much shorter periods (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). Autistic people therefore are much more likely to report "sticky" suicidal thoughts, which may last for long periods. It might be extremely difficult to mentally switch away from these images, intentions, or nightmares (Cassidy, 2020). Rumination has also been shown to increase risk of suicide attempts in autistic people (Arwet & Sizoo, 2020).

8. Seeking means or making plans for suicide or suicidal rehearsal

Scenario

Keshawn was concerned about their son Malik, who had been feeling very depressed, and had not come out of his room or seen friends for months. Malik had said to Keshawn that he "didn't see a reason to keep going." Unexpectedly, Malik came out of his room and seemed much happier than he had been in months. Malik wanted to arrange a party inviting his close friend and family. At this party, Malik wanted to give gifts of his most valued possessions to his loved ones. When asked what the occasion was, Malik said "he had made some plans for a journey and wanted people to remember him when he was gone." Keshawn was concerned at this sudden change and asked Malik more about the journey he had planned. Malik said he had made plans to attempt suicide, to escape from the intolerable situation he was in, as there was no other way out he saw.

Research

In non-autistic people, research has reported that greater time spent visualizing suiciderelated images (Crane et al., 2012) and greater time spent planning for suicide increase the likelihood of more severe physical injury (Mann et al., 1996) and death by suicide (Joiner et al., 2003). Research into this warning sign for autistic people is ongoing, but preliminary results from a study interviewing friends and family of those who died by suicide showed that there are often no obvious warning signs of impending suicidal crisis, such as mental health difficulties. Signs can be very subtle, or hidden, and only realized with hindsight. Autistic strengths involve attention to detail. This warning sign might be seen in a person who is at high-risk for suicide doing extensive internet searches for ways to self-harm, making detailed plans, and/or stockpiling medications (over-the-counter and/or prescription drugs). Someone might mention being unavailable after a certain date or may give possessions away. An individual might have a sudden increase in energy or lifting of mood (as plans are made) that is markedly different than a previous period.

9. Statements about no reason for living or no sense of purpose in life

Scenarios

1. Scenario of when these statements may represent a warning sign (i.e., imminent risk of suicide): Terrance comes home from his part-time job upset. In his interactions with coworkers, he is unsure of the meanings behind things they say and do and is anxious about doing the wrong thing. In his conversations with his family, he shares that "I don't have a purpose for being here. I don't know why I'm even alive." His family wonders if he is experiencing suicidal ideation. Conversations with Terrance reveal that his thinking about *no reason for living* is a great concern as a suicide warning sign because he is expressing a desire to no longer be in the world. In addition, his experiences in his workplace of masking/camouflaging, as well as thwarted belonging, are a concern among autistic adults as they are potential risk factors for suicide.

2. Scenario of when these statements may not be a warning sign (i.e., not imminent risk of suicide): Timmy comes home from his part-time job upset. In his interactions with coworkers, he is unsure of the meanings behind things they say and do and is anxious about doing the wrong thing. In his conversations with his family, he shares that "I don't belong... I don't belong in this world at all". His family wonders if he is experiencing suicidal ideation. Conversations with Timmy reveal that his thinking about *not belonging* is an accurate assessment about not belonging and are not because he is at <u>immediate</u> risk for suicidal behaviors. However, thwarted belongingness can be an important <u>risk factor</u> for suicidal thoughts and behaviors, and Timmy's parents encourage Timmy to talk with his therapist about this for continued monitoring.

Research

There is limited research in this area. Similar to Timmy and Terrance, research suggests that autistic people report feeling thwarted belonging (loneliness and/or absence of feeling socially accepted) more frequently than non-autistic people. This is a consequence of not being accepted for their true self and having to mask or camouflage autistic characteristics to survive in a world not designed for the autistic minority (Bradley et al., 2021; Cassidy et al., 2020; Mitchell, Sheppard, & Cassidy, 2021). These experiences are associated with suicidal thoughts in autistic people, rather than imminent risk of suicidal behavior (Pelton et al., 2020). Imminent risk of suicidal behavior could increase with painful and traumatic events (Pelton et al., 2020), and an external indicator of this could be expressing no reason for living.

10. Hopelessness

Scenario

Ciaran expresses that he no longer wants to go back to his college after returning home for spring break. He recently learned that he did not do well on his midterm exams and has had a hard time connecting with peers in his college classes. He doesn't enjoy the loud parties, but that is where people tend to hang out. Being away from home was challenging when he was at school but being at home during break has also been hard. He reflects "I have no reason for going back... I don't see the point... But I can't stay here at home forever." He chooses to withdraw from college classes, but at home doesn't express any desire to take steps towards independence. Ciaran expresses lack of interest or hope that he will succeed at college, find a partner, or ever live away from home. Ciaran's younger sibling expresses a concern that he is experiencing suicidal ideation. In this situation, Ciaran's parents decide to ask him about this concern by saying "Ciaran, we noticed you are having difficulty making life decisions. We are concerned when you say that you are feeling hopeless about the future. Have you recently had thoughts of killing yourself?" Ciaran is relieved to share his suicidal thoughts and plans for suicide, and how his thoughts about the future keep him up at night. His parents connect Ciaran with a mental health provider whom he has worked with in the past. Ciaran also agrees to tell his parents when he is experiencing distressing thoughts.

Research

In a study interviewing friends and family of those who died by suicide, negative thoughts about the future, including hopelessness, were common amongst people with or without evidence of possible autism (Cassidy, Au-Yeung, et al., 2021). Increased autistic traits are also associated with both hopelessness and suicidality in those with psychotic symptoms (a high-risk group for suicide) (Upthegrove et al., 2018), and rumination on past or current failures is also associated with suicidality in autistic people (Arwet & Sizoo, 2020). Therefore, as in the general population, hopelessness is likely a warning sign for suicide in autistic people too.

Additional Resources for Clinicians & Other Service Providers

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Warning Signs for Suicide in Autistic People

These warning signs are contingent upon a marked increase or change of specific experiences or behaviors that are different than usual for that individual. Often more than one warning sign would be present in an autistic individual at imminent risk of suicidal behavior.

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

This summary is a proposed list of warning signs for autistic people, developed by autistic people, clinicians, and researchers for the purposes of expanding resources for autistic people and their supporters. These warning signs need more evaluation. They should be used as part of thoughtful decision-making, in collaboration with the autistic person in distress. The authors of this resource are not liable for any actual or perceived harm resulting from this information. People experiencing a mental health crisis are encouraged to visit https://findahelpline.com/i/iasp to access support services.