

Crisis Supports for the Autism Community

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SUICIDE COMMITTEE & COMMON GROUND

Purpose of this Toolkit:

This resource was developed to aide crisis center workers in identifying and supporting autistic callers/ texters who are in crisis. A person with autism may or may not disclose their diagnosis to a crisis center worker or even be aware they are on the autism spectrum, yet still need individualized, specific support. This resource includes ways to identify potential callers/texters who show autistic traits and characteristics, as well as ways to support an autistic person in crisis. The resource also explains the unique differences in communication, thought processes, sensory issues, and misunderstandings a crisis worker may encounter while helping an autistic person in crisis.

This resource has been endorsed by the Autism and Suicide committee of The American Association of Suicidology and Common Ground.

About AAS:

Founded in 1968 by Edwin S. Shneidman, PhD, AAS promotes research, public awareness programs, public education and training for professionals and volunteers. We are a membership organization who includes clinicians, researchers, crisis workers as well as people who have lost loved ones to suicide or lived through their own lived experience of suicide. Find out more at suicidology.org.

About Common Ground

Common Ground is a nonprofit organization that has served as an expert on mental health issues and crisis intervention since 1971. Through its 24-hour Resource and Crisis Helpline and in person, Common Ground uses a trauma-informed approach to provide professional, compassionate services to over 80,000 people annually. Common Ground's core purpose is to move people from crisis to hope through three key impact areas: responding to crisis, providing safety & advocacy, and building communities of support. For more information, please visit www.CommonGroundHelps.org or call 248-456-8150.



Author's Statement:

"The decision on whether to use person-first language versus identity-first language is a personal choice. As an autistic adult, I prefer to use identity-first language. I use the word autistic as a descriptive adjective in defining who I am. While other autistic adults may also choose identity-first language, there are people on the spectrum who prefer to use person-first language, not wanting to be defined by autism. In respect for all people diagnosed with autism, I have chosen to use both types of language in this autism-friendly resource to be used in crisis centers as a means to identify and communicate with people in crisis who are diagnosed with autism." ~ Lisa Morgan

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Supporting Autistic Callers/Texters

People with autism are individuals and experience the world differently. Some may respond well to these suggestions and others may not. Callers/texters may have a diagnosis and either choose to disclose that information or not disclose it. Some may not have a diagnosis or even have the insight of a possible diagnosis. This resource will still be relevant for any of those circumstances.

This resource is intended to be used as a guideline to identify and support callers/texters diagnosed with autism, so they feel understood, and therefore receive the help they need. When supporting autistic people, no assumptions based on non-autistic people should be used.

Expresses sensory difficulties - such as with sight, sound, smell, touch

Many people on the autism spectrum have challenges with sensory input from their environment. Any of the senses can be over or under stimulated both at the same, and at different times.

The sensory challenges can affect behavior and have a powerful impact on a person's life.

There are many ways sensory input can be overwhelming to autistic people, including sight, sound, smell, or touch.

The environment can become a place where there's too much information bombarding a person all at once, causing an overload of the senses. Lights can be too bright, sight can be distorted, smells can be extreme or there can be no sense of smell at all. A person on the spectrum can experience pain upon being touched, even lightly, or may seek out touch. Noise can be too loud, piercing, or vibrating and cause pain and discomfort in their ears.

There are myriad ways interaction with their environment can cause sensory overload in an autistic person and affect their behavior, coping skills, ability to process information, hinder communication skills, and cause anxiety and distress.

People on the autism spectrum who are already in a state of crisis due to mental health issues are likely to be even more

sensitive to sensory overload than they usually experience. Sensory overload can have a significant impact on autistic people, which is unique to each person, and cannot be compared to others.

May present with emotions opposite of being in a crisis - like laughter

There are people diagnosed with autism who may express different emotions than they are feeling. They could laugh, sometimes uncontrollably, when they are feeling distressed, anxious, or overwhelmed during a crisis. It's important to understand how they are presenting on a call may be opposite of the way they are feeling. Making assumptions based on how serious their situation is whether they are laughing or not, could cause misunderstanding, lead to miscommunication, and result in an ineffective or unhelpful call or interaction.

Autistic people may still be engaged in activities that normally would seem to be an indication that all is well.

There is no way to tell the state of crisis a person on the spectrum may be in- based on what they are able to accomplish- while they are in a crisis. If a volunteer asks if they are working, or if they are in school, a deeper assessment may be needed as some autistic people may still be continuing these things purely due to their work ethic, or they have not entertained the idea they are too unwell to continue working or going to school, etc. They may not understand it is acceptable for their own emotional well-being, to take a break from work or school.

Difficulty identifying or verbalizing emotions

When a person on the spectrum responds that they do not know how they are feeling, it is a true, literal statement. The thought 'they are being vague' is not the first assumption a crisis center worker should conclude. One defining characteristic of autism is not being able to identify, express, or verbalize emotions. It is important to understand; autistic people are trying to communicate when they have called or texted; they most likely want very much to tell someone how they feel but can't. Giving them time to identify and/or explain their emotions can be helpful.

Additionally, they may explain this in a way that is different than usual, such as trying to describe a situation that evokes the same emotion they are feeling in the moment or whatever way the person can come up with to share their emotion(s). For example, a person may describe a desolate, lonely place or an anxious situation.

May not know how to cope with or what to do with emotions

Alexithymia is the inability to identify, express or describe one's feelings. It is not necessarily an autistic trait, but many people with autism struggle with it.

Autistic people can be flooded with emotions they don't understand, can't identify, and don't know how to handle.

A person on the spectrum may be completely overwhelmed with intense emotions, but not know that is what they are experiencing. They may say they are "feeling bad" or "something is wrong" or "they don't feel good inside" or many other ways to describe such an onslaught of emotions when they don't understand or can't identify their emotions.

It would be best if a crisis center worker could give them more time, use fewer words to communicate, and perhaps use questions with one-word answers.

Literal thinking and understanding

An autistic person can be very literal in how they think and perceive the world. It is important to say exactly what you mean and mean what you say when communicating with a person on the spectrum. If you were to say, "I'm here with you," that can be inferred as a lie, because you are not actually physically there with them – you are on the phone with them.

This type of miscommunication can be enough for an autistic person to end the call because honesty is considered so important. Being on a phone call or writing a text makes it difficult for a person on the spectrum to ascertain whether to trust the person on the other end and words are one of the ways to build trust. Understanding how autistic people are typically very literal thinkers can help facilitate a successful call or text.

Has experienced countless misunderstandings/ miscommunications

Everyone experiences misunderstandings and miscommunications in life. A misunderstanding is an interaction leading to confusion, misinterpretations, and errors, while miscommunication is unclear or inadequate communication.

A defining characteristic of autism is having difficulty with social communicating and social interactions across multiple circumstances. The misunderstandings and miscommunications a person diagnosed with autism experiences can be multiple, in many different relationships, all at once. There can be misunderstandings with a loved one (s), a neighbor, a physician, a waiter, an acquaintance, a bank employee... anyone or all of them at the same time.

There can also be miscommunication between multiple people as well, which are difficult to resolve because of the very nature of autism.

Shares difficulty or inability to make friends and sustain relationships

Relationships are difficult for autistic people due to the nature of autism having difficulties with social communicating and interactions. Many people on the spectrum have shared they can make a friend but find it too difficult to keep a friendship going. Many autistic people have shared they experience the sudden absence and subsequent, complete, withdrawal of a friend that denotes the end of a friendship without closure or any reason why the friendship no longer exists. This rejection can cause a crisis situation for a person on the spectrum; especially if there have been multiple friendships that have ended in this way. Relationships, such as acquaintances, business partners, colleagues, neighbors, retail employees, etc., can also suddenly end with no warning or reason that is understood by an autistic person.

Feels disconnected and isolated from society

People diagnosed with autism can tell of experiences with bullying, being excluded, rejected and ostracized by society for many reasons, but mostly because they are

different. The difficulties with social communication and interactions, whether from autistic, non-autistic or any neurology; can result in autistic people feeling disconnected and isolated from society as a whole. They can feel as if they don't belong to this world because they don't understand it, the environment causes discomfort and distress, and relationships can be very confusing. It is a feeling of deep loneliness and complete aloneness. The feeling will most likely be literal, not rhetorical.

Perseveration - ruminates on thoughts, situations, or circumstances

Perseveration is a defining aspect of autism. It is the rumination of thoughts both positive and/or negative. In crisis, a person on the spectrum perseverating on negative thoughts will have great difficulty shifting their thinking to more positive thoughts. An autistic person may get stuck in a loop thinking about words and phrases because of the perseverating, unable to break out of their thought pattern. It could be perceived by the volunteer as not listening, refusing to cooperate, or being done on purpose.

Perseveration is not something a person on the autism spectrum would do on purpose.

Unusual patterns of speech such as odd pitch, tone, pace, or robotic

Some autistic people may have a way of talking that is not common. People on the spectrum may have a high vocabulary, talk slowly and carefully, and /or pace their words so they sound pedantic or robotic. They are not talking this way to be uncooperative or as a joke. It is their way of talking and a way for a volunteer to identify whether they are communicating with an autistic person.

Verbal or text response time will vary according to processing speed

People on the spectrum have varying processing speeds unrelated to intelligence. Processing speed can be negatively correlated to anxiety; meaning the higher the anxiety, the slower the processing speed. Autistic people may take longer than usual to respond. It is helpful to continue to be patient and wait for the caller/texter to

respond instead of asking more questions, especially if the caller is still trying to communicate. The worst possible action to take at this time is to end the call due to thinking either the caller/texter is done talking.

May use echolalia - repeating words, sounds, and responses

Echolalia (eko-ley-lia) is a reactive, uncontrollable, and immediate mimicking of another person's words, sounds, and/ or phrases. Echolalia is usually due to the enjoyment in repeating a word, sound, or phrase. A person on the spectrum using echolalia may sound like they are taunting, or mocking the person they are mimicking, but they are not; they are finding enjoyment in repeating the words, sounds, or phrases. Echolalia is not something to take personally.

Ask clear, direct questions – use fewer words and be straight to the point

Step to take – ask direct questions.

For example:

Instead of asking, "How are you feeling tonight?"

Ask – "Are you okay?"

For example:

Instead of asking, "What are you calling about?"

Ask – "What do you want to tell me?"

Allow extra time to process thoughts and formulate words

If the caller or texter has been silent for a while they may be processing what has been discussed or the situation they are experiencing. There is a way to ask if they are still there while respecting their need to process.

For example:

Instead of asking- "Hello! Are you there?"

Say - "I'm still here. Talk, when you're ready." {A good practice is telling them you are on the phone, and for them to say "yes or no" if they still want help.}

Help shift the thoughts – ask about any interests or passions

When confronted with repeating words and phrases of a negative thought process, one way to help shift the thoughts to be more positive is to talk about something they are passionate about- particularly a special interest. Most people on the spectrum have an intense level of focus about their special interest or passion.

For example:

Instead of asking, "What do you enjoy doing?"

Say - "What is most special to you?" or "Can you share one thing you love?"

Avoid using metaphors, social nuances, allegories, or slang

A defining aspect of autism is literal thinking. Using these figures of speech and nuances challenges the literalness of speech and can cause confusion for an autistic person.

Metaphor - a figure of speech saying one thing is another.

Ex. - "it's raining cats and dogs" or "life is a rollercoaster"

Social nuances – a nuance is a subtle difference in body language or speech inflection that neurotypical people see and understand, but people on the spectrum may tend to miss

Allegories – stories in which there is a hidden meaning of a moral or a life lesson

Slang – very informal words or phrases like: "pass the buck" which means a person passes responsibility to another

Speak using logical words – not emotional words

Speaking using logic and not emotions means to leave out emotional words such as – "Are you... frustrated, angry, sad, happy, frightened, disappointed, moody, dejected, and/or heartbroken" to name a few?

Speaking logically means there's little to no emotion in the communication. It will be facts and logic and trying to make sense of what happened void of any emotions.

For example, a traumatic experience such as a house fire could be described by a non-autistic person using words such as frightening, sad, a loss, scary, panic, anxious, and heartbreaking; whereas an autistic person could describe the house fire with words such as; how the fire started, the fact that house burned down, did everyone get out, is there anything worth keeping, and/or do we build on the same spot or a different place?

Explain positive coping skills and how they are helpful

Positive coping skills, sometimes referred to distraction strategies by people on the spectrum, such as 'watch tv', 'go for a walk', have a glass of milk', 'listen to music' may not be understood as useful to autistic callers/texters.

These strategies may be taken as meaningless and dismissal. Explaining the reason behind how these strategies are useful can help people on the spectrum understand them and be more willing to use them.

Facilitate a safety plan – help make connections to people or resources

Due to the isolation and withdrawal of autistic people, especially those who have been diagnosed later in life, it will be important to guide them into making a safety plan for after the call/ text session has concluded. You may ask if they have someone they can call and talk to or ask if there is a neighbor they trust to come sit with them or if the adult on the spectrum can go over to their trusted neighbor's house. Help the autistic caller/texter to find local resources to get connected to and suggest support groups followed up by offering the contact information.

Also, give the crisis call/text lines, and any other autistic friendly resources available to the person before hanging up.



CRISIS SUPPORTS FOR THE AUTISM COMMUNITY

Identifying Autistic Callers/Texters

- Expresses sensory difficulties- such as with sight, sound, smell, touch
- May present with emotions opposite of being in a crisis - like laughter
- Difficulty identifying or verbalizing emotions
- May not know how to cope with or what to do with - emotions
- Literal thinking and understanding
- Has experienced countless misunderstandings/miscommunications
- Shares difficulty or inability to make friends and sustain relationships
- Feels disconnected and isolated from society
- Perseveration- ruminates on thoughts, situations, or circumstances
- Unusual patterns of speech such as odd pitch, tone, pace, or robotic
- Verbal or text response time will vary according to processing speed
- May use echolalia - repeating words, sounds, and responses

Steps in Supporting Callers/Texters on the Autism Spectrum

- Ask clear, direct questions -use fewer words and be straight to the point
- Allow extra time to process thoughts and formulate words
- Help shift the thoughts - ask about any interests or passions
- Avoid using metaphors, social nuances, allegories, or slang
- Speak using logical words - not emotional words
- Explain positive coping skills and how they are helpful
- Facilitate a safety plan - help make connections to people or resources