

Crisis Supports for the Autism Community

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Purpose of this Toolkit:

This resource was developed to aid 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 autistic people in crisis. The resource also explains the unique differences in communication, thought processes, sensory issues, and misunderstandings a crisis worker may encounter while helping autistic people in crisis.

Authors' Statement:

"The decision about whether to use person-first language versus identity-first language is a personal choice. While many autistic individuals choose to use 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 with autism, we 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 autistic people in crisis." ~ Lisa Morgan and Brenna Maddox

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People with autism are individuals and experience the world differently. Some may respond well to the suggestions in this resource 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 yet or even have the insight of a possible diagnosis. This resource is still relevant for any of those circumstances.

This resource is intended to be used as a guideline to both identify and support autistic callers/texters in a way they understand as support. The goal is to reduce unintentional harm, caused by invalidation, stigma, ableism, and misunderstanding the nature of autism.

Identifying Autistic Callers/Texters

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 at the same time or 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.

Sensory overload can affect their behavior, coping skills, and 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 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 with autism who may express different emotions than they are feeling. They could laugh, sometimes uncontrollably, when they are feeling distressed, anxious, or overwhelmed. It's important to understand how they are presenting on a call may be opposite of the way they are feeling. Making assumptions about how serious their situation is based on their emotions could cause a 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 an autistic person reports that they are still working or going to school, a deeper assessment is needed because they may be continuing these things purely due to their work ethic or the difficulties associated with changing their routine. They may not understand it is acceptable for their own emotional well-being to take a break.

Difficulty identifying or verbalizing emotions

When a person on the spectrum responds that they do not know how they are feeling, it is most likely a true, literal statement. They are likely not

just being vague, although a crisis center worker may incorrectly assume this. Many autistic people struggle with alexithymia, or the inability to recognize or describe one's own emotions. It is important to understand that 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.

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.

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

Autistic people can be flooded with emotions they don't understand or know how to regulate. The overwhelm of suddenly being flooded with intense emotions can trigger impulsive behavior causing a concern for their safety. 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 communication and social interactions across multiple circumstances. The misunderstandings and miscommunications a person with autism experiences can be multiple, and in many different relationships, all at once. There can be misunderstandings with a loved one, a neighbor, a physician, a waiter, an acquaintance, a bank employee... anyone or all of them at once. 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 can be challenging for autistic people due to difficulties with social communication 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 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 with autism can tell of experiences with being bullied, excluded, rejected, and ostracized by society for many reasons, but mostly because they are different. The difficulties with social communication and interactions 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 might 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 perseveration, unable to break out of their thought pattern. It could be perceived by a crisis center worker as not listening or refusing to cooperate. 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 crisis center worker 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 the caller/texter is done talking.

May use echolalia – repeating words, sounds, and responses

Echolalia 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.

Supporting Callers/Texters on the Autism Spectrum

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

Step to take – ask direct questions.

Example 1

Instead of asking – “How are you feeling tonight?”

Ask – “Are you okay?”

Example 2

Instead of asking – “What’s on your mind tonight?”

Ask – “What do you want to talk about?”

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.

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.

Example

Instead of asking – “What do you enjoy

doing?”

Ask – “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”

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?”

Speaking logically means there are little to no emotional words 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 as distraction strategies by people on the spectrum, such as 'watch tv', 'go for a walk', 'have a glass of milk', 'listen to music', etc., may not be understood as useful to autistic callers/texters.

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

Help identify effective distractions

Short-term distractions can "buy time" to allow suicidal thoughts and urges to decrease in intensity, making suicidal behavior less likely.

Ask the caller or texter: "What helped you stop thinking about your problems in the past, even for a short time?" or "What activities are easiest for you to focus on?" Suggest that the autistic person write down these distraction techniques and utilize them.

It is crucial that the crisis center worker does not insert their own biases when discussing possible distractions. What may be an effective distraction for the crisis center worker may not be helpful at all for the autistic caller or texter – in fact, it could even be harmful. Similarly, do not dismiss an idea because it is novel to you. For example, an autistic individual may say that spinning quarters is a good distraction technique for them; even if that sounds unusual to the crisis center worker, it is still a valid and acceptable answer.

Help develop a list of reasons for living

Reasons for living can remind people why to not die. A crisis center worker can help an autistic

individual develop or update their personalized list of reasons for living.

Visit <https://tinyurl.com/5n7xwwya> for a more detailed resource focused on reasons for living.

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 can ask if they have any pets, objects, activities, or colors that help them feel supported. 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. Help the autistic caller/texter to find local resources to get connected to and suggest support groups.

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

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
- Help identify effective distractions
- Help identify a list of reasons for living
- Facilitate a safety plan - help make connections to people or resources