Supporting autistic children and
young people through crisis

Autistica evidence
resource on suicide
for crisis workers

autistica

Contents

1. About this resource

This document aims to help those working in mental health and crisis services, to support young autistic people experiencing a mental health crisis.

An autistic person may or may not disclose their autism diagnosis. They may not know themselves that they are autistic. This means that having an awareness of the characteristics of autism might be critically important to enable crisis service workers and volunteers to identify autistic traits in those they work with, because individualised, specific support may be necessary, even in the absence of a disclosure or a formal diagnosis.

This resource explains the context of mental health challenges and suicidality in relation to autism. It highlights barriers to accessing services for autistic people and suggests adaptations that should be made to make services more accessible and inclusive.

Abbreviations and terminology:
ADHD – Attention Deficit Hyperactivity Disorder
CYP – Children and young people
Suicidality – Suicidal thoughts and behaviours

2. Understanding autism

Autism affects the way people communicate and experience the world around them.

Every autistic person is different. Some can learn, live and work independently, while many have learning differences or co-occurring health conditions that require specialist support. Some may need forms of support at different stages throughout their life, while living independently.

Social communication difficulties

Autistic people have differences in communication to varying degrees. They may have trouble expressing themselves, either through words or non-verbal communication. They may also struggle to understand some aspects of social communication in others, including being able to identify what other people are thinking or feeling. These difficulties may make social situations anxiety provoking and overwhelming for autistic people, which may then attenuate their social communication skills. As such, the ability to communicate is not fixed. A person who is usually very verbal may have periods in which they are non-verbal. This is strongly influenced by anxiety and energy levels.

Sensory sensitivity

Autistic people can be over- or under-sensitive to sensory aspects of the environment, and have difficulty processing everyday sensory information. They may experience a very strong reaction to some sensory information in their environment (for example some sounds, textures or particular types of lighting may be experienced as highly aversive or uncomfortable). Their senses can feel overloaded and that can cause anxiety, stress and physical pain. Sensory overload can lead to distress, meltdowns or a need to escape.

Some autistic people may experience a low sensitivity to sensory information. They may be less sensitive to pain and may be less able to control balance or physical coordination as they are less aware of their body's position. They may be more susceptible to physical injury, and they may have difficulty sensing or paying attention to their environment. Many autistic people experience a combination of over- and under-stimulation across their senses.

Feeling anxious or distressed may exacerbate these sensory differences which in turn may lead to increased anxiety or distress as these processes interact.

Repetitive behaviour and routines

Autistic people can use repetitive behaviours like rocking, finger-tapping or saying the same phrase over and over. This is known as "stimming" and it can take a huge variety of forms. It often functions to create sensory balance when someone is feeling overwhelmed or can be used to self-soothe in anxiety provoking situations.

All these areas (sensory sensitivity, social difficulties, repetitive behaviours) have been associated with self-harming behaviours in autistic children and adults, with or without intellectual disability (for example, Duerden et al., 2012; Licence et al., 2019).

Autistic people may also adhere to very strict daily routines and may become distressed or anxious if routines are not followed or are disrupted. Both of these types of behaviour function to make the world more predictable and bearable. Routine allows someone to predict what is going to happen, which takes away some of the anxiety around what might happen. Many autistic people struggle with change, especially unexpected or uncontrollable changes.

Research indicates that whilst autistic people ordinarily engage in repetitive behaviours and routines the frequency and intensity of these behaviours may increase when they are feeling anxious or distressed and a change in these behaviours may be an important indicator of a mental health crisis. This may be a particularly important sign to look out for in individuals who would find it difficult to express and describe their emotional experiences.

Highly focused interests
Many autistic people have intense and highly-focused interests, often from a young age. These can be on any topic and can change over time. Engaging with this interest is fundamental to autistic people's wellbeing and happiness and can be a way to recover from the day.

Co-occurring conditions
Autistic people generally experience poorer health outcomes than the general population and are more likely to develop a wide range of conditions including heart disease, diabetes, stroke, Parkinson's disease, allergies, gastro-intestinal disorders, epilepsy and autoimmune conditions. They are also more likely to experience mental health issues such as anxiety and depression, sleep conditions and obesity. (See Autistica, 2019 for a review of co-occurring conditions).

Talking about autism

The words you use to talk about autism are important. Research indicates that the favoured terminology amongst diagnosed adults is generally to use the term "autistic" (Kenny et al., 2016). "Autistic" is typically favoured by those who view autism as a central and defining element of identity, similar to gender or race. "Person with autism" is favoured by those who see autism forming just one element of identity. As these terms can be emotive for individuals, it is best to follow the lead of the person you are speaking to - using terminology that they prefer and giving them control over how they are spoken about.

3. Autism and suicide

Research shows that autistic people are significantly more likely to think about, attempt, and die by suicide than the general population.

In 2018, the National Institute for Health and Care Excellence (NICE) guidance on suicide prevention recognised autistic people as being among those at highest risk. (NICE, 2018). In children and young people, between 7% (Mayes et al., 2013) and 41.7% (Mikami et al., 2009) have self-harmed and/or attempted suicide, and between 10.9% (Mayes et al., 2013) and 72% (Ghaziuddin et al., 1995) show evidence of suicidal thoughts, such as talking about death or suicide (see Oliphant et al., 2020 for a review). The National Child Mortality Database found that there were 26 likely child suicides in the 82 days before lockdown and a further 56 in the first 56 days of lockdown. In each case, 6 of these cases the child or young person was autistic or had attention deficit hyperactivity disorder (ADHD).

Just as with autistic adults, suicidality may not always be recognised in autistic CYP. Research has found that untreated suicidal behaviour can lead to crisis (White et al., 2012), emergency room visits (Durbin et al., 2018), inpatient hospitalisation (Leyfer et al., 2006) and lifelong significant mental health challenges (Leyfer et al., 2006) beginning in childhood.

Late diagnosed autistic adults appear to be at the highest risk of suicidal thoughts and behaviours: 66% of newly diagnosed autistic adults reported feeling suicidal, and 35% had attempted suicide at some point (Cassidy et al., 2014); 72% of autistic adults, most of whom had been diagnosed as adults, scored above the clinical cut off on a suicidality screening tool (Cassidy et al., 2018a, b).

Autistic people are up to seven times more likely to die by suicide than the general population (Hirvikoski et al., 2016; Kirby et al., 2019). Risk of death by suicide is highest in autistic people without co-occurring intellectual disability, and autistic women. Autistic women are markedly more likely to die by suicide than non-autistic women (Autistica, 2016; Hirvikoski et al., 2016; Cassidy et al., 2014).

General mental health challenges and autistic young people
Approximately 70% of autistic young people experience mental health issues (Lever & Geurts, 2016). Between 40-50% meet the diagnostic criteria for two or more psychiatric conditions (Reaven & Wainer, 2015), with internalising conditions such as depression and anxiety most common. For children with neurodevelopmental conditions (of which autism is one), mental health challenges can significantly impact children's daily life, and cause debilitating distress (Baraskewich & McMorris, 2019).

Self-harm/non-suicidal self-injury
Autistic people are significantly more likely to experience non-suicidal self-injury (NSSI) compared to the general population, and non-suicidal self-inury is associated with increased risk of suicidality (Cassidy et al., 2018b; Maddox et al., 2017; Moseley et al., 2019, 2020). Hunsche et al., (2020) found that parents reported self-injury/suicidal behaviour in 14.6% of autistic children.

Why suicidality may be more common

General risk factors

Factors known to increase the risk of suicide in the general population are more common in the autistic community, including social isolation, abuse, low mood, low self-esteem, difficulty identifying and verbalising one's own feelings (alexithymia), rumination, and other social and biological factors that increase the likelihood of mental health problems. However, autistic people are still more likely to have suicidal thoughts in studies where both they and non-autistic people experience comparable rates of these general risk factors. This suggests that there are additional factors that can increase the risk of suicide amongst autistic people. For example, one study found that being employed was associated with increased risk of suicidality in autistic people (but not in non-autistic people). This was likely because the group that took part in that study experienced an inaccessible and unsupportive working environment (Cassidy et al., 2018).

Trauma/painful life experiences

Research suggests that painful or traumatic life events can lead suicidal thoughts to develop over time, increasing a person's capability to take their own life (i.e., reduced fear of death and increased pain tolerance) (Joiner, 2005, Van Orden et al., 2010). Trauma has been reported at shockingly high levels within the autistic community (Griffiths et al., 2019). Even in childhood, such experiences are disproportionately high, with autistic children experiencing higher rates of maltreatment (McDonnell et al., 2019), bullying (Maïano et al., 2016), removal from biological birth family (Green et al., 2016) school discipline, school exclusion, police contact and psychiatric hospitalisation (Humphrey, 2008; Shea, Turcotte & Mandell, 2019a).

These traumatic experiences have been linked to increased capability for suicide, and subsequently suicidal thoughts and behaviours among autistic adults (Pelton et al., 2020).

Barriers to accessing support

Despite being at higher risk, accessing mental health services is frequently problematic for these young people. Some children's mental health problems are dismissed as untreatable after being confused with autistic traits (Autistica, 2018a; Crane et al., 2019; Matson & Williams, 2013). While other families report they have been refused help from CAMHS, because services did not feel equipped to support them or because the specific service was not commissioned to see autistic children. There are rarely many other services for those families to turn to, frequently leading to no professional mental health support being given (Autistica, 2018a, b)

In some instances, overstretched services have used risk assessment tools as a screening tool to determine which young people should be prioritised for access to support due to the service's restricted capacity (Autistica, 2018a). The use of suicidality risk assessments is explicitly criticised in NICE guidelines (NICE, 2011) and has been a repeated theme in coroners inquests (Wilcox, 2018). Using them in clinical practice is particularly dangerous for autistic people, whose unique presentations are more likely to 'fly under the radar' of tools developed for researching the general population (Cassidy et al., 2018).

Autistic characteristics

Autistic characteristics refer to the thinking style, interests and behaviours common amongst autistic people. These can include difficulties with imagination, insistence on sameness, repetitive behaviours, and difficulties attending to more than one thing at once, or switching attention.

In some circumstances, these characteristics might amplify other risk makers for suicide, and/or act as risk markers on their own. For example, autistic people may experience a tendency to ruminate on a particular train of thought or repeat particular behaviours. They may also experience difficulties generating alternative solutions to problems in their daily lives or switching to an alternative course of action in the face of evidence that a particular problem solving strategy isn't working. This could increase an autistic person's risk of feeling trapped in a challenging or difficult situation, with suicide perceived as the only possible escape route (Arwet and Sizoo 2020; Cassidy et al., 2020; South et al., 2019). Autistic traits are associated with increased risk of suicidality in children and adults, regardless of whether or not a person has received an autism diagnosis (Cassidy et al. 2014; Cassidy et al., 2018; Hunsche et al., 2020; Richards et al., 2019).

Camouflaging
Many autistic people feel pressure to pretend not to be autistic. This "camouflaging" takes considerable effort through constant monitoring and modifying of behaviour in an attempt to conform to non-autistic social behaviour (Mandy, 2019). Examples may include developing rules to use eye contact or observing and copying the behaviour of non-autistic people to eventually adapt clothes, gestures and facial expressions. Camouflaging has been identified as a barrier to timely diagnosis (Lai & Baron-Cohen, 2015; Lai et al., 2017). It has also been directly associated with suicidality (Cassidy et al., 2018; Cassidy et al., 2019; Mitchell et al., 2019a; Mitchell et al., 2019b). This contradicts broad assumptions that autistic people are not socially motivated.

Double empathy
Autism is characterised as a condition that impacts social and communicative behaviour. It is typically described in terms of impairments in communication. The "Double Empathy Problem" is a theory which suggests that difficulties in empathy and communication occur between people of very different thinking styles – such as between autistic and non-autistic people. As such, autistic people can misinterpret non-autistic people, and non-autistic people can misinterpret autistic people (Heasman & Gillespie, 2018; Milton, 2012; Sasson et al., 2017; Sheppard et al., 2016). While both groups are misunderstood, as the minority group, autistic people face a higher frequency of misunderstanding, which may contribute to specific and unique feelings of isolation and being burdensome – these are known risk markers for poor mental health and suicidality (Mitchell et al., 2019).

Belonging
A factor often associated with suicidality is "thwarted belonging". This is an absence of reciprocal relationships with family, friends and society. In comparison to non-autistic people, autistic people are more likely to report situations associated with thwarted belonging, such as loneliness (Haertl, Callahan, Markovics, & Sheppard, 2013; Hickey, Crabtree, & Stott, 2018; Müller et al., 2008), childhood mistreatment, family stress and intimate partner violence (Griffiths et al., 2019). Research suggests that autistic women are more likely to have greater social motivation than autistic men (Lai et al., 2015; Sedgewick et al., 2019), but still struggle to build genuine social reciprocity (such as friendships and relationships). which could increase their vulnerability to thwarted belonging (Hull et al., 2017; Tint et al., 2018). A recent study has found that autistic respondents reported strong feelings of both thwarted belonging and burdensomeness (Pelton et al., 2020), both of which have been proposed as significant risk factors for suicide.

4. Adapting services

There are many challenges that autistic people can face when engaging with crisis services that are designed for the general public. Recognising and addressing these barriers could be life saving.

4a. Making initial contact

Formats for communicating
A recent study exploring general access to healthcare found that communication presented the most significant access barrier for autistic people and parents of autistic children (Doherty et al., 2020). Over 60% of those questioned struggled to use the phone to access healthcare. Up to 53% stated that they limited engagement with healthcare providers due to difficulty communicating with their doctor, while over 55% stated that they limited engagement due to not being understood. These barriers may suggest that some autistic young people and even parents of autistic children are constrained by both their ability to use the phone to contact health professionals and by their experiences of being misunderstood. Exploring alternative means of communicating (e.g., emails or text message) may reduce some of these barriers.

Difficulties recognising and understanding emotions.
While not a core feature of autism, it is estimated that up to 50% of autistic people experience difficulties recognising and understanding their emotional experiences (Kinnaird et al., 2019). It may be difficult for an autistic person to identify their emotions which may mean that they do not know that they need to access services. This may lead to a delay in seeking help, which is more likely to occur as their distress becomes more intense. Further, it can take longer for autistic people to process their emotions, which may mean that they experience distress some time after an aversive event.

Difficulties recognising and understanding emotional experiences can still have an impact once a child or young person has made contact with services. Despite being in acute distress, they may still struggle to identify and verbalise their experiences. While they may be feeling extreme emotions, they may be limited to expressing that as, for example, "Feeling bad" or "Something's wrong."

Benchmarking feelings and experiences against others
Central to autism as a condition are challenges with communication and a difference in experiencing sensory information. Even from a young age, autistic people may perceive themselves to be different from their peers and siblings in some ways. While an autistic CYP may be experiencing distress, they may not be able to benchmark their experiences against those of other people. While they may understand that they are in emotional pain, it may be difficult for them to compare and measure whether the distress they feel needs support or is typical for others. This may mean that when someone does reach a point where they are seeking help, they could be further into a crisis than would be typical for many other callers.

4b. Working with parents

While children and young people are the focus of this report, parents will, of course, be key in providing support. Parents can provide very helpful background information in relation to their child's development, their skills, interests and abilities and their difficulties. They may be directly involved in any support that is provided for their child and undertake activities related to intervention outside of clinic settings with their child. Research indicates that parental involvement can facilitate and improve therapeutic outcomes in relation to mental health interventions for autistic children. However, not all parents are able to engage in this way and others may need support to do so. Here are some factors worth considering when engaging with parents of autistic children.

Perceptions

Some parents may need support to make sense of their child's autism diagnosis. They may associate autism with the challenges that their child is facing, and this may influence how they talk about autism. Some parents may choose not to tell their child that they have an autism diagnosis, and they may wish that health care and support providers respect this choice. Many parents may favour person first language (child with autism), which is the approach often used by service providers. As highlighted previously, it is beneficial to ask what terms are preferred or adopt the terminology used by a parent when communicating with them.

Information on local services

While CYP may reach out for support when facing an emotional crisis, it may be the case that parents are more likely to reach out when looking for specific practical services or regional supports for their child. It would be beneficial to have information about local supports available so parents can be appropriately directed to the support they need.

Parents also need support

Some parents may be experiencing mental health difficulties themselves. Research has shown that caregivers of autistic children are at a substantially increased risk of poorer mental health and psychological well-being compared to the general population (Werner and Shulman, 2013; Isa et al., 2013; Samuel et al, 2012; Zablostsky et al., 2013) and even compared to caregivers of children with other types of disabilities including physical and learning disabilities (Blacher & McIntyre, 2006; Eisenhower et al., 2005; Scott et al., 1997; Werner and Shulman, 2015). It is important to be aware that parents themselves may benefit from being signposted to local support services.

Parents can also be autistic

A further consideration is the potential presence of autistic traits in parents. Autistic traits have been reported to be present in around one in five parents of autistic children, while these traits have been found in one in twenty parents who do not have autistic children (Bora et al., 2017). This may mean that some parents may find it difficult to recognise and understand their own emotional experiences and those of their child. In other instances, an autistic parent may have an exquisite understanding of their child's experiences that can be enormously helpful in a therapeutic context. It may be beneficial to use the communication style described on page 12 (*Creating a positive experience* section) with parents of autistic children also. Further, it may be helpful for service providers to have information about routes to adult diagnosis, should any parents enquire.

4c. Identifying if someone may benefit from an alternative communication style

There is a huge variation in how autistic people present when in crisis and in the amount of support they may need. When deciding how to communicate with a caller and what other accessibility changes to make, it is important to consider them as an individual. Make a decision based on your interaction with them specifically – not on what you do or don't know about any diagnosis they might have.

Base the adaptations that you make on the needs of the individual. Adjustments you might make for an autistic caller will not harm a non-autistic caller. Additionally, many callers might not be autistic but have ADHD, sensory processing disorder or communication difficulties and still benefit from many of the recommendations made in this resource.
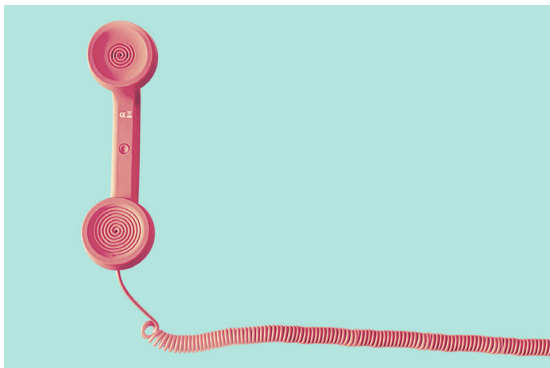
Ask yourself:

Does the caller seem to need more time to answer questions?

Is there an imbalance in how they communicate – are they talking too much or too little? Do they struggle to know when it is their turn to talk?

Do they seem to be struggling to put what they are trying to say in a coherent order? Does the caller struggle to answer questions like "How does that make you feel" or find them upsetting?

If you can see the caller, do they seem more relaxed when not making eye contact or avoid eye contact all together? Are they engaged in repetitive movements (rocking, moving their hands, tapping their foot etc)?

Has the caller prepared notes in order to make sure that they remember and cover everything that is important to them?

Does the caller bounce from topic to topic and gets easily side-tracked from the core narrative of the call?

Do they have difficulty accepting suggestions, particularly when they involve contacting people or making calls?

Do they mention having autistic family members?

Have they made any sensory adjustments, like adjusting the lighting or wearing coloured glasses or are they drawn to or distracted by bright colours, patterns or loud noises?

Has the caller asked for any accessibility changes?

4d. Creating a positive experience

Some autistic people may process or use language in a different way to non-autistic people. By making small adaptations or simply being aware of these differences, crisis workers can create a conversation that supports an autistic caller to make the most of the call. These are some adaptions that autistic people may be likely to benefit from.

Processing speed
Everyone processes information at a different pace. For some autistic people, the pace at which they take in information, make sense of it, and form a response may be slower in comparison to non-autistic people. When feeling anxious, processing speed may be slowed. It can be particularly difficult to process information or a question that has multiple parts, as the CYP may not be able to follow each step. Try to ask questions or make statements that have only one point at a time. If the caller is silent, they may be processing something that you have said. Rather than asking if they are still on the line, it may be helpful to check in while still allowing them space to process. For example: "Take all the time you need…" If someone appears to respond more slowly than you are used to, consider re-adjusting and giving more of a pause before checking in after your questions or statements.

Language used
As well as allowing someone time to process their feelings and the conversation that they are having, it is also important for healthcare professionals to adapt language to increase clarity for autistic people. Understanding figurative language can be difficult for many autistic people (Groen et al., 2008). This means that traditional features of conversation such as idioms, metaphors and ambiguous phrases may create a barrier to understanding. By using concrete language, miscommunication can be reduced. This may take some getting used to as idioms and metaphors are often used by non-autistic people as a way to soften conversation about difficult topics.

Examples of phrases to avoid: Feeling down, under the weather, feeling blue, how are you feeling today, how did you find it?

Be specific in the language that you use. A vague question may cause confusion and anxiety.

For example: By asking "How have you been feeling?" a caller may try to think of all of the feelings that they've had. Instead, you could ask "What has made you happy/angry/frustrated in the past week?"

An autistic person may not understand or express their emotions in the same way as non-autistic callers. They may benchmark their feelings in their own way, so this can be something to listen out for and use with them. Finding out how their current experience or feelings differs from what is usual for them is key here.

In addition, you may ask "What did you do?" rather than "How did you feel" as a way to better understand how an event may have impacted them. The autistic person may not be able describe how they felt but may show how it felt through their actions – did they feel the need to self-harm or comfort themselves or did they want to jump about and shout? You may also be able to use a special interests to support them to explore their responses e.g., can they give an example of when a character in their favourite show might have felt the same way you did. If you are working with the person for an extended amount of time you could collaboratively build a rating scale using these examples as a method of individualised mood ratings.

Emotions may not match behaviour

As mentioned, many autistic people may struggle to recognise and/or verbalise their emotions. This may also impact the way they react to and present their emotions. For example, while someone may be in great distress, they seem apparently calm, logical or objective. As we have discussed earlier, autistic people may camouflage and may have learnt how to act in social situations in a way that allows them to fit in with others. Camouflaging can be very hard to override and may result in the autistic person smiling and engaging in conversation or in other ways appearing to function as usual (completing work or school tasks, continuing with activities or interests) when internally they are distressed or suicidal. It is worth challenging assumptions about the "typical behaviour" of someone in crisis.

Feeling overwhelmed/meltdowns

When in extreme distress some autistic people can experience a 'meltdown'. 'Meltdowns' involve a range of behaviours which may include self-injury, crying, shouting, rocking and other outward signs of distress. While these behaviours are most commonly associated with autistic distress, autistic people may also experience 'shut down', in which they are 'zoned out' and unresponsive to the environment. Some autistic people may experience both of these types of reactions to distress, whilst others might only experience one, and this might change through their lives. Both meltdowns and shutdowns are reactions to extreme distress, and so one should not be considered a sign of stronger or more serious reaction than the other.

Autistic people don't deliberately have meltdowns or shutdowns, they are involuntary reactions to extreme emotional experiences and at this point an autistic person may be and may feel 'out of control'. This might be a scary feeling for them, so the goal when a meltdown occurs is to try and make the autistic person feel safe and calm and reduce their arousal.

For any of us, when we are worked up, our verbal and learning ability shut down, so you may not be able to rationalise with the person at the time and they may act impulsively or illogically. Meltdowns will have their own course and will end in their own time, however social and sensory reduction can help to calm the situation.

It may be helpful to acknowledge that you understand that a person may become overwhelmed and you will not judge them. For example, you could ask "Is there anything that you would like me to do if you feel overwhelmed at any point?".

If an autistic person you are supporting is experiencing a meltdown there are some other things listed below that might help:

Do try to:
- Keep them safe: if you are with them remove anything that they might hurt themselves on and ask anyone who is not needed to distance themselves. If you are not with them, support them to find a comfortable space in the event of meltdown or shutdown.
- Try to stay calm, be assertive and appear confident and in control.
- Allow one person to take control rather than lots of people intervening, which will feel overwhelming.
- Give them space if this is appropriate, in an area that is quiet and calm.
- Provide clear and simple directions and acknowledge emotions, give a reason for direction then give direction. Focus on using short, direct sentences (e.g., "I can see you are feeling stressed. I am going to try and help you. Take deep breaths. Close your eyes")
- As soon as they begin to calm down, recognise it, reinforce it, and encourage them (e.g., "I can see you are feeling much calmer").

- If talking, use a slow, low tone of voice and clear, simple, minimal words.
- If you are with them it may help to sit to one side, at their level. This may feel less overwhelming for them.
- Ask them to sit down, if this is possible – this will help to reduce arousal.
- Use deep breathing and get them to join in when they can.

Try not to:
- Restrain them, unless it is a protective action to stop violence, aggression or injury.
- Match your mood with your speech, instead stay low and slow. This can be hard but remember they are already feeling scared and overwhelmed and if you seem scared or overwhelmed too it will reinforce their feelings and may prolong or escalate the meltdown.
- Talk about consequences of their behaviour. This will increase anxiety, anger or frustration.

Talking about autism
How young people feel about their autism diagnosis will vary. Some may not be aware that they are autistic. Some may not have received an autism diagnosis - difficulties experienced by girls are frequently mislabelled or missed entirely (Lai & Baron-Cohen, 2015). Some parents may opt not to tell their child if they have received a diagnosis, for various reasons.

Some CYP will view their autism diagnosis positively, while others may think that it is negative. It is important for CYP to be able to express their experiences and be accepted, so it is not advisable to challenge a caller on their interpretation of autism. However, it is important to avoid reinforcing negative feelings about their diagnosis, as this situation will not change, but how they feel about it may become more positive over time. It is advisable to take a neutral stance rather than focus on difficulties associated with autism. Avoid sympathising, for example, "That must be so hard…" when someone talks about being autistic.

4e. Creating an action plan

If you are referring someone to another service, there are things you can do to make it easier for them to access that support.

Streamline the process
As much as possible, limit the number of steps they have to take. For example, is there a name or specific type of support they should ask for when they make contact? It may be helpful to organise steps for the caller rather than signposting them on.

Provide continuity
It will be easier for an autistic person to access services if their engagement is predictable. One way to help with this is to provide continuity around the staff/volunteers they will be engaging with. For example, can one person support them with the next steps required, rather than having to deal with a number of people? If this is not possible, can transitions be carefully planned with plenty of notice (see Newcastle University Therapy Leaflets - details in *Further Reading* section) To bring continuity to communication, can you make a note of techniques that you've found helpful when communicating with the caller, for example giving longer processing time or discussing a particular special interest?

Set up expectations
Ambiguous language and unspoken rules can make instructions particularly difficult for autistic people to follow. To ease anxiety, give simple, direct instructions around what a person needs to do and what is likely to happen. For example, who should they contact? What information should they have ready? How will their contact be followed up? How long should it take for them to receive a response? It should be clear to the caller what the next step that they need to take is. If possible, remind them that they can still contact you and that the service is still available to them.

5. Recommendations

For people delivering crisis services

1. Identify when you may need to adjust your communication

Question your assumptions
We all draw on previous experiences and make assumptions when we meet someone new. Autism presents in such a wide variety of ways that it may be difficult to determine whether a caller is autistic. As such, listening carefully to early statements, and adapting your style flexibly and responsively and allowing time to process is key; whether they are autistic, otherwise neurodivergent or are having trouble processing due to anxiety. This is also helpful to remember when working with parents, as they may share some autistic traits and are likely to be experiencing high levels of anxiety.

Behaviours to look out for
Autism presents in a variety of ways and some autistic traits may be camouflaged. For some, there may be subtle signs to look for to indicate that a caller may be autistic. For example:

- Needing more time to respond
- Following tangents and being distractible
- Having difficulty describing emotional experiences
- Expressing difficulty with their sensory environment

(more detailed descriptions on page 11).

Reactions may be different
It is easy to assume that specific responses indicate a person's emotional state. This may not be the case for autistic people. It is important for service providers to set aside assumptions about how people in crisis "typically" present, and instead focus on the words or actions of the person presenting. Ask the caller how their current situation differs from what is usual for them.

2. Adapting your style of communication

Ask for preferences
Ask the caller directly whether they have any preferences in terms of how you communicate with them.

How you talk about autism
Follow the lead of the person you are speaking to by using the terms that they prefer when talking about autism.

Give processing time
Autistic people may process the conversation at a slower pace. When allowing someone extra processing time, indicate that you are not rushing them for a response by using expressions such as "Take all the time you need".

Pace the conversation
Try to ask one question at a time so that the caller is not overwhelmed by the information that they want to provide.
If a caller is slow to respond, it may be better to give them extra time rather than re-phrasing the question, as this may be distracting.

Direct your questions
Try to be direct and specific with questions to minimise confusion. Instead of "How have you been feeling?" ask "What has made you happy/sad today?", If asking an open-ended question, it may be useful to give an example. This gives the caller an idea of the sort of answer you are looking for. Rather than saying "How can I help you?" it may be more beneficial to ask "Why have you called today" (see "Coventry University: A Guide for GPs about mental health and autism" - in *Further Reading* section).

Prepare to use less emotive language:
Use more direct, logical language, focus less on emotions and focus on reducing the use of metaphors and idioms.

Use interests

If a caller has spoken about having a particular passion or special interest, it may be useful to focus on it at times to help to shift the caller's thoughts away from a negative focus. Giving time to talking about interests can also help to build rapport.

3. Making an action plan

Record preferences

To create continuity across service workers, it may be useful to record information that will make the caller's experience easier, for example language preferences or special interests.

Streamline future contact

Where possible, organise future contacts as part of the plan, or limit the number of steps that a person will have to take when they are moving through services.

Set expectations

Describe the next steps and what is likely to happen, simply and directly. This allows the autistic person to prepare, which reduces their anxiety and increases the likelihood that they will continue to engage with services.

For people managing or commissioning crisis services

Build alternative routes for access

We know that making a phone or video call can be challenging for autistic people. People in or at risk of crisis should be able to access support through text or email. Managers should scope what staff, hardware and other operational elements would be required to deliver text or email support. Commissioners must work with services to fund this.

Review materials with autistic people

Review information and documents annually to ensure that they are up-to-date in terminology and appropriate.

Provide clinical links

Ensure that there is an available link to someone with clinical expertise about autism, possibly from a local Specialist Autism Team (if available).

Recruit autistic people

Consider recruiting autistic staff/ volunteers. This will bring lived experience and expertise, and could help callers to feel more accepted and understood. It is possible that a current team member is autistic but has not disclosed.

Share experiences

Make the most of your volunteer/staff expertise. Give them the opportunity to share their experiences working with autistic callers. What worked for them? What could be improved?

Prepare information on local services

Give your volunteers/staff access to information on current, region-appropriate NHS, local authority or third sector services that callers may need. Keep this updated and easily accessible during calls.

Continuity planning

Consider a system that would enable people with particular communication needs to interact with the same (or a small number of) staff, rather than going through a general line. If possible, create a system where the key adjustments can be recorded.

Upskilling new staff

Ensure all new staff members receive this information and any further training that is developed specifically on suicidality among autistic people.

6. Case studies

These case studies given by members of our Insight Group highlight what autistic young people and their family members might be going through when they call.

False names have been used to protect people's privacy.

Harry's story

"Accessing support is very difficult and vague. You have to be motivated which is contradictory to your mental state. No one cares until you try to kill yourself. I shouldn't have to get to that point."

Harry, an autistic young adult, grew up in a dysfunctional family with difficult relationships with his father and mother. He grew to find it difficult to ask for help in any form and expected any attention to come his way to be negative – anger or criticism. As a child they had to move often which he feels impacted his ability to form relationships and supportive connections with other people, which along with other factors poorly impacted his mental health.

Harry first started taking anti-depressants at the age of 13. He has been in and out of therapy since the age of 9, looking for ways to manage his confusion, distress, suicidal thoughts and improve his ability to live or return him to a functioning state after episodes of semi-catatonic depression. Yet he has made slow progress working with various services and support places, often ending up discharged due to time constraints without feeling like he was finished using the service or benefitting from it.

While Harry has found his experience of seeking short term support in between, and during therapy sessions rather poor as a whole, he has had positive experiences with autism-specific support services, and hopes to build up his own understanding of autism and himself, allowing him to better communicate with the outside world.

Caroline's story

"I'm exhausted, frustrated and heartbroken that no-one wants to help my autistic young adult at such a crucial time in his life. I fear he will become a statistic on a report about teen suicide."

Caroline is an autistic parent of two sons, one, Dylan, diagnosed with autism, and the other, Luke, exhibiting ADD traits, as well as a range of co-occurring mental health and neurological diagnoses. She has had to work hard to get both of her sons the support that they need, despite, due to being autistic herself, needing support herself.

Caroline describes Luke's anxiety as a constant worry to her, with Luke becoming most anxious around school and relationship issues. Having been to CAMHS twice before, last year Caroline took him to their local GP as he had stated that he didn't want to be alive anymore. They were referred back to CAMHS and are still currently on the waiting list, leaving Luke reliant on short term support while he waits.

Caroline has faced a similar problem with Dylan, having sought help for his sleep and anxiety issues after his autism assessment in early 2019, feeling that it was Dylan's lack of sleep that was causing a lot of his underlying problems. Again though, they are still waiting for an appointment, despite several conversations between their GP and local children's support service, leaving Caroline feeling unsupported and alone.

Helen's story

"My experience of trying to access support for my child was frustrating, exhausting and soul-destroying. I back my child 100 per cent, but I am not a professional and we need support… It is imperative to be proactive and prevent a crisis we all can predict is going to occur."

Helen is an autistic parent of two autistic children; Sam and Alex who were diagnosed at the ages of 4 and 6 (leading Helen to receive her own diagnosis at the age of 42). Alex was born a boy but realised at the age of 9 that they were actually a girl and now she has fully transitioned to live openly as a girl.

Helen looked for information around gender identity in young children and support for Alex (and herself), contacting both CAMHS and the NHS Gender Identity Development Service. While they are on the waiting lists, both Helen and Alex are struggling with the length of the wait expected, especially as their estimated appointment time takes them into when Alex is likely to be going through puberty. Helen is extremely worried about how Alex might experience going through puberty as the wrong gender without any support, and what that might mean for all three of them as a family unit.

Charlie's story

"This has left me feeling desperation, disillusionment and despair at the lack of support offered and available, especially where this fell into statutory duty. I've never seen a human being in that level of mental pain and at such a young age. Unfortunately I could relate to it and that made me hurt even more for him."

Katie, an autistic adult, has worked with her friend, Elizabeth, to access support for Elizabeth's son Charlie since 2015. Diagnosed at the age of 5, Charlie started off doing well at school, until the end of year 5 where he was told to repeat the year, having skipped a year earlier on. This led to a loss of friends and a change in peer groups and meant that challenging physical behaviours that, until that point, had been limited to home, were now becoming more and more common during school time. He was isolated and after a time Elizabeth was told that there was no place for him anymore as the school could not cope with his needs. At this point Charlie first expressed that he wanted to end his life. After a time at home Charlie was placed into a specialist independent setting as a weekly boarder but due to a number of structural changes that Charlie struggled to cope with, triggering physically aggressive behaviours, he was excluded. He was 13 years old.

When at home, between schools or during weekends, Charlie posed a safeguarding risk to his younger sister who he directed much of his physical behaviours towards. Additionally, Elizabeth has a physical disability which meant that Elizabeth, Katie and their wider social care time were increasingly concerned by whether she could physically intervene when the need arose. After Charlie was excluded his anxiety increased, as did the safeguarding risk he posed and despite Katie and Elizabeth requesting a range of support and therapeutical input for both his current behaviour, and to help him integrate into his next school placement, they were often on their own.

[Charlie's story continued...]

Charlie's mental health reached a crisis point during the time he was out of school after his exclusion and at times Katie had to physically restrain him to allow Elizabeth to leave home with her younger daughter. One late evening Katie was called over:

"When I got there I could hear his screams and crying from quite a distance down the street and it was just pure anguish… [Charlie] was screaming that it was all his fault and he didn't want to be here anymore and that he didn't want any more over and over again and he was crying. This went on for several hours, until we could calm him down, and I've never heard or seen a person in that amount of emotional pain."

This was not an isolated incident. Katie and Elizabeth would call 111 and other crisis lines during these times looking for help and advice but generally found this unhelpful. Due to her own autism, Katie was able to connect with Charlie, understanding the emotions behind many of his actions, and so acted as a carer providing planned respite for Elizabeth. Even with Katie's help and support, the family felt isolated and abandoned by their local authority and services, and the time out of school, that Charlie blamed himself for, left him traumatised and struggling with formal education settings, even as a young adult. Charlie is now 18 years old and still mentally and emotionally in a fragile state, traumatised and lacking the support that will help him understand and process his past.

Maura's story

"I was shocked beyond belief that the readily-available support services are clearly only for the worst-case scenarios and therefore a self-fulfilling prophecy. But I am grateful we were able to access support on our own, which is not always possible even for us and, of course, for many others."

Maura is an autistic parent of Simon, who was diagnosed as autistic the week he started secondary school. Maura's husband and younger child are not autistic. At the time Simon was diagnosed, and for the previous six months or so before, he had been having a lot of difficulty with the upcoming transition to secondary school.

As part of his autism, Simon struggles to have self-awareness of his own feelings of stress and anxiety, but Maura and her husband noticed that he was struggling to sleep, having terrible nightmares, developing tics etc. They were especially concerned by conversations they had with Simon which seemed to border on psychotic episodes – he was paranoid about people following him, and having very strange, seemingly unwarranted concerns about his safety. Once Simon started Secondary school, he also began self-harming (usually scratching his face, sometimes banging his face/head on the wall or hitting himself). Simon had been diagnosed through CAMHS so Maura saw that as their first line of support and called them for counselling or therapy.

Maura found out that as they had been discharged after Simon received his autism diagnosis they would have to get a new referral, which they did. After waiting several months to get a (second) initial appointment with CAMHS they were told that it wasn't possible for them to be offered treatment. This was because while Simon was self-harming and having suicidal thoughts, he hadn't actually attempted suicide and so was not eligible for counselling. Fortunately Maura was able to find and pay for a private psychologist with experience of working with autistic people, who helped Simon understand and communicate some of the emotions he was feeling. While Simon found these sessions tiring, he enjoyed them and the challenge of understanding himself and his emotions better, though now in his early teens he is reluctant to ask for or receive further support.

7. Conclusion

We know that autistic people are particularly vulnerable to suicidal thoughts and behaviours. Crisis services can play a vital role in supporting autistic people and their families through the most difficult times.

By being aware of the different ways that autistic people may present and by making small changes to how you communicate with callers, you can create an accepting and comfortable experience. By adapting to individual needs, service workers can support autistic people to thrive.

Thank you, for all your work.

8. Further Reading

Autism and Covid-19 materials from Autistica: https://www.autistica.org.uk/what-is-autism/coronavirus

Evidence-based presentations on a variety of topics from the Autistica Research Festival: https://www.autistica.org.uk/get-involved/research-conference/festival-recordings-2020

Newcastle University Therapy Leaflets for autistic children and adults: https://research.ncl.ac.uk/neurodisability/leafletsandmeasures/therapyleaflets/

Coventry University: A Guide for GPs about mental health and autism: https://sites.google.com/view/mentalhealthinautism/resources/mhautism-guide-for-gps and hear from mental health champions talking about the guide: https://sites.google.com/view/mentalhealthinautism/resources/champion-videos

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