CARE RESPONDERS

Communicating with Autistic Young People in Crisis

A Language Guide for Professionals



Young People's Mental Health Research Centre
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Introduction

Standard emergency responses often rely on loud instructions, compliance, and sometimes physical restraints. For an autistic young person experiencing a mental health crisis, these approaches can be overwhelming and distressing. Rather than helping, they may increase anxiety, heighten feelings of fear, and escalate a situation that could otherwise be managed safely.



Why This Guide Matters

The way we talk about autism can have a significant impact. Language that mainly focuses on challenges or limitations can unintentionally reinforce stereotypes and contribute to stigma. This guide encourages a neurodiversity-friendly approach by offering practical language and strategies that recognise autistic young people as individuals with their own strengths, identities, and support needs. We encourage professionals to reflect these principles in their conversations, reports, and case notes.

"There should be an approach that assumes you're neurodiverse, even if you're not, because to be honest, that would help everyone"
-A parent who participated in the Care Responders study.

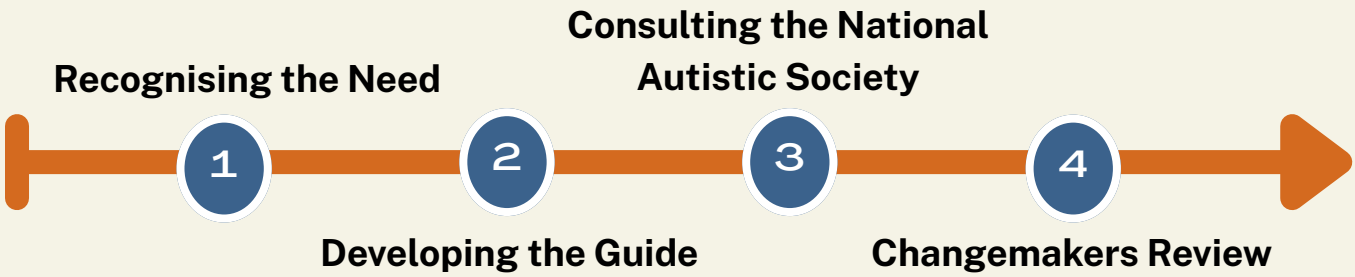
What You Will Find in This Guide

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Who Is This Guide For?

This guide is for first responders to young people experiencing a mental health crisis. This could include **police officers, A&E staff, paramedics, and mental health professionals**.

How This Guide Was Created



Acknowledgements

We would like to thank the children, young people, parents, caregivers, and professionals who participated in the Care Responders study and contributed to the development of this guide. Their experiences and perspectives helped ensure the guide reflects the needs and views of autistic young people and their families.

Origin & Co-production: This guide is adapted from El Dewar's (2024) *Neuro-affirmative Language Guide*, developed with autistic people. It is also based on a co-produced language guide developed with autistic young people and their families living across the Pennine boroughs (Wren et al., 2024).

Consultation and Review: We are grateful to the National Autistic Society for reviewing the guide and providing feedback. We also thank the Changemakers from the Greater Manchester Youth Network, whose lived experience and insights helped shape the content to ensure it is relevant, accessible, and meaningful for autistic young people.

This resource is designed to be used as a guide, not a rigid script. It is important to ask each young person and their caregivers what language and communication is helpful, as everyone's preferences are different.



Language Preferences and Key Terminology

Key Terminology

Neurotypical:	A person whose brain functions in a way that is seen as the 'standard/typical'.
Neurotype:	A person's natural way of thinking, processing information, and experiencing the world. Neurotypical and neurodivergent are different neurotypes.
Neurodivergence/ Neurodivergent:	"All people whose brain functions, ways of thinking and behaviours differ from neurotypical" (The Brain Charity, 2022).
Neurodiversity:	Everyone's brains work differently. People think, learn, and behave in ways that are different to others, but all are part of the natural variety in how humans are.

Language Preferences

Language preferences are different for everyone. Not all autistic young people will agree on the same words, and language can change over time. If you are unsure what language to use, ask the young person and follow their preference.

Autism vs Autism Spectrum Disorder (ASD) / Autism Spectrum Condition (ASC):

- There is a strong preference for the single term autism. It is not a 'disorder'; there are so many positives of autism such as attention to detail, visual skills, unique thought process and creativity.

Preference: Autism

- Example: "Autism is a big part of who I am"
- Note: some of the autistic young people consulted disliked 'special' or 'disability'.

Autistic vs People with Autism

- Most autistic people prefer to say, 'I am autistic'. Separating the Autism from the person ('person with Autism') makes it seem like Autism is something bad that should not be a part of them.

Preference: Autistic person.

- Example: "There are other autistic people in my family"

Stimming vs Fidgeting or Stereotypy

- Stimming describes repeated movements and noises that can help with self-regulation. (e.g., hand flapping, finger flicking, rocking, spinning and head banging). Autistic young people prefer the term stimming or self-regulation. Autistic young people preferred the term 'stimming' over 'fidgeting', which they felt had negative connotations. They also found 'stereotypy' confusing and too closely linked to the word stereotypes.

Preference: stimming/self-regulating

- Example: "When I rock back and forth, I am stimming"

Describing the behaviour vs challenging behaviour

- Challenging behaviour is not specific, places blame on the person, and can feel patronising. If you are saying 'challenging behaviour' or 'behaviours of concern' it labels a person as 'challenging' which creates an unhelpful narrative surrounding that person. For more information, see page 8.

Preference: describing the behaviour

- Example: "My sister is autistic, the environment in the canteen was too loud, this led her to become upset, crying and hitting a wall"

Note: Labelling autistic traits as 'concerning' can attach neuro-normative expectations onto an autistic person (e.g. turn taking in conversation and making eye contact).

"There should be some form of understanding of an autistic child, there's just no understanding at all."

-A parent who participated in the Care Responders study.

Characteristics/Traits vs Symptoms

- Autistic young people reported that 'symptoms' make it seem like their autistic traits are like an 'illness' that should be 'healed/fixed'. Using the terms ‘slightly autistic’ and ‘very autistic’ can also imply that some autistic people are ‘more’ or ‘less’ autistic than others, rather than recognising that autism affects people in different ways.

Preference: characteristics/traits

- Example: "My sister has excellent visual discrimination skills, and she is very detail-focused; these are some of her autistic traits"

Acknowledging fluidity of support needs vs high or low functioning

- Autistic young people cannot be placed into discrete categories of high or low functioning. A person’s support needs are diverse and depend on the context (environment, social support).

Preference: To acknowledge the fluidity of support needs

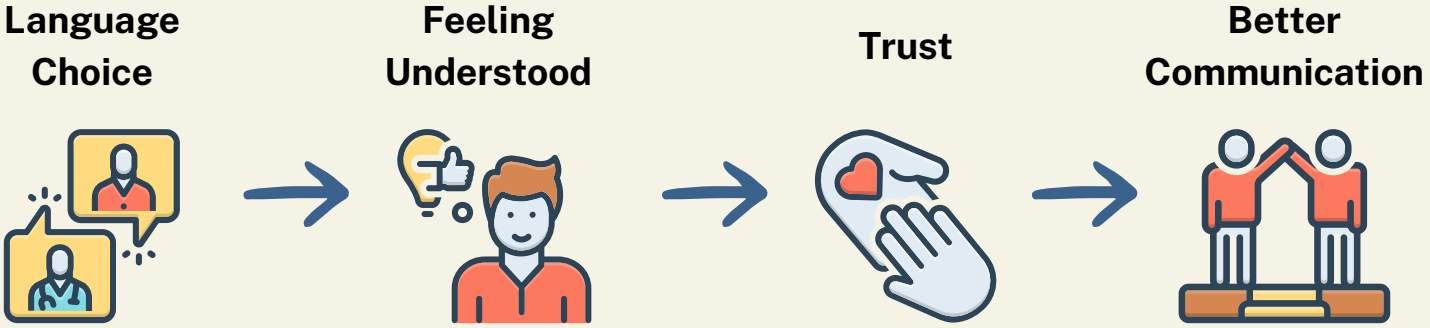
- Example: "When I'm playing with my friends, I don't need much support. When I come home from school, I am tired and my support needs change"

Neurotypical/neurodivergent vs normal/abnormal

- Labelling neurodivergent people (with Autism or ADHD) as ‘abnormal’ suggests they need to be healed, fixed or cured. Most autistic young people strongly dislike this language. There is uniqueness to everyone and no such thing as ‘normal’ and ‘abnormal’.

Preference: Neurotypical/Neurodivergent

- Example: "My class has neurotypical and neurodivergent students"



Key Considerations

Feeling patronised: Autistic young people felt that unspecific advice of 'have a cup of tea and a biscuit' and 'take 5 deep breaths' can be patronising. It is important for your advice and recommendations to be specific, avoid demands, and phrased so that young people understand that one thing will not work for everyone.

Speak to the autistic young person directly:
Young people have said that they feel professionals speak to their parents/carers rather than them, making the young person feel ignored. Where possible, speak to the young person directly.

Trust in professional knowledge:
Autistic young people are experts-by-experience and the biggest advocates for their autistic experience. Some have stated that having professionals who are not up to date with current terminology and language choices would cause frustration, disengagement, and distrust of the professional.

Be cautious when saying 'I understand':
Using the term 'I understand' can unintentionally invalidate an autistic young person's unique and different experiences to your own. It is better to confirm and validate these differences when speaking to them.

Reclaiming language:
Young people feel language around autism is sometimes weaponised by others in an ableist and derogatory way. We should be empowering young people to be confident in their autistic identity and help them reclaim language. It starts with us helping to reduce stigma and challenge negative perceptions of autism by using language that emphasise strengths, individuality, and respect.

"Behaviours of concern":
This term has its place in describing collective behaviour (e.g. "some autistic individuals may exhibit behaviours of concern"). But, when speaking about an individual, use language that is more descriptive and personalised. Clarity helps everyone involved understand what "behaviours of concern" look like, reducing miscommunication and misunderstanding while enabling a focus on the root causes of these behaviours.

Living in a world designed differently:
Everyday life can be challenging for autistic and neurodivergent young people because many environments are set up for people who think and experience the world differently. During a mental health crisis, it can help to remember that the young person is not choosing to struggle. They may be overwhelmed by what is happening around them.

Assumptions about autism and mental health:
Trauma, intense distress, self-harm, and severe anxiety are often incorrectly assumed to be a "normal" part of being autistic. This assumption is harmful. It causes professionals to overlook the true root cause of the young person's distress. Professionals must address these mental health challenges separately, while fully supporting the young person's underlying autistic needs.

Learning From Experience

"What works best for one person with autism might not be the same as another person with autism. So, it's very individual and it can take time. But I think it would give you such a different outcome. A better outcome."
- A professional who participated in the Care Responders study.

"Just because someone has autism, it doesn't mean they are only affected by that. They can still have mental illnesses, especially if they are already diagnosed, please just accept that those things cause them problems too and you can't just ignore them."
- A young person who participated in the Care Responders study.

"They don't understand how autism and mental illness interact and that they can both impact you at the same time. Not just one or the other."
- A young person who participated in the Care Responders study.



Sensory and Environmental Adjustments

Autistic young people can experience sensory inputs (like sights, sounds, smells, and touch) very intensely.

During a mental health crisis, this sensory input is often magnified. Background noise, that other people may not be able to notice, can cause physical pain or overwhelm to an autistic young person.

Turn Off Sensory Triggers	Turn off vehicle sirens and flashing emergency lights as soon as it is safe to do so.
Create a Quiet Space	Dim bright overhead lights. Move the young person away from crowded areas, loud voices, or public onlookers.
Lower Radio Volumes	Turn down staff radios or use earpieces where possible. Unpredictable radio static and loud dispatcher voices may trigger an immediate panic response.
Choose One Person to Speak	Ensure only one professional talks to the young person. Multiple people giving instructions at the same time can cause overload and can make the person shut down.
Avoid Touching without Asking	Do not touch the young person unless it is absolutely necessary to save a life. Touching an anxious autistic person without their clear permission may cause unnecessary distress.
Try Not to Stare	If several people are present, it can be overwhelming if everyone is looking at the autistic young person. Try to ensure that only the person speaking makes direct eye contact.



Communication in Practice

Practical Communication

Try to avoid	Try to
Placing demands on the young person: "Take 5 deep breaths and have a cup of tea."	**Offer specific, clear choices:** "Would you prefer to sit on the floor or the couch while we figure this out?"
Saying phrases like: "I understand exactly how you feel." This can accidentally invalidate their unique experience.	**Validate their feelings directly:** "I can see that you are incredibly overwhelmed right now, and I want to help make this safe."
Ignoring the young person: Speaking only to a parent or carer over the young person's head, making them feel invisible.	**Speak to the young person directly:** Address them first. If they cannot answer, ask if you can speak to their caregiver: "Would it be okay if I ask your mum a question now so I can help?"
Using confusing metaphors or open questions: Asking abstract questions like "What's going on here?" or "Why do you feel this way?"	**Use literal, direct, and clear language:** State exactly who you are and what you are doing: "I am a... My job is to ..."

“She's got all these diagnoses, but they don't actually pay attention to them when we have appointments. The lighting's not changed. The noise isn't quiet.”

-A parent who participated in the Care Responders study.

Core Guidelines for Communication

The 10-second rule: Extreme distress slows down a person's ability to process spoken words. After you ask a question, pause and wait quietly for at least 10 seconds. Repeating yourself or rephrasing forces their brain to restart the entire listening process from the beginning.

Trust their expertise: Autistic young people are the experts on their own lives and experiences. Using outdated, medicalised words can cause frustration and distrust. Young people report feeling exhausted when they are expected to "educate the professional".

Offer alternative ways to communicate: When stress gets too high, a young person might become completely withdrawn (sometimes referred to as a shutdown), lose control due to overwhelming information (sometimes referred to as a meltdown), or agree with everything you say. They may also have difficulty describing how they feel. Be ready to offer a pen and paper, a notes app on a smartphone, or allow them to point to options of words or pictures to help them communicate.

Self-Regulation vs. Restraint

Understanding Stimming

"Stimming" describes repeated movements, noises, or actions that may help an autistic person regulate and manage their emotions. E.g. rocking back and forth, flapping hands or arms, flicking fingers, jumping, spinning, or repeating words or phrases.

- Try not to physically stop or interfere with a young person's stimming unless they are in immediate, serious physical danger.
- Stimming is a vital tool used to lower anxiety. Stopping them will most likely make the crisis worse.

The Dangers of Physical Restraint

Using physical restraint on an autistic person can cause significant, long-term psychological trauma. Restraint may intensify sensory overload and trigger a survival reflex, increasing the risk of injury. Changing the environment should always be prioritised over forcing physical compliance.

Remember

First responders must understand that some behaviours, sounds and movements may be coping mechanisms, not aggression or a refusal to follow instructions.

It's okay to make well-intentioned mistakes. If you're unsure, ask about a person's preferences, acknowledge any corrections, and use them as an opportunity to learn.

- Our language choices help autistic young people define their own experiences, empowering them, and shifting power towards those who are experts in their own experiences.
- Consideration of their experiences and their knowledge is important when describing and talking about them.
- Language can perpetuate stigma and stereotypes, contributing to marginalisation and discrimination. Preferred language promotes a more inclusive, empathic, and respectful environment.
- As professionals, we have a responsibility to act in a person-centred way. Prioritising the wellbeing and dignity of those in our care begins at respecting the way they want to be referred to.

“It's very sensory in custody - it's loud, it's cold, it's boring... The police, I suppose, felt they didn't really understand their neurodiversity or what was happening. So, they felt very unheard."

-A professional who participated in the Care Responders study.

Please share this guide with colleagues and professionals you are working with to advocate for the use of neuro-affirmative communication. Remember that this is guide, not a script. Please ask the people you are working with what their communication preferences are as it may differ from what is listed in this guide.

Key Points to Remember



Allow processing time: Remember the 10-second rule. After you ask a question, pause and wait quietly for at least 10 seconds. Repeating yourself or rephrasing forces their brain to restart the entire listening process from the beginning.



Don’t assume, just ask, preferences can be different: It’s important to ask each young person and their caregivers (if necessary) what language and communication is helpful, as everyone's preferences are different.



Communication Passport: Many autistic people have an “about me” document that outlines their communication preference, sensory needs, and preferred support strategies. If available, review this and use it to guide your approach.



Keep learning and repair mistakes: No one gets it right all the time. If you make a mistake, acknowledge it, make any corrections, and move forward. Be open to feedback, ask about preferences, and continue learning and development.



Consider the environment: Try to reduce noise, bright lights, or the number of people present. If this isn't possible, explain why and acknowledge any sensory challenges and consider how they may be contributing to distress.



Explain what is happening: It’s important to keep the young person informed. Explain what is happening and why. Make sure to involve them in their care wherever possible. Knowing what to expect can help reduce uncertainty and distress.

CARE RESPONDERS

Every interaction can make a difference.

Autistic young people may communicate their needs, feelings, or experiences differently. By making communication clear, and respectful, we can help autistic young people feel more comfortable engaging with services and expressing what matters to them.



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References

El Dewar (2024) Neurodivergent Affirming Language Guide. Neurodiverse Connection 2024. https://ndconnection.co.uk/resources/p/nd-affirming-language-guide

Wren, K., Maher, K., Rodell, S., & Parry, S. (2024). A language guide for professionals when talking about autistic young people. NIHR Applied Research Collaboration Greater Manchester. https://arc-gm.nihr.ac.uk/media/page-images/Mental%20Health/Simple%20Autism%20Language%20Guide%20For%20Professionals.pdf