A Language Guide for Professionals When Talking about Autistic Young People

Our choice of language can perpetuate stigma associated with Autism, especially language that is deficit focussed, which can reinforce negative perceptions and discrimination.

The guide explores how to use language that encourages, accepts and acknowledges the differences in autistic people, by promoting language that is neurodiversity-affirmative and in line with the preferences of autistic young people.

The language in this guide is a shift from traditional medical language that describes autism as a disorder and autistic traits as deficits, to lead to acceptance through using words that emphasise strengths and needs of an individual (Bottini et al. 2023).

The guide was initially adapted from El Dewar's (2024) Neuro-affirmative Language Guide, developed with autistic people. This guide was developed and co-produced with autistic young people and their families residing across the Pennine Boroughs. It has also been developed from feedback from CAMHS professionals across Pennine Care. The flow chart below shows the stages of development:

| Review of the current literature. | > | Online Surveys: CAMHS staff (36 responses) | > | Online Survey: Young people and families (11 responses) | > | Feedback from CAMHS clinical and research teams | > | Four focus groups with autistic young people and their families (Total: 15 young people and 5 parents) | > | Feedback on findings from Spectrum Gaming team | > | Final guide produced |
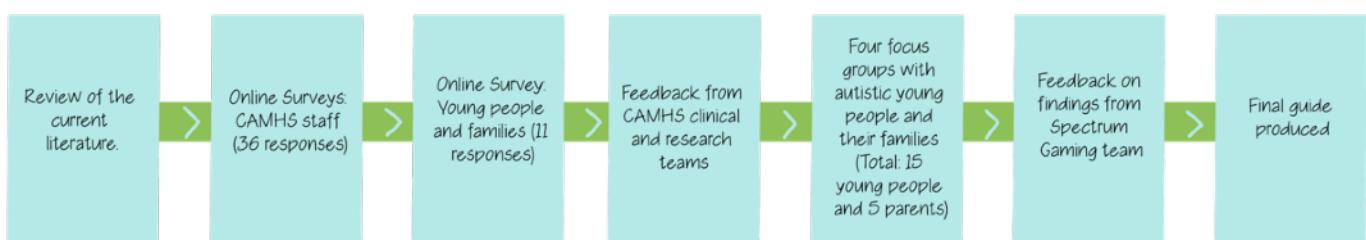
PLEASE NOTE: This resource is a guide for professionals, not a script. It is important to ask each person what language they would like you to use to describe them, preferences are not the same for everyone.

Thank you

To the young people, parents and staff that generously gave their time to speak to us. Thanks to Teen Space based at Hyde Little Theatre, Bramhall High School, Tree of Life, and Spectrum Gaming for your contributions to the guide with your valued opinions.

Thanks also to the young people, parents and CAMHS professionals who provided their feedback via the online survey. This development of this guide would not have been possible without your help.

Key Themes

Feeling Patronised

Autistic young people felt that unspecific advice of 'have a cup of tea and a biscuit' and 'take 5 deep breaths' to be patronising. It is important to for advice to be specific person, to avoid (perceived/actual) demands and to phrase your language so that young people are empowered.

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 expertise of the professional. They feel they are expected to educate the professional rather than being supported by someone who already knows their needs.

Be cautious when you say "I understand"

Using the term 'I understand' this 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 peers in an ableist and derogatory way; and parents felt other parents would apologise to them for having an autistic child. As professionals, we should be striving to empower young people to be confident in their autistic identity and help them reclaim language. It starts with us to help shift the stigma and negative meaning associated with autism by advocating for terms that emphasise strengths and individuality.

"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. Precision and clarity helps everyone involved understand what "behaviours of concern" look like in an individual, reducing reduce miscommunication and misunderstanding to move towards understanding the root cause of these behaviours.

Existing in a neuro-normative society

Being autistic and neurodivergent in a neuro-normative society can lead to what some may perceive as deficits, as the world is designed for neurotypical people. These systemic challenges stem from their environment not accommodating their needs. This guide seeks to promote language adjustments to make therapeutic environments better suited to autistic young people.

Assumptions about autism

Trauma, distress, and anxiety are often assumed to be a part of autism, which is harmful to autistic young people. It overlooks the root cause of these issues, and professionals should address these challenges separately whilst supporting the autistic young person.

Key Terminology

Term	Definition	Example
Neurotypical	A person whose brain functions in a way that is seen as the 'standard/typical'.	"I am not autistic or have ADHD, I am neurotypical."
Neurotype	How someone understands and explores the world, linked to the 'wiring' of the brain. Being neurotypical and neurodivergent are different neurotypes.	"My mum is autistic; I have ADHD, and my dad is neurotypical. We are a neurodiverse family, and we have different neurotypes."
Neurodiversity	Everyone's brains work differently. Everyone thinks, learns, and behaves in ways that are different to others, but all are part of the natural variety in how humans are.	"I am autistic, my best friend has dyslexia, and my other friend is neurotypical. We are **neurodiverse**."
Neurodivergence/ Neurodivergent	"All people whose brain functions, ways of thinking and behaviours differ from neurotypical" (The Brain Charity, 2022). People with neurodivergence are described as neurodivergent.	"Autism and ADHD are a neurodivergences, an autistic person and a person with ADHD are neurodivergent people."

Neurodiversity-Affirmative Language Preferences

(Based on recommendations from El Dewar (2024) and feedback and conversations had with autistic young people, parents and CAMHS professionals across the Pennine Boroughs)

'Autism' vs. 'Autism Spectrum Disorder (ASD)/Autism Spectrum Condition (ASC)'

"The words 'disorder' and 'condition' makes it feel like it's wrong to have, or that you have a problem"
(Girl, 14).

Preference: Autism

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.

"Autism is a big part of who I am"

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'

Preference: Autistic person

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.

"There are other autistic people in my family."

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

'Characteristics/Traits' vs. 'Symptoms'

Preference: characteristics/traits

Autistic young people reported that 'symptoms' make it seem like their autistic traits are like an 'illness' that should be 'healed/fixed'.
There is a preference for traits/characteristics.

Example: "My sister has excellent visual discrimination skills, and she is very detail-focused; these are some of her autistic traits"
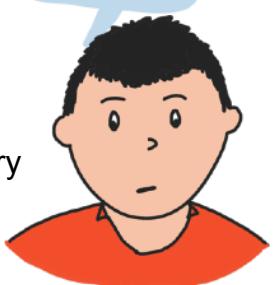
"Traits and characteristics are something that makes you, you; symptoms don't" (Boy, 11).

"Symptoms sound like you caught a virus" (Boy, Age?)

Acknowledging fluidity of support needs vs. 'High or low functioning'

Preference: To acknowledge the fluidity of support needs

"During the day, I'm like a heart monitor – It's up and down all the time; it's not a straight line." (Girl, 15)

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).

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

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"

'Stimming' vs. 'Stereotypy'

Preference: stimming/self-regulating

Stimming describes repeated movements/noises/ways of acting that can help with self-regulation. For example, arm or hand flapping, finger flicking, rocking, jumping, spinning and head banging. Autistic young people prefer the term stimming or self-regulation. Stereotypy is confusing and reminiscent of stereotypes. When professionals name their stimming to be 'fidgeting', autistic young people consulted disliked this and felt fidgeting has more negative connotations.

"When I rock back and forth, I am stimming."

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

Describing the behaviour vs. 'Challenging behaviour/behaviour of concern'

"It's [her behaviour] not concerning to me, so now what?" (Girl, 15)

Preference: describing the behaviour

Challenging behaviour is not specific, and places blame on the person. If you are saying 'challenging behaviour' or 'behaviours of concern' it labels a person as 'challenging' which creates an unhelpful narrative surrounding that person:"It's [her behaviour] not concerning to me, so now what?" Describing the before, during and after of situation is important to gather an accurate understanding of the autistic person.

"My brother is autistic. It was really loud in the canteen today, so he got upset and cried, and started hitting a wall"

Example: "My brother is autistic, the environment in the canteen was too loud, this led her to become upset, crying and hitting a wall"
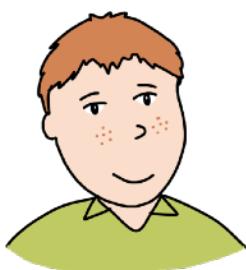
Note: Autistic young people have found their autistic traits to be labelled as behaviours of concern. Labelling autistic traits as 'concerning' can attach neuro-normative expectations onto an autistic person (e.g. turn taking in conversation and making eye contact).

Neurotypical/neurodivergent vs. Normal/Abnormal

"What even is normal? Who is normal?" (Boy, aged 9)
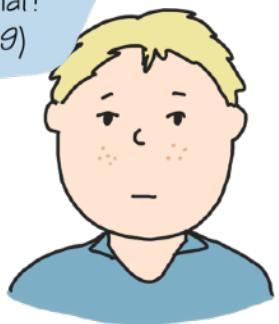
Preference: Neurotypical/Neurodivergent

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'.

"My class has neurotypical and neurodivergent students."

Example: "My class has neurotypical and neurodivergent students"

Share this guide with colleagues and professionals you are working with to advocate for the use of neuro-affirmative language.

Remember that this is guide not a script: please ask the people you are working with what their language preferences are as they may differ from the terms listed in this guide.

"Language is one way in which ableism is perpetuated, when autistic people hear this a microtrauma can occur."
(National Autism Training Programme, 2024)
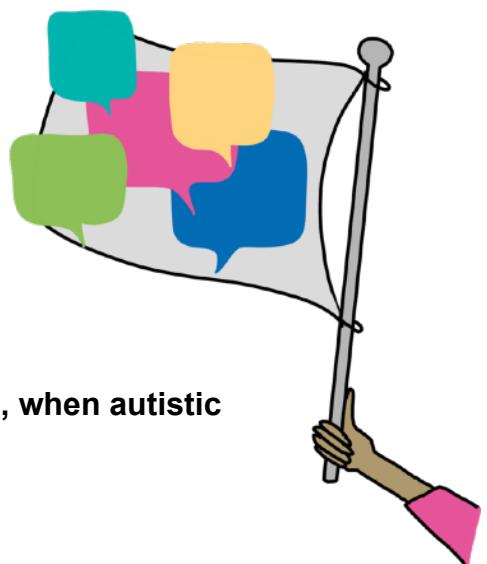
References

Bottini, Morton, Buchanan and Gould (2023) 'Moving from Disorder to Difference: A Systematic Review of Recent Language Use in Autism Research' Autism in Adulthood. https://doi.org/10.1089/aut.2023.0030

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

Websites

National Autistic Society - https://www.autism.org.uk/

The National Autistic Society has lots of useful information and resources including autism-friendly guides, PBS and strategies and interventions.

Autistica - https://www.autistica.org.uk/

Autistica is the UK's leading autism research and campaigning charity. They have information on research projects, shaping policy and working with autistic people.

Autism Unlocked - https://lsc.autismunlocked.co.uk/

Autism unlocked provides free online resources to support autistic children, adolescents and adults.

Signposting for Children/Young People and Families

Autism Central - https://www.autismcentral.org.uk/

Autism Central has great information on resources, one to one hubs to chat and events for parents and carers of autistic young people.

Autism Alliance UK - https://www.autismcentral.org.uk/

Autism Alliance is a not-for-profit organisation that supports autistic people and their families.

Ambitious About Autism - https://www.ambitiousaboutautism.org.uk/

Ambitious About Autism has an online community for parents and carers of autistic and young people to talk without judgement.

Starling - https://starlingcio.org/

Starling offer free creative wellbeing activities for neurodivergent young people aged 13-25 in Droylsden, Hyde, Trafford and Oldham.

Respect for All - https://www.respectforall.org.uk/

Respect for all offer group wellbeing support services for autistic people and their families and carers who live in Greater Manchester.

Action for Children - https://parents.actionforchildren.org.uk/

Action for Children offer 1 to 1 support for parents of children with SEND through Action for Children.

'Teen Space' at Hyde Little Theatre - https://hydelittletheatre.org/

Hyde Little Theatre host a social session for autistic teenagers (aged 13-19 years old), 'teen space', every Friday with Lego, low music, games and consoles.

Spectrum Gaming - https://www.spectrumgaming.net/

Spectrum Gaming is an autistic-led UK charity that supports autistic young people. They provide a safe online space to connect with others, they work on advocacy projects with autistic young people and hold face-to-face meet ups. Please note, Spectrum Gaming are considering new applicants living in Greater Manchester, Bedford, St. Helens or siblings of current members.

Research Articles

Mindshift in autism:

A call to professionals in research, clinical and educational settings.

The paper explores embracing the mindshift to reduce discrimination and the spread of harmful ideologies for autistic people.

https://www.frontiersin.org/articles/10.3389/fpsyt.2023.1251058/pdf

Which terms should be used to describe autism?

Perspectives from the UK autism community.

A study of the views and preferences from 3,470 UK residents and the outcomes of what terms were preferred to describe autism with the reasoning for these preferences outlined.

https://pubmed.ncbi.nlm.nih.gov/26134030/

K. Wren, K. Maher, S. Rodell and S. Parry (2024)

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