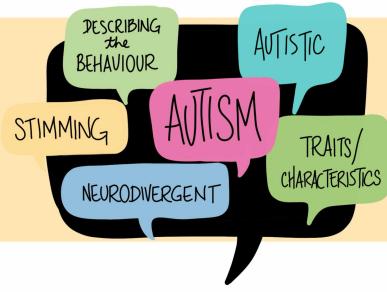


A Language Guide for Professionals when Talking about Autism



Rationale for the guide

To encourage the use of neuro-affirming language to support the communication between autistic young people and professionals. Specifically, we sought to create a guide that reflects autistic young people's preferences.

How we hope it will be used

The guide is not a script. The purpose of the guide is to provide recommendations and considerations of how to use language that aligns with the preferences of autistic young people, to prevent distress and stigmatisation. It is important to ask each young person you work with what language they would like to be used. Each person will have a different preference. The Language Guide aims to scaffold language.

Kate Maher, Sadie Rodell, and Katie Wren

The Invaluable Voices of Autistic Young People

This guide was lead by the passionate voices of the autistic young people at Tree of Life, Bramhall High School, and "Teen Space" at Hyde Little Theatre, and the passionate parent advocates with children on the diagnostic pathway.

It is thanks to them, their parents, and the staff, we were able to create this guide in a co-produced way that reflects their wants, feelings, and insights.

"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)

"The word autistic is kind of ruined now because people use it as an insult or in a mean way"
(11 year old)

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

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

"What even is normal?
Who is normal?"
(Boy, aged 9)

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

The Development of the Guide



01/03/24 - The Team Meets

Sadie (from the Young People's Research Centre) and Kate and Katie (from the Young People's Specialist Support Team) connect to go over the rationale and aims for the language guide, and plan how to form a language guide co-produced with young autistic voices and opinions.

04/04/24 - EI Dewar's Language Guide and Preliminary Guide Draft

The team condensed salient terms and explanations from EI Dewar's language guide, a document guided by the opinions of autistic adults. This formed the preliminary structure of the guide and was sent out with surveys, to see if autistic young people share the same language opinions.

19/04/24 - Surveys Sent Out

Surveys were sent to Pennine CAMHS professionals; autistic young people and parents to assess if current language used in CAMHS reflects the suggestions in the guide; personal reflections; and whether autistic young people feel language used is neuroaffirming.

03/05/24 - Analysing Findings and Secondary Drafts

Changes were made to the guide to reflect the feedback received from the surveys. This marked the first stages of including young autistic voices and opinions in the language suggestions in the guide.

24/05/24 - Autism Pathway Parents (Focus Group)

A focus group with parents of children and young people on the diagnosis pathway was done to ascertain how parents of younger children without a formal diagnosis felt about neuroaffirming language, which we then compared to later focus groups.

17/06/24 - Tree of Life (Focus Group)

Tree of Life is an alternative educational provision in Rochdale. We spoke to the autistic young people and the staff who worked there about their opinions on the neuroaffirming language in the guide using *like, in the middle, dislike, don't understand* prompts.

21/06/24 - Bramhall High School (Focus Group)

Bramhall High School is a mainstream school in Stockport. We spoke to some of the autistic young people from their Thrive department about the neuroaffirming language in the guide and their opinions on each term.

21/06/24 - "Teen Space" at Hyde Little Theatre (Focus Group)

"Teen Space" is an autism-friendly space for young people to socialise and have fun. We spoke to the young people and their parents here about their opinions on the neuroaffirming language in the guide.

09/07/24 - Analysing Findings and Final Drafts

Feedback, thoughts and opinions discussed in all four focus groups were synthesised, which led to major themes. These were used to make final alterations to the guide that consummately reflected how autistic young people, and their parents, felt about the guide and what language they preferred.

30/07/24 - Presenting the Guide

We presented to colleagues in an associated Centre: The Research and Innovation Centre. Their feedback led to presentations to the Associate Network Director of Psychological Therapies for Specialist Services and CAMHSs, Dr. Gordon Milson, and Consultant Lead Clinical Psychologist of the Young People's Specialist Support Team, Dr. Rachel Lancaster, for feedback and next steps.

Next steps - Continuously Updating

We think it is important that this guide is a dynamic piece; consistently updated to reflect the changes in language preference as neuroaffirming language evolves. We are now working to establish a means for regular review and updating of the guide, through review communities and further surveys, ensuring an accessible and transparent feedback loop.

Next steps - Potential for evaluating impact

We have pre-guide implementation survey data from autistic young people and professionals who work with them. Follow up surveys and focus groups would allow for us to measure the effectiveness of the guide in changing attitudes and practices towards more neuroaffirming and inclusive language.