

숬 **Winner** 숬 AHP Leadership for Equality, Diversity & Inclusion Award

2023 Chief Allied Health Professions Officer's Awards

AHPs leading, Improving, Inspiring



Language and Autism

A co-produced guide to using neuro-affirmative language with autistic people

Katherine Simcock Principal Speech & Language Therapist (Katherine.simcock@lscft.nhs.uk) July 2023 1

In early 2023, a service improvement project aimed to consult local autistic people in Lancashire and South Cumbria regarding the language we use about autism. This used contemporary evidence to generate questions about language preferences and vocabulary. Seventeen participant responses were considered, alongside current research. The guide below outlines some of the preferences from both the evidence and the local autistic community.

This provides a generalised guide to language preferences. There will always be differences between individuals and <u>it is</u> <u>essential</u> that language used with all autistic service users is person centred. This means that individuals' preferences should be discussed with people as they access services and preferred language should always be used.

Recently, there has been a shift in language regarding <u>neurodiversity</u>. Neurodiversity refers to the range of cognitive profiles we might see across a population. It is important to recognise that amongst a neuro-diverse population we might see:

- <u>Neuro-typical</u> individuals; people with cognitive profiles which follow an assumed developmental pathway
- <u>Neuro-divergent</u> individuals; people with cognitive profiles which may follow a different developmental pattern



Table below: Autistic people's main preferences from responses

Theme	Language Preferences in local survey	Least popular/ unfavourable options
Identity first language	Autistic person	Person with autism
How autism might be	Difference	Disorder
described	Characteristics	
How a person is impacted	Individual strengths and differences	Mild/ severe
Environmental impact on	Situational mutism	
verbal communication	Selective mutism	
	Non-speaking at times	
Physical actions we may see	Communicating distress	Behaviour that challenges
Communication	Different communication styles	
Sensory perception	Sensory differences	Sensory processing disorder
	Sensory processing differences	Autistic Sensory Perception
Enjoyable activities	Strengths	Current obsession

Katherine Simcock Principal Speech & Language Therapist (Katherine.simcock@lscft.nhs.uk) July 2023



	Special interests	
	Area of expertise	
	Passions	
Making adjustments	Reasonable adjustments	Treatment/ interventions
	Supporting the individual's needs	Equitable requirements
Predictability	Thrives with predictability and structure	Desire for sameness
		Rigidities
The autistic spectrum	You either are or are not autistic (but every	
	autistic person is different)	

The findings of the survey suggest that the local autistic people who participated are broadly aligned with the evidence base regarding neuro-affirmative language choices, although there are individual differences to be seen across the results. The key people in their lives (i.e. parents, siblings or partners) are less firmly aligned and are flexible with some terminology.

Neuro-affirmative language aims to frame a person's profile in a less deficit based way. Strengths and areas of difficulty still need to be identified and considered where appropriate.

Consideration of language preferences should <u>always</u> be discussed and agreed between clinicians and patients.

Katherine Simcock Principal Speech & Language Therapist (Katherine.simcock@lscft.nhs.uk) July 2023



"Language is a powerful means for shaping how people view autism. If [we] take steps to avoid ableist language, researchers, service providers, and society at large may become more accepting and accommodating of autistic people." – Bottema Beutal (2022)

Appendices

Key Themes and References

Theme	Neuro-affirmative language	Evidence
Identity first language	Autistic person/ Autistic neurology	NHS England (n.d.); Kenny et al, (2016); Monk et
		al (2022); Dwyer et al (2022)
How autism might be described	Difference/ differences/ characteristics	Bottema-Beutal et al (2021); NHS England (n.d.);
		Monk et al (2022); Dwyer et al (2022)



		NHS Foundation Trust
How a person is impacted	Focus on strengths and needs	Kenny et al, (2016); Economic and Social
		Research Council, (2022); Monk et al (2022);
		Pellicano and Houting (2022); Mitchell et al
		(2022)
Environmental impact on verbal	Situational mutism/ non-speaking at	Economic and Social Research Council (2022);
communication	times	Monk et al (2022)
Physical reactions we may see	Communicating distress	NHS England (n.d.); Pellicano and Houting (2022)
Communication	Differences / communication style /	Bottema-Beutal et al, (2021); Economic and
	double empathy problem	Social Research Council (2022); Monk et al
		(2022); Pellicano and Houting (2022); Mitchel et
		al (2022)
Sensory perception	Sensory differences/ perceptual	Economic and Social Research Council (2022);
	differences/ autistic sensory perception	Pellicano and Houting (2022); Ratto et al (2022)
Enjoyable activities	Passions / area of expertise / strengths	NHS England (n.d); Monk et al (2022)
Making adjustments	Reasonable adjustments / equitable	Doyle (2020); Economic and Social Research
	requirements / support	Council (2022)
Predictability	Thrives with structure/ thrives with	Economic and Social research Council (2022);
	routine	Bottema-Beutal et al (2021); Doyle (2020)



The autistic spectrum

You either are, or are not autistic

Kenny et al (2016); Bottema Beutal et al (2021)

Bottema-Beutel, K., Kapp, S.K., Lester, J.N., Sasson, N.J. and Hand, B.N., (2021) Avoiding ableist language: Suggestions for autism researchers. *Autism in adulthood*. Volume 3, No 1, p18-26

Doyle N (2020) Neurodiversity at work: a biopsychosocial model and the impact on working adults, *British Medical Bulletin*, 2020, 135:108–125

Dwyer, P., Ryan, J.G., Williams, Z.J. and Gassner, D.L., (2022). First do no harm: Suggestions regarding respectful autism language. Pediatrics, 149 (Supplement 4).

Economic and Social Research Council (2022) More Than Words: Supporting effective communication with autistic people in health care settings. Available at: https://www.boingboing.org.uk/more_than_words/ [accessed on 21/03/2023]

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. <u>https://doi.org/10.1177/1362361315588200</u>

Mitchell, P., Sheppard, E. and Cassidy, S., (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*, *39*(1), pp.1-18.



Monk, R., Whitehouse, A.J. and Waddington, H. (2022) The use of language in autism research. *Trends in Neurosciences*. Vol 45, No 11, pp 791-793

NHS England (n.d.) Getting words right about autism. Available at: <u>https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/</u> [accessed on 21/03/2023]

Pellicano, E. and Houting, J. D. (2022) Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. The Journal of Child Psychology and Psychiatry 63: 4 pp 381-396

Ratto, A.B., Bascom, J., daVanport, S., Strang, J.F., Anthony, L.G., Verbalis, A., Pugliese, C., Nadwodny, N., Brown, L.X., Cruz, M. and Hector, B.L., (2022). Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. Autism in Adulthood. Volume 00, Number 00, DOI: 10.1089/aut.2021.0099