

## Working with Autistic Patients: Clinician Resources and Practice Guidelines

### Meeting Autistic Access Needs

Resource/Link	Access Domain(s)	Citation
More Than Words Communication Guidelines  <a href="https://www.boingboing.org.uk/more-than-words/">https://www.boingboing.org.uk/more-than-words/</a>	Communication	Williams, G. L., Adams, J., Bull, P., Cave, H., Chown, N., Doherty, M., Forrest, K., Foster, R., Fricker, R., Godfree, B., Keaveney-Sheath, K., Knight, J., Marrable, T., Murray, R., Shaw, S. C. K., Ventour-Griffiths, T., Wood, J. (2022) More than words: Supporting effective communication with autistic people in health care settings. Economic and Social Research Council.
Autistic SPACE  <a href="https://pubmed.ncbi.nlm.nih.gov/37127416/">https://pubmed.ncbi.nlm.nih.gov/37127416/</a>	Communication Sensory Executive functioning	Doherty M, McCowan S, Shaw SC. Autistic SPACE: a novel framework for meeting the needs of autistic people in healthcare settings. <i>Br J Hosp Med (Lond)</i> . 2023;84(4):1-9. doi:10.12968/hmed.2023.0006
AASPIRE Toolkit  <a href="https://autismandhealth.org/">https://autismandhealth.org/</a>	Communication Sensory Executive functioning	Nicoladis, C., Raymaker, D.M., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., Baggs, A. (2016). The development and evaluation of an online healthcare toolkit for autistic adults and their providers.e, <i>Journal of General Internal Medicine</i> . Published ahead of print June, 2016. DOI: 10.1007/s11606-016-3763-6

**Screening and Referring for Co-occurring Conditions:** “Everything is Connected to Everything: Improving Healthcare for Autistic and ADHD Adults” by All Brains Belong VT Interdisciplinary Task Force, 2023:

<https://allbrainsbelong.org/clinician-resources/>



“The Physical Therapist’s Role In Supporting Autistic Patients Across The Lifespan”  
CPTA Annual Conference, October 7, 2023

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## Working with Autistic Patients: A Guide to Respectful Language for Clinicians

As clinicians, a simple but powerful thing we can do to improve care for autistic patients of all ages is to use accurate, affirming, and non-stigmatizing language when discussing autistic people, and autism.

Just as we must learn from and honor the preferences of other minority communities in order to speak respectfully about these groups, we must utilize the guidance of the autistic self-advocacy community to understand how to respectfully communicate about autism and the experiences of autistic people.

### The majority of autistic people prefer to be described using identity-first language

Many of us as clinicians have been taught that when discussing disability, we should always use person-first language (PFL), i.e. person with a disability, instead of identity-first language (IFL), i.e. disabled person. However, we must always respect the preferences of each specific disability community when discussing that community.

The vast majority of those in the autistic self-advocacy community prefer IFL, i.e. autistic person, instead of PFL, i.e. person with autism. This is largely for reasons relating to the needs of the community in advocating for acceptance and respectful support.

With that being said, when working with an individual patient, we should always respect that individual's personal language preferences, even if those preferences differ from those of their broader community.

### What about "on the spectrum"?

Sometimes autistic people are described as "being on the autism spectrum" or "being on the spectrum". If a person likes to describe themselves this way, we should respect this preference.

However, many other autistic people find the phrase "on the spectrum" to be offensive because it can be seen as a euphemism used to avoid saying the word "autistic".

### I'm concerned about my pediatric patient overhearing adults describe them as autistic. Will my patient be scared or confused or ashamed by this label?

Talking about autism, and the autistic experience, is only taboo if we as clinicians imply that it should be. For autistic people of all ages, learning about their disability, and learning to use accurate language when discussing their disability, helps to facilitate understanding of and self advocacy for support needs, contextualizes life experiences, and allows people to find community.

For further reading on research on the benefits of educating autistic children about their disability, please see:

Oredipe T, Kofner B, Riccio A, et al. Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. *Autism*. 2023;27(1):200-212. doi:10.1177/13623613221086700



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## Respectful Language: Other Key Points

The following table, from a 2022 article by Monk et al summarizes other key points:

**Table 1. Practical strategies for replacing potentially offensive terms with autistic-preferred terminology to reduce the stigmatisation, misunderstanding, marginalisation, and exclusion of autistic people**

Potentially offensive	Autistic preferred	Insight and perspectives from the autistic community	Example of preferred language use in research
Autism spectrum disorder (ASD)	Autism, autistic	Disorder is unnecessarily medicalised and reinforces negative discourses that autism is wrong or needs curing	'Autism is a neurodevelopmental difference...'
Person-first language (person with autism)	Identity-first language [autistic (person)]	Identity-first language emphasises autism as inseparable from the person and an integral part of their identity, whereas person-first language suggests a separation between autism and the individual	'A total of 125 autistic adults participated in the study.'
Autism symptoms and impairments	Specific autistic experiences and characteristics	Medical terminology pathologises the characteristics and experiences of autistic people as deficient and abnormal	'This study recruited autistic participants with a high sensitivity to sensory stimuli.'
At risk of autism	May be autistic; increased likelihood of being autistic	Danger-oriented terms (vs. probabilistic terms) imply that autism is a negative (possibly preventable) outcome	'Children with an increased likelihood of being autistic were also included in the study.'
Co-morbidity	Co-occurring	Autism is not a disease, even though it often co-occurs with other neurodivergences or medical conditions	'Individuals with co-occurring medical conditions were excluded from the study.'
Functioning (e.g., high/low functioning) and severity (e.g., mild/moderate/severe) labels	Specific support needs	All autistic people have a range of strengths, skills, challenges, and support needs that can vary over time and in different situations and environments	'Individuals with sensory and communication support needs.'
Cure, treatment, or intervention	Specific support or service	Autism does not need to be cured, treated, or modified. Supports should not be targeted at autism characteristics, although autistic people may benefit from individualised supports	'The participants were receiving occupational therapy to reduce sensory overload in those with high sensory needs.'
Restricted interests and obsessions	Specialised, focussed, or intense interests	Deficit-based terminology pathologises the interests of autistic people rather than celebrating their knowledge	'The participant had specialised interests in computers and politics.'
Normal person	Allistic or non-autistic	Allistic is an empowering term that reframes autism and autistic traits as a difference instead of an abnormality	'The comparison group included allistic (non-autistic) people.'

Monk R, Whitehouse AJO, Waddington H. The use of language in autism research. *Trends Neurosci.* 2022;45(11):791-793. doi:10.1016/j.tins.2022.08.009



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## Online Support Resources for Autistic Patients and Families/Caregivers (Updated 08/27/2023)

Autistic Self Advocacy Network

<https://autisticadvocacy.org/>

Autistic Women and Nonbinary Network

<https://awnnetwork.org/>

Autism in Black

<https://www.autisminblack.org/>

Neuroclastic

<https://neuroclastic.com/>

Thinking Person's Guide to Autism

<https://thinkingautismguide.com>

All Brains Belong Brain Club

<https://allbrainsbelong.org/brain-club/>

That Au-Some Book Club

<https://www.facebook.com/groups/thatausomebookclub>



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