

How to talk about autistic ways of being

For years now, many people have been challenging the medical classification that they have a 'disorder', as they experience themselves as having a valid identity among the natural variation of human minds.

Try not to think in terms of 'disorder'

One example of this is what is referred to in the DSM and ICD as 'Autism Spectrum Disorder'. This diagnostic language is problematic for many autistic people who consider their way of being as a valid expression of human variation. This consideration is embedded in the neurodiversity paradigm, which recognises that all types of people are valid and valuable, regardless of having different ways of engaging in the world.

This does not mean that they do not require support. They may need support for any number of reasons to improve their quality of life.

Challenging the classification of 'disorder' is not the same as denying the reality of disability.

Many autistic people are disabled and require support. It is not necessary to say that someone is disordered and to use pathologizing language for them in order to provide them with the help they need.

Translate medical language into identity-affirming language

In some cases, for example, on official paperwork, you may be required to use diagnostic language. This language focuses a lot on 'deficits' and 'lacking'. Wherever possible, especially when talking to autistic people and their families, this diagnostic terminology should be translated into the style of language outlined in this document.

Research has found that the following is how the majority of autistic people wish to be considered. You will find it is often at odds with previous medical framings of autism, and even at odds with the language that some big autism charities and so-called 'autism experts' still use.

However, we hope that you will adhere to the requests of the autistic community where possible. Research finds that respectful language that validates autistic identity can greatly improve the self-esteem and wellbeing of the autistic people you talk to.

Respect the individual

If the autistic person you are talking to expresses a specific preference for the language you use, then this should be respected.

They should feel that you are listening to them and respecting their preferences. However, unless otherwise stated, the following language should be employed.

Most important is to avoid any language that implies the autistic person is 'wrong' or 'broken'. Autistic people are not flawed versions of neurotypical people, but have distinct and valid identities, communities, and ways of being in the world.

1 : Avoid calling it 'Autism Spectrum Disorder', ASD or ASC

Call it 'autism', or just talk about 'being autistic'

Autistic people should not be considered disordered.

Autistic is a neurotype (which in many cases is disabling when not properly accommodated), but autism should not be considered a disorder or condition. This is not to say that people with conditions or disorders are 'less than' people without them—absolutely not!—but that it is just not an accurate descriptor when applied to autistic people.

Talking about autistic people makes more sense than talking about a 'thing' called autism, just as you would talk of neurotypical people rather than 'neurotypicalism'. ALL neurotypes are just as valid and valuable as each other.

2: Say 'autistic person'

instead of 'person with autism'

(...unless the person you are talking to has told you otherwise).

'Person with autism' (person-first language) implies the presence of a condition or disorder or something that can be removed from the person. 'Autistic person' (identity-first language) embraces that being autistic is an integral and valid part of who we are.

3: Don't say 'high-functioning' or 'low-functioning', or use levels. Instead, talk about specific needs for support, access, and/or accommodation

Functioning labels and functioning levels can be inaccurate and harmful. Saying someone is 'low-functioning' ignores their strengths and does not show them respect; saying someone is 'high-functioning' ignores their challenges and the effort it may take to appear outwardly high-functioning.

Functioning fluctuates from year to year and even day to day. Tasks that can be completed on one day in one circumstance may be too difficult at another time. For example, on a good day, someone may be able to hold conversations, but when they are feeling burnt out, talking might feel very difficult. This does not mean they have switched from high-functioning to low-functioning; that kind of language is unhelpful.

The spectrum does not mean from low-functioning to high-functioning, or from mild to severe

The word spectrum is better thought of in the sense of a colour spectrum, not a linear spectrum or a scale. Each person has different skills and challenges in different aspects of their functioning.

4: Don't talk about 'treating autism' or 'interventions'.

Instead, talk about support services, therapies, or strategies to improve quality of life

Autistic people do not need to be 'treated', as we do not have an illness. Being autistic is a valid way of being and does not inherently require therapies. Strategies and therapies may support access to the social world and services, which may help improve quality of life in specific areas where needed. They should never aim to normalise or reduce autistic behaviours unless those behaviours are actively harmful.

An autistic person may need treatments to help with problems that run alongside being autistic—for example, depression or anxiety—but this should not be thought of in terms of 'treating their autism'.

5: Don't talk of 'profound' or 'severe' or 'mild' autism.

Instead explain what the person's challenges are, or whether they also have a learning disability

The sentiments in this document have been previously criticised by those who assert that they do not apply to 'severely' autistic people. This reflects a misunderstanding about being autistic. Just because one autistic person might struggle more with certain things, it does not make them any more autistic. It is not their autistic-ness that is more or less severe, it is the thing they are struggling with that is more or less severe.

When we stop thinking of being autistic as 'having a disorder', then it does not really make sense to talk about severity

We do not talk about someone being severely or mildly neurotypical; we talk about the things they struggle with specifically.

Similarly, when talking about an autistic person, talk about the specific challenges they experience. Maybe they are autistic and have a learning disability. You can also just explain using specific examples, for example, saying that they are autistic and struggle with emotional regulation.

6. Don't say that someone does not 'look autistic'.

There is no autistic 'look'

Saying someone does not look autistic upholds harmful stereotypes. All autistic people are different, because all people are different.

Adults can be autistic, women and girls can be autistic, people who hold eye contact and have conversations can be autistic, people who have friends can be autistic.

To think otherwise is to hold on to outdated stereotypes about what being autistic means. Saying 'you don't look autistic' can feel very invalidating to the person who suspects or knows they are autistic.

If someone suspects they might be autistic, believe them, and do what is necessary to help them look further into it and find out more.

In the case that you need to use diagnostic definitions, whether in person or in paperwork, you can include a caveat in your correspondence, such as:

'As a warning, this language must reflect the diagnostic manual, and so it may seem very negative. Please know that I do not consider you negatively in this way.'

Replacing pathologizing language

If the autistic person you are talking to expresses specific preferences, then please use those. In all other cases, choose the following.

TRY TO AVOID



Autism Spectrum Disorder
or ASD or ASC

Person with autism

High-functioning or
Low-functioning or
functioning levels

Treatment of autism or
interventions

Severe or profound (or mild)
autism

You don't look autistic

Suffering from autism

Special needs

Symptoms

SAY INSTEAD



Autism
or just talk about being autistic

Autistic person

Talk about their specific needs
for support, access, and/or
accommodation

Support services
or therapies or strategies to
improve quality of life

They are autistic and [insert
specific support needs]
or They are autistic and have
[insert a condition]
or They are autistic and have a
learning disability
or They have complex support
needs or access needs

There is no autistic 'look'

They are autistic

They need [insert specific
support needs]

Traits or characteristics

TRY TO AVOID



Challenging/disruptive/
problem/maladaptive
behaviour

At risk of ASD

Normal person

Restricted/narrow/special
interests
or obsessions

Restricted, repetitive
behaviours
or stereotyped behaviours

Resistant to change
or has a rigid routine

Picky eating

Co-morbid conditions

Non-verbal

Selectively mute

SAY INSTEAD



Describe the specific
behaviours e.g., self-injurious
behaviours or the person is in
meltdown or distress

They are likely autistic

Non-autistic person
or allistic person

Passions or hobbies
or passionate interests
or focused interests

Stimming ('stim' or 'stims')
(self-regulating behaviours)
or they enjoy or benefit from
[describe their stim]

Preference for sameness and
consistency

They have specific food
preferences (e.g., due to a
sensitive palate or sensory
needs)

Co-occurring conditions

Non-speaking or AAC user (eg,
uses an alternative
communication device)
or uses sign language etc.

Situationally mute
or sometimes unable to speak
(Note: 'selective mutism' will still
need to be written when making a
diagnosis or writing reports)

Clarifying some terms

Traits/ characteristics:

Because 'symptoms' is used for medical problems and being autistic should not be thought of as a medical problem.

Allistic:

Anyone who is not autistic. They may still be neurodivergent in other ways.

Stimming:

(Sometimes shortened to 'stim' or 'stims'.) Movements, actions or voice utterances, often repetitive, for the purpose of soothing, coping, and reducing anxiety, to aid thinking and processing, or because they feel good.

Co-occurring:

Because comorbid sounds deathly and sinister and implies that being autistic is a medical disorder.

Non-speaking:

Someone who does not use mouth-words. Probably does understand language and may use it in other ways.

Non-verbal:

Someone who does not comprehend words at all.

Mouth-words:

Speaking with your mouth, as opposed to manual languages (e.g., BSL, ASL, etc.) or AAC (augmentative and alternative communication—devices to offer alternative communication means).

Often also called "spoken words" or "spoken language".

Situationally mute, or Intermittently (non)speaking:

Because "selectively mute" sounds like we **choose** not to talk, when actually it is the situation or some other thing that is preventing us from being able to speak.

(Note: 'selective mutism' will still need to be written when making a diagnosis or writing reports)

Neurotype:

Brain type. Our way of being (neurocognitive functioning) because of how our brains (bodyminds) are.

Meltdowns:

Loss of control, usually as a result of sensory or emotional overwhelm. These are not tantrums as they are not purposely motivated towards seeking support.

Shutdowns:

Feeling or becoming unresponsive, dissociative, numb, sometimes resulting in situational mutism (where one is unable to communicate or speak).

Burnout:

Becoming gradually rundown and finding it difficult to cope. Often the result of extended overwhelm, stress and exhaustion, and can last for hours, days, and even years.

Neurotypical (or NT):

Someone who is not neurodivergent.

Neurodivergent (or ND):

Someone whose mind diverges from what society considers 'normal'.

Neurodiverse:

A word that can only be applied to a group, never to an individual. It means a diverse range of neurotypes/minds.

Ableism:

Discrimination in favour of able-bodied and neurotypical people.

Some other terms you may have heard:

AuDHD:

Someone who is both autistic and ADHD.

Neurospicy:

A playful alternative for 'neurodivergent'; spicy originated as a joke to combat the disliked phrase 'mild' autism.

Spoons: .

Units of energy for people with chronic conditions/disabilities. You begin each day with a finite number and completing everyday tasks depletes your spoons until you have 'run out of spoons'.

Forks:

Tolerance limits, how much you can cope with, and what needs dealing with first.

Splns:

From 'Special Interests'. Passions, hobbies, passionate interests.

Same food (and safe food):

Can be eaten every day, feels predictable and trustworthy.

What it means to be autistic...

There are certain theories about autistic people that you may have heard of or learnt about that are now widely seen as harmful misinformation.

Some of the more famous of these theories include:

- Autistic people lack Theory of Mind
- Autistic people lack empathy
- Autistic people lack social motivation



These have since been challenged and research has suggested they are inaccurate and promote stigmatising perspectives.

The following theories are autistic-led, widely approved by many in the autistic community, and have a growing and compelling evidence base:

- **Double Empathy Problem**

Non-autistic people can find it equally difficult to empathise/understand/relate to/communicate with autistic people; the breakdown happens on both parts, not because of a deficit in the autistic person.



- **Monotropism**

Autistic people have minds where attention is distributed in focused 'beams', while non-autistic people distribute focus in broad diffused 'rays'. This explains intense focus, stimming (previously self-stimulatory behaviours), 'sticky' attention and difficulty switching tasks, and desire for routine and predictability. These are not caused by deficit, but by the way attention is focused.

It may be useful for you to be aware that research is finding there are traits that are being described by autistic people as being central to autistic experience, but that are not yet included in the diagnostic manuals. The diagnostic definition of autism focuses more on how behaviours affect and are perceived by others, rather than on the inner experience of being autistic.

The autistic people you speak to may describe the following as part of their autistic experience:

Sensory and motor experiences,

for example, feeling sensory input intensely or processing senses one at a time. This may include 'flow states' of deep immersion and attention on sensory input, autistic inertia (difficulty initiating or ceasing tasks), feelings of 'rightness' of self in space, and stimming (described above).

Deep focus and attention,

including the ability to identify pattern and detail, being greatly absorbed by certain interests, developing deep knowledge, and needing adequate time to shift attention.

Executive Functioning and related traits

affecting how they experience and navigate their lives, including challenges with transitions and overload.

A desire to connect

to others, but not necessarily in a way that fits neuronormative expectations of friendship, play, and connection.

Masking (covering autistic traits)

is very common. It often takes a lot of effort and can be draining. Many non-autistic behaviours can be learnt but that does not mean they feel good (for example, holding eye contact whilst listening).

Burnout

can be very common for autistic people. Whether it be from the efforts of masking, the accumulated stress of sensory input or miscommunications, or just existing in a world that does not feel set up for autistic people, burnout is the experience of spending more resources to cope than are available. Burnout can look like many different things, including depression, shutdown, meltdown, and lethargy.

(Often, autistic people are not recognised as autistic until they have reached such a point of distress that their traits are amplified and they now meet the diagnostic criteria.)

Systemic discrimination and social trauma

are often described by autistic people, and can include being gaslighted, being the target of others' anger, being bullied, being the target of 'uncanny valley' feelings where others see them as not quite human, and being victims of harmful stereotypes, for example, that all autistic people either have a learning disability or they have a special 'savant' skill.

Trust is essential

for mitigating stress—trust that another person will be 'safe' and will be accommodating, and trust that an environment will feel comfortable.

You can signpost people to these sites to learn about what it means to be autistic:

- A website written by an autistic person for supporting neurodivergent people:

<https://coda.io/@mykola-bilokonsky/public-neurodiversity-support-center>

- A downloadable letter for parents to send to their autistic child's support network:

<https://reframingautism.org.au/neurodiversity-affirming-language-a-letter-to-your-childs-support-network/>

- A website of informative articles where you can search for specific terms to read all about that topic:

<https://neuroclastic.com>

Why this document is important

Autistic adults are **9 times more likely to die by suicide** than the general population

Autistic women are **13 times more likely to die by suicide** than the general population

Misinformation leads to misdiagnosis

Professionals MUST have an accurate understanding of what it means to be autistic.

Autistic people are being harmed because they are being misdiagnosed or unrecognised as autistic. Being given the wrong diagnosis means they are receiving the wrong supports, which can have fatal consequences.

If a professional believes outdated stereotypes, they may not recognise when someone is autistic. So cannot help them in the ways they need.

For example,

many women and girls are being misdiagnosed because clinicians believe the stereotype that autistic people are mostly boys, or cannot be married, or cannot hold eye contact. They give them the wrong diagnosis, which means they offer the wrong supports.

For example,

a clinician may assume someone has an eating disorder, when in fact, they are autistic and their food aversions are linked to sensory needs.

For example,

a clinician may assume someone is not autistic because their passionate interests are 'appropriate', for example, autistic girls may be passionately interested in make-up or pop bands, but these do not stand out to a clinician.

For more information....

If you would like more information on the autistic community and preferences, see the list of references that informed the creation of this guide, or refer here:

- Autistic community preferences, by The Autistic Collaboration:
<https://autcollab.org/projects/a-communal-definition-of-autistic-ways-of-being/>
- A letter to professionals working with autistic children, by Reframing Autism:
<https://reframingautism.org.au/neurodiversity-affirming-language-a-letter-to-your-childs-support-network/>
- A paper on avoiding ableist language, by Bottema-Beutel et al:
<https://www.liebertpub.com/doi/10.1089/aut.2020.0014>
- Explaining how to talk about autism AND WHY, by Mykola Bilokonsky:
<https://coda.io/@mykola-bilokonsky/public-neurodiversity-support-center/how-to-talk-about-autism-respectfully-84>
- Shifting away from medical framings towards neurodiversity framings, by Pellicano and den Houting:
<https://acamh.onlinelibrary.wiley.com/doi/full/10.1111/jcpp.13534>
- A short video of autistic young people explaining the 'Language of Autism' survey
<https://youtu.be/F03Dwp5YWw8>

This guide was created by an autonomous workgroup within CAPTAP (Community Against Prejudice Towards Autistic People). Our workgroup includes people from multiple countries with varying experiences. The majority of the group's members are autistic, and the group comprises medical doctors, health professionals, professionals working with autistic people, academics, and researchers.

Reference list.

(For a full bibliography, please visit captapnetwork.wordpress.com/how-to-talk)

“Autistic ways of being”:

- [\(Bettin, 2022\) A Communal Definition of Autistic Ways of Being](#)

Current challenges to (non-autism specific) disorder classifications:

- [\(Kinderman et al., 2020\) Regarding the reform and revision of diagnostic systems](#)
- [\(Kinderman et al., 2013\) Drop the language of disorder](#)
- [\(Davies, 2022\) Sedated. How Modern Capitalism Created our Mental Health Crisis.](#)
- [\(Gray-Hammond, 2022a\) Mental health and the neurodiversity paradigm](#)

Autistic as a valid identity among human variation:

- [\(Bervoets & Hens, 2020\) Going Beyond the Catch-22 of Autism Diagnosis and Research. The Moral Implications of \(Not\) Asking “What Is Autism?”](#)
- [\(Farahar, 2021\) A rose by any other name would smell...of stigma \(or, the psychologically important difference between being a “person with autism” or an Autistic person\)](#)
- [\(AutisticNotWeird, 2022\) Autistic Not Weird 2022 Autism Survey](#)
- [\(Monique Botha et al., 2020\) “Autism is me”: an investigation of how autistic individuals make sense of autism and stigma](#)
- [\(Kenny et al., 2015\) Which terms should be used to describe autism? Perspectives from the UK autism community](#)
- [\(Bury et al., 2020\) “It Defines Who I Am” or “It’s Something I Have”: What Language Do \[Autistic\] Australian Adults \[on the Autism Spectrum\] Prefer?](#)
- [\(Crompton, Hallett, et al., 2020\) ‘I never realised everybody felt as happy as I do when I am around autistic people’: A thematic analysis of autistic adults’ relationships with autistic and neurotypical friends and family](#)
- [\(Kourti, 2021\) Introduction to Working with Autistic Transgender and Non-Binary People](#)
- [\(Maitland et al., 2021\) Social identities and mental well-being in autistic adults](#)

The neurodiversity paradigm:

- [\(Walker, 2021\) Neuroqueer Heresies. Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities](#)
- [\(Heyworth, 2021\) Introduction to Autism, Part 5: Neurodiversity \(What is it and why do we care?\)](#)
- [\(Farahar, 2020\) Stigmaphrenia: Reducing mental health stigma with a script about neurodiversity](#)

Challenging the classification of “disorder” is not the same as denying the reality of disability:

- [\(D. Milton, 2019\) Difference versus Disability: implications of characterisation of autism for education and support](#)
- [\(S. Kapp et al., 2013\) Deficit, difference, or both? Autism and neurodiversity.](#)
- [\(Bilokonsky, 2022a\) How to Talk about Autism Respectfully](#)
- [\(Gray-Hammond, 2022b\) The New Normal. Autistic musings on the threat of a broken society.](#)

It is not necessary to say that someone is disordered and to use pathologizing language for them in order to provide them with the help they need.

- [\(Baggs, 2019\) I need time. This is about accessibility.](#)
- [\(Gray-Hammond, 2022b\) The New Normal. Autistic musings on the threat of a broken society.](#)
- [\(Astle et al., 2021\) Annual Research Review: The transdiagnostic revolution in neurodevelopmental disorders](#)
- [\(Holmes & Patrick, 2018\) The Myth of Optimality in Clinical Neuroscience](#)

Diagnostic language focusses a lot on “deficits” and “lacking”.

- [\(American Psychiatric Association, 2013\) Diagnostic and statistical manual of mental disorders \(5th ed.\)](#)
- [\(Rodas, 2018\) Autistic Disturbances. Theorizing Autism Poetics from the DSM to Robinson Crusoe](#)
- [\(Heilker & Yergeau, 2011\) Autism and Rhetoric](#)
- [\(D. W. Maynard & Turowetz, 2022\) Autistic Intelligence. Interaction, Individuality, and the Challenges of Diagnosis](#)
- [\(Bulluss & Sesterka, 2020\) Reframing Professional Language Around Autism in Practice](#)
- [\(Dinah Murray, 2020\) Dimensions of Difference](#)
- [\(Ida, 2020\) Multiplicity and neurodiversity](#)

Research has found that the following is how the majority of autistic people wish to be considered.

- [\(AutisticNotWeird, 2022\) Autistic Not Weird 2022 Autism Survey](#)
- [\(Monique Botha et al., 2020\) “Autism is me”: an investigation of how autistic individuals make sense of autism and stigma](#)
- [\(Kenny et al., 2015\) Which terms should be used to describe autism? Perspectives from the UK autism community](#)
- [\(Bury et al., 2020\) “It Defines Who I Am” or “It’s Something I Have”: What Language Do \[Autistic\] Australian Adults \[on the Autism Spectrum\] Prefer?](#)
- [\(Keating et al., 2022\) Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation](#)

Big autism charities and 'autism experts' still use medicalised language:

- 'There is currently no cure for ASD' (CDC, 2021)
- Many 'children with autism' require 'behavioural treatments' (AutismSpeaks, 2021).
- Autism is a 'complicated condition' (WebMD, 2021),
- Autism 'may sometimes be passed on to a child by their parents' (NHS, 2021)
- The pathology paradigm (Walker, 2021) Neuroqueer Heresies. Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities

Research finds that respectful language that validates autistic identity can greatly improve the self-esteem and wellbeing of the autistic people you talk to.

- (M Botha & Gillespie-Lynch, 2022) Come as You Are: Examining Autistic Identity Development and the Neurodiversity Movement through an Intersectional Lens
- (Monique Botha, Dibb, et al., 2021) "It's Being a Part of a Grand Tradition, a Grand Counter-culture Which Involves Communities": A Qualitative Investigation of Autistic Community Connectedness
- (Monique Botha, Hanlon, et al., 2021) Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti
- (Monique Botha et al., 2020) "Autism is me": an investigation of how autistic individuals make sense of autism and stigma
- (Cooper et al., 2021) "I'm Proud to be a Little Bit Different": The Effects of Autistic Individuals' Perceptions of Autism and Autism Social Identity on Their Collective Self-esteem
- (Cage et al., 2018) Understanding, attitudes and dehumanisation towards autistic people
- (Farahar & Thompson, 2021) What's in a name? The importance of language for Autistic wellbeing
- (Gray-Hammond, 2022a) Mental health and the neurodiversity paradigm
- (Gillespie-Lynch et al., 2017) Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts
- (Camus, Macmillan, et al., 2022) 'I too, need to belong': Autistic adults' perspectives on misunderstandings and well-being PREPRINT

If the autistic person you are talking to expresses a specific preference for the language you use, then this should be respected.

- (Kenny et al., 2015) Which terms should be used to describe autism? Perspectives from the UK autism community
- (Chapple & Worsley, 2021) Commentary: Considering nomenclature for autism - aligning with the language preferences of the autistic community - a commentary on Kehinde et al. (2021).
- (Bilokonsky, 2022a) How to Talk about Autism Respectfully

Autistic people are not flawed versions of neurotypical people

- (Kenny et al., 2015) Which terms should be used to describe autism? Perspectives from the UK autism community
- (Woods, 2017) Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt

1: Avoid calling it 'Autism Spectrum Disorder', ASD or ASC. Call it 'autism', or just talk about 'being autistic'... Autistic is a neurotype and disability, not a disorder.

- (AutisticNotWeird, 2022) Autistic Not Weird 2022 Autism Survey
All participants (about two thirds autistic) think autism is, in general, a....
17% - it is a disorder
35% - it is a condition
37% - it is a disability
74% - it is a neurotype
- (Keating et al., 2022) Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation
80% see it as a 'neurological/brain difference', 62% a disability, 34% a disorder
- (Kenny et al., 2015) Which terms should be used to describe autism? Perspectives from the UK autism community
The most highly endorsed terms were "autism" and "on the autism spectrum", and to a lesser extent, "Autism Spectrum Disorder", for which there was consensus across community groups.
- Language of Autism survey. Durham: Extreme Group. <https://youtu.be/F03Dwp5YWw8>
Over 500 participants in survey.
Least preferred 'ASD'.
- (Grant & Kara, 2021) Considering the Autistic advantage in qualitative research: the strengths of Autistic researchers
- (Pearson et al., 2021) Creating truly radical change in autism research: A response to Frith and Mottron

2: Say 'autistic person' not 'person with autism' (unless the person you are talking to has told you otherwise).

- (AutisticNotWeird, 2022) Autistic Not Weird 2022 Autism Survey
"Autistic person" preferred by:
Autistic people – 91%
Professionals – 64%
"Person with autism" preferred by:
Autistic people – 19%
Professionals – 45%

- (Keating et al., 2022) Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation
 - 93% prefer 'autism', 61% 'Autism Spectrum Disorder', 30% Autism Spectrum Condition
 - 80% prefer 'autistic person', 24% 'Person with autism'
 - 85% prefer 'is autistic', 39% 'has autism'
- (Kenny et al., 2015) Which terms should be used to describe autism? Perspectives from the UK autism community. "autistic" was endorsed by a large percentage of autistic adults, family members/friends and parents but by considerably fewer professionals; "person with autism" was endorsed by almost half of professionals but by fewer autistic adults and parents.
- Language of Autism survey. Durham: Extreme Group. <https://youtu.be/F03Dwp5YWw8>
 - Over 500 participants in survey.
 - Most preferred 'Autistic'
- (Gernsbacher, 2017) Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma
- (Gernsbacher et al., 2016) "Special needs" is an ineffective euphemism
- (Monique Botha, Hanlon, et al., 2021) Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti
- (Farahar, 2021) A rose by any other name would smell...of stigma (or, the psychologically important difference between being a "person with autism" or an Autistic person)
- (L. Brown, 2011) The Significance of Semantics: Person-First Language: Why It Matters.
- (Ladau, 2015) Why Person-First Language Doesn't Always Put the Person First

3: Don't say 'high-functioning' or 'low-functioning', and avoid the use of levels. Instead talk about specific support needs/ access needs/ accommodation needs.

- (S. K. Kapp, 2023) Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs
- (Alvares et al., 2019) The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis
- (Pukki et al., 2022) Autistic Perspectives on the Future of Clinical Autism Research
- (Keating et al., 2022) Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation
- (Chapple & Worsley, 2021) Commentary: Considering nomenclature for autism - aligning with the language preferences of the autistic community - a commentary on Kehinde et al. (2021).
- (Fennell & Johnson, 2021) Examination of professional biases about autism: how can we do better?
- (Ne'eman & Pellicano, 2022) Neurodiversity as Politics
- (Forbes, 2020) Neurodiversity is for Everyone. That's the Point.
- (Volz, 2019) Why I'm Not a High-Functioning Autistic

The spectrum is not linear:

- (Bury et al., 2020) "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer?
- (Lynch, 2019) "Autism is a Spectrum" Doesn't Mean What You Think
- (S. K. Kapp, 2023) Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs

4: Don't talk about 'treatment of autism' or 'interventions', talk about support services, therapies, or strategies to improve quality of life

We recognise and respect there has been debate about reclaiming the word 'intervention' and using it in a neurodiversity affirming way,

- (Raymaker, 2019) 'Reclaiming Research for the Autistic Adult Community'
 - However, we fear this nuance may be lost in everyday use, and that it may be used in the pathologizing sense, and so we have decided to advise professionals to avoid it altogether.
- (Vance, 2021) Autism: It's not OUGHTism. On making decisions about intervention therapies
- (Milton, 2014) So what exactly are autism interventions intervening with?
- (AssistiveWare, 2022) How to talk about AAC and AAC users (according to them)
- (ASAN, 2022) Open letter to the Lancet Commission on the future of care and clinical research in autism

5: Do not talk of 'profound' or severe' or 'mild' autism, instead explain what the person's challenges are, or whether they also have a learning disability.

- (S. K. Kapp, 2023) Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs
- (Pukki et al., 2022) Autistic Perspectives on the Future of Clinical Autism Research
- (ASAN, 2022) Open letter to the Lancet Commission on the future of care and clinical research in autism
- (Rosa, 2021) Creating a "profound autism" category is segregation, not progress
- (Chapple & Worsley, 2021) Commentary: Considering nomenclature for autism - aligning with the language preferences of the autistic community - a commentary on Kehinde et al. (2021).
- (Shaw et al., 2022) Towards a Neurodiversity-Affirmative Approach for an Over-Represented and Under-Recognised Population: Autistic Adults in Outpatient Psychiatry

The sentiments in this document have been previously criticised by those who assert that they do not apply to 'severely' autistic people.

- (Escher, 2017) The Complacency Monster that Ate Autism
- (Lutz, 2013) Is the Neurodiversity Movement Misrepresenting Autism?
- (Costandi, 2019) Against Neurodiversity
- (Singer et al., 2022) A full semantic toolbox is essential for autism research and practice to thrive
- (Mottron, 2021) A radical change in our autism research strategy is needed: Back to prototypes

Having more challenges does not make one any more or less autistic:

- (Bilokonsky, 2022a) How to Talk about Autism Respectfully
- (S. K. Kapp, 2023) Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs

'Replacing Pathologizing Language' table was informed by:

- (Bottema-Beutel et al., 2020) Avoiding Ableist Language: Suggestions for Autism Researchers
- (Monk et al., 2022) The use of language in autism research.
- Autism New Zealand terminology guide <https://autismnz.org.nz/autism-new-zealand-terminology-guide/>
- (Gernsbacher et al., 2016) "Special needs" is an ineffective euphemism

'AAC user':

- How to talk about AAC <https://www.assistiveware.com/blog/how-to-talk-about-aac>

'Clarifying some terms' list was informed by:

- (Walker, 2014) Neurodiversity: Some Basic Terms & Definitions

It may sometimes be necessary to use the language of the diagnostic manuals so include a caveat when doing so:

- (Bulluss & Sesterka, 2020) Reframing Professional Language Around Autism in Practice "Openly explaining the reasons for (and hesitations about) using medicalized or deficit-based language, can assist in reducing self-stigma, developing positive self-concept, and promoting positive mental health and well-being."

Outdated theories and their challenges:

- (Gray-Hammond & Adkin, 2022) Creating Autistic Suffering: Professionals, why don't they know?

Autistic people lack Theory of Mind:

- (Baron-Cohen, 2000) Theory of mind and autism: A review
- (Yergeau, 2013) Clinically Significant Disturbance: On Theorists Who Theorize Theory of Mind

Outdated theory: Autistic people lack empathy

- (Fennell & Johnson, 2021) Examination of professional biases about autism: how can we do better?
- (Gray-Hammond & Adkin, 2022) Creating Autistic Suffering: Professionals, why don't they know?

Outdated theory: Autistic people lack social motivation

- (Fennell & Johnson, 2021) Examination of professional biases about autism: how can we do better?
- (Camus, Jones, et al., 2022) Autistic traits and psychosocial predictors of depressive symptoms PREPRINT
- (Gray-Hammond, 2022b) The New Normal. Autistic musings on the threat of a broken society.
"I am not asocial, I am Autistically social. I am Ausocial."

Re 'autistic-led theories'; The importance of listening to autistic perspectives:

- (Keating et al., 2022) Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation
"Relevant governments and organizations should update their policy documentation (e.g., the Autism Research Briefing from the UK Parliament, Autism Information from the U.S. Department of Health and Human Services etc.) to be in line with the preferences of the autistic community, thus encouraging appropriate language use amongst researchers, clinicians, and society more broadly."
- The American Psychological Association:
<https://www.apa.org/pubs/authors/equity-diversity-inclusin-toolkit-journal-editors.pdf>
"Community-driven guidelines, or those developed by members of historically excluded communities, are useful for providing participant-led guidance on inclusive and bias-free language in specific topic areas."
- (Pellicano & den Houting, 2021) Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science
- Milton et al., 2019) A critical reflection on the development of the Participatory Autism Research Collective (PARC)
- (Gillespie-Lynch et al., 2017) Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts
- (Grant & Kara, 2021) Considering the Autistic advantage in qualitative research: the strengths of Autistic researchers
- (Yergeau, 2018) Authoring autism. On rhetoric and neurological queerness

Double Empathy Problem

- (Damian E M Milton, 2012) On the ontological status of autism: the 'double empathy problem'
- (Crompton, Ropar, et al., 2020) Autistic peer-to-peer information transfer is highly effective

- (Williams et al., 2021) Mutual (Mis)understanding: Reframing Autistic Pragmatic “Impairments” Using Relevance Theory
- (Gray-Hammond & Adkin, 2022) Creating Autistic Suffering: Professionals, why don't they know?
- (Camus, Rajendran, et al., 2022) Social self-efficacy and mental well-being in autistic adults - exploring the role of social identity and the Double Empathy Problem PREPRINT

Monotropism

- (Dinah Murray et al., 2005) Attention, monotropism and the diagnostic criteria for autism
- (F. Murray, 2019) Me and Monotropism: A unified theory of autism
- (Lesser & Murray, 2020) Mind as a Dynamical System - Implications for autism

Autistic traits that are not deficits:

Stimming:

- (S. K. Kapp et al., 2019) 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming
- (Walker, 2021) Neuroqueer Heresies. Notes on the Neurodiversity Paradigm, Autistic Empowerment, and Postnormal Possibilities
- (Dinah Murray, 2020) Dimensions of Difference

Passionate interests are a valid way to relate to the world.

- (Dinah Murray, 2020) Dimensions of Difference
- (Russell et al., 2019) Mapping the Autistic Advantage from the Accounts of Adults Diagnosed with Autism: A Qualitative Study

Avoiding eye contact can help to listen and engage.

- (Trevisan et al., 2017) How do adults and teens with self-declared Autism Spectrum Disorder experience eye contact? A qualitative analysis of first-hand accounts
- (Forbes, 2021) I'm not looking at you

Echolalia (repeating words) and scripting (repeating scripts) are often a way to make sense of things, engage, communicate and connect.

- (Cole, 2021) Neuroqueering interpersonal communication theory: listening to autistic object-orientations

Playing in ways that seem unusual (for example, lining up toys) is fine, it's still play!

- (Rosa, 2020) Do you want to play?: A children's book on autistic play written by autistics

Research is finding there are traits that are being described by autistic people as being central to autistic experience, but that are not yet included in the diagnostic manuals... part of their autistic experience:

- (Ratto et al., 2022) Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits
- (D Murray et al., 2022) The Human Spectrum: A Phenomenological Enquiry within Neurodiversity
- (Dinah Murray et al., 2005) Attention, monotropism and the diagnostic criteria for autism

Masking:

- (Pearson & Rose, 2021) A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice
- (Radulski, 2022) Conceptualising Autistic Masking, Camouflaging, and Neurotypical Privilege: Towards a Minority Group Model of Neurodiversity
- (Hull et al., 2017) “Putting on My Best Normal”: Social Camouflaging in Adults with Autism Spectrum Conditions

Burnout:

- (Ratto et al., 2022) Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits
- (D Murray et al., 2022) The Human Spectrum: A Phenomenological Enquiry within Neurodiversity
- (Pearson & Rose, 2021) A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice

Autistic people often go unrecognised until they reach a point of distress:

- (J. Davies, 2022) Sedated. How Modern Capitalism Created our Mental Health Crisis.
- (D. Gray-Hammond, 2021). Why requiring Autistic people to be diagnosed is a betrayal of the Neurodiversity movement.
- (Bervoet & Hens, 2020) Going Beyond the Catch-22 of Autism Diagnosis and Research. The Moral Implications of (Not) Asking “What Is Autism?”
- (Rose, K, 2021). Autistic masking and stigma, with Kieran Rose.

Uncanny valley:

- (McConnell, 2023) Stuck in the Uncanny Valley

You can signpost people to these sites to learn about what autism is:

A website written by an autistic person for supporting neurodivergent people and others:

- (Bilokonsky, 2022b) Public Neurodiversity Support Center

A downloadable letter for parents to send to their autistic child's support network:

- (Heyworth & Marsh, 2022b) Neurodiversity-affirming language: A letter to your family, friends and support network

Suicide rates for autistic people and the effects of misdiagnosis

- (Autistica, 2021) Autism Community Priorities for Suicide Prevention, an International Society for Autism Research Policy Brief, April 2021
- (Takara et al., 2015) How and Why is Autism Spectrum Disorder Misdiagnosed in Adult Patients? - From Diagnostic Problem to Management for Adjustment
- (Dell'Osso & Carpita, 2022) What misdiagnoses do women with autism spectrum disorder receive in the DSM-5?

If you would like more information:

Autistic community preferences, by The Autistic Collaboration:

- (Bettin, 2022) A communal definition of Autistic ways of being

A letter to professionals working with autistic children, by Reframing Autism:

- (Heyworth & Marsh, 2022a) Neurodiversity-affirming language: (for professionals) A letter to your family, friends and support network

A paper on avoiding ableist language:

- (Bottema-Beutel et al., 2020) Avoiding Ableist Language: Suggestions for Autism Researchers

Explaining how to talk about autism AND WHY:

- (Bilokosky, 2022a) How to Talk about Autism Respectfully

Shifting away from medical framings towards neurodiversity framings:

- (Pellicano & den Houting, 2021) Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science

Supplementary research and articles that informed the creation of the guide...

The language we use is powerful and important:

- (Natri et al., 2023) Anti-ableist language is fully compatible with high-quality autism research: Response to Singer et al (2023)
- (L. Brown, 2021) Ableism/Language
- (Hayes et al., 2020) Drawing a line in the sand: affect and testimony in autism assessment teams in the UK
- (Heilker & Yergeau, 2011) Autism and Rhetoric
- (Walker, 2013) Throw Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm
- (McGuire, 2016) War on autism. On the cultural logic of normative violence

Towards neurodiversity framings:

- (Angulo-Jiménez & DeThorne, 2019) Narratives About Autism: An Analysis of YouTube Videos by Individuals Who Self-Identify as Autistic
- (Bettin, 2021) From pseudo-philosophical psychiatrists to openly Autistic culture
- (H. Brown et al., 2021) Changing the story: How diagnosticians can support a neurodiversity perspective from the start
- (Craine, 2020) Changing Paradigms: The Emergence of the Autism/Neurodiversity Manifesto
- (Dwyer, 2022) The Neurodiversity Approach(es): What Are They and What Do They Mean for Researchers
- (Nicolaidis, 2012) What Can Physicians Learn from the Neurodiversity Movement?
- (Schwartz, 2019) Neurodivergence. Therapy Reimagined.
- (Shaw et al., 2022) Towards a Neurodiversity-Affirmative Approach for an Over-Represented and Under-Recognised Population: Autistic Adults in Outpatient Psychiatry.
- (Leadbitter et al., 2021) Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice
- (Mueller, 2020) From neuronormativity to neurodiversity: changing perspectives on autism

How a medical professional chooses to talk about autism and how they frame diagnostic language makes an impact on how autism is perceived by the public:

- (Robison, 2019) Talking about autism – thoughts for researchers
“Professionals turn to the DSM and ICD as the standard nosology. It is easy to assume their language is the language to be used in your own work. Ten years ago, that was true. Today, it is a bit more nuanced because increasing numbers of affected individuals dislike the word “disorder” when they perceive it as applied to themselves”
- (Abbott et al., 2013) Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences
- (Anderberg & South, 2021) Predicting Parent Reactions at Diagnostic Disclosure Sessions for Autism
- (Brogan & Knussen, 2003) The Disclosure of a Diagnosis of an Autistic Spectrum Disorder Determinants of Satisfaction in a Sample of Scottish Parents
- (Brower, 2021) Professional Stigma of Mental Health Issues: Physicians Are Both the Cause and Solution.
- (Crane et al., 2018) Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals.
- (Grinker, 2007) Unstrange Minds. Remapping the World of Autism