

Autism Terminology Guidance From the Autistic Community of Aotearoa New Zealand

A Living Resource Created by Autistic People With the Support of Autism New Zealand



We are inviting Autistic artists of all ages to have their illustrations featured in this terminology resource.

Illustrations may relate to:



- Autistic Terminology
- Autistic Experiences
 - Autistic Identity
 - Neurodiversity



Koha will be offered to artists whose illustrations are included in this resource. All Autistic artists who submit illustrations will go in the draw to win a \$100 voucher.

If you are Autistic or if you know an Autistic person who would be interested in submitting an illustration for this resource, please get in touch with Autism New Zealand at research@autismnz.org.nz for information.

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Autism Terminology Guidance From the Autistic Community of Aotearoa New Zealand

Terminology is a powerful tool. Terminology can help change attitudes towards autism and Autistic people. Terminology has an important role in empowering and supporting Autistic people in Aotearoa New Zealand.

There are many different preferences in the Autistic community (Autistic people) and autism community (including family, whānau and wider support networks) for describing autism and Autistic people.

The preferences of the Aotearoa New Zealand Autistic community should be held central to all things autism. Any debate about preferred terminology should only be held within the Autistic community itself.

The terminology used for autism should always be informed by the preferences of the Autistic community, and the terms used for Autistic individuals should respect that person's own terminology preferences.

Development and Updating of This Autism Terminology Resource

Autistic people in Aotearoa New Zealand have developed this resource with the support of Autism New Zealand and the ongoing feedback from members of the Autism New Zealand Community Advisory Group.

The feedback provided by Autistic Advisors at Altogether Autism, ASK Trust, Te Pou Disability, and members of the New Zealand Autistic community has also played a vital role in developing this resource.

As this resource represents a living document, it will continue to be updated to remain consistent with the autism terminology preferences of the Autistic community of Aotearoa New Zealand.

Feedback on this resource is welcome from all members of the Autistic and wider autism communities.

The incorporation of suggestions from the community for additional terminology or modifications of the current content will be determined by Autistic people, consistent with the development of this resource.

Please direct any comments or suggestions for improving this resource to Autism New Zealand (research@autismnz.org.nz) to share with the Autistic creators and their Community Advisory Group.

Te Ao Māori Resource

We are currently liaising with Māori to develop our Māori autism resource.

This document incorporates Te Ao Māori and knowledge of tikanga Māori as passed on from our ancestors before us. We look forward to this evolving and being shared soon.

In the meantime, we would like to thank all of you who are currently contributing to this development.

How to Use This Autism Terminology Resource

This resource was created and reviewed by members of the Autistic community of Aotearoa New Zealand to reflect the terminology and language preferences of the Autistic community of Aotearoa New Zealand.

Some Autistic people may have different terminology preferences for describing their experience of autism. It is important to respect the terminology and language preferences of the Autistic individual themselves.

Preferred, Acceptable, and Potentially Acceptable Terminology

Within the Autistic community there are many acceptable terms for describing autism and Autistic people. Some terms may be strongly and widely preferred in the Autistic community, and others not as much.

The terminology described as **preferred** is recommended as the default for talking about autism and the Autistic community. It is also appropriate to use the terminology described as **acceptable** in most situations.

The terminology described as **potentially acceptable** may not be appropriate for or supported by some Autistic people. It is best to ask the Autistic person for their own preferences before using these terms.

Replace and Reject, Reframe, and Rethink Autism Terminology

Some potentially offensive terms and concepts are largely agreed upon by the Autistic community. Other terms and concepts may not be as unanimous or may represent emerging opportunities for empowerment.

Some potentially offensive terms may be disempowering and misleading. It is recommended to **reject** these misleading terms and **replace** them with terminology that is preferred by the wider Autistic community.

Some potentially offensive terms may reinforce inaccurate stereotypes about autism and Autistic people. It is recommended to reject these terms and **reframe** the understanding of autism and autistic experiences.

Some potentially offensive terms may represent emerging opportunities to **rethink** the use of language in a way that empowers and supports Autistic people and the neurodivergent and disabled communities.

Additional Sources of Information About Autism Terminology

There is a wealth of information about autism terminology available online. It is always best to seek out the perspectives of the Autistic community themselves, such as via Autistic-led platforms and social media.

It is impossible to reference all of the readings, articles, and correspondence related to this resource. However, a selection of readings and journal articles from the Autistic and autism communities are included.

Please note that some of these links may use non-preferred language. These may reflect the terminology used historically or in scientific publications, or may reflect the different preferences of Autistic individuals.

Frequently Asked Questions About Autism Terminology

How can non-autistic people promote Autistic-preferred terminology and positively impact the community?

The key to being a good ally is to ensure that Autistic people are always at the centre of all things autism.

Autistic people are becoming increasingly acknowledged as the experts on autism and Autistic experiences.

The wider autism community plays an important role in changing attitudes towards autism and Autistic people by promoting Autistic-preferred language and encouraging others to seek out Autistic perspectives.

It is important not just to adopt and respect the terminology preferences of Autistic people and the Autistic community but to take the time to understand the meaning and impact of these preferences.

Making a positive impact in the community involves using and understanding Autistic-preferred terminology and, most importantly, listening to Autistic voices no matter how they prefer to communicate.

Why has the preferred terminology for autism changed over time?

The predominant terminology used for autism and other disabilities may appear dynamic and evolving.

In many cases, the shift in the terminology used to describe autism and Autistic people is reflective of the increased recognition and adoption of the terminology the Autistic community has advocated for for years.

For example, Autistic advocate Jim Sinclair published in support of using identity-first language in 1999.

In some cases, the use of potentially offensive language had been encouraged and was thought (primarily by non-disabled people) to be less stigmatising and disempowering than disabled-preferred terminology.

For example, many healthcare and education professionals were encouraged to use person-first language to describe Autistic people, which was picked up and repeated by parents and carers of Autistic people.

In some cases, autism terminology has evolved more recently. It continues to evolve as new opportunities to empower Autistic people through using terms and concepts that better reflect Autistic experiences.

What terminology should be used for Autistic children?

The preferred terminology recommended by the Autistic community should be used for all Autistic people unless that Autistic individual (of any age) has indicated a preference for alternative terminology.

Many people in the Autistic community are empowered by identifying with Autistic-preferred terminology.

It is important to provide Autistic children with the opportunity to identify with the terminology preferred by most people in the Autistic community when they are deciding on their own language preferences.

What if an Autistic person has a different terminology preference than the Autistic community?

Terminology preferences can be highly individual. There is no one set of terms that every single Autistic person prefers. An Autistic person's language preferences should not be viewed as right or wrong.

The terminology an Autistic person would like used to refer to themselves and their autism should always be respected, even if they are different to the preferences of the majority of the Autistic community.

For example, if an individual prefers that their own experience of autism be referred to as them being a person with autism rather than an Autistic person, they should be referred to as a person with autism.

However, the differing preferences of the minority of Autistic people must not be used to justify ignoring the preferences shared by the majority of the Autistic community when talking about autism.

For example, even if a particular individual prefers to be referred to as a person with autism rather than an Autistic person, the term Autistic person should still be used as the default term for other Autistic people.

What should someone do if they use the wrong terminology?

If you use non-preferred terms, make a mistake, or are corrected by an Autistic person, that is okay. The best thing to do is to apologise and make an extra effort to use more accepted terminology in future.

Most Autistic people understand that Autistic-preferred terminology may be new to some people and might even contradict what has been encouraged historically in many healthcare and education settings.

The most important things when talking about autism are to be respectful and show a willingness to learn. Please do not avoid talking about autism or to Autistic people because you are unsure about terminology.

Many Autistic people are happy to share the reasons for their terminology preferences. However, it is respectful to check that the Autistic person is comfortable discussing these, as it may be a triggering topic.

Are there any situations where it is suitable to use non-preferred terminology?

It is important only to use non-preferred or potentially offensive terminology if it is absolutely necessary.

For example, in some clinical or educational settings, non-preferred terminology may need to be used in order to access supports for the Autistic person, such as providing proof of diagnosis.

If non-preferred or potentially offensive terminology is required, all efforts should be made to minimise the use and impact of this by explaining the need to use this terminology and reinforcing preferred terminology.

Have we missed an important question and answer?

Please send any question-and-answer suggestions to Autism New Zealand (research@autismnz.org.nz).

Instead of	Consider using
Autism Spectrum Disorder (ASD)	Autism
Person with autism	Autistic
Suffers from autism	Is Autistic
Asperger's syndrome	(Asperger's is) Autism
Autism symptoms	Autistic characteristics
At risk of autism	May be Autistic
Normal person	Allistic (non-autistic)
Co-morbidity	Co-occurring
Non-verbal autism	Is non-speaking

Reframe Understanding of Autism and Autistic Experiences

Instead of	Consider using
High/low functioning, severe/mild autism	Describe specific support needs
Quantifying autism on a linear spectrum	Describe strengths and challenges
Someone does not look/act autistic	Consideration of Autistic masking
Behaviour challenges/problems	Describe expressions of distress
Autism cure, treatment, or intervention	Focus supports on Autistic wellbeing

Rethink How to Empower and Support Autistic People

Instead of	Consider using
Special needs, learning impairment	Neurodivergent
Mental age	Actual age
Superpower, twice-exceptional	Strengths and support needs
Restricted interests, obsessions	Specialised/focused/intense interests
Pathological demand avoidance (PDA)	Pervasive drive for autonomy (PDA)
Autistic children (referring to the Autistic population)	Autistic people
Autistic people and their families, carers and whānau (referring to Autistic perspectives and experiences)	Autistic people supported by their families, carers, and whānau (and those who make up their support network)
Autism parent or ASD parent	Parent of an Autistic person
Puzzle piece symbol	Infinity loop neurodiversity symbol

Potentially offensive terminology

Autism Spectrum Disorder (ASD)

Terminology preferred by the Autistic community

Preferred: Potentially acceptable:

Autism Spectrum

Autistic Autism Spectrum Conditions (ASC)

Autism Spectrum Neurotype (ASN)

Contexts where the use of offensive terminology may be appropriate

It may be necessary to use DMS-V terms (e.g., ASD) in settings where diagnostic terminology is required (e.g., some clinical settings, accessing support services and programmes).

If diagnostic terminology is required, try to use "identified as being on the autism spectrum" or "identified as Autistic" instead of "diagnosed ASD" to reflect autism as a neurotype.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The use of 'disorder' in ASD can reinforce the negative stereotype that autism is fundamentally something wrong or in need of curing.

Many Autistic people prefer to use autism either alone or in 'autism spectrum' instead of ASD.

Autism spectrum conditions (ASC) is preferable to ASD, but most Autistic people prefer just autism.

Where spectrum terms are used, this should be consistent with the Autistic-preferred <u>colour wheel autism spectrum model</u>. Spectrum terms should not be used to divide autism into categories (e.g., based on perceived functioning or severity or level).

Readings and research from the Autistic and autism communities

Introduction to Autism: What Is Autism?

Neurodiversity (What Is It and Why Do We Care?)

The Autistic Not Weird Autism Survey

11,512 People Answered This Autism Survey. Warning: The Results May Challenge You

What Terms Should Be Used to Describe Autism? Perspectives From the UK Autism Community

Exploring an E-learning Community's Response to the Language and Terminology Use in Autism From Two Massive Open Online Courses on Autism Education and Technology Use

Potentially offensive terminology

Person with autism/ASD

Person who has autism/ASD

Autism/ASD person

Terminology preferred by the Autistic community

Preferred: Potentially acceptable:

Autistic People on the autism spectrum

Autistic person People within the autism spectrum

Autistic people Autie or Autist

Contexts where the use of offensive terminology may be appropriate

The Autistic community largely prefers for identity-first language as the default for Autistic people.

The preferences of individual Autistic people should always be respected.

If an Autistic person would like to be referred to using language that differs from most Autistic people, use the individual's preferences.

If an Autistic person has a preference that differs from the majority, this does not justify ignoring the preferences of the majority when referring to other Autistic people.

Readings and research from the Autistic and autism communities

Articles on Identity-First Language

Why I Dislike Person-First Language

I Am Autistic With a Capital A

"It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer?

Editorial Perspective: The Use of Person-First Language in Scholarly Writing May Accentuate Stigma

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The Autistic community primarily prefers identity-first language (e.g., I am Autistic, they are Autistic) as this emphasises that autism is inseparable from the person, influences the way they experience the world, and is an integral part of the Autistic person's identity.

Many Autistic people use identity-first language for autism to reflect this Autistic identity as they would describe other aspects of their identity (e.g., ethnicity, gender, religion, and sexuality).

The 'A' in Autistic is often capitalised when referring to Autistic people and the Autistic community to reflect being Autistic as an identity, similar to the capitalisation of the 'D' in Deaf signifying Deaf culture.

The Autistic community largely rejects person-first autism language (e.g., person with/who has autism) because it implies that autism can be separated from the person and does not acknowledge that being Autistic is a core part of that person's identity.

While non-autistic people often use person-first language to show that autism does not define the person, Autistic people argue that using Autistic does not imply that autism is the only thing that defines them but instead acknowledges autism as a core part of their identity.

Although the term people on the autism spectrum may be preferable to traditional person-first language, some Autistic people reject these terms as they still represent person-first language.

Where these spectrum terms are used, this should be consistent with the Autistic-preferred <u>colour wheel autism spectrum model</u> and should not be used to divide autism into categories or imply that autism exists on a continuum from less to more autistic.

Some Autistic people may refer to themselves as an Autie or Autist. It is best to ask the Autistic person themselves before using these, and use identity-first language (e.g., Autistic) as the default.

Potentially offensive terminology

Suffers from autism

Is a victim of autism

Is afflicted by autism

Is living with autism

Terminology preferred by the Autistic community		
Preferred:	Potentially acceptable:	
Is Autistic	Is on the autism spectrum	
	Is within the autism spectrum	

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to describe an Autistic person as suffering from autism, a victim of autism or afflicted by autism as autism is not an illness.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Describing Autistic people as suffering from autism and being victims of autism reinforces the harmful narrative that autism is a tragedy.

The term living with autism implies that autism is a burden to the Autistic person themselves and to those around them.

Readings and research from the Autistic and autism communities

A Mum Describes Her Child's Severe Autism from Two Very Different Perspectives

Throw Away the Master's Tools: Liberating Ourselves From the Pathology Paradigm

Don't Mourn for Us

Potentially offensive terminology

Asperger's syndrome

Asperger's disorder

Asperger's is distinct from autism

Asperger's is a mild form of autism

Terminology preferred by the Autistic community

Preferred: Potentially acceptable:

Autism Asperger's

Autistic Aspie

Asperger's is autism

Contexts where the use of offensive terminology may be appropriate

The diagnosis of Asperger's was removed from the DSM-5 in 2013 and encompassed under the diagnosis of Autism Spectrum Disorder.

The difference between Asperger's and autism in the DSM-IV was the requirement for a language delay in autism and not Asperger's.

Those who met the diagnostic criteria for Asperger's meet the DSM-5 Autism Spectrum Disorder criteria.

The DSM-5 recommends updating the diagnosis of those diagnosed with Asperger's to Autism Spectrum Disorder to reflect this change.

Some people diagnosed with Asperger's under the DSM-IV may not have this diagnosis formally updated.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The use of Asperger's remains a contentious issue within the Autistic community (which includes people diagnosed with Asperger's).

Recent links between Hans Asperger's and the Nazi party have further discouraged the use of Asperger's within the Autistic community.

Most Autistic people agree that Asperger's is not distinct from autism.

The majority of people who identify as Asperger's or Aspie also identify as being Autistic.

The Autistic community in general does not support the use of Asperger's by those who are not diagnosed with Asperger's, as this reinforces the harmful idea that Asperger's is not part of autism.

Some Autistic people diagnosed with Asperger's reject this term in favour of exclusively using autism.

It is not appropriate to assume that an Autistic person was diagnosed with Asperger's or would have been diagnosed with it previously.

Unless an Autistic individual indicates a personal preference for using Asperger's (or Aspie), the terms autism and Autistic should be used.

Readings and research from the Autistic and autism communities

'Coming Out' with Autism: Identity in People With an Asperger's Diagnosis After DSM-5

Considering Nomenclature for Autism – Aligning With the Language Preferences of the Autistic Community

Potentially offensive terminology

Autism symptoms

Autism abnormalities

Autism impairments

Triad (or dyad) of impairments

Terminology preferred by the Autistic community

Preferred:

Autistic experiences

Autistic characteristics

Potentially acceptable:

Autistic traits

Contexts where the use of offensive terminology may be appropriate

It is not appropriate to refer to autism using medical/disease terminology.

In clinical settings, it is more appropriate to use "is Autistic" or "meets the diagnostic criteria for autism" instead of autism symptoms.

Readings and research from the Autistic and autism communities

About Autism

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Most Autistic people do not support the medical deficit-focused models of autism that unnecessarily pathologise the characteristics, experiences, and personality traits of Autistic people as deficient.

Referring to autism and autism diagnostic criteria using deficit-based terminology (e.g., symptoms) stigmatises autistic expression as abnormal or different from what is considered socially acceptable.

Different societal and cultural factors can further influence how an Autistic person and those around them experience their autism.

It is important to recognise the extensive diversity of Autistic characteristics and experiences, particularly in populations where Autistic people are misdiagnosed or are identified Autistic later in life.

Potentially offensive terminology

At risk of autism

May develop autism

May become autistic

Terminology preferred by the Autistic community

Acceptable:

May be Autistic

Likely to be Autistic

Potentially acceptable:

Displaying early features of autism

Increased likelihood of being Autistic

Displaying Autistic characteristics

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to use at risk of autism as it suggests autism can be caught or acquired (rather than being neurodevelopmental).

Where autism can accompany an inherited condition (e.g., Fragile X syndrome), it is suitable to indicate that the person may have an increased likelihood of being Autistic.

It may be appropriate to describe someone with autistic characteristics as displaying autistic characteristics or as likely to be Autistic.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The term at risk is misleading as it implies that autism can be prevented in individuals who may not yet have a diagnosis.

For young children who may be in the early stages of assessment, it is more appropriate to use displays autistic traits or is likely to be Autistic than it is to use deficit-focused language like at risk of autism.

Due to the inaccessibility of diagnosis to many adults (e.g., financial reasons, stigma, availability of qualified diagnosticians, lack of support for Autistic adults), the Autistic community largely accepts those who self-identify as Autistic as part of the Autistic community.

Readings and research from the Autistic and autism communities

Attitudes of the Autism Community to Early Autism Research

Potentially offensive terminology

Normal person

Healthy person

Normal behaviour

Normal traits/characteristics

Terminology preferred by the Autistic community

Preferred: Acceptable:

Allistic Neurotypical (if not neurodivergent)

Non-autistic
Not autistic

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to use normal or healthy to refer to non-autistic people or traits as Autistic people are not abnormal or unhealthy.

In clinical settings, development may be described as delayed or atypical, although this is not the terminology preferred by Autistic people.

Readings and research from the Autistic and autism communities

<u>Autistic, Allistic, Neurodiverse, and Neurotypical: Say What?</u>

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Using the normal to describe non-autistic people and traits implies that being Autistic (or displaying autistic characteristics) is abnormal.

Allistic is a term created by Autistic people to describe those who are not autistic. Allistic is an empowering term for Autistic people as it reframes autism as being a difference, and not a deficit or pathology.

Not everyone in the wider community is aware of the term allistic. Using allistic instead of (or alongside) not autistic or non-autistic increases the awareness, understanding, and use of the term allistic.

While neurotypical is often used to describe those who are not autistic, not all non-autistic people are neurotypical.

The term neurotypical is only appropriate for non-autistic people who are not neurodivergent in other ways (e.g., like Autistic people, allistic people with ADHD are neurodivergent, thus also not neurotypical).

Potentially offensive terminology

Co-morbidity

Multiple illnesses

Terminology preferred by the Autistic community

Preferred:

Co-occurring conditions

Co-existing conditions

Multiply neurodivergent

Potentially acceptable:

Diagnosed with multiple conditions

Contexts where the use of offensive terminology may be appropriate

It is not appropriate to describe the co-occurrence of autism and any other condition, neurological or otherwise, as a co-morbidity.

Readings and research from the Autistic and autism communities

Co-Occurring Conditions and Autism

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The term co-morbid is unnecessarily pathologising of autism.

It is important to use the terms co-occurring or multiply neurodivergent when referring to Autistic individuals who are neurodivergent in additional ways (e.g., ADHD).

Co-occurring conditions (medical, neurological, or mental health-related) can intertwine with autism to create additional challenges.

It is essential to acknowledge that these conditions are not just part of autism or being Autistic and should be recognised as their own conditions, even if they do influence a person's experience of autism.

Potentially offensive terminology

Non-verbal

Non-verbal autism

Partially verbal

Does not communicate

Terminology preferred by the Autistic community

Preferred:
Describe specific communication
(e.g., AAC user,

uses sign language)

Acceptable:
Non-speaking
Partially speaking
Limited speaker

Potentially acceptable:

Non-vocal

Unreliable speaker

Contexts where the use of offensive terminology may be appropriate

In a clinical setting, communication differences may be specified in addition to an autism diagnosis.

Customise terminology to the Autistic individual's specific communication (e.g., an Autistic person who uses a mixture of spoken language and AAC, communicates using sign language).

It should be acknowledged that communication methods are often fluid and can change with time and in different situations or environments.

All Autistic people communicate and under no circumstances should be said to be non-communicative.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The term non-verbal disregards verbal forms of communication outside of traditional speech (e.g., using mouth words).

It is preferable to describe a person's specific methods of communication, rather than exclusively focusing on the communication methods that they do not use or prefer.

The use of AAC, sign language, or other non-spoken communication methods (full-time or part-time) is not a failure to communicate.

It is inappropriate to assume that an individual who communicates using non-spoken methods does not understand spoken language.

Using AAC and non-spoken communication does not necessarily mean that the Autistic person has a learning (intellectual) disability.

Some Autistic people experience situational (or selective) mutism, and some may experience chronic or episodic catatonia that can temporarily impact their communication and physical capacity.

Readings and research from the Autistic and autism communities

On Using NonSpeaking, Minimally Speaking, or Unreliably Speaking Over "Non-Verbal": NonSpeakers Weigh In Including Speaking and Nonspeaking Autistic Voice in Research

Potentially offensive terminology

High/low functioning autism

Mild autism/severe/profound autism

Verbal autism and non-verbal autism

At the low/high end of the spectrum

Terminology preferred by the Autistic community

Preferred:

Is Autistic

State specific support needs for that Autistic person or group

Potentially acceptable:
Less obvious support needs
Lower/higher support needs

Complex support needs

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to use functioning or severity labels to describe Autistic people.

Where possible, an Autistic person's support needs should be described in as much detail as possible.

In some clinical settings, a DSM-5 support need level in the social communication domain and in the repetitive movements and restricted interests domain may be required.

Some Autistic people may have higher or more complex support needs due to co-occurring medical or developmental conditions.

It may be appropriate to specify if autism is accompanied by a learning (intellectual) disability or is associated with a genetic condition.

It is important not to use generalised support needs terminology as substitutes for functioning or severity labels, or to indicate the presence of a learning (intellectual) disability.

It is important to recognise that a person's support needs may be fluid over time and across different situations or environments.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The Autistic community rejects the use of labels that divide the autism spectrum into sub-groups (e.g., functioning labels, severity levels).

Functioning and severity labels are often reflective of how non-autistic people experience an Autistic person's autism, and not necessarily how that Autistic person experiences their autism.

Using mild autism and high functioning autism dismisses the very real challenges faced by Autistic people and can deny necessary support.

Using severe autism and low functioning autism dismisses the strengths of Autistic people and can deny them autonomy.

The Autistic community takes a strengths-based approach to describe how Autistic people all experience autism differently and all Autistic people have a range of strengths and skills alongside their challenges.

The strengths, challenges and support needs of Autistic individuals can change over time and in different situations and environments.

The challenges an Autistic person may experience can reflect areas where they may need support and accessibility adjustments.

Support needs should be described as specifically as possible to indicate the domain or domains an Autistic person or people require support in (e.g., communication support, support with motor skills).

Readings and research from the Autistic and autism communities

The Fallacy of Functioning Labels

The Problems With Functioning Labels

The Misnomer of 'High Functioning Autism': Intelligence Is an Imprecise Predictor of Functional Abilities at Diagnosis

Potentially offensive terminology

Autism is a linear spectrum

Some people are a little Autistic
and others are very Autistic

Everybody is on the spectrum

Terminology preferred by the Autistic community

Autism is a non-linear, non-binary, and complex spectrum that represents and encompasses a diverse range of Autistic experiences.

Non-autistic people are not a little Autistic or on the autism spectrum.

Contexts where the use of offensive terminology may be appropriate

It is inappropriate and inaccurate to quantify a person's autism.

In settings where describing Autistic people is difficult at the individual level (e.g., research studies), it may be acceptable to group individuals based on a similar support need(s).

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The experiences and diversity of the Autistic community cannot be reduced to a simple linear spectrum, nor can they be quantified.

The colour wheel autism spectrum model is widely supported by the Autistic community and increasingly by the wider autism community.

This colour wheel autism spectrum model emphasises the range of strengths, skills, challenges, and potential areas where someone may require support as being unique for each Autistic individual.

Readings and research from the Autistic and autism communities

<u>Understanding the Spectrum – A Comic Strip Explanation</u>

Introduction to Autism: The Autism Spectrum Is Not Linear

The Autism Spectrum Is Not Binary

"Autism is a Spectrum" Doesn't Mean What You Think

What is Autism? The Spectrum Doesn't Mean What You Think It Means

Potentially offensive terminology

Appears less Autistic

Does not look (or act) Autistic

Is not obviously Autistic

Has overcome autism

Terminology preferred by the Autistic community

Preferred: Acceptable:

Is Autistic Masking

Camouflaging

Mimicking

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to suggest that an Autistic person does not look or act Autistic or that they appear less Autistic than another Autistic person or group of Autistic people.

These terms can be akin to using functioning labels and can stigmatise and stereotype those who do not or cannot mask their autism as more Autistic than those who do mask.

Readings and research from the Autistic and autism communities

A Conceptual Analysis of Autistic Masking Understanding the Narrative of Stigma and the Illusion of Choice

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Autistic people do not all look, act, or experience autism identically.

Some Autistic people mask consciously or subconsciously mask or camouflage their autistic characteristics in different situations.

Autistic masking can often result from the exclusion, discrimination, and stigma that Autistic people may experience if they do not appear to fit in with non-autistic people (e.g., supressing stimming in public).

Masking is especially common in marginalised Autistic people including those assigned female at birth, members of the LGBTQIA+ community, indigenous communities, and people of colour.

Regardless of whether the masking is intentional or unintentional, masking can be incredibly stressful and tiring for Autistic people and can be a major contributor to Autistic burnout.

Chronic masking may be a contributing factor to the late-diagnosis and mis-diagnosis of Autistic people, especially in those who were assigned female at birth and those with marginalised ethnicities. However, late-diagnosis and mis-diagnosis can also be due to inequities in healthcare, systemic discrimination, and stereotyping.

Potentially offensive terminology

Problem/challenging behaviours

Behaviour problems/challenges

Tantrums/acting out

Naughty/non-compliant

Terminology preferred by the Autistic community

Preferred:

Describe specific experiences (e.g., sensory overload, burnout)

Describe specifically what is happening (e.g., meltdown, shutdown, stimming)

Acceptable:

Expressions of distress

Contexts where the use of offensive terminology may be appropriate

It is best to describe an Autistic person's specific experiences (e.g., sensory overload) and the impact (e.g., meltdown) it has on them.

It is most appropriate to focus on the support needs of the Autistic person.

For example, an Autistic person who has their sensory needs met may be less likely to experience the sensory overload that can lead to meltdowns and other expressions of distress.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Describing autistic experiences as problems or behaviours dismisses expressions of distress and attempts to communicate distress as naughty, deliberate, and in need of correction.

Autistic expressions of distress (e.g., meltdowns, shutdowns, burnout) are not engaged in deliberately by the Autistic person.

Expression of distress can often result from sensory overload, prolonged masking, and difficulty coping with sudden changes.

Unmet support needs often underly behaviours that challenge others, highlighting meeting an Autistic person's support needs as important for the wellbeing of the Autistic person and their support network.

Readings and research from the Autistic and autism communities

Meltdowns and Shutdowns and Burnouts, Oh My!

 $\underline{\textbf{A Guide to Understanding, Developing, and Applying \#Reasonable} \textbf{Accommodations for Autistic People}$

What Interests Young Autistic Children? An Exploratory Study of Object Exploration and Repetitive Behavior

Potentially offensive terminology

Cure

Treatment

Intervention

Autism therapy

Terminology preferred by the Autistic community

Preferred:

Specific supports or services (e.g., occupational therapy)

Adjustments, modifications, and accessibility requirements

Potentially acceptable:

Support program

Support therapy

Accommodations

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to use cure, treatment or intervention as these suggest that autism is something that needs to be fixed or abolished.

Treatments and therapies should never be targeted at autism as being Autistic does not need modification.

Many Autistic people do benefit from supports. It is best to describe these at the individual level and specifically.

For example, an Autistic person may benefit from speech and language services that support the use of AAC.

In some cases, an Autistic person may receive treatment or therapy for cooccurring medical, neurological, or mental health challenges.

It is very important that the terms support and service are not just used as substitutions for cure, treatment and interventions when the aim is to modify the persons autism itself.

Readings and research from the Autistic and autism communities

For Whose Benefit? Evidence, Ethics, and Effectiveness of Autism Interventions

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Autistic people advocate that autism does not need to be cured, treated or modified, as there is nothing wrong with being Autistic.

Autistic people can benefit from supports and services that are not targeted at autism itself but instead are focused on supporting Autistic people to live their lives as authentically Autistic.

The terms support and service, especially in relation to specific supports or services, can be used to describe approaches that are designed to improve the quality of life of Autistic people without aiming to modify the persons autism and autistic characteristics.

The terms intervention, treatment and cure suggest that autism is an undesirable medical condition, such as a cancer or illness.

Although intervention is commonly used in relation to autism by clinicians and educators, the Autistic community largely rejects early interventions that seek to normalise an Autistic person's characteristics or development relative to their peers.

The Autistic community does not believe that Autistic people, particularly young children, need to be engaged with services and supports simply for being Autistic in order to live their best lives.

Many Autistic people advocate that early supports for Autistic people should focus on educating families, carers and whānau about autism and how they can support their Autistic loved one to be themselves.

For example, some Autistic people may have communication and/or sensory needs that can benefit the Autistic person's wellbeing if they have access to supports that help the Autistic person and their families, carers and whānau meet their needs as early as possible.

Adjustments is preferred to describe modifications to social and environmental factors that aim to provide equity, as many people dislike the subjectivity of the term reasonable accommodations.

Potentially offensive terminology

Special needs

Learning impairment

Neurological impairment

Hidden disability

Terminology preferred by the Autistic community		
Preferred:	Acceptable:	Potentially acceptable:
Neurodivergent	Disability	Invisible disability
	Learning differences	

Contexts where the use of offensive terminology may be appropriate

Many with neurodevelopmental and learning differences will identify as neurodivergent and/or as disabled.

In some clinical and educational settings, non-preferred terminology may be required for the acquisition of necessary learning supports or in the context of diagnosis reports.

It is inappropriate to use euphemisms to describe disability and disabled people as they can be condescending, disempowering, and stigmatise being disabled as a negative thing.

Readings and research from the Autistic and autism communities

Neurodiversity Terms and Definitions

Neurodiversity Insider's Perspective

<u>"Special needs" is an Ineffective</u> <u>Euphemism</u>

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Neurodiversity, a term that reflects the diversity of human minds in a population, describes neurological variability as neurotypes.

Neurodivergent people are those who experience at least one minority neurotype (e.g., autism, ADHD, dyslexia, dyspraxia/DCD, dyscalculia, dysgraphia, tic disorders, sensory processing disorder).

Neurodivergence can also include those who experience mental health conditions, acquire neurodivergence (e.g., following brain injury), have a foetal alcohol spectrum disorder, have genetic neurodevelopmental conditions, or have a learning disability.

Some neurodivergent people dislike hidden disability as it can imply that disabilities that may not be immediately obvious to others are being hidden (or should be hidden) by those experiencing them.

Many people with specific learning differences (e.g., dyslexia and dyscalculia) prefer to use the term differences over disempowering terms such as impairments or disorders.

The term special needs can stigmatise the accessibility requirements and adjustments needed for disabled people as a special treatment, rather than recognising that many of the different needs of disabled people are linked to non-inclusive societal and environmental factors.

The needs of disabled people are not special because they are different to those of non-disabled people as all humans have needs.

Potentially offensive terminology

Mental age

Childlike

Cannot learn

Will not develop

Terminology preferred by the Autistic community			
Preferred: Actual age (chronological)	Acceptable: Learning disability (if applicable)	Potentially acceptable: Intellectual disability Developmental delay	

Contexts where the use of offensive terminology may be appropriate

It is never appropriate to refer to an individual as any age other than their chronological age.

In some clinical and educational settings, it may be necessary to describe developmental differences relative to that person's peers.

For a person who may be on a different developmental trajectory than their peers, it may be appropriate to indicate if the person has a learning (intellectual) disability.

Developmental delays can be fluid over time and do not indicate that a person is incapable of learning.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The Autistic community does not support referring to Autistic (or disabled) people as having a mental age different to their actual age.

For example, it is inappropriate to describe a sixteen-year-old as mentally six years old, as that person is both mentally sixteen years old and chronologically sixteen years old.

Describing an Autistic person as mentally a different age than their chronological age is infantilising and patronising towards that person.

Attributing a lower mental age than chronological age to an Autistic person contradicts the need to presume competence in all people.

Describing an Autistic person as having childlike or age-inappropriate interests can lead to that Autistic person being treated like a child.

While some Autistic people may be interested in traditionally childlike things, that does not mean that that individual is incapable of having interests or hobbies reflective of their similarly aged peers.

Readings and research from the Autistic and autism communities

Mental Age Theory Hurts People With Intellectual Disabilities

No One Knows Your Autistic Child's Future

Why Use the Words Learning Disability Instead of Intellectual Disability

Potentially offensive terminology

Superpower

Twice exceptional (2e)

Gifted

Terminology preferred by the Autistic community

Describe the Autistic person's strengths and talents without dismissing or belittling their challenges and possible support needs.

Contexts where the use of offensive terminology may be appropriate

How an Autistic person describes their own experience of autism should always be respected.

Some Autistic people do describe their autism as a superpower or identify with twice exceptional, but this does not necessarily mean that these individuals do not experience challenges or require supports.

Readings and research from the Autistic and autism communities

Mapping the Autistic Advantage From the Accounts of Adults Diagnosed With Autism: A Qualitative Study

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Autistic people can view the terms superpower, twice exceptional, and gifted as functioning labels that inappropriately group Autistic people into those seen to benefit from autism and those who do not.

Many Autistic people dislike their autism being described as a superpower as it dismisses the challenges they may experience and be used to deny them access to social and environmental supports.

The Autistic community advocate that Autistic people can be proud of their Autistic identity and being Autistic without having to dismiss their challenges or need for support.

While often used in education settings to describe neurodivergent people with above average academic achievement, the terms twice exceptional and gifted can stigmatise and marginalise neurodivergent people who are not perceived to fit these terms.

Many neurodivergent people also reject neurotypical measures of intelligence as these measures rarely accommodate the learning and assessment needs of those with communication differences.

Potentially offensive terminology

Restricted interests

Repetitive interests

Obsessions

Terminology preferred by the Autistic community

Acceptable:

Interests, passions, hobbies, specialisation

Specialised interests, focused interests, preferred interests, or intense interests

Potentially acceptable:
Special interests

Contexts where the use of offensive terminology may be appropriate

The diagnostic criteria for autism describe the presence of restricted areas of intense interest.

In some clinical settings, it may be necessary to use this diagnostic terminology to describe the presence of intense interests in Autistic people.

It is important to acknowledge that the number and duration of intense interests vary between Autistic individuals and over time.

The individual preferences of Autistic people should always be respected, and many Autistic people do use and related to the term special interests if it is not used in a patronising way.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Many Autistic people find the diagnostic terminology to describe specialised interests unnecessarily pathological and patronising.

The term special interests may be infantilising to some and imply that a person's interests or areas of expertise are atypical or abnormal.

Many terms used to describe an Autistic person's interests, passions and hobbies do not acknowledge the extensive knowledge the Autistic person may have about that particular topic or topics.

Autistic people may also describe their interests using language common to all people (e.g., favourite hobbies, interests, passions).

Readings and research from the Autistic and autism communities

What's So Special About a Special Interest?

<u>Characterization and Utilization of Preferred Interests: A Survey of</u>
Adults on the Autism Spectrum

Potentially offensive terminology

Pathological Demand Avoidance (PDA)

Terminology preferred by the Autistic community

Acceptable:

Pervasive/Persistent Drive for Autonomy

Demand avoidant (profile of autism)

Extreme demand avoidance (EDA)

Potentially acceptable:

PDAer

PDA profile

Contexts where the use of offensive terminology may be appropriate

PDA is not yet included as a diagnosis or an autism profile in the diagnostic manuals used in New Zealand.

This extreme demand avoidance profile is increasingly recognised by clinicians, support services, and educators as a profile of autism.

As a newer term, the priority for many Autistic PDAers is increasing PDA awareness and understanding and improving supports for PDAers.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The word pathological can stigmatise peoples experiences of extreme demand avoidance as irrational, abnormal, and exaggerative.

It is inaccurate to equate PDA to oppositional defiant disorder (ODD).

As a relatively new term in public spaces, many Autistic people who identify with PDA will describe themselves as a PDAer, or as fitting the demand avoidant profile of autism, or having a PDA profile.

Many PDAers prefer PDA used on its own, or as an acronym for more empowering terms like Pervasive (or Persistent) Driven Autonomist.

Some Autistic people with this profile may use demand avoidant Autistic or extreme demand avoidance instead of PDA/pathological.

Readings and research from the Autistic and autism communities

Changing the Name PDA

Reframing PDA: The Power of an Autistic Perspective

"Pathological Demand Avoidance" or Needing to Be Free?

Emerging Neurodivergent Identities: A Lesson On Pathological Demand Avoidance From Kristy Forbes

Potentially offensive terminology

Autistic children

Children with autism

(referring to the Autistic population, which includes people of all ages)

Terminology preferred by the Autistic community

Preferred:

Autistic

Autistic people

Autistic children and adults

Potentially acceptable:

People on the autism spectrum

Children and adults on the autism spectrum

Contexts where the use of offensive terminology may be appropriate

When referring to Autistic people in general, it is important to recognise that many Autistic people are adults.

It is appropriate to use Autistic child or Autistic children when specifically referring to Autistic children, and to refer to Autistic young people, Autistic adults, older Autistic people, or another age bracket if the context relates to that specific group.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Autistic people are Autistic throughout their entire lifespan, regardless of what age they were diagnosed or their current age.

The focus on children when referring to autism and Autistic people reinforces the incorrect stereotype that autism only impacts a person during childhood and dismisses Autistic people who are now adults.

Readings and research from the Autistic and autism communities

<u>Supporting Self-efficacy and Self-determination on the Autism</u> <u>Spectrum: Refuting the "Autism Can Be Outgrown" Myth</u>

Potentially offensive terminology

Autistic people and their families, carers and whānau

(referring to viewpoints, perspectives, and experiences of Autistic people or of the Autistic community)

Terminology preferred by the Autistic community

Preferred:

Autistic people supported by their families, carers, and whānau

Autistic people and those who make up their support network

Contexts where the use of offensive terminology may be appropriate

It is important to always presume competence in Autistic people and provide Autistic people with agency (autonomy, with support).

The support network of Autistic people should not be used as a substitute to including Autistic people themselves (e.g., in advisory roles).

It is appropriate to include and refer to family, carers, and whānau of Autistic people when talking about the wider autism community.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

Families, carers and whānau can and do play a very important role in an Autistic person's life, wellbeing, and access to support.

However, all Autistic people have their own identity and should not be excluded from making decisions about their own lives.

Many Autistic people can self-advocate for their own needs, either independently or with the support of their support network.

Exclusively referring to Autistic people alongside their support network implies that Autistic people are not able to self-advocate.

Using the voices of those who make up an Autistic person's support network as a substitute for the Autistic person fails to presume competence and does not give the Autistic person with agency.

Readings and research from the Autistic and autism communities

3 Steps to Encourage Independence & Self-Advocacy for Autistic Children

Supported Decision-Making: Why the Right to Make Choices With Support Matters

Ethics and Autism: Where Is the Autistic Voice?

<u>Collaboration Strategies in Nontraditional Community-Based Participatory Research Partnerships: Lessons From an Academic–Community Partnership With Autistic Self-Advocates</u>

Potentially offensive terminology

Autism parent/carer/family

ASD parent/carer/family

Special needs parent/carer/family

Terminology preferred by the Autistic community

Preferred:

Parent/family of an Autistic/neurodivergent/disabled person

Autistic parent/family of an Autistic person (if they are also Autistic)

Neurodiverse family, or neurodivergent family (if all are Autistic)

Contexts where the use of offensive terminology may be appropriate

It is not appropriate for parents or carers to adopt the Autistic identity of their Autistic person for themselves.

If the parent or family member is not Autistic, it is appropriate for them to describe themselves as a parent or family member of an Autistic person.

If the parent or family member is also Autistic, it is appropriate for them to describe themselves as an Autistic parent or family of an Autistic person.

Families with at least one person who is neurodivergent could describe themselves as a neurodiverse family.

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The Autistic community discourages non-autistic people from assuming the identity of their Autistic loved one as their own identity.

It is important to centralise the needs and experiences of the Autistic person themselves in autism advocacy and seeking support services.

Non-autistic parents or family members do not have lived experience of being Autistic, although they can have lived experience of supporting and caring for someone who is Autistic.

An Autistic parent or family member is someone who is both Autistic themselves and a parent or family member of another person.

An Autistic parent or family member of an Autistic person can have lived experience of being Autistic and of caring for an Autistic person.

An Autistic family is a family where every member is Autistic. A family with both Autistic and non-autistic members is neurodiverse.

Readings and research from the Autistic and autism communities

The Language of Identity, or "I Am Not an Autism Parent"

An Open Letter to Parents of Autistic Children

What Happens When Parents Listen to Autistic Adults?

How My Parents Handled My Autism and How They Set a Good Example

Potentially offensive terminology

Puzzle piece as an autism symbol
Puzzle piece ribbons for autism
Blue as the colour for autism

Terminology preferred by the Autistic community

Acceptable:

Rainbow infinity loop (neurodiversity)

Red or gold infinity loop (autism)

Contexts where the use of offensive terminology may be appropriate

It is not appropriate to use the puzzle piece as a symbol for autism or to represent the Autistic community.

While some Autistic people may not mind the puzzle piece symbol, the use of the puzzle piece by organisations and groups that directly harm Autistic people makes it inappropriate to use.

If an Autistic person uses the puzzle piece to represent their own autism, it is important not to use this as justification to use the puzzle piece for autism or other Autistic people.

Readings and research from the Autistic and autism communities

<u>The Ableist History of the Puzzle Piece</u> Symbol for Autism

<u>Do Autism Puzzle Piece Logos Evoke</u> Negative Associations?

Insight and perspectives from the Autistic community regarding potentially offensive and Autistic-preferred terminology

The Autistic community largely rejects the puzzle piece as a symbol for autism, often preferring the neurodiversity-based infinity loop.

The puzzle piece symbol was created without the Autistic community to represent autism as a puzzling condition that children suffer from.

The puzzle piece symbol also implies that Autistic people have something wrong or missing from them, and that autism and Autistic people represent a problem that needs to be solved.

The colourful puzzle piece ribbon was intended to depict the complexity of autism. However, it reinforced harmful misconceptions of autism as being a disease and the need to find a cure for autism.

The use of primary colours with the puzzle piece symbol also reinforces the misconception of autism only existing in children.

The use of blue as the colour for autism was intended to represent the disproportionate diagnosis of autism in males, further marginalising Autistic women and gender diverse people.

Many Autistic people prefer to use the neurodiversity infinity loop to represent the inclusivity and diversity of the Autistic community.

As the traditional rainbow spectrum colouring of the infinity loop is representative of neurodiversity, some Autistic people may use a gold or red infinity loop as a more specific symbol of autism.

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Ruth is Autistic and a member of the Autism New Zealand Community Advisory Group. With the support of Autism New Zealand, they collaborated with the Aotearoa New Zealand Autistic community to compile and write this autism terminology resource.

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