Guide

National Autistic Society | Neuroinclusive Education Network

Terminology Guide: Why Words Matter



This resource has been co-produced with a group of neurodivergent young people.

Their voice is embedded throughout the document.

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Contents

Introduction	3
Autism is a Difference	5
The Autism Spectrum	8
The Medical Model of Disability: Language	10
The Social Model of Disability: Language	11
The Impact of Language	12
Terms Used at the Neuroinclusive Education Network	20
Key Takeaways	21
Acknowledgements and References	22
Further Reading	23
Appendix 1 - Glossary of Terms	24
Appendix 2 - Co-production Boards	36

Introduction

In a world where autistic people face many barriers, it is crucial we make a conscious effort to talk about autism in a positive way.

Language is a powerful means for shaping how people view and think about autism. It can have a huge impact on the way we behave towards and support autistic people.

Video: Autism Re-explained:
Why is Language so Important when talking about Autism?



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Introduction

A lack of understanding of autism can have a significant impact on autistic people leading to feeling the need to mask their autism which can result in 'shutdowns', 'meltdowns' or 'autistic fatigue/burnout'. (See Appendix 1 for further information on these terms).

The Neuroinclusive Education Network promotes and embeds positive attitudes towards neurodiversity. One way to do this is to model the language we would like to see being used. As a result, we hope to create long-lasting culture change and achieve our vision of a world where all autistic children and young people experience a positive education that supports wellbeing.

'Remember that words are powerful. Using the right words is respectful to people and helps show others how to be respectful too'.

(NHS England, Making Information and the Words we use Accessible).



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Autism as a Difference

The Neuroinclusive Education Network approaches autism as a different way of being rather than as a 'deficient' or 'disordered' way of being. Differences should be valued and embraced and being different is something to be celebrated.

Autism is a difference not deficit. Differences are to be valued not 'fixed'. My normal is different from your normal and the aim shouldn't be conformity but well-being.

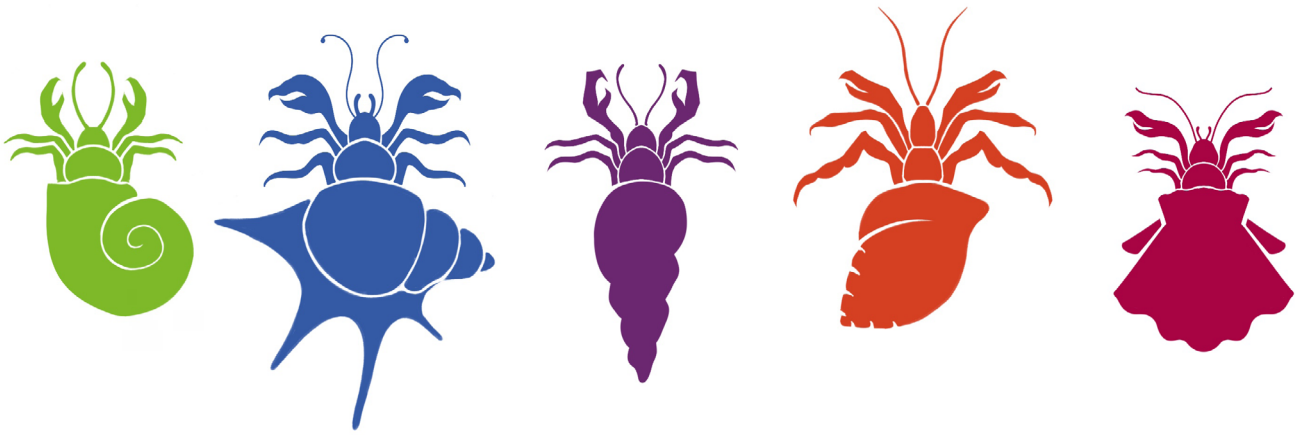
(Autistic Young Expert)

'Life is a river and everyone is stuck in the same storm working out how to live life but autistic people have different boats of different shapes and sizes etc and we all deserve a seat at the table!'

(Meg, Autistic Young Expert)

UNIQUE CRABS CHOOSE UNIQUE SHELLS

We choose our shells to adapt, and grow. No shell is better or worse, only unique.



Created by Matt, Autistic Young Expert

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Autism as a Difference

Autism is a processing difference that can have an impact on many areas of a person's life. Autistic people often experience differences in these three areas:

The Three Areas of Difference



Social Understanding and Communication



Flexibility, Information Processing and Understanding



Sensory Processing and Integration

There is no 'typical' autistic person. Every autistic individual has their own strengths, differences and needs, their own life journey, experiences and their own unique story.

Sometimes I see people in the media talking positively of autism and it makes me proud mostly. I get hope that I am perhaps not a societal failure and may well deserve to amount to something equally like others

(Annabel, Autistic Young Expert).

It is a collection of traits and everyone on the spectrum will struggle with communication at different levels, processing information, executive functioning and sensory differences.

(Alice, Autistic Young Expert).

People should not be judged for being **different** and it is important to talk about autism in a **positive way** to ensure that autistic people are **included** not excluded.

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Autism as a Difference

Video: What is Autism?



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The Autism Spectrum

While autistic people may share some similar characteristics, they are all different from one another. This is because autism is considered a spectrum. The autism spectrum is not linear from low to high but varies in every way that one person might vary from another.

With many different traits defining what autism is for an individual, we should avoid using 'high/low functioning' and instead think of how these traits can fluctuate depending on circumstances.

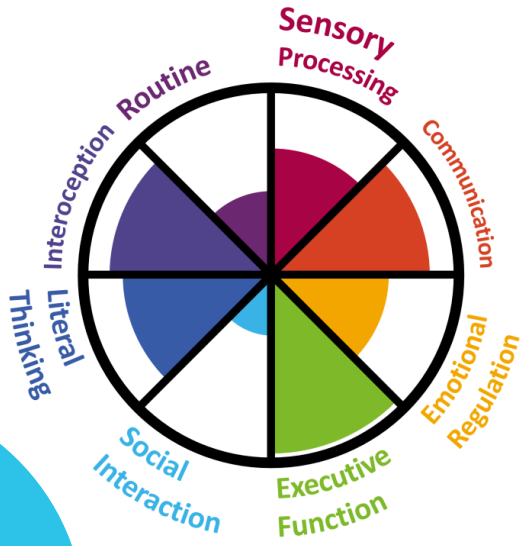
The autism spectrum is not linear



less autistic more autistic

Created by Jaye, Autistic Young Expert

The autism spectrum looks more like



'A multi-layered, non-linear, interconnecting relationship of different attributes/traits'

(Annabel, Autistic Young Expert).

'It's colourful and it paints the world in a different way - every individual on the spectrum has their own picture, or experience, of life'

(Saffron, Autistic Young Expert).

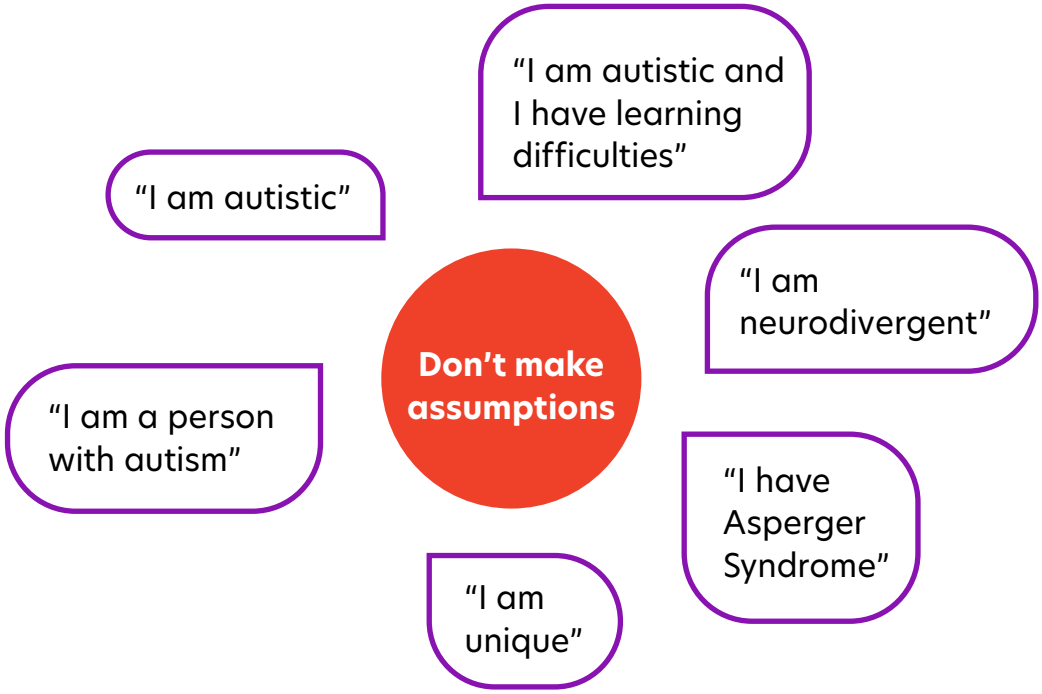
'A representation of how diverse people are and how differently individuals can experience life in accordance to the structure of this world/society'

(Autistic Young Expert).

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The Autism Spectrum

When you meet an autistic person, they might say ***"I am on the spectrum"*** but autistic people could also describe themselves by saying:



People have different preferences when it comes to how they like to describe themselves and autism, so it is always best to ask the individual or someone that knows them well what their preference is as well as what they do not like.

'For me talking positively about autism is not necessarily talking 'about autism', but rather taking the time to learn about me/ (others) and how to support me or reasonable adjustments (some of which are associated with autism) as an individual so I am able to access things without a massive deal around it'

(Autistic Young Expert).

Video: Autism Insights: Why Language Matters - Ollie's lived Experience



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The Medical Model of Disability

The medical model looks at autism as a set of deficits or impairments. Under the medical model, these impairments or differences should be 'fixed' or changed by medical and other treatments, even when the impairment or difference does not cause pain or illness. The medical model looks at what is 'wrong' with the person, instead of what that person needs.

There have been many different terms used to describe autism using this model, some of which are still in use today and all of which have been used as diagnostic labels to describe different autistic profiles.



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The Social Model of Disability

The social model underpins the concept of **neurodiversity** and looks at how we can **accommodate** autistic people in society.

The social model identifies **systemic barriers** as being:

- The physical environment.
- People's attitudes.
- The way people communicate.
- How institutions and organisations are run.
- How society discriminates against those of us who are perceived as '**different**'.

The Autistic Young Experts highlighted that the above descriptions oversimplify these models, and we need to show more of the nuances of the two models.

Watch the video to hear the panel discuss the ongoing debate between the Social and the Medical Model of Disability.

Video: Autism Re-explained: Social vs Medical Model of Disability



The Impact of Language

There is often an assumption that autistic people need to behave and live like neurotypical people. Many autistic people take exception to this assumption and the fact that a lot of early literature on autism uses medical terms such as '**deficit**', '**disorder**', and '**intervention**'.



They argue that such terms are both inaccurate and stigmatising and based on an incorrect notion of what a 'typical' person is.

They argue that such perceptions can further disable autistic people and, if internalised, can lead to crises in self-identity, self-esteem and self-worth. On the other hand, there are others that argue that they are severely impaired and want to retain the term 'disorder' to explain their experience. In recognition of this debate, much of the literature now just refers to 'autism' or 'autism spectrum' and not 'autism spectrum disorder/condition'.

'When I hear stigmatising language used to describe something that is so integral to my identity, I come to understand my Autism as something that is wrong. I'm a sensitive soul, so I internalise this "brokenness" and it is reinforced each time I encounter this language. I've sometimes resented my Autism, and since my Autism is intrinsic to who I am, there are times when I've even hated myself. I battle with low self-esteem and anxiety, and likely everyone blames my Autism rather than the language society uses to describe it, the language that became my inner voice'.

(Emma Ward, Autistic advocate)

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The Impact of Language

The Autistic Young Experts shared some of their experiences of people using both positive and negative language to describe autism and/or autistic people.

Positive language the AYE have encountered	How it made you feel and/ or the impact it had
"Creative"	"Empowered" "Confident" "Empowered, but important to recognise that not all autistic people identify with being creative as we're all different."
"Unique"	"Valued and celebrated for being my true self, however it's important to emphasise that everyone is unique, not just autistic people" "Good because autism is unique and every autistic person is different"
"Different"	"Fine because autism is a difference" "Fine, I am quite happy to be different" "Neutral" "Good about myself and authentic, I am different. I wouldn't change being different and I love when people validate that (especially after years of masking and trying to 'fit in')"
"Different wiring system"	"Good because I find this language the best way to describe it to people" "A bit like a computer, but I can rock being a robot" "A somewhat useful analogy for describing differences between neurodivergent and neurotypical people, but does feel a bit cold and dehumanised"

The Impact of Language

The Autistic Young Experts' experience of people talking positively about autism:

'It's great and makes me feel happy and proud to have autism'.

(Ryan, Autistic Young Expert)



The Impact of Language

Negative language the AYE have encountered	How it made you feel and/ or the impact it had
"Everyone is a little bit autistic"	"Completely invalidates the experiences and struggles of autistic people and it is not accurate." "Annoyed, as you either have autism or you don't" "It is rude, and ignores the experiences of autistic people in a way of diminishing it." "This is super bad, I've had so many teachers tell me this and it makes me feel like they're telling me to 'get over it' or that I'm overreacting - it just tells me that they're ignorant"
"Cold"	"All of the bottom 3 are comments that reinforce the subconscious need to mask, they are hurtful and label us as 'bad' or 'wrong' for being our autistic selves.", "Misunderstood - clearly have made assumptions about me" "Reinforces the incorrect stereotype that autistic people have no empathy"
"Selfish"	"Very annoyed, as I do care for others", "Very frustrated, I often end up ignoring/suppressing my own needs for the benefit of others"
"Too sensitive"	"I can't really help my feelings, but I do rationalise and I usually need someone to reassure me that I have misunderstood something" "This is very rude - it not only ignores someone's needs but also might force an autistic person to ignore their own needs and suffer through it" "This is very dismissive and just downright mean, my needs are different to yours and there is no such thing as being 'too sensitive' either"

The Impact of Language

Negative language the AYE have encountered	How it made you feel and/ or the impact it had
"Disabled"	"I'm neutral, as I don't see this as negative, but society has made it so. Depends on other people" "I am happy with this word as it takes into account the difficulties that I have" "I don't like the word as it means not working. "I use this term to describe myself. It's a nuanced and neutral term. Sometimes I need support and accommodations and I want that to be recognised"

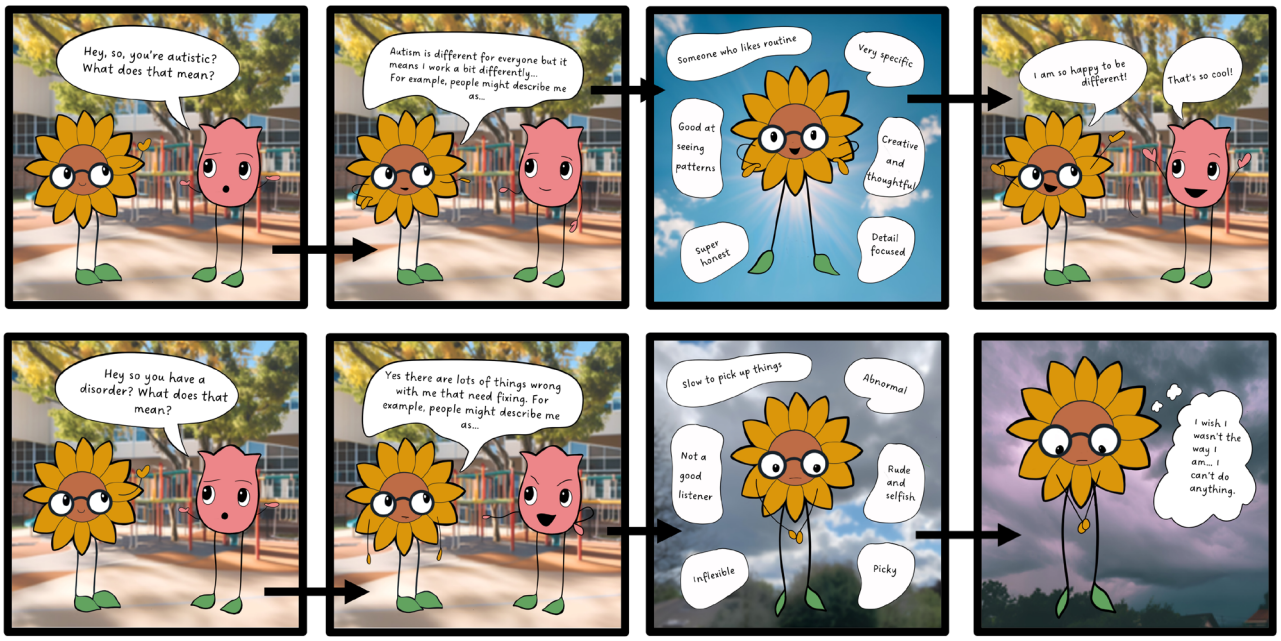
The term 'disabled' created a lot of discussion within the group and not all panel members agreed that this was a negative term.

We should avoid using terms such as 'problems', 'issues', and 'impairments' and instead focus on **language that empowers** and focuses on an individual's **strengths** and **differences**. At the NEN, we describe the level/type of support a person may require.

"In the inclusive classroom, the teacher not only sets up physical opportunities for all students to look included, but the teacher makes students feel included through his/her choice of words and phrases".

(Nicole Eredics, The Inclusive Class)

The Impact of Language



Created by Saffron, Autistic Young Expert

The Autistic Young Experts' experience of people talking negatively about autism:

'It happens often. E.g. only last week my driving instructor said "You need to tell him everything that's wrong with you" or I hear my parents telling me I'm "too sensitive" again. Or someone can't interpret that I'm trying and express things differently and calls me "cold" and "selfish". Naturally, it doesn't feel good. It makes me feel as though this society is entirely incompatible with autism'.

(Saffron, Autistic Young Expert)

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The Impact of Language

Below are some examples of how negative language can easily be replaced with positive language and as a result will have a huge impact on the situation and the individual.

AVOID	REPLACE WITH
"Due to Adam's disorder and his sensory issues, he has problems with being in large groups. He will likely end up lashing out if he is put in these situations for too long".	"Adam has sensory differences and sometimes finds it difficult to be in large groups. We are supporting Adam with this by ensuring he only spends a maximum of ten minutes, at a time, in large groups, with the aim of gradually building on this time".
"Naryan is severely impaired in her gross motor skills, due to her diagnosis of autism spectrum disorder, and is unable to use a knife and fork. This is becoming a problem as she gets frustrated with herself, and she has not made any progress with this lately".	"Naryan has a diagnosis of autism and needs additional support with using cutlery at lunchtime to ensure that she experiences success in this area. Staff are supporting her to first use a spoon and once she has had success with this, they will introduce a knife and fork".

The Impact of Language

AVOID	REPLACE WITH
"Xavier needs to be prompted to make eye contact and reminded that it is rude not to make eye contact when speaking to other people".	"Xavier may find eye contact uncomfortable due to their differences in social understanding and communication, and in auditory processing. Xavier finds talking alongside another activity, such as a walk or drawing, helps them to listen and understand".
"Rebecca has issues in mixing with other pupils. She interrupts when the other children are talking, and she wants to take control of the discussion".	"Rebecca and other children in the class have differences in the way that they communicate. As a result, they don't always understand each other. Rebecca feels like the others don't always give her an opportunity to participate and so she will give her opinion. On the other hand, some of the other children think she is trying to deliberately talk over them, even though this is not her intention".

Terms Used at the Neuroinclusive Education Network

There are specific terms we use frequently at the NEN to talk about autism in a positive way. We believe these terms should be used widely to help **promote and embed equality, diversity** and **inclusion**. Please see Appendix 1.

The Autistic Young Experts discussed each of these terms and a table captures a summary of their insights. To view each member's individual contribution, please see the additional co-production document in Appendix 2.



Key Takeaways

1. Describing autism in a way that it can be easily understood by those who are not autistic can be difficult. This is because there is no single way of experiencing autism and so capturing how it feels to be autistic can be challenging.

2. Language preferences vary from person to person so get to know the individual and ask them what they prefer.

3. It is essential to listen to and value what autistic people say about their experiences. This is why the NEN ensures that its resources are co-produced with autistic young people and their families.

4. The language used to describe a topic affects how people treat the topic. For inclusion to be successful, we need to focus on viewing and talking about autism in a positive way and from a strengths-based approach.

5. Describe 'areas of support' and 'reasonable adjustments'. For example, changing the environment to support the individual rather than trying to change the individual to fit into the environment.

6. Always remember the impact that language can have on another person. Consistently using inclusive language can help promote and embed equality, diversity and inclusion.

Acknowledgements and References

The NEN gives special thanks to the Autistic Young Experts Panel for all of their contributions in the form of quotes, infographics, images and video. Thanks also to Simon Keating of Bitesize films for capturing the video content in this guide.

The NEN would also like to thank the following for permission to reproduce copyright material:

Marsh, E (2022) *Neurodiversity Affirming Language: A Letter to Your Family, Friends and Support Network.* Reframing Autism. https://reframingautism.org.au/neurodiversity-affirming-language-a-letter-to-your-family-friends-and-support-network/

SPECTRUM Centre for Independent Living CIC, (2018) *Sticks and Stones: The Language of Disability* (Spectrum Centre for Independent Living): https://spectrumcil.co.uk/wp-content/uploads/2018/02/ULO19-The-Language-of-Disability.pdf



Further Reading

The Significance of Semantics: Person-First Language: Why It Matters - Autistic Hoya

The Use of Language in Autism Research: Science Direct.

What is neurodiversity? An editorial by Simon Baron-Cohen in Scientific American (2019)

Which terms should be used to describe autism? Perspectives from the autism community written by Lorcan Kenny and other researchers in Autism (2015)

The Social Model of Disability:Inclusion London.

Sticks and Stones: the Language of Disability: Centre for Independent Living CIC.

Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research

Disfigured: On Fairy Tales, Disability and Making Space, by Amanda Leduc.



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Appendix 1

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Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Autistic child/ pupil/learner	Research shows that there is no single way of describing autism that is universally acceptable. We consulted our Autistic Young Experts and the term that they would like the AET to consistently use is 'Autistic child/pupil/learner'. They preferred this phrase over 'child/pupil/learner with autism'. https://www.autism.org.uk/contact-us/media-enquiries/how-to-talk-and-write-about-autism	**AYE Panel:** Most panel members agree that 'identity first' language is preferred because they see it as an integral part of who they are. However, some were indifferent and believe it should be down to the individual. Some preferred 'with autism' due to them feeling that autism does not define them. The conclusion was that the NEN would continue to use 'identity first' but the panel members were in agreement that you should always ask individuals how they feel about specific language as it varies person to person.
Anxious non-attender	An 'anxious non-attender' is the term used for a child or young person experiencing persistent absences due to 'Emotional School Based Avoidance' (EBSA). This is when attendance difficulties arise from experiencing high levels of anxiety at school. https://www.lincolnshire.gov.uk/support-education/emotional-based-school-avoidance-ebsa#:~:text=There%20are%20a%20number%20of,relationship%20difficulties%20or%20academic%20demands	**AYE Panel:** Overall, the panel preferred this term over 'school refuser' because 'school refuser' sounds negative as though the child is trying to be difficult or behaving in a certain way on purpose, where really they are lacking support to access the environment. However, some panel members believed that 'distressed non-attender' is more all encompassing as the young person may not always be experiencing anxiety.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Autistic burnout	The term 'autistic burnout' is used increasingly by autistic people, but there is very little research or practical advice on the subject. It is important to note that it is not a clinically recognised or defined condition. More research is needed to better understand autistic burnout and to support autistic people in managing and preventing it. https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue	**AYE Panel:** There needs to be more distinction between fatigue and burnout - they are seen as different things. For many autistic people, daily tasks can take up a lot more energy for them.
Autistic fatigue	The term 'autistic fatigue' refers to the mental and physical exhaustion that autistic children, young people and adults experience when 'sensory overload' has occurred for a prolonged period of time. https://www.autism.org.uk/advice-and-guidance/mental-health/autistic-fatigue	**AYE Panel:** There is very mixed opinions on this term. Many thought the term 'fatigue' isn't representative of the experience as it isn't like regular fatigue. Sleep can help but also, spending time on ones special interest can help. There needs to be more distinction between fatigue and burnout - they are seen as different things. For many autistic people, daily tasks can take up a lot more energy for them.
Co-production	This refers to the practice of a group of people working together on an equal basis. In the area of SEND, we use it to describe the way in which children and young people, their parents and carers, education practitioners and other involved professionals should work together in the best interests of the child or young person, who should themselves be at the centre of the process. Co-production is at the heart of SEND legislation such as the SEND Code of Practice (2015) and it is an expectation that professionals work with families to most effectively support the child or young person.	**AYE Panel:** "Because my voice and lived-experience deserves to be seen, heard and learnt from!" In schools, parents and young people are often not involved in the decision-making that affects them, when they absolutely should be. They are seen by teachers as a 'problem' to be 'solved', rather than an actual person who should have their feelings, views and experiences listened to and should have a say in any decisions made about them. The phrase 'nothing about us without us' is absolutely true in all situations and environments, including the education system.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Differences in Autistic Profile (See also Spikey profile)	Autistic people can have varying support needs. One third of autistic people also have a learning disability. The autism spectrum isn't linear and many people talk about the 'spiky profile.' This means an autistic person could be a leading expert on nuclear physics but unable to remember to brush their teeth or clean their clothes. https://www.autism.org.uk/advice-and-guidance/what-is-autism/varying-support-needs	**AYE Panel:** 'Autistic Profile' preferred over 'Profile of Autism'. Other suggestions included 'differences profile', 'strengths and differences profile', 'neurodiversity profile'. 'Profile of autism' separates the person from autism. Most panel members do not use the term 'spikey profile' and believe it to have negative connotations around it. They may relate to it but overall do not like the term. The term 'spikey' can be seen as insulting/unfriendly.
Disability	The Equality Act 2010 (section 6) says that a disability is someone who has a physical or mental impairment that has a long-term and substantial adverse effect on his or her ability to carry out normal day-to-day activities. https://www.autism.org.uk/advice-and-guidance/topics/education/resolving-differences/england/disability-discrimination	**AYE Panel:** Mostly not used by panel members because the world around them disables them (emphasis on this). Important to think of autistic individuals as 'differently abled', however with acknowledging the failures of the system to support them. They recommend checking whether individuals identify with it first as it holds a lot of stigma. The panel noted that 'disability' is a protected characteristic under the Equality Act 2010 and therefore, it can hold a lot of power.
Distressed behaviours (See also self-injurious behaviours, anxious non-attender and meltdown').	Distressed behaviours are the stress response of an autistic individual who is experiencing extreme overwhelm. This can be referred to as 'overwhelm' and 'sensory overload'. It is not a tantrum. These can be displayed as a 'fight', 'flight', 'freeze' and 'fawn' behaviours. https://www.autism.org.uk/advice-and-guidance/topics/behaviour/distressed-behaviour	**AYE Panel:** This phrase is preferred over 'challenging behaviours' because 'challenging' implies it is a problem for someone else. It may cause other people challenges, to stop the behaviours, autistic young people need to be looked after. Distress is not intentional. When behaviours are difficult it is due to not coping from not being in the right setting and this can't be expressed so it results in distressed behaviours.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Double empathy	Whilst some autistic people can struggle to process or understand the intentions of others, non autistic individuals can similarly encounter difficulties understanding the experiences and intentions of autistic individuals. This two-way breakdown is known as the 'double empathy' problem: when people with different experiences of the world interact with one another, they can find it difficult to empathise with each other. https://www.autism.org.uk/advice-and-guidance/professional-practice/double-empathy	**AYE Panel:** This term wasn't understood by all and many find it hard to understand. It was suggested that there be a comic strip illustration to show what it means. For those that did know of it, they think it is important for everyone to understand as there is a common misconception that autistic individuals lack empathy. Important to emphasise that autistic people are highly empathetic.
Enabling environment	One of the Four Themes that structure the Making Sense of Autism (MSA) and Good Autism Practice (GAP) training. 'An ethos and environment that fosters social inclusion for children and young people on the autism spectrum'. We have chosen to use the term 'enabling environment' over 'autism friendly environment' as we believe it is important for schools to be enabling and not just friendly places.	**AYE Panel:** There is very mixed opinions on these two terms. 'Autism friendly' environment seemed to be preferred by most. This was due to "enabling" sounding negative and 'friendly' sounds nicer. Many were passionate about inclusivity being part of design from the beginning as 'autism friendly' sounds like an add on.
High focused interest(s) (See also RRBIs)	Many autistic people have a highly focused level of interest in particular topics. Some special interests begin in childhood, but some are picked up later in life. These interests can vary, for example, from a TV show or game to a type of animal, a type of machine or a country. They bring autistic people much joy and can be a positive influence on the rest of their lives - helping them develop friendships, determining what they might study or focusing their career choice. https://www.autism.org.uk/advice-and-guidance/about-autism/focused-and-dedicated-interests	**AYE Panel:** Most panel members prefer the term 'special interests' but there was not a huge preference. The word 'special' encapsulates the joy they bring the autistic person.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Masking/ Camouflaging	"The term 'masking' describes how autistic people consciously or unconsciously hide their autistic characteristics, in order to fit in and feel more accepted. Masking might include: • suppressing stimming and/or natural responses to sensory sensitivities; • mirroring others' facial expressions; • changing speech or tone of voice; • using pre-planned scripts for conversations; • not sharing interests for fear of judgment. Research suggests autistic people often learn how to mask by observing, analysing and mirroring the behaviours of others. https://www.autism.org.uk/advice-and-guidance/topics/behaviour/masking	**AYE Panel:** "Masking is a very important term for me, and learning what it is and how I've been doing it subconsciously all my life was such an important step in my journey." It is also important to take into account the energy it takes to subconsciously or consciously suppress characteristics of autism. 'Masking' can also create a loss of identity.
Meltdown (See also Shutdown and Sensory Overload)	A 'meltdown' is an outward 'loss of control' where an autistic person displayed distressed behaviour due to them experiencing extreme overwhelm. These can include physical aggression and self-injurious behaviours. It is not a tantrum. https://www.autism.org.uk/advice-and-guidance/topics/behaviour/meltdowns	**AYE Panel:** Most panel members use the terms 'meltdown', 'shutdown' and 'sensory overload'. 'Sensory overload' can be the cause of a 'meltdown' or 'shutdown' but not always. 'Meltdowns' and 'sensory overload' are seen as two different things. 'Meltdowns' are not always sensory based. Some believe the term 'meltdown' has negative and childish connotations. An alternative term could be something like 'heightened overwhelm/distress', as during a 'meltdown' the person's nervous system is dysregulated and in 'fight-or-flight' mode - they are unable to control their distressed behaviour or responses, and everything feels too much and too overwhelming.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Neurodivergent	Differences which might be considered neurodivergent include being autistic, dyslexic, having ADHD, a learning disability, bipolar, brain injury, or various other diagnosable conditions or characteristics. Whilst 'neurodiversity' describes the diversity within the entire population, 'neurodivergent' describes the minority who are seen as diverging from what is considered the 'norm'. This is not the same as autistic.	**AYE Panel:** It is important to make it clear that there is more to neurodivergent than autism (including some mental health conditions). Those who have co-occurring conditions may find it useful to describe themselves using an umbrella term.
Neurodiversity	The term 'neurodiversity' describes the natural variation in the way all human brains are structured and work, a biological fact. The term can also be used as shorthand for a philosophical framework, and a social movement. There is no agreed definition of neurodiversity, and interpretations vary, but most descriptions suggest that diversity is undeniable, should be embraced, and that there is no brain type more valid than another. https://www.autism.org.uk/advice-and-guidance/identity/autism-and-neurodiversity	**AYE Panel:** The panel believe there to be a lot of mix up between this term and 'neurodivergent'. People refer to an individual as 'neurodiverse', whereas it's actually society as a whole that is 'neurodiverse'. 'Neurodiversity' is to acknowledge the diversity of ALL human brains as a collective - not as a descriptor for those of us who are not of the predominant neurotype.
Neurotypical	'Neurotypical' can be used to describe someone not displaying or characterized by autistic or other neurologically atypical patterns of thought or behaviour.	**AYE Panel:** This term is used and mostly liked. However, it is important that is is clear that 'neurodiversity' does not only include autism.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
PDA	Pathological Demand Avoidance' (PDA) or 'Demand Avoidant profile' sometimes used to describe a profile of autism. The existence of PDA as a 'diagnostic term' and how it fits within the autism spectrum is widely debated: https://www.autism.org.uk/advice-and-guidance/topics/behaviour/demand-avoidance	**AYE Panel:** Some panel members had heard of the term but think it sounds negative. In particular they dislike the term 'pathological'. The term 'Persistent Drive for Autonomy' could be used instead (still PDA), which is seen as a better description of the experience.

Restrictive and repetitive behaviours and interests (RRBIs) or Repetitive behaviour (see also stimming behaviour, high focused interests)	Repetitive behaviours and body movements (stimming):
	• such as hand flapping; hair twirling; listening to a sound on repeat;
	  • resistance to change and rigid routines that negatively affect the person's daily activities;
	• such as the same routine/journey/meals every day;
	  • restricted, intense interests:
	• such as TV characters; collecting things; specific activities or topics;
	  • these are more intense and frequent than hobbies;
	  • repetitive play in children, oriented towards objects rather than people:
	• often non-social in nature.
	• https://www.autism.org.uk/advice-and-guidance/about-autism/repeated-movements-and-behaviour-stimming
		AYE Panel: Some panel members were not familiar with this term so found it hard to identify with. Most associated the term 'restrictive' with being too negative and representative of the experience. 'Repetitive movement/behaviours' preferred by one panel member. They explained it as: "Any kind of focused, repetitive movement or action or activity, like stimming etc." Disliked due to it sounding very clinical and outdated. The phrase implies the behaviours are somehow 'bad' and something to be 'corrected'.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Self Injurious Behaviour	Self-injurious behaviour' is behaviour that results in someone causing physical harm to themselves. Types of self-injurious behaviour include: • self-biting; • scratching and pinching; • hair-pulling; • skin-picking and rubbing skin; • hitting; • head banging; • slapping. Self-injurious behaviour may lead to physical injury to the person – including cuts, bruises, and broken bones. https://www.autism.org.uk/advice-and-guidance/behaviour/self-injurious-behaviour	**AYE Panel:** Mostly seen as an accurate term but can seem quite formal.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Sensory Overload (see also Meltdown and Shutdown)	Sensory overload can happen when a person's senses become overwhelmed. Some autistic people describe sensory overload as a physical and mental response to sensory stimuli. It can lead to autistic shutdown (although is not the only cause of this). https://www.autism.org.uk/advice-and-guidance/topics/sensory-differences/sensory-differences/all-audiences	**AYE Panel:** Most use 'meltdown', 'shutdown' and 'sensory overload'. 'Sensory overload' can be the cause of a 'meltdown' or 'shutdown' but not always. 'Meltdowns' and 'sensory overload' are seen as two different things. 'Meltdowns' are not always sensory based. Some believe the term 'meltdown' has negative and childish connotations. An alternative term could be something like 'heightened overwhelm/distress', as during a 'meltdown' the person's nervous system is dysregulated and in 'fight-or-flight' mode - they are unable to control their distressed behaviour or responses, and everything feels too much and too overwhelming.
Spikey Profile (see also Differences in autistic profile)	This term is used to describe any uneven levels of functionality across cognitive profiles and skillsets. It is used to explain how an autistic person may excel in some areas and have increased support needs in others. These can change on different days and in different situations. https://www.autism.org.uk/advice-and-guidance/what-is-autism/varying-support-needs	**AYE Panel:** Most panel members do not use this term and believe it to have negative connotations around it. They may relate to it but overall do not like the term. The term 'spikey' can be seen as insulting/unfriendly.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Shutdown	"A shutdown is defined as an unavoidable partial or complete temporary withdrawal from any interaction or activity in which the person: • may not respond to communication; • may be unable to move from the situation/environment that they are in. Anyone can experience shutdowns. When someone feels overwhelmed or overloaded, it may trigger a shutdown, but reasons will be different for everyone."	**AYE Panel:** The term was not known to all members. Similar to a 'meltdown' (but not the same), an instant response to sensory overwhelm of some sort or to cope with another source of high anxiety, but instead of outwardly releasing energy, internalising hiding away from all stimuli - e.g. not speaking, dark room, not reacting to things. A 'shutdown' often happens when a 'meltdown' has reached a point where it's too much for the brain and body.
Spoons	A theory which uses the analogy of having a set number of 'spoons' to use during the day. It aims to make sense of what it feels like to have a limited amount of energy and to have to make choices to reduce burnout and fatigue. Each activity you engage in uses one of your spoons, and eventually there are no more spoons left in the drawer to replace them - you have 'used all your spoons' for that day and need to rest.	**AYE Panel:** Some panel members were not familiar with this term however those that were, find the term useful, especially for those that have a co-occurring condition or physical illness. It is thought of as 'autism energy'. Useful language to help visualise and explain their experiences to others.

Glossary of Terms

Word/Phrase we use	Definition	Autistic Young Experts Input (See also Appendix 2)
Stimming	Stimming is short for 'self-stimulating behaviours' which are repetitive behaviours that involve repetitive body movements or vocalisation. They can vary in type and frequency, depending on the individual and their function. Stimming can occur regardless of a person's emotional state. For example, a person may stim when they are anxious and overwhelmed, and also when they are happy. https://www.autism.org.uk/advice-and-guidance/topics/behaviour/stimming	**AYE Panel:** Most of the panel members use the term and describe it as an action that helps you regulate yourself - sensory-wise or emotionally. Everyone does it but neurodivergent people may do it more or with a more intense movement. A panel member explained that they stim when they're excited and happy, and it's such a beautiful outward expression of autistic joy. It can present in a range of different ways e.g. vocally (humming) or physical (tapping).
Support needs (high/low)	Capturing how a person's needs may vary (they may excel at certain things while finding others very challenging) and fluctuate (according to the situation). Functioning and severity labels are inaccurate and considered offensive; because they locate all challenges innately within the person's ability rather than due to a societal or situational failure to meet the person's access needs.	**AYE Panel:** The AYE had lots of issues surrounding the terms 'high/low functioning'. They strongly recommended not to use these terms as it creates a hierarchy within the autistic community. There is stigma and pressure associated with these terms. There was a preference for 'low/high support needs'.
Three areas of difference	The NEN describes autism in relation to three main areas of difference: Social Understanding and Communication; Flexibility, Information Processing, and Understanding; and Sensory Processing and Integration.	**AYE Panel:** Seen as a good way to describe the differences. Important to recognise the areas of difference can be in relation to both strengths and areas for support.

Appendix 2

Autistic Young Experts Co-Production Boards

National Autistic Society | Neuroinclusive Education Network

Autistic child/pupil/learner/student

Research shows that there is no single way of describing autism that is universally acceptable. We consulted our Autistic Young Experts and the term that they would like the NEN to consistently use is 'Autistic child/pupil/learner'. They preferred this phrase over 'child/pupil/learner with autism'.

I am in agreement, but I don't have strong opinions and am comfortable with using 'with autism' - sometimes I worry people get angry etc when people use 'with autism' because there Is no need for unnecessary conflict!

yes i prefer Autistic student / learner

I agree that there is no specific way to describe autism as its how the young person wants to describe themselves

I absolutely agree, autism is not a 'condition' that I 'have' but instead is an integral part of my identity and who I am. It can't be separated from me or my personality.

Are the panel still in agreement that identity first should be used? If so why?

I 100% agree becuse they are autistic it is part of them not something that is with them.

I prefer being called autistic, but if anyone is in doubt or doesn't know the person, they should just ask the person in question.

It depends on the person, but i am not with autism, i am autistic. it changes who i am

I personally prefer child/pupil/student with autism. Even though autism is a part of me, it doesn't define me. I see it as a neurodevelopmental condition/disorder that I was born with.

I prefer Autistic person over person with autism as it makes autism sound like a disease like person with the flu

i think that person first separates identity from person, which can increase stigma and it makes it less accessible to people, and thus our experiances less spoken about.

National Autistic Society | Neuroinclusive Education Network

Anxious non-attender

An anxious non-attender is the term used for a child or young person experiencing persistent absences due to Emotional School Based Avoidance (EBSA). This is when attendance difficulties arise from experiencing high levels of anxiety at school.

I also agree that 'distressed' would be a more all-encompassing term

I feel this term should be phrased a bit better, as not all anxiety can be school related and I too have face anxiety but have not missed any school days

school refuser implies its on purpose and malicious, anxious non attender is much more kind

i prefer this phrase school refuser sounds as though the child is trying to be difficult out of defiance, where as the other term acknowledges the need for support to access the environment

Definitely prefer this over refuser, but it still feels off. I don't know why :/

school refuser feels like its a deliberate issue (on purpose), whereas anxious non attender feels like its boiling it down to one specific thing

Maybe something related to distress instead. Emphasis on the environment and support not the autistic person.

i also think that this puts the ownus on the person, whereas from my perspective is that the school space is not necisarily safe or comfortable being the problem

Anxious non-attender is a much more accurate term for that situation, as the non-attendance isn't coming from a place of deliberate defiance (which is what 'refuser' implies).

Do you prefer this phrase over School Refuser?

I think school refuser is better, as there could be a range of reasons why someone with autism wouldn't attend school. It may not be solely anxiety

Anxious non-attender is strongly preferred. However, I wonder if there was a more all-encompassing term. It isn't just anxiety that fuels avoidance

I prefer anxious non-attender as they would go to school if they felt like they could

yes does not make it sound so scary

i think this represents my experiance + is definately better than pervious but i completely understand people being uncomfortable with it

prefer to school refuser. Wonder if there's a more specific and all encompassing word to replace anxious as not all non attendance is anxiety

Anxious non-attender is much better because it states more the reason why and more they cant attand beasuse they not in the right setting, not just refusing.

National Autistic Society | Neuroinclusive Education Network

Autistic fatigue/burnout

The term 'autistic fatigue' refers to the mental and physical exhaustion that autistic children, young people and adults experience when sensory overload has occurred for a prolonged period of time.

i think they just need to be presented as seperate things.

I think autistic fatigue is a sperate thing from burnout - I get tired from doing things that most people can do and use no energy - and this is a daily thing, that causes things like needing more sleep or not being able to do as many things every day (like spoons).

Just the fact that I am having to use more energy to live in a world not built for me

I think this is fine - I've used it and I believe I experienced burnout towards the end of my time at senior school. it was... not great

...that causes things like needing more sleep or not being able to do as many things every day (like spoons)

I dont howevery I strugle with fatigue when Im inside or am feeling board for some reson.

I like this term, I use it and I have it, it can be useful to explain to people why sometimes i cant get out of bed or speak, I think that it is often associated with meltdowns but it is

Brunout is just for austic people every one can be fatigued, I geuss.

What does this term mean to you? Do you use this term?

Different to general fatigue - relates to 'spoons' and to me relates to autism energy. Can be helped with special interests and sensory calming/ seeking as desired.

I do not use this phrase but this term should change as it may not be recognised or experienced by all autistic people

Need to explore further what can be used. Fatigue/ burnout doesn't work side-by-side

I use the term 'burnout' and think it's a good description of the experience - I was massively burnout after my traumatic experience in school.

In response to stress or repeated overstimulation, mental and physical exhaustion, prolonged, a slow response. I do use it!

specifically use the term 'autistic burnout', I agree that fatigue doesn't work

I think also I get extremely tired just doing basic things that wouldnt tire alistic people - i agree that there needs to be a distinction between burnout and fatigue though

I have never used this term and no-one has used it for me. Anyone can get fatigue or burnout, whether they have autism or not.

Fatigue can easily be misunderstood or minimised if not understood in context. It's linked to a particular event.

i think autistic fatigue is a sperate thing from burnout - I get tired from doing things that most people can do and use no energy - and this is a daily thing useful to have a destinction

But is still loosely linked/ is affected by general fatigue. So sleep etc does still help!

Co-Production

This refers to the practice of a group of people working together on an equal basis. In the area of SEND, we use it to describe the way in which young people, their parents and carers, education practitioners and other involved professionals should work together in the best interests of the child or young person, who should themselves be at the centre of the process.

What does this term mean to you?

Why is co-production so important?

At the moment I do often feel like our contributions are tokenistic - opinions, we are consulted, but we aren't actually PRODUCING. I value all the opportunities and am grateful, it's more than most charities and you're always made to feel safe, but I would love to be more involved!

Because my voice and lived-experience deserves to be seen, heard and learnt from!

i think in schools parents are rarely listened to when they identify support needs (especially getting diognises and more specificaly primary schools)

I feel like a lot of the time in schools, the young person is not involved in the decision-making that affects them, when they absolutely should be. They are seen by teachers as a 'problem' to be 'solved', rather than an actual person who should have their feelings, views and experiences listened to and should have a say in any decisions made about them.

also if teachers were actually able to identify students having difficulties beond behavoural and sometimes academicaly i think this would be a game changer

I 100% second this

The phrase 'nothing about us without us' is absolutely true in all situations and environments, including the education system - and also charity work like this.

Surprisingly I haven't heard of this phrase in this context before, so I don't have a strong opinion on it. I see how it can be a step-up from general collaboration, though

should be as inclusive and diverse as possible. It also means making everything accessible in a way to ensures that everyone has an equal opportunity to participate fully in an activity in the way that suits them best.

Profile of Autism or Autistic Profile

These phrases are used to describe the different traits, strengths and differences that can present from one autistic individual to another.

Definitely prefer autistic profile, but I feel it should clarify what exactly is talked about through this. Maybe Autistic Trait Profile?

I slightly prefer autistic profile, but I don't mind either. I also just prefer like 'differences profile', 'strengths and differences profile', 'neurodiversity profile'

Which of these terms do you prefer?

for me its not a 'profile of autism' because that seperates me from my autism, whereas 'autistic profile' feels more like a compilement of my autistic needs and traits



Disability

The Equality Act 2010 (section 6) says that a disability is someone who has a physical or mental impairment that has a long-term and substantial adverse effect on his or her ability to carry out normal day-to-day activities.

What does this term mean to you? Do you use this term?

yes and no, a lot of the time I am disabled by my environment. I don't particularly like calling myself disabled however its important part of describing accessibility

I use the term disability - I don't think being disabled means you are less able? Just differently able!

I use the term disability under the SOCIAL model of disability - in that I am disabled by a physical, sensory, social world that is not accessible/designed for my access needs.

Personally, I don't like the phrase 'differently abled' - I think it skirts around the failure of systems to support people with specific support needs.

i agree, differently abled dismisses all the challenges we as autistic people face

I am happy with the word "disability" to describe autism. I wouldn't say I have a strong connection to the term, but I think it is a good word to describe my difficulties.

I feel this could be changed as all not disabilities are visible as someone with (both physical + brain) nonvisable disabilities, I find disabled is a good umbrella term for communicating any accomodations i need without having to be specfic as often things are complicated to explain or i may just not be in a communicative mood

I dont like this term becuse it means not working howvwer I have to use it to accecus certian sevives,

its important to check whether individuals identify with it first as it holds a lot of stigma however as a protected characteristic and identity it can hold a lot of power

I use the phrase disability because the world around me can easily disable me, since a lot of the time I cannot be accommodated for. Same with others, probably.

it also means that we are all different and i think we should learning differences as it sounds more inclusive

I do relate to the term disability, as some environments and situations are disabling to me. While it's important to think of being autistic as being 'differently abled', it's also important to recognise that it can be disabling in a predominantly neurotypical world, and that many of us need differing support and accommodations.

STRONGLY dislike the medical model of disability in relation to autism esp.

Distressed Behaviours

The members of the Autistic Young Experts panel preferred the term 'distressed behaviours' rather than 'challenging behaviours' or 'behaviours that challenge'.

Yes deffently becuse when behaviours are diffiuct it is due to not coping from not being in the right setting and cant exsspree so comes out in distressed behaviours.

Definitely prefer this

Definitely prefer this over challenging behaviours - distress is not intentional, and makes the person in distress sound malicious.

I am not too fussed, either distressed or challenging behaviours.

distressed behaviours feels better to me as challenging behaviour makes it feel like they are acting out on purpose

Distressed behaviours or behaviours of distress. Emphasis being placed on behaviour as communication.

Do you still agree that this phrase should be used rather than 'Challenging Behaviours'? If so, why?

Distressed behaviours is definitely better, as the behaviours are caused by distress rather than the learner deliberately misbehaving (which is what 'challenging' implies).

challenging implies its a problem for someone else. it may cause other people challenges, but to stop those we need to look after the autistic person. challenges are another persons problem whereas distress is much more personal, because when it comes down to it, its not anyone elses issue.

I feel this term should change to behaviours of concern' to highlight the ideal response of a person's support rather than the challenge they must overcome.

i think this is an improvement, it is more likely to enable a response as it invokes empathy and accountability, which is most likely to result in change rather than force them to fix it

Double Empathy

Whilst some autistic people can struggle to process or understand the intentions of others, non autistic individuals can similarly encounter difficulties understanding the experiences and intentions of individuals.

I will come across as having no emtion becuse I find that easier however I can be feeling a lot of emotion.

i think it can be really helpful for everyone to know this as it can help people have more empathy for eachother - for example, non autistic people knowing that autistic people are

not lacking in empathy and to autistic people, they might seem lacking in empathy - it presents that both sides are having a hard time communicating across a gap, and

So, being autistic, we aren't so good at picking up emotions of people who aren't. But we are brilliant at picking up emotions of fellow autistic individuals.

For me I struggle to understand people's intentions and have endless amounts to bullying etc but I do have immense empathy and always help people in society

I don't fully understand the term, but I get the concept - you're not going to be able to work with or understand everyone, regardless of similar neurotypes or not, and that's okay

What does this term mean to you? Do you use this term?

People wrongly believe we don't have empathy, but actually this is because humans, autistic or not, are less able to pick up on/perceive the emotions of people different to us.

that often autistic people are having to bare the brunt and blame for that

I have noticed that because of this effect, autistic people can have higher levels of empathy as on top of having to empathise with people with similar brains to us, we also come into contact with many more people who are different to us, which contrasts with the interactions of a non autistic person

Calling it the 'double empathy problem' maybe reinforces the common stereotype that autistic people have no empathy or a 'problem' with it.

When in fact some autistic people are highly empathetic to the point of it becoming overwhelming (ie. taking on the emotions of those around them)

Yes I use it becuse I can feel I get really up sets by things than nerotipicals dont.

In fact I think studies have shown we're actually, relatively more perceptive. So we pick up emotions, autistic to autistic, better than non autistic to not autistic do!

This term could also change autistic people's connect and communicate effectively with neurodiverse persons or other autistic people such as by taking part in a conversation.

I think a better term for this concept is something like a two-way 'miscommunication' or 'misunderstanding' between the two people

Enabling environment or autism-friendly environment

An ethos and environment that fosters social inclusion for children and young people on the autism spectrum.

Which phrase do you prefer and why?

Autism friendly is preferred by me. As saying, "enabling" is subjective and people may not know whether this relates to autism or another disability.

Autism-friendly environment is preferred by me. Saying "enabling" is subjective and people may not fully understand whether or not this relates to autism

enabling sounds really bad to me to be honest - like has negative social connotations

definativley autism friendly environment is better. it is actually descriptive and says what it is in my opinion.

Enabling environment sounds really good. When I was in the right environment I was enabled and could thrive.

I'm fine with either

Maybe Autism enabling environment

i think that enabling sounds really negative - maybe we could find an alternative. maybe like 'safe autism environment'

Autism-friendly is fine, although this is only one part of making spaces accessible generally.

Autism-friendly because it sounds more fun, but either :)

I am fine with either one as it is about being inclusive and improving the person's performance. All environments should be positive and have a clear intent on what purpose they serve

enabling environment - eventually want inclusivity by design across all environments/ disabilities. autism-friendly sounds more like an add-on

Both, 'enabling environment' is an inclusive term that implies everyone is supported (as they should be), while 'autism-friendly' is a direct reassurance to autistic people.

The term 'friendly' does sound nicer and more human than 'enabling' (which sounds a bit clinical)

autism-friendly. Enabling environment is subjective and you don't know what disability people are talking about - is the environment suitable for people with all disabilities?

High focused interests/special interests/intense interests

I personal prefer special interest

I absolutely do not mind at all, but I use 'special interest' the most!

Highly focused interests. What makes autism 'special' in relation to the experience of being interested in something?

Which phrase do you prefer and why?

i have no oppinion really but i think "special" refers to the interest in relation to the person (eg. maths is special to me)

Personally I like the term 'special interest', as I feel like it more accurately describes the importance of my special interests and the joy that they bring - they are extremely 'special' to me!



Low/high functioning

In the past, 'high-functioning' refers to autistic people who can generally function well in society, often through masking their autistic behaviours. 'Low-functioning' refers to autistic people who may need more support.

Should these terms be avoided and why?

low and high functioning makes it seem like some people with autism are better than others

I have a lot of issues with this - it creates a hierarchy between autistic folks with different needs and pitting them against each other. I prefer the phrases high/low support needs.

I HATE these terms, personally. Built upon ableist assessment of 'normative' levels of capacity for daily tasks and actions.

agree strongly- it makes some people believe that they are superior and is basically a capitalist ideal of are you capable of working or not

use high or low support needs, as functioning dpoesnt have anything to do with what the person needs.

Yes - stigma, expectation, pressure, just because your differences are less visible doesn't mean you are more or less able to manage life

I am not too fussed about these terms, I understand both sides of the argument. An alternative could be "autism with/ without learning disability".

low and high functioning does not imply anything about how that person requires support. it creates a kind of hierarchy between who is functioning and who isnt. instead,

i believe that people can be autistic and "low functioning" without a learning disability (not 10000% sure)

I strongly dislike these terms - 'low functioning' implies that the person is somehow 'less', while 'high functioning' implies that the person doesn't need any support at all.

It very much aligns with the incorrect belief that the autistic spectrum is some sort of linear scale, and that someone can be 'more' or 'less' autistic than another person, when in fact we're

i prefer low/high support needs as its much easier to translate into tangible accomodations. "function" gets a little too close to the idea that there is one way to function insociety

This term should change. Just because a person has typical or expected intellectual abilities, does not necessarily mean they have good skills for their age. In addition to this, both these are phrases are outdated as it reflect what people perceive to see on the outside, such as how an autistic individual communicates or behaves in front of others

all autistic and just have different support needs. Someone can have high-support needs in one area, but low-support needs in another and that people who are unable to function in this way are somehow less valued/important

Masking/camouflaging

The term “masking” describes how autistic people consciously or unconsciously hide their autistic characteristics, in order to fit in and feel more accepted.

Masking is a very important term for me too, and learning what it is and how I’ve been doing it subconsciously all my life was such an important step in my journey.

Very very important to me - important to take account of the energy it takes to subconsciously or consciously suppress characteristics of autism!

I do not use this term but when some people mask they are more likely to pick up traits from everyone else to the benefits of others instead of giving themselves freedom to be who they are. These forms are also a way for people to protect themselves. In addition to this term, masking could suggest that a person removes the mask and, there’s a person’s disability been waiting to be let out this whole time.

And years of masking in school left me with no sense of identity or self, I felt completely lost and as if I couldn’t ever connect with anyone.

What does this term mean to you? Do you use this term?

I’m still on a journey of learning how to unmask, such as allowing myself to stim freely and speak naturally, and I feel so much better in myself and more energetic because of it.

I finally feel like myself and no longer find myself subconsciously masking as much (I know I’m privileged to be in an environment where I feel safe enough to do this, I certainly wouldn’t have been able to unmask in school as I felt constantly unsafe and overwhelmed and had no support)

My masking involves suppressing my stims, mimicking the speech and facial expressions of those around me, forcing myself to make eye contact etc. - it’s extremely exhausting.

Meltdown

I prefer the term sensory overload. I think meltdown belittles the situation and makes it sound like a tantrum.

I feel sensory overload seem more sincere

I do use this term, along with 'shutdown' to differentiate and describe both of the experiences. Sensory overload can be the cause of a meltdown (or shutdown), but not always.

Yes. Meltdown used because it isn't always sensory based

Sensory overload better describes what the person is actually feeling and the trigger for it.

i think meltdown has too many negative connotations and feels like it is used to devalue experiances a lot, that being said i do use it for myself

I use meltdown and shutdown. I do also use sensory overload but to me that could be a meltdown, could be a shutdown, or could just be kind of mild and not lead to anything?

Do you like/use this term? Would you use Sensory Overload instead?

not perfect but something like "overwhelmed response" or something along those lines might be a better/ more accuate descriptor

I do use the term, but I can definitely see the negative connotations in it. Not sure what I feel would be more appropriate though

Like others have said, meltdowns and sensory overloads are two different things - even if they can promote similar reactions in one person

I feel this term should change to emotion overload. The word Meltdown sounds a bit childish in my opinion and always has the negative connotation of 'tantrum', because of the way it's applied to kids. With this phrase heard you may automatically feel judged.

Neurodivergent

Neurodivergent can be used to describe someone who has a neurodiverse condition, for example, autism. This means their brain processes information differently. An autistic young person could identify as neurodivergent but so could someone who has a diagnosis of ADHD or Dyslexia, for example.

I recognise that some people may dislike the term 'divergent', however to me it just means 'different to the most common neurotype', which feels accurate and affirming even.

Yes, with the counterpart as 'predominant neurotype'. Dislike 'neurotypical' due to the suggestions of a state of normativity.

I am fine with this term as I often describe myself as neurodiverse

Do you like/ use this term?

neurodiversity is good as an umbrella term, but going by actual definitions, it doesnt just mean autism, dyslexia, ADHD, etc. which we commonly think of when we say it so some people feel excluded when we say it when we mean neurodevelopmental (which tbh sounds a bit patronising) because neurodiverse includes anything beond the "norm" - eg. anxiety, depression, OCD, schizophrenia... (including neurodevelopmental things like autism) that being said its social definition seems to be mostly autism and ADHD and adjacents which i personaly dont necisarily have a problem with

Personally I like the term and use it to describe myself, especially since I'm both autistic and ADHD and it's nice to have an umbrella term that describes all parts of me.

I am fine with the term neurodivergent but would usual use the exact term when describing myself

I do but I think it's important to make clear that there's more to neurodiversity than just autism

Neurodiversity

Neurodiversity is the idea that the way we think is not always the same. Instead, this term recognises that all variations of human neurology should be respected as just another way of being, and that neurological differences like autism, ADHD and dyslexia are the result of natural variations in our genes.

I think a lot of people mix up the terms 'neurodiversity' and 'neurodivergent' and refer to an individual as 'neurodiverse', whereas it's actually society as a whole that is neurodiverse.

Do you like/ use this term?

neurodiversity to acknowledge the diversity of ALL human brains as a collective - not as a descriptor for those of us whom are not of the predominant neurotype :)

I am fine with this term as there is a wide range of ways that people perceive and respond to the world, and these differences should be embraced



Neurotypical

Neurotypical can be used to describe someone not displaying or characterized by autistic or other neurologically atypical patterns of thought or behaviour.

I like this term and feel like it's important to make the distinction between 'typical' and 'normal' - to me, 'typical' simply means something is more common, which is accurate for neurotypical people, whereas 'normal' is a negative term that reinforces neurotypical norms and the incorrect idea that autistic people are somehow 'wrong'.

Agreed!!

Do you like/ use this term?

I do not use this term but the term "Neurotypical" does not mean "normal,". Some people might think that if we want to change people's thinking about it, changing the word may not do anything

I do use this term! I do like it but important to remember neurodiversity isn't just autism, etc!



PDA (Pathological Demand Avoidance)

or 'Demand Avoidant profile' sometimes used to describe a profile of autism. The existence of PDA as a 'diagnostic term' and how it fits within the autism spectrum is widely debated.

pda makes it sound like a problem which i think presents the perspective that people interacting with people who are demand avoidant's perspective as it being a problem is more significant, which its not - therefore not really a problem. thus i think that just demand avoidance or demand avoidant traits are preferable.

I've heard the term 'Persistent Drive for Autonomy' used instead (still PDA), which seems like a much better description of the experience, since it's the perceived lack of autonomy that causes distress. Demand 'avoidance' makes it sound like a deliberate and defiant choice, which it isn't, it's an automatic fight/flight/freeze reaction.

What are your thoughts on this as a diagnositic term?

I've not heard this term before but the use of pathological and avoidance sound very negative

I do not use this term but I feel it needs to be changed to "extreme demand avoidance" because some people may think the term "pathological" means it's a mental health condition or illness



Restrictive and repetitive behaviours and interests (RRBIs)

Any kind of focused, repetitive movement or action or activity, like stimming etc. I hate the term restricted as it sounds harsh and not like what it means instead I prefer just to use repetitive movements/behaviours!

restrictive is a negative word which perpetuates negative steriotypes and thus should be avoided also i dont think the phrase 'restrictive behavour' or 'restrictive interest' makes much/any sense, and so is unhelpful in making language inaccesable

What does this term mean to you?

Do you use this term?



I think this might work because of a need for a routine, sometimes in long term, short term or both. Maybe? I don't know.

This seems incredibly outdated to me, probably because of the "restricted" part. Maybe "routine behaviours and interests"?

Self-injurious behaviour

Is behaviour that results in someone causing physical harm to themselves. Types of self-injurious behaviour include: self-biting; scratching and pinching; hair-pulling; skin-picking and rubbing skin; hitting; head banging; slapping. Self-injurious behaviour may lead to physical injury to the person.

i like this as injury is a word that doesnt imply that it is self inflicted, which it often isnt

I do use this term but it can feel a bit formal and scary? Also important to distinguish between purposeful and not

What does this term mean to you?

Do you use this term?

This feels like an accurate term - I've more commonly heard it referred to as 'self-harm'.

I do not use this term but it could be changed to "nonaccidental"



Spiky Profile

This term is used to describe any uneven levels of functionality across cognitive profiles and skill sets. It is used to explain how an autistic person may excel in some areas and have increased support needs in others. These can change on different days and in different situations.

I don't use this term - I just describe it as 'differences' or 'strengths and weakness' across a spectrum, but to me it means having different abilities over a number of traits which make up 'autism' and what it means to be autistic. I did a little drawing to describe it.

i don't use this term but to me, I think it means Because we are bad at some things, people often expect us to be bad at other things

What does this term mean to you?

Do you use this term?



i wouldnt want someone to use it for me or use it for others unless specificaly requested

i think it sounds like an insult - like calling a person spiky doesnt sound like a good thing, and it isnt necisarily a clear association with a graph so just sounds rude to me

I have never heard of this phrase before, but the concept is something I very much believe in. Definitely need a new phrase to describe it

Shutdown

A shutdown is defined as an unavoidable partial or complete temporary withdrawal from any interaction or activity in which the person: may not respond to communication; may be unable to move from the situation/environment that they are in. Anyone can experience shutdowns. When someone feels overwhelmed or overloaded, it may trigger a shutdown, but reasons will be different for everyone.

Similar to a meltdown, an instant response to sensory overwhelm of some sort or to cope with another source of high anxiety, but instead of outwardly releasing energy, internalising hiding away from all stimuli - e.g. not speaking, dark room, not reacting to things. Saff

What does this term mean to you? Do you use this term?



I don't use this term but it sounds like a reset for them because they may have lost an interest in a particular thing

I use this phrase less often than meltdown, which is ironic because thinking on it I probably experience these more frequently than meltdowns. Oops

Spoons

I am not familiar with this term but i think its about recognising the capacity of an autistic person and seeing where they are good at/ in

yes! To add, there are different sized 'spoons' to look out for - the more energy the task takes to do, the bigger the spoon/the more spoons needed to do it!

i like spoons, as someone with physical disabilities and experiance with chronic illness its very helpful in describing my experiance without neccisarily having to explain or understand it

What does this term mean to you?

If you are unfamiliar with this term, please write that as your answer.



I use this term a lot - I also think of it as 'autism energy'. The energy required to do executive function and 'normie' or 'daily life' tasks - socialising as well as chores, sending emails and being organised. I gain spoons through rest or through special interesting etc.

Stimming

Repeated actions - be they verbal, physical movement, touching something, visual (like lining things up), oral (like listening to the same lyric) - to calm self or let out energy

I haven't associated this term with myself. to me, it means doing something you may enjoy which can help reduce stress levels

What does this term mean to you?

Do you use this term?



i use the term stimming for myself

stimming is an action that helps you regulate yourself - sensory-wise or emotionally. Everyone does it, but neurodivergent people may need to do it more and with a more intense movement. For example: one person might play with their hair or bounce a leg, while another might pace and flap their hands. Very variable thing, stimming is!

Three Areas of Difference

Autistic people have differences in three areas of development. These are: Social Understanding and Communciation; Flexibilty, Information Processing and Understanding; and Sensory Processing and Integration. We need to look at these areas in terms of both the strengths and differences that might arise.

I think this is a good way to simplify and communicate the many different areas of nuance amongst autistic people.

I also think it's important to recognise that areas of difference can be both strengths and areas that need support.

yes i agree. i think when explaining this to people it is important to consider the order that these are put in - in my opinion, social aspects being put first put the aspects that

Do you think this is a good way to describe autism differences?

I thinks this is a good way to describe the autism differences as its simple and easy to remember the name and its different categories

most commonly effect non autistic people the most and not are the most 'disabling' for autistic people#

I think its good to focus on strengths and I like the reference to differences which doesn't come across as just a negative thing

from the autistic people that i know, I would say that the social aspect of it is the most of 'a thing' when we interact with non autistic people and so this may be best as 3 on the list

Guide

National Autistic Society | Neuroinclusive Education Network

To access NEN Free Resources Click Here

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www.nen.org.uk

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