Autism Education Trust

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Terminology Guide

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AET Terminology Guide

This document aims to give a consistent guide for use of the terminology and language we use within the Autism Education Trust. The aim is to improve consistency across our materials and to encourage others to think about how they talk about autism.

This document has been developed with input from the AET'S Young People's Panel as well as AET partners - Ambitious About Autism (AaA) and the National Autistic Society (NAS).

This document is likely to be added to and amended over time as language and terminology evolves.

What is Autism?

Autism is a processing difference that can have an impact on many areas of a person's life. Autistic people often experience differences in how they process information, their sensory environment and how they interact with other people. It is estimated that one in 100 children, teenagers and adults in the UK are autistic.

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

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

The AET approaches autism as a different way of being rather than as a 'deficient' or 'disordered' way of being.

'Autistic people are not neurotypical people with something missing or something extra added on. They are different. If we are serious about equality and inclusion within any area, then we must first of all understand that difference.'

How do we talk about Autism?

Over the years there have been many different terms and phrases used to describe autism, some of which are still in use today. However, more recently there has been a shift in understanding and changes and developments in how people talk about autism.

When you meet an autistic person, they might use different terms to describe themselves:

- 'Autistic person'
- 'On the spectrum'
- 'Person with autism'
- 'I have Asperger Syndrome'

People have different preferences of what they like used when describing them and autism, so it is always best to ask the individual themselves what their preference is.

Don't assume what someone might be like because they are autistic but instead ask them or someone who knows them well what their strengths and differences and likes and dislikes are. Making assumptions about autistic people may impact on how we interact with them. every autistic person has their own profile of strengths and needs and is unique.

You may hear people talking about Autism using labels such as Asperger Syndrome, Autism Spectrum Condition or Disorder, Atypical Autism, Pervasive Developmental Disorder or High Functioning Autism. These have all been used as diagnostic labels to describe different profiles of autism.

You may have heard the term Pathological Demand Avoidance (PDA) or Demand Avoidant profile being used to describe autism. The existence of PDA as a 'diagnostic term' and how it fits within the autism spectrum is widely debated.

You can find further information about this topic on the NAS website here.

Talking Positively About Autism

When talking about autism don't use terms like 'suffer' or 'disease' or 'problems' or 'issues'. Autism is not a mental health condition or a disease, it is a different way of experiencing and processing the world around you.

Don't use 'high functioning' or 'low functioning'. Instead you could describe a person's support needs. Some autistic people may need higher levels of support than others.

Neurodiversity, neurodivergent and neurotypical

We recognise that terms such as **'neurodiversity'**, which encompasses **'neurotypical'** and **'neurodivergent'** are used widely.

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.

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

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.

Autism as a Difference not Deficit

The way we view autism is very important and can have a huge impact on the way we behave towards and support autistic people. Many autistic people do not view autism as a deficient way of being, but as a different way of being.

Medical Model

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 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, esteem and 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' or 'condition'.

Social Model

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, negative attitudes and exclusion by society (purposely or inadvertently). While physical, sensory, intellectual, or psychological variations may cause individual functional limitation or impairments, these do not have to lead to disability unless society fails to take account of, and include and accommodate people regardless of their individual differences.

To really understand autism, it is essential to listen to and value what autistic people say about their experiences.

Why is the language we use so important?

How we talk about autism is important in order to promote equality. 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.

A lack of understanding of autism and the language used to describe it can have a significant impact on autistic people leading to autistic people needing to mask their autism and can result in meltdowns or autistic fatigue.

You can find further information about meltdowns, on the NAS website here.

You can also find out more about autistic fatigue here.

The Langue we use at the AET

In the table below, we have listed a number of terms that we use across our modules and materials and we have provided an explanation as to why the term has been chosen.

Term we use	Why we use it
One Page Profile	The Education, Health and Care Plan (EHCP) includes a section that captures the child or young person's views, interests and aspirations and how best to communicate with them. This section is often referred to as an 'All About Me' or a 'One Page Profile'. Even if a child or young person does not have an EHCP, 'All about me' or 'One Page Profile' documents can be used to provide important and useful information about the child or young person and how to support them. The AET will use the term One Page Profile.
Autistic pupil/child/young person/learner	Research shows that there is no single way of describing autism that is universally acceptable. We consulted our Autistic Young Experts panel and the term that they would like the AET to consistently use is 'Autistic pupil/child/young person/learner'. They preferred this phrase over 'pupil/child/young person/learner with autism'.
Autistic child	This phrase will be used in the AET's Early Years materials.
Autistic pupil	This phrase will be used in the AET's Schools materials.
Autistic learner	This phrase will be used in the AET's P16 materials.
Co-occurring condition	This phrase will be used when we are describing someone with more than one diagnosis e.g Autism and Epilepsy.
Co-occurring difference	This term will be used when describing someone who may have a diagnosis and experience other differences alongside this e.g an Autism alongside needs in the area of toileting, eating or sleeping.
Distressed behaviours	The members of the Autistic Young Experts panel preferred the term 'distressed behaviours' rather than 'challenging behaviours' or 'behaviours that challenge'.

Enabling environment	When we talk about enabling environments we mean adjusting the environment to ensure that everyone has equal access to the same opportunities and that they are not disadvantaged in any way. 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.
Fixed-Term Exclusion	In line with the current government guidance, the Department for Education has said it will refer to any period of temporary exclusion as 'fixed-term'. The AET will use this term for consistency.
Key person	This term will be used instead of 'key worker' in the Early Years modules and materials as this is the term that is used in the framework for the Early Years Foundation Stage.
Nonverbal	This term will be used when describing a pupil/learner who has not developed verbal language.
Permanent Exclusion	There were concerns across the education sector about reverting to the term 'expulsions'. In line with current government guidance, the Department for Education has confirmed the use of the term 'permanent exclusion' and this will be used in the AET modules and materials.
Pre-verbal	This term will be used to describe a child in Early Years who has not yet developed verbal language.
Three areas of difference	The AET will refer to three areas of difference as being: 1. Sensory Processing and Integration 2. Social Understanding and Communication 3. Flexibility, Information Processing and Understanding. This has changed from four areas of difference based on stakeholder feedback that when separating social understanding and communication in the training materials they was repetition in some sections. The Autistic Young Experts panel were also in agreement that we should reduce this from four areas to three areas. Please note that these three areas of difference are not diagnostic criteria for autism.

References

AaA Autism Toolkit - https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/include-autism

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Timpson Review of School Exclusion May 2019 - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/807862/Timpson_review.pdf

https://consult.education.gov.uk/school-absence-and-exclusions-team/behaviour-strategies-in-schoolunits-managedmoves/

DSM V – https://www.psychiatry.org/psychiatrists/practice/dsm and https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-criteria

SEND Code of Practice - https://www.gov.uk/government/publications/send-code-of-practice-0-to-25

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