north east autism society



Universities and Higher Education Toolkit

Autism Acceptance ~~Awareness~~

The North East Autism Society is passionately campaigning for autism acceptance, rather than simply awareness. We've been joined on this journey by organisations – across the North East and beyond - that are committed to making real change and improving inclusivity for those of us who are neurodivergent.

Your pack contains:
Helpful resources covering everything from what is autism to reasonable adjustments, designed to help higher education institutions better promote inclusivity and offer bespoke support to students with additional needs.

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What is Autism?

Autism is the word used to describe a lifelong difference in a person's neurology. It's very difficult to say exactly what 'it' is because it can't be separated from the person.

Edinburgh university describe it as: "A way of being in the world; it's a way of processing the things that come into your body (sights and sounds and so on). It affects how you perceive and interact with people. There will also be differences in how you plan and manage activities, and organising that information can translate into different behaviour."

In essence, an autistic person will see, process and understand the world in a different way from someone who isn't autistic, for all of their life.

Historically the focus on autism has been through the language of impairments and deficits, instead of differences or even skills and abilities.

We at the North East Autism Society have had to change the way we think and as a result, the work that we do, with most of this stemming from listening to and working with autistic people, who have been the voices consistently missing from the autism narrative.

Without denying challenge, our aim has been to help the wider world shift to understand and accept those of us who are autistic.

Thirty-six percent of autistic undergraduate students who enrolled in 2019 did not complete their degree after three years. The rate compares to 29% for the general student population and is higher than that for any other disability group.

Neurodiversity explained

Neurodiversity is more than just a term – it's both a fact - and a movement.

It's the belief that all 'brain wiring' – or neurological difference - is essentially a normal variation in humanity.

Like biodiversity - neurodiversity understands and sees wonder in the fact that differences exist, but doesn't place more or less value on these different variations. In a nutshell - we're all in this together.

No more us and them.



Dyslexia, dyspraxia, autism, ADHD, Tourette Syndrome and many more neurodevelopmental 'differences' would come under this banner, alongside what has traditionally been termed 'neurotypical'.

This helps us understand the complex nature of 'brain wiring' where there is both individuality and overlap; commonalities and difference.

This new understanding helps remove the stigma of deficits and disorders - and with it a toxic cure culture, subjecting people to harmful therapies and treatments in pursuit of an elusive 'normal.'

THIS BETTER WORLD FOR ALL OF US IS POSSIBLE.

WILL YOU JOIN US?

Why language matters

As a general rule language, particularly in this field, changes frequently. It can be difficult to remember all of the dos and don'ts.

So, to make it easier, we've worked with our Autism and Neurodiversity Think Tank to pull together some simple 'golden rules'.

DO... SAY AUTISTIC

Use 'autistic' not 'has autism'. Also avoid using ASC/ASD and Asperger's Syndrome.

"Autism is not a removable condition, it is central to your being. It's an important aspect of your identity, as much your race gender, job etc."

DON'T... USE FUNCTIONING LABELS



Functioning labels are stigmatising and create assumptions. 'High' functioning implies less need and 'low' functioning presumes a lack of competency.

DO... ADVOCATE ONE VOICE



Avoid anything that conveys a sense of 'us' and 'them'

When we speak about autistic people we say 'those of us who are autistic'

DON'T... SAY LIVING WITH AUTISM



Or People with autism / born with autism.

"Autism isn't a dog that lives with me, or a twin who was born alongside me... it's who I am"

DO... TALK ABOUT HAVING NEURODIVERSITY



Neurodiversity isn't another word for autism. We all fall under a banner of neurodiversity. It's about individuals having different brains. Within that though, some of us have typical neurology and others are Neurodivergent in different ways.

DON'T... CONVEY PITY



Or suggest that autism is inherently negative.

No using terms like 'suffers from', and avoid talk of deficits.

Never say definitives – ie. Autistic people can't.

Sensory differences

Our senses help us understand what is happening in the world around is. We all experience messages from our senses differently, and many autistic people can have difficulty processing this sensory information.

That can make them feel overwhelmed, anxious or distressed. It can even be painful.

We have eight senses, and all are vital to how we experience the world and how we react:



Sight. If we struggle to process visual stimuli, we might find it difficult to organise visual information or filter out unnecessary details.



Sound. If we struggle with auditory stimuli, we may have difficulty filtering out back-ground noise.



Touch. If we struggle with tactile stimuli, we may feel certain types of touch as painful or dangerous.



Taste. If we struggle with gustatory stimuli, we may be a picky eater and object to certain food textures.



Smell. If we struggle with olfactory stimuli, we may find smells distracting and over-whelming.



Vestibular – our sense of balance. If we struggle with vestibular processing, we may come across as clumsy.



Proprioception – an awareness of where our body is in space. If we struggle with proprioception, we may have difficulty waiting in line or knowing how hard or soft to push or pull things.



Interoception – our internal body sensations, like hunger, stress, or pain. If we struggle with interoception, we may not be aware that we are thirsty or need the toilet.

Some people are described as **"hyposensitive"** or under-responsive to certain sensory stimuli. They might actively seek sensations by fidgeting, rocking or chewing non-food items.

Meanwhile, others are described as **"hypersensitive"** to certain stimuli, such as loud noises or bright lights. They can be in a constant state of alert, waiting for the next sensory assault.

People can be a mix of both hyper- and hyposensitive to certain senses at the same time.

It is vital to understand that sensory processing difficulties are not a case of simply "liking" or "disliking" things but affect every aspect of life. We must be aware of people's sensory profiles and respectful of how it feels for them.

See

The senses – Autistic advocate Kieran Rose

Sensory - North East Autism Society factsheet

Communication differences

Autistic people may communicate differently to non-autistic people, but it shouldn't be seen as a deficit or a flaw.

Common differences include:

- Understanding non-verbal cues such as facial expressions or gestures
- The speed, pitch or intonation of someone's speech
- Understanding abstract language, humour or sarcasm
- Using other ways to communicate, rather than speech

Research shows that autistic people can communicate well with other autistic people. So rather than seeing the autistic person as having a problem communicating with non-autistic people, we should see it as a shared responsibility to come up with a solution.

This may involve adapting how you communicate, rather than assuming you are automatically right.

You should check you are making sense. A lot of slang words and phrases (like "hang on a minute") do not make sense in a concrete way.

It's important to give someone time and space to process what you are saying. Simply repeating things can be overwhelming.

Be aware that the context – background noise, or someone's emotional or physical state – can affect someone's ability to communicate.

Finally, don't make presumptions. If someone doesn't use speech, it doesn't mean they can't understand what you're saying .. or vice versa.

"Neurodivergent individuals – those who have neurological differences such as autism, ADHD, or dyslexia, for example - may experience distinct communication differences compared to neurotypical individuals in a university setting. This can range from difficulty interpreting non-verbal cues, such as facial expressions, to issues concentrating in busy or loud environments, such as lecture theatres. It's important to note that these differences can vary widely among individuals, and it is crucial that universities strive to be inclusive and supportive of the diverse communication needs of all students, regardless of their neurodiversity."

Ashley Jones, Deputy Services Manager, NEAS Employment Futures.

See

An introduction to the double empathy problem - Autistic advocate Kieran Rose

Communication - North East Autism Society factsheet



What is stimming?

Stimming is a term used to describe self-stimulating behaviour. In other words, any actions done which will provide some physical, sensory or emotional input.

Stimming can take many forms but more common 'stims' include rocking, spinning, flapping or making repetitive sounds.

We know there are many reasons for stimming; most often it comes from a need for self-regulation or a way for someone to feel in control, but it can simply be because it feels good.

Some other examples of why people may stim include:

A means of emotional regulation:
Stimming is part of an autistic person's body language and the key to supporting someone regarding stimming is to accept this and encourage it where appropriate. Stimming may be used as a coping mechanism for emotions such as anxiety but it's equally important to understand stimming as a way of expressing positive emotions too, for example, hand flapping, which can be a way of showing and experiencing excitement.

A means of sensory regulation:
Hyper or hyposensitivity can be another reason for an individual to stim. For example, if an individual is under stimulated in a sensory context, they may stim by rocking or spinning to get more sensory input. If an individual is hypersensitive to certain stimuli, they may use stimming as a way to focus on different sensations.

Social regulation: Social situations, such as attending a job interview or joining a new group, can be very uncomfortable for some people and stimming can help to relieve feelings of discomfort or overwhelm, helping an individual to manage their interactions better.

It is fun: More and more we are hearing from autistic people that stimming is also a huge source of fun.

See

An Autistic Frequency – Kieran Rose, The Autistic Advocate

Sensory – NEAS factsheet

Stimming – on www.autisticality.co.uk

What is masking?

Autistic masking is the term used to describe a psychological safety mechanism, in which a person suppresses parts of their identity in order to meet the expectations of those around them.

Masking starts from birth and is initially based on sensory suppression. It can be conscious or unconscious and is a tool that some autistic people use to navigate the social world without being identified as ‘different’, providing protection and enabling them to 'fit in'.

For many autistic people who mask, this can become unsustainable (either in the short term of long term) and lead to autistic burnout.

Masking might involve:

- **Mimicking other people’s facial expressions and how they talk**
- **Pretending to have the same interests as other people and playing down your own interests**
- **“Scripting” or having ready-made sentences to use in social situations**
- **Suppressing your “stims” (see “Stimming”)**
- **Hiding when you’re stressed or overwhelmed by sensory stimuli**

"Masking is a psychological safety mechanism made up of layers of physical and social complex actions which Autistic person uses 'fit in' and self-protect in an endless variety of differing situations and environments. This happens by applying, in fluctuating degrees, often uncontextualised and sometimes rehearsed, learnt behaviours to appropriate situations; whilst simultaneously suppressing both natural behaviours and self-identity. All this happens portly consciously with, over time, the person dissociating from the act; and portly subconsciously: pre-emptive, reactive and unplanned; And all at great mental and physical cost."

Kieran Rose, The Autistic Advocate

See

What is masking?

NEAS Behind the Mask campaign

What are reasonable adjustments?

Reasonable adjustments are changes that organisations providing services must make if someone's physical or mental disability puts them at a disadvantage compared with others who aren't disabled.

Institutions providing education or training are required by law, under the Equality Act, to support individuals who are disabled with reasonable adjustments.

By nature, reasonable adjustments are unique and should be tailored to suit the needs of individual students. Our specialist mentors can support your institution to implement reasonable adjustments in a bid to better support autistic and neurodivergent students.

Examples of reasonable adjustments

- **Providing lecture materials and notes in advance**
- **Offering alternative ways to access lectures (e.g. virtually)**
- **Allowing extensions for coursework**
- **Allowing extra time for exams / option to complete exams in a smaller room**
- **Accessible rooms and venues, e.g. quiet spaces**
- **Equipment or aids, such as scribes or specialist equipment (provided by DSA)**
- **Comfort breaks**
- **One-to-one support**
- **Support accessing the university facilities, e.g. library, study rooms**
- **Brief assignment guides/offer of a 1-1 with a staff member to explain what they need to do for the assignment**



What autistic students want you to know

Every student will have their own requirements when it comes to sensory or communication needs, and what works for one will never work for all. However by listening to the voices of autistic and neurodivergent individuals, we can hopefully make the world a more welcoming and accessible place.

The same should be said for universities – and no student should feel excluded because of any additional needs they may have.

So we asked a number of students to offer feedback around their own university experiences, including how inclusivity could have been improved.

Here is what they had to say.

"I could access all of my lectures online which I found very helpful. I found the transition from first to second year really hard and didn't go in-person to anything."

"I like the idea of a sensory room. Somewhere students could go, that is sound proof, where they can study and just get some work done."

"I feel like when someone is newly diagnosed, or during university, someone should reach out to that student and make sure they know what support is available."

"There needs to be some form of support group I think. Disability services need to turn around and say, 'right here is a support group for neurodiverse people'. That would be a really good idea."

"Every university or place of education should have a person who knows neurodiversity. They would facilitate staff training and ensure that policies were in place to ensure that students received the correct support and interventions. They would liaise with neurodiverse students to ensure that they are receiving the appropriate support that they require and that they are mentally ok as they wouldn't necessarily be able to ask for help."

"It's important for students to know that they can reach out, they can ask for the support and they don't need to worry about whether they are going to be judged or thought less of for it if they access that support."

"Provide the support and accommodations that autistic students need, without making judgements on whether you think they need that level of support based on their academic abilities or attaching any kind of stigma to that."

Our student mentor service

Our dedicated team of Specialist Mentors and Mental Health Mentors offer support to students to help them succeed in their studies. They provide one-to-one support for autistic students in higher education, helping to identify various barriers learning and develop strategies to overcome them.

What happens at a mentor session?

Our mentors meet with students, on campus, on a regular basis and are trained to assist in a wide range of areas, including:

- Getting settled into university life
- Accessing university resources and social opportunities
- Time management and organisational skills
- Planning and starting assignments
- Developing communication and group work skills
- Managing stress and anxiety
- Preparing for exam revision
- Maintaining motivation

Is there a cost?

We receive student referrals from being approved as a Disability Student Allowance (DSA) Registered Provider. We are happy to receive referrals from education providers and individuals if the person seeking support is in receipt of DSA.

We do not charge additional costs for travel, however, we can currently only support students attending universities in the North East or the surrounding areas.

We provide study skills support, working on a one-to-one basis with students to meet their individual needs and support them to develop their academic skills. This can include areas such as planning, organisation, research, literacy, note taking, and memory and revision techniques.

Contact the team

Visit our website



Testimonials

"I don't think I could've got through that year and passed without the support of NEAS. They built my confidence back up and supported me through any problems I had, giving me solutions to problems and communicating with my university to advise them and pass on any information to them.

"I felt like my issues were taken more seriously when they were backed up and supported by my mentor. I also felt better being able to talk to someone who understood my struggles as an autistic person after feeling so alienated within my previous university."

Imogen Cox
Photography student,
University of Teesside

Click here to read Imogen's Story

"I am fairly well organised, and that's the autistic part of me, but the ADHD part of me means that I don't stick to it ... so every week, my mentor, Sophie, and I go through what I am working on, what is priority, what needs to be done.

"I will take whatever support and help I can get, because you can't survive in this world without help and support, no matter how much you think you can. But the world has to change its attitudes and I hope that one day people won't need a diagnosis to get the support they need."

Tania Scott,
Psychology student,
University of Sunderland

"University was slightly different from college, in that a lot of the support services that are available, unlike college where it was all quite seamlessly set up from school, at university they kind of leave you to sort that out on your own.

"The tutors at university were very supportive and they were very easy to talk to. I don't think I ever really had to explain in lots of detail about why I needed certain accommodations."

Jonathan Raiseborough
Art graduate,
University of Teesside

Click here to read Jonathan's Story

"Mainly for me it has been organising my time. I get really overwhelmed I give got lots of tasks to do and I just can't arrange it. So it's been about creating a schedule and breaking down assignments. So rather than 'I've got two weeks to do assignments, I will do proof reason on this day.

"Since accessing this help I get less overwhelmed. Because when I get overwhelmed with things I just don't do anything, and then I will have lots to do in one go, and then I will get burned out."

Charlie Greenall,
Psychology student, Durham University

Autism Acceptance Award

The North East Autism Society established the Autism Acceptance Award as a way of recognising organisations that are committed to making a real difference for autistic and neurodivergent individuals.

Since its inception in 2019, we have worked with a number of businesses and organisations across the North-east – and we're always on the lookout for additional corporate partners who can help us to champion our message of acceptance and understanding.

Our Autism Acceptance Award is currently open to businesses working within retail, hospitality, leisure and recreation, health and transport.

Our Autism Acceptance Award is split into three phases (bronze, silver and gold) and places a focus on four key areas within an organisation: knowledge and understanding, changes to practice, environmental adjustments and collaboration.

To find out more, please email acceptanceaward@ne-as.org.uk.



The award focuses on key areas within an organisation:

- **Knowledge and Understanding**
- **Changes to Practice**
- **Environmental Adjustments**
- **Collaboration**

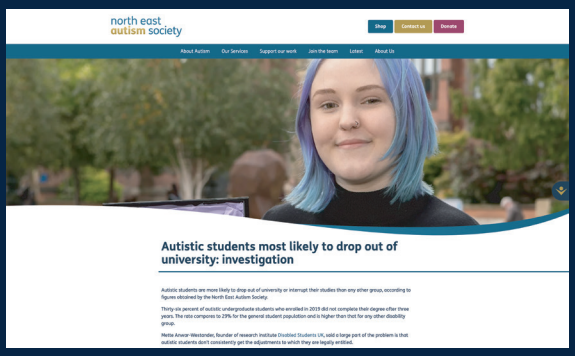
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Additional Resources

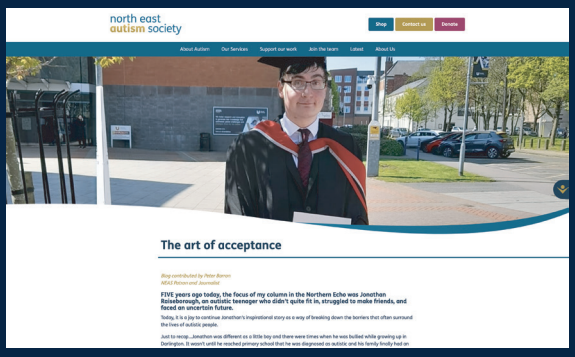
Autistic students most likely to drop out of university



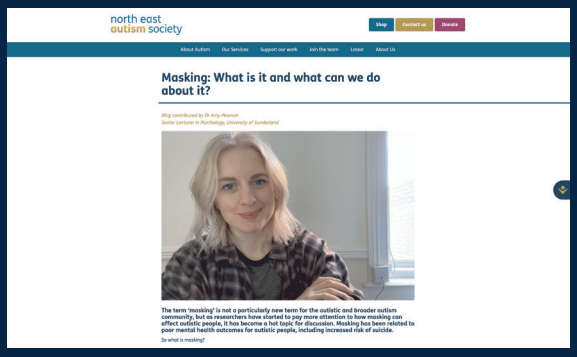
This is Autism: NEAS Podcast



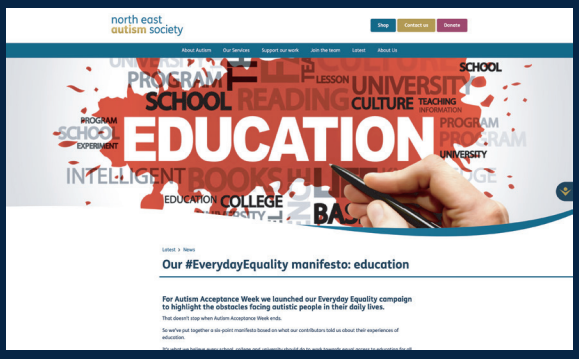
The art of acceptance



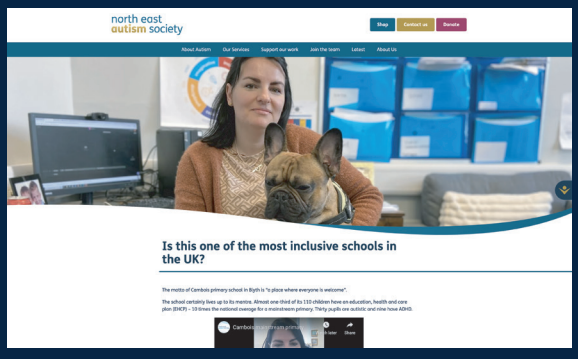
Masking: What is it and what can we do about it?



Our Everyday Equality Manifesto: Education



Is this one of the most inclusive schools in the UK?



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