'What is?'

A terminology glossary to help create a better understanding of autism





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What is Autism Acceptance Week?

Autism charities around the world will be taking part with the aim of creating more understanding of what it means to be autistic. There is still a huge lack of understanding of what it is and what it isn't.

Join us to increase acceptance and create a society that works for autistic adults, children, and their families.

Join us from 27th March - 2nd April to support autism acceptance, accommodation, and appreciation!

How to get involved

Support our 'What is?' Campaign

Our campaign will focus on terms associated with autism, the definitions of those terms, and how to use them correctly to help create a better understanding of autism.

Follow our social media throughout Autism Acceptance Week to keep up to date with our campaign.

Silly Socks Day - 31st March

On Friday 31st March join us and wear your silliest socks to help promote autism acceptance, accommodation, and appreciation.

Tag us on social media or email marketing@autismhampshire.org.uk to show us your silly socks! <u>Donate here!</u>

Online Art Exhibition - What is autism to you?

Submit your artwork to our online art exhibition. An opportunity to express 'What autism means to you' through any means that you wish. Whether this be through painting, drawing, dancing, singing, or poetry, the option is yours.

Please email marketing@autismhampshire.org.uk to submit your work.

What is autism?

Autism is a lifelong developmental disability that affects how people communicate / interact with others and see the world around them; autistic people have said that the world, to them, is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety. It is estimated that around 1.76% of the UK population are autistic.

Like everyone, autistic people have their own strengths and weaknesses. However, many autistic people share and experience particular difficulties with social interaction / social communication, repetitive and restrictive behaviours, over- and under-sensitivity relating to the senses, highly focused interests or hobbies, poor mental health, meltdowns and shutdowns. Autism is **not** a mental health condition, but 80% of autistic people experience poor mental health, are 9 times more likely to commit suicide, report significant social isolation and often suffer from high anxiety and low self-esteem.

Understanding and relating to other people and taking part in everyday situations may be harder for autistic people. Other people appear to know, intuitively, how to communicate and interact with each other, and some autistic people may wonder why they are 'different'.

In educational settings, autistic students are three times more likely to be excluded from school; only 22% of autistic adults are in paid, full-time work.

Autism is **not** a learning disability; only 40% of autistic people have a learning disability.

Autism is **not** a disease and it cannot be 'cured'.

How do we talk about autism?

How we talk about autism is influenced by our attitudes and perspectives of autism. This is aligned with either the medical or social model of disability.

The **medical model of disability** works on the premises that there is a correct way to be. There is a model of the typical person and the medical model looks to fit people into this model by changing the person using strategies such as medicines and therapies. For instance, the medical term 'Autism Spectrum Disorder' (ASD) is used to help identify / diagnose autism and get support for someone - but in a practical way in daily life, these terms aren't necessarily helpful or appropriate.

The **social model of disability** looks at people individually and builds the correct support around them rather than changing the person you change the environment for example to make it more accessible. You provide support and therapies based on what would enhance the persons access and quality of life. The premise being that people are disabled by society/environment.

The **Neurodiversity paradigm** is very much aligned with the social model of disability focusing specifically on neurological differences. Accepting neurological variation is as important as any other form of diversity. More information can be found on the next page.

For a lot of autistic people, autism is a part of their identity, so it's important to use positive language. And, if you are referring to a particular person or group, ask them how they would prefer to be described. The National Autistic Society has guidance on how to talk about autism here.

The importance of using needs-led vocabulary over high / low functioning labels

High and low functioning labels can be detrimental to an autistic person. **Who is to say how much someone can function?** Functioning ability can change on a minutely, hourly and/or daily basis. Calling someone high-functioning may add a lot of pressure to that person and them assuming they need to keep up with society and function at a pace that might not work for them.

What is 'Neurodiversity', 'Neurodivergent', 'Neurotypical'?

Neurodiversity

Neuro = brain
Diverse = different
A term to describe all humans - different brains.
One person cannot be neurodiverse - it has to be multiple people.

Neurotypical

Someone who has a 'typically' functioning brain, according to current society.

Neurodivergent

Someone who learns and processes information differently to what is perceived as 'normal'.

Other neurodivergences include Dyslexia, Dyspraxia, ADHD/ADD along with others.

Therefore, when talking about an autistic person, they are neurodivergent, not neurodiverse. A group of people are neurodiverse and might include some neurotypical and neurodivergent people. A group of neurotypical / neurodivergent people are still neurodiverse.

What is **Sensory Processing?**

We all constantly process the sensory world around us and there are different levels of sensory input we can cope with and sensory input that we seek.

There are **8 key senses** we tend to talk about:



Sight



Hearing





Smell Interoception





Taste 🖔 Vestibular





Touch Proprioception

Processing

Many neurotypical people are able to adapt to the sensory experience around them, and some have described it as being able to dull the sensory things happening around them. For example, they can zone in on a conversation with one person and block out ten other conversations nearby.

For a lot of autistic people they will take in the full sensory world around them in a lot of detail and the artificial filtering that happens in a lot of neurotypical brains won't happen. This leads people to have a lot of their capacity and energy taken by processing all the information they are being presented with.

We each have a level of sensory input that we need and anything above or below that would mean we are over or under stimulated.

What is Sensory Processing?

Hyper- vs. Hyposensitivity

Hypersensitivity

If you are hypersensitive then your level for the right amount of sensory input is quite low. This means you are most comfortable with just a bit of sensory input. People who are hypersensitive can often be overstimulated by the sensory world around them. Being overstimulated can be painful and leads to people trying to avoid the sensory input or put a control measure in place. For example, if you are hypersensitive to sound then you may block your ears or you may chose to drown out multiple background noises with one louder, more predictable noise.

People can be both
hyper- and hyposensitive
as someone may be
hypersensitive to touch
but hyposensitive to smell.
This can also fluctuate
and change.

Hyposensitivity

If you are hyposensitive then the right amount of sensory input for you is quite high. This means you are comfortable with a lot of sensory input. This can often mean people who are hyposensitive are under stimulated and will seek additional sensory input. For example if you are hyposensitive to sound you may prefer louder noises, multiple noises at once, creating louder noises.

What is **Stimming**?

Stimming is a behaviour anyone can do to self-stimulate, calm ourselves, express ourselves and process information and emotions. Neurodivergent and neurotypical people stim, such as by humming or fidgeting with a pencil.

It is an amazing strategy that sometimes people can feel like they need to mask or stop themselves from doing because of what others may say or think, or they have been told to sit still, be quiet or stop fidgeting. Think about all the reasons stimming is good and imagine the harm it can cause to NOT do it. Stimming can be anything and look different for everyone. Stimming can also be aided/enhanced by using sensory tools. Stimming is a fantastic strategy that should be encouraged. For some people embracing stimming and figuring out what works for you can be one of the first steps in unmasking.

What is communication?

What is autistic communication?

Communication happens when one person gives information to another person. This can be verbally or non-verbally. Interaction happens when two people respond to one another, i.e. two-way communication.

Most autistic people experience difficulty with:

- interacting with others
- initiating interactions, responding to others, or using interaction to show people things or to be sociable
- understanding and relating to other people
- taking part in everyday family, school, work and social life. These can be harder.

Every autistic person will have their own preferred method of communication.



As Information, Advice, and Guidance officers we communicate with many autistic individuals and feel it is always important to bear in mind the communication preferences for that individual, considering the type of interaction and environment in which the communication is taking place. We are very person-centre led, aiming to meet the needs the clients.



What is non-verbal communication?

Some autistic children are delayed in their use of language, and some autistic adults don't use speech. In those cases, other methods of communication need to be established.

An autistic person may appear not to hear what you say to them, not respond to their name, or appear indifferent to any attempts you make to communicate.



The assumption is that if someone doesn't use speech, if their words are infrequent or produced in unanticipated ways, then their thoughts must also be limited, jumbled and infantile...



This derogatory view can be harmful to autistic people and those who use nonverbal ways to communicate.

Augmentative and Alternative Communication (AAC)

A range of tools and strategies help autistic people who struggle with speech. Tools like a letter or picture boards or sophisticated computer-based systems. AAC helps someone to communicate as effectively as possible, in as many situations as possible.

Autism & gender identity

What is Gender Identity?

It's important to recognise that gender is separate to sex. Gender identity is how an individual feels about their gender and how they express themselves, whether they present as masculine, feminine, androgynous, or otherwise. Presentation and expression are both terms commonly associated with gender identity because it's how an individual chooses to express and present their gender identity, if at all.

There are many gender identities out there, including:

- Cisgender
- Non-binary
- Transgender
- Questioning

Gender dysphoria is the discomfort or distress some people feel when their assigned sex (eg. the 'Female' or 'Male' marker given on birth certificates) is different from their gender identity.

Some research has shown a link between gender dysphoria and autism, and that autistic people may be more likely than other people to have gender dysphoria. However, there is little evidence about the reason(s) why, and some recent research suggests the link between autism and gender dysphoria is not so clear. More research is needed.

Further Information and Support

- NHS
- Stonewall
- Switchboard
- Mind Out
- Gendered Intelligence

Glossary of other helpful terms

LGBTQ+ community - stands for Lesbian, Gay, Bi, Trans, Queer/Questioning, and more.

Gender expression - how a person displays their gender through their appearance: clothing, hair, makeup, speech, mannerisms

Gender non-conformity - when someone does not conform to society's expectations of gender roles, typically used by all gender identities and regardless of gender identity. It's about how someone presents themself.

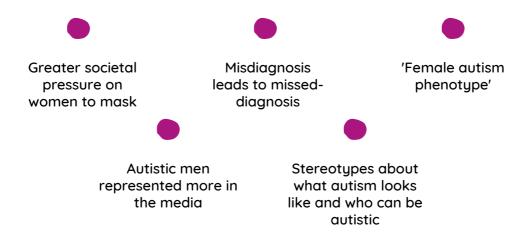
Pronouns - words that refer to a person such as he/she/they or his/her/their **Queer** - an umbrella term used to include people within the LGBTQ+ community, as well as a term for people who don't 'fit into' any labels or prefer not to use specific labels

Autism & women / girls

Why are more men / boys diagnosed as autistic than women / girls?

In the past, it was assumed that autistic people were overwhelmingly men and boys, and only very rarely women and girls. This is incorrect. There are many autistic women, girls and non-binary people. While the estimated ratio of autistic males to females is around 4:1 respectively, it is not that there are necessarily fewer girls and women who are autistic.

We don't know exactly why more men and boys are diagnosed as autistic than women and girls. It is clear that many autistic women and girls are missed or misdiagnosed. Many theories to explain the diagnosis gap have been put forward, but none have been conclusively proven. These include:



Research and knowledge about autism changes constantly. Some of these theories may not reflect how we think about autism today.

There is still much research to do in this area, but there is enough to demonstrate that autism is not a male condition, so we should expect numbers of diagnoses to continue to increase over time.



Attitudes towards autism and gender are changing. We feel optimistic for the future in that more women are becoming diagnosed. BUT we still have a long way to go.



Autism & people from ethnic minority backgrounds

Autistic people and their families come from a variety of ethnic, cultural, and religious backgrounds.

BUT not all autistic people are able to access the same diagnostic services and support. Research has shown that autistic people and families from ethnic minority groups can face double discrimination, due to their ethnicity and disability (National Autistic Society, 2014).

Factors such as language barriers, stigmatisation and a lack of cultural understanding can impact an autistic individual's path to assessment, diagnostics, and support.

The National Autistic Society's 'Stories from the Spectrum' highlights some of the diverse experiences of autistic people and their families; including, attitudes towards autism within their communities, being a part of more than one minority group, and why it's important to represent autistic people from all backgrounds.

"I love being an autistic, Muslim Pakistani woman. My identity in itself is so diverse, which I am really proud of! It does make it harder to live so freely however, with all of the stigma and discrimination that surrounds both autistic people and Muslims. Race and autism intersect a lot and talking about race in autism conversations is so important."

- Iqra Babar, autistic artist

(taken from NAS <u>'Stories from the Spectrum'</u>)

We are aware that research in this area is long overdue and that efforts must be made to provide culturally appropriate support and representation for everyone in our community regardless of their ethnicity.

What is the 'Experts By Experience' (EBE) forum?

EBE is a forum of diverse, autistic people who meet regularly to review and advise on Autism Hampshire's strategy, policies and services as well as providing advice to local organisations who may need help to ensure they are being inclusive to autistic people.

The forum has the following responsibilities:

- Endorsing/approving research proposals and surveys
- Contribute views to draft strategies and developments
- Feedback on Autism Hampshire processes/policies and planning for future developments
- Discussing current challenges/developments for neurodivergent people nationwide and how Autism Hampshire could support these locally
- Personal updates from forums and meetings attended both local, national and international
- National/International developments and research

What is the Information, Advice & Guidance Service?

Our team are able to offer support, guidance, information and advice relating to autism matters. They have extensive knowledge of Southampton, Portsmouth and Hampshire autism-related services and community opportunities.

They work with individuals, familes, and professionals to:

- Help work out coping and adaptive strategies for anxieties, behaviours and/or social interactions
- Signpost to other organisations that can offer further support
- Advise on how to request autism diagnostic assessments for adults and children
- Design and provide visual scheduling support packs to aid communication
- Give presentations of appropriate equipment and resources to try before you buy
- Suggest reading material and websites to assist your understanding of autism

Our friendly team are available on the telephone (Monday to Friday 9 am - 5 pm) and by email:

General Enquiries

Tel: 02380 766162

Email: information.advice@autismhampshire.org.uk

What is Serendipity?

Our Serendipity groups are a great way for autistic adults to meet in a supportive and non-judgmental setting. Each group is welcoming and encourages new members to join and participate in any way they feel able to. If a new member just wants to come to a group and listen to others, then that is respected and there is no expectation that every member needs to participate.

Some groups are delivered online, and some groups are delivered in person. All groups are facilitated by a trained volunteer as well as our Serendipity team and/or community partner organisations.

To find out more about who the groups are for, when they run, and how to join, head to:

https://www.autismhampshire.org.uk/how-we-can-help/serendipity-social-groups/

Get in touch

Tel: 01489 880881 and ask for Serendipity

Email: serendipity@autismhampshire.org.uk

What is Training & Consultancy?

Autism Hampshire offers high-quality, CPD-accredited training, and consultancy which differs significantly from that offered by many other providers in that the content is created, designed and, wherever possible, delivered by autistic people themselves.

We also give priority to the work of autistic authors and academics, and only cite mainstream research if it has been coproduced and/or accurately reflects the lived experience of autistic people.

By combining first-hand insights with innovative, & immersive exercises, our trainers and consultants can offer fresh & authentic perspectives to both total newcomers, and those with experience in more standard 'awareness' training, or consultancy.

You can find out more about the different types of training and consultancy, as well as the fees associated, in our Training & Consultancy brochure and by contacting the training team.

Get in touch

Email: trainingadmin@autismhampshire.org.uk

What is the Specialist Mentoring Service?

The specialist mentoring service is a person-centred service; our mentors tailor strategies and techniques to an individual's learning styles, needs and preferences. Students' one-to-one sessions are based on what is important to them and how they can achieve academic success and progress towards their personal goals.

Who does the service support?

- Students referred to us by the University of Portsmouth through the ASDAC team or Student Finance England and Disabled Students' Allowance funding
- Students with additional needs a diagnosis of autism, mental health concerns or other specific learning differences

Mentors empower students to:

- Develop a better understanding and awareness of their individual needs and how to ensure that these are met in university life and academic study
- Design coping strategies and approaches that enable students to overcome barriers to learning and manage their studies successfully and independently
- Create person-centred strategies that support with time management and organisation
- Establish routines that promote positive wellbeing
- Discover effective strategies that facilitate communication with university services, peers or a department or faculty,

Mentors can also signpost to local and university services for support available when needed.

Email: ahspecialistmentoring@autismhampshire.org.uk

What is Supported Living?

Autism Hampshire provides support teams to people living in their own homes. Support varies dependent on individual needs, but can include support with personal care, leisure activities, cooking, cleaning and household chores.

People we support include autistic people, people with learning disabilities, mental health problems and physical disabilities.

Our supported living service is regulated by the Care Quality Commission (CQC). For more information on our supported living service, please contact us on:

C Tel: 01489 880881

Email: info@autismhampshire.org.uk

What is the Autism & Health project?

Autism Hampshire launched an innovative new project in July 2022 to help autistic people get the best out of health care services.

We aim to support autistic people to access health services, addressing some of the difficulties that autistic adults can experience in getting the care they need.

Why is this support needed?

Getting to see a GP or other healthcare professional can be an incredibly stressful experience for autistic people, as well as anybody who may need to support someone to access their health services. Research published in 2021 shows autistic people experience multiple barriers in accessing support for their mental or physical health, and are more likely to end up in hospital care or using emergency services. In addition, autistic people are less likely to be satisfied with the healthcare they receive.

Difficulties may include making an appointment, fear of the unknown or unexpected when attending a healthcare site, staff not understanding the autistic person's needs, and processing the information given by the health professional.

What support can Autism Hampshire offer?

Working in tandem with GP practices, the Autism & Health project will provide better support for autistic people through a number of practical measures.

For more information, head to our website:

https://www.autismhampshire.org.uk/how-we-can-help/autism-and-health/

Autism Hampshire has funding from Hampshire County Councils' Get Going Again fund to pilot the project for one year in the following locations:

- Stubbington Medical Centre
- The Willow Group, Gosport
- Havant (location to be confirmed)

The aim of the project is ultimately to provide the services at as many Hampshire GP practices as possible and assist autistic people from this area with hospital appointments and dental appointments too.

To find out more please get in touch through the contact details below:

Tel: 01489 880881 and ask for Autism & Health Email: autismhealth@autismhampshire.org.uk

How to support us

Donate

You can donate to our Silly Socks Day appeal here: https://givepenny.com/appeal-for/silly-socks-day-AAW2023

- 1. Click 'Donate'
- 2. Choose how to donate login, or continue with apple, google, facebook or as a guest
- 3. Leave a message
- 4. Upload a photo for your silly socks!
- 5. Then click 'Donate'

Get sponsored to take part in Silly Socks Day, take on a challenge or organise your own event

Download 'Our Guide to Fundraising' pack here: https://www.autismhampshire.org.uk/events/fundraising-pack

You can create your own fundraising page here: https://givepenny.com/charity/autism-hampshire

Share your page on social media and email to all your friends and family, they can follow the link and sponsor you directly online, making it quick and easy without the need for you to collect cash / cheques.

In Person

We ask that you use the Autism Hampshire sponsorship forms to get cash sponsorships, which are available upon request.

Gift Aid

For every £1 you raise, we can claim an extra 25p back from the government on taxpayers' donations. Please don't forget to tick the gift aid box on your sponsor form or online to make sure the Gift Aid is added. This will need to be completed on all forms of sponsorship including sponsorship forms and online donations.

How your support can make a difference



£10

Could pay for transport for someone we support to access an activity

Could buy craft / art supplies for a community group or supported living

£25

£50

Could buy items for our 'try before you buy' library which includes noise-cancelling headphones and weighted blankets

Could pay for 3 hours of autism training for schools, companies, and community settings

£300

£500

Could buy garden furniture, tools, and plants & seeds for supported living houses



Could cover the costs of running (at least) one Serendipity group for a year

£1000

Thanking and Banking

Don't forget to thank those who have helped make your fundraiser successful. You could do this by phone, email or letter. Our team can offer advice on how to draft letters and emails, and can also provide certificates of achievement / acknowledgment.

Paying in the money you've raised couldn't be simpler and can be done in four ways:

- By post
- Over the phone
- By bank transfer
- Bring us the cash

For more details, check out 'Our Guide to Fundraising': https://www.autismhampshire.org.uk/events/fundraising-pack

Meet our team



Cheryl Claxton

Community and Fundraising Manager



Lizzie Nash

Community and Events Fundraiser



Issy Ward

Marketing Officer

We would love to hear about what you get up to throughout this campaign so make sure you tag us on social media!

Alternatively, you can email us at: marketing@autismhampshire.org.uk

AutismHampshire

outism_hampshire

HampshireAutism

in Autism Hampshire

Autism Acceptance Week Resources

Ol Silly Socks Day poster

02 Bunting

Get involved with

SILLY SOCKS DAY

Wear Silly Socks on Friday 31st March

Help promote autism acceptance, accommodation, and appreciation



