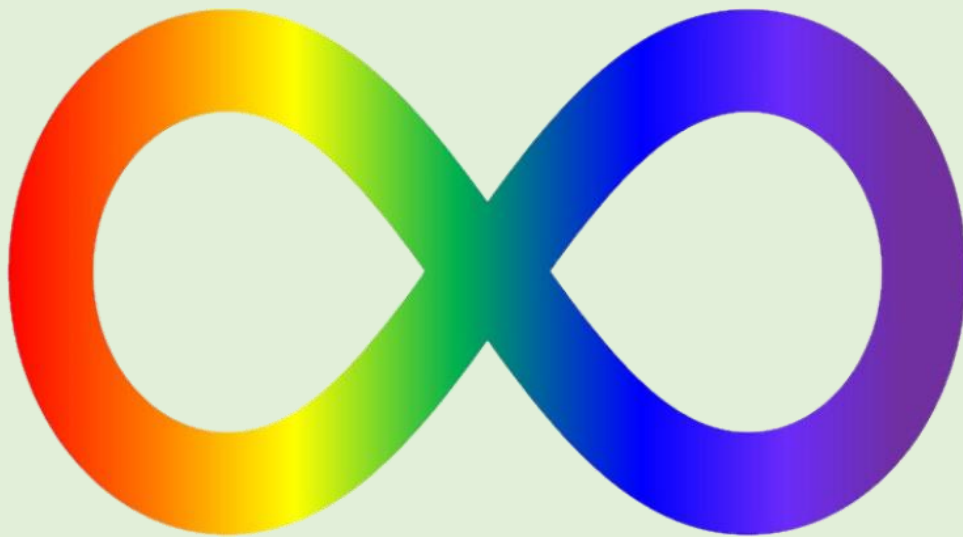


Post Diagnostic Information



**Bedfordshire, Luton and Milton Keynes
Adult Autism Diagnostic Service**

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1) What is Autism?

Formal definition

Autism is a diagnosable neurological difference noted by behavioural categories.

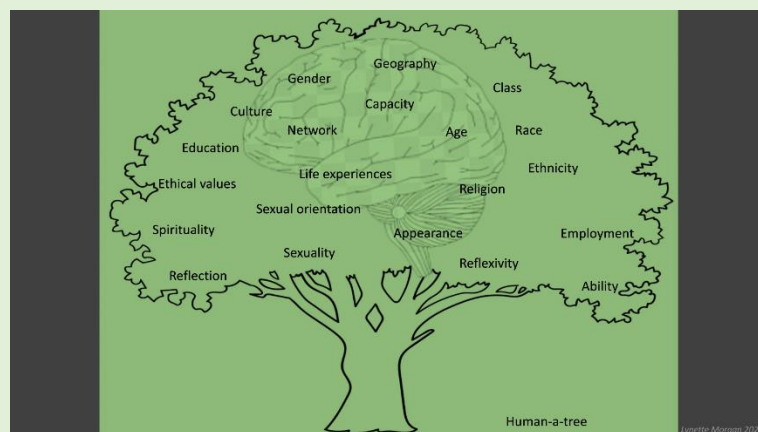
The behavioural categories for diagnosis are set out in two diagnostic manuals. International Classification of Diseases eleventh edition (ICD-11) and Diagnostic and Statistical Manual of Mental Disorders version five (DSM-5).

We measured these behaviours during your diagnostic assessment, along with your developmental history. We look for how they diverge from what is considered 'neuronormative' behaviour.

Contemporary interpretation of autism

There are no scans or genetic tests to identify either the cause or to diagnose autism. However, over the last 20 years there has been significant progress in understanding the autistic perspective.

A way that is considered helpful is to think about autism as part of a diverse experience of life. That all humans are 'neuro diverse' and are equally influenced by many different factors like those in the image below:



Neurodiversity

The way that humans behave is a complex combination of influences from all these and other things like our genetics as well our emotional and cognitive function. This means that not one person will be the exact same as another and therefore will have some variation of the way they behave. What has been known for over a century is that there is a group of people who diverge (neurodivergent) from this variation, and that the similarities in those behaviours have been described as per the diagnostic manuals mentioned above.

Neurodivergent

Autistic people experience interactions with others differently regardless of social or cultural contexts. Their senses may enhance or reduce certain external or internal experiences. Autistic people may find their attention is pulled to:

- Details of routine
- Interests
- Reducing ambiguity
- Sensory processing

to a degree that differs significantly from non-autistic people (Monotropism). Other diagnoses such as ADHD, dyspraxia etc have also been described as neurodivergent.

Monotropism

Monotropism is a term to describe flows of attention for autistic people. It is a theory that helps describe the pull of attention to a single point as a way of finding joy and interest as well as managing the 'noisy' and unpredictable nature of life. It suggests that being forced to change from this focus of routine, interest or plan can cause a broad range of reactions from anxiety, inertia, to significant distress (like a meltdown/ shutdown).



Conversely polytropism is a term used to describe focus across multiple flows of attention, it allows a person to have a broader scope with less detail. This is a cognitive profile that nonautistic people are more likely to have and thus be able to multitask and switch between tasks with relative ease. Whilst ADHD appears to have both polytropic and monotropic flows of attention, often described as being pulled in several directions at once. Sometimes this is highly effective whilst other times it precipitates inertia.

Our service perspective

Autism is much more than 'behavioural' categories. We have to use the diagnostic manuals for a valid diagnosis, but we acknowledge their limitations. Not just in the language that is used but more importantly in understanding the context and narrative behind people's experiences. Especially in relation to personal experiences of their sensory world, environments, intersectional identity or any life impacting events that may have occurred.



In Summary

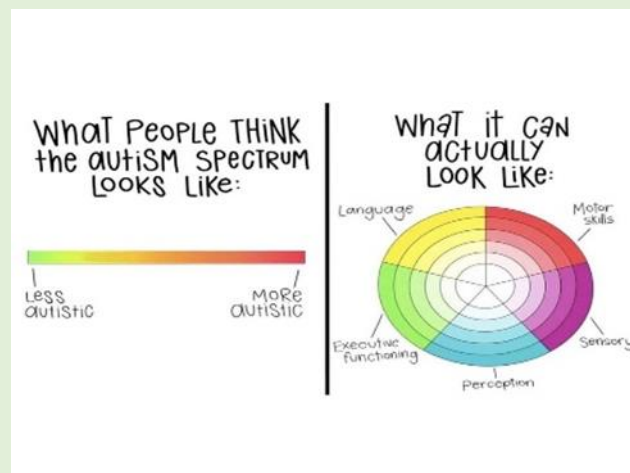
Autism is diagnosed using diagnostic tools which are used to measure the categories outlined in the diagnostic manuals.

Autism is neurological, lifelong and may mean that your development and experiences are not the same as the expectations of society. How you experience being autistic or may have experienced it, is likely to be affected by what sort of environment you are in, as well as what resources and community has been or is available to you.

We do not know why people are autistic and some are not, but we do know that it is highly heritable and therefore families will often have a number of autistic relatives.

2) What autism isn't?

- Autism is not caused by vaccines
- It is not something that can be cured or even be considered curable.
- Definable by high or low functioning
- It is not always accompanied by a learning disability
- That you don't have a sense of humour
- Autistic people are geniuses (+/ have savant skills) or are cognitively impaired.
- It is neither an excuse nor a precursor for 'behavioural difficulties or immorality'
- It does not mean that you cannot empathise
- You do not have a superpower
- It does not mean that you cannot make eye contact.
- Being autistic does not mean that you don't have treatable mental health conditions
- That you cannot or do not want relationships/ friendships
- Not everyone is a little autistic or 'on the spectrum'
- It is not caused by bad parenting



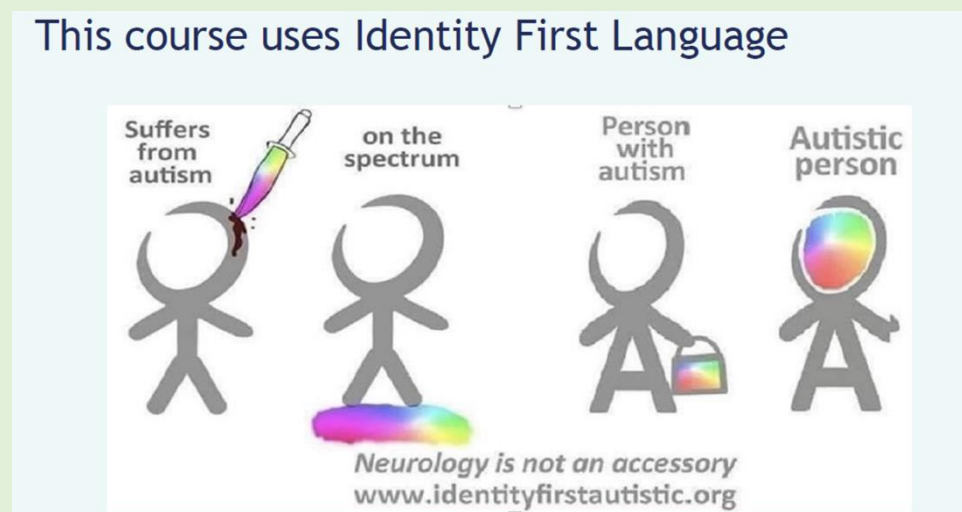
3) Different terms for Autism

The term 'autism' was first used by a psychiatrist in 1908. Following this; many other terms over the years have been used to describe autistic individuals. You may have heard of some, or all, of the previously used terms which include: *Childhood Autism*, *Kanner's Autism*, *Infantile Autism*, *Pervasive Developmental Disorder (PDD-NOS)*, *High Functioning Autism (HFA)*, *Asperger's Syndrome*, and *Autism Spectrum Disorder (ASD)*. ASD is the term currently used in diagnostic manuals for formal diagnosis. Autism may also be referred to by some people as Autism Spectrum Condition (ASC) or more colloquially as someone being 'on the spectrum'.

Among the autistic community, as well as developing professional practice, it is recognised that the term 'disorder' is one of deficit and carries negative connotations. It is not the preferred term to use when describing autism, therefore you may see 'disorder' replaced with 'condition' in literature, or alternatively just the word 'autism'.

A more recent addition to the language used to describe autism, is the term 'neurodivergent/ce'. The official Oxford dictionary definition is: *differing in mental or neurological function from what is considered typical or normal (frequently used with reference to autistic spectrum disorders); not neurotypical*. Essentially, being neurodivergent is to differ neurologically from the perceived neuro-majority (non-autistic or neurotypical individuals).

A note on language: Many in the autistic community prefer identity first language (i.e. 'autistic person' instead of 'person with autism'). Some autistic individuals do not necessarily prefer identity first language, therefore it is always best to ask.



A helpful resource around language to describe autism is this blog, written by an autistic researcher: <https://annsautism.blogspot.com/2021/07/appropriate-descriptions-around.html>

4) What these differences might mean for you?

The double empathy problem

Damian Milton first used the phrase 'the double empathy problem' in 2012. This revolutionary reframing of autistic experience has enabled both autistic people and non-autistic (neurotypical) people to understand the mismatch in communication and the burden this puts on autistic people. It is generally expected that autistic people will adjust their way of communicating and living to conform to neurotypical behaviour. The way this may impact your life and wellbeing is significant as it is not only suggestive of fault, but it is also cognitively exhausting.



If you want to learn more about the double empathy theory, we recommend that you watch this video recorded by Kieron Rose; The Autistic Advocate for the National Autism Training Program. https://youtu.be/qpXwYD9bGyU?si=XIXhKevmRT_rLVqI

Sensory Processing

Like everything, the way we process and experience different sensory information is unique to everyone. There are eight main senses which are useful to understand how you may experience the world differently from others.



Hearing Many, but not all autistic people have sensitive hearing (hyperacusis), this can mean that sounds that aren't audible to others can be intrusive and difficult to ignore. It may also mean that it is difficult to distinguish between people talking; if many are talking at once or in the same room. Conversely some people seek sound as a positive stimulation, music for example. It is entirely possible to be both sensitive to sound as well as enjoy stimulus from sound. Many autistic people use familiar noise like music or sounds to block out unexpected noises.



Sight A classic example of sensitivity for autistic people is artificial lights (like strip lighting), but sometimes lots of different visual information can be overwhelming and confusing just as much as lighting. Equally many autistic people enjoy visual stimulus in detail and enjoy lights or colours in a way that neurotypical people do not seem to.



Vestibular sense gives us information about body position and movement in relation to gravity, whether you are still or moving when we are moving (in what direction and

at what speed). It impacts on balance, posture, spatial awareness, coordination and movement. Examples of some difficulties associated with vestibular sense are things like stepping down from a curb or leaning back can be overwhelming, some autistic people are particularly sensitive to motion in the form of travel sickness. Examples of positive feedback and calmness can come from movements like swinging/ swaying, jumping, spinning. It is important to remember that these are just examples and may differ for you.



Interoception how we experience our internal bodies. Things like hunger and thirst for example are sensations that some people find difficult to monitor and may not be able to distinguish from physical sensations of anxiety. Whilst others may find that every sensation has an effect on mood. It is possible for people to seek sensations which are felt through our bodies either through what you consume or other sources of feedback. Although thermoception (temperature) and nociception (pain) are also senses they are part of our internal sensory system. There are studies that suggest that how autistic people experience, process and react to pain is different from neurotypical people.



Proprioception active signals from muscles and joints (different from deep pressure which is passive and signals through the skin). Force and applying pressure eg gym activities is regulating- can be both calming and alerting. is our sense of place and position in space. A good way to consider proprioception is to think of shutting off all other senses and make judgements about where you are and where your body is in relation to the environment. The way that proprioception is experienced in the context of everyday life is more specifically how we feel the pressure of things, people, animals that are in contact with our bodies. For example, there are people who enjoy pressure of firm cuddles, or weighted blankets, people who find light touch excruciating and people who find any kind of contact extremely upsetting.



Taste Something that gets talked about a lot in respect of autistic experience is sameness. This is not excluded from taste. Sensory perception about specific tastes and how they can differ has been known to create food aversions. With some people sticking to the same foods which are predictable and unchanging- things like processed foods for example. It goes without saying that a balanced diet allows us to consume the right nutrients to remain healthy. But it is also important to understand that this can be harder particularly if you are needing to reduce ambiguity. Something to note that the flavours of medicines as well as the sweet tasting coating on some medicines can be unpalatable for some who's sensitivity is attuned to these particular tastes.



Touch Many people enjoy the sensory feedback of different textures and temperatures. A classic example is an intense feeling of discomfort as a result of clothing labels, materials, or wet/ slimy sensations. Some may enjoy these feelings and others may find it difficult to discriminate between textures. Other examples include sensations of being touched either lightly or firmer, either of which may trigger pleasant or unpleasant sensations. Vibrations are also sensations known to create either particular pleasure or discomfort.



Smell Is a primal sense that has a fast synaptic connection with our emotional and memory cortices. For example, disgust from smells and moral disgust comes from the same part of the brain. Smell also affects our taste. So, whilst it is usually easy to name smells we like or dislike, the part about smell which is particularly interesting is how it may trigger memories, emotions or physical sensations like nausea.

Our senses are how we understand our external and internal world. We build learning and memories around these senses which influence our behaviour. This is why understanding your own sensory experiences can be helpful to learn what brings you joy and what may cause distress. It is also useful to understand that sensory processing experiences are not fixed; they can change sometimes as a result of things like stress, illness or hormonal fluctuations, and/or changes in your environment. They can also change at different times in your life. I.e. between childhood and adulthood and so on.

Many of these things can occur without you knowing, so you may find that you are exhausted, feeling overwhelmed or unable to function without really knowing why. Senses interplay not just with your brain they also relate to each other. For example, as described above with smell and taste. Developing a healthy sensory diet is about learning what things bring you joy and what causes you overwhelm. By understanding these you can learn to balance your life around allowing you space to experience positive sensory feelings.

Spiky skills profile

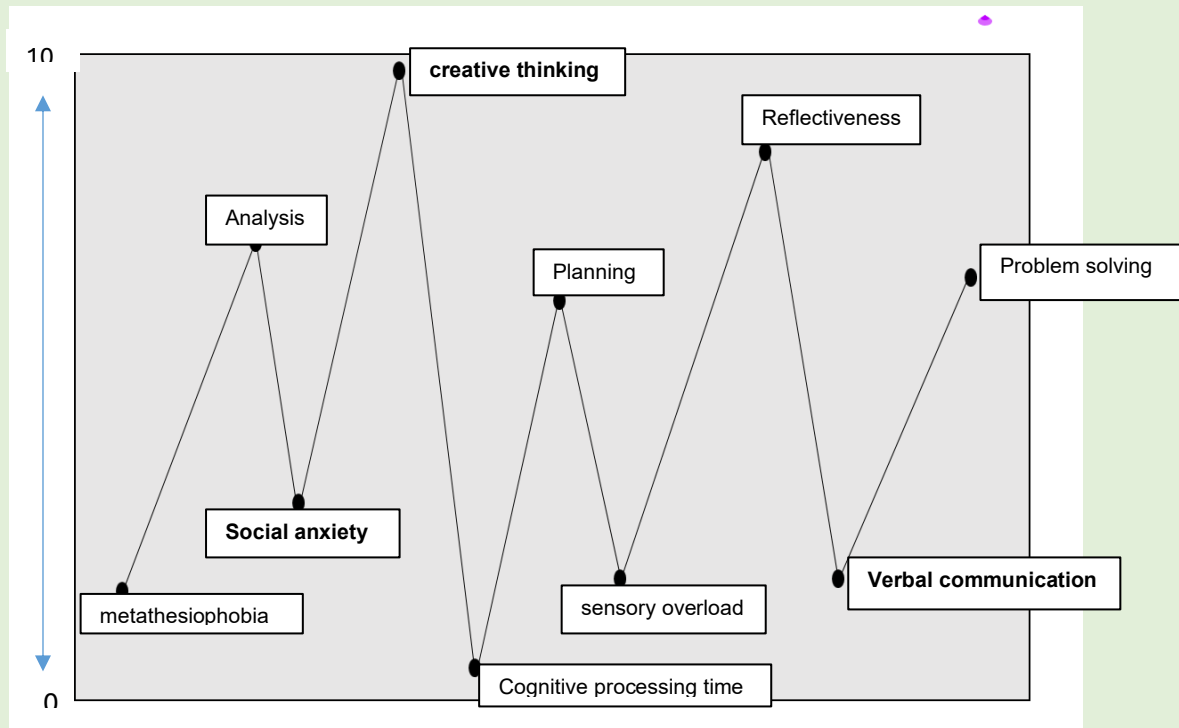
For many years autistic people were seen as being either 'high functioning' or 'low functioning'. There are some problems with this description.

- 1) functioning is a broad term, which without context is meaningless.
- 2) People assumed functioning is equal to 'IQ'.
- 3) Ability to 'function' regardless of what that might mean is not static for any human.
- 4) People have been positively and negatively discriminated by these labels.
- 5) Assumptions have been made about people's ability to maintain their own safety and wellbeing based on these labels.

It is also evident that for some who were deemed 'high functioning' the pressure to succeed regardless of how difficult this may be has taken its toll on their mental health. Whilst those with a low functioning label would not have opportunity to succeed and may not have any autonomy in their lives at all.

This is why we believe that the spiky skills profile is a much more accurate way to describe the autistic experience.

1) Intelligence Quotient. IQ tests measures things like memory, problems solving, recall and the speed at which these can be achieved.



Spiky skill diagram (*metathesiophobia- phobia of change or the unknown*)

This diagram is a basic representation of a spiky skills profile as an example. Getting a diagnosis can help you build an understanding of some of the things which you may find have caused difficulty and others which have helped you. Being good or bad at something, finding that some things are easier for you whilst others are harder and noticing that all these things can change some degree over years and sometimes minutes is part of the human experience. What we see is that autistic people experience different degrees which can have varied impacts dependant on how well their differences are catered for through things like reasonable adjustments.

5) Benefits of getting a diagnosis:

We recognise that not everyone who receives a diagnosis will feel it is beneficial, there are many reasons people say they do not like it, these are examples of reasons people have shared with us:

- they don't want to be different,
- they feel that their lives will never get better,
- Their culture or family have a negative view of autism
- They frame every negative experience because of 'autism' and see it as something separate from themselves.
- They have difficulty shifting their understanding from a medical model of disability (deficit base) to the social model of disability.

We hope that we can address some of those difficulties in this book. Being autistic *is* an intrinsic part of who you are; many people feel validation after diagnosis. Many autistic individuals have reported that either formally or self-identifying as autistic has allowed:



Identity and belonging: Autistic identity and a sense of belonging has been found to be a key factor in thriving and wellbeing of autistic people. Many autistic people find that a formal diagnosis stops them from feeling like they are less than non-autistic people. It further enables clarity on authentic identity.

Masking and reframing of experiences: Masking is a coping strategy which everyone does. However, for autistic people it is both protective and harmful. In simple terms masking allows people to seem/ feel/ be socially accepted, in more broader terms masking restrains and suffocates identity. Masking is a behaviour that is learnt in early development and is almost entirely subconscious and natural. Where that changes from being protective to harmful is very difficult to determine, especially for later diagnosed people whose authentic self may have been deeply suppressed from early childhood.



Reframing of experiences After diagnosis this realisation can be very difficult exposing trauma that may require support. If you feel that this is the case for you, please know that you are not alone many autistic people experience this. There are helpful resources at the end of this book.



Self-compassion: Self compassion is a natural healer after a late diagnosis. For those who have internalised ableism, trauma, and low self-worth, building self-compassion, allows you to acknowledge that difficulties you may have experienced are not of your making. Often people feel anger, at the world, at others around them and at themselves. Self-compassion helps understanding and perspective so that you can process difficult feelings.



Advocacy: a formal diagnosis can give many autistic people the courage to voice the societal barriers and their experiences in a way that feels validating and safe, without the fear of non-autistic individuals questioning or challenging them. Remember- autistic people have the right to equity in all services, work and education if you are finding any of these inaccessible, it is not a failing in you, it is a failing of society in removing barriers. ***'Adjustments reflecting diversity of humanity make accessibility reasonable for all, not just the privileged'.***

Reasonable adjustments: See section 9) below

6) Disclosing your diagnosis

It is completely your choice, no one should make you disclose your diagnosis. Telling people about your diagnosis can be beneficial but it can also sometimes create difficulties. So, you may wish to consider some of context and purpose before you share with others (for example the points below):

1. What is the person's or individual's understanding of autism?
2. What impact will their understanding have on you and your life?
3. What can you do to help people understand?
4. Why do you want to tell them about your diagnosis?
5. What role do they have in your life and how will this knowledge impact your relationship with them?
6. How will you respond to people if they have strong opinions or beliefs about what autism is?
7. What are the Pros and cons of disclosing.

It may be helpful think about it like this:

<p>What you hope will happen Vs What is likely to happen</p>

What can you do to help these to be as close to the same as possible?

Some people may find it very hard to understand; whilst others may not even believe that autism exists. Some people may be overjoyed, not surprised, or disinterested and others may be hurt by your disclosing it. You may find it useful to share this book with them or direct them to the resources listed at the end.

This strategy may not help everyone; it is important to note that there is no way to capture the nuance and context of your experience. But we would encourage you to take your time in making this choice.

When you tell employers and professionals supporting you there is a legal duty to make reasonable adjustments under the Equality Act 2010. **Please see reasonable adjustment section no. 9** for more information.

7. Possible co-occurring diagnoses

There are several other diagnoses that autistic people may have, and this is evolving all the time as new research is published.



ADHD - A lifespan diagnosis thought to affect 1 in 5 people. This affects every person differently and in adults can include forgetfulness, struggles with maintaining concentration and planning as well as sensory differences. Research shows between 50 and 70% of autistic people also have ADHD.

[Help & Resources - ADHD Foundation](#)



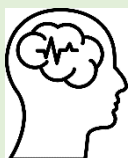
Dyslexia – a specific learning difficulty which affects word reading and spelling and can also affect processing speed and working memory.

[Dyslexia - British Dyslexia Association](#)



Dyspraxia/Developmental coordination disorder – Affects coordination, motor skills and learning of new skills. Can also experience sensory differences as well as difficulty with things like planning and memory. Up to 60% of people with dyspraxia/DCD are thought to be autistic/ADHD.

<https://dyspraxiauk.com/diagnostic-criteria>



Epilepsy – It is estimated that 12% of autistic people also have epilepsy compared to 1% of the general population.

[What is epilepsy? - Epilepsy Action](#)



Ehlers-Danlos syndromes – A group of 13 genetic conditions affecting the connective tissues that can cause hypermobility, joint pain and instability, dizziness and extreme tiredness.

[What is EDS? - The Ehlers Danlos Society](#)



Alexithymia – Higher rates amongst neurodivergent people 50% of autistic people versus 5% of non autistic people. Alexithymia can be across several areas including: difficulty in distinguishing between emotions and body sensations, difficulties in identifying and describing feelings, paying more attention to things happening around you than to internal experiences.

[What is Alexithymia? Alexithymia Defined and Explained - Neurodivergent Insights](#)

[Alexithymia | Autistica](#)

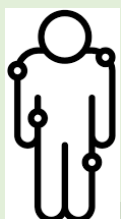


Eating disorders – Estimates vary but indicate around 35% of people with an eating disorder are autistic or have high autistic characteristics. Most reported are anorexia nervosa and ARFID (avoidant and restrictive food intake disorder) although autistic people can experience other types of eating disorder too.

[Eating disorders and autism - Beat](#)

[ARFID Awareness UK](#)

[PEACE Pathway - Home](#) - recommendations for supporting autistic people with an eating disorder.



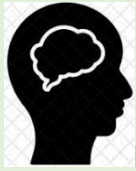
Fibromyalgia- A long-term condition that causes widespread chronic pain and fatigue. This also can affect memory and concentration and cause increased sensitivity to sensory input.

[Fibromyalgia | NHS inform](#)



Gastrointestinal issues – Constipation, diarrhoea, IBS, GERD and food sensitivities are all reportedly more common in autistic people but research conclusions vary.

[Guts UK - committed to fighting all digestive diseases](#)



Mental Health conditions – There are higher rates of mental health diagnoses including anxiety, trauma and depression in autistic people (80%-90%). Mental illness in autistic people can be as a result of fitting into neurotypical society.

[Autism and mental health - Mind](#)

Please consider speaking to your GP for advice if you are worried about any of the conditions mentioned above.



LGBTQ+ Community

Research indicates that neurodivergent individuals are more likely to identify as LGBTQ+ compared to the neurotypical population.

The intersectionality of being autistic and LGBTQ+ can increase vulnerability to mental health problems due to minority stress and discrimination. The minority stress model is the idea that stigma and discrimination of being in a minority adds layers of marginalisation which can cause poorer physical and mental health outcomes.

Transgender people



Transgender is used here as an umbrella term encompassing people whose gender identity differs from their sex assigned at birth. This includes people who identify as non-binary or gender diverse (e.g. genderqueer, agender).

There are various studies that indicate autistic people are more likely to identify as transgender or non-binary, with one study of transgender adolescents and young adults citing this as 22.5%.

Additionally, the trans community report significant barriers to accessing the right physical and mental health care with GP's often not being aware of their needs. They often experience higher rates of depression, anxiety and suicide than cis-gender people with 46% reporting considering suicide.

<https://www.stonewall.org.uk/young-futures/disabled-and-neurodivergent-lgbtq-support>

<https://lgbt.foundation/autistic-and-neurodivergent-programme/>

<https://transactual.org.uk/law/>

<https://www.cam.ac.uk/research/news/autistic-individuals-are-more-likely-to-be-lgbtq>
[Gender-related self-reported mental health inequalities in primary care in England: a cross-sectional analysis using the GP Patient Survey - The Lancet Public Health](#)

8) Changes and transitions

Big milestones or changes to everyday life can be a challenge for many individuals to experience, and for autistic individuals this challenge may/can feel particularly overwhelming due to a number of factors; such as: sensory, cognitive and emotional processing, sudden vs. planned changes, the control one has over proposed or implemented changes, differences in executive functioning and processing of information etc.

Every individual 'deals' or 'copes' with change in their own way, and an autistic individual will need to explore how they personally deal with change. This will likely look different to the neurotypical majority and expectation.

Common changes that can impact on well-being:

- Educational transitions
- Parenthood
- Bereavement
- House moves
- New job
- Relationship breakdowns/New relationships
- Menopause/ pregnancy

9) Reasonable Adjustments:

Equality Act 2010

- As an autistic person you may not consider yourself as disabled, but the important thing to know is that autism comes under this category in the Equality Act.
- The Act lists disability as a 'protected characteristic' and includes a duty for employers, education providers and other organizations (such as hospitals or local councils) to make reasonable adjustments.
- You do not need to have a formal diagnosis to meet the legal definition of a disability as the focus is on the effects being long term (has lasted or is expected to last over 12 months) and substantial (defined as more than minor or trivial).
- There is a duty for employers and education institutions when they could 'reasonably be expected to know' that someone may meet the legal definition of disability.

Reasonable adjustments

These are changes that organizations, employers or education should make to ensure that you are not at a disadvantage compared with non-disabled people. There are three categories of reasonable adjustments:



- Changing a rule or way of doing things - for example changing your work hours.
- Changing a physical feature of a building - for example steps or lighting.
- Giving you equipment or help - for example a screen reader or software.

Education: Under the Act higher education institutes (e.g. colleges or universities) must provide reasonable adjustments for students with disabilities and take steps to find out if any students are disabled.

Case law – University of Bristol Vs Abrahart – the EHRC upheld claims against the university related to disability discrimination and failure to make reasonable adjustments for a student without a reported disability. **This clarified that *knowledge of a disability does not depend on a formal or official diagnosis from a medical professional or disability support services at the university.***

[Unleashing the anticipatory reasonable adjustment duty: University of Bristol v Abrahart \(EHRC intervening\) \[2024\] EWHC 299 \(KB\) - Achas K Burin, Shreya Atrey, 2024](#)

Employment:

There is no clear definition of what is ‘reasonable’ and this can vary depending on the situation. Factors that will be considered by your employer include what you need and the difference it will make to you, cost, practicality and whether the adjustments would have a negative impact on access needs or health and safety for other people.

Example:

An employee finds working in a busy office environment challenging due to the noise levels causing sensory overwhelm. Reasonable adjustments could include:

- To provide the employee with noise cancelling headphones.
- Working in a smaller office with less noise.
- Agreeing to do some work from home.

Further information and how to request reasonable adjustments:

<https://www.acas.org.uk/reasonable-adjustments>

[Asking for reasonable adjustments if you're disabled - Citizens Advice](#)

If you are not sure what might help you the reasonable adjustment checklist below may be a helpful starting point:

<https://www.cwp.nhs.uk/ra>

Autism and Education

Autistic children, teenagers and young people may need additional help and support with education. Some will need highly specialised educational placements. Others will stay in mainstream education with little support.

You can find details of your council's local offer on their Council websites:

Milton Keynes: <https://www.mksendlocaloffer.co.uk/>

Bedford Borough Council: <https://localoffer.bedford.gov.uk/kb5/bedford/directory/home.page>

Central Beds Council:
<https://localoffer.centralbedfordshire.gov.uk/kb5/centralbedfordshire/directory/home.page>

Luton Borough Council:
<https://directory.luton.gov.uk/kb5/luton/directory/advice.page?id=l46o14gRVL0&directorychannel=0&directorychannel=0>

10) Resources

Some autistic people may need formal referrals to additional services for their health and social care needs, following their diagnosis of Autism. Some services may be related to mental health needs, housing advice, benefits support, or carer's needs. Further information on this can be found below:

The Milton Keynes Council website <https://www.milton-keynes.gov.uk/>

There are links to Adult Social Care on this website that may be helpful in providing more information on any support you may require: [Request for Care and Support, and Eligibility Checker - MyCouncil \(milton-keynes.gov.uk\)](#)

Bedford Borough Council website <https://www.bedford.gov.uk/>

There are links to pages about adult social care and how to request an assessment: <https://www.bedford.gov.uk/social-care-and-health/adult-social-care/support-we-can-offer-you>

Central Bedfordshire Council website <https://www.centralbedfordshire.gov.uk/>

Information regarding adult social care and eligibility can be found here: https://www.centralbedfordshire.gov.uk/info/18/health_and_social_care

Luton Borough Council website <https://m.luton.gov.uk/Page/Show>

Pages on adult social care and eligibility for support are available here:

https://m.luton.gov.uk/Page/Show/Health_and_social_care/adult_social_care/Pages/default.aspx

Carers MK (www.carersmiltonkeynes.org)

This is an independent local charity who support unpaid carers in the Milton Keynes area.

They offer support such as counselling, creating emergency plans, support groups and carer workshops. They can also refer to other services if that be helpful for other needs.

Carers in Bedfordshire <https://carersinbeds.org.uk/>

A registered charity who offer support to unpaid carers across Bedfordshire (including Luton). They hold regular groups and workshops as well as offering phone support and signposting to other services if required.

Talkback ([Autism and Learning Disability Services | Talkback | Your choices \(talkback-uk.com\)](#))

Talkback is an autism and learning disability charity that provides a number of different programmes aimed at personal development, such as: employment support, personal skills, and transitional support.

For community and connect across the entire of Bedfordshire and Milton Keynes TalkBack have a peer led (autistic led) program where you can meet other people locally and share your experiences, learn from them and gain reciprocal validation.

Autism Bedfordshire ([Support for Adults » Autism Bedfordshire](#))

Autism Bedfordshire is a charity that helps to break down barriers to social participation for autistic people and their families.

They provide pre and post diagnostic support for autistic individuals in the form on social groups, open days, workshops, skills groups, support for autistic carers, and a helpline.

Track NN ([Home | Northampton | TRACK | Consultancy](#))

Track NN was set up in Northamptonshire in 2018 to support autistic people to access employment, through training, support services, and creating opportunities.

Additional web resources

- ❑ **The National Autistic Society** (www.autism.org.uk)
- ❑ **Autism Alliance** (www.autism-alliance.org.uk)
- ❑ **Autism Central** ([Autism Central for Parents and Carers | Autism Central](#))
- ❑ **Autistica** ([About-us | Autistica](#))
- ❑ **The Curly Hair Project** (www.thegirlwiththecurlyhair.co.uk/)
- ❑ **Autistamatic** <https://www.autistamatic.com/>
- ❑ **Autistic Girls Network** [Welcome to the | Autistic Girls Network](#)

Books about autism

- ❑ **The Reason I Jump** Naoki Higashida
- ❑ **Neurotribes** Steve Silberman

- ❑ **We're not broken** Eric Garcia
- ❑ **Autistic masking** Kieran Rose and Amy Pearson
- ❑ **Untypical** Pete Wharmby
- ❑ **Autism in Adults** Luke Beardon
- ❑ **Avoiding anxiety in autistic adults** Luke Beardon
- ❑ **The Electricity of every living thing** Katherine May
- ❑ **Letters to my weird sisters** Joanne Limburg
- ❑ **Rediscovered** Catherine Asta
- ❑ **I want to be where the normal people are** Rachel Bloom
- ❑ **Strong female character** Fern Brady
- ❑ **Autism and being monotropic: What medical and other practitioners need to know** Wenn Lawson
- ❑ **Empire of Normality** Robert Chapman
- ❑ **Improving mental health therapies for autistic children and young people** Georgia Pavlopoulou et al
- ❑ **Neuroqueer Heresies** Nick Walker
- ❑ **Safeguarding autistic girls** Carly Jones
- ❑ **Young autistic and ADHD** Sarah Boon
- ❑ **Unmasked- ultimate guide to ADHD and autism and neurodivergence** Ellie Middleton
- ❑ **Being Autistic nine adults share their journeys from discovery to acceptance** Ed Caroline Hearst
- ❑ **Autistic burnout** Megan Anna Neff
- ❑ **Autistic and black** Kala Allen Omeiza
- ❑ **The autistic trans guide to life** Yenn Purkis and Wenn Lawson
- ❑ **Ten steps to Nanette** Hannah Gadsby
- ❑ **The awesome guide for Trans teens** Yenn Purkis and Sam Rose
- ❑ **Self-reported camouflaging behaviours used by autistic adults:** <https://reframingautism.org.au/self-reported-camouflaging-behaviours-used-by-autistic-adults-a-summary-for-non-academics/>
- ❑ **Psychological Therapy for autistic adults:** <https://www.authenticistic.uk/>

Blogs

- ❑ **Emily@21andsensory** - who is an amazing autistic graphic designer, blogger and podcaster www.instagram.com/21andsensory
- ❑ **Dean Beadle** - deanbeadle.wordpress.com/
- ❑ **Pete Wharmby** - www.patreon.com/pwharmbyautism
- ❑ **Ann Memmott** - <http://annsautism.blogspot.com/2019/01/autismsome-vital-research-links.html>
- ❑ **Chris Bonello** – writer of the Underdogs children’s novels, based on the adventures of a group of neurodiverse children. Blog Autistic Not Weird - Insights from an Autistic Teacher and Speaker: <https://autisticnotweird.com/>
- ❑ **Kelly Mahler** [Kelly Mahler](#)

Urgent support

Milton Keynes

<https://www.cnwl.nhs.uk/patients-and-carers/help-mental-health-crisis>

Phone: 01908 724365 or 111

Email: cnw-tr.spa@nhs.net

Beds and Luton

For Bedfordshire and Luton: <https://www.elft.nhs.uk/Contact-Us/Get-Help-in-an-Emergency>

Call NHS 111 (Option 2) for the Mental Health Crisis Line (available 24 hours per day, 7 per week)

Recovery Lounge (formerly Crisis Café) Beds and Luton

<https://www.mind-blmk.org.uk/how-we-can-help/out-of-hours-support/recovery-lounges-formally-known-as-crisis-cafe-2/>

Crisis Café Milton Keynes

<https://www.mind-blmk.org.uk/how-we-can-help/out-of-hours-support/crisis-cafe-milton-keynes/>

Mind BLMK

<https://www.mind-blmk.org.uk/how-we-can-help/>

Mind support line (national) 0300 102 1234 (9am-6pm Mon-Friday))

Talking therapies

Bedfordshire Talking Therapies

<https://www.elft.nhs.uk/bedfordshire-talking-therapies>

email: elft.bedfordshiretalkingtherapies@nhs.net

Phone 01234 880400

Total Wellbeing Luton

<https://www.totalwellbeingluton.org/>

Email: info@totalwellbeingluton.org

Phone: 0300 555 4152

Milton Keynes Talking Therapies

<https://mktalkingtherapies.nhs.uk/>

Email: cnw-tr.iaptmiltonkeynes@nhs.net

Phone: 01908 725099

Bedfordshire Open Door (13-25 year olds)

Bedford and North Beds

<https://www.bedfordopendoor.org.uk/>

Phone: 01234 360388 or 07922 105200

Beds & Luton Recovery College: The Recovery College is open to any adults who live or work in Bedfordshire and Luton. The courses and workshops focus on mental health, wellbeing, and recovery. They are delivered by people with lived experience and professional experience and are free of charge, and a prospectus is available online.

<https://www.elft.nhs.uk/service/382/Bedfordshire-and-Luton-Recovery-College>

Milton Keynes Recovery College: Courses are offered by CNWL's recovery college in London to any adults using CNWL services or living in their catchment area (including Milton Keynes). Their prospectus is available online:

<https://www.cnwl.nhs.uk/services/recovery-and-wellbeing-college/recovery-and-wellbeing-college-london>

National charities/support organisations

Papyrus HOPELINE UK (prevention of young suicide) People under 35 years old

<https://www.papyrus-uk.org/papyrus-HOPELINE247/>

Email: pat@papyrus-uk.org

Phone number: 0800 068 4141

Text: 88247 (24/7)

CALM (Campaign against living miserably)

<https://www.thecalmzone.net/>

Phone number: 0800 58 58 58 (5pm-midnight)

Also have live chat and WhatsApp (from 5pm-midnight)

Samaritans

<https://www.samaritans.org/>

Email: jo@samaritans.org

Authors. Greig, K. Harris-Mandy, F. & Morgan, L (July 2025)

Phone: 116 123 (24/7)

Suicide Prevention UK

<https://spuk.org.uk/national-suicide-prevention-helpline/>

Phone: 0800 587 0800 or 0800 689 0880 (6pm-midnight)

Shout

<https://giveusashout.org/>

Text: 85258 (24/7)

SANEline

<https://www.sane.org.uk/>

Email: support@sane.org.uk

Phone: 0300 304 7000 (4:30pm-10pm daily)