



U USDAW
**CELEBRATING
DIFFERENT
MINDS**

Understanding Neurodiversity

An Advice Guide
for Usdaw Members

U **USDAW**
EQUALITIES

What is Neurodiversity?

Neurodiversity is a term used to describe the diverse, unique and different ways people communicate and interact with others and the world around them.

Around one in five people in the UK are neurodivergent – meaning that they think, learn, process information and communicate differently from what society considers ‘typical’, or neurotypical.

It can be helpful to think of neurodiversity in the same way as we think about physical differences between people. Some people are taller than others, or stronger. Just as we recognise and accept that we are all physically different, the same is true of our brains.

You may know a friend, colleague or family member who is neurodiverse, you may be a parent to neurodiverse children, or you may be neurodiverse yourself.

This guide is designed to provide more information about neurodiversity and where to go for further support.



Neurodiverse Conditions

Common neurodiverse conditions include autism, ADHD, dyslexia and dyspraxia, as well as dyscalculia and Tourette's.

You may hear them referred to as 'spectrum conditions'. This means that everyone's experience of their condition is different. Even people with the same 'type' of neurodivergence will be very different in the way they experience it, the way they prefer to work and their needs.

Neurodiverse people can often have more than one type of neurodivergence; for example, an autistic person may also be dyspraxic, or a person with ADHD may also be dyslexic.

Like everyone, neurodivergent people have things they're good at as well as things they struggle with. While everyone is different, some common strengths associated with neurodiversity can be thinking creatively, attention to detail and the ability for deep focus or concentration on particular tasks or projects.

Being neurodivergent does not mean people can never make friends, have relationships or get a job. But some people may need some extra support and others may need the support of a parent or carer every day.

Making space for neurodiverse people to be themselves, and working to their strengths while being aware of the challenges they may face, is key to creating inclusive and supportive environments.



Signs of Neurodiversity

Signs of neurodiversity are often identified in children at school, but increased awareness of neurodiverse conditions means many adults are receiving a diagnosis later in life.

These signs can present differently in adults and children, as adults have usually spent more of their life trying to 'fit in' by suppressing or trying to hide their usual behaviour.

We have listed some of the more common signs but there are many, many more. Each individual is different and you can find more information about each condition online or by speaking to your GP or health professional.

Autism

Autism is a condition that affects a person's social interaction, communication, interests and behaviour. Autistic children and adults may:

- Find it hard to communicate and interact with other people.
- Find it hard to understand how other people think or feel.
- Find things like bright lights or loud noises overwhelming, stressful or uncomfortable.
- Get anxious or upset about unfamiliar situations and social events.
- Prefer the same routine every day and get anxious if it changes.
- Seem blunt, rude or uninterested in others, without meaning to.
- Take things very literally – for example, they may not understand sarcasm or phrases like 'break a leg'.
- Have a very keen interest in certain subjects or activities.
- Do or think the same things over and over/repeatedly.

ADHD

Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD) can affect how a person behaves and thinks. People can be hyperactive and impulsive or inattentive (meaning people have difficulty concentrating and focusing): you can fall into one or both categories.

Signs of hyperactivity are often picked up in children at school; however, girls tend to present as less hyperactive and more inattentive, disorganised and introverted, and are often under-diagnosed in childhood.

Adults with ADHD may find they have problems with:

- Organisation and time management.
- Following instructions.
- Focusing and completing tasks.
- Coping with stress.
- Feeling restless or impatient.
- Impulsiveness and risk taking.
- They may also have issues with relationships or social interaction.

Dyspraxia

Dyspraxia, also known as Developmental Co-ordination Disorder (DCD), is a condition that affects a person's co-ordination, balance and movement.

Delays in reaching developmental milestones can be an early sign of dyspraxia in young children. For example, your child may take slightly longer than expected to roll over, sit, crawl or walk.

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As people get older, they may have:

- Poor balance; for instance, walking up and down stairs or riding a bike.
- Poor hand-eye co-ordination, find catching or hitting a ball more difficult, or struggle driving a car.
- Poor posture and fatigue, difficulty standing for a long time, weak muscle tone.
- A clumsy gait or movements, and a tendency to trip or bump into things.
- Difficulty with fine motor skills such as typing and handwriting.
- Lack of manual dexterity, or inadequate grip or grasp of objects.
- Issues with speech such as putting their words in the right order, unclear speech or pronunciation.

Dyslexia

Dyslexia is a common lifelong learning difficulty that means people have problems with reading, writing and spelling. Around one in ten people in the UK is dyslexic. A person with dyslexia may find they:

- Read and write very slowly.
- Confuse the order of letters in words.
- Are confused by letters that look similar, and write letters the wrong way round (such as "b" and "d").
- Have poor or inconsistent spelling.
- Understand information verbally, but have difficulty when it's written down.
- Struggle with planning and organisation.

Dyscalculia

Around one in 20 people have dyscalculia, which is a specific and persistent difficulty in understanding numbers. This may include:

- Difficulty counting backwards.
- Difficulty remembering 'basic' mathematical facts.
- Being slow to make calculations.
- Struggling to do basic sums in your head.
- A poor sense of numbers and estimation.

Tourette's

Tourette's, or Tourette's syndrome, is a condition that causes a person to make involuntary sounds and movements called 'tics'. Tics usually begin to appear in childhood between the ages of two and 14 and can include:

- Blinking, wrinkling the nose or grimacing.
- Jerking of the head or limbs.
- Clicking the fingers.
- Touching other people or things.
- Coughing, grunting, sniffing or whistling.
- Repeating a sound or phrase – in a very small number of cases, this may be something obscene or offensive.

Tics happen randomly but can be made worse by stress, anxiety and tiredness. Some people can control their tics for a short while in certain social situations, like in a classroom or workplace, but it requires a lot of additional concentration and can be extremely tiring.



What is Masking?

Neurodiverse people often feel under pressure to hide their true selves to fit in. This is called 'masking'. It is a way of, consciously or unconsciously, trying to blend in and be more accepted by suppressing or hiding your usual behaviour, speech or movements.

Research suggests neurodiverse people learn how to mask by watching, analysing and mirroring the behaviours of other people around them, either in real life or on TV.

Masking who you are takes a huge amount of energy and can be exhausting. In the words of one Usdaw rep:

"I can behave just like a neurotypical person, but it takes me a lot more to get there. It's like watching a stage show. You see the Peter Pan character flying across the stage. But you don't see all the work and all the extra people and effort that are behind stage making that happen."

The term is most often used to describe the experiences of autistic people; however, many neurodivergent people will find themselves masking throughout some or all their lives.

Neurodiverse women and girls may be more likely to mask than men and boys, due to different social expectations of how men and women should behave. Neurodivergent adults who are diagnosed later in life may also mask more compared to people who are diagnosed in childhood.



Parents of Neurodiverse Children

Raising a neurodivergent child can be a rewarding, yet challenging experience for parents.

Neurodivergent children and young adults, including those with ADHD, autism, dyslexia and other conditions, have unique needs that can require support, patience and understanding.

Day-to-day activities such as getting your child to sleep at night, getting ready for school on time, listening to and following instructions and attending social and family occasions may be more difficult for you and your child.

Parents can face challenges related to stress, anxiety and feelings of isolation. Connecting with other parents in similar situations can provide valuable support and reassurance.

Usdaw wants to support parents who are members to take care of their own well-being so that they can continue to offer the best support to their children.

Navigating the education system can be really challenging. Making sure your child receives the appropriate educational support can be a complex process, but there are resources available to help parents advocate for their child's needs.

You can find out more about sources of support in the 'Where to Go for Further Support' section on page 12 of this guide.

Parents and carers of neurodiverse children, teens or adults may also need more flexibility at work in order to support children or family members at appointments, leave work early or rearrange shifts at short notice to deal with an emergency.

There are a number of rights at work that are available to parents, including Parental Leave, Carer's Leave and Time off for Dependants.



More information about these rights is outlined in our leaflet, *Autism - An Advice Guide (Leaflet 459)*:
www.usdaw.org.uk/459

You can speak to your Usdaw rep for more information about how to use these rights.



Neurodiversity in the Workplace

Neurodiverse workers may have important rights at work under the Equality Act 2010 (Disability Discrimination Act in Northern Ireland).

You may not think of yourself as disabled, but if you are struggling with certain aspects of work because you are neurodiverse, the Equality Act (DDA in NI) can help.

Once you are covered by the Act, employers are required to make reasonable adjustments to your job role or work environment to support you.

Examples of adjustments could include:

- Working in a quieter area, or permitting someone to wear noise-cancelling headphones or use other sensory aids, such as 'fidget tools' which help people to regulate and concentrate.
- Allowing extra time for neurodivergent workers to finish tasks or training, and follow up to see if they need any additional support in understanding any part of their work.
- Create fixed routines and rotas where possible for neurodivergent workers who work better knowing when and where they will be working each week.
- Provide specific instructions, deadlines or expectations and put them down in writing.

It's important to note that you don't need a diagnosis to qualify for the support of the Equality Act or to have reasonable adjustments put in place.

Your Usdaw rep can help to guide you through the process of using the Equality Act to secure reasonable adjustments in work.



Getting a Diagnosis of Neurodiversity

While you don't need a diagnosis to be covered by the Equality Act, a diagnosis can be crucial in neurodiverse people getting the right help and support at school, in work or at home.

Current pressure on NHS assessment centres that specialise in diagnosing autism and ADHD mean that many people are facing years on waiting lists, depending on where they live. Usdaw supports calls for increased funding to ensure that everyone can access assessments and support as soon as possible.

The pathway to getting a diagnosis is not always straightforward. We have produced a guide to help you navigate the process of getting an assessment and diagnosis for yourself, your child or other family member (see pages 9 and 10).



Getting a Child Diagnosis

1. Speak to the GP, health visitor, or school SENCO

Discuss concerns with the child's GP, health visitor (for younger children) or school Special Educational Needs Coordinator (SENCO). They can help determine whether a referral for further assessment is needed.

2. Referral to a specialist

They may refer the child to a specialist service, such as a paediatrician, child psychiatrist, or a neurodevelopmental team. This often involves local Child and Adolescent Mental Health Services (CAMHS). Additionally, who the child is referred to will depend on the country-specific guidelines.

3. Initial assessment

The specialist will gather information about the child's development, behaviour, and challenges through parent interviews, observations, and questionnaires. Wait time for this can vary based on local availability and the deduced urgency of the assessment.

4. Further assessment

The child may undergo structured diagnostic assessments (eg, ADOS-2 for autism) and additional tests, such as speech and language assessments or educational evaluations.

5. Diagnosis and Support

Once the assessment is complete, the specialist provides a formal diagnosis and recommendations for support and interventions. This can be helpful for putting any reasonable adjustments in place, as well as understanding your child's individual needs.

Getting an Adult Diagnosis

1. Speak to a GP

Discuss your concerns with a GP, who can refer you to an adult neurodevelopmental service if your symptoms align. They may also choose to investigate any mental health concerns separate to this.

2. Referral process

The GP may refer you to a specialist or local mental health services. For ADHD and autism, this often involves a psychiatrist or clinical psychologist. The process usually requires you to complete various information-gathering surveys before the assessment.

3. Assessment

The specialist collects information on your developmental history (sometimes involving family input), behaviour and symptoms. This is because it is widely understood that neurodiversity is present in childhood and does not develop later in life. Standardised diagnostic tools may be used.

4. Diagnosis and Support

Following the diagnosis, recommendations are provided, such as therapy, workplace accommodations or medication. This can be used to support a request for reasonable adjustments. In some circumstances, employers may refer you to occupational health. If you feel your request isn't being handled correctly, please contact your Usdaw rep.





If Your GP Says There is no Service in Your Area

England, Wales and Northern Ireland

If there is no local provision then your local NHS has an obligation to fund you to receive the service elsewhere. You can access that funding through the Individual Funding Request process. Your clinician independently decides that an assessment is needed; in England and Wales, the 'clinician' can be a GP, but in Northern Ireland, they must be a Hospital Clinician. They can then submit an IFR on your behalf. If they decline to do so, you have the option to challenge that decision through the process of making a complaint.

England

If you are based in England under the NHS, you now have a legal right to choose your mental healthcare provider and your choice of mental healthcare team. This important right means that, for instance, should you decide the waiting time for your assessment is too long, you can choose alternative providers. It also means there is not a 'postcode lottery' on whether services are available to you.

Choose Your Provider

In England, you have a legal right to choose your mental healthcare provider. You are not restricted by your location.

Your GP should inform you of this right and help facilitate the process if needed.

If Your GP Refuses to Provide a Referral

If your GP refuses to provide a referral, consider the following options:

Second GP Opinion

- Formally – request through your GP practice.
- Informally – book a new appointment with a different doctor and inform them of your previous discussion.

Changing GP

If limited by a small practice, consider changing your GP.

Use the NHS 'find a GP' service or explore online-based NHS GP services.

Where to Go for Further Support

Usdaw

See Usdaw leaflet *Autism – An Advice Guide For Usdaw Reps (Leaflet 459)*:

www.usdaw.org.uk/459

This guide for Usdaw reps and members contains more detailed information about workplace rights and reasonable adjustments for neurodiverse members, as well as workplace rights for parents and carers of neurodivergent children and family members.

NHS UK

Comprehensive advice about symptoms of neurodiverse conditions, diagnosis pathways and available support and treatments.

web: www.nhs.uk

National Autistic Society (NAS)

National charity supporting autistic people and their families, including advice on supporting an autistic child or family member and an online community to share experiences.

web: www.autism.org.uk

email: nas@nas.org.uk

Autism Central

NHS-commissioned programme connecting parents and carers of autistic children and young people with local support.

web: www.autismcentral.org.uk

ADHD UK

Charity providing information and support for childhood and adult ADHD, including online support groups and Facebook groups for parents of children with ADHD.

web: www.adhduk.co.uk

British Dyslexia Association

Support, information and resources for children and adults with dyslexia and dyscalculia, as well as help and advice for parents supporting a dyslexic child or young person.

Helpline: **0333 405 4567**

web: www.bdadyslexia.org.uk

Tourettes Action

UK charity supporting individuals with Tourette's syndrome and their families, including online support groups.

web: www.tourettes-action.org.uk



The Social vs the Medical Model of Disability

For some time now, disabled people have emphasised that it is not so much their disability that prevents them from fully participating in society, but instead it is the way in which society fails to make adjustments for their disability that excludes them.

This emphasis on changing the barriers put up by society, rather than seeing the disabled person as the 'problem', is known as the 'social model of disability'. In other words, disabled people are people with impairments/ health conditions who are disabled by discrimination, exclusion, prejudice and negative attitudes towards disability. Their impairment is not the problem.

The 'medical model' attributes the problems resulting from a disability to medical conditions alone. It concentrates on a person's impairment. Rather than focusing on the barriers society throws up that prevent disabled people from participating equally, the 'medical model' focuses on what disabled people should do to adapt to fit into the world as it is. If they are unable to adapt, the medical model accepts their exclusion.

For example, while a mobility difficulty can have an adverse effect on a person's ability to walk, the fact that the transport system is inaccessible to them has a far greater effect on their ability to get around.

The law is unfortunately rooted in the medical model. It has been rightly criticised for focusing on an individual's impairments and their ability to carry out normal day-to-day activities, rather than on getting rid of the barriers society puts in the way of disabled people.

This leaflet is designed to help understand how the law can support disabled members in the workplace, and therefore tends to focus on the medical model.



More Information

Usdaw Nationwide

Wherever you work, an Usdaw rep or official (Area Organiser) is not far away. For further information or assistance, contact your Usdaw rep or local Usdaw office. Alternatively, you can phone our Freephone Helpline **0800 030 80 30** to connect you to your regional office or visit our website **www.usdaw.org.uk**

You can also write to the Union's Head Office. Just write **FREEPOST USDAW** on the envelope and put it in the post.

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