Choice
WELLBEING SERVICE

All Things Diagnoses

Parent Carer Guide to Understanding Your Child's Diagnosis

Looking at Autism, ADHD, Dyslexia, Dsygraphia and Dyscalculia and Right to Choose

Autism

Autism is a lifelong difference in how people's brains work. It affects how they experience and interact with the world. While every autistic person is unique, they share some common traits: different ways of thinking, feeling, and communicating. Social situations can be confusing or tiring, and loud environments can be overwhelming. Some autistic people have strong interests, value routine, and use repetitive movements for comfort. Sometimes, they might hide their discomfort to fit in, which can negatively impact their mental health.

We now understand that autism is a spectrum, meaning every autistic person is unique. They have their own blend of strengths and challenges. How these traits appear can vary greatly and change over time or with masking. It's crucial to avoid making assumptions about an autistic person's abilities or needs.
Autism is not a learning disability or a mental health condition. But around a third of autistic people also have a learning disability. And autistic people are more likely to experience mental health problems.

Where does Autism come from?

Research indicates that autism has a genetic basis. Scientists are working to identify the specific genes involved, and it's believed that multiple genes contribute, rather than just one.

Communication

Autistic people may communicate differently than non-autistic people. They might interpret words, tone of voice, and body language in unique ways. Some autistic people might have limited or no spoken language and communicate through writing, sign language, gestures, sounds, or using communication aids like picture cards or electronic devices.

Is Autism a Disability?

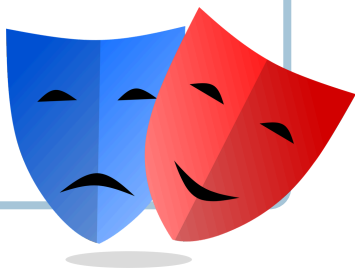
Legally, autism is considered a disability in the UK, offering protection from discrimination and the right to support in education, work, and services. Some autistic people prefer to view their challenges as arising from societal barriers, a concept known as the "social model" of disability. Many also identify as neurodivergent. And like anyone, autistic people may have other disabilities or health conditions.

What is Masking?

Some autistic people use a strategy called "masking" to appear non-autistic and fit in better. They might do this consciously or without realising it, in places like school, work, or even at home. Masking, also known as camouflaging, involves observing and mimicking the behaviour of others, either in person or from media like TV and books.

Autistic people have described masking as:

- hyper-vigilance for and constant adaptation to the preferences and expectations (whether expressed, implied or anticipated) of the people around you
- tightly controlling and adjusting how you express yourself (including your needs, preferences, opinions, interests, personality, mannerisms and appearance) based on the real or anticipated reactions of others, both in the moment and over time



What is ADHD?

Most young children are active, and this usually decreases over time. However, persistent difficulties with attention, hyperactivity, or impulsivity may be signs of attention deficit hyperactivity disorder (ADHD).

ADHD is a developmental disorder characterised by an ongoing pattern of one or more of the following types of symptoms:

- Inattention, such as having difficulty paying attention, keeping on task, or staying organised
- Hyperactivity, such as often moving around (including during inappropriate times), feeling restless, or talking excessively
- Impulsivity, such as interrupting, intruding on others, or having trouble waiting one's turn

ADHD is a neurodevelopmental condition involving a consistent pattern of behaviour that affects children across various situations from an early age and can last into adulthood. It often becomes apparent in school when children struggle to sit still, focus, or control impulsive responses.

Untreated ADHD can have a significant negative impact on a child's schooling, relationships, self-image, and family life.

Impact

Learning can be challenging for children with ADHD, who often struggle with executive functions – a set of skills crucial for guiding behavior, such as planning and self-control. Their performance on learning tasks can be inconsistent across different situations, and one theory suggests this may be due to an underlying difficulty with regulation. Furthermore, the intensity of ADHD symptoms is often reported to vary based on the child's engagement in an activity or the availability of rewards. Approximately 60 to 80 per cent of children with ADHD will have at least one other condition; such as a social communication disorder, reading (dyslexia) or motor (dyspraxia) difficulties.

Diagnosing ADHD:

ADHD diagnosis relies on a comprehensive evaluation by a qualified healthcare professional (such as a Paediatrician, Psychiatrist, or Clinical Psychologist), not specific tests. This assessment typically involves gathering a detailed history of the child's development and social-emotional wellbeing, observing the child, using standardised questionnaires, and sometimes administering psychological tests. Crucially, the child's own perspective on their difficulties and their impact on daily life is also considered.

To accurately diagnose ADHD and exclude other similar conditions, a professional assessment is necessary, potentially involving a team of specialists like Speech and Language Therapists, Clinical Psychologists, and Occupational Therapists.

Although concerns may arise earlier, an ADHD diagnosis is usually considered around the age of six when children start school. However, it can also be identified later, especially for those with inattentive symptoms that become more evident in secondary school. Input from teachers, who observe the child in a structured school setting, is very important and is usually part of the assessment.

Helping your child

Parents can significantly support children with ADHD by understanding the disorder, creating a structured environment, establishing healthy routines, and collaborating with schools and healthcare professionals. They should also focus on their child's strengths, offer consistent positive reinforcement, and learn effective communication and behavioural management techniques.
ADHD like many other diagnoses is a lifelong diagnosis. Assessments are usually long and thorough to ensure the right diagnosis is given.

Dyslexia (Reading and Language Processing)

Dyslexia is a common learning difficulty that primarily affects reading, writing, and spelling. It's important to understand that:

It's a specific learning difficulty: This means it primarily impacts certain learning abilities, particularly those related to language.
It's not related to intelligence: People with dyslexia have a wide range of intelligence levels.
It affects language processing: Dyslexia often involves difficulties in processing the sounds of language, which can lead to challenges in connecting those sounds to letters and words.
It's a spectrum: The severity of dyslexia can vary significantly from person to person.
It's a lifelong condition: While strategies and support can greatly help, dyslexia is typically a lifelong condition.
It can cause other difficulties: Although the primary difficulties are with reading and spelling, it can also effect things such as organisation, and short term memory.
In essence, dyslexia is a neurological difference that impacts how the brain processes language, leading to challenges with reading and related skills.

Dyscalculia is a specific learning difficulty that affects a person's ability to understand and work with numbers. It's often described as "dyslexia with numbers." Here's a breakdown of key aspects:

Difficulty with Numbers: People with dyscalculia struggle with basic math concepts, such as number sense, counting, and calculations. They may have trouble recognising and understanding numerical symbols.
Impact on Daily Life: Dyscalculia can affect everyday tasks, including:

- Managing money
- Telling time
- Following directions
- Understanding measurements

Not Related to Intelligence: Like dyslexia, dyscalculia is not an indicator of intelligence. People with dyscalculia can have a wide range of cognitive abilities.
Neurological Basis: Dyscalculia is believed to have a neurological basis, affecting how the brain processes numerical information.
Varied Severity: The severity of dyscalculia can vary, and it can occur alongside other learning difficulties.

In essence, dyscalculia is a learning difference that makes it challenging to grasp and use mathematical concepts.

Dysgraphia

Dysgraphia is a learning difficulty that affects handwriting and other fine motor skills related to writing. It's not simply "bad handwriting"; it's a neurological condition that makes the physical act of writing challenging. Here's a breakdown:

Handwriting Difficulties: People with dysgraphia often struggle with forming letters correctly, spacing words, and writing legibly. Their handwriting may be slow, laboured, and inconsistent.
Fine Motor Skills: Dysgraphia can also affect other fine motor skills, such as drawing or using scissors.
Spelling and Composition: While primarily a motor skill issue, dysgraphia can also impact spelling and written expression, as the effort of writing can interfere with the thought process.
Not Related to Intelligence: Like other learning difficulties, dysgraphia is not related to intelligence. People with dysgraphia can have a wide range of cognitive abilities.
Neurological Basis: Dysgraphia is believed to have a neurological basis, affecting the brain's ability to process and execute the motor skills required for writing.
Varied Severity: The severity of dysgraphia can vary significantly.

Essentially, dysgraphia is a learning difference that makes the physical act of writing difficult, affecting both handwriting and related fine motor skills.

Right to Choose

What is the 'Right to Choose'?

The "Right to Choose" refers to a patient's legal right within the NHS to choose their healthcare provider when referred by a GP for a first appointment, whether this is for a physical or mental health condition. This means you can choose which hospital or service you'd like to attend for your assessment or treatment.

Patients are entitled to choose any provider, this includes private or independent providers in England, but they must hold a relevant NHS commissioning contract for the services they require and be considered clinically appropriate by their referrer.

What should you look for in a 'Right to Choose' provider?

When trying to decide on who you like to be referred to, it's important to remember there are some restrictions to who you can choose from. The provider must:

- Have a commissioning contract with the Integrated Care Board (ICB) or NHS England for the required service
- Be led by a consultant or mental healthcare practitioner

How does the process work?

- Firstly, most providers have self-report questionnaires you need to complete and are usually found on the providers website.
- Next. visit your GP and there you can discuss the questionnaire, your concerns, history and anything else relevant.
- You can then ask them to refer you to your chosen provider - this can usually be done by either writing a letter or completing an online form.
- The provider will then contact you to arrange an appointment. If there is anything further you need to do in preparation for your appointment, the provider will let you know either via phone or email so that you are aware.

When can you use 'Right to Choose'?

- When a patient has an NHS elective referral (referred for non-urgent or planned treatment by GP) for their first outpatient appointment
- Patient is referred by a GP, Dentist or Optometrist.
- Referral is clinically appropriate (this is determined by whoever refers the patient).
- Provider service and team are led by a consultant (physical and mental health) or a mental healthcare professional (mental health only).
- Provider has a commissioning contract with any ICB (Integrated Care Board) or NHS England for the required service.

When can you not use 'Right to Choose'?

- If you have self-referred
- Are already receiving care following an elective referral for the same condition
- Have been referred to a service that is commissioned by a local authority (not part of a joint commissioning arrangement) or delivered through primary care
- Accessing urgent or emergency (crisis) care
- Serving as a member of the armed forces
- A prisoner, detained in hospital under Mental Health Act 1983 or a secure service.

For more information use the QR code to view 'Your Choices in the NHS'

This includes the NHS Choice Framework, which sets out in more detail what options are available.

Remember: when choosing a provider, do your research! Do their assessments follow NICE guidelines? Also check out the reviews of their service.

What happens after your appointment?

- After your appointment, you may need medication, monitoring or review appointments.
- This can be done by your GP through what is called a Shared Care agreement.
- A shared Care agreement is not mandatory, so a GP does not have to agree to take over care from a private provider.

What happens if a Shared Care agreement is agreed?

- If a Shared Care agreement is agreed on by the GP, the specialist private provider will usually write the first prescription, and the GP will then be responsible for dispensing and monitoring the medication.

What happens if a Shared Care agreement is declined?

- If a GP declines to take over the care of a patient, then all monitoring, care and medication must stay with the specialist private provider.
- This is something to be aware of when going ahead with Right to Choose, as this would mean the patient is responsible for the costs of any medication of care from the private provider.

Tips for Right to Choose

Research Providers: Look up approved providers that fit your needs and check their current waiting times online. The charity ADHD UK offers a comprehensive guide and tools for finding local options.

Understand Medication: If diagnosed with ADHD and medication is required, discuss "shared care" with your GP. If your local GP refuses to take over NHS prescribing, you will want to select an RTC provider that agrees to handle ongoing prescriptions at standard NHS prices.

There are many organisations that offer support for parent carers and provide information. and resources, including:

National Autism Society

National Autistic Society

National Autism Society

Talking with your child about their diagnosis

ADHD UK

ADHD UK

Contact

contact *For families with disabled children*

Choice
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Your Child, Your Choice

Because one size doesn't fit all

Find our website here:

SEND IN SUNDERLAND | Choice WELLBEING SERVICE | RAINBOW Guide
Sunderland's Guide to SEND Support By Parent Carers for Parent Carers