

Neurodevelopmental services in Wales

Research Briefing

June 2024



The Welsh Parliament is the democratically elected body that represents the interests of Wales and its people. Commonly known as the Senedd, it makes laws for Wales, agrees Welsh taxes and holds the Welsh Government to account.

An electronic copy of this document can be found on the Senedd's website:
research.senedd.wales

Copies of this document can also be obtained in accessible formats including Braille, large print, audio or hard copy from:

Welsh Parliament
Tŷ Hywel
Cardiff Bay
CF99 1SN

X: [@SeneddResearch](https://twitter.com/SeneddResearch)
Senedd Research: research.senedd.wales
Subscription: [Newsletter](#)

© **Senedd Commission Copyright 2024**

The text of this document may be reproduced free of charge in any format or medium providing that it is reproduced accurately and not used in a misleading or derogatory context. The material must be acknowledged as copyright of the Senedd Commission and the title of the document specified.

Neurodevelopmental services in Wales

Research Briefing

June 2024

Author:

Gwennan Hardy

This briefing provides information and data about neurodevelopmental services in Wales.

It focuses on the demand for neurodevelopmental diagnostic services, what services are available, and Welsh Government action to develop and improve the services offered in Wales.

It also provides answers to some common questions about the rights of adults and children with neurodevelopmental conditions when it comes to education and social care.



Contents

1. What are neurodevelopmental conditions?	1
2. How common are neurodevelopmental conditions?	1
3. What diagnostic services are available in Wales?	2
Services for children and young people	2
Services for adults.....	2
Private assessments	3
How long does it take to get an assessment?	3
4. What is the Welsh Government doing to improve neurodevelopmental services?	4
Autism services.....	4
The neurodivergence improvement programme.....	5
5. Education and neurodevelopmental conditions	6
Do education providers require a diagnosis before providing support?	6
6. Social care and neurodevelopmental conditions	7
7. Other sources of help and support	8
Mental health support.....	8

1. What are neurodevelopmental conditions?

Neurodevelopmental conditions are a group of **behavioural and cognitive disorders** that affect the functioning of the brain. They can impact on things like social behaviour, language skills, motor skills and learning ability.

Some common neurodevelopmental conditions are:

- attention deficit hyperactivity disorder (ADHD);
- autism or autism spectrum disorder (ASD);
- learning difficulties (such as dyslexia or dyscalculia);
- dyspraxia or developmental coordination disorder (DCD); and
- Tourette syndrome and other tic disorders.

2. How common are neurodevelopmental conditions?

The **National Autistic Society** estimates that approximately 1% of the population in the UK are on the autism spectrum. According to **ADHD UK**, the prevalence of ADHD is estimated to be around 5% for children and between 3 - 4% for adults in the UK.

There is currently no comprehensive data source on the number of people diagnosed with neurodevelopmental conditions in Wales. However, there is some data showing the number of people accessing services or getting support for neurodevelopmental conditions.

In 2022-23:

- over 5140 referrals for adults **were made to the Integrated Autism Service**, of which 72% were requesting autism diagnostic assessments; and
- 2.2% of pupils in Wales **were reported to have** ASD as an Additional Learning Need (ALN) / Special Educational Need (SEN), whilst 0.6% were reported to have ADHD.

A 2022 Welsh Government **review of neurodevelopmental services** found that growing numbers of children and adults in Wales are suspected to have neurodevelopmental conditions. The review attributes this growth to increased awareness of different conditions, the broadening of diagnostic criteria and

thresholds, the establishment of new neurodevelopmental services, and the introduction of new responsibilities for neurodevelopmental services.

An **academic study published in 2023** assessed the feasibility and viability of using data from the Wales Secure Anonymised Information Linkage (SAIL) database to identify those who had received a diagnosis of ADHD or ASD in childhood. Amongst a sample of individuals born between 1 January 1991 and 31 December 2000, a total of 7726 individuals had a recorded diagnosis of ADHD by the age of 18 years, representing 1.4% of the total Welsh population within that age group. 5001 individuals had received a diagnosis of ASD in childhood, representing 0.9% of the population.

3. What diagnostic services are available in Wales?

There are different diagnostic and assessment routes available for adults and children.

Services for children and young people

Children under 18 can access the **all-Wales Neurodevelopmental pathway** for assessment and diagnosis. Each health board has a dedicated Children and Young People's Neurodevelopmental Assessment and Diagnosis Service. A referral from a GP or education professional is generally required in order to access this service.

Please note, children and young people should not need a diagnosis in order to begin getting support through their school or further education institution (see Section 5 below).

Services for adults

Each health board has an **Integrated Autism Service** which offers adult autism diagnostic assessment, and support services for autistic adults, parents/carers, and professionals. Adults can generally access this service directly, or you may be referred by a health or social care professional.

Whilst there is no consistent offer across Wales for adults with other neurodevelopmental conditions, some health boards do provide dedicated services for conditions (such as ADHD). A GP should be able provide information about relevant services in their area.

The Welsh Government **has stated** it is working towards filling gaps in provision for neurodevelopmental conditions such as ADHD as part of its Neurodivergence Improvement Programme.

Private assessments

There are a number of services that offer paid-for assessments for neurodevelopmental conditions. Whilst a private assessment service may offer shorter wait times, individuals will need to pay the costs of an assessment, which will vary depending on the provider.

Getting a private diagnosis also does not guarantee that someone will be able to access treatment or medication through the NHS. Whilst it may be possible to get a **shared care agreement** in order to access NHS treatment after getting a private diagnosis, **there have been reports** that people in Wales struggle to get agreement from their GP to do this. **ADHD Aware** states that whilst some GPs will recognise a private diagnosis, others will not, meaning that it may not be possible to get medication or treatment through the NHS. They recommend speaking to a GP before getting a private diagnosis.

The National Autistic Society states that some local authorities may not accept the results of private autism diagnoses and recommends staying on the waiting list for an NHS assessment, even for those who decide to also seek a private assessment.

How long does it take to get an assessment?

There can be long waiting times to get an assessment for neurodevelopmental conditions.

The Welsh Government has **set a target** that children and young people referred to the all-Wales neurodevelopmental pathway should attend a first assessment appointment within 26 weeks of a referral. There is currently no waiting time policy for adults.

The National Institute for Health and Care Excellence (NICE) **guidelines for children and young people** recommend that a diagnostic assessment should be started within 3 months of a referral to autism services. Whilst NICE guidelines **are used in Wales** to plan and deliver services, they are not mandatory requirements.

The Welsh Government does not regularly publish data on waiting times. However, data published through Freedom of Information (FOI) releases shows that:

- In December 2023, there were 16,812 children and young people in Wales **waiting for an ADHD or ASD neurodevelopment assessment**.
- In June 2023, 67.4% of children and young people waiting for an ADHD or ASD neurodevelopmental assessment in Wales **had been waiting for 26 weeks or longer**.

4. What is the Welsh Government doing to improve neurodevelopmental services?

In 2015, the Welsh Government established an NHS-led **Together for Children & Young People (T4CYP)** programme with the aim of exploring ways to reshape and improve the emotional wellbeing and mental health services provided for children and young people in Wales.

From 2019, work to improve neurodevelopmental services was included as a key focus for the programme. The programme published a **Vision for Neurodevelopmental Support & Services**, which argued for a whole systems approach which would break down barriers between services for children and young people.

Autism services

The Welsh Government published an **Autistic Spectrum Disorder Strategic Action Plan** in 2016, which established new **Integrated Autism Services**. This was **backed by a £13m investment** to 2021, and **a recurrent payment** of £3m a year to support autism services in Wales after 2021.

In 2017, an **Autism (Wales) Bill** was brought forward by Paul Davies MS following a successful Member's Bill ballot. The Bill was ultimately rejected in the Senedd after a motion to agree the general principles was not agreed.

Instead, in September 2018 the Welsh Government made **a series of commitments to improve autism services**. These included introducing a statutory **Code of Practice on the delivery of autism services**. This code of practice provides local authorities with information on the level and range of services and support they are expected to provide for autistic people under existing legislation, the **Social Services and Wellbeing Act (Wales) 2014** and the **National Health Service (Wales) Act 2006**.

An evaluation of the Code **is being undertaken** to assess the extent to which the duties in the Code are being met and develop recommendations for improvement.

The neurodivergence improvement programme

In 2022, the Welsh Government **published a review** of the demand, capacity and design of neurodevelopmental services for children, young people and adults. The review identifies that demand for diagnostic assessment has outstripped the capacity of both children's services and Integrated Autism Services, stating that:

Demand-capacity gaps in relation to diagnostic assessments increase waiting times for children, young people, adults and families far beyond that which most would consider acceptable, delaying support (in those cases where support depends upon a diagnosis) and fuelling frustration. It means problems can multiply and/or escalate as opportunities to intervene early are missed and adults and families interviewed described what they felt were 'lost years' as a consequence of long waits before they felt their, or their children's, difficulties were properly understood.

Following the review, **the Welsh Government announced** the creation of a new national improvement programme for neurodevelopmental conditions, backed by £12m in funding up until 2025. In her announcement, the Deputy Minister for Social Services stated that the programme will:

...support the development of timely and consistent all-age neurodevelopmental services and will include much-needed additional advice and support services for parents and carers.

In May 2023, **the Minister stated that** the programme is intended to address the 'identified gaps' in support for other neurodivergent conditions, such as ADHD and Tourette syndrome.

The Welsh Government held **a series of stakeholder engagement events** on the neurodivergence improvement programme in November 2022. A number of themes were identified during these events, which the Welsh Government has stated will be used to help guide the development of services.

5. Education and neurodevelopmental conditions

Children and young people with neurodevelopmental conditions may be entitled to additional help or support at school or in further education.

Schools, further education institutions (FEIs), local authorities and NHS bodies have duties under the **Additional Learning Needs and Education Tribunal (Wales) Act 2018** relating to children and young people who have Additional Learning Needs (ALN).

The ALN system is gradually replacing the previous Special Educational Needs (SEN) system, with the changes being phased in between September 2021 and August 2025. You can read more about these changes in **this Senedd Research article**.

Children and young people **are recognised as having ALN** if they:

- have a significantly greater difficulty in learning than the majority of others of the same age (that can't be addressed solely through differentiated teaching); or
- have a disability (for the purposes of the Equality Act 2010) which prevents or hinders them accessing education or training that's generally provided for others of the same age; and
- the learning difficulty or disability calls for Additional Learning Provision (ALP).

If a child has ALN then they have a right to a statutory plan **called an individual development plan (IDP)**. Young people up to the age 25 with ALN will be entitled to an IDP if they stay in education.

The Welsh Government has published **a series of guides** on the ALN system which provide more information.

Do education providers require a diagnosis before providing support?

A diagnosis is not required before decisions are taken on whether a child or young person has ALN, and additional support is put in place. Paragraph 1.48 of the **ALN Code** states:

Even if there might remain some outstanding evidence yet to be received which might provide a fuller picture of the extent of the ALN or the ALP – including, for example, where a diagnosis of a particular

condition might have been sought but not received - if the IDP can be prepared, then it needs to be prepared.

This has been confirmed several times by the Welsh Government. For example, **letter published in August 2023** from the Minister for Education and Welsh Language and the Deputy Minister for Social Services in August 2023 states that:

A medical diagnosis is not required to access support in education or to inform a decision on a learner's additional learning needs. The preparation of an IDP by the school, is based on presenting needs identified by person centred planning.

6. Social care and neurodevelopmental conditions

Under the **Social Services and Well-being (Wales) Act 2014**, local authorities have duties relating to the provision of adult social care services for people and carers who need support. These apply to everyone with care and support needs, including people with neurodevelopmental conditions.

The local authority has a legal duty to carry out an assessment of anyone living in its area who may need care and support services, once it becomes aware of this need. It will determine whether an individual's needs meet the eligibility criteria for a formal care and support plan and the provision of social care services.

You can read more in our Senedd Research **guide for constituents** on accessing care and support. The guide sets out the initial process, individual rights and the responsibilities of local authorities in the provision of adult social care. It also signposts to other useful sources of help and support.

In addition, **the Code of Practice on the delivery of autism services** provides more detail on arrangements for providing care and support services for autistic people and their family / carers.

7. Other sources of help and support

- **Neurodivergence Wales (previously Autism Wales)** provides information and resources about autism and other neurodevelopmental conditions, and about the services and training opportunities available online and across Wales.
- The **Community Advice Listening Line** (CALL) provides a 24-hour listening line service which is open to neurodivergent individuals and their families and friends. The operators can also provide service information on local or national services across Wales. You can reach CALL on 0800 132737 or by texting the word HELP to 81066.
- The **National Autistic Society** provides support services for people on the autism spectrum and their families.
- **ADHD UK** provides online resources for people with ADHD, including information about requesting reasonable adjustments at work and support at school.
- The **ADHD Foundation** offers support to people with a range of neurodevelopmental conditions, including ADHD, autism, dyslexia, dyspraxia, and Tourette syndrome. They also provide training and resources for businesses, education institutions and healthcare bodies.
- The **British Dyslexia Association** provides information and services for people with learning difficulties like dyslexia or dyscalculia, as well as for parents, carers or teachers.
- **Tourettes Action** is a support and research charity for people with Tourette syndrome and their families.

Mental health support

Whilst not everyone with neurodevelopmental conditions will experience mental health difficulties, there are **high rates of mental health problems** amongst people with certain neurodevelopmental conditions.

Senedd Research has published a **constituency factsheet on mental health support** which provides information about sources of help with mental health problems and other associated issues.