



Factsheet

Autism assessments and diagnosis in Wales



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Thank you.

Autism assessments and diagnosis in Wales

Aims

This factsheet aims to provide information and useful resources to parents in Wales who suspect that their child may have autism. It explains how to obtain an autism assessment, highlights the importance of a timely diagnosis and what support you and your child may be entitled to if a diagnosis is made. It takes into account the [Code of Practice on the Delivery of Autism Services](#) (the Code) published in September 2021 and its [Supporting Guidance Document](#) (the Guidance). We would suggest that the Code is read alongside the Guidance which often has useful clarifying information

Key points

- What is autism?
- Who provides autism services for children in Wales?
- How do I request and prepare for an autism assessment?
- How long will it take my child to be seen?
- Why is a timely diagnosis so important?
- My child has been diagnosed with autism- what support are we entitled to?
- What can I do if I don't agree with the decision?

What is autism?

Autism, also known as autism spectrum disorder (ASD), is a developmental disorder which affects social interaction and communication. Autism also tends to be characterised by specific interests and activities which are carried out repetitively.

Individuals with autism tend to struggle communicating and relating to other people as their brains process information differently to those without autism.

Autism is a lifelong disability and there is no 'cure'. However, the earlier someone is diagnosed, the sooner they are able to access various therapies and support to help make their lives easier and more comfortable. It is important to note that autism is a spectrum disorder meaning that every autistic person is different; some people need little or no support at all while others may need 1:1 help from a parent or carer every day.

Girls and boys can both get autism however it is generally easier to recognise and diagnose in boys as autistic girls may be quieter and often 'mask' their autistic characteristics.

You can read more about autism characteristics in the resources below:

Autism Wales:

<https://autismwales.org/en/>

National Autistic Society:

<https://www.autism.org.uk/about/what-is/asd.aspx>

Child Autism UK:

<https://www.childautism.org.uk/about-autism/what-is-autism-symptoms-of-autism/>

AP Cymru:

<https://apcymru.org.uk/>

Ambitious About Autism:

<https://www.ambitiousaboutautism.org.uk/information-about-autism/understanding-autism/what-is-autism>

NHS website:

<https://www.nhs.uk/conditions/autism/what-is-autism/> and

<https://www.nhs.uk/conditions/autism/signs/children/>

Great Ormond Street Hospital:

<https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/autism>

Who provides autism services for children in Wales?

Each of the seven Welsh health boards has a dedicated Children and Young People's Neurodevelopmental Assessment and Diagnosis Service which follow a nationally agreed pathway based on **National Institute of Health and Care Excellence (NICE) guidelines**.

Similar services for adults are provided by Integrated Autism Services (IAS) in each health board. Although an IAS cannot provide services to children with autism, it can provide support to their parents/ carers.

For young adults moving from children's services to adult services the Guidance¹ says:

Young adults may need a combination of adult/child approaches which may be facilitated by the IAS. This is agreed locally in each region between the IAS and neurodevelopmental services. Currently (2021) the referral age to the IAS to join the waiting list is 17 (years) and 9 months. In most areas the Neurodevelopmental team either expedite the referral to be seen as soon as possible or work with the person past their 18th birthday.

How do I request and prepare for an autism assessment?

If you suspect that your child may have autism, it is sensible to start thinking about the path to diagnosis as soon as you can.

If you have concerns about your child, you can ask for a referral to your local Children and Young People's Neurodevelopmental Assessment and Diagnosis Service. The Guidance² sets out the following referral routes for children:

For pre-school children; referrals can be made via the Pre-school Pathway by:

- health visitor
- GP
- therapist

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- Paediatrician and directed to the Community Paediatrician.

For children who are attending school (including nursery pupils) the referral should be made via the:

- School-age Assessment Pathway
- self-referral for older children or by parents for younger children – neurodevelopmental teams state that they accept self-referrals. However, they are keen to highlight that these referrals are considered on a case by case basis because collating the information is difficult for individuals and accessing some records for individuals is onerous and time consuming,

Information for referrers with downloadable resources can be found [here](#), and an explanation of the Neurodevelopment Diagnostic Assessment Pathway [here](#).

Further information about your local Children and Young People's Neurodevelopmental Assessment and Diagnosis Service can also be found on your Health Board's website:

- Aneurin Bevan University Health Board (Unavailable at the time of writing³).
- [Betsi Cadwaladr University Health Board](#).
- [Cardiff and Vale University Health Board](#).
- Cwm Taf Morgannwg University Health Board (Unavailable at the time of writing).
- [Hywel Dda University Health Board](#).
- [Powys Teaching Health Board](#).
- [Swansea Bay University Health Board](#).

You can follow the links below for further information on requesting an assessment and how to prepare for the assessment process:

Autism Wales:

<https://autismwales.org/en/>

NHS Website:

<https://www.nhs.uk/conditions/autism/getting-diagnosed/assessments/>

National Autistic Society:

<https://www.autism.org.uk/about/diagnosis/children.aspx> and

<https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/professionals-involved>

Ambitious About Autism:

<https://www.ambitiousaboutautism.org.uk/information-about-autism/early-years/how-assessments-and-diagnosis-works>

How long will it take for my child to be seen?

The Guidance⁴ says that the Welsh Government acknowledges the standards of NICE guidance have currently set the waiting time policy from referral to an initial appointment at 26 weeks for children. Whilst children are awaiting diagnosis it is expected that schools identify and develop any additional

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learning needs (ALN) support following the timescales within the ALN guidance. (Also see the 'Support at school' section).

Unfortunately, it is not uncommon for families to experience long delays in obtaining this initial assessment. If it has been 26 weeks or longer since your child was referred for an assessment, you can use our [template letter](#) to write a complaint to your local health board.

Why is a timely diagnosis so important?

The earlier an autism diagnosis is made, the sooner the child's needs can be understood and the sooner it can be established what therapy and support is required to meet those needs. Unfortunately, it is not uncommon for a diagnosis or even an initial assessment to take several months or years which can be desperately frustrating and worrying for you, your child and your family. Along with sending a [letter of complaint](#) regarding the delay, there are a number of different organisations that you can contact for support and advice during this time:

National Autistic Society have a list of branches and groups in Wales for help and support:

<https://www.autism.org.uk/what-we-do/local-branches?searchTerm=wales&postalcode=&radius=0>

Child Autism UK's helpline:

<http://www.childautism.org.uk/for-families/autism-helpline/>

The Challenging Behaviour Foundation:

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

Contact's helpline or support groups:

<https://contact.org.uk/conditions/autism-spectrum-conditions/>

MIND:

<https://www.mind.org.uk/about-us/our-policy-work/equality-human-rights/mental-health-of-people-with-autism/>

My child has been diagnosed with autism- what support are we entitled to?

Following a diagnosis of autism, it can be daunting to know where or how to start looking for support that is needed for your child and the rest of the family. We have categorised some of the support services that you may wish to explore and some useful sources below:

Therapy and interventions:

As mentioned above, there is no 'cure' for autism however there are some therapies and techniques that can be put in place to enable your child to fulfil their potential. Cerebra do not recommend any specific therapies or interventions, however the information below may be of interest to you:

The National Autistic Society have some information here about different types of therapy and interventions:

<https://www.autism.org.uk/advice-and-guidance/topics/strategies-and-interventions>

If your child needs hospital treatment, you may wish to use the National Autistic Society's 'Health

Passport' to make it easier for medical professionals to understand your child's needs and wishes:

<https://www.autism.org.uk/advice-and-guidance/topics/physical-health/my-health-passport>

Some Welsh hospitals also have their own 'Health Passport':

<https://www.wales247.co.uk/new-health-passport-to-help-people-with-rare-diseases>

In early 2020, Ambitious About Autism launched a new toolkit with the aim to get support for children right from the start. The toolkit has some helpful tips and templates which can be downloaded here:

<https://www.ambitiousaboutautism.org.uk/information-about-autism/early-years/parent-toolkit>

Financial support:

You can find out what benefits your family may be eligible for on the National Autistic Society's website [here](#) or by contacting your local [Citizens Advice](#).

You can also download our free [Disability Living Allowance guide](#) which takes you through all the questions on the DLA form, explaining what each one means and giving tips on how to answer.

Support at school:

If your child is struggling at school, they may be able to get some extra help in the form of an Independent Development Plan (IDP)⁵. An IDP is a document that sets out a child's additional learning needs, and other non-educational needs and the provision to meet those needs. It may also name the child's school. Again, it is worth being aware that your child may be eligible for extra support in school prior to a medical diagnosis.

The Welsh Government have issued [parental guidance](#) on the new Additional Learning Needs system. And if your child still has a statement our Education in Wales guide: <https://cerebra.org.uk/download/education-in-wales-a-guide-for-parents/> remains relevant with regard to annual reviews and the transition process.

Social care support:

Local authorities have a duty to assess the needs of all children who meet the legal definition of a 'child in need'. Autism is a disability and all children with disabilities qualify as children in need. However, it is important to realise that even if your child hasn't been diagnosed with a disability such as autism, they still may have the right to an assessment and subsequent support services. This is because local authorities have specific duties to all children in their area who appear to be in need of care and support in addition to, or instead of, the care and support provided by the child's family.

You can read more about 'child in need' assessments and your right to a parent carers needs assessment in our [Social Care in Wales guide](#). Section 4 of the guide provides examples of social care support that you may be entitled to including short breaks and home adaptations. Our [Carers' Assessments in Wales Factsheet](#) gives you an insight of what your rights are as a parent or carer of a disabled child.

⁵ IEPs are replacing Statements of Special educational Needs as the new ALN system is phased in. If your child had a statement when the phased transfer started, they will continue to have one until it is transferred to an IDP or they leave education. The phased transfer is scheduled to be completed by the end of the 2023-24 academic year.

Other support services:

National Autistic Society have a list of support and advice for parents and carers of autistic children here:

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

Contact have specific information and support groups for families in Wales:

<https://contact.org.uk/help-for-families/local-contact-offices/contact-in-your-area/offices/cardiff/>

Children with autism can struggle with their sleep routines which can have a detrimental effect on your child and the whole family. If you would like to get help with sleep, please contact our sleep service by completing our [online request form](#). If you have any queries regarding your family's legal entitlements, please contact our Legal Entitlements and Problem-Solving (LEaP) Project team by completing our [online request form](#). Please read our [Project Guidelines](#) first for information about our eligibility criteria and the type of legal problems we can deal with.

What can I do if I don't agree with the decision?

According to the Guidance⁶:

The Code of Practice sets out the Welsh Government's expectations about the planning and delivery of autism services by local authorities and health bodies in Wales. There may be occasions where individuals, including children and young people, may disagree with decisions made about the range of services available in their local areas.

Therefore, complaints information must be available in formats accessible to all. When disagreements arise, individuals should first raise their concerns directly with the local authority or health body at a local level, if agreements cannot be reached quickly, there will be formal complaints procedures in each organisation. In line with the statutory guidance for public service providers, complaints are not 'appeals against properly made decisions' but are a route for individuals to express dissatisfaction or concern about a service providers lack of action or the standard of service provided

If complainants continue to be dissatisfied or concerned about the outcome of a local authority or health body investigation, they will then have recourse to go to the office of the [Public Services Ombudsmen](#) to have their complaint assessed.

The Public Services Ombudsman has issued a factsheet on NHS complaints which can be found [here](#).

You can get advice and advocacy support to make a complaint from your [Community Health Council](#).

Alternatively, the [National Autistic Society's helpline](#) can provide you with support and advice.

DISCLAIMER- This factsheet should not be used for the diagnosis or treatment of autism. Please contact your local Integrated Autism Services (IAS) if you have specific questions about autism and how this relates to your child. More information about IAS in general and links to your local IAS can be found [here](#).

About the author

Sophie Champion joined Cerebra in August 2019 as project co-ordinator for the Legal Entitlements and Problem-Solving (LEaP) Project. The Project team is led by Professor Luke Clements at the University of Leeds and aims to provide legal information and support to families who are experiencing difficulties in accessing health, social care and other services. Following her law degree and Legal Practice Course in 2015, Sophie worked as a Paralegal helping families appeal decisions in which family members were being wrongly denied NHS Continuing Healthcare funding. Sophie later transferred to a Medical Negligence department which involved investigating cases where individuals alleged negligence by an NHS medical professional.

About the reviewer

Professor Luke Clements is based at Leeds Law School and is a solicitor. He is a leading expert on community care law. He has drafted and assisted in the parliamentary passage of a number of Private Members bills. He has provided training for many Local Authorities, national organisations and charitable bodies. His books include: *Community Care and the Law* (Legal Action Group 6th ed 2017—jointly written with Pauline Thompson), *Disabled Children: a legal handbook* (Legal Action Group 3rd edition 2020—jointly written with Stephen Broach) and *Carers and their Rights* (Carers UK 4th ed 2010).

The findings of this report are those of the author, not necessarily those of Cerebra.

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