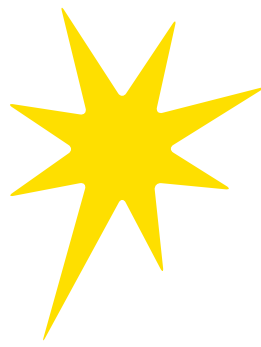




Factsheet

Autism assessments and diagnosis in England



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Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides give us a call on **01267 244216** or donate at <https://cerebra.org.uk/get-involved/>.

Thank you.

Autism assessments and diagnosis in England

Aims

This factsheet aims to provide information and useful resources to parents in England 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.

Key points

- What is autism?
- Why is a timely diagnosis so important?
- How do I request and prepare for an autism assessment?
- 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 be autistic 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:

NHS:

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

National Autistic Society:

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

Ambitious About Autism:

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

Great Ormond Street Hospital:

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

Child Autism UK:

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

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. The first step is to discuss your concerns regarding your child's development with your GP and request a referral to rule out or diagnose autism.

Alternatively, your child's school may pick up on the possibility of autism and can therefore make a formal request for an assessment.

In England, once a referral has been made, the initial assessment should commence within 3 months. Unfortunately, it is not uncommon for families to experience long delays in obtaining this initial assessment. If it has been 3 months or longer since your child was referred for an assessment, you can use our [template letter](#) to write a complaint.

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

NHS:

<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>

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: the National Autistic Society have an Autism Services Directory to find local support:

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

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>

Ambitious About Autism's toolkit aims 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 in an early years setting or at school:

If your child is struggling in an early years setting or at school, they may be able to get special educational provision. This is called SEN Support. If SEN Support is not appropriate or progress is not being made, further help can be provided in the form of an Education, Health and Care Plan (EHCP). An EHCP is a legal document that sets out a child or young person's special educational needs, health and social care needs, what support is required to meet those needs and the outcomes they would like to achieve. Again, it is worth being aware that support is not dependent on receiving a medical diagnosis, it is dependent on needs.

IPSEA have further information on their website including what special educational needs are and how to get an assessment of your child's needs:

<https://www.ipsea.org.uk/what-are-special-educational-needs> and

<https://www.ipsea.org.uk/how-should-the-local-authority-help>

You can also find more information regarding support for your child in our Education in England guide:

<https://cerebra.org.uk/download/education-health-and-care-ehc-plans-education-in-england-a-guide-for-parents/>

Department for Education Special educational needs and disability code of practice: 0 to 25 years:

<https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>

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 a 'child in need' assessment and subsequent support services. This is because the definition of 'child in need' also includes children who are unlikely to reach or maintain a reasonable standard of health and development, or whose health and development will be significantly impaired, unless services are provided by your local authority.

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

Local authorities also have legal obligations to provide free school transport for eligible disabled children in England. You can read our [School Transport in England guide](#) for more information.

Other support services:

The National Autistic Society website provides support and advice for parents and carers of autistic children here:

<https://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-children>

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?

If, following an assessment, you are told that your child doesn't have autism and you disagree with this decision, you can ask your GP to refer you to another team for a second opinion.

DISCLAIMER- This factsheet should not be used for the diagnosis or treatment of autism. Please see your GP if you have specific questions about autism and how this relates to your child.

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 reviewers

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).

John Furlong works in the LEaP team supporting parents who have difficulties accessing social care for their disabled children. He previously worked in SEN law and has campaigned for the improvement of services for disabled children.

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

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