

Autism Spectrum Disorder Assessments

Neurodisability Team
Ryegate Children's Centre
Centenary House

Your child/young person is on the waiting list for an assessment for possible Autism Spectrum Disorder (ASD). The wait for an assessment can be very long and we know this is a difficult and frustrating time for your child and your family.

This booklet is designed to help you understand:

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What is Autism Spectrum Disorder?

An Autism Spectrum Disorder (ASD) is a lifelong, developmental condition that affects how a person communicates with and relates to other people, and how they experience the world around them.

All children with an ASD share certain difficulties but being autistic will affect them in different ways. This is why it is known as a spectrum disorder.

Children and young people with an ASD have long standing difficulties with social communication and social interaction. They also have difficulties with restricted and repetitive patterns of behaviour, activities and interests as well as sensory issues. These difficulties have a significant impact on their everyday functioning.

Communication and social skills help children to make connections with others and to learn and develop by interacting with others. They enable children to share pleasure and get comfort from others. Children with ASD may find this very difficult. They may seem less interested in people or seem to be “in a world of their own”. They may find it hard to see things from others points of view. Some children with ASD may like being sociable but not seem to be able to understand how to do this. Children with ASD often can’t make sense of people and may find them frightening and unpredictable.

Some children with ASD may not speak or have fairly limited speech. Others may have good language skills but may struggle to understand the expectations in a conversation or talk at length about their own interests. Children with ASD have difficulty interpreting spoken language and non-spoken language such as gestures, facial expressions or tone of voice.

Children with ASD have a rigid way of thinking and difficulty with imagination. Some children show limited interest in toys or pretend play while others may seem to play imaginatively but this may be repetitively copied from things they have seen. Children need to use their imagination to understand things from other people's perspectives, to predict what new situations may be like or to understand what might be expected of them in a situation. This is difficult for children with ASD and may lead to them being very anxious or trying to control or avoid situations.

All children with ASD will have restricted and repetitive behaviours but these will show in different ways. Some repetitive behaviours are obvious like rocking, spinning or hand flapping, while other may be more subtle like blinking or tapping fingers. Children with ASD may not like change and may cope better if they are prepared for any changes. They may like things to be the same or rigidly stick to the rules. Children with ASD may have special interests that take up much of their time. These may change with time and are sometimes interests that children like to do alone or, for other children with ASD, are ones they want to share in great detail with others.

Children with ASD often have sensory issues. They may experience over- or under-sensitivity to sounds, touch, tastes, smells, light, colours, temperatures or pain. At times sensations can be overwhelming for a child with ASD and cause them distress, anxiety and even physical pain. At other times a child with ASD may need to seek out certain sensations as a way of reducing anxiety or getting comfort.

In order for a child or young person to be given a diagnosis of Autism Spectrum Disorder they need to have an autism assessment. There needs to be evidence of significant difficulties in the above areas. These areas of difficulty are known as the diagnostic criteria and are what we use to decide if a child's difficulties can be called ASD. If children have significant

difficulties in the above areas that interfere with their daily lives and are evident in different settings then they will be given a diagnosis of ASD.

Some children may have difficulties in some of the areas discussed above but not in all of the areas. Other children may have difficulties in all of the areas but not at a level that causes a significant impairment. Sometimes children may show difficulties in all these areas but there may be other reasons for this. These children may not be given a diagnosis of ASD but this does not mean they do not have significant difficulties and need support.

Further information about ASD can be found at:

The National Autistic Society www.autism.org.uk

NHS website www.nhs.uk/conditions/autism/

What to expect at the assessment

There are two parts to undertaking an autism assessment.



The first part is taking a very detailed history from you, the parent or carer. This will cover information all the way from before your child was born to the present day. We will want to know about your child's health, their development, and how they play. We will ask about yours and your family members health. We will ask lots of questions about how your child interacts with others, how they communicate with you and others, their friendships and their interests. You will have the chance to tell us about any concerns you have around specific behaviours, sleep, eating, anxiety, difficulties in nursery or school and any other worries you have.



The second part is observing your child and gathering observations from different settings. This is done in different ways depending on the age of your child. Members of the assessment team will interact with your child during their assessment and carefully observe for their areas of strength and areas of difficulty. We gather information from other settings in different ways. Preschool children may be observed in different clinic settings, during speech and language therapy groups, in nursery or at specific play sessions. In older children we gather detailed information from staff who know them at nursery or school and can undertake additional observations in school if needed.

All this information is then discussed by the professionals undertaking your child's assessment. A decision is made as to whether your child fits the criteria for a diagnosis of Autism Spectrum Disorder or if their difficulties are best described in a different way. We may sometimes need to gather additional information before coming to a conclusion.

There are a number of different ways in which we can do these assessments and we aim to pick the best combination of professionals to assess your child's difficulties and come to a conclusion. For some children this can be done in one extended appointment with two professionals such as a doctor and speech therapist or a psychologist and speech therapist. For other children they may need a different combination of professionals in the appointment or a different way of undertaking the observations.

The information we have when your child is referred is used to decide which the best assessment pathway is for them. This can mean some children have to wait slightly longer than others to have the best combination of professionals and assessment method for them.

If your child is between 2 years and 4 years old your first appointment will be a video, telephone or home visit (where required) appointment with one of the specialist speech therapists. They will start gathering the information about your child and will discuss with you what the next steps in the pathway will be, usually a face to face appointment. This first appointment will be around 45 minutes. The subsequent appointment will be longer.

If your child is around 4 years or older you will be offered a face to face appointment. This may be a multi-professional appointment where we will aim to conclude at the time if possible. These appointments may be 1 ½ to 2 hours long.

Face to Face appointments can take place at any of the Sheffield Children's Hospitals sites but are mainly held at Ryegate Children's Centre or Centenary House. The members of the assessment team will be wearing personal protective equipment and it may be helpful to prepare your child for this.

There are different possible outcomes from the assessment;

- your child may be given a diagnosis of Autism Spectrum Disorder
- your child may be given an alternative diagnosis that better describes their difficulties
- your child may need further assessment for other conditions such as ADHD, developmental impairment/learning disability or specific language disorders.
- your child may have a mixture of difficulties that do not fit neatly under one diagnostic heading and may need a description of their difficulties that can be used to inform what help and support they need.

Help with video appointments:

<https://www.sheffieldchildrens.nhs.uk/patients-and-parents/outpatients/video-appointments/>

Preparing your child for a face to face appointment:

<https://www.sheffieldchildrens.nhs.uk/patients-and-parents/coronavirus-resources-for-children-and-families/>

What happens if your child gets a diagnosis of Autism Spectrum Disorder?

Having an Autism Spectrum Disorder or being autistic does not mean your child has an illness or a disease. ASD is not a medical condition with treatments or a cure. There are a range of strategies and approaches that help children with ASD to develop and learn. Once your child has been given a diagnosis much of the intervention and support is delivered in education and via workshops and parent groups.

Much of the information, the support and strategies for children with ASD can be accessed before a child has had an assessment and does not depend on having a diagnosis. There may be some very specialist areas of support, services or educational placements that do need a child to have a formal diagnosis.

After the assessment, if your child is given a diagnosis of Autism Spectrum Disorder, you will:

- Be given/sent a short letter confirming the diagnosis and the next steps, within a week of the assessment.
- Be sent information about the ASD post diagnostic workshops run by the neurodisability team along with the details of how to book on to these workshops.
- Be contacted by telephone by one of the specialist neurodisability support workers to talk through the ASD resource pack and what support is available.
- Be sent a copy of the ASD resource pack.

- Be sent a report that outlines the details of the assessment, your child's areas of strength and areas of need and the evidence for giving the ASD diagnosis. We will ask for your consent to share this with your child's nursery or school and any other relevant professionals that can help support your child. You should receive this within 3 months of the assessment.

- Be offered one further appointment with a doctor to discuss the diagnosis and any investigations that may be needed.

- Be offered ongoing follow-up in medical clinic only if there are ongoing medical concerns such as extremely restricted eating, significant sleep difficulties, emotional or mental health difficulties or other developmental conditions such as ADHD, developmental impairment or motor-coordination difficulties that need further assessment or monitoring. If there are no ongoing medical concerns your child will be discharged from follow-up but we will always accept a referral back if anything changes for your child in the future.

- Be referred to the specialist neurodisability nursing team or onto one of the other available workshops depending on your child's age and their individual needs. The workshops include:
 - Managing Difficult Emotions
 - Understanding Sensory Processing
 - Social Stories
 - Pre-school Speech and Language Therapy workshop

Follow-up with other specialist teams will be arranged as needed. For example, if it is identified during the assessment that your child needs ongoing input from Speech and Language Therapy then this will be arranged.

What happens if your child does not get a diagnosis of Autism Spectrum Disorder?

Your child may not be given a diagnosis of Autism Spectrum disorder after the assessment. This can be for a number of different reasons and these will be explained in detail to you at the assessment.

Not being given a diagnosis of ASD does not mean we are saying your child doesn't have significant difficulties and needs.

There are many different reasons why children have difficulty with communication, talking, interacting with others or have a need for routine. Many children and young people will demonstrate autism type difficulties and these difficulties overlap with other conditions. It is really important that we understand this in the right way so we can suggest the right strategies to help and get the right support for your child.

Sometimes it becomes clear during the assessment that there may be another condition causing the behaviours and difficulties you are seeing in your child. It may be that we need to look in more detail at these other possible conditions. This can include getting more information about your child's learning ability or getting more information about how well they can concentrate and pay attention.

Sometimes, children have real strengths in some of the areas we are looking at which means they don't quite fit the diagnostic criteria. They can still have very significant difficulties in the other areas and still need help and support with these difficulties.

Sometimes we can see difficulties in all of the areas but your child has some strengths and is currently doing OK in settings such as at home or at school. We may feel that your child needs to grow and develop some more so we can be sure what impact their difficulties are going to have on them. We need to

be absolutely certain that these difficulties are going to cause an impairment and need to be diagnosed as a disorder before we give a child a lifelong diagnosis.

After the assessment, if your child is not given a diagnosis of ASD, you will:

- Be given/sent a short letter describing your child's difficulties with a description of what the causes might be (called a formulation). This letter will outline what the next steps are.
- Be referred to any relevant service for further assessment and investigation if this is identified as a need during the assessment.

- Be sent a report that outlines the details of the assessment, your child's areas of strength and areas of need, why a diagnosis of ASD was not right for your child and their formulation. We will ask for your consent to share this with your child's nursery or school and any other relevant professionals that can help support your child. You should receive this within 3 months of the assessment.

- Be offered a follow-up appointment with a doctor to discuss the outcome of the assessment and any other investigations or assessments that are necessary

Sheffield Support Offer

For children and young people with social communication difficulties and suspected autism.

This section is designed to help you understand what support you can access whilst you are waiting for the assessment. In many cases this is exactly the same as the support you will be offered after diagnosis.

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What support and help can you access while you are waiting for an assessment?

There are lots of services in Sheffield that offer help and support for children with additional needs. The majority of these do not need a child to have a specific diagnosis. Many of these services are the same ones we refer families to after a diagnosis.

The Local Offer is a way of giving children and young people with special educational needs and/or disabilities (SEND) and their parents or carer's information about what activities and support are available in the area where they live.

www.sheffielddirectory.org.uk

Pre-school children

Health Visiting is part of the Sheffield Children's 0–19 Service which delivers the Healthy Child Programme through which children and their families are seen at home and at school from birth to 19 years for routine health screening and development assessment

Your **Health Visiting Team** may be able to offer additional support. They have specific support packages for children with developmental or communication difficulties and have links with other services in the community if you need further information or referral.

Your Health Visitor contact details are in your child's Red Book or you can call 0114 3053224. Health Visiting is part of Sheffield Children's 0–19 service – more information can be found at:

<https://www.sheffieldchildrens.nhs.uk/services/health-visiting/>

If you have concerns about your child's talking or their communication you can self-refer to the **Speech and Language Therapy Team**. Your child's nursery can also make a referral to SLT for your child. To make a referral contact the Speech and Language Therapy main office at Flockton House, telephone number 0114-2262335 or 0114-2262333.

<https://www.sheffieldchildrens.nhs.uk/services/speech-and-language-therapy/>

Small Talk is a parent/carer support group for parents/carers of pre-school children with speech, language and communication needs. Parent/carers meet to support one another while the children can benefit from speech and language therapy offered by speech and language therapists and students who are training to be speech and language therapists

<https://cottomcommunicationclinic.group.shef.ac.uk/smalltalk.html>

If your child is in nursey, speak to their keyworker or the SENCO about your concerns. There may be additional support they can offer.

Sheffield Family Centres run lots of different courses including Baby and Toddler sensory groups. These are running on-line during the coronavirus pandemic. Places can be booked by visiting:

<http://sheffield-family-centres.eventbrite.com>

<http://www.sheffielddirectory.org.uk/kb5/sheffield/directory/family.page?familychannelnew=5>

Sheffield Parent Hub has a range of programmes specifically designed for parents and carers of children with additional needs. The groups are friendly and welcoming. You will have the opportunity to meet other parents and

carers and discuss experience and ideas. They are currently running programmes online including:

ASD Incredible Years

Changing negative behaviours into positive behaviours

Positive parenting for children with a disability

<https://www.sheffield.gov.uk/parenting>

School-age children

One of the most important areas for accessing support for your child is in school. Children and young people do not need a diagnosis to access much of the support schools are able to offer. All schools in Sheffield work using the **Sheffield Support Grid**. This is a document which sets out what schools should be offering those children who need some additional support, based on their areas of need. There are sections that detail what support should be offered to a child who has communication and interaction difficulties, social communication difficulties, emotional regulation difficulties and behavioural difficulties. More information about the Sheffield Support Grid can be found at:

<http://www.sheffielddirectory.org.uk/kb5/sheffield/directory/advice.page?id=xY4E0cnkvvg>

The **Education Autism Team** provides advice and support to schools and families for children and young people who have social communication difficulties. They are funded by the local authority and are free to all schools/settings and families. Children do not need to have a diagnosis to access this support.

The Education Autism team Support line number is: 0114 2736567

<http://www.sheffielddirectory.org.uk/kb5/sheffield/directory/service.page?id=F1OM07rcvZA>

Sheffield SEN & Disability Information Advice and Support

(SENDIAS) provides impartial, confidential information, advice & support to parents/carers of children and young people with special educational needs and/or disabilities on a range of topics including; SEN/disability specific information, education, SEN statutory processes, available services, disability related benefits, grants and funding.

They offer support to parents of children and young people (aged 0–25) with any level or kind of difficulty or disability, from mild to multiple, severe conditions. They operate across the city and only take referrals from parents/carers.

Telephone 0114 273 6009

E-mail ssendias@sheffield.gov.uk

Website <https://www.ssendias.org.uk>

Facebook <https://www.facebook.com/SheffieldSENDIAS/>

Sheffield Parent Hub has a range of programmes specifically designed for parents and carers of children with additional needs. The groups are friendly and welcoming. You will have the opportunity to meet other parents and carers and discuss experience and ideas.

They are currently running programmes online including:

ASD Incredible Years Programme (2–8 years)

Changing negative behaviours into positive behaviours

Positive parenting for children with a disability

<https://www.sheffield.gov.uk/parenting>

Sleep

We know it is incredibly hard to have a child who is not sleeping. It not only impacts on your child but on the whole family. There is a lot of support available in Sheffield for children and young people with sleep difficulties. The services available and support offered is the same for all children, whether or not they have a diagnosis.

The key to managing sleep difficulties is putting the right bedtime routines in place and using the right behavioural strategies.

The programmes run by the Sheffield Parent Hub include sessions on managing sleep difficulties and many of the strategies learnt on these programmes will help with establishing good sleep routines.

Sheffield Parent Hub <https://www.sheffield.gov.uk/parenting>

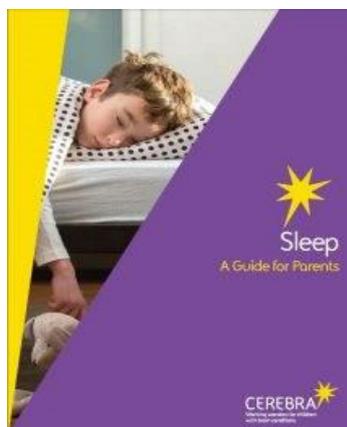
The Multi Agency Support Teams (MAST) are part of the local early help offer. Many of the MAST practitioners are trained sleep practitioners and will be able to help with sleep difficulties. Your child's school can make a referral to the MAST team or you can contact them directly.

MAST <https://www.sheffield.gov.uk/home/social-care/early-help-for-children-families>

There are also charities that have advice on their website to help with sleep problems.

There is advice on the National Autistic Society website about sleep:

<https://www.autism.org.uk/about/health/sleep.aspx>



Cerebra provide information and resources about sleep for children with additional needs

<https://www.cerebra.org.uk/help-and-information/sleep-service/sleep-information/>

Telephone: 01267 244210

Behaviours that challenge

Children and young people with ASD or ASD type difficulties may at times behave in ways that seem unusual or in ways that are challenging to manage. There will be a reason for these behaviours, although it may not always be obvious what it is. All children often communicate their feelings through their behaviour and this can be more so for children with ASD or social communication difficulties. The behaviours may be a way of communicating distress or anxiety or it may be that your child is completely overwhelmed in a particular situation. Your child may be using certain behaviours to try and cope in a particular situation.

Having a variety of different strategies to use when your child is behaving in ways that are challenging to manage can be really helpful.

Sheffield Parent Hub has a range of programmes specifically designed for parents and carers of children with additional needs. The groups are friendly and welcoming. You will have the opportunity to meet other parents and carers and discuss experience and ideas.



They are currently running programmes online including:

ASD Incredible Years Programme (2–8 years)

Changing negative behaviours into positive behaviours

Positive parenting for children with a disability

EPEC parenting for children with ASD

<https://www.sheffield.gov.uk/parenting>

There is lots of information available on the National Autistic Society website about different types of behaviour seen in children with autism and autism type difficulties. There is information about what may be causing different behaviours and what strategies may be useful.

<https://www.autism.org.uk/about/behaviour.aspx>

The NHS website also has some useful information and further links:

<https://www.nhs.uk/conditions/autism/autism-and-everyday-life/help-with-behaviour/>

Eating

It is incredibly hard as a parent to have a child who will not eat or is very picky with food. Feeding and eating problems are very common in children and young people with ASD and similar difficulties. Your child may only accept a very limited range of foods, may go long periods without eating, may suddenly change their preferred foods, refuse to eat at nursery/school, need their food presenting in a very specific way or eat non-food items (pica).

The Speech and Language Therapy Team have produced a leaflet discussing these difficulties and suggesting some strategies:

<https://www.sheffieldchildrens.nhs.uk/download/389/child-development/6826/children-with-neurodevelopmental-difficulties-who-avoid-or-refuse-food.pdf>

<https://www.sheffieldchildrens.nhs.uk/services/speech-and-language-therapy/eating-and-swallowing/>

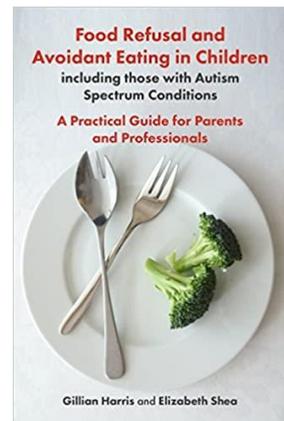
One of the specialist SLTs has written an article on the Sheffield Parent Carer Forum about restricted eating:

<https://sheffieldparentcarerforum.org.uk/information/health-wellbeing/when-its-not-just-fussy-eating/>

There is also information available to help with these difficulties on the National Autistic society website:

‘Eating, Problems, Finding the Cause and General Pointers’
www.autism.org.uk/about/health/eating

‘Food Refusal and Avoidant Eating in Children, Including Those with Autism Spectrum Conditions: A Practical Guide for Parents and Professionals’ Book by Gillian Harris and Elizabeth Shea (2018)



Anxiety and Emotional Health

Everyone can feel worried or anxious at times. Children can feel anxious about different things at different ages. Many of these worries are a normal part of growing up but we know children and young people with ASD and ASD type difficulties often have problems with anxiety. Anxiety becomes a problem if it starts to affect your child’s wellbeing or gets in the way of their everyday life. There are lots of online resources to help you help and support your child or young person with their anxiety.

<https://www.nhs.uk/conditions/stress-anxiety-depression/anxiety-in-children/>

<https://www.barnardos.org.uk/blog/5-things-you-need-know-about-anxiety>

<https://youngminds.org.uk/find-help/for-parents/parents-guide-to-support-a-z/parents-guide-to-support-anxiety/>

There are some helpful websites specifically about children and young people's emotional and mental health:

Young Minds <https://youngminds.org.uk/>



HappyMaps <https://www.happymaps.co.uk/>

There are some resources in Sheffield for help with mental health:

<https://www.sheffieldmentalhealth.co.uk/>

Kooth is a free online counselling service that provides a free online chat service for young people, available Mon to Fri 12pm to 10 pm, Sat and Sun 6pm to 10pm.



<https://www.kooth.com/>

The **Golddigger Trust** is a Sheffield based charity that works with young people aged 11–18 years and can support young people in areas such as self-esteem, managing emotions, healthy relationships and wellbeing.

<https://www.golddiggertrust.co.uk/>

Toileting

It is common for children with autism, autism type difficulties or developmental delays to be delayed in potty training. Continence problems such as constipation and soiling are also more common in children with additional needs.

Information and advice on these difficulties can be found at:



The eric website has information and downloadable guides on potty training, bowel problems (constipation and soiling), daytime bladder problems and bedwetting. They have a helpline for families to talk to or email an expertly trained childhood continence advisor as well as parent & carer workshops to inform and give support on potty training and bowel & bladder conditions

'Toilet Training'

www.autism.org.uk/about/health/toilet-training

Sensory

Children and young people with an Autism Spectrum Disorder and ASD type difficulties will often have sensory processing difficulties. Difficulties processing sensory information can make every day activities really challenging for your child/young person and your family.

The Sensory Service Therapy team at the Ryegate Children's Centre have put together some resources, which are aimed at helping families of children with sensory processing difficulties. The webpage includes a downloadable booklet 'Making Sense of Your Senses' which includes key information and ideas about how to help your child if they experience sensory processing difficulties.



<https://www.sheffieldchildrens.nhs.uk/services/child-development-and-neurodisability/sensory-processing-difficulties/>

There are also demonstration videos you can watch, a bite-sized presentation, as well as “Top Tips” sheets for specific sensory issues such as:

Eating
Coping with smells
Chewing
Showering and bathing
Coping with overload
Haircare and nailcare



Additional information can be found about sensory difficulties on the National Autistic Society website:

<https://www.autism.org.uk/about/behaviour/sensory-world.aspx>

Local Charities and resources

The **Sheffield Parent Carer Forum** are an independent group of parents and carers of children and young people (0–25) with special educational needs and disabilities. Their main aim is to ensure the needs of children are met. They bring together parent carers from across Sheffield to provide mutual support, exchange information, and influence policy and practice. There is a large amount of information covering a variety of topics as well as links to other local charities and resources.

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

Sparkle Sheffield is a local registered charity that supports children and young people from birth to 25 with Autism Spectrum disorders and other social communication difficulties. Founded and run by parents who have children with Autism they understand what life is like and how to work together to improve children's and family's life. They run playgroups, sibling support groups and parent support groups.

<https://sparklesheffield.co.uk/>

The **Sheffield Autistic Society** is a local charity for autistic people and their families. They provide support and information, and campaign for a better world for autistic people in Sheffield – children, young persons and adults.

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

National charities and resources

The **National Autistic Society** has a huge amount of information for parents/carers on its website and in booklets that you can request. There is advice about managing a range of the difficulties we see in children with ASD and autism type difficulties. The advice and strategies they suggest may be helpful for your child whether or not they go on to get a formal diagnosis.

www.autism.org.uk

The **NHS website** has information and links about autism:

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

Ambitious about Autism are a national charity for children and young people with autism. There is information on their website about understanding autism, behaviors, early years, education and transition to adulthood.

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

Advice about benefits

Disability Living Allowance

Disability Living Allowance (DLA) can be claimed for children who have additional care needs or difficulty with walking which are caused by a disability or health condition. DLA is a non-diagnosis specific benefit, so not having a diagnosis does not mean you cannot claim DLA if your child has significant additional needs. Having a diagnosis of autism will not automatically lead to an award, but many children on the autism spectrum do qualify for the benefit. It is also entirely non-means tested, so your income and savings are not taken into account. DLA can be awarded at several different rates depending on the level of additional care that the child requires.

To apply for DLA you will need to complete a detailed application form. You can order a form by ringing the Department for Work and Pensions on **0800 121 4600**. You can also download the form online:

<https://www.gov.uk/government/publications/disability-living-allowance-for-children-claim-form>

Filling in the DLA form can be difficult for a parent, but don't be put off.

Someone at your nearest Citizens Advice Bureau might be able to sit with you and help you with the form, or even fill it in for you.

Advice about completing the form on CA website:

<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/disability-living-allowance/help-with-your-dla-claim/help-with-dla-form/>

You can also call Contact (for families with disabled children) helpline if you have questions – they're experts in DLA for children.

Contact (for families with disabled children)

Telephone: 0808 808 3555

Monday to Friday, 9:30am to 5pm

Calls to these numbers are free.