

Autism Assessments

This booklet is designed to help parents/carers understand the autism assessment process. It covers the following areas:

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Updated January 2022.

What is autism?

Autism, also known as Autism Spectrum Disorder or 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.

Autism covers a very wide range of difficulties and abilities. Not all children and young people will be affected in the same way and not all the descriptions below will apply to every child. We know that all children and young people with autism and social communication difficulties are unique and will have their own strengths. There will be situations where children with autism may not be obviously different to their peers, but other times when they really struggle in situations. When undertaking diagnostic assessments for autism we must consider very specific criteria. These criteria are currently based on things children and young people with autism do differently from the majority of children and things which children and young people have difficulty with.

Autistic children and young people have differences in their social communication and social interaction skills. They may see and understand the world differently to their peers and may have difficulties forming and maintaining friendships or relationships. They may also have specific and passionate interests which take up a lot of their focus. They may present with repetitive movements or noises, known as stimming. Autistic children and young people also can have unusual reactions to sensory input like smells, sensations or sounds, and they may find change or unfamiliar situations difficult. These differences and difficulties have a significant impact on children and young people's everyday functioning.

Communication and social interaction skills help children make connections with others, and children learn and develop by interacting with others. They enable children to share pleasure and get comfort from others. Autistic children may find this difficult. They may seem less interested in people or seem to be “in a world of their own”. They may sometimes find it hard to see things from others’ points of view. Some autistic children like being sociable, but it may not come as naturally as it might to non-autistic children. Sometimes autistic children can’t make sense of other people. They may find them unpredictable and difficult to relate to. Autistic children can find it difficult to engage in mutual, shared, back and forth interaction (known as reciprocal interaction). They may also not understand and communicate their emotions in the same way as non-autistic people.

Some autistic children may not speak, or they may have limited speech. Others may have good or advanced language skills but may struggle to understand expectations in a conversation or talk at length about their own interests. Autistic children can have difficulty interpreting spoken language and non-verbal communication such as gestures, facial expressions or tone of voice.

Autistic children can 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 can be difficult for autistic children so may lead to them being very anxious or trying to control or avoid situations. Autistic children 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. They can have a strong sense of justice.

Autistic children can have specific, passionate interests. They may have keen interests that take up much of their time and focus. These interests may change with time and are sometimes things that children like to focus on alone or, for other autistic children, they are interests they want to share in great detail with others.

Autistic children can show repetitive behaviours or noises. Some of these behaviours are obvious like rocking, spinning or hand flapping, while others may be more subtle like blinking or tapping fingers.

Autistic children 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 autistic children and cause them distress, anxiety, and even physical pain. At other times, autistic children 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 they need to have an autism assessment. This should be carried out by two or more professionals. 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 autism. If children have significant difficulties in the above areas that interfere with their daily lives and are evident in different settings (e.g. home and school, or home and the clinic) then they will be given a diagnosis of autism.

Some children may have difficulties in some of the areas discussed above but not in all the areas. Other children may have difficulties in all the areas but not at a level that causes them significant difficulty in their everyday lives. 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 autism, but this does not mean they do not have significant difficulties or do not need support.

Further information about autism can be found at:

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

The National Autistic Society www.autism.org.uk

Ambitious about autism www.ambitiousaboutautism.org.uk/

What to expect at the assessment?

The aim of your assessment appointment is to identify whether your child fits the diagnostic criteria for autism. The assessment team will work with you and your child to find out about your children's strengths and needs.

We will NOT be able to provide specific individual advice and strategies at the assessment, as this appointment is only to identify whether your child has autism or not. However, we will make recommendations about how you can find further information and support after the assessment. The assessment will have a different format depending on the age of your child and the team conducting the assessment.

Your child will either be assessed by the Child Development and Neurodisability Service (known locally as the "Ryegate Team") or Child and Adolescent Mental Health Service (known as CAMHS). Professionals will select the most appropriate pathway based on your child's needs. Autism assessments can take place at Ryegate Children's Centre, Centenary House, Becton or perhaps in another location. Your appointment letter will tell you where to go.

We have some resources on our website to help children and young understand the assessment process and what to expect.

There are multiple parts to undertaking an autism assessment:

1 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 questions about how your child interacts with others, their communication style, 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.

2 Another part of the assessment involves a specialist clinician **interacting with, and observing, your child**. This is done in different ways depending on the age of your child. Members of the assessment team will interact with your child and carefully observe for their areas of strength and any areas of difficulty. Depending on their age, children and young people will have an opportunity to share their thoughts and concerns.

3 A further part of the assessment is to **gather information from other settings**. This is done in different ways depending on the age of your child. Preschool children may be observed in different clinic settings, during speech and language therapy groups, in nursery or at specific play sessions. For older children we gather detailed information from staff who know them at school (or alternative provision) through the questionnaires and we may contact their education setting and do a visit if this is needed.

4 Finally, we will **consider all information** from the different parts of the assessment to decide if your child fits the criteria for autism or if their profile is best described in a different way. Your child's difficulties could be explained by another developmental condition such as Attention Deficit Hyperactivity Disorder (ADHD) or a learning disability. There could be other explanations such as anxiety, low mood, trauma or early life

experiences with significant others (attachment). We may sometimes need to gather more information before concluding, such as assessing your child's learning ability or their language skills. We will discuss the outcome of the assessment with you and talk through what will happen next. We will give you information about any support which would be useful for you and your child.

Assessment with the child development and neurodisability team ("Ryegate Team")

If your child is school age (around 4 years or older) you will be offered a multi-professional face-to-face appointment where we will work with you to decide whether your child fits the criteria for autism. These appointments may be 1½ to 2 hours long.

If your child hasn't started school yet your first appointment will be with one of our team (e.g. a psychologist or a speech and language therapist). This may be a video or telephone call or a home visit. This first appointment will be around 45 minutes. They will start gathering the information about your child and will discuss with you what the next steps in the pathway will be. A speech and language therapist may also contact your child's nursery (if applicable). After this, you and your child will have a multi-professional face-to-face appointment in a clinic. This next appointment will be approximately 1 ½ hours and we will work with you to decide whether your child fits the criteria for autism.

Both the pre-school and school-age assessment will involve a range of professionals (e.g. doctors, psychologists, speech and language therapists). We will choose the best combination of professionals for your child based on the information from the referral. The information we have when your child is referred is used to decide which is the best assessment pathway 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.

Assessment with Child and Adolescent Mental Health Service (CAMHS)

If your child is assessed within CAMHS they will be seen by one of our clinicians with specialist skills in assessing for neurodevelopmental conditions. This could be a clinical psychologist, a psychiatrist or a specialist nurse. Sometimes, your child may have had another CAMHS clinician before this assessment, within our six-session clinic. This clinician may have requested that an autism assessment is completed, in which case you would have been placed on an internal waiting list for our specialist neurodevelopmental assessment team (NAT). Sometimes, the clinician your child sees in six-session clinic may be one of our neurodevelopmental clinicians and they therefore may be able to do the autism assessment within the clinic, without referring your child to someone else.

The assessment will consist of multiple parts, as explained above. This includes collecting a detailed history from the parent/carer, collecting information from the child or young person through observations and discussions, collecting information from others, discussing as a multi-disciplinary team, and feeding back to the family. This process can take place over a few different sessions, and this will all be explained to you.

Possible outcomes from the assessment

The following are possible outcomes from the autism assessment:

- Your child receives a diagnosis of autism
- Your child needs further assessment for other conditions such as ADHD, developmental impairment/learning disability or developmental language disorder. Further assessment may show your child has other conditions alongside autism, or your child may be given a different diagnosis which better suits their needs.

- Your child has a pattern of difficulties that do not fit neatly under one diagnostic heading and they may need a description of their difficulties that can be used to inform what help and support would be beneficial.

What happens if your child gets a diagnosis of autism?

Receiving a diagnosis of autism can often help families, schools and others make sense of a child's preferences and needs. Autism is not a medical condition with treatments or a cure, but most children benefit from different strategies and approaches to help them develop and learn. It is also important for those around the child to learn about autism and how they can adapt their interactions and the environment to support children.

Information and support for your child, your family and those educating or caring for your child is delivered through online resources, parent workshops and in nursery and school settings. Much of this information and support 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.

If your child is assessed by the child development and neurodisability team ("Ryegate Team")

After the assessment, if your child receives a diagnosis of autism, you will:

- Be given a short letter confirming the diagnosis and the next steps.
- Be sent information about the autism support videos created by the neurodisability team.

- Be sent a copy of the autism resource pack. This will include information about autism and what support services are available in the local area and nationally.
- Be contacted by telephone by one of our specialist neurodisability support workers to talk through the autism resource pack. You will also have the chance to ask any questions you might have following the assessment.
- Be sent a report that outlines the details of the assessment, a description of your child's strength and needs, and the evidence for giving the autism 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.
- Be offered one further appointment with a doctor for a medical review. You will be offered ongoing follow-up by doctors 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, but we will always accept a referral back if anything changes for your child in the future. You can continue to access support through education and in the community.
- You may be referred to the specialist neurodisability nursing team or offered a place on further workshops depending on your child's age and their individual needs. These 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.

If your child is assessed by CAMHS

After the assessment, if your child receives a diagnosis of autism, you may be offered a space in our CAMHS autism follow-up clinic, if it is felt that this would be helpful. Sessions can be arranged if requested by parents, typically every few weeks to every few months. We are unable to offer very regular slots. Clinic slots are often used for parents to meet with the clinician on their own to discuss their child's difficulties. The clinician will give you information and support to help you understand your child's difficulties and needs.

The clinician may also be able to think with you about strategies to support your child or may signpost you to helpful resources or other avenues of support. If you do wish to be seen in the follow-up clinic, you will be sent a letter which gives you six months to contact the team and request an appointment. If we do not hear from you within six months, we will assume you do not need the support of the clinic and you will be discharged.

What happens if your child does not get a diagnosis of autism?

Your child may not be given a diagnosis of autism 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 autism does not mean we are saying your child doesn't have significant difficulties and need, but children must meet very specific criteria to receive a diagnosis.

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 certain that these difficulties are going to cause an impairment before we give a child a lifelong clinical diagnosis.

If your child is assessed by the child development and neurodisability team ("Ryegate Team")

After the assessment, if your child does not receive a diagnosis of autism, you will:

- Be given a short letter confirming the outcome of the assessment and the next steps.
- Be referred to any relevant services for further assessment and investigation if this is identified as needed during the assessment.
- Be directed to information sites and support services to help you and your child

- Be sent a report that outlines the details of the assessment, a description of your child's strengths and needs, and why a diagnosis of autism was not right for your child. 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.
- Be offered a follow up appointment with a doctor if there are ongoing medical needs.

If your child is assessed by CAMHS

After the assessment, if your child does not receive a diagnosis of autism, we will discuss next steps with you. Your child may require further therapeutic support from CAMHS, e.g. for anxiety or low mood. Your child may not require any further support following assessment and therefore discharge from CAMHS would be agreed with you as a family. You may be signposted to other services who are better placed to help than CAMHS.

What autism support is available?

The wait for an autism assessment can be very long and we know this is a difficult and frustrating time for your child and your family.

Across the city there is a wide range of support whether your child is waiting for an assessment, has been diagnosed or you just think you might value a little more help as a family. You do not need to have a confirmed diagnosis to access much of this support, so you do not need to wait until your assessment appointment to explore the supports available.

A range of support services are detailed in this booklet, but for the most up to date resource, please visit our website

<https://www.sheffieldchildrens.nhs.uk/services/autism-support-resources/>

Sheffield Children's Hospital and Sheffield City Council are also working together to contact all families on the waiting list to have a conversation about the support available to you.

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. Organisations across Sheffield are working closely together to ensure all children and families get the support they need. This support offer is not based on whether or not a child/young person has a diagnosis or is awaiting an assessment.

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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. 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 (SLT) 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 01142262335 or 01142262333.

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

Small Talk is a group for pre-school children with speech, language and communication needs held at The University of Sheffield. Services are offered by students who are training to be speech and language therapists, supervised by qualified therapists.

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

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 run programmes online such as:

- ASD Incredible Years
- Changing negative behaviours into positive behaviours
- Positive parenting for children with a disability

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

0-5 SEN/D Service (including the Portage Home Visiting Service) offers support for children with Special Educational Needs and disabilities, their carers and education providers for children from 0-5+. They are a team of qualified SEN specialist teachers, teaching assistants and Portage home visitors delivering a citywide offer. They work closely with families, settings and schools and partner agencies across education, health and care services to meet the needs of children with significant and complex additional needs. Referrals into this service can be made by nurse or other early year's settings.

School-age children

One of the most important areas for accessing support for your child is in school. If you have concerns, speak to your child's **school SENCO**. There may be additional support they can offer. There will be a few children with similar needs in all primary schools and a small group in all secondary schools. All schools have experience of providing for the majority of children with autism and autism type difficulties. Local education authority schools can access consultation and advice from the **Educational Psychology service**.

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 **Inclusion and Attendance Team** offer advice and support to schools where children and young people are experiencing barriers to engaging in their education (such as being at risk of exclusion or having poor attendance). The team works collaboratively with schools to consider how to overcome those barriers with a focus on better outcomes for children. Please speak to school's SENCO if you would like to know more about this service.

The **Education Autism Team** provides advice and support to schools and families for children and young people who have significant 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 Autism Support Service have a parent phone line which operates Monday to Thursday (term time) 1.00pm to 4.00pm phone number 0114 2506800. Parents can ring and leave a message and one of the support teachers in the team will call back.

Alternatively parents can email the team on the following address and one of the team will make contact.

autism.educationteam@sheffield.gov.uk

The Education Autism Team in Sheffield is a training hub for the **Autism Education Trust**. The Autism Education Trust mainly support schools through training but has some helpful information on their website for parents/carers:

<https://www.autismeducationtrust.org.uk/shop/parents-guide/>

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 2736009

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>

The **Multi Agency Support Teams (MAST)** support families by delivering parenting programmes, whole family key worker support and through health and play based activity in your local Family Centre. They will work with you as a family to identify the most appropriate type of help and support and consider the needs of the whole family. They will co-ordinate the help and support available and bring together different relevant organisations and can help with a wide variety of difficulties.

All schools have MAST workers allocated to them who can be contacted via school. Alternatively, you can contact them directly:

Phone: 0114 2037485

Email: <https://www.sheffield.gov.uk/form/your-city-council/enquiry-form>

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>

Many of the **Multi Agency Support Team (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:

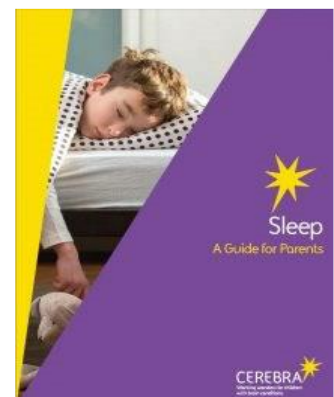
<https://www.autism.org.uk/about/health/sleep.aspx>

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

E-mail: sleep@cerebra.org.uk



Behaviours that challenge

Autistic children or young people, or people with autism-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 autism 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 run programmes online such as:

- 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 autistic children and young people and similar profiles. 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 (SLT) 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 with the Sheffield Parent Carer Forum about restricted eating:

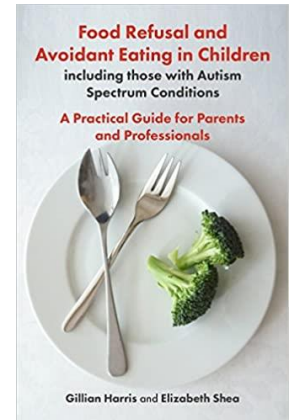
<https://sheffieldparentcarerforum.org.uk/information/health-wellbeing/when-its-not-just-fussy-eating/>

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

A useful book is ‘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 autistic children and young people and those with autism-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 Monday to Friday 12.00pm to 10.00 pm, Saturday and Sunday 6.00pm to 10.00pm.



<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/>

The Sheffield Parent Carer forum have also produced an overview of the mental health services that are available in Sheffield:

<https://sheffieldparentcarerforum.org.uk/information/health-wellbeing/accessing-mental-health-support/>

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:



ERIC: The Children's Bowel and Bladder charity. 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' resource from the National Autistic Society

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

Sensory

Autistic children and young people, and people with autism-type difficulties will often have sensory processing difficulties. Difficulties processing sensory information can make everyday 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 a Virtual Therapy Area aims to provide parents and carers with knowledge, ideas and strategies to support your child or young person with sensory needs that may be impacting on their everyday life. 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. This covers a range of specific sensory issues such as eating, toileting, teeth brushing and bathing plus many more.

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

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

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

Parent/carer support groups

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/>

Aspergers Children and Carers Together (ACCT) is a parent-led support group for children and families affected by Asperger's Syndrome and High-Functioning Autism. They run activity groups for children and teenagers with Asperger's and Autism, as well as family days out and other trips. Siblings are welcome too. They run coffee mornings for families that are starting out on the journey to a diagnosis. Phone: 0114 2230242

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

Ray of Hope is a support group based in North Sheffield, for families of children with any kind of additional needs. The group aims to provide peer support through regular meetings, coffee mornings and fun activities, and provides access to useful information.

<http://www.ray-of-hope.co.uk/>

Sheffield Carers Centre offers advice, information and support to anyone in Sheffield who provides unpaid care for someone else, regardless of whether the cared-for person is a child or an adult. Their services include benefits and legal advice, counselling, employment support, telephone befriending, and more. They also publish a regular newsletter.

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

Short breaks and respite

The **Short Breaks grant** can be applied for by families with a disabled child. They provide grants up to £400 to be used to arrange activities for your child. It is dependent on household income. More details can be found at:

<https://www.sheffield.gov.uk/home/social-care/short-breaks>

Special Needs Inclusion Playcare Service (SNIPS) support children with disabilities to access clubs and activities. They provide families with a short break with the knowledge that their child or young person is in a club that they enjoy.

<http://www.sheffielddirectory.org.uk/kb5/sheffield/directory/advice.page?id=UrgO9wgJmTg>

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 autistic children 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/>

Ambitious about Autism have produced a very helpful toolkit for parents of young children with suspected or newly diagnosed autism:

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

Independent Provider of Special Education Advice (known as IPSEA) is a registered charity operating in England. IPSEA offers free and independent legally based [information, advice and support](#) to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). They provide [training](#) on the SEND legal framework to parents and carers, professionals and other organisations.

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.

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

Carers Allowance:

Carer's Allowance is the main benefit for carers. You might be able to get it if:

- your child receives the middle or highest rate care component of DLA, or the daily living component of PIP at either rate, AND
- you spend at least 35 hours per week caring, AND
- you don't earn more than £123 per week.

In calculating your earnings, you can make certain deductions (such as tax, national insurance contributions, childcare costs) from your gross wages. Only your earnings (not your partner's) are counted. It does not matter what savings you have.

How to apply

You can [make a claim](#) for Carer's Allowance online. Alternatively, if you would prefer to use a paper claim form, you can call the Carer's Allowance Unit on 0800 7310297.

Carer's Allowance should be backdated to the start of the DLA/PIP award so long as you claim within three months of receiving the decision awarding your child DLA or PIP.

You can also call **Contact (for families with disabled children)** helpline if you have questions – they're experts in DLA for children. Contact have specialist advisors who can do a full benefits check for you over the phone.

Telephone: 0808 8083555

Monday to Friday, 9:30am to 5.00pm

Calls to these numbers are free.