



Guide for parents and carers

Suffolk Neurodevelopmental Disorder Pathway

NHS

Norfolk and Suffolk
NHS Foundation Trust



NHS

West Suffolk
NHS Foundation Trust

About this guide

This guide has been produced by Suffolk and North East Essex Integrated Care Board in collaboration with West Suffolk NHS Foundation Trust and Norfolk and Suffolk Foundation Trust, as well as the Suffolk Parent Carer Forum. It aims to help parents and carers understand the Neurodevelopmental Disorder Pathway for children and young people living in Suffolk. It contains the information that parents and carers have said they would have found helpful when they had a child or young person going through the diagnostic process for a neurodevelopmental disorder.

Who is this guide for?

This guide is for families of children and young people who may have a neurodevelopmental disorder. It will help you understand the support available to your child or young person and family and explain how neurodevelopmental disorders are assessed and diagnosed in Suffolk.



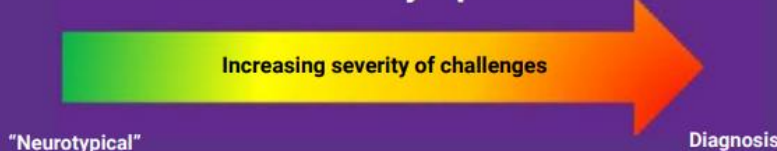
“The human brain is as diverse as the human fingerprint.”

Victoria McGovern

What is neurodiversity?

Neurodiversity is not as simple as neat categories of traits and symptoms in clear diagnostic boxes. Neurodivergent conditions exist on a spectrum, a scale of increasing severity or impact of the differences associated, at the extreme end of which a young person may meet current diagnostic criteria for a particular condition. For example, social communication difficulties exist along a spectrum, at the extreme end of which some people may meet diagnostic criteria for autism. Similarly, attention and hyperactivity problems exist along a spectrum, at the extreme end of which some people may meet criteria for a diagnosis of ADHD. What’s important, however, is that only a small minority of people will have difficulties and traits that fit diagnostic criteria for a certain diagnosis, but actually other people along the spectrum will still significantly struggle with some aspects of life and could really benefit from support. So, when we talk about neurodiversity in childhood, we’re not talking just about young people who fit into the diagnostic bubble at the end, but about a broader range of neurodivergent young people whose brains work differently, who have unique strengths and find some aspects of life really challenging.

Neurodiversity Spectrum



Parent top tip



We understand that you probably have lots of questions right now.

To try and address some of these Dr Beth Mosely; Consultant Clinical Psychologist, and Dr Annie Byrant; Clinical Psychologist, have developed a workshop:

Childhood Neurodiversity: What You Need to Know as a Parent or Carer.

The workshop covers:

- What is neurodiversity?
- Neurodevelopmental diagnoses
- Co-occurring challenges
- Talking to children and schools about neurodiversity
- Further support and resources

To view this workshop please go to: [Childhood Neurodiversity: What You Need to Know as a Parent or Carer \(youtube.com\)](#)

To sign up for future workshops please go to: [Psychology in Schools Team - NSFT Events | Eventbrite](#)

What does neurodevelopmental disorder or condition mean?

A neurodevelopmental disorder (NDD) or neurodevelopmental condition is a term used for individuals whose brain functioning in selective areas such as learning, attention, emotions, impulses, sensory processing, and social behaviours, is at an extreme for their age, which impacts their ability to perform tasks and activities in their daily lives.

What is Autism?

Autism or an autism spectrum disorder (ASD) is a lifelong neurological difference that affects how people communicate and interact with others. Most autistic people see, hear, and experience the world differently from neurotypical people, but like neurotypical people, every autistic person is unique and complex.

Historically, there was a common misconception that the autistic spectrum is a straight line between low and high functioning, but as understanding has increased, it is clear that everyone is completely different and has different strengths and weaknesses - you might hear this referred to as a 'spiky profile' and it is a great way to explain the differences of ability that are associated with neurodiverse conditions. For example, one autistic person may be highly creative, but struggle to organise themselves. Another may excel at maths but find it hard to join in two-way conversations.

This graphic below shows that when a person is on the autism spectrum, they may demonstrate great strengths in some areas but be lacking in skills in another.

For more information on autism, as well as advice and guidance on local support and resources, please go to: [NDD Supporting Your Neurodivergent child \(suffolklocaloffer.org.uk\)](https://www.nsd-supporting-your-neurodivergent-child.org.uk)

Parent Workshops

For further information about parent workshops on a whole range of topics including:

- Neurodiversity
- Mental health: anxiety, low mood, OCD, self-harm, Tourette's/tics
- Managing big feelings and emotions
- Understanding the teenage brain
- Supporting your child to attend
- And many more

Please visit: [Parent workshops | Norfolk and Suffolk NHS \(nsft.nhs.uk\)](https://www.nsfth.nhs.uk)

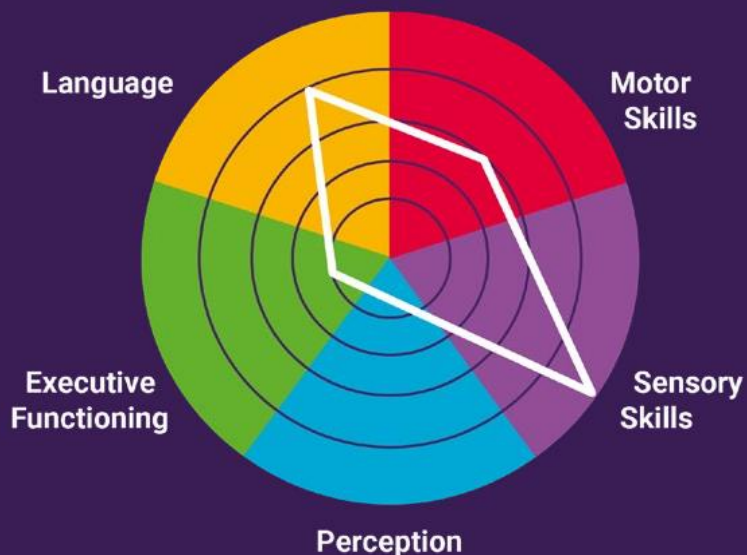
What people think the autism spectrum looks like:



Less Autistic

More Autistic

What it can actually look like:



What is ADHD?

Attention Deficit Hyperactivity Disorder or ADHD is a neurodevelopmental disorder where individuals have difficulty regulating their attention because of poor neurotransmitter activity (the way chemicals are released and transferred within the brain) and differences in the structure of the brain. Attention Deficit Disorder or ADD is similar, but without the hyperactivity. ADHD usually presents in three different ways, hyperactivity (which means the need to move around more), impulsivity and inattention. Children with ADHD may be labelled as disruptive, for behaviour which they cannot control. These are the main features of ADHD but there are many more that have a significant impact on a child's organisational skills and emotional well-being.

For more information on ADHD, as well as advice and guidance on local support and resources, please go to: [NDD Supporting Your Neurodivergent child \(suffolklocaloffer.org.uk\)](https://www.suffolklocaloffer.org.uk)



If you have any concerns about your child or young person, then trust your instincts.

You know them better than anyone else and are their greatest advocate.

I think my child or young person has a neurodevelopmental disorder, what happens now?

The next steps are different for each child or young person and their families, this means that timescales can be different between individuals. Over the following pages you will find information that shows you the pathway and the potential outcomes at each stage, as well as information about the variety of services that can support you and your child or young person. This booklet will provide details of these services and how you can access them.

"This doesn't mean your child is broken, just that their brain works differently. Give your child the tools to operate in a neurotypical world on their terms, without dimming who they are."

"Some days I wondered whether I was imagining her difficulties but when I started to keep a note of things that happened on difficult days a pattern started to emerge, and it helped me understand the things that triggered her behaviour."



The neurodevelopmental Disorder pathway

Overview of the diagnostic pathway
and what to expect

First steps

You may have a sense that some of your child's reactions seem to be extreme or excessive, or don't follow similar development patterns of other children their age. Sometimes you might have support from those around you, but for many it can feel that staff at school/ preschool, family members and friends may see things differently and dismiss your concerns or seem to be judgmental. If this happens, talk to another professional such as your GP, health visitor or a trusted member of staff from school/pre-school.

Not all families will want to seek a diagnosis and that is ok, it is an individual family choice. Sometimes it can be that you are not the first to notice differences. Some parents will naturally make adjustments to their own communication and interaction with their child to compensate, without realising, especially if there is no sibling for comparison. If your child's difficulties are pointed out by other family members or staff at pre-school/school in the first instance, it is not your fault for not seeing it. For younger children, sometimes the first difference you or others become aware of is their delayed communication.

For a diagnosis of either ASD and/or ADHD, it requires the child or young person to have difficulties in areas such as communication, interaction, play, friendships, attention, emotions, and behaviour, which impacts their ability to perform tasks and activities in their daily lives. These difficulties need to be pervasive, meaning that their symptoms have been present for a significant amount of time, rather than due to a specific event, and present across different settings such as home and school. For example, for an autism diagnosis, there would need to be evidence of differences and/or difficulties in key areas of language and communication, reciprocal or to and fro social interactions, as well as restricted patterns of interests and rigid behaviours, which have and continue to impact their ability to function day to day. If your child has needs within one or two or these areas; for instances social communication and interaction, it may be that an assessment for ASD may not be appropriate.

Similarly, many difficulties associated with ASD and/or ADHD, can be due to other causes, for example, speech and language difficulties, learning needs, emotional difficulties, and hearing impairment. Whilst it may seem sensibly to be referred for an ASD/ADHD assessment at the earliest opportunity, it is usually better for the child or young person to be assessed first by a single agency, such as:

- ▶ Speech and Language Therapy
- ▶ Occupational Therapy
- ▶ Audiology
- ▶ Child and Adolescent mental health teams
- ▶ Educational Psychology

The right intervention and support at the right time

This is so they receive the **right interventions and support** as their needs arise. Immediate referral for ASD/ADHD assessment may mean the child or young person misses or is delayed accessing the most appropriate support for them.

For example, if you are concerned that your child may have difficulties in their learning and may need additional support at school, the first step would be to talk with your school's SENCo and/or teacher and see if your child should be considered for an initial assessment by education services. If it is then felt that their needs are significant enough to warrant a medical assessment, the school can help support you with a referral for an educational psychology assessment in the first instance. Similarly, if you are concerned that your child is social anxious, they would not benefit from having an ASD assessment before they receive an assessment from and Child and Adolescent Mental Health teams.



IMPORTANT TO KNOW

DIAGNOSIS NOT IS NECESSARY to access a wide range of locally commissioned support services. Access to these, and strategies known to be useful for children and young people with neurodevelopmental needs can be found below as well as on the Suffolk Local Offer website: [Home - Suffolk SEND Local Offer \(suffolklocaloffer.org.uk\)](https://www.suffolklocaloffer.org.uk). Please see the following page for more information.

It is NOT necessary to have an ASD and/or ADHD diagnosis to apply for an Education Health Care Plan (EHCP), nor does a diagnosis of ASD and/or ADHD mean that a child will require an ECHP.

Support available

The Suffolk Parent Carer Forum have devised a resource pack; Supporting your neurodivergent child, which can be accessed via the following link: [NDD Supporting Your Neurodivergent child \(suffolklocaloffer.org.uk\)](https://suffolklocaloffer.org.uk).

This resource has been devised by parents who have shared their own experiences, tips, and best practices, along with many other families across Suffolk and Essex to aid you on your own journey. The pack provides an overview of what has been found to be the most relevant information from sources such as the NHS and local websites, national and regional charities and IPSEA. There are also links included on specific topics so you can find out more as well as recommendations of books, videos, blogs and resources that we have found useful.



Universal Support Services

- All families can access **Universal Services**. Universal Services include Children's Centres, GP's, Health Centres, School Nursing, Education and funding for early education.
- **SEND Local Offer**
- **Early Help** is support that improve a family's resilience and outcomes or reduce the chance of a problem getting worse
- **Local parent and carers workshops**
- **NDD Resource pack and resources**



Targeted Support

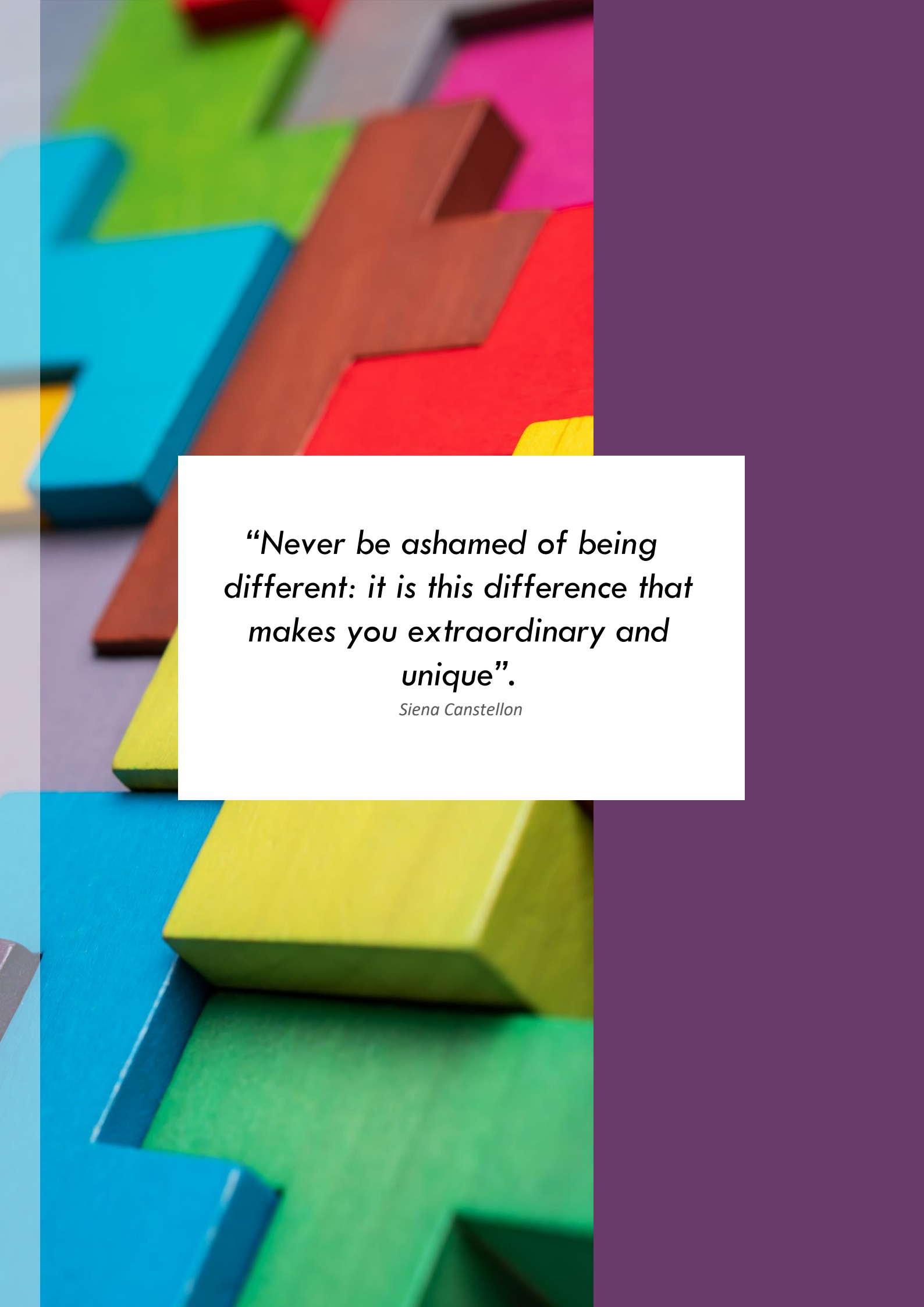
- **Suffolk SENDIASS**
- **Specialist Education Services**
- **School Nursing Alternative Provision Team**
- **Local NDD workshops**
- **Mental Health Support Team**
- **Emotional Wellbeing Hub**



NDD Support

- **Families Together**
- **Access Community Trust**
- **BEANs service**
- **Green Light Trust**
- **Suffolk Family Carers**
- **Family Action West Suffolk**
- **Noise Solution**

No diagnosis is necessary to access these services, however some require a referral from a professional and may have eligibility criteria.



“Never be ashamed of being different: it is this difference that makes you extraordinary and unique”.

Siena Canstellon



“Originally, I didn’t want to label my child...because I was worried about what people would think. Now my child has been diagnosed, I am so glad that we did because it has really helped me to understand him.”

The Diagnostic Pathway

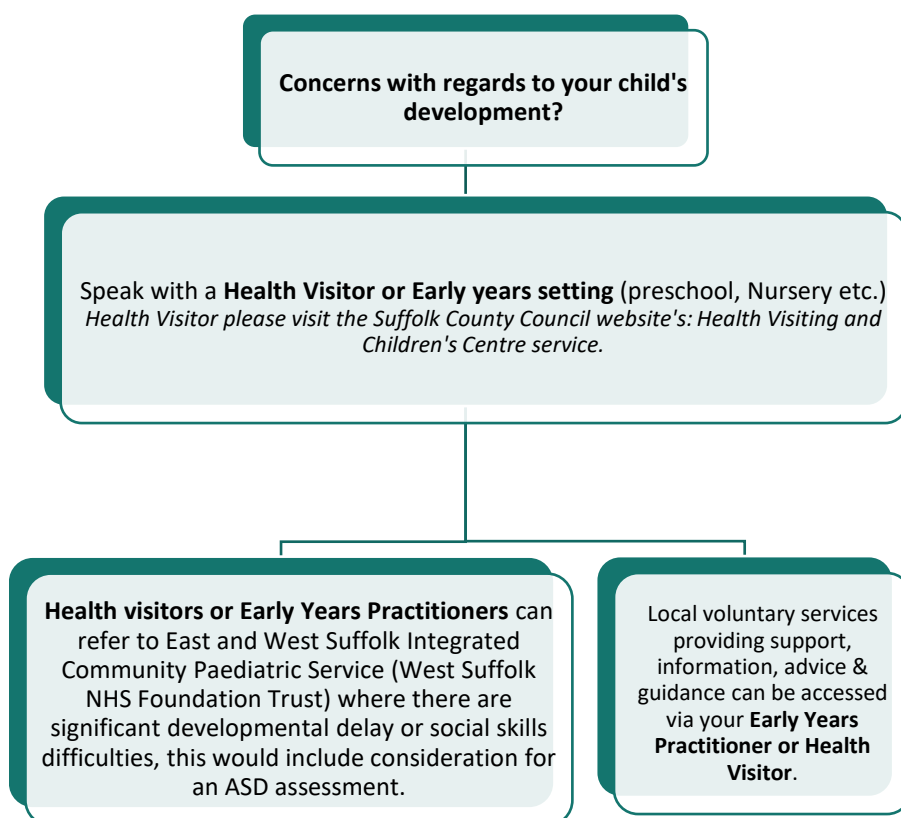
The waiting time for a neurodevelopmental diagnosis are nationally at an all-time high. We recognise that for children, young people, and their families, this can be an incredibly worrying and confusing time, as it is often unclear who is involved at what stage of the pathway and who families can contact if they have any questions.

In Suffolk, there are currently two pathways:

- ▶ The Under 5’s ASD Pathway
- ▶ The NDD pathway for Children and Young People between the ages of 5-18 years old (up to their 18th birthday).

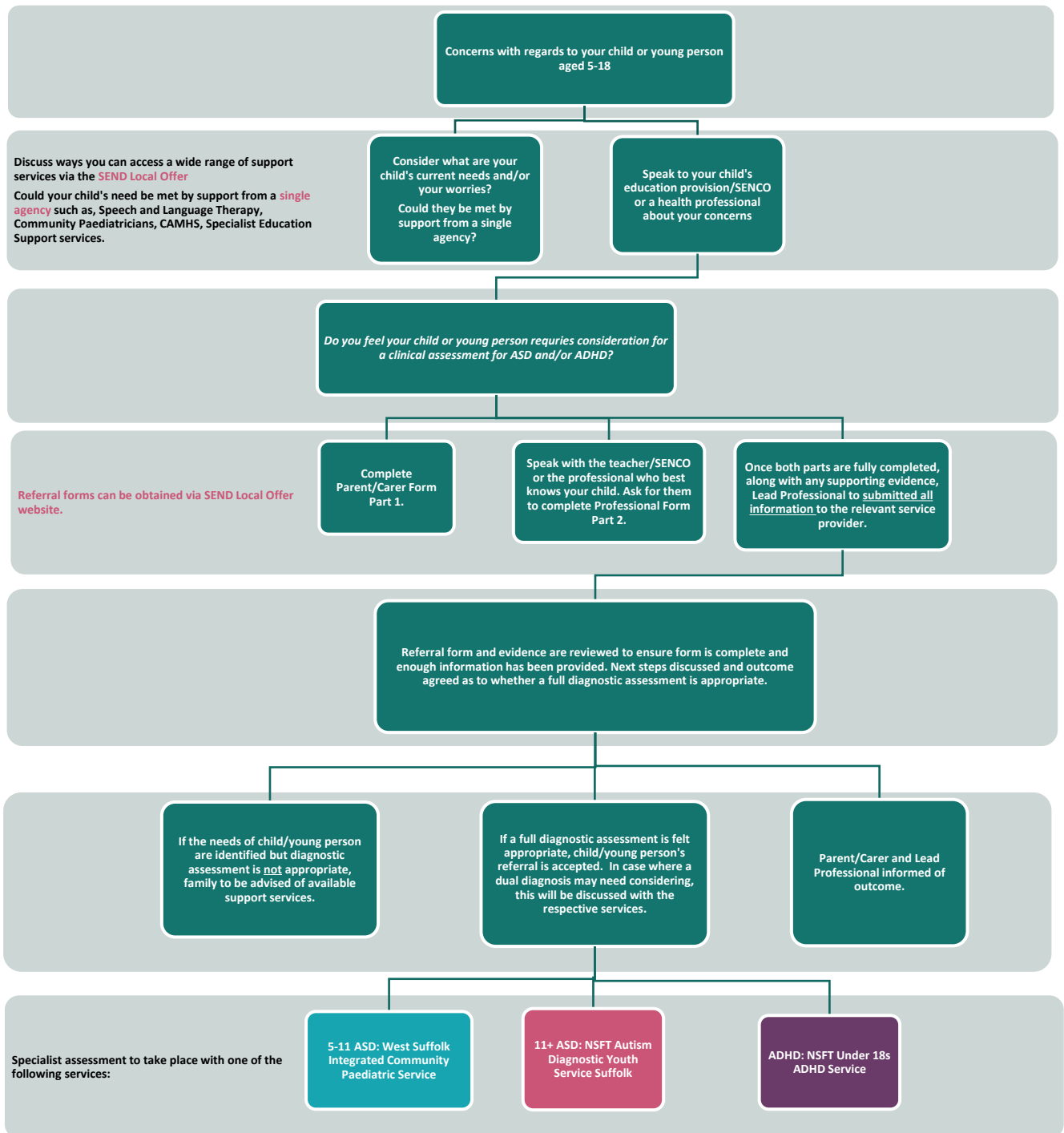
Below are two diagrams explaining the separate pathways and the key differences.

Under 5’s Pathway



Please note the East and West Suffolk Integrated Community Paediatric Service **do NOT** assess for ADHD.

The NDD Pathway for Children and Young People up to the age of 18 years old



**Please note if your child is already under the community paediatric service for their long-term medical needs, they would not require a separate referral for an ASD assessment whilst still under that service.*



Referral form

We understand that when it comes to the stage that you are thinking that your child may need to be considered for a neurodevelopment disorder assessment, it can be a very worrying and confusing time. To make it easier for children and families to access the neurodevelopmental pathway, we have developed one referral form for all diagnostic assessments.

Referral forms can be found on the SEND Local Offer website at: [Making a referral and the process - Suffolk SEND Local Offer \(suffolklocaloffer.org.uk\)](https://www.suffolklocaloffer.org.uk)

There are two parts to the referral form:

- ▶ Part 1: Parent/carer Form
- ▶ Part 2: Professional's Form

NHS NHS
West Suffolk Norfolk and Suffolk
NHS Foundation Trust NHS Foundation Trust

PARENT/CARER FORM PART 1

This form is to be completed by parents and carers who would like to refer their child or young person for a Neurodevelopmental Disorders (NDD) assessment.

So that we are in the best position to understand your child or young person's needs, please complete this form and submit it along with the 'Professional Form Part 2', which can be found on the Suffolk Local Offer website (www.suffolklocaloffer.org.uk). The professional form Part 2 **must** be completed by one or more professionals (such as a health care professional, family support worker, school nurse, or education staff).

For this referral to be processed, all sections on the form **must** be completed or marked as non-applicable.

IF YOUR CHILD IS NOT IN EDUCATION, ACCESSING ALTERNATIVE EDUCATION PROVISIONS OR IS ELECTIVELY HOME EDUCATED, PLEASE USE THE 'ALTERNATIVE EDUCATION REFERRAL FORM', WHICH CAN BE FOUND ON THE LOCAL OFFER WEBSITE.

Observations and additional reports are encouraged to be provided as supporting evidence. Please refer to the parent and carer NDD referral guidance (which can also be found on the Local Offer website) for further details of what documents you may wish to include. **Please do not send photographs and/or videos as supporting evidence.**

ONCE COMPLETED, PLEASE RETURN THIS FORM TO THE LEAD PROFESSIONAL (REFERRER), ALONG WITH ANY SUPPORT EVIDENCE FOR THEM TO SUBMIT IT ALONG WITH THEIR FORM (PART 2) TO: NDDreferrals@nhs.uk

REFERRAL REQUEST

Please select below which type of assessment you are requesting. Please tick all that are relevant (this may be more than one).

AUTISM (ASD) ASSESSMENT

ADHD ASSESSMENT

SUPPORT SERVICES- please be aware due to high demand, access to support will be determined by a needs assessment based on the information within this form and supporting evidence.

SECTION ONE: CHILD AND FAMILY DETAILS

CHILD/ YOUNG PERSON'S DETAILS

Full name: Date of birth:

Any other names your child or young person has been known by:

Name the child/young person prefers to be called by, if different from above: Age:

NHS number: Religion:

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On the form you will be required to tick a box to state if you are requesting a referral for either a diagnostic assessment for autism or ADHD. If you are unsure which would be the most appropriate, it is best to consider your child's primary needs and/or differences. For example, if your child's primary needs are in relation to difficulties or differences in their communication, social interactions and rigidity, an autism assessment is likely to be the most appropriate request. However, if your concerns are more in relation to attention and concentration difficulties, hyperactivity and impulsive behaviours, an ADHD assessment would more likely be appropriate. For more information of signs and symptoms of autism and ADHD, please see the NDD support pack on the following link [NDD Supporting Your Neurodivergent child \(suffolklocaloffer.org.uk\)](https://www.suffolklocaloffer.org.uk).


On both parts, you and the professional who knows your child best; also known as the lead professional, will be asked to provide information and examples of any strengths and/or difficulties they may have in the following areas:

- ▶ Communication
- ▶ Social interactions
- ▶ Rigid behaviours, thinking and special interests
- ▶ Sensory
- ▶ Attention and concentration
- ▶ Hyperactivity
- ▶ Impulsivity
- ▶ Any other current concerns

You will also be asked to share some information about your child’s education as well as medical and developmental history.

Make sure to include **examples** within your referral and not just a list of symptoms and/or behaviours. We want to know what **life is like for your child**. For example:

 *“Thomas frequently finds it difficult to look at people when he is talking to them or when they are talking to him. He will often not look directly at them but look out the corner of his eyes or sometimes in a different direction. This is more noticeable when he is talking to unfamiliar people or is in a new environment. Thomas does make eye contact with those he is comfortable around.”*

 *“Thomas does not make eye contact.”*

Along with your referral form you will be asked to submit any support evidence that you feel may be useful to the assessment process.

This may include (but not is limited to):

- ▶ School Observations
- ▶ Child/Young person’s own views
- ▶ Medical report (birth and early development, medical history, GP/hospital letter)
- ▶ Speech and Language Therapist Report
- ▶ Occupational Therapist Report
- ▶ Community Paediatrician Assessment
- ▶ School Nurse or Health Visitor Report
- ▶ Educational Psychologist Report
- ▶ CAMHS/LDCAMHS/Other specialist CAMHS
- ▶ EHCP / education provision Agreement / support plan
- ▶ Individual Education/Behaviour Plan (or equivalent)
- ▶ Early Help Assessment
- ▶ Personal Education Plan for LAC Child
- ▶ Behaviour Intervention/Youth Offending Team Report
- ▶ Children’s Social Care Report

For young people aged 11+

At the end of the end of the parent referral form, there is an page for your child to share their views.

This section is optional and will not be looked at negatively if it is not completed.

SECTION EIGHT: CHILD OR YOUNG PERSON'S VIEWS
This section is optional and for young people 11+ to complete
 The form is all about you!
 Below are some questions that will help us understand what you like and do not like, and how you are feeling.
 You can draw or write your answers and can share as little or as much as you would like.

What is important to me e.g. hobbies, friends, family, every day?

Do I feel safe? This may be at home, at school or elsewhere.

What is good now? This may be at home, at school or elsewhere.

What could be better? This may be at home, at school or elsewhere.

What are my main worries? This may be at home, at school or elsewhere.

What would I like help and support with?

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Lead Professional- who can act as one and what is their role?

The lead professional is the professional who knows your child’s needs best. This is mostly likely to be someone from your child’s education setting, such as a teacher or special needs co-ordinator (SENCO). However, a referral can come from a professional in a different setting (please see table 1 below of examples of professionals who may make a referral for an NDD assessment, and the areas in which they may work). When choosing the lead professional to assist you with your referral, it is important to consider the information required on the referral form and how if the person you have selected will be able to answer all the questions asked. For example, a GP is unlikely to gain all the information needed in a single appointment, if they do not know your child well. In this instance, it may be best to consider a different professional to act as the lead professional.

Table 1.
Setting

Professional

| | |
|---|--|
| <i>Health</i> | School Nurse Health Visitor Paediatrician Psychiatrist Nurses Clinical, counselling, or forensic psychologists Occupational therapists Speech and language therapists Primary mental health worker GP |
| <i>Children and young people’s services</i> | Social worker Early help practitioner Family support worker Occupational therapist Speech and language therapist |
| <i>Education</i> | Special Educational Needs Coordinators (SENCO) Teachers at schools or colleges Educational psychologists Speech and language therapists |

When the lead professional is not from your child's education provider, we would highly recommend that the form is completed jointly to include information from your child's education setting, as they will be able to provide information and examples of your child's strengths and difficulties. If your child is home educated or not in school, please see the following section for further information.

It is the lead professional responsibility to support the family in accessing the support that may be suggested in the recommendations. For example, signposting and/or referring to the recommended health service, children service or education support provision.



Once completed, please [return your part 1 parent/carer form](#) to the [lead professional \(referrer\)](#), along with any supporting evidence for them to submit along with their [part 2 professional referral form](#) to the relevant service provider below:

ASD 5-11: Suffolk.ccc@esneft.nhs.uk

ASD 11+: U18autismdiagnosticservice@nsft.nhs.uk

ADHD Under 18s: ADHDReferrals@nsft.nhs.uk

What if my child is not in an education provision, in an alternative education provision, or I have electively chosen to home educate?

We understand that every child is different, and to meet their needs may require a more flexible form of education. Unfortunately, when speaking to local parents and carers, this has historically caused challenges when trying to access support, as it may be difficult to identify who would be best placed to act as the child's lead professionals and/or share their views on the child's education.

We have developed a separate referral form for children and young people who may be accessing alternative education or not currently in education, to ensure that the neurodevelopmental pathway is easily accessible by all.

This form may be used for children and young people who are:

- ▶ Electively home educated.
- ▶ Enrolled at a school but not in the education setting.
- ▶ Attending an alternative education provision (such as a pupil referral unit, therapeutic provision)
- ▶ Awaiting a placement but not in education

- ▶ Not in education

In order to be in the best position to understand your child or young person's needs, you will need to complete the parent/carer form is completed, along with supporting evidence from **multiple sources; one of whom must be a professional**, to ensure that enough information is provided to process the referral. Ideally it should be written by a professional with regular involvement in your child's care who completes part 2 of the referral form. However, if there is not a professional who is regularly involved with your child, it may be best to ask multiple individuals to complete a copy of the form to the best of their knowledge, so a comprehensive understanding of your child's needs can be gained. It is important that **at least one or more professionals'** views are submitted as part of the referral.

Sources of evidence can be provided by:

- ▶ a paid carer
- ▶ relative or friend
- ▶ health care professional
- ▶ social worker
- ▶ Teacher or tutor

Suggested professionals to assist with the referral could include (but is not exclusive to):

- ▶ School Nursing Team/School Nursing Alternative Provision Team
- ▶ Specialist Education Services (if accessing)
- ▶ Alternative Tuition Service (if accessing)
- ▶ Key adult from education provision.
 - If your child **remains on roll**, the school continue to have a **duty of care to your child**.
 - If you child is no longer register at the school, information from their previous education placement may be considered as part of the support evidence.
- ▶ Elective Home Education Team
- ▶ Social Worker/ Family Support Worker
- ▶ Health professional; GP, medical specialist, primary mental health worker, mental health professionals
- ▶ Therapeutic provision practitioner (e.g., P.L.O.T)
- ▶ Private Tutor

Once completed, please submit part 1 parent/carer form and part 2 professional and other involved form(s), along with any supporting evidence together to the relevant service provider below:




ASD 5-11: Suffolk.ccc@esneft.nhs.uk

ASD 11+: U18autismdiagnosticservice@nsft.nhs.uk

ADHD Under 18s: ADHDReferrals@nsft.nhs.uk

What happens next?

Once a referral form and supporting evidence has been submitted it will be reviewed by one of the below providers to ensure it is complete and enough information has been provided.

| | | |
|---|---|--|
|  <p>Integrated Community Paediatric Services</p> <ul style="list-style-type: none">• ASD referrals 5 years up to age 11• Autism assessment for ages 5 up to the age of 11 years old.• 0-18 years for long term neurological, developmental, and genetic disorders and physical disabilities such as cerebral palsy. |  <p>Autism Diagnostic Youth Service Suffolk</p> <p>ASD referrals 11+</p> <ul style="list-style-type: none">• Autism Diagnostic Service provides assessments to identify if a person has autism or not. The youth team provides assessments for young people between the ages of 11 and 18. |  <p>Children and young people's ADHD Service</p> <ul style="list-style-type: none">• ADHD referrals Under 18• Suffolk county-wide Attention Deficit Hyperactivity Disorder (ADHD) service offers specialist assessments. The team also offers diagnosis and treatment for symptoms of ADHD in children and young people where appropriate. |
|---|---|--|

Once the referral has been reviewed and needs are identified, if there are definite indicators that your child or young person could have either ASD and/or ADHD, they will progress for diagnostic assessment. At this point information will be provided to you on your acceptance letter of how you can access NDD specific support services (please see page. 8 for more information).

If the child or young person's presentation could potentially be explained by something else, then the recommendations will be made to access other support services that may be more appropriate to their needs.

There is currently an unprecedented demand and backlog for diagnostic services for both ASD and ADHD assessment in Suffolk. This has meant that any new referrals into the service may take over a year before assessment. Please be assured that the ICB and commissioned service providers within the neurodevelopmental disorder pathway, are committed to reviewing and developing the local delivery and protocols for pathways for children and young people with neurodevelopmental disorders and would like to thank you for your patience and understanding.

ADVICE FROM PARENTS AND CARERS

KEEP A DIARY

When you are speaking with professionals about your concerns, or you are providing information for a referral it helps to have kept a diary of your experiences and why you are concerned.

DON'T COMPARE YOUR CHILD OR YOUNG PERSON TO SOMEONE ELSE'S

The way your child or young person's development progresses is different to another. Neurodevelopmental disorders are a spectrum and whilst there are distinctive characteristics that must be present to obtain a diagnosis, how they present in your child or young person and the impact they have on their development will differ between individuals.

TALK TO OTHERS AND TRY NOT TO BECOME ISOLATED

Families often say they felt alone when their child or young person was initially identified as having a neurodevelopmental need, especially where the child or young person displayed challenging behaviour. There are several voluntary organisations across Suffolk that are ran by parents of children with a neurodevelopmental disorder who will be happy to have a chat with you about their experience and what techniques they found helped their child or young person. Information about these services can be found on the SEND Local Offer website.

TAKE NOTES

When you are attending appointments with clinicians you will likely be provided with a lot of information, and it can be overwhelming. If you can, take a pen and paper and write down anything of significance as this will help you remember at a later point.

ASK QUESTIONS

You will have lots of questions throughout the process and it is never a wrong time to ask them. Sometimes it is helpful to write these questions down, so you do not forget them when you are attending an appointment with clinicians. If there is more practical help you are needing, you can access services through the SEND Local Offer. Even if the person you speak to doesn't know the answer, they will know someone who will.

ACCESS TRAINING COURSES AND RESOURCES

Lots of organisations provide free training for parents and carers of children and young people with neurodevelopmental disorders and how to meet their needs. Some are specific to a particular diagnosis such as ASD or ADHD, but others are topical such as sleeping or toileting. You will also find lots of tips and advice in the Suffolk Resource Pack or can attend one of Neurodiversity parent Workshops.

YOU DO NOT NEED A DIAGNOSIS TO ACCESS THE SUPPORT YOU AND YOUR CHILD OR YOUNG PERSON NEED The prevalence of neurodevelopmental disorders is increasing, this means that the length of time you are waiting for a diagnosis may be long. However, access to support for you and your child or young person's needs is not reliant on a diagnosis.



Parent top tip

"Buy a big folder and start keeping a copy of everything, literally everything, to build a complete picture of your child. My son bit a child at school, and the teacher spoke to me on the school gate, at the time I was upset and couldn't really focus on what they were saying so I asked them to confirm in writing and this was actually really useful information when I spoke to my GP about my son's difficulties"

Useful Contacts and Links

The following is a list of useful contacts and agencies that may be able to provide you with further information and support during this time:

SEND LOCAL OFFER

Access information, advice and services for children and young people with SEND in Suffolk

Telephone: 0345 606 1490

Website: [Home - Suffolk SEND Local Offer \(suffolklocaloffer.org.uk\)](http://suffolklocaloffer.org.uk)

Email: localoffer@suffolk.gov.uk

CHILDREN AND YOUNG PEOPLE'S EMOTIONAL WELLBEING HUB

The Emotional Wellbeing Hub provides information, advice, and guidance if you are worried about the mental health of a child or young person aged 0-25 years, or you're a young person experiencing emotional wellbeing difficulties.

Telephone: 0345 600 2090

Press option 3 to make a referral to access specialist mental health services. (Monday-Friday 8am-8pm).

Website and to make online referral: [Children and Young People's Emotional Wellbeing Hub \(East and West Suffolk\) - Suffolk County Council](#)

NHS Crisis Support Line

For urgent mental health support, contact:

- Call 111 and press option 2 NHS Mental Health Crisis Line (24/7 helpline for anyone of any age)
- Contact the Samaritans on 116 123 for free (24hours, 365 days a year)
- If it's a life-threatening emergency call 999.

EARLY HELP

Early Help is support that improve a family's resilience and outcomes or reduce the change of a problem getting worse. This can include support available to families from universal services like schools, community health teams, family hubs and local voluntary and community services, through to targeted services such as Social Care and Youth Justice.

Website: [Suffolk InfoLink | Social Care and Early Help Services](#)

Access to the Early Help Service is via something called a Common Assessment Framework or CAF. You can read more about this and begin the process on the following website: [Common Assessment Framework \(CAF\) - Suffolk County Council](#)

SENDIASS

The Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS) provides confidential, impartial information, advice and support to young people and children with SEN or disabilities aged 0 -25, and their parents/carers.

Telephone: 01473 265210

Address:
SENDIASS, Purple, Ground floor
Endeavour House
Russell Road
Ipswich
Suffolk IP1 2BX

Email: enquiries@suffolksendiass.co.uk

Website: <https://www.suffolksendiass.co.uk/>

THE SOURCE

Information, advice, and sources of support for young people in Suffolk aged 11-18 years old (up to 25 for young people with additional needs).

Website: [Home - The Source](#)

Email: thesource@suffolk.gov.uk

ACTIVITIES UNLIMITED

Activities unlimited is a short break service for disabled children and young people in Suffolk. Families who have children with additional needs can visit their website, register their child(ren) to become a member and then book lots of exciting activities and short breaks online.

Telephone: 01473 260026

Email: info@activities-unlimited.co.uk

Website: <http://www.activities-unlimited.co.uk>

Address:

Suffolk County Council, Endeavour House
Russell Road

Ipswich

Suffolk

IP1 2BX

INTEGRATED COMMUNITY PAEDIATRIC SERVICES

Supports children and young people aged 0-25 with additional needs, including developmental concerns, medical and long-term health conditions, learning and physical disabilities.

Telephone:

East Suffolk: 01473 321200

West Suffolk: 01284 741700

Website: [Integrated community paediatric services \(wsh.nhs.uk\)](http://www.integratedcommunitypaediatricservices.wsh.nhs.uk)

Address:

West Suffolk NHS Foundation Trust

Child Health Centre

Bury St Edmunds

Suffolk

IP33 3ND

AUTISM DIAGNOSTIC YOUTH SERVICE SUFFOLK

Autism Diagnostic Service Suffolk provides assessments to identify if a person has autism or not. The youth team provides assessments for young people between the ages of 11 and 18.

Telephone: 01449 745389

Website: [Children and young people | Norfolk and Suffolk NHS \(nsft.nhs.uk\)](http://www.childrenandyoungpeople.norfolkandsuffolknhs.uk)

Address:

Haymills House

Station Road East

Stowmarket

Suffolk

IP14 1RQ

CHILDREN'S ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) EAST AND WEST SUFFOLK

Suffolk county-wide Attention Deficit Hyperactivity Disorder (ADHD) service offers specialist assessments. The team also offers diagnosis and treatment for symptoms of ADHD in children and young people where appropriate.

Telephone:

East Suffolk: 01473 237070

West Suffolk: 01284 733188

Website: [Children and young people | Norfolk and Suffolk NHS \(nsft.nhs.uk\)](http://www.childrenandyoungpeople.norfolkandsuffolknhs.uk)

Address:

Bungalow 6,
Walker Close,

Ipswich,

Suffolk

IP3 8LY

Address:

G Block

Hospital Road,

Bury St. Edmunds

IP33 3NR



Norfolk and Suffolk
NHS Foundation Trust



West Suffolk
NHS Foundation Trust