

# Guide for parents and carers East and West Suffolk Neurodevelopmental Disorder Pathway







# About this parent and carer neurodevelopmental disorder pathway guide

This guide has been produced by Suffolk and North East Essex Integrated Care Board (SNEE ICB) in collboration with Suffolk County Council, West Suffolk NHS Foundation Trust, Norfolk and Suffolk Foudation Trust and Barnardo's, 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 (referred to in this guidance as NDD). 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 does neurodevelopmental disorder mean?

We understand that when you may be considering if your child or young person might need an assessment for a neurodevelopmental disorder, such as Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD), this can be a very worrying and confusing time. This can often be made more complicated by the language used interchangeably such as neurodiversity, neurodivergent and neurodevelopmental disorders and or conditions.

Below we have tried to provide a brief explanation of the different definitions for neurodiverse, neurodivergent and neurodevelopmental disorder:

**Neurodiversity**- neurodiversity is a word used to describe the different thinking styles that affect how people communicate with the world around them. It is an umbrella term which can be used to describe a range of neurological differences that are within a normal range of function in a group of people at a particular age, for example children or adolescents. Neurodiversity is a characteristic of the whole population, not a specific individual.

**Neurodivergent**- neurodivergent describes individuals whose brain functions in selective areas such as learning, attention, emotions, impulses, sensory processing, and social behaviours, falls outside what is perceived to be societal norms, these can be strengths as well as differences. They do not necessarily have a neurodevelopmental disorder.

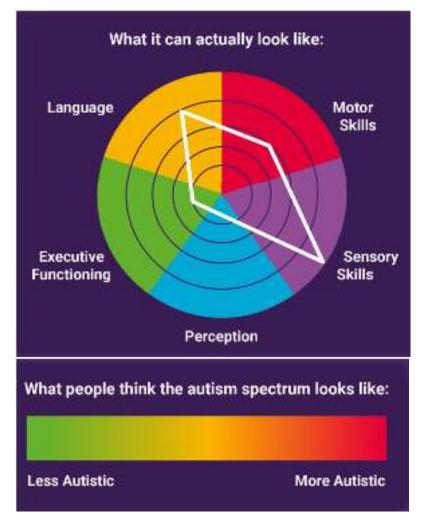
**Neurodevelopmental disorder (NDD)** or **neurodevelopmental condition** is a term used for individuals whose brain functioning in selective areas such as learning, attention, emotions, impulses, sensory processing, and social behaviours, is at an extreme for their age, which significantly impacts their 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 challenges - 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.

The graphics below show that when a person is on the autism spectrum, they may demonstrate great strengths in some areas but experience challenges in another.



## 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.

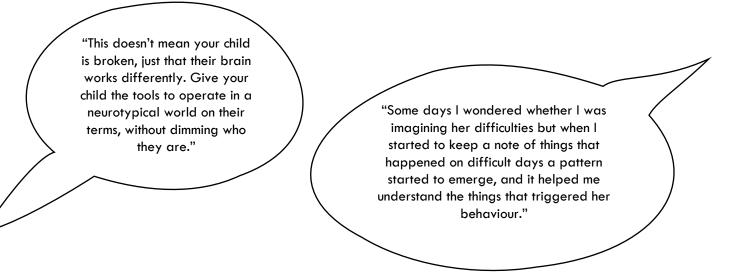
Children with ADHD may be labelled as disruptive, for behaviour which they cannot control. These are the main features of ADHD but there are many more that can have a significant impact on a child's organisational skills and emotional well-being.

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 steps you take are different for each child or young person and their families, which means that timescales can be different between individuals. Over the following pages you will find information that shows you the NDD 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 guide will provide details of the support services and how you can access them.





## 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/carers will naturally make adjustments to their own communication and interaction with their child or young person 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 pervasive 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. If your child or young person has needs within a small number of these areas, it may be that an ASD and/or ADHD assessment is not appropriate.

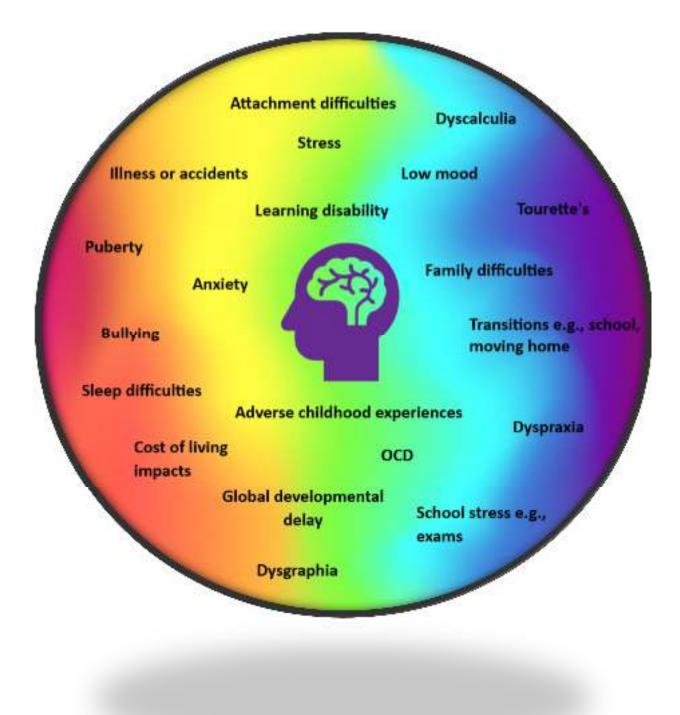
Similarly, many difficulties associated with ASD and/or ADHD can be due to other causes, such as, speech and language difficulties, learning needs, emotional wellbeing difficulties, and hearing impairments. Whilst it may seem sensible to be referred for an ASD/ADHD assessment at the earliest opportunity, 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
- Community Paediatricians
- Child and Adolescent Mental Health Teams
- Educational Psychology

This is so they receive the **right interventions and support** as their needs arise.

## The right intervention and support at the right time

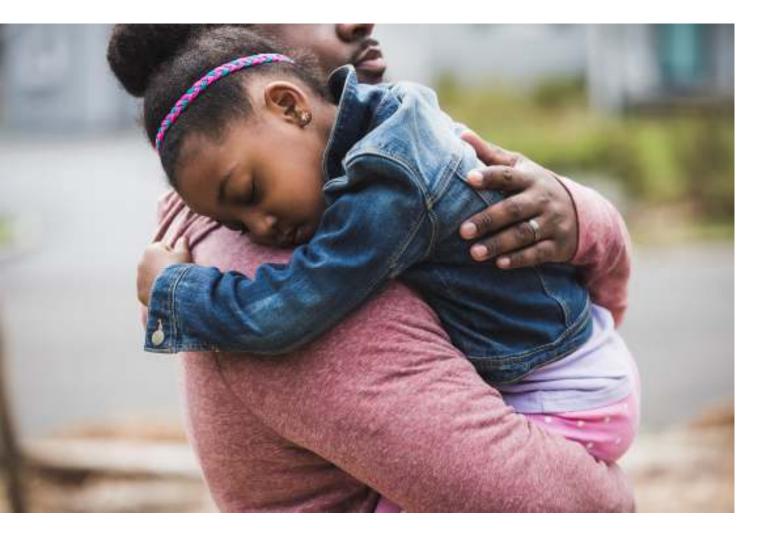
There are many conditions or differences that appear similar to ADHD and ASD, which may impact a child or young person's day to day functioning. Immediate referral for ASD/ADHD assessment may seem sensible, but also may mean the child or young person misses or is delayed accessing the most appropriate support for them. Below are some examples of conditions or differences of symptoms and characteristics that are like ASD and ADHD:



For example, a young person who has experienced stressful or potentially traumatic events or situations during their childhood and/or adolescence (often known as adverse childhood experiences), is likely to have sensory sensitivities, social interaction difficulties, challenges in their learning and concentrating, sleep difficulties, as well as difficulties managing their emotions.

Similarly, a child who is anxious is likely to display characteristics such as avoiding eye contact, sleep difficulties, being highly anxious in social situations such as school, challenges in their concentration and leaning, as well as difficulties managing their emotions and a dislike for change.

When considering if a referral for an ASD/ADHD assessment is appropriate, it is really important to try and consider **all your child's needs as well as other aspects of their lives first,** to ensure that they access the correct intervention, so that they can receive the **right support that is right for them.** 



NO DIAGNOSIS IS NECESSARY to access a wide range of locally commissioned support services. Information about how to access these services 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: <u>www.suffolklocaloffer.org.uk</u>

It is NOT necessary to have an ASD andor 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 EHCP.

• Universal Support

#### Universal Support:

- Universal Support Services (e.g. school nursing)
- SEND Local Offer website
- Digital Resources.
- Early Help
- Parenting Offer

#### Targeted Support:

- SENDIASS
- Specialist Education Services (SES)
- School Nursing Alternative Provision Team
- Local NDD workshops
- Mental Health Support Team (MHSTs)
- Emotional Wellbeing Hub

#### Neurodevelopmental Disorders NDD Specialist 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

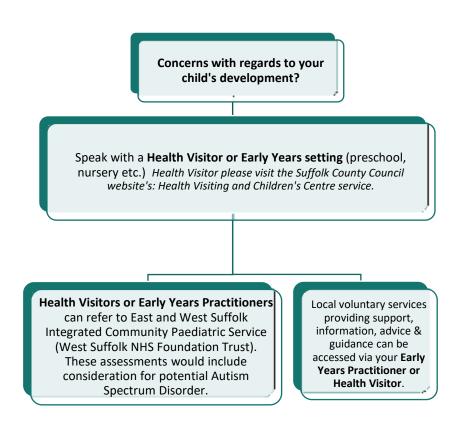
The waiting time for a neurodevelopmental disorders (NDD) diagnosis is nationally at an all-time high. We recognise that for children, young people, and their families, this can be an incredibly worrying and confusing time, as it is often unclear who is involved at what stage of the pathway and who families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

In Suffolk, there are currently two pathways:

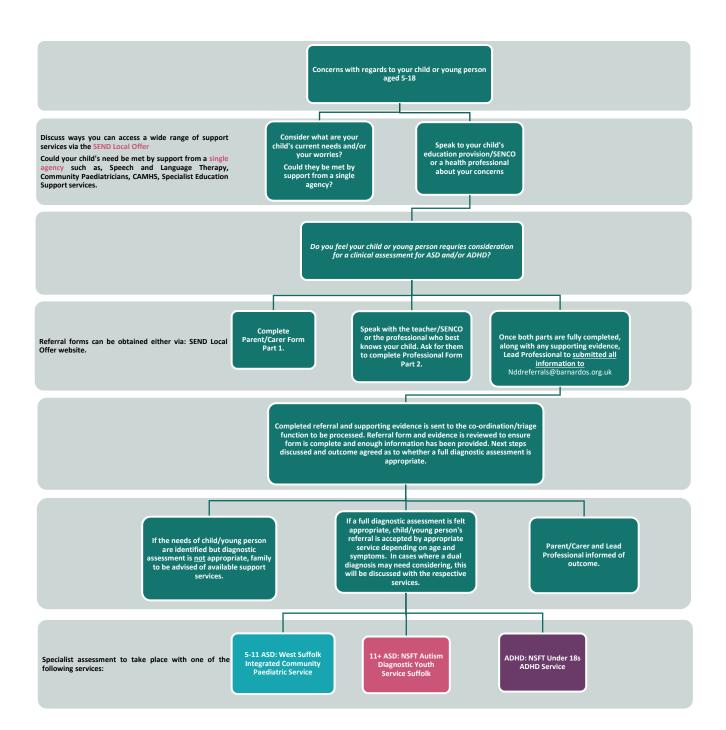
- ► The Under 5's Pathway
- The NDD pathway for Children and Young People between the ages of 5-18 years old (up to their 18<sup>th</sup> birthday).

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

## **Under 5's Pathway**



## The NDD Pathway for Children and Young People between the ages of 5-18 years old





## **Referral forms**

We understand that when you are thinking that your child may need 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 Disorder (NDD) Pathway, we have developed one referral form for all diagnostic assessments. (Note this service is for families who live in East and West Suffolk)

The NDD referral forms can be downloaded from the SEND Local Offer website at: <u>www.suffolklocaloffer.org.uk</u> (also known as the <u>Suffolk InfoLink website</u>).

There are two parts to the NDD referral form:

- Part 1: Parent/Carer NDD Referral Form
- Part 2: Professional's NDD Referral Form

And if your child or young person is not in education, we have these new forms which can be used instead (for details see page 17)

- Part 1: Alternative Education Parent/Carer NDD Form
- Part 2: Alternative Education Professional's NDD Form

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#### Why are there two parts?

When looking at the *referral* forms, it may seem strange that we are asking the same or similar questions to both you (the parent/carer) and the *lead* professional. The reason for this is, to help better understand your child's needs and how these may present differently in different settings i.e., home and school/educational setting.

On both parts 1 and 2, you (parent.carer) and the professional; who knows your child best, will be asked to provide information and examples of any stengths and/or difficulties they may have in the following areas:

- Communiction
- Social interactions
- Rigid behaviours, thinking and special interests
- Sensory
- Attention and concentration
- Hyperactivty
- Impulsivity
- Any other current concerns

You will also be asked to share some information about your child or young person'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:

#### A clear example of a difficulty:

"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."

#### A poor example of a difficulty:



"Thomas does not make eye contact."

Along with your parent/carer NDD referral form you will be asked to submit any supporting evidence that you feel may be useful to the assessment process.

This may include (but is notlimited 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
- Child and Adolescent Mental Health Service (CAMHS)/ Learning Disability Child and Adolescent Mental Health Service (LD CAMHS)/Other specialist CAMHS

- EHCP (Education Health & Care Plan)/education provision agreement/ support plan
- Individual education/behaviour Plan (or equivalent)
- Early Help assessment

- Personal education plan for Looked after Child(ren) (LAC)
- Behaviour Intervention/Youth justice service report
- Children's social care report

## For young people aged 11+

At the end of the parent/carer Part1 NDD referral form (section eight), there is a page for your child or young persom to share their views.

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

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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 educational setting, such as a teacher or Special Needs Co-ordinator (SENCO), however it may be a health visitor, school nurse, GP, social worker and/or a mental health practitioner.

When the lead professional is not from your child's education provider, we would recommend that the form is completed jointly to include information from your child's education setting if possible. If your child is home educated or not in school, we welcome referrals from a professional who is known to the family.

It is the lead professional's responsibility to let you know the outcome of your NDD referral, as well as follow up on any recommendations that may be suggested. For example, if further information is requested, it would be the role of the lead professional to ensure that enough evidence is provided so that your NDD referral can be processed.



Once you have completed Part 1 of the Parent/Carer NDD referral form, please <u>return your form</u> to the <u>lead professional (referrer)</u>, along with any <u>supporting evidence</u> for them to submit along with their Part 2 Professionals NDD referral form, to: <u>NDDreferrals@barnardos.org.uk</u>

# 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 professional and/or share their views on the child's education.

To try and get around this, we have developed a separate referral form for children and young people who may be accessing alternative education or are not currently in education, to ensure that the Neurodevelopmental Disorder Pathway is accessible by all.

These forms which are the 'Alternative Education NDD Parent/Carer Part 1 Referral Form' and 'Alternative Education NDD Professionals Part 2 Referral Form', can 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

#### Completing your NDD referral:

To be in the best position to understand your child or young person's needs, you will need to ensure your NDD parent/carer part 1 referral form is completed, along with supporting evidence from <u>multiple sources; one of</u> <u>whom must be a lead professional</u> 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 can complete part 2 of the referral form. However, if there is not one professional who is regularly involved with your child, it may be best to ask multiple individuals to complete a copy of the part 2 form to the best of their knowledge, so a comprehensive understanding of your child's needs can be gained. It is important that <u>at least one or more professionals'</u> views are submitted as part of your NDD referral.

#### Sources of evidence can be provided by:

- 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
  - o If your child is registered at a school, the school continues to have a duty of care to your child.
  - If your child is no longer registered with a 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

Example of the Alternative Education NDD Referral Form:



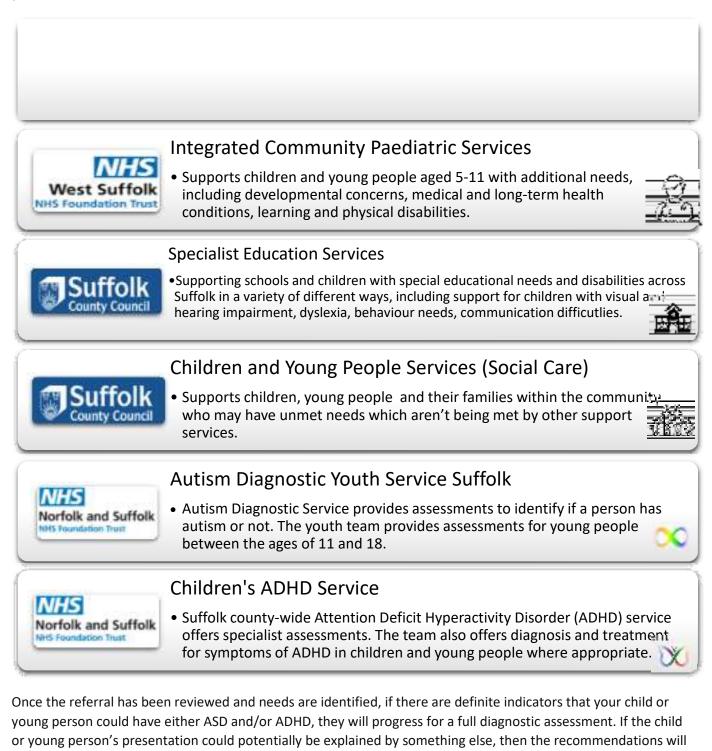
Once you have completed, <u>Part 1 parent/carer referral form and Part 2 professionals and others</u> <u>involved referral form, submit it along with any supporting evidence to:</u> <u>NDDreferrals@barnardos.org.uk</u>

If you have any questions when completing the form please contact Barnardo's NDD Coordination Function either via email or request a call back at: <u>NDDAdmin@barnardos.org.uk</u>

Once submitted, the referral forms and evidence are reviewed by the co-ordination and triage function (via Barnardo's) to ensure the forms are completed correctly and enough information has been provided. Following this, the next steps and referral outcome will be agreed as to whether a full diagnostic assessment is appropriate, and an outcome letter will be sent summarising the key information.

## **Co-ordination and Triage**

As part of the co-ordination function and triage, the following service providers may be involved in reviewing your NDD referral:



be made to access other support services that may be more appropriate to their needs.

## **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 experiences and what techniques that they have found helped their child or young person. Information about these services can be found on the SEND Local Offer website (Suffolk Infolink) or a Facebook support group (like Suffolk Parent Carer Forum).

#### Take notes

When you are attending appointments with clinicians you will likely be provided with a lot of information, which 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 you need more practical help, you can access services through the SEND Local Offer website. 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 look out for Neurodiversity parent/carer Workshops via the Local Offer website.

## 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.



"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 Email: localoffer@suffolk.gov.uk Website: www.suffolklocaloffer.org.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 2 to contact Barnardo's phoneline service- this helps families looking for general wellbeing information and guidance to help address common emotional wellbeing issues in children and young people.

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

#### Website and to make online referral:

www.emotionalwellbeinggateway.org.uk

#### **Wellbeing Education website**

The Wellbeing Education website has a wide range of resources, workshops, and training materials to support mental health and wellbeing. www.suffolk.gov.uk/wellbeingeducation

#### **NHS Crisis Support Line**

For urgent mental health support, contact:

- Call 111 and press option 2 for the NHS Mental Health Crisis Support 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 can improve a family's resilience and outcomes or reduce the likelihood 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: <u>www.suffolk.gov.uk/caf</u>

#### 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 Email: <u>enquiries@suffolksendiass.co.uk</u> Website: www.suffolksendiass.co.uk

#### Address:

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

#### THE SOURCE

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

Website: <u>www.thesource.me.uk</u> 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: www.activities-unlimited.co.uk

#### Address:

Suffolk County Council, Endeavour House Russell Road, Ipswich IP1 2BX

#### NEURODEVELOPMENTAL PATHWAY COORDINATION- BARNARDO'S

Barnardo's deliver the coordination function for the Suffolk NDD pathway. They provide support and guidance for children, young people (aged 5-18) and families who are seeking consideration for an autism or ADHD assessment within Suffolk.

Email: <u>NDDAdmin@barnardos.org.uk</u> Website: <u>Suffolk Neurodevelopment Pathway | Barnardo's (barnardos.org.uk)</u>

#### INTEGRATED COMMUNITY PAEDIATRIC SERVICES

Supports children and young people aged 5-11 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)

#### Address: West Suffolk NHS Foundation Trust

Hardwick Lane Bury St Edmunds, IP33 2QZ

#### **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) Address: Haymill's House **Station Road East** Stowmarket **IP14 1RO** 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) Address: Bungalow 6, Walker Close, Ipswich IP3 8LY Address: G Block Hospital Road, Bury St. Edmunds IP33 3NR