

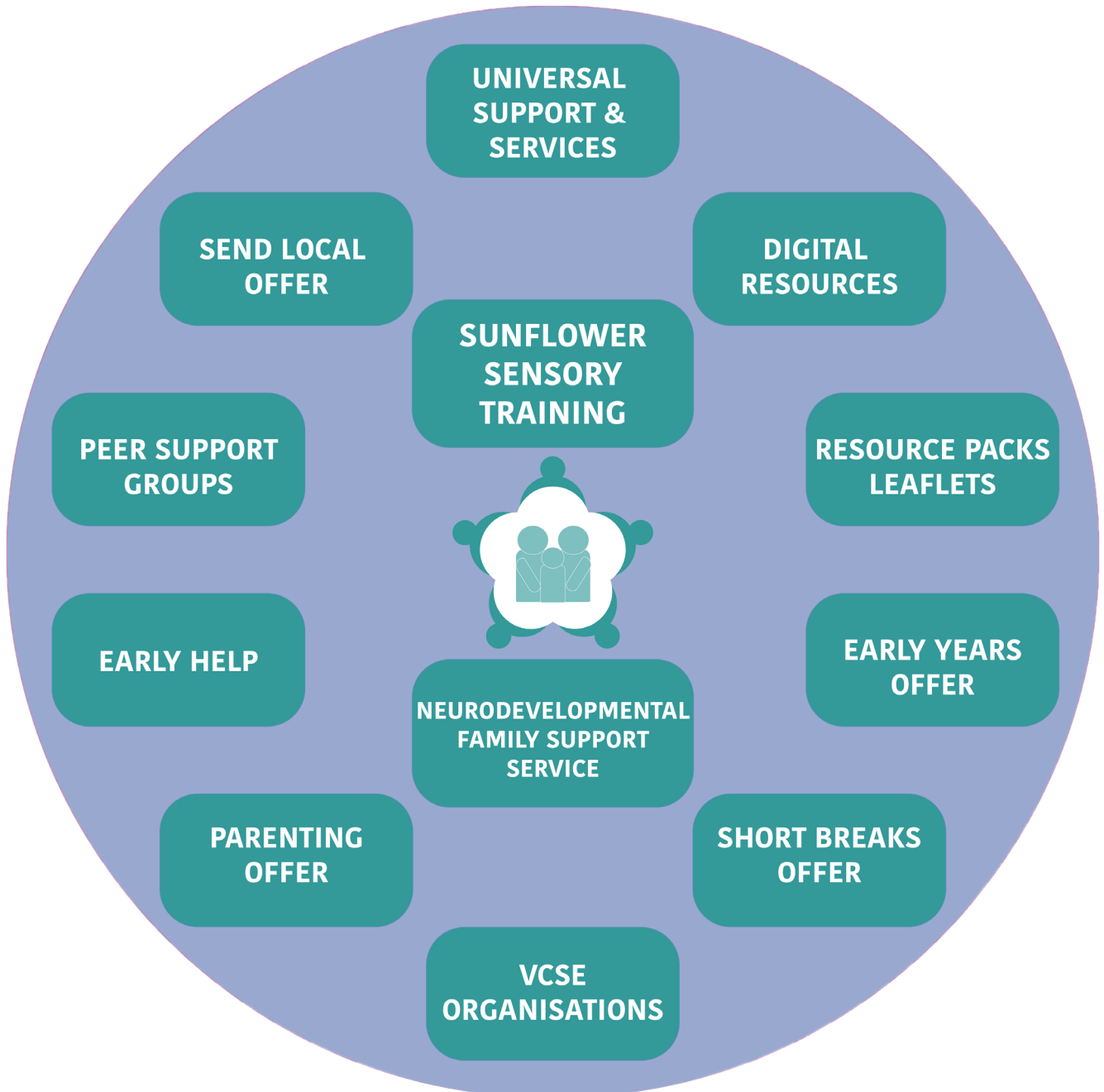
Stockton-on-Tees Neurodevelopmental Pathway: A Guide for Parents & Carers



BUBBLE OF SUPPORT

Support services available to children/young people with a neurodevelopmental need and their family in Stockton on Tees.

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



Families told us that they found it difficult to navigate the system and access support for themselves and their children/young people whilst waiting for assessments. Responding to this, we have worked to develop a needs led pathway. This means that you can access support for your child/young person with or without a diagnosis.

ABOUT THIS GUIDE

This guide has been produced by Stockton on Tees Borough Council, Tees Valley Clinical Commissioning Group and Stockton Parent Carer Forum. Contains the information that parents and carers said they would have found helpful when they had a child/young person going through the diagnostic process for a neurodevelopmental disorder.

WHO IS THIS GUIDE FOR?

This guide is for parents and carers of children and young people who may have a neurodevelopmental disorder or needs associated with one.

It will help you understand the support available to your child/young person and family and explain how neurodevelopmental disorders are assessed and diagnosed in Stockton on Tees.

WHAT DOES NEURODEVELOPMENTAL MEAN?

The term neurodevelopmental refers to the development of the nervous system, including the brain. Autism, ADHD and learning disabilities are examples of neurodevelopmental disorders. Often these disorders are a spectrum, with variations in the characteristics and severity of any potential deficits. This may mean that your child/young person requires more support than a neurotypical child/young person.

WHY HAVE I BEEN OFFERED THIS INFORMATION?

You may have been given this because you or a professional has expressed concern about your child/young person's development and behaviours. The traits of neurodevelopmental disorders are varied and each child/young person is unique however, some of these concerns may be:

Doesn't like or manage changes to routine

Struggles to regulate their emotions

Delayed speech/ language development

Has restricted and intense interests

Has trouble navigating social situations

Difficulties concentrating

Restlessness or Hyperactivity

Sensory seeking or avoiding

I THINK MY CHILD/YOUNG PERSON HAS A NEURODEVELOPMENTAL DISORDER, WHAT HAPPENS NOW?

The next steps are different for each children/young people and their families, this means that timescales can be different between individual. There is a slightly different pathway for those children under the age of five, On the next page, there is a chart that shows you the pathway and the potential outcomes at each stage.

Throughout this, you will have access to a variety of services that can support you and your child/young person. This booklet will provide details of these services and how you can access.

NEURODEVELOPMENTAL PATHWAY

The waiting time for a diagnosis is nationally long, whilst we have taken steps to try and reduce this significantly, the whole process can still take a long time. Recognising that families were unclear on pathways, who is involved at what stages and what support they can access, we have developed a new pathway. This pathway is needs led, so any support you and your family might need is available throughout without needing a diagnosis. You can see from the diagram on the next page that all paths lead back to the bubble of support.

The pathway displayed is for children/young people aged 5 - 17 years that live in Stockton on Tees or Hartlepool, for those under the age of 5 there is information below that explain the key differences.

Hartlepool and Stockton both have a bubble of support, however the services available within this bubble will vary. There is further information regarding the services accessible on the neurodevelopmental pathway website.

Under 5's

The pathway for children under the age of five is slightly different. It is led by a community paediatrician, but a diagnosis is still made by a Multi Agency Assessment Team.

Parents/carers will need to request that their child be referred to a Community Paediatrician via their GP or their Health Visitor. They will request further information from other agencies such.

The child will still need to go through the Triage Panel, but the referral can only come from the Community Paediatrician. The referral must still be completed in conjunction with parents and carers.

If there is not enough evidence to suggest a referral to the Neurodevelopmental pathway is currently necessary the Community Paediatrician may still keep the child under their service and monitor their progress as well as referring to the bubble of support. You will need to discuss this with your child's Community Paediatrician and they will advise accordingly.

When a child is discharged from any service, you will be provided with information on how you can access the service again if there is a need to do so.

Please note:

¹ A significant professional is one that knows the child/young person and family well. This could be a health visitor, social worker or teacher

² Referrals to the Neurodevelopmental Triage Panel MUST be completed with the parent/carer and where possible the child/young person

³ The co-ordinator will contact you to let you know the outcome of the panel. They will also write to the referer and they will continue to direct you to the available services

Child/Young persons concerns Parent/Carer concerns Professional concerns

Concerns are discussed with a significant professional¹

Referral to the Neurodevelopmental Triage Panel (NTP)²

Professional recommends watchful waiting and recommends accessing the bubble of support

Referral form is reviewed by the co-ordinator to ensure the form is complete and enough information is provided

The Neurodevelopmental Triage Panel will review the information and discuss next steps

Child/young person and parent/carer will be asked to attend a screening to obtain further information

Co-Ordinator will write to the family and referer to inform them of decision and signpost where necessary

Needs of the child/young person are identified but further diagnostic assessment is not appropriate
Family referred to the bubble of support

A Co-Ordinator will review evidence provided and information from the Neurodevelopmental Triage Panel to decide whether child/young person should have a full diagnostic assessment

Specialist assessments will take place. These are different for each child/young person and the co-ordinator will provide an appointment tracker

The Multi Agency Assessment Team³ hold a formulation meeting to decide whether to make a diagnosis based on information and evidence gathered.

Diagnosis Provided

Diagnosis Not Provided

A Clinician will provide feedback from the formulation and talk through whether the child/young person has been given and diagnosis

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PATHWAY FAQ'S

WHAT IS THE BUBBLE OF SUPPORT

The bubble of support (visible on page 4) is the offer available to families of children/young people with a neurodevelopmental need in Stockton on Tees. These are all accessible with or without a diagnosis. The offer provides information, advice, support and training to help you meet the needs of your child/young person.

HOW DO I ACCESS THE BUBBLE OF SUPPORT?

Most services are accessible without a referral. There is further information in the booklet with the contact details of services, what they offer and how you can access them.

WHY IS THERE A NEURODEVELOPMENTAL TRIAGE PANEL NOW?

Families told us that they were struggling to get professionals to listen to their concerns and access services. The NTP has been put in place so that the needs of the child/young person and their family can be identified quickly. The NTP is made up of professionals from education health and care services.

HOW DO I GET REFERRED MY CHILD/YOUNG PERSON REFERRED TO THE NEURODEVELOPMENTAL TRIAGE PANEL?

You should discuss any concerns that you have regarding your child/young person with a significant professional. This should be professional that knows your family well, as they have to provide information in the referral, we recommend that this is your child/young persons teacher or health visitor where possible. If you do not feel comfortable speaking with a professional or feel that they do not support your request to be referred you can speak to a member of the Neurodevelopmental Family Support Service or your GP. They provide 1:1 sessions and are able to make referrals if they believe this would be beneficial for you and your child/young person.

WHAT DO THE NEURODEVELOPMENTAL TRIAGE PANEL DO ONCE THEY IDENTIFY MY CHILD/YOUNG PERSONS NEEDS?

Once needs are identified, if there are definite indicators that the child/young person could have a neurodevelopmental disorder they will progress to a clinical screening. If the child/young person's presentation could potentially be explained by something else then the panel will make recommendations to access specific elements of the bubble of support. This could be a referral to a speech and language specialist, some additional support provided to your child/young person in school or an early help assessment.

WHAT IS WATCHFUL WAITING?

Sometimes, a child/young person presents with characteristics of a neurodevelopmental disorder for various reasons, it could be a significant life event or their needs not being met appropriately. There needs to be evidence that the behaviours and delays that your child/young person are displaying are consistent over a period of time. The period of watchful waiting is dependent upon each child/young person and you can discuss timescales with the professional, you can however contact them any time before this if your concerns deepen.

WHO DO I CONTACT ABOUT WHERE MY CHILD IS ON THE PATHWAY?

This is dependent on which stage of the pathway you are at. Your significant professional will be able to answer any questions leading up to the Neurodevelopmental Triage Panel, after this, you will be contacted by a co-ordinator and they will be your point of contact whilst the child/young person remains on the pathway.

MULTI AGENCY ASSESSMENT TEAM PATHWAY

INFORMATION GATHERING & ASSESSMENTS

Prior to your child/young person being placed on the ASD diagnostic pathway you will have provided information to the Neurodevelopmental Triage Panel.

This includes information about:

- Your concerns
- Health issues that your child/young person has
- Their interests and hobbies
- Their friendships and social interactions
- A developmental history
- Your family, who does the child live with and any significant life events

There are a range of assessments that your child/young person and you as parents/carers may be asked to participate in. Not all assessments are required for every child/young person. The information and evidence gathered previously and a screening with a clinician will help the MAATeam decide which assessments your child/young person will need. You will be provided with a timetable of all assessments required.



AIDE MEMOIRE: Parents/Carers are asked to provide an in depth description of their child/young persons development. Questions focus on the diagnostic criteria. Parents/carers attend this appointment without the child/young person,

ADOS: The Autistic Diagnostic Observational Schedule is a semi-structured, standardised observation of your child/young person without a parent/carer present. There are usually two people present, one who carries out the assessment and the other who makes a record of observations. The test assesses communication, social interaction, play and restricted/repetitive behaviours.

SPEECH & LANGUAGE: This may consist of a formal assessment of your child/young persons speech and understanding of language as well as more informal observations of their communication and getting a history of their development from you.

DIFFERENTIAL DIAGNOSIS: Autism has a variety of different traits that are similar to other conditions. You and your child may be asked to participate in a differential diagnosis assessment, this will help the MAATeam understand any other potential causes for your child/young persons presenting traits.

SCHOOL OBSERVATION: A clinician will observe your child/young person in their education setting. They will observe them in a structured and unstructured environment like their classroom as well as as break times. Your child/young persons teacher may also be asked to provide information about how your child/young person learns and interacts with their peers and staff and any behavioural concerns they have.

MAAT FORMULATION

The Multi Agency Assessment Team is made up of a number of specialists. They have expertise in their field and therefore when a decision is made whether to diagnose it is.

ASD Clinician: Specialist in the field of Autism and will have experience of working with children/young people with different autism profiles and their families.

Consultant Psychiatrist: This is a senior, medically trained doctor who specialises in diagnosing mental health disorders and/or behavioural issues.

Psychologist: Their role is to understand the strengths and weaknesses a child/young person has and how best to teach them.

Speech & Language Therapist: They assess the speech, language and communication abilities of an individual and will help in deciding if there are any other reasons for the child/young person difficulties with communicating and social interaction.

The team are provided with documentation containing all of the information about your child/young person. This group of professionals then work through the diagnostic criteria from the ICD-10. The information gathered will help them decide whether each of the diagnostic criteria has been MET, NOT MET or in some circumstances INCONCLUSIVE.

DIAGNOSTIC CRITERIA

The criteria is broken into two sections, A & B

Section A looks at the development of your child or young person's language & communication skills, social interaction and function/symbolic play before the age of three

Section B is split into three subsections and each of these have four criteria. The Multi Agency Assessment team must agree that the child/young person meets at least 6 of the criteria in total. This needs to include:

Communication

A minimum of 2 criteria from this subsection must be met

Social Interaction

A minimum of 1 criteria from this subsection must be met

Restrictive, Repetitive Activities & Interests

A minimum of 1 criteria from this subsection must be met

After discussing both sections and deciding if the child/young person has MET 6 or more of the criteria then they will be diagnosed with one of the possible autism profiles, unless it can be better explained by another reason. This could be a specific speech and language difficulty, levels of learning or attachment.

When a decision has been made, the co-ordinator will provide the outcome to parents and carers, and where appropriate the child/young person. Information will be provided on each section and whether the evidence demonstrated sufficient difficulty in each of the areas to meet the criteria.

You will have an opportunity to ask any questions at this stage, but we recognise that this can be a very overwhelming time. The co-ordinator will contact you 6 weeks after the formulation and this will be an opportunity for you to ask anything. At this point, unless there are any other significant underlying mental health needs, your child/young person will be discharged.

ASSESSMENT FAQ'S

HOW WILL I KNOW WHAT ASSESSMENTS MY CHILD NEEDS?

When a child/young person is accepted on to the MAAT pathway, they are assigned a co-ordinator. They will be your point of contact and will work with clinicians to understand what assessments they need. They will then write to you with a timetable outlining what assessments are needed and when.

WHERE DO THE ASSESSMENTS TAKE PLACE?

We try to hold as many assessments as possible at our Neurodevelopmental Pathway unit at the Ragworth Centre. Some assessments though, may need to be carried out elsewhere, you will be advised when you receive your invitation where to attend for each.

DOES MY CHILD/YOUNG PERSON NEED TO BE PRESENT WHEN I AM PROVIDING INFORMATION ABOUT THEM AND THEIR DEVELOPMENT?

You will be told if you need to attend an appointment with your child in the invitation letter. Some appointments you will need to attend with your child, if you are wanting to discuss something that you do not want your child/young person to hear and they are expected to attend speak to your co-ordinator and ask to have some time in private.

CAN I BE PRESENT AT THE OBSERVATIONS AND ASSESSMENTS MY CHILD ATTENDS?

Some assessments like the ADOS are carried out without a parent/carer present. The ADOS is a standardised observation, in order to get accurate results the conditions must be the same for each child.

HOW LONG WILL THE ASSESSMENTS TAKE?

This varies between individuals. Autism is a spectrum and therefore presentations can be different. It is important to gather all of the information that is needed to make sure the MAATeam are able to make the right decision.

WILL I HAVE AN OPPORTUNITY TO MEET WITH THE MEMBERS OF THE MAATEAM?

Unless one of these members is also carrying out one of your child/young persons assessments it is unlikely you will meet with them. Your co-ordinator will be able to answer any questions you have or liaise with other professionals where necessary.

WHY DO WE NEED TO ATTEND SO MANY DIFFERENT ASSESSMENTS?

Different assessments provide different information from various perspectives, this means that the information provided to the MAATeam will give a whole picture of the child/young person and they will be able to make the correct decision.

WHAT IF I DON'T AGREE WITH THE DECISION?

If you feel that the outcome from the Neurodevelopmental Triage Panel or the MAAT Formulation is wrong, you will need to discuss this with the co-ordinator. If after speaking with them you are not happy you are able to follow the Tees Esk & Wear Valley NHS complaints policy. You can request a second opinion following the MAAT formulation and your co-ordinator will be able to advise you on this.

WHAT HAPPENS NOW?

There are lots of services that are able to support you and your child/young person following on from the assessment. Further information and advice are provided overleaf.

ADVISE FROM PARENTS AND CARERS

Throughout the development of this pathway, agencies have gathered feedback from parents and carers who have had children/young people go through an assessment. This was important to understand what would make the process a better experience for them and their family. You told us that it would have been a better experience if you knew what to expect at each stage. Here are the most commonly suggested pieces of 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/YOUNG PERSON TO SOMEONE ELSE'S

The way your child/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 these present in your child/young person and the impact they have on their development will differ between individuals.

TALK TO OTHERS AND TRY NOT TO BECOME ISOLATED

Families said that they often felt alone when their child/young person was initially identified as having a neurodevelopmental need, especially where the child/young person displayed challenging behaviour. There are a number of voluntary organisations in Stockton on Tees that are run by parents of children with a neurodevelopmental disorder who are happy to have a chat with you about their experience and what techniques they found helped their child/young person. More information about these is available overleaf.

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 are able to, 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. When you are assigned a co-ordinator, they will be able to answer questions about the process and what to expect. If there is more practical help you are needing, you can access services within the bubble of support. Even if the person you speak to doesn't know the answer, they will know someone who will.

ACCESS TRAINING COURSES

Lots of organisations provide free training for parents/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 a ADHD but others are topical such as sleeping or toileting. They won't provide you with all of the answers, but they will provide you with lots of information and techniques to support your child/young person.

YOU DO NOT NEED A DIAGNOSIS TO ACCESS THE SUPPORT YOU AND YOUR CHILD/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 lengthy. However, access to support for you and your child/young person needs is not reliant on a diagnosis.

USEFUL CONTACTS & 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:

NEURODEVELOPMENTAL PATHWAY TEAM:

North and South Teams,
The Glades, Acklam Road Hospital,
Acklam Road, Middlesbrough, TS5 4EE
Tel: 01642 529790

CHILDREN & ADOLESCENT MENTAL HEALTH SERVICE (CAMHS)

Hartlepool
1-5 Lynn Street
Hartlepool
TS24 7JZ
Tel: 01429 285 049

Stockton on Tees
Viscount House, Falcon Court
Wesland Way, Preston Farm Industrial Estate
Stockton On Tees
TS18 3TX
Tel: 01642 368 400

NEURODEVELOPMENTAL CHILD & FAMILY SUPPORT

Daisy Chain, Calf Fallow Farm
Calf Fallow Lane, Norton
Stockton On Tees
TS20 1PF
www.daisychainproject.co.uk

Tel: 01642 531 248

STOCKTON PARENT CARER FORUM

Newtown Community Centre
Durham Road
Stockton on Tees
TS19 0DE
www.stocktonparentcarerfourm.co.uk

Tel: 07985 245 668

1 HART 1 MIND 1 FUTURE

Email: HartMindFuture@yahoo.co.uk

Tel: 07896 065 361

SENDIASS

Provides impartial confidential information advices and support to parents/carers children and young people aged 0-25 on matters relating to Speical Educational Needs and/or Disabilities

Hartlepool

HARTLEPOOLIASS@hartlepool.gov.uk
<http://www.hartlepool.gov.uk/hartlepooliass>
Tel: 01429 284 876 / 0776 491 662

Stockton on Tees

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LOCAL OFFER

Access information, support and guidance available in your local area

Hartlepool

www.hartlepool.fsd.org.uk

Stockton on Tees

www.stocktoninformationdirectory.org

