

Darlington's Neurodevelopmental Pathway Guide

A GUIDE FOR PARENTS AND CARERS



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1. ABOUT THIS GUIDE

ABOUT THIS GUIDE

Why have I been given this guide?

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



What does neurodevelopment mean?

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

ABOUT THIS GUIDE CONTINUED

What happens next if you have accessed support and still feel your child needs to be assessed for a formal diagnosis?

The next steps are different for each child/young person and their families, this means that timescales can be different between individuals, and it is important that you should not compare your child's journey to another child's journey. All children's needs are different, which means each experience is different. Hence the term 'Needs Led'.

Throughout your journey, you can continue to have access to services offered in the Bubble of Support, which means there is support for you and your child/young person.

The waiting time for a diagnosis can be long, not just in Darlington but nationally. Whilst we have taken steps to try and reduce this significantly, the whole process can still take a long time. This booklet will provide details of these services and how you can access.

The pathway displayed is for children/young people aged 5-17 years that live in Darlington, for those under the age of 5 there is information on the next page that explains the key differences.

ABOUT THIS GUIDE CONTINUED

Under 5s

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 (MAAT). 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.

2. DARLINGTON BUBBLE OF SUPPORT

DARLINGTON BUBBLE OF SUPPORT

Families told us they did not know where to start to understand their child's needs, and felt alone and worried. So 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. The Bubble of Support is where to look first, it will signpost you and will help you plan any support and understand your child's needs. The no diagnosis no support is a myth. We suggest looking at the bubble of support as a first step. This can lead on to you finding services that can help, other people to talk to, and if needed, progress on the Neurodevelopmental pathway. For more information please see <https://teesvalleyccg.nhs.uk/our-work/darlington-needs-led-neurodevelopmental-pathway/>



3. NEURODEVELOPMENTAL PATHWAY

Referral Form

- Screened by a professional alongside parents.
- Forms will be screened by the co-ordinator and further information requested if needed.

Neurodevelopmental Pathway Panel

- Completed forms are discussed by a multi-agency information sharing panel and the young person's needs are considered.
- Outcome letter sent to parents and referrer.

Diagnostic
assessment
not
appropriate

Comprehensive Initial Assessment

- Interview with parents, including historic assessments to look at differing characteristics/traits.
- Observation of young person, either in school or in a group.
- Outcome discussed within the team, and if indicated, specialist assessment is planned.

Diagnostic
assessment
not
appropriate

Specialist Assessment

- Specialist assessment components depending on the needs of each young person.
- Timetable of planned appointments shared with parents.

Multi-disciplinary Diagnostic Discussion

- Information from the specialist assessment is discussed and considered against the diagnostic criteria for ASD and/of ADHD.

Formulation Meeting

- Outcome of multi-disciplinary diagnostic discussion shared with parents (and young person).
- Final meeting and recommendation are co-produced.

Discharge

- Comprehensive report shared with all relevant parties.
- Transferred to CAMHS if ongoing treatment required.

Ongoing
support and
intervention

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MAAT FORMULATION

New 'needs led' pathway

Over an 18 month period, health services, local authority, parent carer forums and Voluntary, Community and Social Enterprise (VCSE) organisations have worked together to design a new 'needs led' pathway to help support parents/carers and children where the child has a need associated with a neurodevelopmental condition, Autism (ASD) and/or Attention Deficit Hyperactivity Disorder (ADHD).

Working more closely together

Historically, the focus has been on the diagnosis, but more often than not, the diagnosis did not always meet the needs of the child. Consultation carried out with parents, revealed that the health, education and local authority systems needed to work more closely together to make sure services were available to meet the needs of children.

Changes also needed to be made to the diagnosis stage within the service to ensure children did not have to undergo unnecessary assessments over an elongated period of time. We still have work to do to get the waiting times down but new processes will help with this and more importantly, your child and family should feel supported during this assessment process.

4. MAAT FORMULATION

MAAT FORMULATION

Once your child has had all of the assessments which they need, all of the professionals come together for a formulation (decision making).

The Multi Agency Assessment Team (MATT) is made of professionals within different specialities, they use their skills to decide together whether a diagnosis is needed. In all of this remember you are the expert of your child, and the professionals are experts in their fields.

Here is a list of some of the professionals your child may see. The team is based upon your child's needs.

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.

MAAT FORMULATION CONTINUED

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. You may see this team referred to as SALT.

MAAT PROCESS

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 (a coding system to help identify health conditions and the criteria used for diagnosing autism in the UK). This will also include information that has been provided to the team, from your child's place of education if appropriate.

The information gathered will help them decide whether each of the diagnostic criteria has been MET, NOT MET or in some circumstances INCONCLUSIVE (meaning no firm conclusion or result).

5. DIAGNOSTIC CRITERIA

DIAGNOSTIC CRITERIA

The criteria is broken into two sections, A and B

Section A looks at the development of your child or young persons 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 six of the criteria in total. This needs to include:

Restrictive, Repetitive Activities & Interests

A minimum of 1 criteria from this subsection must be met.

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.

DIAGNOSTIC CRITERIA CONTINUED

After discussing both sections and deciding if the child/young person has MET six 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 also receive some guidance as to how your child's needs can be met through the Bubble of Support.

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 six 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 from Tees Esk & Wear Valley NHS (TEWV). Ongoing support is not provided by TEWV, but all the support you and your child/young person need can be accessed through services in the Bubble of Support.

6. FAQs

FAQS

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, but 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 that my child attends?

Some assessments like the ADOS (Autism Diagnostic Observation Schedule - a semi structured, standardised assessment of communication, social interaction, and play or imaginative use of toys) are carried out without a parent/carer present. The ADOS is a standardised observation, and 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 can make the right decision.

FAQS CONTINUED

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 Sedgefield Community Hospital.

You may be invited to attend Sedgefield if your child/young person needs to meet with a member of the team for a face to face appointment. This might be a cognitive assessment, a speech and language assessment, or a play based observation.

Some assessments though, may need to be carried out elsewhere, you will be advised when you receive your invitation where to attend. We also usually arrange for young people to be observed in school or college as part of our assessment process.

FAQS CONTINUED

Will I have an opportunity to meet 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. After this you can 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 in the Bubble of Support.

7. ADVICE FROM PARENTS AND CARERS

ADVICE 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.

Talk to others and don't isolate yourself

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.

The Parent Carer Forum in Darlington is run by parents of children/young people 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. These can be found in the Useful Contacts section.

ADVICE FROM PARENTS AND CARERS

CONTINUED

Keep a diary

When you are speaking to 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. For example it would be useful to know about how things are working within school settings, are there any teachers involved, are they giving any other support? Or have you tried to access support elsewhere, what was it? did it help? All of this is very important information and can help build a picture of your child's/young persons journey.

Don't compare your child/young person to anyone else's

The way your child/young person's development progresses is different to others. Neurodevelopmental disorders are a spectrum, and while 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.

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.

ADVICE FROM PARENTS AND CARERS CONTINUED

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 don't need a diagnosis to access the support you and your child/young person needs

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.

8. USEFUL CONTACTS

USEFUL CONTACTS

Daisy Chain

Telephone: 01642 531 248

Email: info@daisychainproject.co.uk

Website: <http://www.daisychainproject.co.uk>

Address: Daisy Chain Respite Care & Family Support Centre.

Calf Fallow Farm, Calf Fallow Lane, Norton, Stockton-on-Tees, TS20 1PF

DARLINGTON PARENT CARER FORUM

Box 28, Northern Echo Arena, Neasham Road, Darlington, DL2 1DL

Website: <https://darlingtonpcf.co.uk> or find us on Facebook.

SENDIASS

You can contact the service Monday- Friday - 8:30am-5pm

Telephone: 01325 405878

Contact Name :- Helen Daly

Email: iass@darlington.gov.uk

CAMHS County Durham and Darlington Crisis Team

If a child/young person presents as a significant and immediate risk of harm to self or others as a result of a potential mental health concern please contact 0800 051 61 71 (available 24 hours a day / 7 days a week).

USEFUL CONTACTS CONTINUED

Mental Health Adult Crisis Team (for 16+ between 22:00 – 08:00)

If there is a significant and immediate risk of harm to self or others as a result of a potential mental health concern please contact 0800 051 61 71 (available 24 hours / 7 days a week).

Darlington Needs Led Neurodevelopmental Pathway

To find about TEWV and the pathway, this is the web address;
<https://teesvalleyccg.nhs.uk/our-work/darlington-needs-led-neurodevelopmental-pathway/>

Darlington's SEND Local Offer

Look and see what services there are at the click of a button:
<https://livingwell.darlington.gov.uk/Categories/528>

TEWV Neuro Team

To find out a bit more about the team;
<https://www.tewv.nhs.uk/services/child-and-adolescent-mental-health-service-autism-assessment-team-county-durham-and-darlington/>