

Neurodiversity and Autism Update December 2023

Welcome to our Second Edition. Thank you for the feedback we have received from October, and we will continue to keep listening and keeping you informed. In this issue we are covering:

- Neurodevelopmental Service
- Support services in North East Lincolnshire
- Access Pathway Waiting List – 5 and over
- Access Pathway Waiting List – under 5
- Working with Partners on specialist assessments
- Support for Parent and Carers of children and young people with Neurodiverse Needs
- Settings, Parents and Carers for Education (SPACE) Forum
- Autism Central
- Would you like to get involved?
- You Said, We Did?



Neurodevelopmental Service

In this section, we wanted to tell you a bit more about the Neurodevelopmental Service (NDS) that we are excited to be launching in the New Year.

Who are we?

The Neurodevelopmental Service is a specialist child and adolescent assessment service for children and young people. We will offer assessments to determine whether a child or young person has a neurodevelopmental presentation, that meets the criteria for neuro-diverse conditions such as Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD).

Who's in the team?

Our team is made up of professionals from a range of different backgrounds who work together to provide multi-disciplinary assessments. This includes Child and Adolescent Psychiatrists, Clinical Psychologists, Learning Disability Nurses, Speech and Language Therapists and a Paediatrician. You can learn more about our team members in the next issue and we are currently working on a new section on the [Navigo website](#) which will tell you more so do keep checking for further updates.

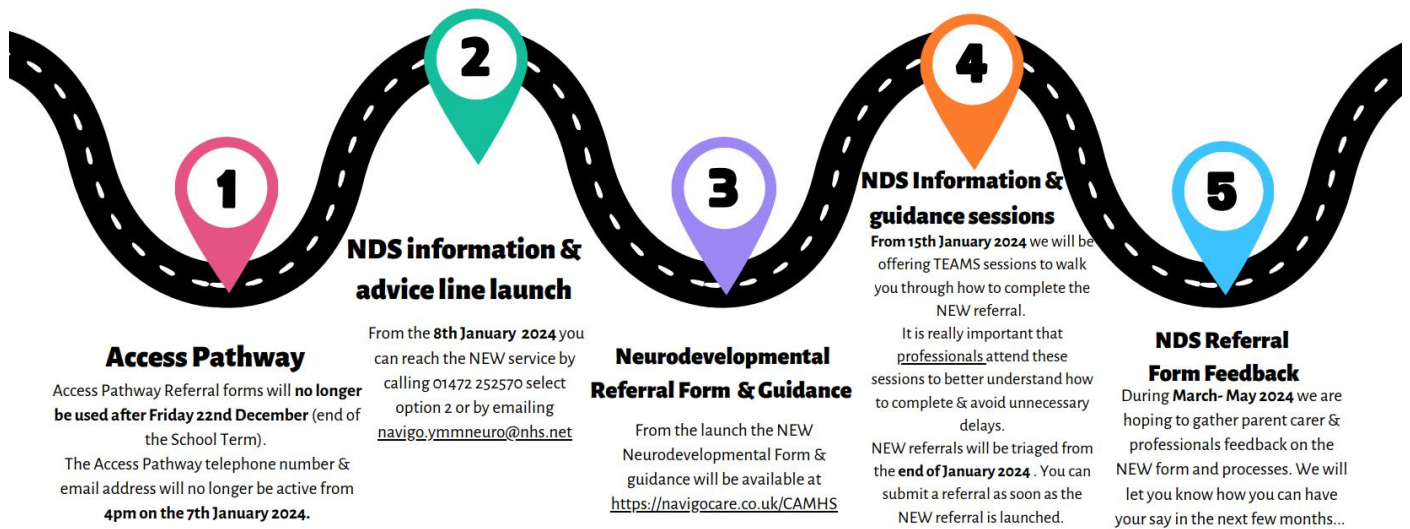
What will they do?

During our engagement with parent carers and professionals over the last few years *you said* you wanted 'a clearer process' of what an assessment entails and how decisions are made. *The PDF attachment 'NDS Simple Flow' provides more details on this – sent with this newsletter.*

We have not included timescales into the diagram yet. Once we have launched the new process and tested it over a few months we will have clearer timescales. This will help you to understand what to expect and when. We have also summarised key diary dates for you (see below) as the service rolls out but please do keep visiting our [webpage](#) for more information.

Over the page you will find a diagram of key dates relating to the launch of the new referral form and service. Please note after the **22nd December 2023** referrals can no longer be made using the Access Pathway referral form and a NEW referral form and process for submission will come into effect **January 2024**. Access Pathway referrals already received and those submitted up to the **22nd December 2023** will be screened and triaged by the NDS by the end of January. The NDS will then start screening using the NEW referral form from **31st January 2024**.

TIMELINE FOR LAUNCH OF 0-18 YEARS NEURODEVELOPMENTAL SERVICE (NDS)



A clear feedback process

When we consulted with you service developments 'You said' you would like a clear complaints/feedback process. So, before we launch the NDS we are setting out the feedback process early to ensure you can let us know what is going well or where you might need some additional guidance.

The Patient Advice and Liaison Service (PALS) offers confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers.

There may be times when you have concerns, you need advice or you want to tell us what you think about our services. Whether you have a small problem or you want to make a formal complaint, say thank you for a job well done or you have an idea for how we can make things better. This is where our Patient Advice and Liaison Service (PALS) can help you [Navigo PALS](#)






Contact details

- 01472 583040
- navigo.pals@nhs.net
- <https://navigocare.co.uk/useful-contacts/pals>

Support services in NEL

After our engagement events with parent carers and stakeholders there is still some confusion with regards to referral routes for services and assessment pathways across the system. We have summarised some key services and referral routes as requested by you.

Where to start and look for information and what to do if you feel your child needs some support with part of their development?

 <p>WHERE TO LOOK FOR TRUSTED INFORMATION</p> <p>NEL SEND local Offer is a good source of information for CYP with Special Educational Needs & Disabilities (SEND). Even If your child does not have SEND but you feel they need support in some part of their development, this website will help with information and details on support services visit</p> <p>www.sendlocaloffer.nelincs.gov.uk</p>	 <p>TALK TO A PROFESSIONAL</p> <p>Raise concerns with a professional that knows the Child or Young Person well such as Health Visitor, School Nurse, Nursery Nurse, Class Teacher or SENCO. This professional should support you to access information & help through the SEND local offer.</p>	 <p>WHAT TO DO WHILE YOU ARE WAITING</p> <p>Talk to other parent carers contact NELPCF or SEND Parent Engagement Champion. Write down all the positive things your child can do, what works for them & how they like to interact with other people - share this with those who support your child. Make small adjustments in your daily routine like keeping choices limited to two, de-clutter bedrooms & where possible plan ahead... Try and take some time for YOU!</p>	 <p>ONGOING SUPPORT</p> <p>Support strategies & early Intervention should continue which should be reviewed by the professional you are working alongside. The 'graduated response' should be used by educational & early years settings following the 'Assess, Plan, Do & Review' where there are difficulties accessing education. Decisions & actions should be regularly reviewed & updated if needed; making sure that your child has the right support in place.</p>	 <p>CONCERNS REMAIN</p> <p>If concerns remain after support/ intervention &/or a review of the graduated response. The professional in consultation with you & CYP (where appropriate) should explore next steps e.g. onward referrals to specialist services &/or assessment. You should also be supported to understand what this means.</p>
---	---	---	--	--

Summary of support services in NEL and what they do - these can be found on www.sendlocaloffer.nelincs.gov.uk

Service	What they do	How to contact
Health Visitor	The Health Visiting service is available to all families who are expecting a baby, have a newborn or a child up to the age of 5. You can see your health visitor at a family hubs or health centres. We also make visits to your home.	HealthVisitingAdvice@nelincs.gov.uk 01472 323660 07507 329910
School Nurse	The School Nursing service is available to children from the age of 4 and a half years, young people, and their families. School Nurses also offer help with: <ul style="list-style-type: none"> • Healthy lifestyles i.e., sleep, smoking, growth, dental health • Bladder and bowel concerns • Relationships and sexual health • Health issues impacting on school attendance. • School transition support • Vulnerable children – unmet physical needs 	schoolnursingadvice@nelincs.gov.uk 01472 323660 If your child is aged between 11 and 19 years they can still contact the school nursing team via text on 07507 331620.
Family Hubs	Family hubs bring together services to offer help and support to children and young people aged 0 to 19 and their families. You can speak to a range of professionals such as our advisers, health visitors, school nurses and other family support services to work through issues that may arise during a child or young person's life.	Family hubs NELC (nelincs.gov.uk)

FIS - Families First Information Service	<p>The Families First Information Service is a free, impartial information service for families with children aged 0-19 years.</p> <p>If you are looking for childcare, you can use the directory to search for childcare or contact the service directly.</p>	<p>fis@nelincs.gov.uk 01472 326292 option one Family Information Service Directory NELC (nelincs.gov.uk)</p>
Children's Disability Service	<p>The Children's Disability Service (CDS), like Family Information Services, will provide you with information about universal services and more specialist groups that can offer support, without the need for an assessment.</p>	<p>01472 326292 (option 5) https://www.nelincs.gov.uk/children-families-and-schools/childrens-disability-service/</p>
Compass Go	<p>Compass Go accepts self-referrals... both from Parent carer and Child/Young Person. Every school in NEL also has a Mental Health Support Team (MHST) link worker where referrals can also be discussed directly.</p>	<p>compass.go.mhst@nhs.net nelincsmhst@compass-uk.org 01472 494250 Compass GO... North East Lincolnshire Mental Health Support Teams - Compass (compass-uk.org)</p>
Child and Adolescent Mental Health Service (Young Minds Matter)	<p>Child and Adolescent Mental Health Service (Young Minds Matter) duty line continues to support professionals and parent carers when they have concerns with a child or young person</p>	<p>01472 252570 Child and Adolescent Mental Health Services (Young Minds Matter) :: Navigo (navigocare.co.uk)</p>
Kooth	<p>Kooth is a free, safe, confidential, and non-stigmatised way for young people (11-25 years) to receive counselling, advice, and support on-line 365 days a year. There is no need to complete a referral professionals can signpost and young people can create their own account.</p>	<p>Home - Kooth</p>
Speech and Language	<p>If your child's speech and language skills do not improve, even after you have:</p> <ul style="list-style-type: none"> • Tried different activities at home • Raised your concerns with your health visitor or had support from your child's nursery, preschool, or school <p>Your health visitor or your child's place of learning can make a referral to the NHS speech and language therapy service. Parent carers can also make a direct referral themselves.</p> <p>Your child does not need an education, health and care (EHC) plan to get support from the speech and language therapy service.</p>	<p>NELC SEND Local Offer Speech, language and communication needs (SLCN) - NELC SEND Local Offer (nelincs.gov.uk)</p> <p>Services for children in North East Lincolnshire - Northern Lincolnshire and Goole NHS Foundation Trust (nlg.nhs.uk)</p>
Occupational Therapy Physio	<p>We see children with a wide variety of conditions which can affect their everyday skills, learning, social opportunities, and independence.</p>	<p>For more information contact each of the services below Occupational therapy for children - Northern Lincolnshire and Goole NHS Foundation Trust (nlg.nhs.uk)</p>

Nutrition and Dietetics	We work closely with the child or young person, their family and other professionals involved. We offer specialist assessment and advice and a range of interventions.	Children's physiotherapy - Northern Lincolnshire and Goole NHS Foundation Trust (nlg.nhs.uk) Children's dietitians - Northern Lincolnshire and Goole NHS Foundation Trust (nlg.nhs.uk)
Developmental Disorder Condition (also known as Dyspraxia)	<p>Developmental Coordination Disorder (DCD) Developmental Coordination Disorder (DCD), also known as Dyspraxia, is a common disorder affecting fine and gross motor coordination in children and adults.</p> <p>There is an Occupational Therapy (OT) Toolkit for you to complete and share with the GP to support the referral.</p>	NELC SEND Local Offer Developmental Coordination Disorder (DCD) - NELC SEND Local Offer (nelincs.gov.uk)
Global Developmental Delay (0-5 years)	<p>Some parent carers think their child is not developing as they ought to be, or they have been told that their child has developmental delay or global developmental delay.</p> <p>The key areas of development are:</p> <ul style="list-style-type: none"> • Communication – such as smiling, listening, responding to words • Physical – such as holding and handling objects, sitting up, crawling, walking • Thinking – learning about the world, developing understanding • Personal, social and emotional – such as copying facial expressions, responding to what parents say, forming close attachments <p>If any of the above concerns you, please talk to your health visitor.</p>	HealthVisitingAdvice@nelincs.gov.uk 01472 323660 07507 329910
Portage	<p>The Portage Service is a term-time home visiting educational service for pre-school children with additional support needs.</p> <p>The service usually takes requests from Health Visitors or other practitioners who have concerns regarding a child's development. With the parent carers permission, they can refer children up to 3-years-old.</p> <p>Please speak to your Health Visitor for more information</p>	HealthVisitingAdvice@nelincs.gov.uk . 01472 323660 07507 329910 NELC SEND Local Offer Portage team - NELC SEND Local Offer (nelincs.gov.uk)
Hearing and Vision	We offer a wide range of services to support children and young people who have been diagnosed with hearing and/or vision loss from birth to leaving school.	https://sendlocaloffer.nelincs.gov.uk/hearing-and-vision/

	If you suspect you, your child or young person, has a hearing or visual loss, you should contact your GP or other health professional in the first instance e.g. Health Visitor or School Nurse	
Sleep	We know that children and young people with Special Educational Needs and Disabilities (SEND) might face unique sleep difficulties. From difficulty falling asleep to frequent night-time awakenings, we're here to address it all. Our Sleep Service is like a personalised sleep toolkit for your family. Through a range of methods, including one-to-one telephone sleep clinics, hints & tips videos, advice, and guidance, we're dedicated to finding what works best for you. Support is provided through a range of methods, including workshops and drop-ins, 1:1 support, and telephone/e-mail support.	01472 467540 Enquiries.yorkshire@kids.org.uk South Bank SEND Sleep Service (N.E. Lincolnshire) - Kids
SEND Parent Engagement Champion	SEND Parent Engagement Champion role offers support, signposting to support/services, host regular engagement events (such as pop-ups with multiple professionals in attendance) and listen to parent carer views.	abi.fleming@nelsendiass.org.uk 07552743370
Parent Carer Forum	NELPCF is a collective voice for parent carers of children and young people with SEND in North East Lincolnshire. They make sure that parents' views and experiences influence local services to make things better.	nelpcf@gmail.com NELPCF
SENDIASS	SENDIASS North East Lincolnshire is a free service for children and young people with special educational needs and disabilities and their parents and carers. It's impartial and we give confidential information, advice and support in relation to special educational needs and disabilities (SEND) and related health and social care matters.	ask@nelsendiass.org.uk 01472 326363 www.nelsendiass.org.uk

If you are concerned that a child is being abused, or they may be at risk of harm, you should contact NELC [Integrated Front Door Service](#) to make a referral
For concerns around mental health use the 24/7 mental health Single Point of Access on 01472 256256 (option 3) or freephone 08081 968442
If life is at imminent risk, call the emergency services on 999.

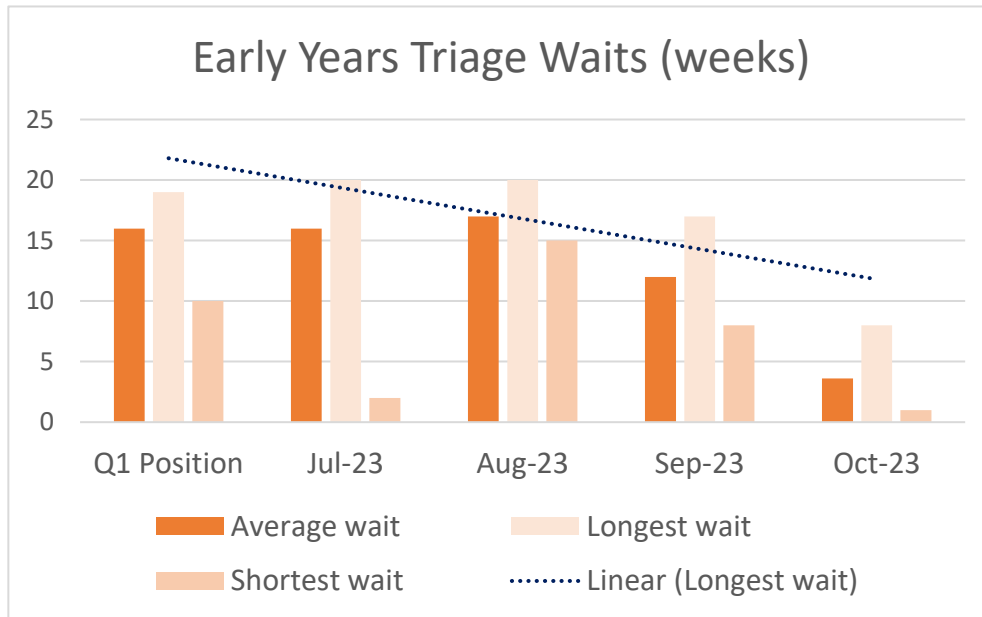
Access Pathway Waiting List (Over 5s)

What are the waiting times looking like?

In the last newsletter we shared with you that the waiting times have reduced to 40 weeks (end of September 23) and we are pleased to share the wait has continued to decrease by a further 3 weeks to 37 weeks at the end of October 2023. And by the end of November 2023 this has further reduced to 31 weeks a reduction of 39% since Q1 (April- June) where the longest wait was 51 weeks.

Access Pathway Waiting List (Under 5s)

Early Years triage and screening waiting time is also decreasing with the average wait in October 2023 down to 4.2 weeks for the MDT discussion.



There are also lots of exciting projects happening in the Early Years and we wanted to share the work of the Early Years Team (Education & Inclusion) who are offering exciting training programmes to early years settings:

- [Autism Education Trust’s ‘Making Sense of Autism’](#) course. So far, 84 practitioners from across early years settings and Local Authority services have booked places.
- [‘All About Attention’ professional programme of intervention.](#) We’ve had 33 providers express an interest and have started to rollout the support.

For more info on Early Years Training [NELC SEND Local Offer](#) | [Early years - NELC SEND Local Offer \(nelincs.gov.uk\)](#)

Working with our Partners on Specialist Assessments

As covered in the last update Navigo CAMHS (Young Minds Matter) have begun to work alongside an external provider to support with the number of children waiting for an ASD assessment. The provider, The Owl Centre currently have 90 referrals and feedback from parent carers has been very positive:

“Thank you for everything, you took the time to listen and understand the data gathered and provided. Communication was clear and concise and the timing between appointments wasn't too long. It's been a very long road for us to get the assessment undertaken, but you showed care, compassion and empathy throughout which has been amazing. As a parent I feel valued and listened too and no longer under the neurotic parent label because you have seen what I have been seeing for so long. A child that just needed someone to see her for her. Thank you.”

“This service for ASD assessment was fantastic, great communication, easy to book convenient appointment and a quiet Sunday appointment was fantastic. The staff doing the assessment were great at putting my son at ease.”

“The whole experience with owl has been fantastic, they listened to us and was very understanding.”

The collaboration between Navigo and The Owl Centre has assisted in the reduction of the YMM ASD assessment waiting list, which has reduced from approximately 60 weeks (13.8 months) to 35 weeks (8 months).

Support for Parent and Carers for CYP with Neurodiverse Needs

MAG (Managing ADHD Group) for parent/carers of children with Attention Deficit Hyperactivity Disorder (ADHD). The course aims to reduce reliance on medication especially Melatonin, support parent carers on ADHD and how to support their child/young person. This 7-week course for parents covers:

- Introduction to ADHD
- Behaviour
- Emotional regulation
- Medication
- SENDIASS
- Sleep
- Living with ADHD

The MAG train the trainer was attended by six members of the NAVIGO Adult ADHD Service, one member of the NAVIGO team, four members from NELC and Early Help, five members of the Child and Adolescent Mental Health Service (Young Minds Matter) team, and two members from a local non-profit organisation. Feedback about the train the trainer sessions:

“The training was very engaging and allowed the conversation of ADHD to flow easily.”

“...see the merit in the training and how valuable this will be.”

We are excited to share with you that the first MAG training course started on Monday 13th November 2023 and ten parent carers were invited to join this course. Initially, this course has been offered to those parent carers of children/young people (CYP) who already have a diagnosis of ADHD. If your child/young person has a diagnosis of ADHD and you would like to know more about the course or register your interest, please email navigo.neladhd@nhs.net with your details and the team will get in touch with you.

The initial group will be invited to share their thoughts and views via evaluation and feedback sessions. The purpose of these sessions is to ensure that we are offering exactly what parent carers want and will allow any amendments to the course to be made before starting the next group.

Settings, Parents & Carers for Education (SPACE) Forum

The SPACE Forums are led by Abi Fleming, Parental Engagement Champion (SENDIASS) and Nicola Chappel, Service Manager (ICB). This is the only forum within North East Lincolnshire that includes parent carers and setting staff working in partnership. Please follow this link for more information and notes of the last meeting: [Settings, parents and carers for education- SPACE Forum - NELC SEND Local Offer \(nelincs.gov.uk\)](#).

The next SPACE Forum: 16th January 2023 ,Grimsby Town Hall, 9.30am - 11.30am

Autism Central programme

We are excited to share with you the Autism Central Programme in collaboration with Daisy Chain which offers families and carers of autistic people high-quality and easily accessible autism education, training, and support through peer educators, alongside a dedicated [website](#).

You can access the training sessions if you have a young person with traits, undergoing, or diagnosed with autism, ADHD, FASD or sensory processing differences by visiting <https://www.daisychainproject.co.uk/event/learning-workshops/>.

8th December 2023	Introduction to Autism	10am-11:30am
15th December 2023	Parent/carer Wellbeing over Christmas	10am-11:30am
22nd December 2023	ADHD	10am-11:30am
5th January 2024	Sibling Support/Young Carers	10am-11.30am

8th January 2024	Attendance & Challenges Accessing Mainstream School	5pm-7pm
12th January 2024	EHCPs	10am-11.30am
19th January 2024	Attendance & Challenges Accessing Mainstream School	10am-11.30am
22nd January 2024	After School Distressed Behaviour	5pm-7pm
26th January 2024	Introduction to Autism	10am-11.30am

Virtual support sessions are also available which provide an opportunity for parents/carers of autistic and neurodivergent children to connect with each other and get advice from the Autism Central team. This group is suitable for you if you have a child who is diagnosed / going through the diagnostic process / has been identified by a professional as having a need relating to: autism, ADHD, FASD, Sensory processing differences, anxiety and social and communication differences. For more information visit <https://www.daisychainproject.co.uk/event/autism-central-virtual-support-sessions/>

Monday 15th January 2024	5.30pm-7pm
Monday 29th January 2024	5.30pm-7pm
Monday 12th February 2024	5.30pm-7pm
Monday 26th February 2024	5.30pm-7pm

Would you like to get involved? Please feel free to come along - We look forward to seeing you!

Event	Who is it for?	When is it?	How do I get involved?
Wybers Wood Academy - Christmas Fair	Parent carers of children and young people who attend this school	Thursday 14 th December 2pm - 4pm	Come along to the Christmas Fair and meet Abi Fleming, SENDIASS Parent Engagement Champion, and Lauren Thompson, Local Offer Coordinator. Abi and Lauren will be there to showcase the Local Offer and provide support, guidance and signpost further help within NEL.

You said... We did...

We have received some feedback that the title of this newsletter may cause some confusion. Therefore, we would like to hear your views and any suggestions you may have for an alternative title of this newsletter. Please use the QR Code or the link below to share your thoughts and ideas: <https://forms.office.com/e/qnfXP86mux>



And finally... On behalf of us all we wish you a very Merry Christmas and look forward to updating you in the new year



END OF UPDATE

BLANK PAGE