

Neurodiversity and Autism Update October 2023

Welcome to our very first North East Lincolnshire Neurodiversity and Autism Update.

This update has been written to provide an overview for parents/carers and professionals on our programmes of work for Neurodiversity and Autism across the North East Lincolnshire Health and Care Partnership. We are aiming to send this out on a monthly basis through the SEND newsletter. Please excuse the length of this first edition – but we have a lot of great progress to share!

In this issue we are covering:

- [Neurodevelopmental Team](#)
- [Access Pathway Waiting List](#)
- [Working With Partners on specialist assessments](#)
- [Support for Parent and Carers for CYP with Neurodiverse needs](#)
- [Settings, Parents and Carers for Education \(SPACE\) Forum](#)
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Neurodevelopmental Team

As you maybe aware we have been developing plans over a number of years towards a single pathway for Children Young People (CYP) 0-18 (25) years for Neurodiverse conditions. We are now underway with the first steps of this plan after receiving investment from the NEL Integrated Care Board.

What does this mean?

We are working with NAViGO CAMHs over the next 12 - 24 months to enhance their current service provision to create a single front door. They will coordinate and manage the assessment and diagnostic processes for CYP who present with neurodevelopmental needs.

Our CYP and their families will

- Have access to timely and high-quality personalised support and assessment for neurodevelopmental concerns aged 0 - 18 years* (to 25 years)
- Experience a multi-disciplinary/multi-agency neurodevelopmental offer whereby duplication is avoided and good communication between agencies is evidenced.
- Have access to appropriate support services and personalised recommendations to meet their needs, irrespective as to whether a diagnosis has been received.
- Have a named point of contact for any queries and to help navigate the process.
- CYP and their families are actively involved in the assessment process and are clear about the most appropriate support and interventions required, based on their needs.
- Health, education and care staff working with children and young people with Neurodiverse needs across a range of settings (including early years, education and home) receive appropriate training, guidance and resources that enable them to confidently and competently support those children and young people and their families in managing their needs through a range of tools and techniques.

What have we done?

The North East Lincolnshire Access Pathway and team has been transferred to NAViGO, who were recently appointed as the new provider of Child and Adolescent Mental Health Services. The pathway will be integrated with the current Young Minds Matter specialist assessment team which will allow for improved collaboration between care teams.

This will create a single point of access to a Neurodevelopmental Assessment Team for the referral and specialist assessment of neurodevelopmental disorders for Autism Spectrum Disorders (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

This new way of working will not negatively affect those waiting but will mean that all future correspondence will come directly from NAViGO, as the new provider of the service.

Subsequent changes, later in the year, will include the introduction of more clinical staff and a new streamlined referral process which will strengthen our ways of working with partner services. This will make the referral and assessment processes easier and quicker.

Engagement and participation with system partners, children and young people, parent and carers, will continue to inform the service changes.

The clinical team are continuing to work on an initiative which is already seeing a positive impact in the reduction of the waiting times for children and young people who have been referred to this pathway.

In the meantime, we will continue to triage the referrals that are next on the list until the new referral process is launched.

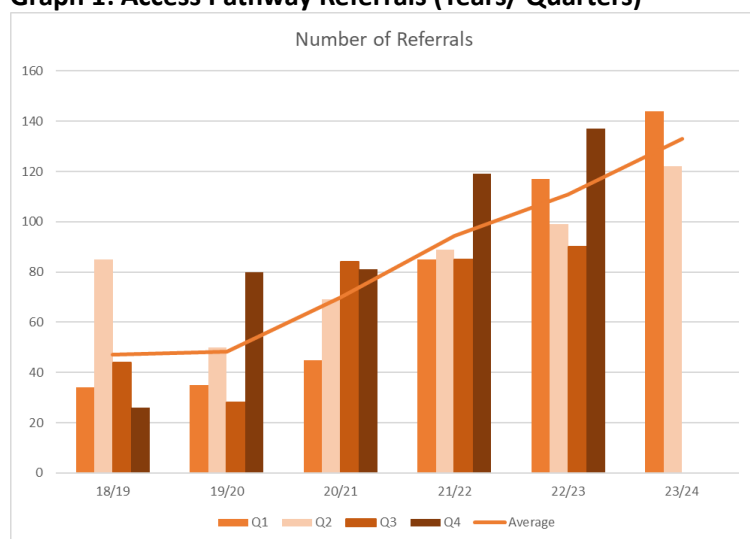
In the next edition we will tell you more about

- Who is who in the Neurodevelopmental Team
- What the new process will look like?
- How we are working with our partners to improve our pathways
- Aspirations for future waiting times once we are fully up and running

Access Pathway Waiting List

We wanted to update you about the improvements that we are implementing to address the Access Pathway waiting list. Whilst there has been an increase in referrals and the impact of the COVID pandemic is still being seen, we do not want children/young people and their families to be waiting longer than they need to for a decision about accessing a specialist assessment.

Graph 1: Access Pathway Referrals (Years/ Quarters)



After listening to feedback from professionals, parents and carers about the current length of wait and the best options for tackling this issue, we have committed to increasing capacity into the pathway further to address the current waiting list.

By responding to the new national framework to deliver improved outcomes in assessment pathways and following this operational guidance, we have been able to create a new way of working.

- [NHS England » A national framework to deliver improved outcomes in all-age autism assessment pathways: guidance for integrated care boards](#)
- [NHS England » Operational guidance to deliver improved outcomes in all-age autism assessment pathways: Guidance for integrated care boards](#)

The Clinical Team will review the referrals on the waiting list more often and authors of the referrals will not be required to attend the discussions.

At this stage should further information from the author or the setting be required by the clinicians this will be requested and reviewed before the final recommendation is made.

As the number of clinical discussions are increasing this will reduce the wait to a decision about whether a child/young person requires a specialist assessment. The new way of working came into effect from 25 September 2023 and we are pleased to demonstrate that length of wait is reducing.

Graph 2: Access Pathway Wait – over 5s (weeks)

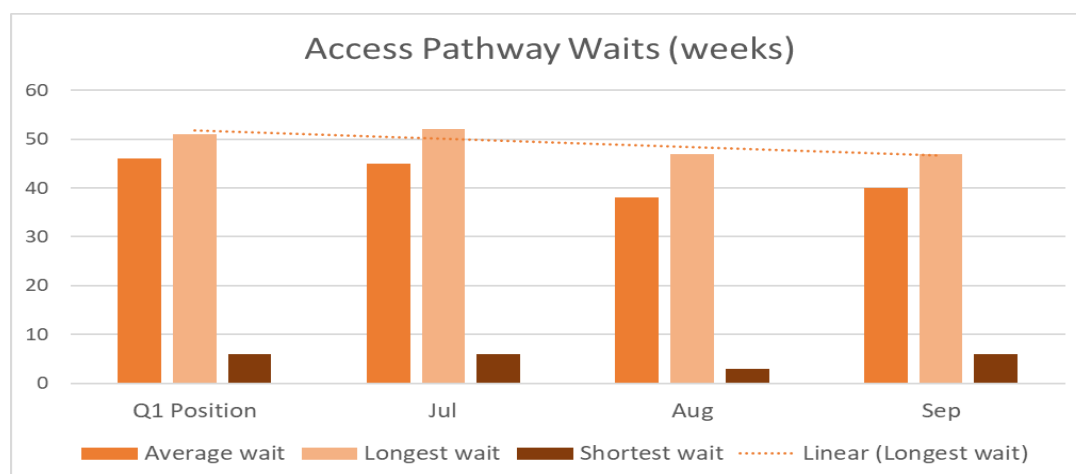


Table 1: Access Pathway Waiting Times from referral to screen/ triage (over 5s)

Waiting	Baseline Q1 (April-June)	September 2023
Average wait from referral to screen/ triage	46	40
Longest wait from referral to screen/ triage	51	47
Shortest wait from referral to screen/ triage	6	6

Next issue we will tell you more about what we have been working on with the Early Years Team.

Working with our Partners on Specialist Assessments

To reduce the number of children waiting for an autism assessment NAViGO CAMHS (Young Minds Matter) have begun to work alongside an external provider to support with the number of children waiting. The provider is The Owl Centre.

The ASD assessments carried out by The Owl Centre complies fully with the NICE guidelines (National Institute for Clinical Excellence). The Owl Centre is a recognised private provider commissioned by the NHS and is also registered with the Care Quality Commission.

The assessment will include pre-assessment questionnaires to be completed by parents/carers and school; a structured developmental history completed remotely with parents/carers; and a face-to-face clinical assessment and observation with your child. The appointment will be face to face and held at the Young Minds Matter offices in Freshney Green Primary Care Centre, Grimsby, during a weekend clinic. This process usually takes approximately 6-8 weeks.

The Owl Centre will be provided with all relevant information already gathered about a CYP. This may include the Access Pathway referral form, reports/correspondence from other agencies (such as Educational Psychology and Paediatrics), and any additional information NAViGO CAMHS (Young Minds Matter) may have already gathered (such as ASD specific information from school).

What can you do to help us?

We must let you know that due to the costs associated with non-attended appointments if you or your child do not attend appointments with The Owl Centre, this could result in a child being placed back on the waiting list with NAViGO CAMHS (Young Minds Matter) for their assessment to be completed.

Please try and keep your appointment and let the assessment provider know if you can't make it. If appointments are attended this can help us to reduce our waiting times and help all children who need seen quicker.

If you have updated your mobile number or email address since your child was referred to the Access Pathway, or since any previous contact with NAViGO CAMHS (Young Minds Matter), please contact The Owl Centre directly to provide up to date contact information.

We continue to work with partners across the Integrated Care System to improve the Neurodiversity Assessment process and are doing everything we can to prioritise seeing children faster. Through initiatives like the Owl Therapy partnership, we want to ensure children can be seen as quickly as is possible. **In the next issue we will share with you how these initiatives are impacting on our waiting times.**

Support for Parent and Carers for CYP with Neurodiverse Needs

As part of the YMM team transferring over to NAViGO, there were a series of engagement opportunities with parent carers and staff. A focused session was held with the parent carers of children of ADHD and the staff that provide this service.

Parent carers wanted to be educated and upskilled in ADHD and to expand their skills and knowledge on how to help their child. Parents wanted to look at ways of reducing medication that their child is or will be taking for the condition.

The MAG service in Sheffield was recommended and so NAViGO reached out to Family Action to fully understand what [MAG had to offer](#).

The project aims to support families of children and young people diagnosed with ADHD by raising knowledge and awareness of the disorder, providing strategies for managing the symptoms associated with ADHD and promoting the individuality and potential for those affected.

MAG is delivered over 7 sessions at 2 hours each. Topics include Introduction to ADHD, Understanding behaviour, Emotional Regulation, Medication, SENDIAS, Sleep hygiene and living with ADHD

Aspirations of the MAG programme

- To upskill and education parent carers
- To reduce the reliance of medication especially Melatonin
- To create peer support networks
- To reduce crisis referrals
- To give children and young people living with ADHD the opportunity to thrive with their condition.
- Behavioural techniques have been widely established as a key component of the treatment for children with ADHD. Upskilling parent carers will teach strategies to change or challenge behaviours and improve the parent carer relationship with their child.

A two day train a trainer course has been held in NEL. In the next issue we will look forward to sharing with you what we are planning to do with this training!

Settings, Parents & Carers for Education (SPACE) Forum

The SPACE Forums are led by Abi Fleming, SEND Parental Engagement Champion (SENDIASS) and Nicola Chappel, Service Manager (ICB) you can read a little about us via this link: [NELC SEND Local Offer | Meet the team - NELC SEND Local Offer \(nelincs.gov.uk\)](#)

For the last two years we have been working with parent carers and schools on an NHS funded project - Autism in Schools [NELC SEND Local Offer | Autism in Schools - NELC SEND Local Offer \(nelincs.gov.uk\)](#). One aspect of this project was the Parents Supporting Parents (PSP) Forums - this was one of the most successful elements of the project. It provided parent carers, school staff and other professionals an opportunity to work in partnership to improve the educational experiences of children/young people (CYP), access training, share good practice and network with people in similar situations (parent carers and professionals). We are pleased to announce that these forums will continued in 2023/24 and we invite all educational settings and parent carers to come and join in!

The SPACE Forums are held monthly on a Tuesday morning (apart from February) at 9.30am - 11.30am at Grimsby Town Hall; 21st November 2023, 16th January 2024, 9th February 2024 (Friday), 19th March 2024, 23rd April 2024, 11th June 2024 and 9th July 2024.

In the next edition we will tell you about the workshop we held this week on Tuesday 17th October where we went through a 6-week programme called Understanding Myself. The programme has been developed specifically for young people who either have a neurodevelopmental diagnosis or are experiencing traits associated with a neurodevelopmental difficulties. The sessions have been designed to help the young people who attend them to understand and be able to communicate their needs. Topics covered include:

- Session 1: Getting to know me
- Session 2: Sensory challenges
- Session 3: Anger and anxiety
- Session 4: The 5-point scale
- Session 5: Self-esteem & positivity
- Session 6: Communication passports

This intervention programme and all its resources are currently being offered to all educational settings within NEL.

Where to go to get information, advice, and guidance?

In this section we will share with you examples of good sources of information and advice. If you find a new service or a resource that would benefit parent carers and professionals in NEL then let us know by emailing nicola.chappel@nhs.net

Find out more about	Who/Where?	What will you find?
SEND Local Offer – provides information for children and young people with SEND and their families.	North East Lincolnshire Council Special Educational Needs and Disabilities (SEND) and Local Offer For more information, visit: NELC SEND Local Offer Home (nelincs.gov.uk)	The Local Offer is the place that provides and directs you to information that will support children and young people aged 0 to 25 years with Special Educational Needs and Disabilities (SEND). If your child does not have SEND but you feel they need support in some part of their development, the information on this website can help.
SEND Parent Engagement Champion	SEND Parent Engagement Champion 01472 323236/ 07552743370 or abi.fleming@nelsendiass.org.uk	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. Coffee Mornings are held, during term time, Monday at Central Children’s Hub 9:30 - 11:30 Thursday at Nunsthorpe Children’s Hub 9:30 -11:30.
Parents Supporting Parents Group	Parents Supporting Parents Group led by Children’s Disability Service. The group is held: Every Monday (term time only) at Central Family Hub from 9:30 - 11:30. Every Thursday (term time only) at Nunsthorpe and Bradley Park Family Hub from 12:00 - 2:00.	The group provides an opportunity parents and carers of children and young people with any additional need to come together with a group of likeminded parent carers and share their experiences in a safe and understanding space. They will offer support, advice, signpost to services and give parent carers the respect and the time to talk.
SEND Parent carer voice	North East Lincolnshire Parent Carer Forum (NELPCF) 01472 242277 or info@nelpcf.org.uk Facebook: North East Lincolnshire Parent Carer Forum Grimsby Facebook	NELPCF are a group of parent carers passionate about driving positive change. Making your voice heard. For more information on NELPCF see NEL Local Offer: NELC SEND Local Offer North East Lincolnshire Parent Carer Forum (NELPCF) - NELC SEND Local Offer (nelincs.gov.uk)
Support as a carer	Carers’ Support Centre 01472 242277	The Carers’ Support Service is the main port of call for Carers in Northern Lincolnshire. There is a range of free and confidential practical and emotional support on offer. The full offer of support that is available is on their website. Carers Support Service

Parental Training and Workshops

Please visit the local offer [Events and Training](#) for further training opportunities

<p>Workshops for Parents and Carers :: NAViGO (navigocare.co.uk) workshops to help increase their understanding of mental health issues and build confidence in supporting children and young people in the family home.</p> <p>These are totally free of charge, online and able to be taken at a time that suits you.</p>	<p>Includes topics such as</p> <ul style="list-style-type: none"> - ADHD - Autism - Anxiety - Health Anxiety - Social Anxiety
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<p>MindEd For Families</p>	<p>Some topics include:</p> <ul style="list-style-type: none"> • Anger & Aggression
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<p>Free learning resource about the mental health of children, young people and older adults. Brief introductions to common issues and problems and it will then direct you to more detailed sessions of learning elsewhere in the MindEd portal MindEd For Families</p>	<ul style="list-style-type: none"> • Autism Spectrum Disorders Feelings & Emotions • Poor Concentration & Over-Activity • Sleep Difficulties • Tics & Twitches • Wetting & Soiling
<p>Workshops Contact Workshop topics include:</p> <ul style="list-style-type: none"> • New! Speech Language and Communication • Money Matters – for parents/carers of children aged up to 16 with additional needs 	<ul style="list-style-type: none"> • Encouraging Positive Behaviour in children aged up to 16 • Educational support for school age children with additional needs in England • Helping your child (aged up to 16) sleep • Growing up workshops • Handling meetings: for parents/carers

Would you like to get involved?

We would like to encourage further engagement and participation with system partners, CYP, parents and carers to help shape service changes. Please feel free to come along to one of the below events by registering your interest. ***We look forward to seeing you.***

Event	Who is it for?	When is it?	How do I get involved?
Wybers Wood Academy	Parent carers of children and young people who attend this school	Monday 13 th November 2-3:15 Wybers Wood Academy	Come along to the event if your CYP attends this school
ND Team Referral presentation to the SPACE (Settings, Parent and Carers for Education) Forum	All Educational Setting staff/SENCOs and Parent Carers	Tuesday 21 st November 9.30am - 11.30am Grimsby Town Hall	For this session you will need to register your interest to attend by using the following link: https://forms.office.com/e/FFxm5vPj0G

END OF UPDATE