

NORTH LINCOLNSHIRE COUNCIL

Health and Wellbeing Board

Neurodiversity Update on Pathway

1. OBJECT AND KEY POINTS IN THIS REPORT

This report provides an update to the Health and Wellbeing Board on progress and developments relating to children's neurodiversity in North Lincolnshire. The paper explains current diagnostic demands and describes the actions being taken to address this, whilst highlighting how the increase in children being diagnosed as neurodiverse requires a whole-system response, to ensure children and families needs are met.

2. BACKGROUND INFORMATION

Neurodiversity has been identified as a priority area for North Lincolnshire's Integrated Children's Trust (ICT) and the Special Education Needs Disability (SEND) standards board, due to the increased number of requests to assess North Lincolnshire children, over recent years. Children who are neurodiverse receive support from a wide range of education, social, health and voluntary services, to meet their identified needs.

2.1 Neurodiversity as a Concept of Celebrating Differences.

"Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no "right" way of thinking, learning and behaving, and differences are not viewed as 'deficits'".

Over recent years, in North Lincolnshire, there has been a push to move away from the concept of viewing neurodiversity as deficit model/ concept, to one which celebrates differences. This fundamental shift in vision has been a guiding principle for all partners work with children who are neurodiverse. Complimenting this is the vision that all services and agencies should be supporting a children's needs, according to their presenting needs, irrespective of a diagnosis. As such, in North Lincolnshire, all services and support should be accessed based on need and not diagnosis, enabling children and young people to receive the support they need regardless of whether they have received a diagnosis.

2.2 Children Aged Under 5 Years Old

For children aged under 5, Autism assessments are currently delivered through a multi-agency model of Speech and Language Therapists (NLaG) and Clinical Psychology (RDaSH). An additional senior Clinical Psychologist has been appointed (although not yet commenced in post), providing additional capacity and enhanced clinical leadership to the under 5's pathway. Referrals for the pathway are received through an Early Years Triage panel, whereby there is a joint multi-agency decision to assess. This process also enables all agencies to explore how local services are meeting the child and families identified needs and mobilise any additional support the child, family or education setting, may require.

Currently 53 children, aged under 5, are waiting for a full Autism assessment, with the longest wait being 15 months. All children on the pathway are receiving support services, including active Speech and Language involvement, and being supported by the co-ordinator of the service. With the additional capacity into the pathway, and improvements that have already been made in productivity, it is anticipated that waiting times will be significantly improved when the role starts.

2.3 Children and Young People Aged over 5 Years.

For children aged over 5 years, in North Lincolnshire, RDaSH is commissioned to provide the diagnosis assessment pathway.

In 2020 a more integrated assessment pathway was implemented, with greater emphasis on joint working between Children and Adolescent Mental Health Service (CAMHS) and local authority children support services, including Autism Spectrum Education Team (ASET), Behavioural Support Services and Education Psychology. This co-ordinated approach enables a thorough triage of a child/ young person's presenting needs and allows key service areas to offer the required interventions / support, whilst waiting for a diagnosis. Subsequently a revised referral system for assessments was launched, placing schools at the heart of the referral process - however also creating the flexibility for other services to refer (for example GP's and Paediatricians), if required. This process has gone well and with an average diagnosis rate of 90%, indicates that the current referral process is identifying the correct children and young people requiring an assessment.

Following this initial triage stage of the assessment process - where partners, schools and parents are consulted, a plan of support is recommended for each child or young person, based on need. This initial element of the assessment is prioritised by the CAMHS service, with 60% of families receiving the initial triage assessment in 2 weeks and 90% in 18 weeks – please note that any longer waits are normally due to families not wanting to engage or consent being difficult to obtain from the family or young person.

To support all families waiting for a full assessment, the CAMHS service provide open telephone access to parents for any required support and schools benefit from a weekly virtual clinic from the Psychology team, whereby they can book an appointment to gain advice on supporting any of their pupils – including how to support children waiting for a full assessment. To further support families both pre- and post-diagnosis, a Neurodiversity Support Worker is currently being advertised to work within CAMHS.

2.4 Waiting List Numbers

Following the initial triage assessments, a full Neurodevelopmental assessment is completed by CAMHS, which comprises of an in-depth differential diagnosis assessment, in line with the National Institute of Clinical Excellence (NICE) guidelines and involving a multicomponent assessment process including, but not exhaustive to: family meetings, one-to-assessments/clinic appointments, engagement with schools, observations in the schools environment, psychometric tests etc. Unfortunately, due to the increase demand for the service and the impact of COVID, there is a wait for these assessments, with the latest data indicating that 287 children between the ages of 5-18 years are currently waiting for a full assessment, with data from January 2023 indicating that the average waiting time from initial referral to the start of a full assessment was 46 weeks (please note all these children have had an initial assessment) with longest wait being 87 weeks.

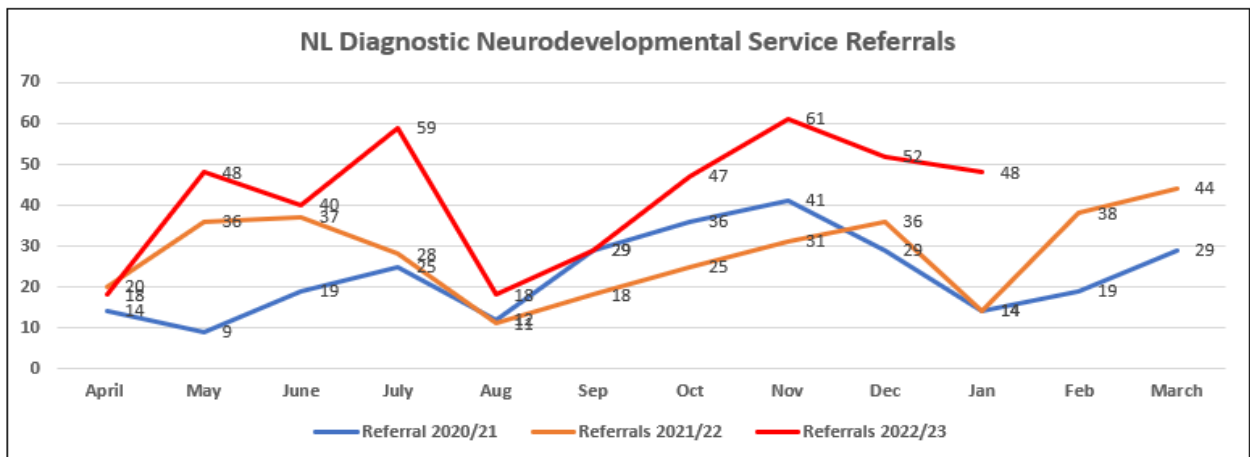
To support a reduction in waiting times a variety of waiting list initiatives have, or are being implemented, including:

- The commissioning of additional capacity within CAMHS
- The subcontracting of the company, Healios to provide 142 additional assessments in 2022 – with a further 114 assessments commissioned from December 2022, to be completed over the next 6-months.
- Plans to commission another 139 assessments from an external company, with the aim start to commence these assessments in March 2023.

With these two additional subcontracts, 281 assessments aim to be achieved over the next 6 months, in addition to the assessments being conducted by RDaSH. With these two sub-contracts and the work of RDaSH, it is anticipated that in the majority of the 287 children waiting for a full assessment, will have had their assessment commenced and the waiting list reduced significantly, in line with the 18-week ambition.

2.5 Demand for Neurodiversity Assessments – 5 – 18 years

Referrals numbers are monitored weekly and reported back the Integrated Care Board (ICB) monthly. The below graph provides a pictorial representation of referral trends since 2020 identifying an increase in referral numbers, with 224 referrals being made in 2020/21, 375 referrals in 2021/22 and 383 in 2022/23, between the months of April 2022- Jan 2023. Unfortunately, there are no regional or national comparative figures to accurately compare these against, however comparison with other trusts across the ICB identified a similar increase in referrals.



The above chart demonstrates the significant variation in monthly referral numbers in which monthly monitoring is starting to identify trends in children being identified as requiring an assessment, each year. Based on an average diagnostic rate is 90.3 % (calculated on diagnostic rates between April 2022 and January 2023). These figures illustrate an increase in children being identified as being Neurodiverse in North Lincolnshire, and in turn a predicted increase in prevalence which will require all services across health, education and social care, to be responsive to this increased level of need.

2.6 CAMHS Service Inclusion Project / Evaluation

To support the ongoing development and review of the assessment and support pathway, CAMHS have embarked on a Service Inclusion Project, which aims to understand children, young people, parents and professionals experience of the local diagnosis process, including the support they received post-diagnosis. Interviews are currently underway and the project outcomes are expected by the end of April. Initial feedback is that the project has been received extremely positively by children, young people, and their families, with SENCO's also showing keen engagement in the project too. The findings of this work will inform the further development of the diagnostic pathway and help to inform what support families feel they need from all agencies before, during and after the diagnosis pathway.

2.7 Adults aged 18-25 years

All adults aged 18-25 have access to adult support and diagnostic services and pathway.

Young adults with ADHD are transitioned from the NLAG Paediatric pathway to the RDASH ADHD service if they require ongoing support and medication management. Any young adults requiring ADHD assessment, are referred to the Adult ADHD service. To help with long waits, NAVIGO have recently been commissioned to provide assessments for adults with the longest waits. Latest performance figures from RDASH identify that all adults currently on an internal waiting list for ADHD have been waiting under 12 months. Unfortunately, we are unable to identify from the data how many of these adults are aged under 25.

Matthews' Hub is a voluntary sector organisation and has been commissioned by North Lincolnshire Health and Care Partnership to provide support and information to all adults and young people aged over 14, around Autism, irrespective as to whether a diagnosis has been received. To date, the service has been able to support over 200 people. Care Plus Group has recently been commissioned to assess 34 adults for Autism, in which there was a 67% diagnostic rate. Of these adults who were assessed none wished to engage in the post-

diagnostic support offered by Care Plus Group. Under the NHS 'Right to Choose' policy, adults can choose where they would like an Autism assessment and we have seen an increase in adults accessing assessment from a number of different providers.

2.8 Partnership Working and Support for Children and Families on The Pathway

When the pathway was first launched, partnership working practises were identified as key to the success of the pathway. As previously described the current pathway operates a multi-disciplinary decision-making forum including CAMHS, ASSET, Behavioural Support and Education Psychology. In 2021/2022 the local partners developed an ambition for how they would work together, setting a number of priorities both. In January 2023, partners agreed integration ambitions and joint planning aspirations. Acknowledging that the increase in number of children being diagnosed requires a whole system response across health, education and social care, senior leads are now looking to initiate a dedicated project, with the appropriate project capacity, to develop a whole system response to ensuring the needs of our children and young people are being met.

3. OPTIONS FOR CONSIDERATION

N/A

4. ANALYSIS OF OPTIONS

N/A

5. FINANCIAL AND OTHER RESOURCE IMPLICATIONS (e.g. LEGAL, HR, PROPERTY, IT, COMMUNICATIONS etc.)

N/A

6. OTHER RELEVANT IMPLICATIONS (e.g. CRIME AND DISORDER, EQUALITIES, COUNCIL PLAN, ENVIRONMENTAL, RISK etc.)

N/A

7. OUTCOMES OF INTEGRATED IMPACT ASSESSMENT (IF APPLICABLE)

N/A

8. OUTCOMES OF CONSULTATION AND CONFLICTS OF INTERESTS DECLARED

N/A

9. RECOMMENDATIONS

The Health and Wellbeing Board is recommended to accept and note this report.

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