

**AGENDA ITEM**

**REPORT TO HEALTH  
AND WELLBEING  
BOARD**

**20 OCTOBER 2021**

**REPORT OF:  
Alex Sinclair - Director  
of Commissioning, NHS  
Tees Valley CCG**

**NEEDS LED NEURODEVELOPMENTAL PATHWAY FOR CHILDREN & YOUNG PEOPLE**

**1. PURPOSE OF REPORT**

1.1 To provide a final update to HWBB on the Neurodevelopmental Needs Led pathway.

**2. BACKGROUND**

2.1 As previously reported to the Health & Wellbeing Board, there has been considerable partnership activity between Tees Valley CCG, Tees, Esk and Wear Valley (TEWV), North Tees & Hartlepool Foundation Trust (NTHFT), Stockton-on-Tees Borough Council, Hartlepool Borough Council, and the Parent Carer Forums to improve the Autism Spectrum Disorder (ASD) pathway for children & young people.

2.2 The report presented to HWBB in February 2021 outlined the changes which had been implemented to improve waiting times and expand the support which families could access to meet the needs of their child.

2.3 The over 5 years Needs Led Neurodevelopmental Pathway went live in September 2020 with the under 5 years pathway mobilising in April 2021. Both pathways have been impacted by the Covid-19 pandemic, as an aspect of the assessment process for diagnosis is required to be undertaken face-to-face (and this was paused nationally for a period of time).

2.4 This report reflects on the first 6 months of the over 5 years pathway and provides an update around the implementation and early reflections of the under 5 years pathway.

**3. Review of first 6 months the over 5 years pathway**

3.1 There were 175 referrals during the first 6 months of the pathway being live. Figure 1 below, highlights the breakdown of referrals which were seen during this period.

Referrals started off low due to schools being closed and a national pause on face-face assessments.

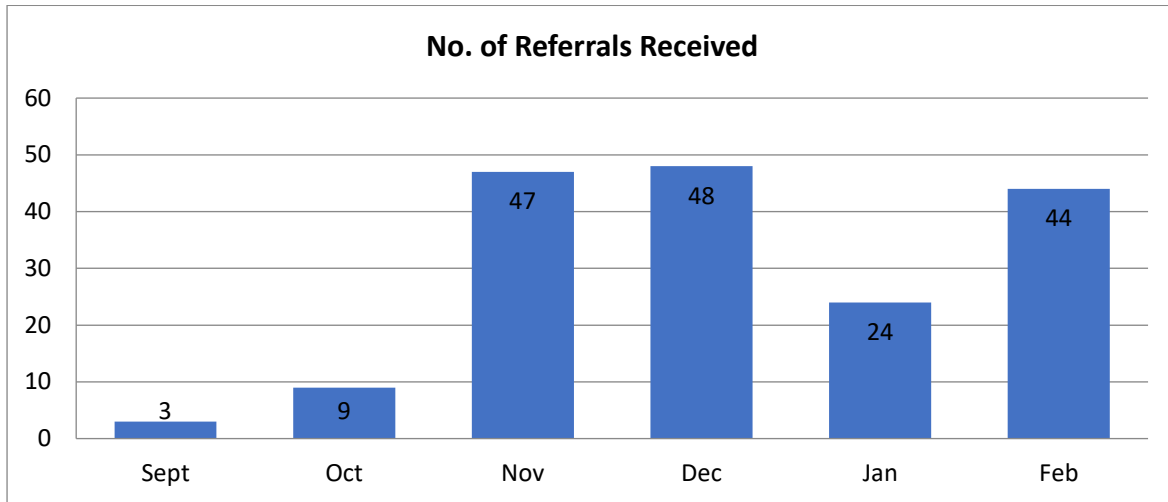


Figure 1 – Referrals September 2020 to February 2021 for the over 5's pathway

- 3.2 The model was built on receiving an average of 30 referrals a month. Consequently, these higher number of referrals have led to a position of 60 children waiting for their referral to be triaged as of February 2021. We are working as a system to review this position, as since February 2021 referrals have continued to be higher than the planned trajectory.
- 3.3 During September 2020 to February 2021 the triage process has identified 45% of referrals were not referred onto the specialist pathway. This was because, although the child had needs, they were not needs associated with ASD. This, combined with the multi-agency approach and valuable information from Local Authority systems, allows for families to be signposted to more appropriate support. For example, a high proportion of the 45% not referred to the specialist pathway were children who came from a family where there was a history of domestic violence and it was determined that their needs were behaviour traits of a child who had been subjected to trauma, adversity or had attachment issues.
- 3.4 Utilising this information strategically, we are then able to review the pathways which exist into other services and make changes to enhance the Neurodevelopmental Bubble of Support – further details are included later in this report.
- 3.5 The number of children referred to the Multi Agency Assessment Team (MAAT) for potential diagnosis, has increased steadily over the 6-month period (September 2020 – February 2021) as shown in Figure 2.

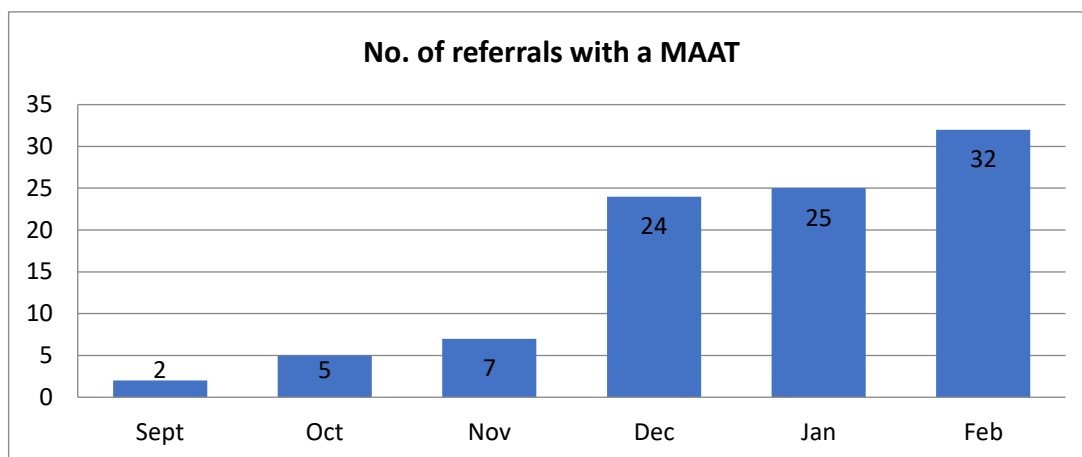


Figure 2 – Number of MAAT's carried out between September 2020 and February 2021

3.6 Since September 2020, TEWV are contracted to provide 24 Multi-Agency Assessments a month, which is double that previously contracted for. However, the pandemic impacted on the number of children being discussed by the Multi Agency Assessment Team (MAAT) between September 2020 and November 2020.

From the 95 children who received a Multi-Agency Assessment, 65 received a diagnosis of ASD. These children were referred via the previous non-needs led model with a diagnosis rate of 68%. The levels of ASD diagnosis via the new needs led neurodevelopmental model will be assessed once we have 12 months of data, whereby we anticipate the diagnosis rate will have significantly increased.

3.7 Partner organisation feedback was gathered as part of the review and although it is acknowledged there were some initial teething problems, in terms of embedding processes and ensuring parents received the necessary communication, the pathway is now receiving favourable feedback. The extract below is from the Co-Chair of Stockton Parent Carer Forum:

*'One of the major areas of change has been the introduction of the Neurodevelopment pathway since September 2020. As a forum we have expressed the importance of communication with parents around this. This has resulted in the production of easy-to-understand information and a direct link with the neuro team with a telephone number and a newsletter too.*

*Areas of concern had been previously raised, especially around communication and information sharing, but we have seen action and progress in moving towards a resolution.*

*In turn we have seen a much more settled response from parents compared to those on the previous pathway prior to September 2020, with evidence showing that parents understand the diagnostic process and how to access this. This is seen by parents sharing the CCG/TEWV pathway information as a point of reference and the telephone number to enable parent/carers to make direct contact to get concerns answered quickly (There is an element of empowerment and responsibility taking, for parents, linked to this).*

*Since September 2020 we have not heard one piece of negative feedback regarding the over 5's Neurodevelopment pathway from those parents currently on it- in fact those parents are now sharing their positive reflections which is a refreshing change.'*

- 3.8 From a Local Authority perspective we are aware that there has been resistance from some schools in relation to completion of the referral form, as they perceived other professionals were relying on the schools to complete the form. We have subsequently worked with services such as Speech and Language, Occupational Therapy and 0-19 teams to ensure they are also making the referrals and not solely relying on schools to carry out this role.

We will be meeting shortly with school SENCOs to deliver training and listen to their views.

Local Authority feedback also highlighted that sometimes the triage panel paperwork is not coming through in a timely enough manner. They also requested that the consent section on the referral form is amended to enable the panel to make referrals direct into a service e.g. Early Help, rather than the current process which signposts the family and the person who made the referral to services which can meet the child's needs. It was felt by being able to make referrals direct to services, we would get more take up. TEWV are currently exploring amendment of the consent form to potentially allow the panel to refer directly into support services.

Both the Parent Carer Forums and the Local Authorities have requested we review the impact of the Bubble of Support, as feedback has highlighted that only a limited number of parents and professionals are accessing services prior to referral. We have commenced this piece of work and are taking a multi-faceted approach by working with the CCG Communications team, Parent Carer Forums, Local Authorities and liaising with St Helen's Neurodevelopmental Team and Commissioners to gain an insight into how they have encouraged families to access support prior to seeking or waiting for a diagnosis.

#### **4. Under 5 pathway - Implementation**

- 4.1 The co-ordination and management of the under 5 years pathway transferred from TEWV to North Tees & Hartlepool Foundation Trust (NTHFT) in April 2021. Due to some recruitment delays the triage process was not established until May 2021; however, this service now runs effectively with representation from Speech & Language, 0-19 Service, Early Years education team and Paediatrics. The process has replicated that of the over 5 years pathway where families are signposted to the Bubble of Support services whilst waiting for the ASD assessment to commence.
- 4.2 Although too early to complete a full-service review, we can report that additional investment and reshaping of services is enabling approximately 20 children from Stockton to be discussed in triage per month. The waiting time for the referral to be triaged is approximately 4 weeks, with time to assessment by the Multi-Agency assessment team being approximately 10 months. Work has been carried out with the Parent Carer Forums to review communication and develop information packs for parents at the triage stage to encourage access to support services.

## 5.0 Lessons Learnt

- 5.1 The introduction of the new service model for the over 5's from September 2020 has been well received with agencies working well together with a greater sense of communication and engagement with families.

As highlighted, the number of new referrals continues to rise and the number of children waiting to be discussed at triage, and the waiting time for this, has been further impacted by legacy referrals being transferred to the Neurodevelopmental Team from Child & Adolescent Mental Health Service (CAMHS). The triage panel is effective and works well; however, the resource for this and joint assessments are currently insufficient to meet demand.

Whilst capacity to undertake triage has been increased as an interim measure to respond to demand (including triage covering Attention Deficit Hyperactivity Disorder (ADHD) from February 2021), any changes to increase triage capacity has an automatic impact on the rest of the pathway as staff resource is moved to meet the immediate pressures. These short-term fixes are unsustainable and we are currently exploring the options to sustainably meet the increased demand and further understand the reasons for referrals not being referred to the specialist pathway. Although these children have needs which are being represented in the referral form, they are not needs which require a formal diagnosis and therefore work needs to be done with the wider system to understand why these needs are not being proactively met.

The evaluation with 12 months data will provide a clearer picture of the position and impact of the revised service model.

- 5.2 We have however already convened as a partnership to review the triage process and determine how sustainability can be achieved and how further improvements can be made. In addition, the North Tees Oversight Group continues to meet monthly to oversee progress.
- 5.3 As mentioned earlier in the report, the strategic intelligence which we are now able to access through the triage process is enabling us to improve the services which are linked into the Bubble of Support. For example, we are in discussions with the Mental Health & Learning Disability Partnership (MHLDP) to enable the triage panel to refer children direct into the 'Children & Young People Improving Access to Psychological Therapy' (CYPIAPT) providers who could support them with low level anxiety.
- 5.4 We have also utilised this information to inform a successful bid to NHSE to further improve the needs led neurodevelopmental pathway. We have been awarded 12 months additional funding to align Occupational Therapy to the triage process and to enable sensory programmes to be developed for under 4's and over 12's (as we already have the Sunflower programme for 4–12-year-olds). We will then have a substantial sensory offer for all young people, without the need for a diagnosis. Additionally, the funding, awarded by NHSE will be used to develop an offer for children who have experienced trauma. We recognise that this is a system gap and a development which will be worked through with our Parent Carer Forum and Local Authority partners.

## **6.0 Next Steps**

6.1 The North Tees Oversight Group will continue to monitor progress against the following actions:

- Multi-agency planning to the promotion of the Bubble of Support
- Review and monitoring of the triage process
- Implementation of the Occupational Therapy and Trauma offer and associated outcomes (12-month pilot)
- A review of 12-months of data from TEWV and the CCG will be presented to the SEND Strategic Group in due course along with further information relating to the Under 5 pathway.

## **RECOMMENDATIONS**

The Health & Wellbeing Board is asked to:

- Acknowledge the work undertaken to date
- Continue to support the 'needs led' approach
- Enable the work to be monitored through the SEND Strategic Group

## **FINANCIAL IMPLICATIONS**

N/A

## **LEGAL IMPLICATIONS**

N/A

## **RISK ASSESSMENT**

N/A

## **COMMUNITY IMPACT IMPLICATIONS**

N/A

## **CONSULTATION, INCLUDING WARD/COUNCILLORS**

N/A

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