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| Meeting Date | 27th July 2021 | | Agenda Item | 2.2 |
| Report Title | Position Update Neurodevelopment Service | | | |
| Report Author | Michelle Mason-Gawne/Kathryn Ellis | | | |
| Report Sponsor | Jan Worthing | | | |
| Presented by | Michelle Mason-Gawne/Kathryn Ellis | | | |
| Freedom of Information | Open | | | |
| Purpose of the Report | The purpose of this report is to provide a further update on the performance position of the Neurodevelopmental Service, Childrens Services since presentation at Performance and Finance committee in April 2021. | | | |
| Key Issues | The key points of this paper are to provide an update on progress of service delivery including demand and capacity issues related to performance. | | | |
| Specific Action Required <i>(please choose one only)</i> | Information | Discussion | Assurance | Approval |
| | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| Recommendations | <p>Members are asked to:</p> <ul style="list-style-type: none"> • NOTE the current Neurodevelopment Service position, the actions taken to increase capacity to date, and to seek support for the further actions identified necessary to build a sustainable service, reduce waiting times and improve performance. | | | |

Neurodevelopmental Disorders Service Position Statement

Childrens & Young People Division

1. INTRODUCTION

The purpose of this paper is to provide a position statement of the Neurodevelopmental Disorder service.

2. BACKGROUND

The Neurodevelopmental Disorders (ND) team was established in November 2017, and since then, the team has aimed to provide a robust and equitable service to children and young people requiring an assessment of Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) or both.

Performance has been significantly impacted upon by the large demand on the service, and limited capacity. Subsequently, the ND team received funding, in 2019, to support the expansion of this specialist team with an aim of increasing capacity to meet demand. This funding has now been confirmed as recurrent in support of the service need. Due to the specialist nature of the service, recruiting into these posts has taken considerable time to deliver.

A detailed paper was provided to the Committee in April 2021 outlining the background to the Neurodevelopmental Service, and the ongoing increase in demand causing insufficient capacity to meet the unreported Referral to Treatment waiting times.

3. CURRENT POSITION

3.1 Referrals

Referral rates have been steady over recent months but there is an expected rise in month to date, as schools submit all outstanding referrals before their six week summer break.

The type of referrals received by the ND team continue to vary, with the primary reason for referral being ASD. The referral variance provided gives evidence as to the importance of recruiting the appropriate skill mix within the team, as each diagnosis (ASD, ADHD or Dual) will require a different skill mix and a variable appointment pathway. 'Dual' are those children who will be assessed for both ASD and ADHD simultaneously - the coding of these patients on the waiting list has now been reviewed as part of the planned validation of the waiting list to ensure there are no duplicate entries and to enable a more specific profile of demand which will in turn, inform capacity planning.

3.2 Capacity

The ND team continue to be dedicated to continuously strive to review their capacity, in order to ensure each clinician's time is maximised. They have continued to operate within an altered capacity throughout the pandemic whilst some Health Boards have not been able to deliver their activity.

The team successfully appointed an additional Clinical Nurse Specialist (0.8WTE) and two Specialist Speech and Language Therapists (1.6wte, of which 0.6 wte is a replacement post of a leaver). The new staff joined the team throughout February 2021 to April 2021, the period of induction has now been completed and they have now integrated into the team well which has contributed to increased delivery of activity from capacity of 21 assessment appointment January 2021, to an increase to a minimum of 38 assessment appointments currently.

The ND team continue to revise their capacity plan adopting a Prudent Healthcare approach, whereby the workforce have been organised around the specific skills of each member of the team i.e. “only do what you can do” principle. Following initial review, together with these recent new appointments, there is now a noticeable increase to the team’s capacity due to the team’s continuous efforts.

Additional Waiting List Initiatives have been utilised where possible but these have been limited and dependent on clinician availability. Training in waiting list management and capacity planning continues to progress, together with refining referral pathways and processes.

The Clinical Lead has held discussions with CAMHS regarding additional Consultant hours to replace capacity lost due to retirements. This has resulted in an agreement to create an additional shared post with 0.5 capacity for ND assessments from baseline funding. The post has now been approved at Vacancy Control Panel and recruitment can be progressed to advert.

It was hoped that the ND service could have secured further additional funding in May through the Welsh Government CAMHS funding stream. Unfortunately, the criteria for applications was specifically restricted to Specialist CAMHS services, e.g. crisis, eating disorders, inpatient services. ND were not eligible to apply or secure funding. A business case will be developed to highlight the requirement to increase capacity further and secure a funding source.

With further funding, recruitment to further Band 7 posts would increase capacity to take cases off the waiting list for ASD assessments. They would function in the same way as the existing workforce with all work delegated by the Clinical Lead as named diagnostician.

3.3 Waiting times

The increased demand on service, together with impact from Covid pandemic, has resulted in continued long waiting times for this service. However, there are some small improvements being achieved. Table 1 demonstrates the waiting list position as at 31st March 2021.

Table 1

| Pathway type | < 11 weeks | 12 - 17 wks. | 18 - 25 wks. | 26 - 35 wks. | 36 - 51 wks. | > 52 weeks | Grand total |
|--------------------|------------|--------------|--------------|--------------|--------------|------------|-------------|
| ADHD | 68 | 16 | 43 | 15 | 26 | 152 | 320 |
| ASD | 87 | 24 | 44 | 49 | 64 | 341 | 609 |
| Grand Total | 155 | 40 | 87 | 64 | 90 | 493 | 929 |

Table 2 demonstrates the waiting list position as at 14th July 2021 (mid-month report).

Table 2

| Pathway type | < 11 weeks | 12 - 17 wks. | 18 - 25 wks. | 26 - 35 wks. | 36 - 51 wks. | > 52 weeks | Grand total |
|--------------------|------------|--------------|--------------|--------------|--------------|------------|-------------|
| ADHD | 86 | 22 | 13 | 30 | 13 | 92 | 256 |
| ASD | 119 | 20 | 36 | 31 | 59 | 272 | 537 |
| Dual diagnosis | 0 | 3 | 10 | 10 | 8 | 54 | 85 |
| Grand Total | 205 | 45 | 59 | 71 | 80 | 418 | 878 |

Through increasing capacity and validation of waiting list, July’s waiting list position shows 569 patients waiting over 26 weeks compared to 647 in March 2021, a reduction of 78 patients listed.

Of the overall waiting list, 10% of patients waiting account for the Cwm Taf Morgannwg Health Board cohort of patients, which the ND team continue to provide support as part of the ongoing Service Level Agreement (SLA). These are specifically young people of secondary school age who are waiting for an assessment for Autism Spectrum Disorder. If the team were to serve notice, this would release much needed capacity within the service but this would create a cost pressure as no posts could be released with this disaggregation. There has been recent indication on an informal basis from CTMHB that they have confirmed their intention to give notice to terminate the SLA by the end of March 2022. The service would like to work with Cwm Taf Morgannwg Health Board in the future to repatriate patients which currently equates to 118 patients.

4. RISKS

As within any team in the current climate, the impact of Covid on the team has been a significant risk, both to staff members and due to the current restrictions in place. There are also risks associated with a long-term absence/HR issue, which is in the process of being resolved.

The lack of service sustainability has been included on the risk register since October 2018, with a risk score of 16 for demand on the service and the limited capacity available. The size of the team is small, highly specialist, and is therefore sensitive to normal periods of leave, which have a direct impact on performance.

More recently, a risk has been identified with transition for children and young people to the Integrated Autism Services (IAS) as they approach their 18th birthday. Currently IAS only accept new referrals from 17;9 years. If young people are already on our ND waiting list, we cannot transfer them because they would join the bottom of the IAS list. Any time served on our ND waiting list is not counted. This means ND must expedite their assessment before they turn 18 years because ND is a Children's Service whose staff are not qualified to assess adults. This leads to waiting list management risks with patients appointed out of chronological order.

The service is now experiencing an additional clinical risk associated with a sharp rise in mental health comorbidity for all ND cases, and face clinical risks with these, now adult patients, within Children's Services workforce. The service aims to expedite these patients in order to complete their six month assessment process before their 18th birthday. We now have clear, high level principles from WG regarding waiting list transfers from ND to IAS/Adult services. This was sent in April by Dr. Williams, Senior Medical Officer for Welsh Government. Operational processes are now under review, in partnership with all stakeholders.

It is important to note that there are considerable mandatory training requirements for all staff within a multiagency regional response to new Additional Learning Needs Education Tribunal legislation (ALNET). In May 2021, this resulted in a 20% reduction in initial assessment capacity. This could impact on capacity for initial assessments until at least the end of this year.

5. ASSURANCE

It is important to note again, that the appointment of the Clinical Lead has increased diagnostic capacity and implemented a clear governance structure with quality assurance which was not present previously. Every case receives standardised clinical care at every stage. Assessments are evidence based using DSM-5, the international diagnostic criteria. The service meets all six of the All Wales Neurodevelopmental Disorders standards, and clinical practice reflects NICE guidelines for ASD (NICE CG 128) and ADHD (NICE NG 87).

The waiting times and lack of sustainable capacity remain a concern for the clinical staff, however, where they are concerned that a specific patient requires expediting, this is discussed and agreed as a multi-disciplinary team and actions taken to ensure all patients remain as safe as possible whilst waiting for their initial assessment.

The service applies Prudent Healthcare principles with a robust model of delegated care from senior practitioners, with a named Doctor or Advanced Practitioner as the diagnostician. Every case is discussed in full detail, in order to reach diagnostic consensus. This model ensures an efficient, safe flow through each assessment stage, within the All Wales Delegation Framework. Family and Friends feedback confirms that parents/carers feel they have been listened to and are satisfied with their care.

The clinical team are committed to exploring further solutions, including further benchmarking of services at every opportunity, together with working and striving to improve the current position in order to reduce the waiting times for the patients.

Additional support was made available to every Health Board from NHS Wales Delivery Unit in the form of demand and capacity training. As planned, the Clinical Lead has participated in the first stage of the independent review into demand, capacity and design of Neurodevelopmental services commissioned by Welsh Government. They are currently planning for the second stage of the ND Demand, Capacity and Design Review which will identify priorities for action and identify two options for a national ND service that would improve and maximise the timeliness and quality of services – one of which could be achieved within the existing budget and another which could be achieved with an increased budget. Due to service pressures, further implementation of these processes have been delayed and will take place in the autumn.

6. NEXT STEPS

A number of key steps have been highlighted and agreed for the next 6 months, which include:

- Continue to take opportunity to further redesign pathway in line the independent national review with National guidance and standards;
- Progress further work to understand the true release of clinical time should notice be given on SLA with CTM HB, including analysis of impact on both services;
- Appoint substantively to the remaining Consultant hours in order to step increase capacity by the end of 2021;
- Demand and capacity planning review with senior managers October 2021;
- Secure further additional funding to close capacity gap through progression of full business case.

7. RECOMMENDATION

The Performance and Finance Committee are asked to note the current Neurodevelopmental Disorders Service position, the actions taken to increase capacity to date and support further actions necessary to build a sustainable service.