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Bae Abertawe
Swansea Bay University
Health Board



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| Meeting Date | 23 February 2023 | Agenda Item | 4.2 |
| Report Title | Position Update Neurodevelopment Disorder Service | | |
| Report Author | Michelle Mason-Gawne, CYP Divisional Manager, Kathryn Ellis, Clinical Lead ND service | | |
| Report Sponsor | Jan Worthing, Service Group Director, NPTSSG | | |
| Report Presenter | Sue Kotrzuba, Assistant Divisional Manager, CYP Division | | |
| Freedom of Information | Open | | |
| Purpose of the Report | The purpose of this paper is to provide an updated position statement of the Neurodevelopmental Disorder service as at 31 January 2023. | | |
| Key Issues | <p>The key points of this paper are:</p> <ul style="list-style-type: none"> • the current waiting times, • increased rate of referrals • interim actions being taken whilst awaiting the Welsh government funding to improve services to children waiting • impact of the CTMUHB (Cwm Taf Morgannwg University Health Board) SLA (service level agreement) disaggregation | | |
| Specific Action Required <i>(please choose one only)</i> | Information | Discussion | Assurance |
| | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Recommendations | Please note the current Neurodevelopmental Disorders Service position and next steps. | | |

Neurodevelopmental Disorders Service Position Statement Childrens & Young People Division

1. INTRODUCTION

The purpose of this paper is to provide an updated position of the Neurodevelopmental Disorder service as at 31 January 2023.

2. BACKGROUND

The Neurodevelopmental Disorders (ND) team was established in November 2017, and since then, the team have strived to provide a robust, efficient and equitable service to patients with Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) or both.

Performance has been significantly impacted by the large demand on the service, and limited capacity which has been much lower than demand on the service. Subsequently, the ND team received funding from the Health Board in 2019, to support the expansion of this specialist team in order to increase capacity to meet demand at that time but this has continued to rise.

Welsh Government review update: Welsh Government published a report in July 2022, which reviews the demand, capacity and design of ND services for children, young people and adults in Wales with age range 0 years to adulthood. As part of publishing this report, Welsh Government have confirmed an additional £12m available to support a new national improvement programme for neurodevelopmental conditions over a three-year period to 2025.

The National Review report published July 2022 has highlighted:

- Demand for diagnostic assessment has outstripped the capacity of ND teams and is expected to remain high;
- The fundamental problem has been the small size of services relative to demand, rather than issues or constraints in the diagnostic assessment process or the design and structure of ND services;
- No change is not an option;
- The current unmet need causes significant human, social and economic cost.

The review recommends clear short-term actions:

- Increase efficiency and capacity of ND teams through increased funding;
- This funding should also tackle issues such as lack of administrative support, adequate IT and clinical space;
- Implement the guidance and agree protocols for young people on the ND waiting list, who are approaching their 18th birthday, to transition to the waiting list for adult assessment, Integrated Autism Service.

Health Boards were advised that the National Delivery Unit team will be visiting Health Boards to undertake a detailed demand and capacity assessment, which will inform funding allocation per Health Board. Whilst some data has been returned as requested, no visit has taken place to date. Engagement workshops and follow-up workshops have commenced, however, there

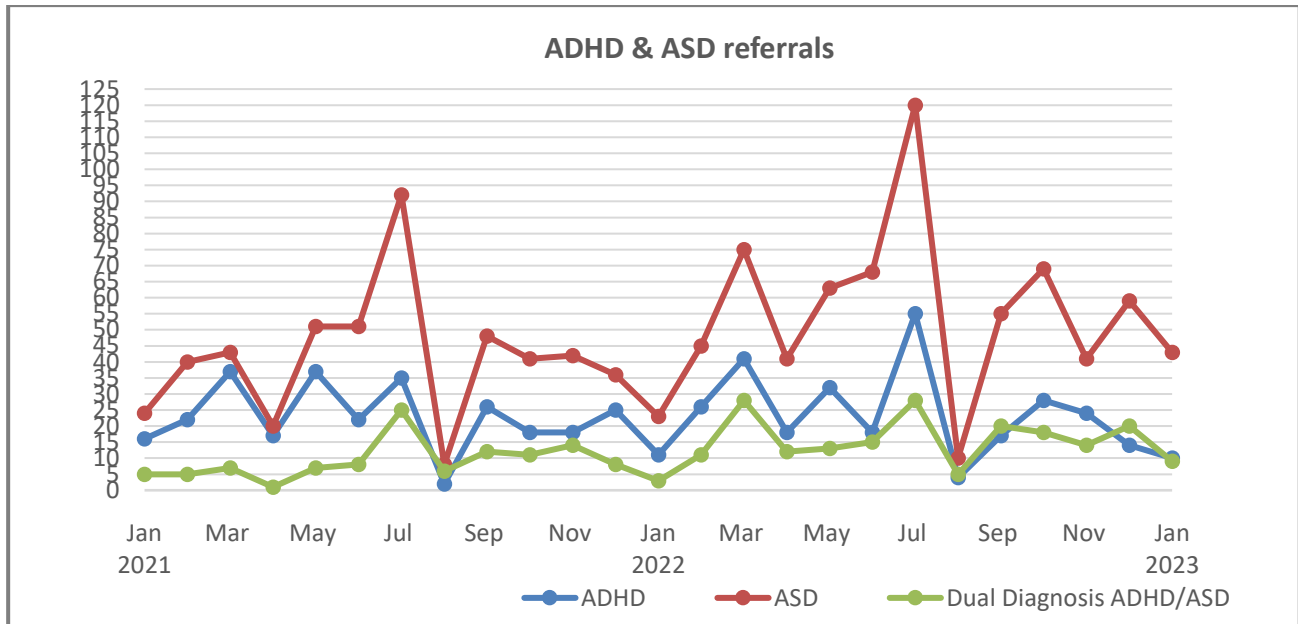
is concern around the pace of this work – urgent action and funding release is required in order for services to be able to start reducing the waiting times for our patients and families.

3. CURRENT POSITION

3.1 Neurodevelopmental Disorders (ND) service (5 – 18 years) referrals

Demand continues to be higher than available capacity. There is a continued need to increase the staffing establishment in order to close this gap, which will make a positive impact on reducing the waiting times. There has been a steady increase in referrals since the inception of the service in 2017, although no consistent performance data was captured until 2020.

Table 1



Tables one and two illustrate this rise, with table 1 above showing trend of referral numbers and table 2 detailing the annual number referrals received and also the number of assessments carried out per year.

Table 2

| | Referrals received | Number of first appointments | Second/next appointment |
|------|--------------------|------------------------------|-------------------------|
| 2017 | 276 | | Not known |
| 2018 | 1117 | | Not known |
| 2019 | 982 | | Not known |
| 2020 | 859 | 416 | 1423 |
| 2021 | 880 | 487 | 1931 |
| 2022 | 1144 | 423 | 2122 |

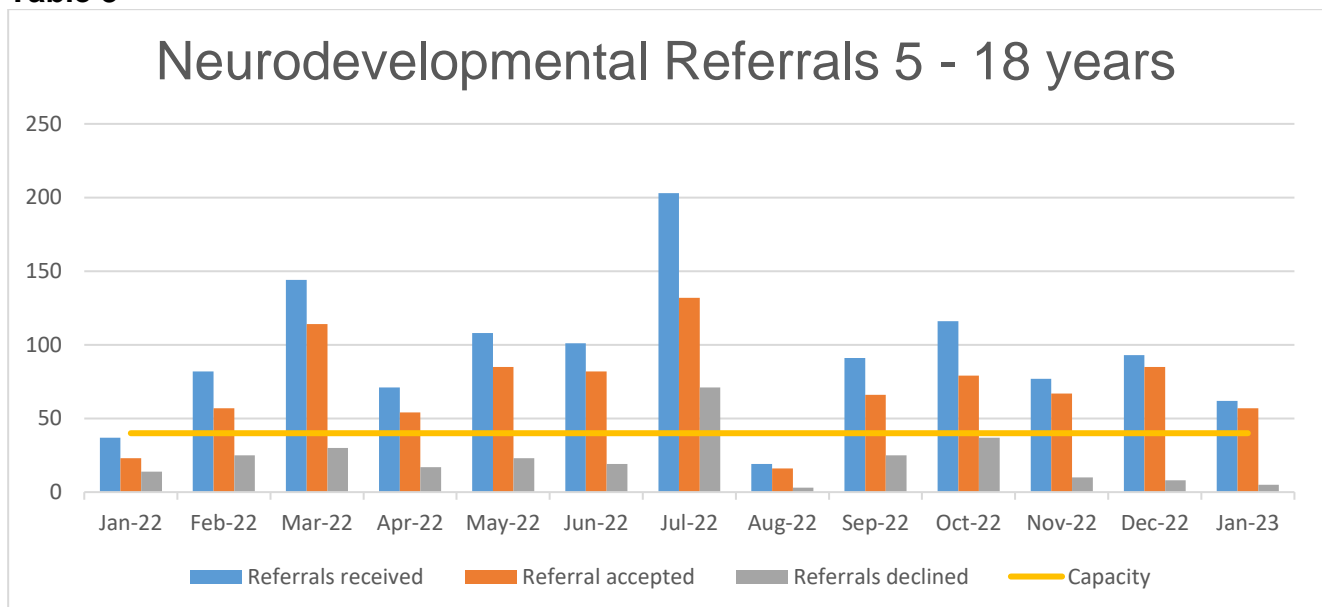
Within the rising demand, the monthly referral average in 2022 was 95. However, monthly referral rates vary significantly during the year. This is due to different factors. Firstly, schools review progress at different times of the year, the reviews would lead to the decision to refer. The termly holidays also create peaks in referral rates, as teaching staff finalise referrals before their holidays. The largest spike is during the summer term, before the school’s six-week break. In the three months from May – July 2022, the service received 412 referrals, 36% of the annual total.

This monthly variation is also a significant factor in patient experience and means the service cannot give families a predicted date for when they will be seen. Every case is seen in turn, according to the date their referral was received and put on the waiting list. The monthly capacity for first appointments, which takes a new case off the waiting list, is fixed. However, the volume of referrals received in any month will affect how long it will take to see every new case from that same month. For example, in 2022, the service received 203 referrals in July, but only 19 in August. For families waiting since July 2022, the fixed monthly capacity for new cases, means that with approximately 40 new case slots per month, it will take five months for those 203 new cases to be seen. By contrast, families waiting since August 2022, will all be booked for their first appointment within one month's new case capacity.

Whilst referral numbers received during 2020 and 2021 were lower than 2018 (possibly due to the pandemic although the service didn't close), over the past year there has been a further rise in referrals, the rising trend is seen in both Swansea Bay UHB and CTM UHB referrals (via boundary change service level agreement). In total, we have received an additional 262 referrals during 2022. Validation work is underway in relation to the Bridgend referrals received as part of the CTM UHB service level agreement (SLA). This will be discussed with CTM UHB colleagues as part of planned discussions around disaggregation of the SLA during 2023. Whilst appreciating there is a financial risk of £163k to disaggregate from the SLA, it is felt in patients best interests, together with reducing the demand on our service and releasing triage and assessment capacity.

The Clinical Lead has been undertaking significant work with referrers in order to reduce the number of inappropriate referrals rejected by the service as each referral has to undergo a detailed triage before return to referrer. The number of referrals received, accept and rejected are illustrated below:

Table 3



With current workforce establishment, the service has capacity to see up to 40 patients per month, with overall annual capacity of 504 first initial assessments slots against demand in 2022 of 1110, minus inappropriate referrals rejected equals 880 referrals during 2022 with a 1:4 ratio ASD:ADHD. For 2022, the service has a capacity gap of 376 assessments plus current backlog.

3.2 Waiting times

There are 1003 patients waiting for ND service assessments as at 31/1/23, which is an improved position of previous month with 1048 waiting. Currently 384 patients waiting over 52 weeks and 457 who would be waiting over 52 weeks as at 31/3/23. Some additional sessions are being undertaken to reduce this number by end of March 23023. The reduction trajectory can be seen on page 6.

Table 4

| Jan 23 - weeks wait group | ADHD | ASD | Dual diagnosis | Total |
|----------------------------------|-------------|------------|-----------------------|--------------|
| <=11 weeks | 26 | 111 | 31 | 168 |
| 12-17 weeks | 9 | 50 | 12 | 71 |
| 18-25 weeks | 9 | 26 | 9 | 44 |
| 26-35 weeks | 39 | 113 | 17 | 169 |
| 36-51 weeks | 30 | 114 | 23 | 167 |
| >51 weeks | 99 | 225 | 60 | 384 |
| Total | 212 | 639 | 152 | 1003 |

Since the service was established, 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 by the large demand on the service vs limited capacity. The waiting times for the service continue to be unacceptable and unsustainable.

The current overall referral rate remains much higher than planned capacity, which is the contributable factor to the long waiting times experienced by our patients and families. The complexity of the referral position and the SLA position makes plotting a trajectory difficult.

3.3 Early Years ND service (under 5 years)

As the Welsh Governments review of demand, capacity and design included age range from 0 years to adulthood, it was felt important to note the current early year neurodevelopment status here, which is delivered by the Community Paediatric team. There are currently 180 patients who will be waiting over 26 weeks at 31/3/23 listed on the paediatric community services waiting lists, awaiting assessment for the early years ND service, which is delivered by the Community team and speech and language therapists. The service currently receives approximately 40 referrals per month and has capacity to see 32 patients. There is a requirement to undertake additional sessions in order to clear the backlog and then increase capacity to allow an increase of patients to be seen, and meet demand. It is felt the waiting times can be reduced to 26 weeks within 12 months if we continue with additional sessions during that time. Further information of improvement plans are detailed on page 7.

4. STATUS UPDATE

As noted earlier in the paper, the Welsh Government has provided non-recurrent funding in support of services. Swansea Bay UHB allocation equals £182,000. This is non-recurrent funding until March 2023. This funding is to support patients ranging from early years to adult services. Given the funding allocation is non-recurrent until March 2023, the proposals outlined within this plan are interim measures that are being put in place during January, February and March 2023 to support children and families currently waiting to be assessed and also to take an opportunity to see an increased number of children through undertaking temporary additional clinical sessions.

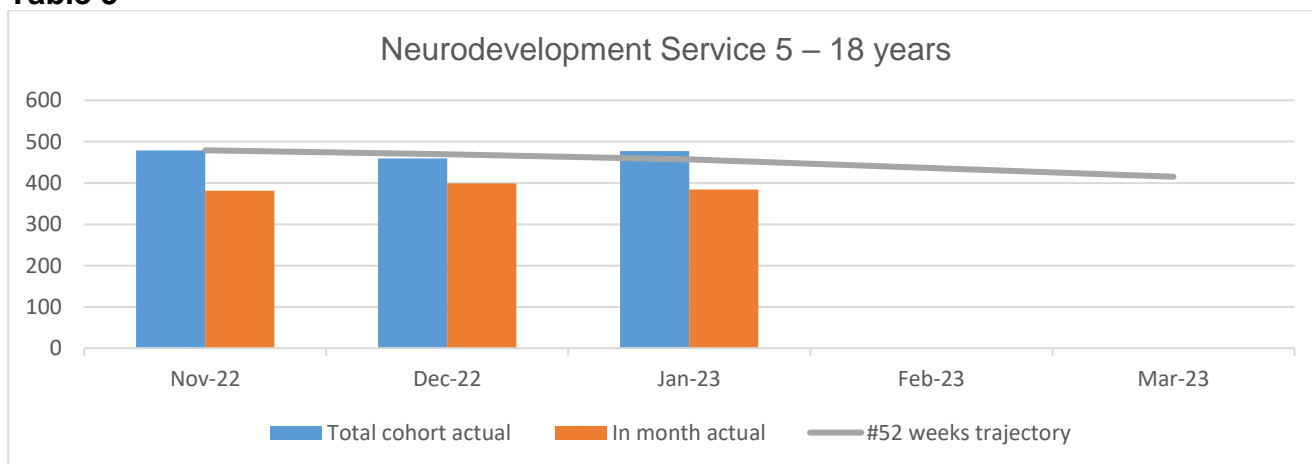
There are some key actions that are being taken to support for children and families whilst on waiting list:

4.1 ND services – 5 – 18 years – proposed plan to see 24 additional assessments:

1. Current Consultant colleagues increase by 4 sessions per week, This will provide capacity for 8 assessments per month between January – March 2023 (consideration must be given per each assessment takes 15 – 30 hrs dependent on agreed pathway)
2. Increase of administrative support for typing reports and administrating waiting list/clinics– Band 4 Medical secretary/administrative support hour’s required 1.0 wte (for 3 months) – will need to use agency due to short notice requirement.
3. Temporary additional learning needs (ALN)/teacher resource to provide time for support line which will release clinical time to see patients in clinic – proposal one day per week (0.2 wte) at Band 7 level salary commencing January 2023 (3 months). Recruitment process underway.
4. QB Tech – assessment system and consumable costs – a digital tool for ADHD assessment, QBTech, has been costed which would reduce the number of appointments for cases where further information is needed. The annual subscription would be £6000, which includes the computer hardware, software, training and technical support. Each case would cost £29; with reducing individual cost per case for more than ten cases per month. This would reduce assessment times for families and release clinical capacity. This tool is already being used by other Health Board teams; we have discussed its application with our ND colleagues in Hywel Dda.

The number of children waiting to be seen will reduce by a minimum of 24, depending on type of pathway assessment for 5 – 18 year olds. The current overall referral rate remains much higher than planned capacity, which is the contributable factor to the long waiting times experienced by our patients and families. The complexity of the referral position and the SLA position makes plotting a trajectory difficult. It was felt that the easiest way to plot the over 52 weeks position can be seen below :

Table 5



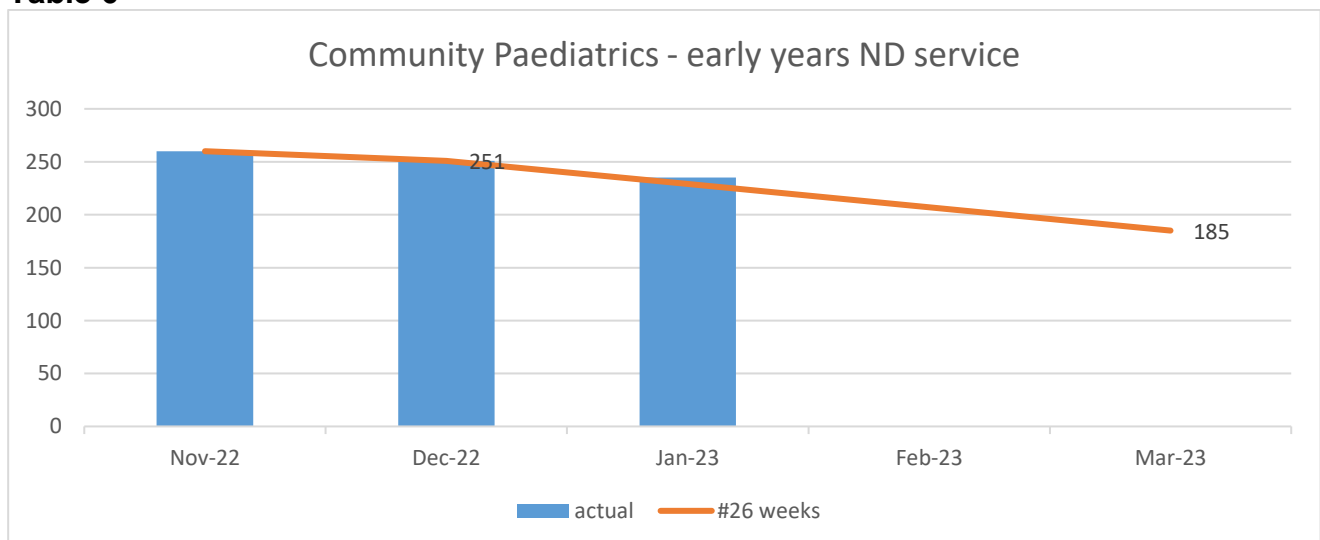
4.2 Early years ND service delivered by Community Paediatricians – proposed plan – to see an additional 50 patients by March 2023:

This will be delivered by:

1. Additional clinics – solo (Clinician) and joint clinics (clinician with Early years ND service SALT team). We aim to offer 10 additional clinics a month seeing 2 children per clinic i.e. 20 extra assessments each month. Over a 4-month period, these clinics alone will allow feedback Autism Spectrum Disorder assessments and us to complete for approximately 50 patients.
2. Develop an Early years ND service coordinator role as a seconded role, this post is going through internal recruitment process currently.
3. Provide post diagnostic support services – currently gap in the service - Specialist Health Visitor/ Community Nurse (Band 7) who can support the family following diagnosis, one key recommendations for patient satisfaction. This could be put in place as a secondment
4. Autism diagnostic observation schedule (ADOS) Training – developing a workforce who are trained with evidence based assessment tools will be equipped with the ability, confidence and skills in making robust diagnosis of ASD with the reduced need for second opinions and repeated assessments. This improves the quality of care and patient confidence in the assessments.
5. Autism diagnostic observation schedule (ADOS), Brief observation of symptoms of autism (BOSA) and Griffiths 3 kits. To facilitate multiple assessments at the same time and avoid limitations due to lack of kits.

Completion of Autism Spectrum Disorder assessments resulting in reduction in number of children waiting by 50 by end of March 2023. The following table illustrates an improvement trajectory considering the actions outlined above. Further trajectory work will be completed when the service receives confirmation of the next steps and next funding allocation from Welsh Government.

Table 6



5. Impact of SLA Disaggregation

The service continues to diagnose and treat 11 – 16 year olds, as part of an SLA with CTMUHB as part of temporary boundary change arrangements.

A meeting was initiated recently by Cwm Taf Morgannwg (CTM) University Health Board colleagues who informally informed the service that they intend to disaggregate the SLA agreement from 1st August 2023. This would release capacity to see Swansea Bay UHB patients, however, there are financial risks associated with this action as this SLA is worth £163,000.

The commissioning documentation is being completed by both Health Boards in order to present to the Commissioning and contracting oversight group outlining the CTMUHB plans and discussions have commenced by operational managers to agree a plan in readiness to repatriate patients. The current number of Bridgend area patient son the SBUHB is detailed in table 7 below:

Table 7

| weeks wait group | ADHD | ASD | Dual Diagnosis | Grand Total |
|--------------------|----------|------------|----------------|-------------|
| <=11 weeks | 6 | 36 | 6 | 48 |
| 12-17 weeks | | 10 | 2 | 12 |
| 18-25 weeks | | 9 | 1 | 10 |
| 26-35 weeks | | 20 | | 20 |
| 36-51 weeks | | 22 | | 22 |
| >51 weeks | 1 | 34 | | 35 |
| Grand Total | 7 | 131 | 9 | 147 |

6. Service Development Business Case

In view of the announcement by Welsh Government in July, which following the National review of ND services, they will be making an additional £12 million pounds available to support a new national improvement programme for ND to 2025. The Clinical Lead has revisited the ND workforce plan and considered every opportunity to demonstrate best value, including patient outcomes and cost at every stage of their ND pathway experience.

The ND team have been working on a business case in readiness to implement the recommendations of the report. This business case seeks support and approval for the preferred option to fund £1,940,225 full year staff costs recurrently and approximately £271,000 capital costs non-recurrently, supporting the requirement to increase capacity to meet demand and clear current backlog. These actions and funding will provide sustainability to service, improving patient, family and staff experiences and outcomes.

As part of the business case development, the Welsh government report's recommendations have been considered. Together with the Neurodevelopment service; there is a requirement for 20.5 wte (whole time equivalent) specialist staff. These service improvements propose new roles at band 6 levels for succession planning, as well as further extended scope roles such as additional advanced practitioner (band 8a) and a Consultant Practitioner role (Band 8B).

The creation of an Advanced Practitioner role to deliver Autism Spectrum Disorder diagnostic assessment, instead of a Consultant role, has increased capacity and shown value for families through reduced waiting times and improved outcomes, i.e. evidence informed practice for diagnostic formulation from AHP (allied health professional) perspective, in line with ALNET

legislation. As this post is now established, there is now opportunity to further extend scope of AHP within the team by creating a non-medical Consultant Practitioner, 8b role to include the Clinical Leadership of ND service. As described in the Modernising AHP Careers in Wales, they would bring expert clinical practice to enhance quality of assessment and diagnosis to deliver improved outcomes for families. Beyond that, they would work strategically to influence policy and decision making with impact on clinical outcomes. As with the Advanced Practitioner role, it creates a sustainable succession plan and best value for cost and patient outcomes, as an alternative to solely medical Consultant recruitment.

In line with the National Review, the necessary administrative support is also fundamental to meeting the needs of families and professional partners through timely processing of referrals, typing and distribution of reports following diagnosis, which are comprehensive, detailed and lengthy (usually >10 pages), providing advice and support for those waiting and those in the process of assessment.

Given the slow pace of release of funding from Welsh Government, and the proposed changes to demand as a consequence of the CTMUHB SLA disaggregation, the clinical and managerial team now need to revisit the business case and highlight to the Health Board solutions to deliver a phased approach to reducing the waiting times of patients and therefore a number of actions will be progressed:

- Phased proposals to reduce the number of patients waiting at key milestones – reduce to 52 weeks, reduce to 36 weeks, reduce to 26 weeks.
- Meetings held with IAS have resulted in agreement between clinical leads for a smooth transfer of rising 18-year-old cases as an alternative to current expedite process.

7. Risks and Assurance

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. It is important to note here that the service has recently become extremely fragile with a 30% sickness rate and therefore workforce is a high risk to delivery of service and opportunity for additional work. Availability of agency/overtime is also a risk, which must be noted. The sickness position has started to resolve with supportive phased returns and two posts are now vacant and will be advertised as soon as possible.

In the interim, whilst revising the business case and awaiting direction from Welsh Government regarding funding allocation and bidding process, the Division will ensure the capacity and workforce available will be delivered to its maximum and will continue to support families and local authority colleagues as much as possible. It must also be noted that:

- 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 Autism Spectrum Disorder (NICE CG (National Institute for Clinical Excellence Clinical Guidance 128) and ADHD (NICE NG 87).
- The service has very little concerns raised regarding the standard of care provided by the service, the main theme of concerns raised are the waiting times.

- As a Division we have been holding engagement Task & Finish group to review parent and children and young person's engagement and feedback from the service they provided – this will be captured by various ways including the use of QR codes. This has been successfully used across our areas and we are now going to introduce to ND service as family and young person's feedback is important to us.
- The service provides a daily advice, support and sign posting service for families, young people, referrers, local education colleagues as appropriate – this support was put in place due to the waiting times and anxiety that this can cause waiting.

8 RECOMMENDATION

Please note the current Neurodevelopmental Disorders Service position and next steps.

| Governance and Assurance | | |
|---|---|-------------------------------------|
| Link to Enabling Objectives <i>(please choose)</i> | Supporting better health and wellbeing by actively promoting and empowering people to live well in resilient communities | |
| | Partnerships for Improving Health and Wellbeing | <input checked="" type="checkbox"/> |
| | Co-Production and Health Literacy | <input type="checkbox"/> |
| | Digitally Enabled Health and Wellbeing | <input type="checkbox"/> |
| | Deliver better care through excellent health and care services achieving the outcomes that matter most to people | |
| | Best Value Outcomes and High Quality Care | <input type="checkbox"/> |
| | Partnerships for Care | <input type="checkbox"/> |
| | Excellent Staff | <input checked="" type="checkbox"/> |
| | Digitally Enabled Care | <input type="checkbox"/> |
| | Outstanding Research, Innovation, Education and Learning | <input type="checkbox"/> |
| Health and Care Standards | | |
| <i>(please choose)</i> | Staying Healthy | <input type="checkbox"/> |
| | Safe Care | <input checked="" type="checkbox"/> |
| | Effective Care | <input checked="" type="checkbox"/> |
| | Dignified Care | <input checked="" type="checkbox"/> |
| | Timely Care | <input checked="" type="checkbox"/> |
| | Individual Care | <input checked="" type="checkbox"/> |
| | Staff and Resources | <input checked="" type="checkbox"/> |
| Quality, Safety and Patient Experience | | |
| This paper provides a summary position statement and outlines associated risks. | | |
| Financial Implications | | |
| The ND team within Swansea Bay University Health Board have been working on a business case alongside awaiting the above-mentioned report. In order to operationalise the recommendations of the report, this business case submission now requires review in light of the notice to be given for the disaggregation of the SLA with CTMUHB. The disaggregation of the SLA with CTMUHB will create a 163k cost pressure but will release capacity to see long waiting patients. | | |
| Legal Implications (including equality and diversity assessment) | | |
| Nil | | |
| Staffing Implications | | |
| There will be significant recruitment challenges but it is hoped this can be achieved by a phased approach, which will also provide time to continuously review demand on service. | | |
| Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015) | | |
| N/A | | |
| Report History | | |
| Appendices | None | |