

**PWYLLGOR DATBLYGU STRATEGOL A CHYFLENWI GWEITHREDOL  
STRATEGIC DEVELOPMENT AND OPERATIONAL DELIVERY COMMITTEE**

<b>DYDDIAD Y CYFARFOD: DATE OF MEETING:</b>	27 February 2025
<b>TEITL YR ADRODDIAD: TITLE OF REPORT:</b>	Update Paper: Additional Measures to improve Children's ASD service performance
<b>CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:</b>	Andrew Carruthers, Chief Operating Officer
<b>SWYDDOG ADRODD: REPORTING OFFICER:</b>	Angela Lodwick Assistant Director, Mental Health & Learning Disabilities Catherine Vaughan, Service Delivery Manager ND Services

**Pwrpas yr Adroddiad (dewiswch fel yn addas)  
Purpose of the Report (select as appropriate)**

Ar Gyfer Trafodaeth/For Discussion

**ADRODDIAD SCAA  
SBAR REPORT**

Sefyllfa / Situation

In September 2022, Hywel Dda University Health Board (HDdUHB) was escalated to Targeted Intervention, for finance and planning and more recently quality and performance in respect of Children's Autistic Spectrum Disorder (ASD) services.

In July 2024, Welsh Government (WG) identified ASD services across Wales as an area that is unable to meet the current 26 week performance standard due to increased demand and limited local service provision.

At that time, Welsh Government confirmed the number of children and young people across Wales awaiting a diagnostic assessment, was 20,149 but *could* increase to 61,000 children and young people (CYP) by March 2027, if service re-design is not implemented at pace.

Increased demand has been consistently evidenced in HDdUHB and although a slight improvement in performance was reported throughout Quarter 1 to 16.3%, in Quarter 3, performance has dropped once more and currently stands at 12.9%, with further deterioration inevitable as demand continues to outstrip capacity.

This paper provides an update on the current position and a proposal to revise service provision necessary to bring about an improvement in performance.

Cefndir / Background

The Children's Neurodevelopmental (ND) service was established and launched in November 2015 under the Together for Children and Young People (T4CYP2) framework to undertake diagnostic assessment of autism in children and young people. The programme ended on 31 March 2022 and Children's Neurodevelopmental services are now included within the Strategic Programme for Mental Health & Neurodiversity and Welsh Government's Neuro-divergent Improvement Programme.

Individuals accessing ND services can experience significant cognitive, sensory, and behavioural differences which, without proper support, may impact their quality of life, educational outcomes, social integration and mental health.

Consequently, improving access to ND services in Wales has been identified as a key WG priority. A recent independent review of all-age ND service provision identified significant gaps in services and long waiting times for assessment and support. Subsequently, a three-year Neuro-divergence Improvement Programme (NDIP) was established by WG to address immediate pressures and help develop sustainable, integrated and needs-led services for the future.

On 4 November 2024, the West Wales Regional Partnership Board (WWRPB) held a regional Neuro-divergence event, bringing together front-line staff, statutory and third sector agencies to explore regional ways of working to meet the needs of neuro-divergent children, adults and their families. The aim was to promote greater alignment of local practice and policy in keeping with Welsh Government Neuro-Divergence Improvement Program priorities, develop a shared vision for the West Wales Region and create a unified road map for future action. A report and outline of agreed priorities will be published shortly, and the Neuro-divergence Improvement Board (NIB) will, supported by the Regional Partnership Board (RPB), develop and implement an action plan in collaboration with all stakeholders.

In addition, Welsh Government held a Rapid Design Event to achieve critical, systemic and needs-led transformation of Children's ND pathways on 27 and 28 November 2024. 165 key stakeholders including service users/parents and carers were in attendance and contributed to discussions on a future re-design of children and young people's neuro-developmental services fostering needs-led integrated models of support.

Welsh Government and the NHS Wales Executive are developing an improvement programme and implementation plan.

Alongside this, Welsh Government has committed the following additional funding to Health Board and RPB's respectively to address waiting lists and provide support for children and families on the waiting lists during this financial year. This is being actioned as follows:

- **HDdUHB:** Funding allocation of £312k to address the 3-year-waits-and-over for diagnostic assessments in CYP by March 2025. Procurement of 182 diagnostic assessments is underway with our current provider. An additional 100 diagnostic assessments funded through Health Board slippage (amounting to £171k) has been procured with the same provider simultaneously.
- **RPB:** £100K to outsource to Third Sector, support services for CYP and families who are currently on the waiting list, targeting longest waits.

### Asesiad / Assessment

#### **Performance:**

Current waiting list as of December 2024:

	<b>Waiting</b>	<b>Breached 26-week target</b>
Children and Young People	3499	3046
Performance	12.9%	(decrease from 14.4% in November 2024)

### Current Diagnostic Conversion Rate:

Children's ND service	100% (January 2025)
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### Referral rates

Average referral rates for HDdUHB stand at 116 per month in 2024. In January 2025, the service received 143 referrals and accepted 123 - evidence of exponential demand, with insufficient capacity to meet local need.

### National Trend

The publication of The Review of Demand, Capacity & Design of Neuro-developmental Services (WG, 2022) and the All-Wales Review of Children's ND Services (NHS Executive, 2023) confirms demand for diagnostic assessment for both children and adults in Hywel Dda is in keeping with the rest of Wales.

Quarterly scrutiny meetings are held with the NHS Executive and current data confirms HDdUHB's Children's ND (ASD and Attention Deficit Hyperactivity Disorder - ADHD) position as:

Performance at 19.3% remains low with further decline noted from 19.9%
Health Board position compared to other regions - third from bottom (unchanged)

Additional weekly scrutiny meetings with the NHS Executive are in place to monitor the impact which additional monies to outsource diagnostic assessments will have on overall trajectory by 31 March 2025.

A 1% monthly improvement trajectory has been set and worked towards in the Children's ND service. However, despite outsourcing, which is costly and has little long-term impact, our position by the end of financial year will be just 14.9%.

In the absence of additional outsourcing moving forward, position likely to deteriorate considerably further.

### Current actions in place to mitigate risk

A series of procurement exercises have been undertaken over recent years, using COVID-19 recovery monies, Health Board and Neuro-divergence programme slippage to outsource autism diagnostic assessments over a 3-year period. A single provider was awarded a sole contract for CYP which started in 2022 and ends on 31 March 2025.

**446 assessments** were outsourced via original contract. It is anticipated between October and March 2025, **288** assessments will be completed by the core team and existing outsourced provider, which gives an average of **48** completed assessments a month in this time period.

Utilising the £312k and the additional £171k to outsource, the external provider is due to start an additional **26** assessments each week between 17 February and 31 March 2025.

There are concerted efforts to tackle longest waits within the service, with on-going data validation, robust referral and triage processes, caseload allocation, monitoring of first appointments and improved discharge rates.

### Improving the Trajectory October 2024-25 and beyond

In order to improve performance and bring about transformational change, a number of factors are required which include additional staffing and changes to the service model:

- Capacity needs to be greater than demand. Currently average core activity allows between **32-34** diagnostic assessments to be commenced each month. Whilst significant investment has been made over the years to increase staff numbers, several posts within the service are dependent on non-recurring Neuro-Divergence Improvement Programme funding. Funding allocated to the RPB is then dependent on a successful application being made by ND services. The short term and ad-hoc nature of allocation, does not account for the challenges of recruiting and retaining highly skilled staff. Furthermore, the caveat to receipt of monies is a commitment and evidence to prioritise pre and post diagnostic support.
- Monies to date have been insufficient to enable a two-pronged approach to address existing waiting list pressures and develop upstream, whole system ways of working.

### **Short term solutions to bring about change – 3-9 months**

#### **Stabilise fixed term posts**

- Offer substantive positions to the two clinical and two support staff reliant on NDIP funding, whose contracts expire 31 March 2025. This will increase staff and team morale and enable us to tackle our waiting lists further.
- Provide additional investment in core budget to fund the 8b Clinical Lead for the service and the 8b Service Delivery Manager to help bring about transformational change and enable additional recruitment of clinical and support staff through NDIP monies to progress upstream, whole system working through training, engagement and professional consultation across all sectors.
- More preventive option-working with education to reduce onward referrals etc.

#### **Service Improvement Initiative**

- In collaboration with the Research & Development team, the service wishes to progress development of a Fast-tracking pathway to diagnosis which would remove the need for lengthy clinical assessments and multi-disciplinary panels when not clinically indicated. Given the service's consistently high diagnostic conversion rate, a proposal to pilot a rapid access to diagnosis and subsequent support has been developed which has potential to significantly reduce waiting lists and bring about positive change for children, young people and their families (see Appendix 2).
- This would begin with a trawl of all referrals on the existing waiting list. The service is aware of differences in the quality of information provided by certain specialities, for example Community Paediatricians, CAMHS, Speech and Language Therapists and Health Visitors, will be greater than others.
- The next step will be to consult with parent carers to ascertain whether they would be happy for their child to be part of a fast-tracking initiative and ensure informant and school-based information is available.
- A pilot to explore how many referrals have come from Community Paediatricians could be a starter as these will contain qualitatively rich and relevant information.
- Should the pilot be successful, the service could then liaise with parent carers informing them their child may be eligible for fast-tracking IF all information is available

There are well-documented benefits to prioritising early diagnosis of neurodevelopment conditions. In the absence of a whole system approach to identifying and meeting the needs of

neuro-divergent CYP, early diagnosis allows for timely interventions that help individuals thrive academically, socially, and professionally, which in turn can reduce future healthcare costs and social support needs. Given the growing prevalence of neurodevelopment in society and its significant impact on the NHS and related services, a comprehensive approach to early diagnosis is essential.

The above pilot could then be extended to undertake a comprehensive review of existing waiting lists *and* new referrals and if sufficient information is available from the referrer, parent carers and the child's school, to indicate concerns around neuro-divergence are pervasive, it would allow clinicians to confirm a working diagnosis without seeing the child. This new way of working is currently being piloted by Cwm Taf University Health Board.

### Medium Term solutions – 9 -18 months

#### Digital Innovation

- Investment in Digital innovation to help streamline referral processes, share information between clinicians and other relevant teams and populate diagnostic reports could bring about significant benefits. Meetings have already been held with several providers, of which one, could potentially transform assessment process across ND services and radically increase capacity within services.
- Strengthening the interface across all sectors through joint working, professional consultation, training and engagement to support with profiling of children's needs potentially reducing the need for diagnostic assessment in the first place.

#### Argymhelliad / Recommendation

The Committee is requested to:

- **RECEIVE ASSURANCE** that the Service is actively working through alternative models with key stakeholders to ensure improved future access to ASD services.

#### Amcanion: (rhaid cwblhau)

#### Objectives: (must be completed)

Committee ToR Reference: Cyfeirnod Cylch Gorchwyl y Pwyllgor:	3.1 Seek assurance on delivery against all Planning Objectives aligned to the Committee considering, and scrutinising the plans and programmes that are developed and implemented, supporting and endorsing these as appropriate.
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	Not Applicable
Parthau Ansawdd: Domains of Quality <a href="#">Quality and Engagement Act (sharepoint.com)</a>	7. All apply
Galluogwyr Ansawdd: Enablers of Quality: <a href="#">Quality and Engagement Act (sharepoint.com)</a>	3. Data to knowledge 4. Learning, improvement and research 5. Whole systems perspective

Amcanion Strategol y BIP: UHB Strategic Objectives:	All Strategic Objectives are applicable
Amcanion Cynllunio Planning Objectives	5 Mental health and CAHMS
Amcanion Llesiant BIP: UHB Well-being Objectives: <a href="#">Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022</a>	2. Develop a skilled and flexible workforce to meet the changing needs of the modern NHS 4. Improve Population Health through prevention and early intervention, supporting people to live happy and healthy lives

<b>Gwybodaeth Ychwanegol: Further Information:</b>	
Ar sail tystiolaeth: Evidence Base:	Not Applicable
Rhestr Termiau: Glossary of Terms:	Within Report
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Datblygu Strategol a Chyflenwi Gweithredol: Parties / Committees consulted prior to Strategic Development and Operational Delivery Committee:	Integrated Quality, Financial Performance and Delivery Group

<b>Effaith: (rhaid cwblhau) Impact: (must be completed)</b>	
<b>Ariannol / Gwerth am Arian: Financial / Service:</b>	TBC when an alternative service delivery model has been agreed
<b>Ansawdd / Gofal Claf: Quality / Patient Care:</b>	TBC when an alternative service delivery model has been agreed
<b>Gweithlu: Workforce:</b>	TBC when an alternative service delivery model has been agreed
<b>Risg: Risk:</b>	TBC when an alternative service delivery model has been agreed

<b>Cyfreithiol:</b> <b>Legal:</b>	TBC when an alternative service delivery model has been agreed
<b>Enw Da:</b> <b>Reputational:</b>	TBC when an alternative service delivery model has been agreed
<b>Gyfrinachedd:</b> <b>Privacy:</b>	TBC when an alternative service delivery model has been agreed
<b>Cydraddoldeb:</b> <b>Equality:</b>	TBC when an alternative service delivery model has been agreed