

**Y PWYLLGOR ANSAWDD, DIOGELWCH A PHROFIAD  
QUALITY, SAFETY AND EXPERIENCE COMMITTEE**

<b>DYDDIAD Y CYFARFOD: DATE OF MEETING:</b>	15 August 2024
<b>TEITL YR ADRODDIAD: TITLE OF REPORT:</b>	Update on Autism Spectrum Disorder (ASD) Diagnostic services for Children, Young People & Adults
<b>CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:</b>	Andrew Carruthers, Chief Operating Officer
<b>SWYDDOG ADRODD: REPORTING OFFICER:</b>	Angela Lodwick – Assistant Director Mental Health and Learning Disabilities (MHLD) Catherine Vaughan – Service Delivery Manager Neuro-developmental services

**Pwrpas yr Adroddiad (dewiswch fel yn addas)**

**Purpose of the Report (select as appropriate)**

Er Sicrwydd/For Assurance

**ADRODDIAD SCAA**

**SBAR REPORT**

**Sefyllfa / Situation**

In September 2022, Hywel Dda University Health Board was escalated to Targeted Intervention by Welsh Government for finance and planning and recently Quality and Performance in respect of Children and Adult ASD services have been escalated to Targeted Intervention.

In July 2024, Welsh Government de-escalated the Specialist Child and Adolescent Mental Health Services (S-CAMHS) from Targeted Intervention due to a sustained performance improvement across a number of clinical areas. In addition ASD services were identified by Welsh Government as an area that cannot meet the current 26 week performance standard due to increased demand and a lack of local service provision and this is a national view across Wales. In view of this it was agreed to focus on the quality of support available to the population by continuing to provide Diagnostic assessments but to also ensure pre and post diagnostic support is available.

This paper provides an update on the current position, control measures instigated at a service delivery level to monitor progress and improve performance and service developments that align with policy and legislative requirements to provide assurance that all monitoring processes are in place to address the waiting list, improve efficiency and ensure quality of care is prioritised whilst the Welsh Government Neurodivergence Improvement Programme (NDIP) is planned and implemented.

**Cefndir / Background**

The Children's Neurodevelopmental service was established and launched in November 2015 under the Together for Children and Young People (T4CYP) (2) 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 in Welsh Government's Neuro-divergent Improvement Programme.

West Wales Integrated Autism Service (IAS) was established in 2019, in line with the Refreshed ASD Strategic Action Plan (WG: 2016). This Regional Integration Fund (RIF) funded initiative is

hosted by HDUHB and offers diagnostic assessment of autism in adults and brief, outcome-focused, support for adults (and their families) who do not meet eligibility criteria for statutory services such as secondary Mental Health and Learning Disability services. The service also offers professional consultation, training and engagement across all sectors.

Improving access to Neurodevelopmental (ND) Services in Wales has been identified a key Welsh Government 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 Welsh Government to address immediate pressures and to develop sustainable, integrated and needed services for the future.

However, since September 2020, when ND service performance data for children and young people (CYP) was first reported, the Health Board has struggled to meet performance standards of 26 weeks for diagnostic assessment. Performance targets have yet to be set for adult ASD services whose service model stipulates 60% time should be allocated to providing support.

### **Referral Pathways:**

Both services have a single point of access to manage referrals. Any professional can make a referral into the Children's ASD service.

The pathway complies with all-Wales ND referral pathway standards. However, following the NHS Executive's Review of CYP ND services in Hywel Dda, it was noted there is no single point of access to manage referrals for *both* ADHD and Autism. Subsequent recommendations are that the Health Board works to align services more closely. An action plan has been developed and a series of task and finish groups established to promote alignment and improve transition arrangements between children and adult services. Work progressing well and to timescale.

Anyone can refer into the Integrated Autism Service for diagnostic assessment and support and welcomes self-referrals, or those made on behalf of individuals such as from family and friends or professionals.

Although HDUHB performance is reported to be the lowest in Wales, it is important to recognise that current data does not take in to account the difference in size and configuration of each regional service, nor does it factor in individual Health Boards' interpretation of Welsh Neurodevelopmental Pathway standards around waiting times, which differ and significantly impact overall performance.

### **Average Referral Rate Trends**

2019	75.6
2020	67.9
2021	78.1
2022	90.6
2023	110.3
2024*	125

\*average referral rate Jan – June '24

## Asesiad / Assessment

### **Performance:**

Current waiting list as of June 2024

	Waiting	Breached 26-week target
Children & Young People	3319	2785
Adults	1816	1487

### **Diagnostic Conversion Rate:**

Children's ND service	85%
Integrated Autism Service	96%

Since the inception of both services, demand has outstripped capacity. Demand for diagnostic assessment has remained exponential with referral rates increasing year on year. Referrals for Diagnostic Assessment of ASD for CYP averages at

Whilst not as high, referrals into the IAS for diagnostic assessment *and* support are consistent, averaging at 85 per month. This does not include referrals for access to advice hubs, training, or professional consultation.

Average monthly *contacts with both* services are more than 1100.

### **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 – the most recent held on 27th May 2024 which confirmed HDUHB Children's ND (ASD and ADHD) position as:

Performance at 18.7% remains low with slight improvement noted.
Referral demand ranks 4th out of 7 Health Boards
3rd highest referral acceptance %
Waiting list is 2nd highest in volume
Highest % waiting over 52 weeks
HDUHB child population is ranked 2nd lowest (out of 7)*

\*0-15 year olds

A 1% monthly improvement trajectory has been set and worked towards in Children's ND service. The slight improvement noted by the NHS Executive was due to the service making a concerted effort to tackle the longest waits, on-going data validation exercise and robust caseload allocation and monitoring. Discharge rates have significantly improved.

However, with the continued escalated demand for Diagnostic Assessment alongside no major increase of current resources, further decline in performance is anticipated as robust referral and triage processes are resulting in fewer referrals being accepted. This in turn leads to a reduced number waiting less than 26 weeks.

The impact of short term, fixed funding is also impacting on ensuring a high quality and experienced workforce is in place to meet the known need .

Additional demand and subsequent diversion of resources from tackling waiting lists has arisen from Neuro-Divergence Improvement Programme and legislative requirements to further develop pre and post diagnostic support for children, young people, adults and their families. A lack of additional appropriate, long-term, and ring-fenced investment is especially challenging for the Children’s ND service whose original remit was to offer diagnostic assessment only.

**Outsourcing:**

To help manage waiting lists, Covid-19 recovery monies were used to outsource a portion of autism diagnostic assessments for both children and adults over a 3-year period. Two providers awarded contracts between 2022-2025.

**IAS – 369 assessments** (including additional 20 procured through slippage RIF 23/24)

**Children’s ND – 445 assessments** (including additional 66 assessments procured through NDIP slippage 23/24)

No issues to date, from a service or service user perspective. From a Quality Assurance perspective and to ensure the contract runs smoothly, with maximum engagement, the following is in place:

- NHS procurement processes complied with
- Meet NICE guidance for children and adults
- Robust risk stratification and case allocation within Children’s ND and IAS
- Extensive preparatory work with parents and schools and adults pre-referral
- Monthly catch-up meetings between providers and Team Leads
- Quarterly contract monitoring meetings with Service Delivery Manager (SDM) and Head of Transformation & Partnership
- Monthly activity reports shared by providers.
- Monitored through service monthly performance monitoring meetings
- Adherence to national and local safeguarding policy
- robust risk assessment, management and escalation processes in place
- Provider personnel compliant with safeguarding training and relevant clinical training.
- Diagnostic conversion rate variable month on month, as expected and in keeping with both IAS and Children’s ASD service.
- Healios service evaluation – 94% of respondents would recommend
- Problem Shared - the NPS score is 82 – NPS is the key customer satisfaction benchmark used worldwide – if effectively measures whether your customers are promoters (recommenders) of your service, ambivalent, or detractors. A score of 82 is exceptional.

	Assessments outsourced	No. Completed	Diagnostic conversion Rate	Parents/services users who declined to proceed post – pre clinical*	Parents who declined to proceed – post clinical**	No. Discharged
Children’s ND	285	224	89% (over past 6 months)	26	1	279

IAS	339	256	91.4%	48	8	TBC
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\*No charge incurred

\*\*charge incurred

### **Pre & Post Diagnostic Support**

For children's ASD 5 workshops have taken place in 2024. 70 invitations were sent out so in total 350 families/parent carers have been invited to attend workshops on ASD management and support. An average of 30-40 families attended per workshop equalling 150 -200 people in total attending. Data collection will become more robust in time

In addition, Advice hubs for children's have commenced, these are averaging 10 clients per month. The future aim will be to promote these as a form of early support and intervention.

For the Adult population the IAS post diagnostic courses are held on a rolling basis. Invitations sent out at a time targeting 35 clients/ families with an average 10-12 attendees. Face to face courses will be held in September with a view to increasing again the number of courses available for clients which addresses common presentations such as managing anxiety and sleep disorders.

The IAS advice hubs - current capacity allows 25 1:1 sessions per month.

### **Risk management & Control measures:**

**Directorate Risk Register :Risk 1032**

**Service Risk Register : Risk 1287**

To improve performance across ND services and to mitigate associate risks of lengthy waiting lists, the following are in place:

1. Monthly waiting list performance monitoring meetings with Team Leads/SDM +/- Assistant Director.
2. Four monthly 'Keeping in touch' letters sent to service users signposting to sources of support whilst waiting.
3. Expedite pathways in place for under 5's, those who are deemed high risk and those close to 18 in CYP service. Expedite pathways in place for adult services.
4. Robust risk stratification process in place across children and adults
5. Working with partner agencies to develop early intervention and whole system pathways
6. Service Delivery Manager in post to provide strategic and operational leadership.
7. Outsourcing of diagnostic assessments for children and adults.
8. SMS messaging system in place to reduce DNAs. Children's ND service has zero DNA rates
9. Action Plan in place to implement recommendations from the Delivery Unit (NHS Exec) review of children's ND services
10. Quarterly meetings with NHS Executive to review performance and establish trajectory.
11. Internal audit into timely access recommendations received and action plan developed to meet recommendations.
12. Monitoring of compliance against the recommendations in the Code of Practice, and Neurodivergence Improvement Programme, continues both internally and via the RPB regional Neurodivergence Improvement Board as this is a multi-agency directive.
13. All-age weekly virtual/telephone Autism advice hubs in place for parent carers, autistic adults/family members

14. Improved partnership working and development of transition pathways between Child and Adult ASD and Adult ADHD services.
15. Data validation exercises on going
16. Caseload allocation and monitoring in place.
17. Use of blended approach for information-gathering, assessment of children and adults and feedback to include telephone, digital platforms and face to face
19. Interactive Neuro-developmental services website in development as an additional resource for autistic CYP, adults and parent carers and wider public
20. Workshops being run for parent carers awaiting assessment of their child/ren around sleep and toileting.

**Actions achieved:**

- With the exception of psychology in the IAS, all posts recruited in to, with no retention issues
- Migration on to WPAS
- Robust procedures for ensuring timely access for expedite cases
- Job planning, case load allocation and review in place
- Process mapping of all clinical and administrative processes complete
- Arrangements for management and triage of referrals strengthened
- Establishment of weekly autism advice hubs for parent carers whose children are awaiting diagnostic assessment
- Establishment of pre-assessment workshops for parent carers. Workshops held targeting children aged 11 and under and young people, aged 12 and over.
- Establishment of three-county, multiagency 'Early Help' steering group to explore whole-system, partnership, upstream working. Task group for early years established and completed referral and pathway work involving under 5's with health visitor colleagues involving closer working links with ND; revised pathways, promote information sharing and coproduced resource packs for parent carers of suspected neurodivergent children.
- Neuro-developmental services are now a ratified placement for student nurses
- Contribution at training and engagement events – in partnership with HDUHB Learning & Development Team and National Neurodivergence team for Wales, Carmarthenshire County Council and Pembrokeshire Local Authority and Parent Partnership forum
- Collaboration with the national Neurodivergence Team to develop webinars/ pre-recorded workshops, bite size themed recordings, representing themed analysis of evaluation responses from parent carers and autistic adults.
- Development of a co-curring framework for adults affected by co-curring substance misuse and/or mental health issues and neuro-divergence.
- Development of a co-curring framework for children and young people affected by co-curring substance misuse and/or mental health issues and neuro-divergence.
- Training package for Adult Mental health Services developed in partnership with IAS, Adult ADHD service and IPTS anticipated roll-out from September onwards.
- ND services are working towards Investor in Carers bronze level award – aim to achieve by June 30th 2024.
- Children's ND service - Development of post diagnostic support workshops ongoing. Anticipated roll-out September 2024
- Development of a Health-Board wide Neurodivergence Strategy – HDUHB is on course to be the first in Wales to become an autism accredited employer and organisation.

**Service feedback:**

Despite the waiting lists, due to the revision in service delivery which is structured, dynamic, flexible and person-centred, complaints in to both the IAS and Children's ND service have reduced over the past 9 months and compliments increased.

Service	Compliments received Quarter 4
Children's ND Service	61 (including workshop feedback)
Integrated Autism Service	11 (excluding workshop feedback)

**Next Steps:**

- Welsh Government are exploring the use of profiling tools to encourage whole system, upstream approaches to managing exponential demand and identifying and addressing support for neuro-divergence needs. Engagement event held 18th July. ND service working in partnership with Carmarthenshire County Council to further explore the role of ND profiling and opportunities for partnership working.
- Neurodivergence Services will continue to monitor demand and capacity plus output via the monthly Performance monitoring meetings.
- The service will ensure pre and post diagnostic support is prioritised to ensure all clients waiting, receive support in line with the Code of Practice on the Delivery of Autism Services
- The Assistant Director will support the service in contributing and implementing national recommendations and works collaboratively with partner agencies to ensure the needs of people with Neurodiverse conditions receive timely and responsive support and services.

**Argymhelliad / Recommendation**

The Committee is asked to take ASSURANCE that the Neurodiversity service is focused on addressing the needs of Neurodiverse individuals and ensuring that timely support and interventions are provided during a period of national transformational change.

<b>Amcanion: (rhaid cwblhau) Objectives: (must be completed)</b>	
Committee ToR Reference: Cyfeirnod Cylch Gorchwyl y Pwyllgor:	
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	Directorate Risk Register: Risk 1032  Service Risk Register: Risk 1287
Parthau Ansawdd: Domains of Quality <a href="#">Quality and Engagement Act (sharepoint.com)</a>	All Apply
Galluogwyr Ansawdd: Enablers of Quality: <a href="#">Quality and Engagement Act (sharepoint.com)</a>	6. All Apply

Amcanion Strategol y BIP: UHB Strategic Objectives:	1. Putting people at the heart of everything we do 5. Safe sustainable, accessible and kind care 6. Sustainable use of resources
Amcanion Cynllunio Planning Objectives	
Amcanion Llesiant BIP: UHB Well-being Objectives: <a href="#">Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022</a>	

<b>Gwybodaeth Ychwanegol: Further Information:</b>	
Ar sail tystiolaeth: Evidence Base:	
Rhestr Termiau: Glossary of Terms:	
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Ansawdd, Diogelwch a Phrofïod: Parties / Committees consulted prior to Quality, Safety and Experience Committee:	

<b>Effaith: (rhaid cwblhau) Impact: (must be completed)</b>	
<b>Ariannol / Gwerth am Arian: Financial / Service:</b>	Contained within the report
<b>Ansawdd / Gofal Claf: Quality / Patient Care:</b>	Contained within the report
<b>Gweithlu: Workforce:</b>	Not Applicable
<b>Risg: Risk:</b>	Contained within the report
<b>Cyfreithiol: Legal:</b>	Contained within the report
<b>Enw Da: Reputational:</b>	Contained within the report
<b>Gyfrinachedd: Privacy:</b>	Not Applicable