



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

<b>DYDDIAD Y CYFARFOD: DATE OF MEETING:</b>	07 December 2023
<b>TEITL YR ADRODDIAD: TITLE OF REPORT:</b>	NHS Wales Executive : All Wales Review of Children and Young Peoples Neurodevelopmental (ND) Services Autism Spectrum Disorder (ASD)/ Attention Deficit Hyperactivity Disorder (ADHD)
<b>CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:</b>	Andrew Carruthers, Director of Operations
<b>SWYDDOG ADRODD: REPORTING OFFICER:</b>	Angela Lodwick, Assistant Director, Mental Health and Learning Disabilities

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

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

Er Gwybodaeth/For Information

### ADRODDIAD SCAA

#### SBAR REPORT

##### Sefyllfa / Situation

As part of the ministerial programme of reform, the NHS Executive Performance and Assurance division was asked to undertake a review of children and young people's neurodevelopmental services within all Health Boards across Wales.

This SBAR summarises actions taken by Hywel Dda University Health Board (HDUHB) in response to the recommendations following the review.

##### Cefndir / Background

The review aims to understand how services are organised including areas of consistency and variation between policy, performance, and clinical guidelines in each Health Boards service offer, waiting times, reporting arrangements, and performance management processes.

The review also sought to identify factors challenging the delivery of timely assessment, and the actions taken by Health Boards to support and improve access and high-quality care. Data collected from Neurodevelopmental Services in all Health boards in Wales will be collated to support the primary objective of the review to produce a national snapshot of current service delivery arrangements including factors that challenge and support performance.

This information will be used to inform the Neurodevelopment ND ministerial improvement programme and support the determination of national actions to improve access to ND diagnostic assessment. Each Health board will also receive a report outlining alignment with key standards and reporting definitions, demand, performance against the target, and performance management and improvement actions. Improvement recommendations will be provided if applicable.

## **Sefyllfa / Situation**

As part of Welsh Government's three year Neuro-divergence Improvement programme, NHS Executive were commissioned to undertake a review of Children's ND services (ASD and ADHD) within all Health Boards across Wales. This was to identify how services are organised and to identify consistency and variation between policy, performance and waiting times. It also aimed to identify factors that affect timely access and what HB's have done to address this.

Key findings include:

- The Health Board (HB) meets or partially meets 5 out of the 6 All Wales ND Standards
- Extensive process mapping and robust performance management processes in place
- The HB is not meeting its 26 week target for starting an assessment
- Referral rates and number of referrals accepted are consistent with the rest of Wales
- Separate Access points for ADHD and ASD referrals
- Neither ADHD or ASD services offer dual assessment
- Estates and IT provision are barriers to timely services

The report included 9 recommendations to improve services, but pertinent to Children's ASD service, include:

1. The HB should review access to pathways and processes to ensure equitable provision for both ASD and ADHD
2. The HB should review processes to facilitate the delivery of dual ADHD and ASD assessment
3. The HB should review how children accessing ASD diagnostic assessment can receive physical health screening
4. The HB to review arrangements for transition of CYP between children's and adult ASD and ADHD assessment should be clarified and strengthened to ensure that CYP are not disadvantaged in relation to waiting time or access to age-appropriate expertise.
5. The HB should ensure that patient administration systems are able to collect data to meet national reporting requirements. Services would also benefit from a review of their data needs to support and effective referral management and capacity and demand planning.
6. The HB may wish to consider ways to expand use of information technology to support timeliness and efficiency of information gathering and signposting at referral and along the patient pathway.
7. The HB should ensure the availability of accessible and appropriate accommodation for diagnostic assessment of CYP with sensory sensitivities and physical impairments.

## **Next steps**

A joint Action Plan will be formulated by the Neurodevelopmental Service for Children and Young People in collaboration with Child Health /Paediatrics to meet the recommendations outlined above over seen by the respective service leads - Ms Angela Lodwick, Assistant Director Mental Health and Learning Disabilities (MHLDD) and Ms Lisa Humphreys, General Manager.

The time scale for this is to be completed is during December 2023 and will be presented to the Director for MHLDD and Director for Operations for final approval at end of December 2024.

A series of meetings will be arranged to implement the actions within the stated time scales during 2024.

### Argymhelliad / Recommendation

For QSEC to note the report and agree for an update to be presented to the Committee on the action plan and progress in February 2024.

<b>Amcanion: (rhaid cwblhau)</b> <b>Objectives: (must be completed)</b>	
Committee ToR Reference: Cyfeirnod Cylch Gorchwyl y Pwyllgor:	2.3 Provide assurance that the Board has an effective strategy and delivery plan(s) for improving the quality and safety of care patients receive, commissioning quality and safety impact assessments where considered appropriate.
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	
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>	6. All Apply
Amcanion Strategol y BIP: UHB Strategic Objectives:	All Strategic Objectives are applicable
Amcanion Cynllunio Planning Objectives	
Amcanion Llesiant BIP: UHB Well-being Objectives: <a href="#">Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022</a>	4. Improve Population Health through prevention and early intervention, supporting people to live happy and healthy lives

### **Gwybodaeth Ychwanegol:** **Further Information:**

Ar sail tystiolaeth: Evidence Base:	
Rhestr Termiau: Glossary of Terms:	

Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Ansawdd, Diogelwch a Phrofiod: Parties / Committees consulted prior to Quality, Safety and Experience Committee:	
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--

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

# Children and Young Person's Neurodevelopmental Services All Wales Review

Hywel Dda University Health Board

September 2023

Mae Gwelliant Cymru, Cydweithrediad  
GIG Cymru, yr Uned Gyflawni, a'r Uned  
Cyflawni Cyllid bellach yn rhan  
o Weithrediaeth GIG Cymru.  
[www.gweithrediaeth.gig.cymru](http://www.gweithrediaeth.gig.cymru)

Improvement Cymru, NHS Wales  
Collaborative, Delivery Unit, and Finance  
Delivery Unit are now part of the NHS  
Wales Executive.  
[www.executive.nhs.wales](http://www.executive.nhs.wales)

## Context

Improving access to Neurodevelopmental (ND) services in Wales has been identified as a key Welsh Government priority. A recent independent review of all-age ND provision identified significant gaps in services and very long waiting times for assessment and support. Therefore, a three-year ND service improvement programme has been established by the Welsh Government to address immediate pressures within services as well as developing sustainable integrated needs-led services for the future. In addition to this review of HB services, a further review has been commissioned by WG to understand the extent to which the duties of the Code of Practice on the Delivery of Autism Services (WG21-60) are being met across agencies.

## Introduction to the review

As part of the ministerial programme of reform, the NHS Executive Performance and Assurance division have been asked to undertake a snapshot review of children and young people's neurodevelopmental services within all Health Boards across Wales.

The review aims to understand how services are organised including areas of consistency and variation between policy, performance, and clinical guidelines in each Health Boards service offer, waiting times, reporting arrangements, and performance management processes. The review also sought to identify factors challenging the delivery of timely assessment, and the actions taken by Health Boards to support and improve access and high-quality care.

Data collected from Neurodevelopmental Services in all Health boards in Wales will be collated to support the primary objective of the review to produce a national snapshot of current service delivery arrangements including factors that challenge and support performance. This information will be used to inform the ND ministerial improvement programme and support the determination of national actions to improve access to ND diagnostic assessment. Each Health board will also receive a report outlining alignment with key standards and reporting definitions, demand, performance against the target, and performance management and improvement actions. Improvement recommendations will be provided if applicable.

## The approach

The review consisted of three phases:

### Phase 1: Desktop Information (April & May 2023)

- Collection of desktop information from all HB's including completion of a structured excel workbook and a request to provide recovery plans, policies, and pathways where available.

### Phase 2: Fieldwork and Reporting (June to September 2023)

- Semi-structured interviews with service managers and clinical leads
- Analysis and triangulation of desktop information, interview findings, and nationally reported demand and waiting list data for each HB.
- Completion of local briefings reflecting service process and reporting arrangements to identify any variation between service delivery and reporting processes and national guidance, and a summary of recommendations outlining opportunities for improvement if applicable.

### Phase 3: National Report (September to November 2023)

- Following accuracy checking of local reports by HB's, a national thematic report will be produced for Welsh Government, aggregating key findings to produce national themes and provide recommendations to service and performance improvement.

# Report of Hywel Dda Neurodevelopmental Assessment Services for Children and Young People

This report provides an overview of Hywel Dda Neurodevelopmental Assessment Services for Children and Young People.

Desktop information was received from the HB on 28<sup>th</sup> April 2023. The Performance and Assurance Division met with representatives of the HB on the 7<sup>th</sup> June 2023.

## Key Findings

- The HB offer ASD and ADHD diagnostic assessments and meet or partially meet five out of the six All Wales Neurodevelopmental standards.
- The HB has separate access points for ASD and ADHD referrals. All Wales ND standards recommends a single point of access for ND referrals.
- The Hb has written information detailing referral pathways for ND assessment. There is some written information describing the assessment pathway, however, both services acknowledge that this is not comprehensive and have a plan to address this.
- The HB was not offering routine physical health screening for ASD assessment, however, other recommendations made by NICE were highly evident in both pathways.
- The service does not provide dual assessments of ADHD and ASD. Single assessments are accessed by separate referrals to the ND or ADHD service which may inhibit timely formulation of a CYP's ND diagnostic profile and needs.
- Reporting of referrals received and accepted is in line with reporting guidance. The ADHD service is currently unable to report referrals rejected.
- Referral demand and the number of referrals accepted for neurodevelopmental assessment has increased in keeping with the upward trend observed in the All-Wales data.
- The HB is not meeting the 26-week target for starting a neurodevelopmental assessment. Average waits for ASD assessment currently sit at 1.42 years and ADHD at 1.92 years. Longest waits were reported as 6.2 years (ADHD) and 4.13 years (ASD).



- Services are multidisciplinary. However, service leads reported there was insufficient overall administrative and clinical capacity to meet current levels of demand.
- Patients waiting for assessment are offered information and signposting advice. The ASD service has recently established a consultation service where families waiting for assessment can access single or multiple advice sessions from ND clinicians. The service reported that this has been well received by families and are keen to extend the offer.
- There are long waits for initiation of medication for CYP diagnosed with ADHD. At the time of review waits were approximately 92 weeks.
- The children's ND offer advice and signposting to CYP and their families following diagnosis but does not currently offer any other post diagnostic interventions.
- The children's ND service has arrangements in place to transfer referrals of CYP aged 17 years and 9 months to the adult ASD service however there is no agreement to transfer CYP already on the waiting list. Consequently, CYP approaching eighteen are expedited or assessed after the age of eighteen by the children's ND service.
- The ADHD service accepts referrals up to age 18. Assessments of CYP approaching their eighteenth birthday are prioritised where possible as there is no agreement for transfer to adult ADHD services who also face high levels of demand. This is a significant challenge for the service and consequently some CYP not assessed before their 18<sup>th</sup> birthday are referred back to the GP.
- Both services have performance management processes in place. At the time of the review, electronic data collection and activity reporting systems did not fully meet service capacity and demand planning needs.
- The children's neurodevelopmental (ASD) assessment service has undertaken extensive pathway review and have established capacity and demand forecasting and management processes.
- The ADHD service have validated waiting lists and are planning pathway review to improve equity of access across localities and waiting list management. The service plans to strengthen capacity demand management in keeping with processes in place across the wider paediatric service.
- Both services highlighted that availability of accessible rooms could be challenging.

- There are opportunities to deliver a service in Welsh, with some reliance on Language Line.
- Both services highlighted the need for enhanced partnership working and long-term investment in services to deliver a timely and needs based service.

## Recommendations

1. The HB should review access pathways and processes to ensure they are equitable for ASD and ADHD.
2. The HB should review processes to facilitate the delivery of dual ADHD and ASD assessments.
3. The HB should review how children accessing ASD assessment can receive physical health screening as part of the assessment process.
4. The ADHD service would benefit from continuing to progress their plan to review service pathways and embed capacity and demand management processes to improve equity, consistency, and efficiency.
5. Given the potential impact of delays in ADHD medication initiation on a CYP's social development and educational attainment, the HB should review processes and capacity to support timely initiation of treatment for ADHD.
6. Arrangements for transition of CYP between children's and adult ASD and ADHD assessment should be clarified and strengthened to ensure that CYP are not disadvantaged in relation to waiting time or access to age-appropriate expertise.
7. The HB should ensure that patient administration systems are able to collect data to meet national reporting requirements. Services would also benefit from a review of their data needs to support and effective referral management and capacity and demand planning.
8. The HB may wish to consider ways to expand use of information technology to support timeliness and efficiency of information gathering and signposting at referral and along the patient pathway.

9. The HB should ensure the availability of accessible and appropriate accommodation for diagnostic assessment of CYP with sensory sensitivities and physical impairments.

# 1. Clinical Service Model

## 1.1 Service Context

Local Health boards must:

- Provide access to services which can assess for autistic spectrum and associated conditions which take account of NICE best practice guidance for multidisciplinary involvement.
- Ensure the provision, publication and regular review of assessment and diagnostic pathways for children, young people and adults which take into account NICE best practice guidance.

***Code of Practice for the Delivery of Autism Services WG21-60 p.12***

Mental health services for children, young people and adults, and child health services, should form multidisciplinary specialist ADHD teams and/or clinics for children and young people. These teams and clinics should have expertise in the diagnosis and management of ADHD, and should:

- provide diagnostic, treatment and consultation services for people with ADHD who have complex needs, or where general psychiatric services are in doubt about the diagnosis and/or management of ADHD

***Attention deficit hyperactivity disorder: diagnosis and management. NICE guideline [NG87] (Section 1.1.2)***

The Health Board provide both autism (ASD) diagnostic assessment and attention deficit hyperactivity disorder (ADHD) assessment and treatment services for children and young people.

ADHD assessment is provided by locality-based Community Paediatricians and is delivered as part of a holistic medical assessment. Community paediatrics sit in the women and children's division. The service is operationally managed by the paediatric service delivery manager, and clinical leadership is provided by the divisional clinical director pending identification of a specific clinical lead role.

ASD assessments for CYP aged two to seventeen and nine months presenting with or without learning disability are provided by a standalone children's neurodevelopmental service (children's ND service). The service sits in the mental health and learning disabilities division. Operational management is provided by the neurodevelopmental service delivery manager who oversees the children's ND (ASD) diagnostic assessment service, adult ASD service, and the adult ADHD service. This new role was created to support the clinical governance of growing neurodevelopmental services facing increased demand across the age range.

The ADHD service has a detailed written referral pathway and process. At present, the ADHD assessment and diagnostic process is determined by locality community paediatrician clinical judgement. The service exploring how to enhance consistency between and across localities.

The ND service has developed a leaflet describing the ASD referrals and assessment process. A high-level flow chart outlining steps in the referral and assessment pathway and their alignment to all Wales neurodevelopmental (ND) standards is also available. The service reported that the development of a more comprehensive service specification was underway.

Both services are keen to expand joint working opportunities to improve patient experience of CYP who require both paediatric and mental health assessment as part of their neurodevelopmental assessment, however, access currently relies on separate referrals to each service. Services honour the original date of referral to either service for both assessments however the different service waiting times do not support joint formulation.

## Findings

- The HB has separate services for ASD and ADHD assessment.
- Services had written referral pathways, with ND additionally having an assessment flow chart and leaflet for service users.
- The HB does not offer dual ASD and ADHD assessments.
- Children's ADHD and ASD services are exploring opportunities to improve joint working processes to facilitate holistic assessments.

## 1.2 Access and assessment pathways

An all-Wales neurodevelopmental pathway for referral, assessment, and diagnosis of neurodevelopmental disorder was produced in 2016 by the Neurodevelopment Workstream Steering Group. The pathway sets out six high level standards based on the Code of Practice for the Delivery of Autism services.

An updated version of the standards produced in 2018 included two additional standards concerning the provision of follow up support and post diagnostic intervention. These have been challenging to implement due to high levels of assessment demand. Consequently, this review will aim to understand the alignment of HB service delivery processes and pathways with the 2016 standards as included on the Autism Wales website. However, a summary of follow up support and interventions provided will be described in the report.

### ***Standard 1: There is a single point of access for diagnostic assessment of all neurodevelopmental disorders***

Hywel Dda HB has separate points of access for ADHD and ASD assessment referrals.

Requests for ADHD assessment are directed to locality paediatric departments in Llanelli, Carmarthen, Pembrokeshire, and Ceredigion.

Autism assessment referrals are submitted to a single HB wide designated neurodevelopmental (ASD) service e-mail inbox.

Where a CYP presents with suspicion of ASD and ADHD at referral, referrals must be made to both services.

#### **Finding: Standard 1 not met**

- Hywel Dda has separate points of access depending on clinical presentation.
- The HB has a single point of access for ASD assessment and multiple points of access for ADHD assessment.

***Standard 2: The decision as to whether to accept a referral or not is made on the quality of information provided (as outlined in NICE guidelines). Where there is adequate information to support concern access should not be subject to permitted referrers, the use of screening questionnaires or other specifications.***

Both services have a referral form requesting information about reason for referral, presenting behaviours and features indicative of a neurodevelopmental disorder, family functioning, and prior assessments and interventions. The ND referral form also requests information about any identified risks to the child or others.

Both services promote screening and information gathering in early years settings and schools to identify what needs-based interventions may be helpful and should be offered before or alongside a referral for diagnostic assessment.

For ADHD, pre-referral requirements depend on age and clinical presentation. Pre-school children are screened by a Health Visitor or GP using tools such as the Family Resilience Assessment Instrument and Tool (FRAIT) and Schedule of Growing Skills (SOGS). The ADHD assessment service prefers school aged children to be referred by education and requests a summary of teacher assessments and interventions, completed school reports, and the SNAP IV teacher and parent questionnaire as part of the referral.

For children presenting with features indicative of global developmental delay and ADHD, the pathway recommends a referral to the community paediatrician. Referrers are advised to refer children presenting without suspicion of developmental delay to the family support service (TAF) to access tailored interventions and parent training programmes prior to making a referral for ADHD. However, there is flexibility in the system to support referral of CYP with severe impairment to their functioning before recommended steps in the referral pathway have been completed.

The ND (ASD) service accepts referrals from any registered professional. A joint multiagency pathway like the early years ADHD pre-assessment screening and support pathway has been developed with Pembrokeshire local authority (LA), however this is not yet in place with all LA's. The ND (ASD) service does not require any specific screening tools be completed to make a referral in other local authorities or age groups; however additional information may be requested from the referrer if there is insufficient information to outcome a referral.

Individual locality community paediatricians triage ADHD referrals on a weekly basis, although frequency may sometimes vary depending on paediatrician capacity. The child's global presentation is considered before determining whether there is a specific requirement for ADHD or other developmental assessments. Paediatricians may consult with other MDT colleagues for complex referral presentations. Although

limited measures are in place at present to support consistency across paediatric localities, the service is exploring the potential to introduce joint triage of ADHD referrals across local authority areas to mitigate variation in thresholds and/or referral outcomes.

The ND (ASD) service triage referrals on a weekly basis. Triage is conducted by a single experienced clinician. A checklist based on the ICD-11 criteria is used to support consistency. The team leader is available to provide consultation and/or advice to the triage clinician. Further information may be requested following the initial referral triage with the waiting time clock paused until information has been received.

**Finding: Standard 2 met with opportunity for improvement**

- HB neurodevelopmental assessment services have a standard referral form and request additional information aligned to NICE Guidance recommendations.
- The ADHD pathway includes preferred screening and referral sources however there is flexibility to support access for CYP with severe impairment.
- The service does not currently accept self-referrals.
- The ND (ASD) service has processes in place to support consistent referral decision making.
- A decision to accept or reject an ADHD referral is based on individual clinician judgement. The service is considering how to improve consistency of approach.

***Standard 3: When referrals are not accepted, the referrer is provided with a rationale for this, alongside advice on how to improve the referral or which other service to refer to as appropriate***

When a referral is not accepted for assessment, the referrer is informed of the reason in writing. Referrers are given the opportunity to provide additional information when a service is not accepted due to insufficient detail. The children's ND (ASD) assessment service include parents in referral outcome responses enabling them to follow up or provide the additional information if able.

When a referral is declined due to not meeting the referral criteria, the ND (ASD) and ADHD service provide alternative suggestions and signposting advice where applicable.



### **Finding: Standard 3 met**

- Additional information may be requested from parents or referrers if required.
- In the event a referral is not accepted, a rationale for referral rejection is given and advice and/or signposting to alternative sources of support is provided.

### **Standard 4: Assessments are planned in a child centred way ensuring sufficient information to create a profile of the child's need is gathered (as outlined in NICE guidelines), whilst ensuring a prudent, flexible approach to the use of resources.**

*NICE Guidance for ADHD diagnosis and management (NG87) recommends that diagnostic assessment includes a clinical and psychosocial assessment including behaviours and symptoms across multiple domains, a developmental and psychiatric history, and include observer reports and assessment of a mental state. Rating scales and school observations may provide valuable adjuncts in the event of diagnostic uncertainty.*

In addition to the information gathered at referral, completed parent and teacher Connor's rating scales are also requested prior to the first appointment. CYP may also be offered a QB test.

The paediatrician conducts a general assessment during the first half of the appointment which is considered alongside the developmental and behavioural information gathered to decide whether full ADHD assessment is indicated. In the event it is, further information may be gathered during the second half of the appointment, or a second appointment may be arranged where there is diagnostic uncertainty or need for further investigations.

*NICE Guidance for ASD in under 19's: recognition, referral, and diagnosis (CG128) recommends allocation of a single point of contact/care coordinator during the assessment process, collection of information about parental and CYP concerns and current functioning across domains, developmental history based on diagnostic criteria, interaction with and observation of the child, medical history and physical examination, and consideration of differential diagnosis.*

The service collects information from a range of sources to support the diagnostic process. The admin team coordinate the completion of parent and school questionnaires and request child health records for the assessing clinician to collate a developmental history and understanding of the presenting concerns. Following review of the information, the clinician may contact the parent/guardian to obtain any further information required.

A face-to-face observation using a standard service template or full ADOS assessment is provided in clinic, depending on the individual CYP's needs and presentation. On occasion, both may be required. School and home-based observations, speech and language, sensory and cognitive assessments may be requested on a case-by-case basis to aid formulation.

Children under five are referred to the community paediatric department for a medical assessment, however the medical screen does not always occur before the diagnostic assessment takes place. Over fives are not routinely assessed by a paediatrician, though child health notes are reviewed and referrals for health investigations may be made on a case-by-case basis.

### **Dual**

The service does not currently offer dual assessments. Separate referrals must be made for ADHD or ASD assessment. Developmental assessment completed by one service may be used by the other to avoid duplication of information gathering.

#### **Finding: Standard 4 partially met**

- The health board provided written or verbal evidence suggesting that assessment information gathered is largely aligned to NICE Guidance.
- Further assessments and observations may be completed or requested in the event of diagnostic uncertainty.
- The HB reviews child health records but does not routinely include recommended medical screening as a component of assessment for CYP over the age of five.
- The service does not offer dual ASD/ADHD assessments.
- Service pathways have built in flexibility to add or remove assessment components matched to a CYP's need or presentation to support prudent use of resources.

***Standard 5: There is a timely multi-disciplinary discussion (NICE/ ICD-11/DSM 5) involving all those involved in the assessment process which leads to a decision about the outcome of the assessment, and a profile of the child's strengths and difficulties.***

#### **i) ADHD**

Diagnosis is made by the assessing community paediatrician. Diagnosis may be given on the day or at a second appointment.

## **ii) ASD**

The process for diagnostic discussion depends on complexity and age. For over fives, the service has weekly MDT panels consisting of three or more disciplines for complex cases. Routine slots are also available if an opinion is required from a specific attending discipline. Where there is less complexity and/or diagnostic certainty, two clinicians may convene a “pop up panel” to support timely diagnosis and feedback to the family. Under-fives are discussed at a monthly MDT panel.

The ASD diagnostic report outlines the CYP’s profile. Follow up appointments may be offered on a case-by-case basis to develop detailed strengths and challenges profile with family/carers and CYP, however this is not a standard part of the pathway.

### **Finding: Standard 5 partially met**

- Diagnosis of ADHD is made by a paediatrician with experience in the assessment and diagnosis of ADHD who may also seek consultation with a broader MDT as required.
- The children’s ND (ASD) assessment service has access to a wide range of recommended disciplines. Diagnostic decisions are made by more than one discipline and clinicians may access a larger MDT panel to discuss complex cases.
- Strengths and difficulties profiles are completed with families offered a follow up by the ND service, but this is not a standard step in the pathway for all CYP.

***Standard 6: A professional who has been involved in the assessment process will communicate the outcome of the assessment with the family (and where appropriate the child). This is followed up in writing, and where consent is given, should be shared with other professionals who support the child. For children who have received a diagnosis, advice about how best to meet the child’s needs and support or signposting is provided.***

## **i) ADHD**

Feedback is given at the end of the first or second appointment. A standard clinical letter is written outlining the diagnosis and recommendations which may also include signposting to alternative sources of support.

## ii) ASD

A face to face or virtual feedback appointment is offered depending on the preference of the family. The feedback appointment can take between 45 and 90 minutes and may involve one or more clinicians depending on the CYP's presentation and family's needs. Following agreement of outcome, a report including summary of the assessment and findings, diagnostic profile, and recommendations for further support is provided.

### Finding: Standard 6 met with opportunity for improvement

- Verbal and written feedback of diagnostic outcome and recommendations is provided.
- The structure and detail of written feedback is not currently consistent across ASD and ADHD assessment services.

## 2. Interventions

### Nice Guidance (ADHD – NG87) recommends:

Children under 5: offer ADHD focussed group parent training programme and seek tertiary/specialist advice and consultation if group interventions are not effective

Children over 5: Give information and support through brief one to one or group-based session, consider parent training/individual programmes of support in presence of oppositional defiant/conduct presentation, or medication if significant impairment exists after environmental modifications have been implemented.

### NICE Guidance (ASD – CG128) recommends:

Provision of individual information or support available locally according to the family's needs.

Medication is the primary post diagnostic intervention for CYP who receive a diagnosis of ADHD. The average wait for prescribing is 92 weeks with 154 CYP waiting at the time of review. The service is unlikely to commence prescribing for CYP aged 16+ before their 18<sup>th</sup> birthday due to length of wait. An additional nurse prescriber is being trained and the service is in discussion with GPs to explore shared care for follow up prescribing as initiation, titration, and follow up is currently delivered in service.

E-prescribing has been introduced to increase efficiency, however, the service is hoping to reach a shared care arrangement soon to enable more timely prescribing for newly diagnosed CYP.

Post ADHD diagnosis, families may also be offered follow up with the paediatrician or another member of the MDT for advice, and/or be referred to other agencies such as team around the family (TAF) to access behaviour management support.

The children's neurodevelopmental assessment service does not currently provide post diagnostic intervention; however, families are signposted to sources of advice and support available from other services in keeping with the guidance.

The mental health division and women's and children's service are exploring jointly establishing a behaviour support service/pathway for CYP with ND conditions.

#### **Findings: Interventions**

- The HB offer access to information and support through post-diagnostic signposting, in addition to scheduled or patientt initiated follow up with a paediatrician or ADHD nurse.
- The HB offer pharmacotherapy for ADHD however there are capacity constraints impacting on the timeliness of access to this intervention.
- Children diagnosed with ASD are provided with person centred advice and signposting information.
- HB ND services are exploring joint development of a behaviour support service.

### **3. Equality and Diversity**

The service reported that requests are rarely made for assessments through the medium of Welsh, however, they can offer assessment in Welsh if requested. Services have access to language line and a HB translation service for languages other than English.

Services ask whether a CYP or family member has any additional support needs at referral and try to make arrangements to accommodate physical or cognitive impairments where indicated. The paediatric team can access members of the wider child health workforce for additional support including play therapists and staff who can use sign language.

Access and appropriate accommodation was reported as the primary barrier to offering person-centred services to CYP and families with additional needs or sensory issues associated with an autism spectrum disorder presentation. The ADHD service highlighted that clinics delivered in portacabins could be difficult to access for service users with physical impairments. In the event an appropriate environment is not available, the ASD service may do home visits.

## **4. Transfers & Transitions**

### **4.1 Second opinions**

Both services accept second opinion requests. Community paediatrics accept requests from referrers and families and may refer to another paediatrician if accepted. The ND (ASD) assessment service accept second opinion requests from referrers only and have an arrangement with the CAMHS service to provide second opinions.

### **4.2 Validation of external assessments**

Requests to validate an ADHD diagnosis for the purpose of ongoing prescribing or review are assessed by the community paediatrician. If satisfied that the information provides evidence of sufficiently robust adherence to diagnostic assessment processes the service will see the CYP without another assessment.

The children's ND (ASD) service reported that education can be reluctant to accept private ASD diagnoses and that they may be asked to ratify the validity of an external assessment. Information is reviewed by the ND service MDT panel to ensure adherence to evidence-based assessment processes. In the event there is insufficient information, the family or referrer will be asked to obtain additional information or make a referral for re-assessment.

The intention to commission an external provider to deliver ASD assessments has been discussed with education colleagues and assurance given that standards and processes have been stipulated within the tender and are subject to regular review and scrutiny to ensure they meet quality standards.

### **4.3 Transition to Adult Services**

#### 4.3.1 Transitions or transfer at referral stage

Community Paediatrics accept referrals for ADHD assessment for CYP up to the age of eighteen. Referrals for ASD assessment for CYP 17 years and 9 months or older are forwarded to the Integrated Autism Service.

#### 4.3.2 Transition or transfer of CYP on waiting list for assessment

CYP aged sixteen and seventeen years old on the ASD waiting list are prioritised to support before they turn eighteen where possible. In the unusual event that a CYP turns eighteen whilst waiting, assessment will be completed by the children's service rather than transfer a CYP to adult services.

Assessment of CYP on the waiting list for ADHD and nearing transition age was reported to be a significant management challenge for the community paediatric service. As with the ND service, the department will expedite assessments of transition aged young people where possible. There are currently no arrangements in place for transfer to the adult ADHD service established in the HB. It was reported that the adult ADHD service also has significant capacity challenges and waits at triage, assessment, and treatment stages of the pathway due to elevated levels of demand for the service. As paediatricians are not trained to conduct adult ADHD assessment, some CYP may be discharged back to the GP to make alternative arrangements or referrals if the paediatric service is unable to provide an assessment before their 18<sup>th</sup> birthday.

#### Findings: Transitions and Transfers

- Services have a second opinions process.
- The HB receive requests to validate external ADHD and ASD assessments and have processes in place to facilitate this.
- Referral acceptance arrangements for young adults varies between ADHD and ASD services.
- Services aim to prioritise young adults approaching transition age as there is no agreement for transfer to adult assessment services without extending a CYP's waiting time.
- CYP awaiting ADHD assessment may be discharged back to GP without assessment if they are still waiting at 18.

## 5. Reporting

Local Health boards must:

Ensure the collection of information on waiting times for assessment for children, young people and adults complies with current national waiting time standards for autism assessment and diagnosis **Code of Practice for the Delivery of Autism Services WG21-60 p.12**

ADHD referrals are placed on WPAS and assigned an ADHD clinical condition code within the community paediatric waiting list for initial medical assessment. The clinical code enables data to be extracted for reporting and performance management purposes. The service is unable to capture rejected referrals at present. Data is validated by the service delivery manager prior to submission of national report.

At the time of review, ASD referral, rejection and waiting list data was being recorded on an excel spreadsheet. However, the service had recently migrated to WPAS and hoped that data could be managed and activity retrieved from the patient administration system in time. Data is validated monthly by the assistant director, supported by an information analyst and service/team lead.

The reporting guidance requires HBs to report data on referral demand, number of CYP on a waiting list for assessment and how long they have waited up to and over 52 weeks.

- i) Number of neurodevelopmental referrals received by the neurodevelopmental service during the month and number of referrals rejected at triage.*

The service reports number of referrals received for ASD and ADHD. Number of ASD referrals rejected are reported, however, the HB is unable to meet this reporting requirement for ADHD due to the electronic data collection system in use. They hope to rectify this issue in the 23/34 fiscal year.

- ii) Number of patients waiting to start an ADHD or ASD neurodevelopmental assessment. Clock start is defined as the date the referral is received by the service.*

ASD and ADHD referrals are registered as waiting from the date the referral was received by the service in line with reporting guidance.



- iii) Reporting guidance advises that CYP can be removed from waiting status on the date of the first face to face or virtual attendance at the first appointment of the assessment process (may be with parent/guardian only).**

CYP waiting for ADHD assessment are removed on the date of the first face to face appointment in keeping with the reporting guidance.

For ASD assessment, the service has reviewed its assessment pathway to improve efficiency and patient experience resulting in most of the clinical history and presentation data being collected before the first appointment. This includes seeking written and if required verbal reports over the telephone from parents or carers. The CYP is removed from the waiting list once pre-assessment information and questionnaires have been received. The service reported that there are no significant delays between this date and the first appointment date for observation of a child's interactions and presentation.

#### **Findings: Reporting**

- Reporting of referrals received by the service is adherent to reporting submission guidance.
- Number of referrals rejected by the ADHD service is not currently included in reported data.
- The ASD clock stop reflects an alternative service model adopted to improve prudent use of resources and patient experience where information is collected virtually prior to the first face to face appointment.
- Data is captured using a combination of manual and electronic patient administration systems and reported data is validated by a manager prior to submission.

## **6. Demand and Capacity**

### **6.1 Demand**

The number of children and young people referred for a diagnostic assessment in neurodevelopmental services has been reported nationally since 2020 (Figure 1). Data has been sourced from monthly HB data submission reports.

The number of referrals received by HD can be seen in Figure 2. Although there is fluctuation in monthly referral demand, data shows an upward trend over the past twelve months with 1628 referrals received between August 2022 and July 2023 compared to 1063 over the same period during 2021/22.

Fig 1

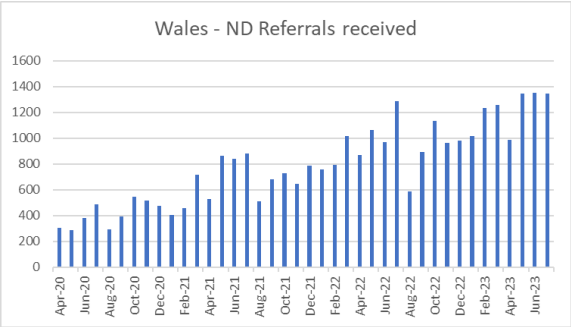
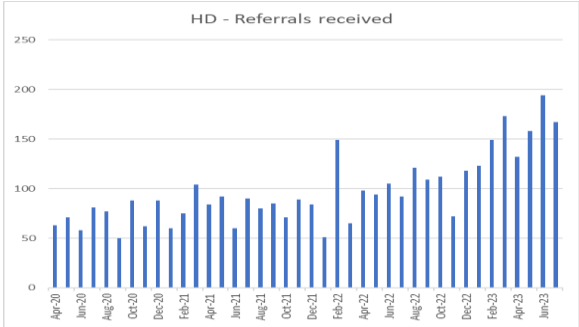


Fig 2



The number of children and young people accepted on to the waiting list for a diagnostic assessment across Wales can be seen in figure 3. In keeping with the All Wales picture, HD accepted a higher number of referrals over a three-month period between May and July 2023 than ever before. Number of referrals accepted was also higher between August 22 and July 23 with 1374 accepted during that period compared to 1020 between August 21 and July 22 (Figure 4)

Fig 3

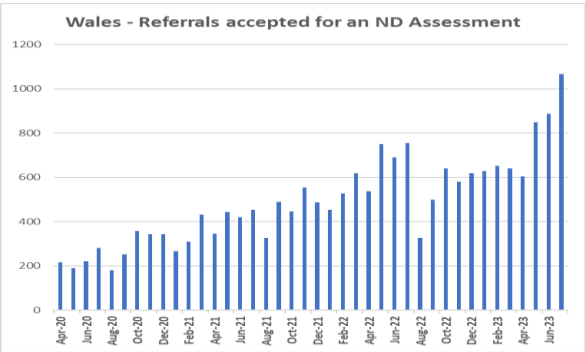
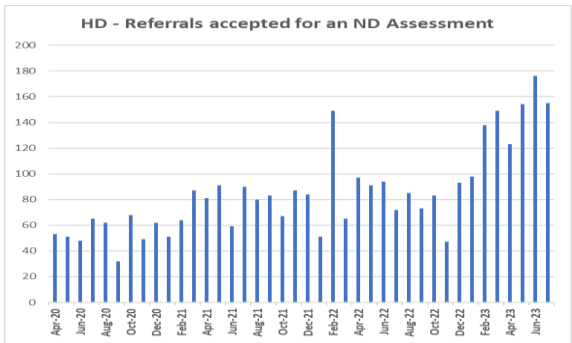


Fig 4



This evidence suggests that the service is facing increasing demand for triage which includes clinical review of referral information, seeking further information where required, and provision of advice and signposting letters for outcomed referrals, in addition to increased demand for the diagnostic assessment process itself.

### Findings: Demand

- Referrals received broadly reflects the upward trend in demand seen on an All-Wales basis
- The service received and accepted significantly more referrals in the twelve months preceding the review (Aug-22 – Jul-23) than in same time the previous year (21/22)
- Demand increases present significant capacity challenges across the patient pathway including triage, waiting list support and management, feedback and reporting stages, as well as capacity for diagnostic assessment stages.

## 6.2 Workforce

ADHD assessments are delivered by consultant and middle grade community paediatricians as part of their overall community paediatric caseload. An ADHD nurse also provides follow up support and prescribing capacity.

Although recruitment was not considered a challenge, the service reported that the current budget inhibits access to sufficient administrative support and a broader skill mix. Though the team has limited access to a small child health psychology service for advice, further investment in psychology, behaviour support, and occupational therapists who can provide sensory processing assessments and interventions would be welcomed by the service.

Table 1: ADHD assessment & treatment workforce

Clinical Role	Budgeted WTE	Actual WTE	Comment
Community paediatrician (consultant)	5.5	5.5	Not ADHD specific - covers locality community paediatric caseload
Community paediatrician (middle grade)	3.6	2.6	Not ADHD specific - covers locality community paediatric caseload
ADHD Nurse (6)	2	1	
<b>Total</b>	<b>11.1</b>	<b>9.1</b>	
Managerial/Administrative support	Budgeted WTE	Actual WTE	Comment
Service delivery manager - community paediatrics	1	1	Covers community paediatric service as a whole
Administrative staff			Community paediatric admin
<b>Total</b>	<b>1</b>	<b>1</b>	

The children’s neurodevelopmental assessment service is multidisciplinary and includes nurses, occupational therapists, speech and language therapists, clinical psychology, and has access to a consultant psychiatrist and community paediatricians who input to the MDT diagnostic panel. The service is overseen by a team leader and service manager and is supported by two administrative staff, although one post was vacant at the time of data collection. The service is also commissioning an external provider to deliver 379 assessments between March 2023 and March 2025.

The team report that recruitment can be challenging due to the limited pool of specialist staff available. Consequently, they are exploring developmental “grow our own” band six practitioner career pathways. Capacity demand modelling conducted by the service suggests an additional 3WTE administrative staff, 3 WTE Band 6 neurodevelopmental practitioners, 1 WTE occupational therapist, 0.6-1WTE additional community paediatricians, and 2WTE health care support workers are required to meet the increased demand faced by the service.

Table 2: ASD assessment workforce

Clinical Role	Budgeted WTE	Actual WTE	Comment
Team Leader (7)	1	1	70 / 30 % clinical managerial split
Nurse (7)	1.6	1	
OT (7)	2	2	
SALT (7)	1.21	1.21	
Psychology (8B)	1	0	No direct assessments - attends MDT panel
Medical (Cons)	0.54	0.36	
<b>Total</b>	<b>7.35</b>	<b>5.57</b>	Vacancies/sickness/maternity leave
Managerial/Administrative support	Budgeted WTE	Actual WTE	Comment
Service manager (8B)	1	1	Also covers Adult ASD & ADHD service
Administrative staff (3)	2	1	
<b>Total</b>	<b>3</b>	<b>2</b>	

<b>Findings: Staffing Capacity</b> <ul style="list-style-type: none"> <li>- ADHD assessments are delivered by community paediatricians as part of their locality community paediatric caseload; however, they have access to</li> </ul>
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

an ADHD nurse and other child health disciplines in the wider service if needed.

- The children's neurodevelopmental (ASD) service is multidisciplinary and includes nurses, occupational therapists, SALT, psychology, and medics.
- Actual capacity in both teams is less than budgeted capacity due to vacancies, sickness, and maternity leave.
- Both services report insufficient administrative and clinical capacity to meet current demand.

### 6.3 Capacity demand management

The service reported that there was limited ADHD capacity and demand planning in place. However, at the time of review, there was a plan to start discussing job plans at business meetings alongside starting a capacity demand modelling process.

CYP are allocated to clinicians in chronological order of entry to the waiting list for an initial medical assessment other than if expedited for an urgent appointment. Allocation occurs when a new clinic appointment becomes available.

Significant capacity demand and flow improvement work has been undertaken within the children's neurodevelopmental (ASD assessment) service with a focus on understanding capacity and demand, using resources effectively, and reducing delays in completing active diagnostic assessments. The service has introduced response and completion timescales within the assessment pathway and have diarised available assessment slots each month based on a clinician's forecasted capacity.

Cases are allocated in chronological order other than for CYP who are under 5 years old or meet criteria for being expedited.

#### Findings: Capacity & Demand

- Work to establish more effective capacity demand management and modelling is currently underway in the ADHD service.
- The children's neurodevelopmental (ASD) assessment service has completed substantial work to improve capacity demand understanding and management to support access, flow, and forecasting.
- IT capability inhibits data availability for capacity and demand planning in the community paediatric service (section 4)

## 7. Waiting List Management & Booking Processes

### 7.1 Waiting List

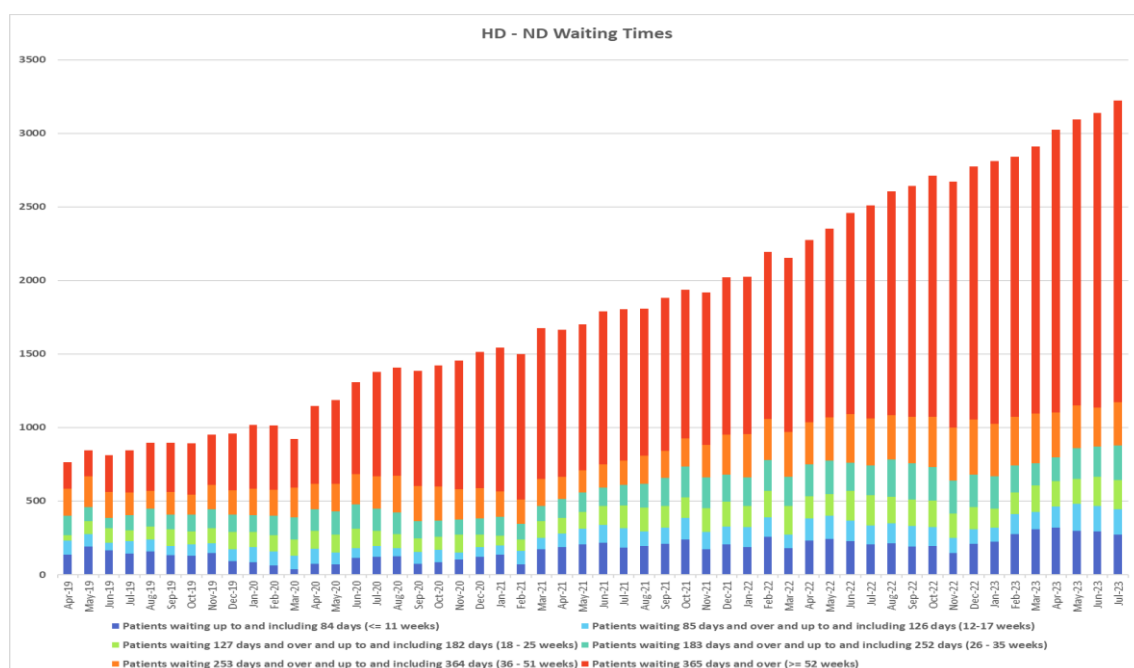
Local Health boards must:

Comply with current national waiting time standards for assessment and diagnosis and deliver diagnostic assessment within 26 weeks of referral. **Code of Practice for the Delivery of Autism Services WG21-60 p.12**

Reporting guidance indicates that first assessment appointment is considered the point at which a CYP is no longer considered waiting.

The number of children and young people on the waiting list for a diagnostic assessment in neurodevelopmental services has been reported nationally since 2019. Across Wales the waiting list has grown from 4561 children and young people in April 2019 to 14,332 in July 23. Showing a similar upward trajectory, the neurodevelopmental waiting list in HD has grown from 763 in April 2019, to 3224 in July 23 (Figure 5)

Fig 5



## **7.2 Organisation of the Waiting List**

There are currently separate waiting lists for ADHD and ASD assessment.

CYP accepted for ADHD assessment are added to generic locality community paediatric waiting list for initial medical assessment. The service is aiming to develop a single waiting list across localities. Guiding principles based on risk and impairment and clinical judgement is used to prioritise CYP on the waiting list.

The ASD waiting list is separated by age. Under-fives sit on a sub-list as they are allocated to specialist under-five's clinicians within the ND (ASD) diagnostic team. Children under five are also referred to community paediatrics for medical screening and may sit on both lists simultaneously. Young people over the age of seventeen are prioritised to facilitate assessment before their eighteenth birthday. CYP aged five to 17 are not prioritised and are booked in chronological order unless they meet criteria for being expedited.

## **7.3 Arrangements for expediting CYP on the waiting list.**

CYP waiting for ADHD assessment are expedited on a case-by-case basis. Clinicians consider factors such as risk of family breakdown, complexity, and overall impact on a CYP's functioning. If a decision is made to expedite, the CYP will be booked into the next available clinic.

The ND (ASD) assessment service prioritise existing expedite requests over routine cases to address the backlog that has developed prior to implementing a new approach to their management. The service now reserves slots for cases where a decision to expedite has been made to enable a timely response maintaining the flow of routine cases. The service has a set criteria and triage form to support new expedite decisions and aim to see CYP who are urgently prioritised within 6 weeks of the request.

## **7.4 Waiting Times as at 31.3.23 snapshot reported by the HB**

HBs are asked to report numbers waiting up to and including 11 weeks, 12-17 weeks, 18-25 weeks, 26-35 weeks, 36-51 weeks, and over 52 weeks.

Current reporting does not request length of longest waits if over 52 weeks. The review requested a snapshot of average and longest waits as of 31.3.23.

Table 3 shows average and longest waits per clinical condition. As of 31<sup>st</sup> March 23, the HB had significantly more CYP waiting for an ASD assessment with an average waiting time of 1.42 years and a longest wait of 4.13 years. However CYP were waiting longest for ADHD assessment with average waits at 1.92 years and the longest at over 6 years.

Of the total number of CYP waiting for neurodevelopmental assessment, 64% had been waiting over 52 weeks.

Table 3

Suspected Clinical Condition	Number on List	Longest Wait (weeks)	Average Wait (weeks)
ADHD	433	326 (6.2 years)	100 (1.92 years)
ASD	2478	215 (4.13 years)	74 (1.42 years)

7.5 Support for CYP on the waiting list

People on the autism referral pathways must be offered support whilst awaiting assessment, this includes the provision of clear information on the diagnostic process and the autism condition, in plain language format with consideration given to first language, ethnicity and cultural differences.

**Code of Practice for the Delivery of Autism Services WG21-60 p.8**

All children on the Community Paediatric waiting list pre-December 2022 were contacted by letter by the waiting list support service offering written signposting information and an opportunity to access telephone advice and support. The service is also developing an information pack to be sent to all CYP waiting for ADHD assessment. Additional funding has been requested to increase nursing capacity to enhance the availability of pre assessment support.

CYP waiting for ASD assessment receive a letter signposting them to advice and alternative sources of support. The service sends keeping in touch letters every three months to reassure families that they are still on the waiting list and has established a weekly consultation rota enabling families to contact the service to discuss any challenges or concerns. Consultation slots are reported to be well used with families providing positive feedback and on occasion no longer requiring



assessment. Families can access single or multiple consultations depending on their needs. The ND service is also keen to strengthen their pre-assessment consultation model to support a more needs led approach and have applied for funding for a band six clinician and support worker.

## 7.6 Booking and referral management

No opt in process is required for admission to the ADHD assessment list. Prior to being offered an appointment for ASD assessment, families and carers are asked to complete pre-assessment information questionnaires. Return of the questionnaire denotes opt in from the family. Failure to return the questionnaire following a reminder may result in the CYP being removed from the waiting list.

Appointment booking is admin led in both services with a combination of full and partial booking processes used for initial appointments. Follow up appointments are booked by the administrative team.

Clock stops for DNA are not applied to CYP waiting for ADHD assessment. The clock is re-set when a family does not attend for ASD assessment.

Removal from the community paediatric waiting list is clinically led in all circumstances. For ASD assessment, removal following non-return of pre-assessment information is an admin led process and discharge or removal following non-attendance is a clinically led decision.

Neither service has a text reminder system in place, however families on the ASD waiting list are contacted by telephone to remind them about the appointment. A text-based system is being trialled in the mental health division with a view to future roll out to the children's neurodevelopmental (ASD assessment) service.

### Findings: Waiting list and booking processes

- The waiting list has increased in keeping with All Wales trends.
- The HB is not meeting the 26 week performance target.
- Access to ADHD and ASD assessment is not equitable. The longest wait for ADHD at the time of review was 6.2 years and for ASD was 4.13 years. Average waits were almost 2 years and 1.5 years for ADHD and ASD respectively.
- Clock re-sets and removals differ between services.
- All CYP are given signposting information and advice whilst waiting for an assessment. The ASD assessment service has established a consultation line for families seeking advice.

- There is a criteria and an agreed process for expediting CYP.

## 8. Performance Management and Improvement

### 8.1 Performance management arrangements

Both services have performance assurance and management processes in place at team, service, and divisional levels.

ADHD waiting lists are reviewed weekly at team level to identify long waiters and CYP approaching their eighteenth birthday. Waiting lists are reviewed every two to four weeks by the women and children's service management team and discussed at monthly divisional service meetings.

Referral rates and triage progress is checked weekly by the children's neurodevelopmental service/team lead. Two to four weekly service level meetings led by the service manager and assistant director provide oversight of service and externally commissioned activity, capacity, demand, and waiting times with performance reported at monthly BPPAG meetings.

### 8.2 Performance Improvement strategies undertaken/planned

The ASD service highlighted that backlog and steady state demand significantly outstrips service capacity to deliver assessments within the 26-week waiting time target. The ADHD service reported that it would be able to meet incoming demand if the backlog were addressed.

Actions undertaken to support performance and/or quality in the face of increasing demand include:

#### ***i) ADHD service***

- Extensive waiting list validation including identification of support needs for CYP and families waiting.
- Development of ADHD support information pack in progress.
- Planned capacity and demand planning i/c job planning, skills matching clinical presentation to paediatrician, review of allocation to localities to enhance equity of access.
- Recruitment and training of nursing staff including non-medical prescribing to support timely follow up and prescribing.
- Improving data capture and booking systems to inform capacity and demand planning and improve reporting and booking processes.

- Discussions with GP's around establishing shared care to facilitate timely initiation and titration of ADHD medication.

## **ii) ASD service**

- Pathway review introduced up front information gathering reducing the standard number of face-to-face appointments needed. More face-to-face appointment or telephone contacts can be incorporated on a flexible basis determined by clinical need.
- Introduction of information gathering templates to support consistency within the triage and assessment process.
- Selective use of time intensive ADOS assessments – using only when information indicates the need for a more in-depth observation to aid diagnosis or formulation.
- Introducing 'pop up' MDTs whilst retaining access to a wider MDT for complex cases or where there is diagnostic uncertainty.
- Skills matching – deploying clinicians with early years specialism for under-five's assessment and diagnosis to improve quality and efficiency of diagnostic processes.
- Reducing the length of diagnostic reports & introducing a timescale for completion.
- Expediting appointments on a case-by-case basis ratified at weekly MDT to ensure proportionate response and prevent build-up of an additional waiting list.
- Investment in improving access to consultation to support CYP and families waiting for an assessment.
- Clarification of the pathway for CYP in SCAMHS requiring ND assessment.

## **iii) Both services**

- Exploring joint investment in behaviour support service
- For CYP placed on both service lists or referred to the other following an ADHD or ASD assessment, initial date of referral to either service is honoured.

### **Findings: Performance Management and Improvement**

- Both services have performance management and oversight processes in place at team, service, and divisional level.
- The children's neurodevelopmental (ASD) assessment service has established capacity demand management processes and undertaken pathway re-design to improve quality and efficiency.

- The ADHD service have a plan to enhance capacity and demand management, equitable access, and enhance the support offer for CYP waiting for an assessment.

## 9. Barriers and Enablers

The service was asked to describe challenges and factors that enabled them to deliver timely access and high-quality assessments.

### i) Information Technology

Neither service had a fully operational IT system that can capture the service data required and run reports to support national reporting requirements and waiting list management. Both services anticipated that recent or imminent developments would assist them to move closer to the use of electronic system and improve the breadth and reliability of data available.

The service suggested that access to IT resources to enable delivery of an online offer similar to that of the external provider commissioned could support more prudent use of service resources and enhance choice for service users.

The service felt that IT solutions to streamline completion and collection of questionnaires reducing delays incurred by postal and paper-based systems would be helpful. Introduction of QR codes on consultant letters to provide access to electronic signposting and advice information had also been considered.

### ii) Estates

Access to appropriate rooms can be challenging for both services.

### iii) Partnership working

Partnership working was considered a challenge and an enabling factor. Achieving shared recognition and commitment with partners to develop a needs led support service for CYP that was not wholly dependent on diagnostic assessment was considered a critical step to providing timely support to CYP.

### iv) Investment and Support

Both services described the positive support they had received from senior managers within the division and health board. Whilst welcoming national investment and strategic planning, the service was concerned that the current short term funding model and award process was unlikely to enable the service growth and transformation required to improve access. The ADHD service also reported that

being outside the mental health division had meant they had not had access to previous mental health SIF funding investment received by the HB.

Services highlighted the need to increase clinical staff from a range of disciplines in addition to increasing administrative and clerical posts to enhance clinical capacity by reducing the current admin demands placed on clinicians.

#### **v) Recruitment**

The children's neurodevelopmental assessment service reported recruitment challenges across disciplines and are exploring options for training and development posts which will require release of internal capacity to ensure appropriate supervision. This is challenging due to the focus on addressing the current backlog but was considered a critical enabling factor for sustainable performance improvement.

## **Conclusion**

The review aimed to understand how services are organised including areas of consistency and variation between policy, performance, and clinical guidelines in each Health Boards service offer, waiting times, reporting arrangements, and performance management processes. The review also sought to identify factors challenging the delivery of timely assessment, and the actions taken by Health Boards to support and improve access and high-quality care.

The service expressed strong commitment to needs led person centred approaches. In keeping with the All-Wales picture, HD ND assessment services have faced an increase in referral demand and accepted referrals constraining capacity to meet incoming triage, assessment, and follow up demands. Consequently, there are long waits for ASD and ADHD assessment, in addition to post diagnostic prescribing for ADHD. The review also found inequity of access to the service and medical screening, waiting times, and transition processes between ASD and ADHD services. Additionally, CYP requiring assessment of both conditions must access both pathways, inhibiting timely holistic diagnosis and formulation. The review recommends the HB explore opportunities to improve equity across pathways to ensure CYP are not disadvantaged by age or clinical presentation.

Despite demand challenges, services demonstrated a high degree of commitment and desire to provide timely and high-quality assessment based on evidence-based practice. Five out of six of the All-Wales Neurodevelopmental standards were met or partially met. There was evidence of action or reported intent to improve quality and efficiency across both patient pathways. The ASD service has already undertaken substantial capacity demand modelling and pathway review, whilst the ADHD service plans to review access arrangements, assessment pathways, and use of capacity to

meet demand. Ensuring the availability of appropriate clinical space, adequate resource to increase virtual consultations, and access to electronic data/activity collection systems may facilitate further local improvements.

The NHS Wales Executive Performance and Assurance Division would like to extend thanks to the staff of Hywel Dda University Health Board for their co-operation and contributions during the review.