Neurodevelopmental Services – Adults

Internal Audit Report

2025/26

Cardiff and Vale University Health Board

Limited Assurance

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Review Reference	CVU-2526-27
Fieldwork	November 2025 – February 2026
Executive Sign Off	30 April 2026
Audit Committee	May 2026
Executive Lead	Paul Bostock, Chief Operating Officer
Audit Team	Ian Virgill, Head of Internal Audit Lucy Jugessur, Deputy Head of Internal Audit

Executive Summary

Purpose

The purpose of our audit was to review the procedures for assessing whether adults are added to waiting lists, and the subsequent management of those lists to ensure that those referred are assessed in a timely, fair and consistent manner.

Overview

The original scope of our review covered referrals for both Adults and Children for Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactive Disorder (ADHD). Due to the significant differences in approach between services for children and adults, we agreed with the Health Board to produce separate reports and so this report relates solely to the services provided for adults. There are also significant differences in the services provided to adults for ASD and ADHD. ASD referrals are largely directed to the Integrated Autism Service, which is a Welsh Government funded initiative established in 2017. ADHD referrals have no stand-alone service and therefore the Health Board's Community Mental Health Teams (CMHTs) have had to take on responsibility for the referrals without any significant additional resource. Any additional Welsh Government funding for ADHD services is currently being totally directed at children.

Whilst waiting lists for ASD referrals are increasing, our review did not note any significant issues with this service. The procedures for dealing with ADHD referrals do however raise significant concerns, in spite of these being subject to substantial change during the course of our review. At the start of our fieldwork, interviews with key staff demonstrated that there was an inconsistent approach to ADHD referrals across the CMHTs and that this led to a perception of a postcode lottery within the Health Board. This inconsistency has since been addressed by the issue of a Standard Operating Procedure (SOP), which although in draft at the time of our review, was already being adopted across the CMHTs. Although all referrals are initially screened by a multi-disciplinary team, the instruction via the SOP is that they will now be automatically added to the waiting list unless their needs are more complex in which case they will be seen more urgently. The rationale for this approach is that if referrals are not accepted to the waiting list, patients often submit complaints, which in turn takes up considerable clinical time to address. The SOP also states that one in ten appointments should be given over to an ADHD referral (but this can be less dependent on demand for other services) and given that once a patient is diagnosed with ADHD they need to be followed up on a regular basis, the availability of appointment for new referrals comes under increasing pressure. Shared Care responsibility is only accepted from a small proportion of GP surgeries resulting in stabilised patients being kept indefinitely on CMHT caseloads for perpetual monitoring and prescribing of medication. Clinicians interviewed during our audit were of the opinion that those joining the waiting list now are unlikely to ever be seen unless there is a radical change in approach. Their preference would be for a specialist nurse-led service that could be overseen by clinicians. Currently, the most skilled, highly trained and expensive resource (consultant psychiatrists) are seeing the population of CMHTs with the lowest need in comparison to the rest of their workload. Moving to a nurse-led service, for which a detailed business case has previously been produced but not progressed, would be a more effective use of resource but would require substantial investment to establish it.

The root cause of the issues with ADHD referrals is obviously the surge in demand for services and this issue is replicated across the UK with a number of NHS Trusts in England seeking to close their waiting lists to new adult ADHD referrals. Limitations with current reporting systems make it difficult to accurately predict numbers and wait times but a report by ThirtySixDegrees, who are a specialist consultancy undertaking a review of Adult Mental Health Services for the Health Board, quoted that as of December 2025, 3,762 people were waiting for an ADHD assessment across the Health Board's CMHTs with suggested wait times of between 20 and 50 months dependent on the CMHT, as each operates their own waiting list. Feedback from those interviewed during our review suggested wait times of eight years and possibly longer for those now joining the lists. Work was ongoing during our audit to identify children approaching the age of 18 who had not yet been seen by children's services and who therefore should normally transition to the adult waiting list. It is estimated that this would increase the wait time for those currently at the end of the adult waiting list by a further year, and that this increase will be replicated annually going forward. We now understand that Adult Services are refusing to take on these cases (for ADHD and ASD) and they will remain on the children's list. The figures reported for Adult Mental Health performance in the Integrated Performance Report do not cover neurodevelopment services for adults although the performance for children is reported.

We have concluded **limited** assurance on this area. The significant matters requiring management attention (acknowledging the financial constraints on the Health Board) are:

- The service is being delivered by a highly skilled, trained, and expensive resource when it could largely be a nurse-led service, with consultant psychiatrist oversight. The current approach to managing ADHD referrals is unsustainable and results in extremely long waits for patients, with patients joining the waiting list now possibly never likely to be seen.
- Referrals are not received in a consistent format which can result in inefficiencies in the process as more information may be required.
- Unlike children's services and ASD, there is no stand-alone service for adult ADHD referrals and consequently there is very limited information for adults and their families who may be exploring a potential ADHD diagnosis.
- A majority of GPs are refusing to take back stabilised patients resulting in the Health Board effectively having to follow them up for life.
- There is insufficient administrative support resulting in tasks either not being completed or being undertaken by clinicians and/or nurses, reducing capacity for direct patient care.
- Management information is very limited and the system for recording and reporting patient data is nearing end-of-life.

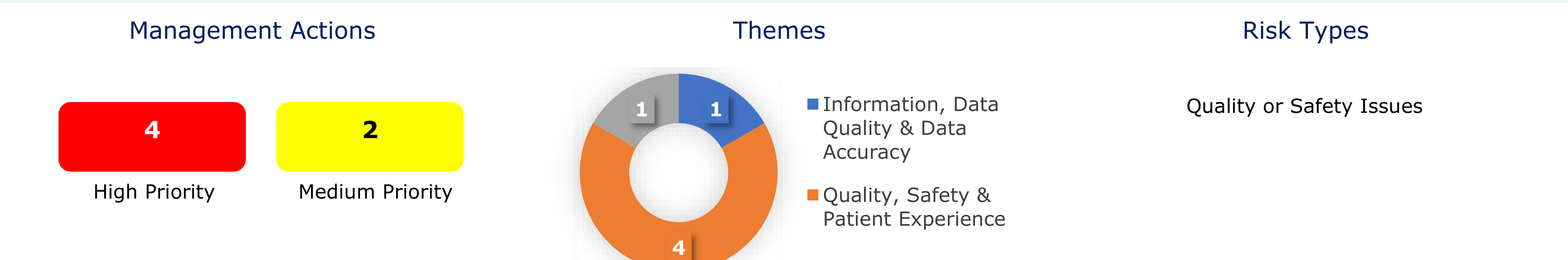
Full details of matters arising are provided within the Findings & Agreed Action Plan. The following opportunity for enhancement has been identified that does not impact the overall opinion and is highlighted for management information:

- Although non-attendance of patients for scheduled appointments is not seen as a particular problem due to patients being contacted for updated information shortly before their appointment, there is not a consistent approach between ASD and ADHD services, and in the case of the latter between the CMHTs to minimise the number of DNAs.

Scope & Assurance Summary

Objectives The objectives and associated assurance ratings are not necessarily given equal weighting when formulating the overall audit opinion.

	Objectives	Related Findings	Assurance
1	Referrals to the service for adults are subject to a formal and consistent form of triage.	1,2,3,4	**Unsatisfactory**
2	All adults referred are notified on a timely basis as to whether they have been accepted for inclusion on waiting lists for neurodevelopmental services.	-	**Substantial**
3	All accepted patients are added to the waiting lists promptly, and lists are appropriately managed and accurately updated in terms of any changes notified to the Health Board.	5	**Reasonable**
4	Any patients removed from waiting lists due to failure to attend appointments are notified that they have been discharged from the service.	-	**Substantial**
5	The process for transition from Children's to Adult Services is formally documented and complied with.	-	**Not Applicable**
6	Management Information reported to assess the performance of the service is accurate and up to date.	6	**Limited**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Information, Data Quality & Data Accuracy
Quality, Safety & Patient Experience
Risk Types
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Findings & Agreed Action Plan

Objective 1: Referrals to the service for adults are subject to a formal and consistent form of triage.	Unsatisfactory

Overview / Summary of Observations

There is a formal and consistent approach for the triage of adults referred to the Integrated Autism Service. However, the increasing number of referrals to this service is causing the timeliness of the triage process to slip from the three-month target to closer to six months.

As stated in the Executive Summary, there is no dedicated stand-alone service for adult ADHD referrals and there is very limited, if any, information available to adults and their families to understand what services might be available to them. Referrals are made through the six Community Mental Health Teams (CMHTs), but there has not been a formal and consistent triage process for adult ADHD services, and this has led to a perception of a postcode lottery across the six CMHTs. This is now being addressed through the issue of an additional Standard Operating Procedure (SOP) which at the time of our audit was still to be approved. This suggests that all referrals should be screened by a multi-disciplinary team but also that all referrals should be added to the waiting list unless there is a good reason not to. We understand that the patients not added to the waiting list are likely to be those with more complex needs and/or assessed as higher risk, who therefore require more urgent attention. Therefore, in essence, no referral is being turned down. We further understand that the reason for this is that non-acceptance of referrals onto waiting lists in the past has invariably led to complaints which in turn take up considerable clinical time in responding. Private diagnoses, which previously were accepted so long as from a recognised provider, are also no longer being accepted as it is considered that it would create a two-tier service. The SOP also directs that only one in ten appointments should be for an ADHD referral (but this can be less independent on demand for other services) and given that once diagnosed the patient effectively has to be regularly followed up, the pressure on available appointments for new referrals will continue to grow. A majority of GPs are also refusing to take back stabilised patients for their ongoing follow-up, which effectively means that the Health Board has to follow them up for life.

The service is currently led and delivered by Consultant Psychiatrists, who are a highly skilled, trained and expensive resource, who have heavy demand for their time from patients with far more complex needs and at greater risk of harm, or potentially causing harm to others. Providing a specialist nurse-led service is seen by many of those interviewed as a more effective use of resource and a business case to take this forward was developed during 2024 and 2025. However, it required significant additional funding to establish the service and financial constraints have resulted in this not being taken forward.

Key Findings		Risk & Impact	Agreed Management Action
1	**Triage Assessment** There is no single point of access or service for adult ADHD referrals which instead go to one of the six Community Mental Health Teams (CMHTs). Previously there was no consistency in approach to the referral and the subsequent triage. During the course of our audit a revised SOP has been produced which aims to provide a consistent approach, and which does include a screening of all referrals by a Multi-Disciplinary Team. However, the SOP effectively states that all referrals should be added to the waiting list unless more complex needs are identified in which case the adult would be fast-tracked for an appointment. The reason for this is that those adults who have previously not been added to the waiting list are likely to complain which takes up valuable clinical time in responding to the complaint. The simpler solution is therefore to add them to the waiting list. However, given the policy that only one in ten patients seen in clinic is an ADHD referral (which can even be less than this dependent on local priorities), and the fact that those diagnosed with ADHD will need to be continually followed up, it is considered by some clinicians interviewed during our audit that those joining the waiting list now may never be seen in clinic.	Waiting lists will continue to grow and some patients may never be seen.	The issue of ever-increasing waiting lists for adult ADHD referrals is one that is impacting all mental health services across the UK with some English NHS Trusts closing their waiting lists. One answer to this issue is a stand-alone service similar to how the Integrated Autism Service is currently run. This could be led by specialist nurses with oversight by clinicians, which will be a more cost-effective alternative than the current service model but will require substantial investment to make in-roads into reducing waiting lists. A proposal along these lines was produced in 2024 and updated in 2025 but has not progressed due to a lack of funding. The Health Board will review whether investing in such a service will be a justifiable option in comparison to its other priorities. **Expected Evidence of Implementation:** Consideration of changes to future service provision for ADHD referrals.
		High Priority	**Officer: Samuel Barrett** **Target Implementation Date: September 2026**
	Theme: Quality, Safety & Patient Experience	Control Design	
2	**Referral Documentation** Referrals for ADHD appointments are often not received in a standard format or are missing vital information which either makes the screening process harder or requires further information to be sought, which lengthens the referral process and takes up valuable staff time. Children's services also used to suffer from this problem, but the introduction of a standard questionnaire has helped to ensure that correct and complete information is received at the first attempt.	Incomplete information makes the triage/screening process less efficient, causing delays and wasting staff time.	The use of a standard questionnaire to be completed by GPs, patients and their families, and other referrers will be considered. **Expected Evidence of Implementation:** Production of standard questionnaire.
		Medium Priority	**Officer: Samuel Barrett** **Target Implementation Date: January 2027**
	Theme: Quality, Safety & Patient Experience	Control Design	

	Key Findings	Risk & Impact	Agreed Management Action
3	**Publicly Available Information** Services listed on the Health Board website include the Integrated Autism Service and ADHD services for children. Searching for ADHD services for adults brings up only Freedom of Information requests. None of the 31 services listed under the headings of Adult Mental Health Services mention ADHD in their title. This is due to the ADHD provision for adults not being a stand-alone service but rather one of the responsibilities of the Community Mental Health Teams. The newly issued ADHD SOP states that: *Neurodevelopmental conditions are **not considered mental illnesses** in themselves. However, individuals with these conditions are at **higher risk of developing co-occurring mental health issues**, such as anxiety, depression, or obsessive-compulsive disorder. This overlap can sometimes lead to confusion in classification and care pathways.*	There is no information available for adults and their families to assist them if they suspect that they might be suffering from ADHD.	Whether or not the Health Board changes the structure and current approach (as noted under Finding 1), it will ensure that there is clear information provided to assist adults and their families who suspect that they might have ADHD.
			Expected Evidence of Implementation: Provision of ADHD information for adults.
		High Priority	**Officer: Samuel Barrett** **Target Implementation Date: September 2026**
	Theme: Quality, Safety & Patient Experience	Control Design	
4	**Shared Care Responsibility** Mentally ill patients whose condition is stabilised through treatment and medication are often accepted back by their GP for ongoing follow-up. However, in the majority of ADHD cases, this shared care responsibility is not being accepted by the GPs, despite the needs of a typical ADHD patient being far less complex than other patients that they do accept shared care responsibility for.	The capacity to treat new referrals is further reduced due to the need to follow up existing patients potentially for life.	**Suggested Action:** The Health Board will pursue this issue with Primary Care to seek a more equitable sharing of responsibility.
			Expected Evidence of Implementation: Evidence of consultation with Primary Care representatives.
		High Priority	**Officer: Samuel Barrett** **Target Implementation Date: January 2027**
	Theme: Quality, Safety & Patient Experience	Control Design	

Objective 2: All adults referred are notified on a timely basis as to whether they have been accepted for inclusion on waiting lists for neurodevelopmental services.	**Substantial**

Overview / Summary of Observations

Although systems and processes for ADHD and ASD are very different, in both cases patients referred for the service are notified as to the outcome of the triage process. In ASD the triage is a face-to-face appointment, so the patient is notified immediately. With ADHD the patient will now either be added to the waiting list in which case they will receive a standard letter or be invited in for an appointment as their needs are more urgent and complex.

Objective 3: All accepted patients are added to the waiting lists promptly, and lists are appropriately managed and accurately updated in terms of any changes notified to the Health Board.	**Reasonable**

Overview / Summary of Observations

Through discussion with relevant staff, we were informed that adults referred for either ASD or ADHD assessments are added promptly to the lists, however, there is insufficient administrative support to enable any proactive management of the lists. As patients approach the top of the lists they are contacted in order for more information to be provided and checks are undertaken to ensure that patients are still in the area and planning to attend their appointments. For ADHD patients, each CMHT maintains its own waiting list, and it can often be difficult to differentiate ADHD referrals from other mental health patients. (See also finding 6 for suggested action to address this issue).

Key Findings		Risk & Impact	Agreed Management Action
5	**Administrative Support** The financial constraints and resulting recruitment freezes have meant that there are gaps in numbers of administrative staff. This results in tasks either not being able to be performed, or clinical and nursing staff having to undertake the tasks, thus reducing the capacity for direct patient care.	The capacity to treat patients, and the effectiveness of the approach is reduced.	Acknowledging the financial constraints on the Health Board there are opportunities for the service to be delivered more efficiently and cost-effectively, and these will be considered alongside competing priorities. **Expected Evidence of Implementation:** Formal consideration of structure of current service provision.
		Medium Priority	**Officer: Samuel Barrett** **Target Implementation Date: September 2026**
	Theme: Resourcing	Control Design	

Objective 4: Any patients removed from waiting lists due to failure to attend appointments are notified that they have been discharged from the service.	Substantial

Overview / Summary of Observations

Did Not Attend (DNA) rates are not perceived by staff interviewed during our audit as a particular issue, and patients are contacted prior to their appointment for more information and/or to confirm that they are planning to attend. The approach does differ between ASD and ADHD, and in the latter case it has also differed between CMHTs. This issue has not been raised as a formal finding but has been identified as an opportunity for improvement, as the limited capacity for appointments means that any DNA is a waste of valuable resource.

Objective 5: The process for transition from Children's to Adult Services is formally documented and complied with.	Not Applicable

Overview / Summary of Observations

The Children's service covers children up to the age of 18. Given a waiting list that is approaching four years for an appointment for children, there is therefore a risk that a teenager added to the waiting list might not be seen for an assessment appointment by the time that they reach 18 years of age. In planning for the audit, the issue of transition to Adult Services was one that the Children's Service were keen to include as at the time Adult Services were not receiving children (i.e those aged 17 who were still awaiting an appointment) on to their waiting lists particularly as all additional funding has been transferred by the Welsh Government to Children's services at the expense of Adult Services. Equally, for the child, they were potentially leaving a Waiting List with a three and a half year wait to one where they might have to wait a lot longer for a consultation, albeit that their date of original referral would be used to determine where they would sit on the adult waiting list.

Since commencing the audit, Children and Adult Services agreed to work together to find a solution to a better transition for both ADHD and ASD cases. The Children's Service identified all those children currently on the waiting list that are likely to turn 18 and who will have been waiting for more than three years as at April 2026 and April 2027. This information was shared with Adult Services so that the potential impact on their waiting lists could be assessed. It was estimated that the transfer of older teenagers to adult waiting lists will increase the wait for those adults towards the end of the list by a further year, and this would occur every time the transfer is made, which was assumed to be annually. We have now been advised that Adult Services including the Integrated Autism Service have not agreed to the transition and these teenagers will remain on the children's list even though they may potentially be over 20 by the time that they are seen. The Children's service is hoping to be able to recruit practitioners who are experienced in dealing with this age group. Children that already have a diagnosis are however transferred to Adult Services on reaching 18 for the ongoing provision of their medication and follow-up.

Given the changes in process and discussions around the transition arrangements, we are unable to provide assurance for this objective.

Objective 6: Management Information reported to assess the performance of the service is accurate and up to date.	Limited

Overview / Summary of Observations

Management information is very limited, but relevant staff do not see this as being such a big issue for adults as it is for Children, as there are no specific reporting requirements associated with adult ADHD referrals.

The performance statistics for Mental Health included in the Integrated Performance Report to the Board do not include neurodevelopment referrals. ASD referrals are reported to Welsh Government on a quarterly basis, and no particular issues were noted.

The fragmentation of the approach for ADHD referrals in Adult Services means that CMHTs operate their own waiting lists and coding limitations can make it difficult to identify ADHD patients resulting in the need for manual workarounds. The PARIS system is nearing the end of life with the contract due to expire in 2028, although it is likely that the Health Board will be able to agree a one-year extension to March 2029. However, the system is very limited and while there is some work on-going to make better use of PowerBI dashboards within Adult Mental Health, nothing has been developed thus far for Neurodevelopmental Services.

Key Findings		Risk & Impact	Agreed Management Action
6	**Management Information** The PARIS system is extremely limited in its use in recording and reporting of ADHD referrals and performance. The system is reaching end-of-life and is unlikely to be available after March 2029. No information on the performance of the Health Board in responding to adult ADHD referrals is currently being included in the Integrated Performance Report, although children's services are included due to this being a Welsh Government requirement.	The Health Board is unable to accurately record and monitor the position for adults waiting for an ADHD referral.	Acknowledging that the current PARIS system is approaching end of life, and that there are many different service users to accommodate in any replacement system, the Health Board will ensure that where possible, recording and reporting of ADHD information is enhanced so that there is up to date and accurate information on the position with adults waiting for an ADHD assessment. **Expected Evidence of Implementation:** Updated and improved reporting.
		High Priority	**Officer: Samuel Barrett** **Target Implementation Date: September 2026**
	Theme: Information, Data Quality & Data Accuracy	Control Design	

Appendix A

Assurance Opinion

	Substantial	Few matters require attention and are compliance or advisory in nature. **Low impact** on residual risk exposure.
	Reasonable	Some matters require management attention in control design or compliance. **Low to moderate impact** on residual risk exposure until resolved.
	Limited	More significant matters require management attention. **Moderate impact** on residual risk exposure until resolved.
	Unsatisfactory	Action is required to address the whole control framework in this area. **High impact** on residual risk exposure until resolved.
	Advisory	Given to reviews and support provided to management which form part of the internal audit plan, to which the assurance definitions are not appropriate. These reviews are still relevant to the evidence base upon which the overall opinion is formed.

Prioritisation of Findings

Priority	Explanation
High	Significant risk to achievement of a system objective OR evidence present of material loss, error, or misstatement. Poor system design OR widespread non-compliance.
Medium	Some risk to achievement of a system objective. Minor weakness in system design OR limited non-compliance.

Website: [Audit & Assurance Services - NHS Wales Shared Services Partnership]

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