



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

DYDDIAD Y CYFARFOD: DATE OF MEETING:	12 February 2026
TEITL YR ADRODDIAD: TITLE OF REPORT:	Update on Progress Against PSOW Public Services of Wales (PSOW) Public Interest Report Recommendations – Learning Disabilities Epilepsy Service
CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:	Andrew Carruthers, Chief Operating Officer
SWYDDOG ADRODD: REPORTING OFFICER:	Dana Scott, Director of Midwifery

Pwrpas yr Adroddiad (dewiswch fel yn addas)

Purpose of the Report (select as appropriate)

Er Sicrwydd/For Assurance

ADRODDIAD SCAA

SBAR REPORT

Sefyllfa / Situation

This paper provides an update to the Quality, Safety & Experience Committee (QSEC) on progress made against Recommendations issued by the Public Services Ombudsman for Wales (PSOW) in the *Public Interest Report* concerning the Learning Disabilities (LD) Epilepsy Service.

Significant work has been undertaken by the LD Epilepsy Task & Finish Group to strengthen pathway clarity, governance, external clinical assurance, and oversight of the LD epilepsy patient cohort.

Cefndir / Background

PSOW Public Interest Report

The Ombudsman’s Public Interest Report (2025) identified concerns regarding pathway clarity, access to specialist support, the need for external clinical assurance, and the requirement for strengthened governance for adults with Learning Disabilities and epilepsy.

Summary of Ombudsman Recommendations

Recommendation A

Implement a clear and accessible LD Epilepsy Care Pathway, aligned to external clinical review findings, and update the Ombudsman within four months of the report.

Recommendation B

Ensure action plans include timescales and are subject to formal Board oversight.

Recommendation C

For each of the 7 complainants, provide a written apology for the lack of communication and lack of alternative provision put in place for the care of their relatives following the end of the LD Epilepsy Service

Recommendation D

Provide a comprehensive breakdown to each of the 7 complainants about the current care that is being offered to their relatives, the status of and responsibility for any ongoing monitoring/ care reviews/ risk plans, and who to contact for advice or concerns.

Recommendation E

Undertake a thorough audit of LD epilepsy patient lists to confirm:

- All have up-to-date care plans, risk assessments, and emergency medication plans.
- No patients have been missed or are awaiting neurology review without oversight.
- Board oversight is in place to ensure completion of the audit.

Asesiad / Assessment

Recommendation A – LD Epilepsy Care Pathway

- The Adults with Learning Disability and Epilepsy Pathway was **formally approved on 31 July 2025**.
- A Learning Disabilities Epilepsy Services **Task & Finish Group** was established to review and refine the Pathway following the Ombudsman's findings.
- Membership includes multidisciplinary stakeholders and, more recently **external professional representation** from a Swansea Bay University Health Board Neurology Consultant.
- A **pathway mapping workshop** took place (against the revised pathway) on **24 November 2025**, identifying ambiguous processes across Technology, Staff, Patients, Communication, Education, and Safety.
- A **driver diagram** was produced to inform improvement options.

Position: The Pathway is approved and undergoing further redesign to address learning emerging from the Public Interest Report and audit findings.

Recommendation B – Timescales and Board Oversight

- Quality Improvement and Transformation teams shared pathway review outputs with stakeholders in **December 2025** and at the Task & Finish Group on **9 January 2026**.
- An additional meeting on **12 January 2026** generated an **initial action plan with defined timelines**, overseen by the T&F Group.
- Ongoing oversight is provided through the Integrated Quality, Finance, Planning and Delivery Group (IQFPD) and through QSEC and ultimately the Board.

Position: Governance oversight and timescales are in place; further actions will mature as pathway development proceeds.

Recommendation C: Recommendation c – written apology letters

- Letters were issued on 24 November 2025, fulfilling PSOW compliance. However, feedback during the meeting in December with the Nursing & Medical Directors and Chair of the Task and Finish Group carers identified inaccuracies in some of the letter content and a requirement to strengthen review criteria and feedback mechanisms. Thus, while the recommendation is technically complete, the work is not closed, and feedback is being addressed via the Task and Finish Group.

Recommendation D – care summaries

- Care summaries were issued to all seven complainants. Work is ongoing to further refine the responsibility for ongoing monitoring/ care reviews/ risk plans aligned to pathway review work progressing via the Task and Finish Group.

Recommendation E – LD Epilepsy Patient Audit

A tri-county audit has been completed across Neurology, Community Team Learning Disabilities (CTLD) and LD Epilepsy Nursing, reconnecting with families and assessing safety and visibility of support.

Audit Findings:

- **154 LD epilepsy patients identified** across the three counties.
- **94%** have in-date reviews.
- All **8 overdue reviews** have planned appointments.
- **No patients lost to follow-up.**
- All patients have oversight from **Neurology, CTLD or GP.**
- Risk and emergency medication plans are either **in place or booked.**
- Oversight is provided through **IQFPD → QSEC → Board.**

The audit identified variation in waiting times across counties, with longer neurology waits evident in Carmarthenshire due to population size and historical complexity. Families reported heightened anxiety associated with delays and uncertainty.

Position: The audit requirement has been met; further analysis will be presented to QSEC in future report for assurance on equity, access, and variation.

Task & Finish Group – Ongoing Workstreams

The T&F Group continues to progress:

- Finalisation of the pathway redesign and external clinical assurance.
- Review and refinement of audit findings.
- Development of improvement actions from pathway mapping.
- Strengthened communication processes for families.
- Continued governance oversight through IQFPD, QSEC and the Board.

The Ombudsman process has supported reflective learning and reinforced a commitment to dignity, compassion, transparency and partnership.

The LD Epilepsy Task & Finish Group will continue to progress work to strengthen the current pathway and ensure that compliance with the organisations response to the recommendations set out in the Public Interest Report is continuously strengthened. The T&F Group will utilise the Risks, Assumptions, Issues, Dependencies (RAID) tool to give structured oversight of the

workstreams. Work has also progressed aligned to a thematic analysis of complaints received on cessation of the service in 2021 to identify cross cutting themes and address feedback received from service users i.e. access delays, Specialist Nurse Capacity, Workforce constrains, loss of Specialist LD- Epilepsy Clinic, communication and pathway confusions, risk and safety concerns.

A clinical Accountability Map has been developed to define the balance of responsibility between **Neurology, CTLD clinicians, LD Epilepsy Nurse Specialist, General Practitioner (GP), and carers**, to ensure clear escalation routes for seizure deterioration or Sudden Unexpected Death in Epilepsy (SUDEP) risk, set out “who does what” when families are unsure whom to contact and to provide assurance that ambiguity has been removed.

Clinical Accountability Map (LD) Epilepsy Care

Clinical function	Responsible Service	Further Detail / Clarification
Annual epilepsy care review	CTLD Nursing	Planned annually; may be joint with LD Epilepsy Nurse Specialist for complex needs.
Early review triggered by change in seizure pattern	CTLD Nursing / LD Epilepsy Nurse Specialist	Triggered by family, GP, Emergency Department (ED), community teams or neurology; triaged same week.
Neurology review (consultant-led)	Neurology	Outpatient or PIFU model; only undertaken when specialist input is required.
SUDEP risk assessment	CTLD Nursing / LD Epilepsy Nurse Specialist with Neurology oversight	Completed annually and at any change in presentation.
Rescue medication governance (prescribing, training, review)	CTLD Nursing (competency), Pharmacy (accuracy), GP/Neurology (prescribing)	Annual competency check required; rescue pathways must be family friendly.
Best Interest MDT participation	CTLD MDT + LD Epilepsy Nurse Specialist	LDENS input essential for epilepsy-related decisions; CTLD nurses attend when broader LD care involved.
Crisis or urgent deterioration pathway	LD Epilepsy Nurse Specialist, Neurology/ ED	Clear escalation route required in pathway redesign

Work is also progressing in relation to the workforce requirement to stabilise the LD Epilepsy Service linked to capacity and demand modelling, also the development of a ‘Carer Feedback Loop & Communication Protocol’ is progressing to ensure families receive clear information and can raise questions safely.

It is recognised that the LD epilepsy service faces continued systemic risks, but the issues are known, documented, and now consolidated into a single improvement programme. This improvement programme is not simply a response to regulatory recommendations; it is a commitment to providing equitable, safe and compassionate care for some of our most vulnerable patients. By strengthening our pathway, clarifying clinical responsibilities, improving

communication and stabilising our workforce, we will rebuild trust and create a sustainable epilepsy service that meets the needs of people with learning disabilities and their families.

The LD Epilepsy Task & Finish Group will continue to report into Formal Executive Team.

Argymhelliad / Recommendation

The Quality Safety and Experience Committee is asked to:

- **Take assurance** on the progress made against Recommendations thus far.
- **Acknowledge the continued work** of the LD Epilepsy Task & Finish Group.
- **Receive a further update** at a future meeting for full assurance on equity, access and variation.

Amcanion: (rhaid cwblhau) Objectives: (must be completed)	
Committee ToR Reference: Cyfeirnod Cylch Gorchwyl y Pwyllgor:	2.1 Scrutinise, assess and seek assurance in relation to the patient impact, quality and health outcomes of the services provided by the Board.
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	
Parthau Ansawdd: Domains of Quality Quality and Engagement Act (sharepoint.com)	Not Applicable
Galluogwyr Ansawdd: Enablers of Quality: Quality and Engagement Act (sharepoint.com)	6. All Apply
Amcanion Strategol y BIP: UHB Strategic Objectives:	3. Great care
Amcanion Cynllunio Planning Objectives	Not Applicable
Amcanion Llesiant BIP: UHB Well-being Objectives: Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022	10. Not Applicable

Gwybodaeth Ychwanegol:
Further Information:

Ar sail tystiolaeth: Evidence Base:	
Rhestr Termau: Glossary of Terms:	
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Ansawdd, Diogelwch a Phrofïod: Parties / Committees consulted prior to Quality, Safety and Experience Committee:	LD Epilepsy Task & Finish (T&F) Group

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