



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

DYDDIAD Y CYFARFOD: DATE OF MEETING:	14 AUGUST 2025
TEITL YR ADRODDIAD: TITLE OF REPORT:	Learning Disabilities Epilepsy Pathway
CYFARWYDDWR ARWEINIOL: LEAD DIRECTOR:	Sharon Daniel, Executive Director of Nursing, Quality & Patient Experience
SWYDDOG ADRODD: REPORTING OFFICER:	Olwen Morgan, Assistant Director of Nursing, Quality & Patient Experience, Planned Care & Specialist Services

Pwrpas yr Adroddiad (dewiswch fel yn addas)

Purpose of the Report (select as appropriate)

Er Sicrwydd/For Assurance

ADRODDIAD SCAA

SBAR REPORT

Sefyllfa / Situation

The purpose of the report is to present an update to the Committee on the external review into the epilepsy care pathway and respond to concerns raised by families regarding the epilepsy care pathway provision for their adult children, who also have a Learning Disability (LD).

Concerns relate to ongoing difficulties in accessing neurology services with the appropriate expertise in managing individuals with both Learning Disabilities and Epilepsy. These challenges have highlighted the need for a comprehensive review of the clinical pathway to ensure that service users are supported across all parts of the system—community, primary, and secondary care.

Cefndir / Background

Following the External Review, a Learning Disabilities Service Improvement Programme (LDSIP) was undertaken and a new service model developed.

Work to implement the recommendations from the external peer review of adult services for individuals with a Learning Disability and Epilepsy is close to completion. Most actions have been delivered, with only one remaining item outstanding.

This final task involves analysing the original stakeholder survey to establish a baseline for future service evaluations. Access to the survey data was delayed due to circumstances beyond the control of the health board, this has now been resolved. Analysis of the responses is underway and is expected to be completed by the end of September. The findings will support the task and finish group in shaping the next phase of service improvement.

The new service model adopts a health facilitation and educational approach to supporting mainstream health services to ensure that people with learning disabilities receive fair, equal and person-centred access to health care. The development of clinical pathways supports this approach.

A report summarising progress of the LDSIP and included the nursing and allied health professional posts required for the new structure was presented to the Executive Team in December 2024. Approval was provided to progress with recruitment.

Current progress:

- Occupational Therapy, Physiotherapy and Speech & Language Team posts all recruited.
- Band 6 Community Learning Disability (CLDT) nursing posts recruited.
- 2.7 Whole Time Equivalent Band 6 vacant nursing posts in the Health Facilitation and Liaison (HFLT) team recruitment progressing to interview.
- 3 newly registered nurses commencing in CLDT from September 2025.
- 3 Band 3 Healthcare Support Worker (HCSW) posts being filled via redeployment as part of Organisational Change Process.

Updated Epilepsy Care Plans and Risk Assessments were developed to facilitate consistency for person centred care. A Patient Initiated Follow Up (PIFU) is in place for those who access Community Learning Disability Team (CLDT) nursing, informing the annual review of their care plan and risk assessment. This strives to better support individuals and carers to have ownership of their care plan and to initiate a review when needed.

The Learning Disabilities Service has a LD non-medical prescriber Pharmacist, who supports CLDTs as well as the LD Epilepsy Specialist Nurse (LDESN) with specialist advice regarding anti-epileptic medication, associated side effects and medical interaction.

Asesiad / Assessment

The Health Board does not currently provide a specialist Learning Disability Epilepsy Service.

A Learning Disabilities Epilepsy Specialist Nurse (LDESN) supports the CLDTs, Neurology and Primary Care Services. The Health Board has employed an LD Pharmacist who works alongside our CLDTs and the Learning Disabilities Specialist Nurse (LDSN). GP's or Consultant Psychiatrists will refer to Neurology as per any other referral required for Epilepsy / first seizure. Additional support from the LDESN or CLDT is available if requested by the neurologist.

Ongoing challenges remain in accessing neurology services with the appropriate expertise in managing individuals with both Learning Disabilities and Epilepsy. Currently some individuals cared for within Learning Disabilities Service are also under the care of Neurology due to the complexities of their epilepsy, whilst others are awaiting a neurology assessment.

These challenges have highlighted the need for a comprehensive review of the clinical pathway to ensure that service users are supported across all parts of the system—community, primary, and secondary care.

A Learning Disability Epilepsy Task & Finish Group has been established to review and improve the epilepsy care pathway for individuals with Learning Disabilities and Epilepsy within Hywel Dda University Health Board (HDUHB). The group will facilitate collaboration with Swansea Bay UHB (SBUHB) and establish a Service Level Agreement. The Group will ensure a more equitable and effective service by addressing key concerns and integrating Quality Improvement methodologies.

At the first meeting on 6th August, the T&F Group focused on the recent Ombudsman Report and the response to its findings and recommendations. Identification and inclusion of key stakeholders including Llais, service users and SBUHB reps was agreed. The next meeting to approve the response to the Ombudsman Report is scheduled for 11th August. Pathway workstreams will be agreed at the next meeting.

The Learning Disability Epilepsy Services Pathway Task & Finish Group will report to the Integrated Quality, Finance and Performance Delivery Group (IQFPD).

Argymhelliad / Recommendation

The Committee is asked to note the update and take assurance from the plan to review and improve the pathway for individuals with Learning Disabilities and Epilepsy.

Amcanion: (rhaid cwblhau)

Objectives: (must be completed)

Committee ToR Reference: Cyfeirnod Cylch Gorchwyl y Pwyllgor:	2.2 Provide evidence based and timely advice to the Board to assist it in discharging its functions and meeting its responsibilities with regard to the quality and safety of health care provided and secured by the University Health Board.
Cyfeirnod Cofrestr Risg Datix a Sgôr Cyfredol: Datix Risk Register Reference and Score:	Risk:1181; score 20 Risk: 818; score 16
Parthau Ansawdd: Domains of Quality Quality and Engagement Act (sharepoint.com)	7. All apply
Galluogwyr Ansawdd: Enablers of Quality: Quality and Engagement Act (sharepoint.com)	6. All Apply
Amcanion Strategol y BIP: UHB Strategic Objectives:	All Strategic Objectives are applicable
Amcanion Cynllunio Planning Objectives	Not Applicable
Amcanion Llesiant BIP: UHB Well-being Objectives: Hyperlink to HDdUHB Well-being Objectives Annual Report 2021-2022	

**Gwybodaeth Ychwanegol:
Further Information:**

Ar sail tystiolaeth: Evidence Base:	
Rhestr Termau: Glossary of Terms:	Contained within the body of the report
Partïon / Pwyllgorau â ymgynhorwyd ymlaen llaw y Pwyllgor Ansawdd, Diogelwch a Phrofiod: Parties / Committees consulted prior to Quality, Safety and Experience Committee:	

Effaith: (rhaid cwblhau) Impact: (must be completed)	
Ariannol / Gwerth am Arian: Financial / Service:	No direct impacts
Ansawdd / Gofal Claf: Quality / Patient Care:	Please see report
Gweithlu: Workforce:	No direct impacts
Risg: Risk:	Please see report
Cyfreithiol: Legal:	Not Applicable
Enw Da: Reputational:	Not Applicable
Gyfrinachedd: Privacy:	Not Applicable
Cydraddoldeb: Equality:	Yes, impact on equity of access to an epilepsy service for people with a learning disability.