GIG CYMRU NHS WALES

Bwrdd Iechyd Hywel Dda Health Board

Mental Health & Learning Disabilities Directorate

Epilepsy Services

Situation

- Prior to June 2021, Learning Disability Services provided a specialist clinic for people with learning disabilities suffering with epilepsy. The clinic was based in Carmarthen and consisted of a psychiatrist with specialist knowledge of epilepsy and a nurse with a special interest in epilepsy. The service was provided via outpatients and community visits when required. In June 2021, both the psychiatrist and the nurse left the organisation. As a result of this, the clinic was no longer able to be provided. The psychiatrist was embedded within the neurology service.

- Subsequently, a caseload/desktop review was undertaken of all patients, of which there were 170, known to the clinic. This review was undertaken by the Community Learning Disability Team (CTLD) Managers (by geographical location). A key outcome of the review revealed paper based record keeping processes and outstanding patient reviews.

Action Taken

- All Epilepsy Management Plans were reviewed within the CTLD team, prioritising those individuals who had not been seen within the previous 12 months.
- The Professional Lead Nurse, utilising National Institute for Health and Care Excellence (NICE) guidelines, developed a priority matrix, based on risk, to identify the level of care-need going forward. Utilising the database which incorporated all the clinic letters, a desktop review was undertaken and the results were shared with Neurology Services and the CTLDs and the Psychiatrist.
- The revised process allowed the staff to familiarise themselves with every patient who was being seen in the clinic. All patients had been seen by CTLDs (and remained under the CTLDs) and all Epilepsy Management Plans have been reviewed and updated.
- Easy Read letters were sent to all clinic patients to inform them of the service change and to contact their CTLD Nurse or GP if they had any concerns.
- In May 2021, an audit of compliance with the epilepsy pathway was completed. This consisted of two pieces of work, one undertaken by the Professional Nurse Lead and one by CTLD Team Leaders. A number of recommendations were identified, including a full review of the pathway and subsequent documentation and identified a need for a dedicated tag on the Care Partner electronic patient record system.
- A rolling programme of future audits has been initiated.

Action Taken

- In conjunction with colleagues in Neurology and Chronic Condition Management, a Clinical Nurse Specialist post was developed and recruited into. This post sits within the Epilepsy Service and professional supervision is provided by the professional lead/senior nurse.
- LD Psychiatrist and Epilepsy Nurse specialist attend a weekly epilepsy referral meeting within Swansea Bay UHB.
- Where required referrals have been made (and patients have been seen via tele-clinic) to HDD Neurology Service.
- The service have received approval to utilise the SUDEP (Sudden Unexpected Death in Epilepsy) checklist. This is a key assessment tool which helps to identify the risk of SUDEP and any consequential night time monitoring required.
- The HDD has committed to supporting our epilepsy nursing workforce to gain a Masters in Specialist Epilepsy Care once the course has completed accreditation (expected September 2022).
- All avenues have been explored with neighbouring Health Boards to provide honorary contracts or commissioned services, this has been unsuccessful in identifying Neurology input into the service.

Concerns, Incidents and Mortality Reviews

- **Concerns:** Since April 2021 the Health Board has received 49 items of correspondence raising concerns about Epilepsy Service Provision. 15 complaints have been received by the Patient Support Team from service users or carers, and have been responded to via the Putting Things Right process. 34 letters have been received by the Chief Executive's office from multiple sources (including: Service users/carers; MS and MP; Minister for Health and Social Care; Chief Medical Officer; Third Sector – such as Epilepsy Wales; Media Outlets – BBC) which have been responded to by the Assistant Director, Legal and Patient Support Services.
- **Incidents:** The Learning Disabilities Health Action Team (HAT) are embedded within each district general hospital (DGH) and their role is to ensure the Improving Access to Hospital Care bundle is utilised, part of which is the expectation that DGH staff inform them of every hospital admission with a patient who has a suspected learning disability. The HAT team will review and record the reason for admission, length of stay and outcome, recording on Care Partner and the prescribed Welsh Government database. Professional Lead for Learning Disabilities reviews all admissions. The trend appears to be that attendance and discharge to Accident & Emergency (for those presenting with epilepsy) occurs on the same day. Those patients subsequently admitted to an inpatient bed are treated for any underlying infection which may have exacerbated their seizure activity.
- **Mortality Reviews:** For those living in the community with learning disabilities and known to the CTLDs, all deaths are reported via our incident reporting system. The incidents are subsequently reviewed by the Professional Lead for Learning Disabilities (required in response to the LEDER Report). Deaths in DGHs are managed via the Health Board's mortality review process. There have been no Sudden Unexpected Death in Epilepsy (SUDEP) reported over the last 12 months of patients known to our Learning Disability Services.

Mental Capacity Act 2005

- The primary legislation relevant to people with learning disabilities is the Mental Capacity Act 2005.
- We have seen an increase in challenges to the clinical decisions made regarding the method of monitoring of seizure activity (in particular overnight), over the last 12-24 months . These issues have been raised by advocates challenging the impact based on Article 5: Right to Liberty and Security. These cases highlighted that the Best Interest Process required improvement.
- Actions: A review of all cases where monitors were in use, capacity assessments were completed and best-interest meetings held. Decisions are recorded and uploaded to Care Partner. Each CTLD has a process for ensuring (as a minimum) annual review, or when the patient condition changes.
- Mental Capacity training is a mandatory requirement and compliance is monitored through monthly LD governance meeting. Where required improvement plans are put in place.

The Psychiatrist's Role in Epilepsy Service Delivery

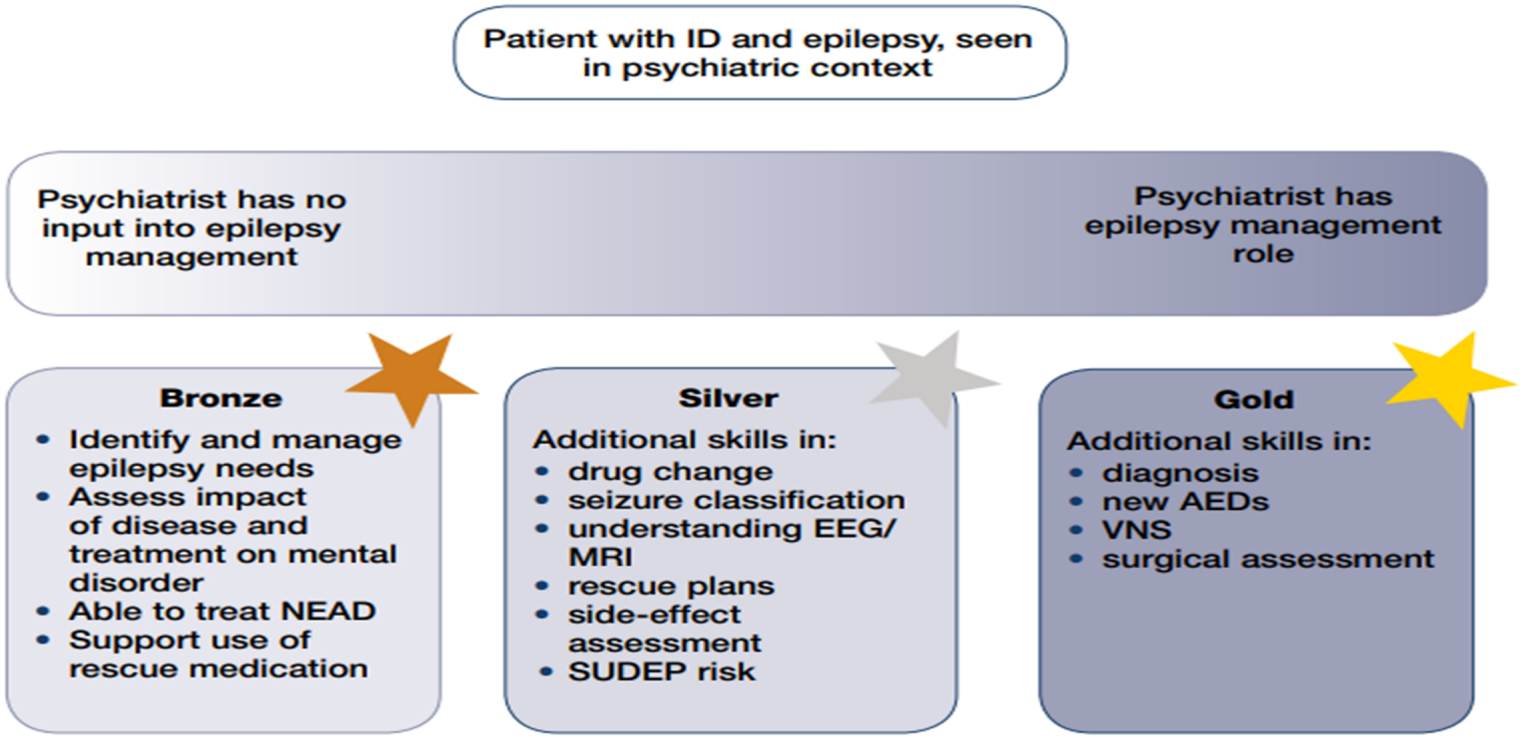

Fig. 2 The psychiatrist's role in epilepsy service delivery. AED, anti-epileptic drugs; EEG, electroencephalogram; ID, intellectual disability; MRI, magnetic resonance imaging; NEAD, non-epileptic attack disorder; SUDEP, sudden unexpected death in epilepsy; VNS, vagus nerve surgery. Figure adapted with permission from *Epilepsy in People with ID: Can we Reduce the Burden of Disease?* Keynote presentation by Professor Mike Kerr at the Faculty of Psychiatry of Intellectual Disability Annual Conference, 26–27 September 2013.

Medical Provision Going Forward

- An external review has been commissioned by the Health Board which is due to commence in April 2022 and this will be based around the standards identified in the previous slide and whether this is achievable.
- Continuous engagement with Medacs Workforce Agency to identify an agency locum to provide the medical input has also been sought. No appropriate individual has been identified.
- An independent review led by Professor Rohit Shankar (a clinical director for Learning Disabilities in Cornwall, and a Professor at University of Plymouth), and supported by Ms Paula Hopes (Head of Nursing for Learning Disabilities in Swansea Bay University Health Board has been commissioned. Professor Shankar is an international expert, who wrote the current UK national guidance on Learning Disabilities Epilepsy pathways.
- The review will consist of 2 stages:
  - Stage 1: A questionnaire will be sent to service users, carers, staff and stakeholders to establish a baseline assessment of the service. An easy ready version of the questionnaire will be available ~~too~~ to maximise response. This will lead to an interim report by the summer which will indicate any further immediate actions that need to be addressed to ensure the safety of the service. Early warning will be given if there are any urgent issues that require action.
  - Stage 2: This will consist of workshops with the above groups to develop the required improvement plan for the development of the service in the short to medium term. This will be undertaken in the Autumn, with a final report ready to inform the Integrated Medium Term Plan planning cycle next year.

Recommendation

- For QSEC to take assurance by the actions taken to review the Epilepsy pathway in the Learning Disabilities Service.