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Mental Health & Learning Disabilities Directorate

Epilepsy Services
Update June 2023

Quality, Safety and Experience Committee

13 June 2023

- Prior to June 2021, the Learning Disability Services provided a specialist epilepsy clinic. 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. In June 2021, the psychiatrist and the nurse left the organisation and recruitment to these specialist roles was not possible so the specialist clinic closed.
- An external review was commissioned lead by Professor Rohit Shankar, Professor of Neuropsychiatry at the University of Plymouth Medical school. The aim of the review was to define the functions and roles for the management of epilepsy in line with NICE guidelines (Epilepsy in Adults, 2013)
- A draft interim report has been received and the following slides summarise the key findings and recommendations.
- NB the final report was due to be reported to this Committee, but due to sickness of the author this has been delayed. A further meeting is planned for 12 June 2023.

Key Findings

- There was widespread recognition that the previous consultant was an expert in the field and one of only a handful of Psychiatrist with the combined experience and specialism in the management of psychiatry and epilepsy for people with a Learning Disability which has made succession planning challenging as recruitment of a like for like Professional when there are so few specialists available.
- A specialist epilepsy nurse has been recruited and is working closely with Neurology Consultants to ensure the necessary follow up measures are in place. This role needs to be strengthened and supported through administration support, supervision, input of pharmacy and improved contact information, such as a direct phone line.
- Families and carers should be given a stronger voice in helping to shape future service configuration.
- Stakeholders fed back a desire to work together to ensure that there is an integrated pathway for patients to access Epilepsy care through Neurology Specialists and that Learning Disability Services would help to ensure reasonable adjustments were in place to support Learning Disability Patients to access core services.



- To use the results of the survey to empower workshops, involving all stakeholders including experts by experience to discuss meaningful change. It is very important that future developments are co-produced ensuring input from patient and families. The lived experience of people with a learning disability and epilepsy and their families is essential to help shape future meaningful services.
- A dedicated named lead to facilitate governance and operational developments would be desirable. Consider commissioning further specialist advice to help design a more long term sustainable solution.
- Consider a suitable model of care for delivering the epilepsy and learning disability clinical care. Ideally recruiting a specialist learning disability consultant with competency in epilepsy is desirable. However, there are significant challenges of such specialists being available. In such a situation;
 - Consider the existing work force and supporting those psychiatrists working in the current Learning Disabilities service interested in physical health care in developing epilepsy skills and competencies. This should naturally be done as part of service re-design and include suitable job planning (based on work activity) and resource for any potential interested person. There needs to be a good peer group and continued professional development arrangements made.
 - Offer similar opportunities to neurologists or GPs interested in this clinical area.

Next Steps



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- Continue to work with Professor Shankar to finalise the report, evaluate the questionnaires and develop a short and medium term plan.
- The Services will review their practice and ensure at least Bronze standard is achieved in line with Royal College recommendations. A Training Needs Analysis will be completed for any areas that require an additional skill set.
- Continue to work with the Improving Together Team and Improvement Cymru who are assisting in the wider transformation of Learning Disabilities Service.
- Engage Neurology colleagues to develop an integrated pathway for Epilepsy Services and access to core Neurology Services with agreed reasonable adjustments.
- Identify additional pharmacy capacity to assist with medication review and monitoring.
- Recruit a full time Professional Lead Nurse for Learning Disabilities to provide professional support for the development of an integrated pathway and support the wider transformation programme within Learning Disabilities.

Committee Recommendation



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For the Quality, Safety and Experience Committee to receive the update regarding the interim report from the external review.



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