

1. What catchment area does your service look after?

2. Approximately how many adults are looked after within your service?

3. Approximately how many adults have a diagnosis of epilepsy within your service?

Number _____ Not sure

4. Does your service maintain an updated epilepsy register? Yes / No

5. Does your service run an epilepsy clinic? Yes / No

If yes, what does it consist of?

—

6. Does the LD Consultant in your team have a particular interest in epilepsy? Yes / No

COMMUNITY INTELLECTUAL DISABILITY EPILEPSY

SERVICE AVAILABILITY QUESTIONNAIRE

Name of the Community Learning

(Intellectual) Disability Team:

Address: _____

Date: ____ / ____ / ____

7. Relevant LD Team members How many?

Consultant Psychiatrists.....

Non-consultant doctors.....

Community LD nurses.....

Epilepsy Nurse Specialists (ENS)

LD Nurses with a specialist interest in epilepsy.....

8. In general, what role does the ENS/LD nurse have in the management of someone's epilepsy?

Please tick all that are relevant

Initial assessment.....

Ongoing follow-up.....

Training/care plan writing for emergency medication.....

Telephone contact to support and advise families.....

Visits to support and advise families.....

Liaison with other services.....

Other _____

8. If there are no ENS's in your team do you have access to neurology or general hospital-based

Epilepsy Nurse Specialists?

Yes / No

If yes, what sort of access?

9. Does your LD service have direct access to epilepsy investigations, for example EEG and brain scans? Yes / No

10. Does your service provide training to carers about the emergency treatment of prolonged seizures? Yes / No

Please continue overleaf

11. Is the local learning disability service the main provider of epilepsy care to *any* of your patients?

Yes / No

If yes, please estimate the percentage of patients where this is the case: _____%

12. Is the local neurology service the main provider of epilepsy care to *any* of your patients?

Yes / No

If yes, please estimate the percentage of patients where this is the case: _____%

What are the referral criteria for neurology services?

All patients with LD and epilepsy.....

Those with the most difficult to treat epilepsy.....

Other: _____

13. Is there a shared management approach between neurology and LD services for any of your patients that involves joint discussions about management?

Yes / No

If yes, please estimate the percentage of patients for whom this is the case: _____%

14. Does your learning disability service play a role in diagnosing new cases of epilepsy?

Yes / No

If yes, please give details:

15. Please list any other services that you liaise with regarding epilepsy care. For example, voluntary organisations, private health providers, specialist epilepsy centres (e.g. David Lewis Centre, Chalfont).

16. Does your service follow any sort of epilepsy care pathway that makes explicit reference to people with LD? Yes / No

If yes, is this pathway used for diagnosis or continuing treatment? Diagnosis / Treatment / Both

Who was responsible for its design? Your local team / PCT / SHA

17. Are there any plans to change or restructure the epilepsy services that you provide?

Yes / No

If yes, please give details:

18. Please add any other comments you would like to make about the epilepsy services provided by your team.

Thank you for completing this questionnaire.

Developed by members of the CIDDRG. University of Cambridge, UK

We may wish to discuss your responses to the questionnaire. If this is acceptable, please would you provide your contact details:

Name:_____ Contact email/telephone

no.:_____