

THE PROVISION OF CARE TO ADULTS WITH AN INTELLECTUAL DISABILITY IN THE UK:

A SURVEY BY THE BRITISH CHAPTER OF THE ILAE

Authors

The British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with intellectual disability and epilepsy

Kerr, MP,¹ Watkins, LV,² Angus-Leppan, H,³ Corp, A,⁴ Goodwin, M,⁵ Hanson, C,⁶ Roy, A,⁷ Shankar, R.⁸

1. Professor Learning Disability Psychiatry, Institute of psychological medicine and clinical neuroscience, Cardiff University.. 2. Higher Trainee (ST6) Psychiatry of Learning Disability, Wales Deanery. 3. Consultant Neurologist and Epilepsy Lead, Royal Free London NHS Foundation Trust and Honorary Senior Lecturer University College London. 4. Learning Disability Epilepsy Specialist Nurse, NHS Greater Glasgow and Clyde. 5. Clinical Nurse Specialist in Epilepsy, Northampton General Hospital NHS Trust. 6. Clinical Nurse Specialist in Epilepsy, Abertawe Bro Morgannwg University Health Board. 7. Consultant Psychiatrist, Coventry & Warwickshire Partnership NHS. Trust. Chair, Intellectual Disability Faculty, Royal College of Psychiatrists. 8. Consultant Neuropsychiatrist, Cornwall Partnership NHS Foundation Trust and Honorary Associate Clinical Professor, Exeter Medical School.

Content

Introduction	3
Methods	4
Findings	5-7
The views from respondents-opinions and solutions	8-14
Summary	15
Recommendations	16-17
References	17
Appendix	18-20

Introduction

“It is not always clear who should be responsible for care of these patients and their epilepsy. In some areas learning disability services offer epilepsy management, this may be in place of or in addition to neurological services.”(respondent).

“The care this population receive appears fragmented and inadequate.” (respondent).

The British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with epilepsy and intellectual disability (previously referred to as learning disability) were instructed to provide a response to: *A White Paper on the medical and social needs of people with epilepsy and intellectual disability: The Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy, Epilepsia 55(12):1902-1906 doi: 10.1111/epi.12848.*¹ The group’s terms of reference were to reflect on care for people with an intellectual disability and epilepsy in the UK.

The White paper highlights key areas of concern where action is needed to improve the care provided for people with intellectual disability and epilepsy. The aim of this report was to explore the views of a wide range of health professionals involved in the delivery of care to this population in the UK relating to the following four key domains in the White paper:

- Diagnosis and medical treatment,
- Delivery of service,
- Risk
- Broader impact upon quality of life.

This report to the UK Chapter council highlights key strengths and weaknesses of current care provision for people with Intellectual Disability and epilepsy in the UK, so they may be addressed by the Chapter in educational or other initiatives.

METHODS

The British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with intellectual disability and epilepsy was assembled inviting representatives from key stakeholders. The recommendations made within the White Paper formed the basis for gathering information on current service provision. The Group identified that the most valuable resource available was the membership of the UK ILAE Chapter and that of organisations represented by the members of the Group. Patient/carer based organisations were the source of information provided in the White Paper, and were thus not included again in the current working group. The data was collected via an online survey readily accessible to respondents. The survey content was developed from the key themes identified in the White Paper and by consensus of the working group. The electronic survey was distributed via email with support from the ILAE to the target audience. This target audience included a wide range of health professionals involved in delivering care to people with intellectual disability and epilepsy. The survey was distributed to membership of the ILAE UK, Royal College of Psychiatrists (RCPsych) Faculty of Intellectual Disability, Epilepsy Nurses Association (ESNA), and the Association of British Neurologists (ABN).

The survey included a mixture of quantitative questions and free text for qualitative data. The questions can be seen in Table 1.

On initial distribution a four week time-frame was allocated for gathering responses. Following the four week consultation period a further email was distributed to extend to a final deadline two weeks later. The respondents data was then collated, anonymised and distributed to the working group in order that opinion statements could be gathered from the representatives of key stake holders.

FINDINGS

The survey was completed by a total of 54 respondents. The professions of those completing the survey were Psychiatrist in Intellectual Disability (37%), Epilepsy Specialist Nurse-Registered General Nurse (RGN) (16.7%), and Neurologist with specialist interest in epilepsy (14.8%), Epilepsy Specialist Nurse-Learning Disability Nursing (13%), Neurologist (7.4%), Learning Disability Nurse (5.6%), other (13%).

The professionals involved in delivering care to people with intellectual disability and epilepsy review this population in a variety of settings. Almost half (46.3%) review patients at a District General Hospital (DGH), 44.4% work within Learning Disability services, 37% work in community clinics, 31.5% use community domiciliary visits, and 25.9% review patients at a tertiary epilepsy centre. The percentage of workload spent treating epilepsy by these professionals ranged between 9.3% and 29.6%. The percentage of case load with a diagnosis of intellectual disability showed two distinct peaks at 10-30% and 70-100%.

Diagnosis, Medical Treatment and the Delivery of Service

New Onset Epilepsy

The time taken for patients with intellectual disability and new onset epilepsy to undergo MRI investigation varied between 0-2 weeks (9.3%), 2-4 weeks (18.5%), 1-3 months (38.9%), 3-6 months (9.3%), none wait longer than 6 months, with 27.8% of responders having to refer through other clinicians to request the investigation.

The length of time for MRI under general anaesthetic (GA) was 0-2 weeks (3.7%), 2-4 weeks (3.7%), 1-3 months (24.1%), 3-6 months (20.4%), more than 6 months (14.8%), with 38.9% of clinicians unable to request such investigations and needing to refer to other departments.

The usual waiting time for a standard Electroencephalogram (EEG) was 0-2 weeks (5.6%), 2-4 weeks (33.3%), 1-3 months (38.9%), 3-6 months (0%), more than 6 months (1.9%), with 22.2% of clinicians unable to request this investigation and needing to refer to other departments.

Established epilepsy and ongoing management

The expected waiting time for a Computerised Tomography (CT) scan in this population was 0-2 weeks (11.1%), 2-4 weeks (31.5%), 1-3 months (31.5%), 3-6 months (1.9%), more than 6 months (0%), 25.9% are unable to request such investigation are required to refer through other clinicians.

The expected waiting time for MRI is 0-2 weeks (3.7%), 2-4 weeks (14.8%), 1-3 months (44.4%), 3-6 months (5.6%), more than 6 months (1.9%), 27.8% are unable to request such investigation are required to refer through other clinicians.

The expected waiting time for MRI under GA was 0-2 weeks (1.9%), 2-4 weeks (5.6%), 1-3 months (20.4%), 3-6 months (22.2%), more than 6 months (13%), with 37% unable to request such investigation are required to refer through other clinicians.

Rescue Medication

79.6 % of clinicians surveyed are involved in the prescription of Midazolam (buccal), 48.1% Diazepam (rectal), 22.2% Paraldehyde (rectal), 40.7% Lorazepam (tablets), and 31.5% other.

The majority of respondents play an active role in the implementation and management of rescue medication protocols. This includes devising rescue medication protocols (75.9%), renewing rescue medication protocols (75.9%), providing education/training to other professionals around rescue medication (40.7%), and providing education/training to families or care providers around rescue medication (55.6%).

Non pharmacological interventions

Epilepsy Surgery: The majority (77.8%) of responders have access to and consider epilepsy surgery for people with intellectual disability and epilepsy. A small percentage (5.6%) have access to epilepsy surgery but do not consider it for this population group. 14.8% of responders do not have epilepsy surgery available but would consider it, and 1.9% would not consider it even if it was an available option.

Vagus Nerve Stimulation (VNS): Nearly all responders (85.2%) have VNS available and would consider it for people with intellectual disability and epilepsy. 7.4% of responders do not have access to VNS but would consider it if they did. A minority of responders (5.6%) who have access to VNS would not consider it for this patient group, and a 1.9%) do not have access to VNS and would not considers it in any case.

Ketogenic Diet: 31.5 % of responders have access to implementation of a ketogenic diet and consider it as a management strategy. 18.5% have access to a ketogenic diet service but do not consider it. About one-third of responders (35.2%) do not have access to the ketogenic diet

but would consider it, the remainder (14.8%) do not have access and would not consider the use of a ketogenic diet.

Deep Brain Stimulation: Only a minority of clinicians involved in this survey (11.1%) have access to deep brain stimulation and would consider it for this population. A similar proportion (13%) of clinicians who have access to deep brain stimulation would not consider it. The majority of respondents do not have access to deep brain stimulation, of this group the half would not consider it, and 29.6% would, if it were available.

Risk

Epilepsy is associated with a wide range of risks. The National Institute for Health and Care Excellence (NICE) 137 guidelines state that all individuals and their families should be provided with, and have access to, information around risk management.² Respondents were asked to consider a number of common risks associated with epilepsy in people with an intellectual disability and whether they are actively involved in assessing and managing these risks. 87% of responders are actively involved in the assessment and management of sudden unexplained death in epilepsy (SUDEP), risk of drowning (83.3%), hospitalization (68.5%), side effects of medication (94.4%), observational devices and sensors (48.1%). Nearly 9/10 respondents assess and discuss SUDEP, drowning risk and medication side effects. It is important to raise the level of assessing and advising nocturnal monitoring.

Broader impact on quality of life

Epilepsy impacts all aspects of an individual's life and can have significant effects on quality of life. It is particularly important for people with intellectual disability and epilepsy that clinicians consider this broader impact as this population may already have significant restriction upon their ability to live independently. Responders were asked to consider particular areas that a diagnosis of epilepsy may impact upon. The majority of responders are involved in addressing these core areas including education (61.1%), employment (59.3%), social factors (83.3%), and family support (88.9%).

THE VIEWS OF RESPONDENTS- OPINIONS AND SOLUTIONS

The need for information about the individual with epilepsy and intellectual disability.

“Basing treatment decisions on inadequate information is a massive challenge”

“We rely heavily on engagement with family and carers to provide accurate information and observation during the assessment process.”

“There is a lack of supporting tools for person centred communication and a lack of (evidence-based) systems to ensure robust delivery of observations.”

“Coming to the epilepsy clinic with a carer who knows nothing, poor records, interfering family, inaccurate notes regarding seizures and behaviours”

“Share information and try to be available between appointments”

“Availability of easy read/accessible information, Training and support for care providers.”

“I rely on staff, when they are good that is marvellous and the attention and care shown by many carers is a joy to behold. Sometimes I ring family or home matron from clinic (not very time efficient) When they are "not-bothered", or "agency for the morning", or incapable of seeing that it might be their responsibility to provide MAR charts, seizure charts and information about the patient's health and wellbeing over the last year (as I see many of my patients only once a year) I get frustrated, as I have taken to getting the contact details of the holding company and copying a somewhat menacing letter to them about standards and this often produces a response (albeit sometimes a defensive one). I used to CQC this but it is futile (see above). One of the roles of the newly appointed community epilepsy nurses is to train up the poorer nursing homes - we are making a list of those we wish to see first...”

“Education, specific liaison with nursing homes and residences, providing seizure charts, behaviour charts and medication charts to those attending with patients will go some way to improving this.”

“A standardised recording of seizure activity for families or care staff to complete and bring to clinic appointments would aid clinicians’ assessments, this would be best supported by the community learning disability nurses.”

“There should be strong consideration of implementing multi-professional team meeting, particularly for more complex cases of refractory epilepsy with neuropsychiatric disturbance. This will improve communication and ensure that all of the individuals needs are considered in planning patient centred care.”

*“Hospital based neurology services - need to understand the importance of **seizure recordings** and demand these from carers. Often they will act on verbal information received at the clinic which is biased or wrong, I don't think it's fully appreciated how social care is delivered, the staffing issues including transient and rotational carers, poor pay and working conditions etc. Secondary care epilepsy services will complain about the quality of carer while still acting on the information. “*

Individual carer information can be very partial, this is not particular to disinterested/unmotivated carers and can often be more so the case with interested and caring carers who give their biased opinion. Recordings (when done properly) allow a less partial more complete picture of the epilepsy. Where recordings are presented at clinics then it is incumbent on the clinician to review them. Clinicians should recognise that it may take several appointments, liaison with ID colleagues, phone calls etc. be sure about carer information.

The challenges of investigation.

“Knowing whether patients will tolerate the investigations and the extra time these tests can take with these patients”

“Challenges getting the GP to refer for further tests / investigations”

“Not being able to request scans directly”

“Difficulty in suggesting investigations due to a presumption that people with ID will not cope or co-operate.

“It is a challenge to ensure that individuals with intellectual disability and epilepsy are referred appropriately in a timely manner for assessment and diagnosis.”

“People with intellectual disability and epilepsy are waiting far longer for investigations, way beyond the limits set by NICE.”

“The NICE clinical guidelines do not offer any specific guidance on the assessment and treatment of people with intellectual disability and epilepsy.”

“Referral, lack of understanding of needs. Lack of reasonable adjustments. Lack of service for scans under GA”

“Clinicians involved in the assessment and treatment of people with intellectual disability and epilepsy should have direct access to referral pathways to ensure that investigations take place in a timely manner.”

Special knowledge.

“Clinicians working with people with intellectual disability and epilepsy lack the knowledge and understanding of basic principles such as the Mental Capacity Act (MCA) 2005.”

“There should be a minimum level of standardized training provided to all clinicians involved in the care of people with intellectual disability and epilepsy. This training should include a focus on the MCA 2005, working with people with intellectual disability, and epilepsy competencies.”

“There should be specific training on prescribing, and monitoring of seizure rescue medication to all prescribers and those involved in developing rescue medication protocols.”

“Closer liaison between key bodies including the ILAE, ESNA, ABN, Psych ID faculty may help develop consensus guidelines on how best to meet the needs of this population.”

“Integrated / accessible patient information, training and education for primary, secondary care and ID services.”

“More education for neurologists/ epilepsy CNS esp. in behavioural issues and ID/ ID CNS in neurological issues to improve and maintain standards.”

“Education to recognise that in cases with treatment resistance and ID the best interest process be used to define and guide treating principles.”

Fragmented care.

“Lack of clarity about who takes the lead in the delivery of care”

“Transition as a whole is a challenging issue.”

“It is not clear who should be responsible for care of these patients and their epilepsy. Some learning disability services are content to manage epilepsy, others are not and refer to neurology.”

“Open collaboration communication between community and hospital based services so that all professionals involved in an individual’s care has access to the most recent clinical outcomes and management plans.”

“Intellectual disability services are well placed to monitor epilepsy and the effect it has on functioning and QOL. I don’t think that LD professions should opt out of this role. This does not mean diagnosing and treating all epilepsy of ID, but does mean having an awareness of the effect of epilepsy, the effects of the drugs and I would like hope straightforward treatment changes, especially with particular patient groups like Down’s syndrome dementia. I would promote the development of specialist roles in ID nursing including both epilepsy specialist nursing and acute care liaison.”

“Lack of good communication between hospital and community services”

“Lengthy waiting times in clinic areas, adding to distress for patients and carers there is a range of appointments and settings with no clear guidance on best practice developed on local knowledge and resources.”

“Care pathways and multidisciplinary working.”

“This is a recurrent theme. Need better communication e.g. MDTs/ skype to facilitate communication and joint clinics.”

“A set of good practice pathways need to be made available.”

“MDTs for refractory patients with ID + uncontrolled epilepsy. These would need to be mandated to have any impact (as they now are for cancer services).”

“Need extra TIME and resources to give good care to this group.” “Need resolution of whether and when ID psychiatrists will deal with epilepsy in their patients.”

“Multi-disciplinary working/ communication, the links between community based ID services and Neurology services are often informal and intermittent. There are many models of delivering epilepsy services but in my view there should always be routes of formal communication /working arrangements, e.g. meeting, letters supervision, I would prefer all epilepsy services to employ ID specialists as integral team member’s e.g. ID ESN. Agreement about who should be doing what in the form of clinical pathways can be helpful to minimise inappropriate referral, duplication and disproportionate caseloads, and improve access.”

Medication issues.

Side effects of AED medication – *“I have found that side effects (often severe) of AED treatment are common. Clinicians worried about under treating epilepsy (more likely in non - ID services) will ‘accept side effects over seizures’ at all costs, I think that carefully thought out (evidence based where possible) principled guidance would help clinicians to balance side effects and quality of life .”*

Medication Errors – *“In my experience AED medication errors are common at all stages of the patient pathway. As an example I had a patient discharged from hospital with on a third of his routine AED dose, the GP practice did not pick this up, and it was 4 months later at my clinic that the error was noted. Patients are routinely given the wrong drug, wrong dose in social care settings, transcribing of medicine is common practice, There is no way of collecting the data for this as unlike acute NHS care there is no one reporting system. In my experience it is likely that the errors I know about are very likely to be an underestimate of the ongoing situation. I would like to see more comprehensive reporting systems which are not isolated so that on overall picture can be built up of the problem along with a potential to problem solve.”*

A lack of services.

“I find that I am not given enough clinic time for these patients, they are given a routine 15 minute follow up slots, they are often accompanied by carers who do not know them at all and have not been given the appropriate information to make the appointment useful.”

“Flexibility of appointments (longer appointments, home visits, school clinics, and joint clinics) interagency working issues including communication (acute care, primary care and ID services) Transition issues – multitude of problems”

“In my own experience in a large city with a regional neurology service and ID epilepsy specialist services we have worked through times of growth and shortage of key personnel in both primary and secondary care, these issues come and go and are made worse or better in their effect on people with intellectual disability depending on the background supports available to them in social care. Right now there are extreme pressures affecting both health and social care delivery to our client population.”

Making reasonable adjustments.

“There is a Lack of understanding of reasonable adjustments required for individuals with intellectual disability and epilepsy”.

“Acute services are not always willing to make reasonable adjustments required, or it’s difficult to liaise with decision makers around implementing reasonable adjustments.”

“Depends on ID psychiatrist as to whether they will accept patient with epilepsy for assessment in their service.”

“The reasonable adjustment required to ensure that this population receive an equal service including diagnostic investigations is not universal.”

“People with extremely complex needs are expected to have their needs met in consultant clinics that are designed for the general population.

*“Alongside the need for good accurate seizure and related information is the development of LD sensitive approaches to care delivery or reasonable adjustment - These must include, longer appointment times, no wait appointments, flexible venue and times, including home outreach where necessary. There should be access to the full range of diagnostic procedures with reasonable adjustments made to allow these. Guidelines on sedation and anaesthesia for scans would be welcome. Finally there should be a range of easy read/accessible information sources for **adults** with ID and carers.”*

“There may be a role for specialist skilled staff in supporting Primary Care to make appropriate diagnostic referrals, this role may include epilepsy specialist nurses or learning disability nurses.”

“There needs to be increased emphasis on ensuring that services are offering the reasonable adjustments required to ensure that all patients have access to the appropriate specialist assessments and investigations. There may be a role for further development of Learning Disability Liaison nurses in the acute secondary care setting to co-ordinate this process.”

“Longer appointment times for people with ID, modified clinics with no wait, community outreach, and ground floor wheel chair access.”

“Possibly guidance need to be given to commissioners on the minimum standards of time and settings requirement.”

Accessing good quality care.

“GP’s don’t refer to Community LD teams try to manage epilepsy without the appropriate support and input from an epileptologist, so patients who may be surgical candidates are not being referred in a timely manner. Also their records/ notes are kept for their own reference and cannot be accessed by hospital staff making management of these patients if they come to hospital particularly challenging and often drugs are not written up correctly which can cause further problems.”

“Examples of poor care while in hospital – omitting medication/ discharging without consultation with relatives/carers/ ID services”

“ID patients admitted to hospital have unique difficulties and poor care is common.”

The importance of risk.

“Risk assessment and interventions are extremely important given the rates of mortality and preventable death to raise SUDEP risk assessment and discussion as suggested by NICE/SIGN to 100%.”

“Carers should be asked to send someone who knows the patient, should bring clear documentation about treatment, seizure charts and active issues consider the SUDEP and seizure Safety checklist.”

Environmental risk assessment

“Use risk assessments with patients who have drug resistant epilepsy and continued seizures, training in risk assessment/ more guidance to improve person centred assessment of risk especially nocturnal monitoring issues.”

“To ensure structured risk assessments are used to both record and communicate holistically.”

“There needs to be more awareness of risks of epilepsy and ID including highlights of the Connor Sparrowhawk case. Closer links need to be fostered between local ID services and epilepsy services led by clinicians to identify local support for local needs”.

“Important to balance risk versus safety versus QOL and evidence it.”

Broader Impact upon quality of life.

“Probably about half the time with these patients is spent on these areas. (I education/ employment / family factors) Incidentally, these are often some of the most professionally rewarding areas, and I have had recent patients where dealing with carers, specialist nurses, social services etc. in some detail we have really managed to improve patients quality of life (and seizure control) by addressing these issues“

“However the concerns with families are for the whole system such as respite, health needs being met, and day time occupation following on from school.”

“Cuts in Social care budgets. Services much reduced.” “Care for people with ID in the community is in meltdown, only solution is investment”

“Social care staff need to understand the risks of person’s epilepsy when reviewing and cutting care packages”

“Decreased amount of time or difficult to quantify time spent on QOL.”

“One of the most professionally rewarding areas as I have discovered lately.”

“Important to embed QOL tools into clinical practice.”

SUMMARY

The survey and assessment from the working group identified key themes of care delivery and meeting complex needs. Importantly these came from the membership of the ILAE and other representative professional bodies.

Adults with intellectual disability and epilepsy appear to exist in a unique, but inadequate, segment of epilepsy care delivery. This contrasts with paediatric epilepsy, mainly specialist driven by paediatric service, or adult epilepsy without intellectual disability, residing in adult neurology and primary care.

Care of adults with an intellectual disability is shared between a triumvirate of neurology, Intellectual disability and primary care services. At its best these service can manage individuals with a high level of excellence either uniquely within one service or working together. This model provided the material to meet the needs of people identified by the White paper.

There is evidence that care delivery is sometimes fragmented. This leads to significant disparity and inequality of care across Britain.

Recommendations:

The group has made the following recommendations. These are graded by degree of priority

High Priority – an end to fragmented care

The ILAE should promote collaboration between the ABN, RCPSYCH, ESNA, and the RCGP to develop care pathways to improve care and allow audit of the care delivery to this population. We recommend a one day ILAE conference, and further work within the royal colleges through cross representations and joint projects.

High priority – risk reduction

The ILAE should develop and recommend standardised risk assessments/checklists that can be easily accessed and used by all clinicians involved in the care of people with epilepsy and intellectual disability. This could be progressed working with charities and professional grouping, in particular epilepsy nurses.

High priority –equitable access to care

All NHS hospitals should have defined and auditable standards for accessing investigation and management in people with an intellectual disability, such as access to expert clinicians and MRI under GA.

Medium priority –training and education

The ILAE should provide education for the training of health care providers who support the delivery of rescue medication and emphasize the importance of accurate seizure recording using standardized recording charts for seizures and behavioural changes.

The ILAE hosts a website linking useful information for people with ID in user-friendly form, family and carers, and healthcare professionals. This could include templates for rescue medication, scales and Apps, and audit templates. Resources will be needed to keep this updated.

Medium priority – working in generic services

The ILAE should publish guidance for standards of care, including reasonable adjustments within generic (non learning disability) services for people with epilepsy and intellectual disability. This may include the development of LD liaison nurses within secondary care to facilitate hospital admission, greater time for consultations or shared clinics/working between general and psychiatric services.

REFERENCES

1. Kerr, M., Linehan, C., Thompson, R., Mula, M., Gil-Nagal, A., Zuberi, S. M., & Glynn, M. (2014). A White Paper on the medical and social needs of people with epilepsy and intellectual disability: the Task Force on Intellectual Disabilities and Epilepsy of the International League Against Epilepsy. *Epilepsia*, 55(12), 1902-1906.
2. The National Institute for Health and Care Excellence (NICE). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. (2012) NICE clinical guideline 137 [guidance.nice.org.uk/cg137](https://www.nice.org.uk/guidance/cg137)

Table 1.

ILAE

Care provision for adults with an Intellectual disability (or Learning Disability) and Epilepsy

The questionnaire with consist of the following sections:

- A. Demographics**
- B. Diagnosis and Medical Treatment**
- C. Delivery of Service**
- D. Risk**
- E. Broader Impact upon Quality of Life**

A. DEMOGRAPHICS

1. What is your profession/speciality?
2. Where do you work?
3. Where do you see your patients with Intellectual Disability and Epilepsy?
4. Approximately what percentage of your caseload has a diagnosis of ID?
5. Approximately what Percentage of your workload is treating epilepsy?

B. DIAGNOSIS AND MEDICAL TREATMENT

6. For your patients with Intellectual Disability and new onset Epilepsy what is the usual waiting time for the following investigations?

- A. EEG
- B. CT
- C. MRI
- D. MRI under anaesthetic

7. For your patients with established epilepsy and intellectual disability what is the usual waiting time for the following investigations?

- A. EEG
- B. CT
- C. MRI
- D. MRI under anaesthetic

8. What are the barriers you face when trying to access these investigations?
9. Are there any barriers that you face when trying to prescribe Antiepileptic Drugs? This may include factors such as GP prescribing, and prescribing the newer AED's.
10. Are you involved in prescribing any of the following rescue medication?
11. On average, what proportion of your weekly workload is focused upon implementing and monitoring rescue medication Guidelines? This work may include the education and training of care staff or families.
12. Are you directly involved in providing any of the following?
13. Do you have access to the following interventions for individuals with Intellectual Disability and Epilepsy, and do you consider them in your management?
 - A. Epilepsy Surgery
 - B. Vagus Nerve Stimulation (*VNS*)
 - C. Ketogenic Diet
 - D. Deep Brain Stimulation (*DBS*)
14. How do you manage behaviours that challenge and mental illness in people with Intellectual Disability and Epilepsy?
15. How satisfied are you with this process, and access to these services?
16. How do you manage behaviours that challenge in people with Autism and Epilepsy?
17. How satisfied are you with this process, and access to these services?
18. When you are concerned that your patients' may have unmet physical health needs in addition to their epilepsy (which may be affecting seizure control/treatment) do you have any problems accessing physical health review, if so, can you suggest any specific solutions?
19. Do you find NICE (CG137) and SIGN (143) guideline on the diagnosis and management of epilepsy helpful when managing your patient's with Intellectual Disability and Epilepsy? In your experience what is missing from the guidelines that may help you overcome the challenges you face?
20. Do you feel adequately trained to manage ethical considerations and capacity decisions when treating people with Intellectual Disability and Epilepsy?
21. a) In your experience what are the barriers to delivering good care to people with Intellectual Disability and Epilepsy and, b) how can these barriers be addressed?

C. DELIVERY OF SERVICE

22. Do you have access to a specialist inpatient epilepsy assessment service for people with Intellectual Disability in your region of practice, if so where is this located?
23. Are there any adaptations to service provision in your workplace to meet the reasonable adjustments expected for people with Intellectual Disability and Epilepsy, please give examples?

24. Are there any challenges you face when working with general practice when delivering epilepsy care for people with Intellectual Disability and Epilepsy?
25. How long are you given for a new consultation with an individual with Intellectual Disability and Epilepsy?
26. How long are you given for a follow up consultation with an individual with Intellectual Disability and Epilepsy?
27. Please describe your experience of the Transition of individuals with Intellectual Disability and Epilepsy from child to adult services? For example what has been done well, and what are the challenges?
28. Do you believe that your service meet the needs for people with intellectual disability and epilepsy when compared to the general epilepsy population, if not, what are the reasons?
29. Do you know who the relevant individuals including commissioners, finance directors, involved in planning service developments and advancements in your area, and are you able to access them?
30. Think of your patients with severe learning disability and communication difficulties; How does this impact upon your consultation? How do you overcome the challenges of gathering accurate information?
31. What are the challenges you face when monitoring the *effectiveness of treatment*, and what strategies have you employed to overcome them?

D. RISKS

32. Are you involved in assessing or supporting people with Intellectual disability and Epilepsy around any of the following?

Sudden Unexplained Death in Epilepsy (SUDEP)

Risk of Drowning (Bathing)

Hospitalization

Side effects of medication

Listening/observational devices and sensors

E. BROADER IMPACT UPON QUALITY OF LIFE

33. What proportion of your time is spent on issues related to the following for your patients with Intellectual Disability and Epilepsy?

Education

Employment

Social factors

Family support

34. What are the challenges you face when addressing these areas, and do you have any solutions to overcome them?

