The provision of care to adults with an intellectual disability in the UK. A Special report from the intellectual disability UK chapter ILAE


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

a Institute of Psychological Medicine and Clinical Neuroscience, Cardiff University, United Kingdom
b Psychiatry of Intellectual Disability, Abertawe Bro Morgannwg University Health Board, United Kingdom
c Institute of Neurology, University College London, United Kingdom
d HS Greater Glasgow and Clyde, United Kingdom
e Northampton General Hospital NHS Trust, United Kingdom
f Abertawe Bro Morgannwg University Health Board, United Kingdom
g Royal College of Psychiatrists, Faculty of Psychiatry of Intellectual Disability, United Kingdom
h Cornwall Partnership NHS Foundation Trust, Exeter Medical School, United Kingdom

ABSTRACT

Purpose: This article reflects the report by the British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with epilepsy and intellectual disability (ID). Its terms of reference was to explore the current status of aspects of the care of people with an ID and epilepsy. Methods: Survey content was developed from key themes identified by consensus of the working group. An electronic survey was distributed via email. The sample population was the membership of the ILAE UK, Royal College of Psychiatrists (RCPsych) Faculty of ID, Epilepsy Nurses Association (ESNA), and the Association of British Neurologists (ABN). Following a six week response period the data was then collated, anonymised and distributed to the working group in order that opinion statements could be gathered. Results: The time taken for individuals with both new-onset and established epilepsy to undergo routine investigation was commonly at least 1–3 months, far beyond recommendations made by NICE (CG20). A small minority of clinicians would not consider non-pharmacological interventions including epilepsy surgery, vagus nerve stimulation, and ketogenic diet for this population. Almost universally responders are actively involved in the assessment and management of key risk areas including risk of drowning, hospitalization, medication side effects, and sudden unexpected death in epilepsy (SUDEP). Conclusion: This investigation identifies key themes and recommendations relating to care delivery and meeting the complex needs of people with ID and epilepsy. Adults with ID and epilepsy appear to exist in a unique, but inadequate, segment of epilepsy care delivery.

1. 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). This article reflects the report by the British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with epilepsy and intellectual disability. Its terms of reference was to explore the current status of aspects of the care of people with an intellectual disability and epilepsy as a response to the White Paper; a special report on the medical and social needs of people with epilepsy and intellectual disability by the task force on intellectual disabilities and epilepsy of the ILAE [1]. The White paper highlights key areas of concern where action is needed to improve the care provided for people with intellectual disability and epilepsy developed using the views of patient groups and carer organizations.

Areas of concern in the care of people with epilepsy and intellectual disability:
Diagnosis and medical treatment
Service delivery
Education and employment
Social, romantic, and family life
1.1. Epilepsy and intellectual disability

There is a strong positive correlation between epilepsy and intellectual disability (ID). Both may be caused by a wide range of pathological insults during neurodevelopment. The prevalence of epilepsy increases with the severity of ID [2], and people with epilepsy and ID often experience multiple seizure types that are resistant to drug treatment [3]. People with ID and active epilepsy are also at greater risk of mental illness compared to the general population [4]. There are consensus guidelines for the management of behavioural manifestations and neuropsychiatric disturbance [5,6]. Good management of epilepsy in this population is particularly important as there is increased risk of sudden unexplained death in epilepsy (SUDEP) [7]. An evidence based risk factor checklist is available to guide person-centred discussion around risk [8]. The presence of other physical, psychological, and neuro-developmental co-morbidities may alter the approach to assessment and diminish the reliability of generic assessment tools and accuracy of information. People with epilepsy and ID often have a wide range of complex needs – but undergo less diagnostic investigations and have less contact with specialist epilepsy services [9]. The health inequalities experienced by the ID population have been well established [10], and part of the reason for poorer health outcomes is related to problems with diagnosis and medical management [10,11]. Reasonable adjustments should be in place to ensure equitable access to specialist health care and prevent fragmentation of care. This is of particular importance to people with ID who may lack the capacity to make decisions.

2. Methods

The British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with ID and epilepsy was assembled inviting representatives from key stakeholders including ILAE (MPK), Royal College of Psychiatrists ID Faculty (AR, RS, LVW), Association of British Neurologists (HAL), Epilepsy Nurses Association (AC, CH, MG). 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 survey content was developed from themes identified by consensus of the working group following consecutive rounds of discussion. These themes were developed from the key areas of concern identified in the White paper and include additional aspects of epilepsy care relevant to professionals. The survey included a mixture of quantitative questions and free text for qualitative data in order to ensure main aspects of enquiry were covered and that respondents had space to provide a narrative. The data was collected via an online survey. The electronic survey was distributed via email with support from the ILAE to the target audience, including a wide range of health professionals involved in delivering care to people with ID and epilepsy. The sample population was the membership of the ILAE UK (800 total members approximately), Royal College of Psychiatrists (RCPsych) Faculty of ID (2361), Epilepsy Nurses Association (ESNA) (340), and the Association of British Neurologists (ABN) (756). A six week response period was allocated. The respondents’ data was then collated, anonymised, and distributed to the working group in order that opinion statements could be gathered. Key themes identified by working group:

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

3. Results

The results of this survey and subsequent recommendations arise from the opinions of professionals involved in the care of people with epilepsy and ID. The results do not draw comparisons of service provision or their relative efficacy. The survey was completed by a total of 54 respondents. The professions of those completing the survey were Psychiatrists in ID (20), Epilepsy Specialist Nurse (15), Neurologist (12), Learning Disability Nurse (2), and other (5). Responses were received from a wide range of geographical locations across the United Kingdom, and also included a small number of international responses.

The professionals involved in delivering care to people with ID and epilepsy work in a variety of settings. Almost half (46%) review patients at a District General Hospital (DGH), 44% work within Learning Disability services, 37% work in community clinics, 32% use community domiciliary visits, and 26% review patients at a tertiary epilepsy centre. The percentage of workload spent treating epilepsy by these professionals ranged between 9% and 30%. The percentage of case load with a
diagnosis of ID showed two distinct peaks at 10–30% and 70–100%. The main body of results are presented as per the key domains identified by the working group at the outset.

3.1. Diagnosis, medical treatment and the delivery of service

3.1.1. New onset epilepsy
The time taken for patients with ID and new onset epilepsy to undergo MRI brain scan varied between 0-2 weeks (9%), 2–4 weeks (19%), 1–3 months (39%), 3–6 months (9%), none wait longer than 6 months, with 28% 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 (4%), 2–4 weeks (4%), 1–3 months (24%), 3–6 months (20%), more than 6 months (15%), with 39% 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 (6%), 2–4 weeks (33%), 1–3 months (39%), 3–6 (0%), more than 6 months (15%), with 28% of clinicians unable to request this investigation and needing to refer to other departments.

The usual waiting time for a standard Electroencephalogram (EEG) was 0–2 weeks (6%), 2–4 weeks (33%), 1–3 months (39%), 3–6 months (0%), more than 6 months (2%), with 22% of clinicians unable to request this investigation and needing to refer to other departments.

3.1.2. Established epilepsy and ongoing management
The expected waiting time for a Computerised Tomography (CT) scan in this population was 0–2 weeks (11%), 2–4 weeks (32%), 1–3 months (31.5%), 3–6 months (2%), more than 6 months (0%), 26% are unable to request such investigation are required to refer through other clinicians. The expected waiting time for MRI is 0–2 weeks (4%), 2–4 weeks (15%), 1–3 months (44%), 3–6 months (6%), more than 6 months (2%), 28% 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 (2%), 2–4 weeks (6%), 1–3 months (20%), 3–6 months (22%), more than 6 months (13%), with 37% unable to request such investigation are required to refer through other clinicians.

3.1.3. Rescue medication
Almost four in five (80%) of clinicians surveyed are involved in the prescription of Midazolam (buccal), 48% Diazepam (rectal), 22% Paraldehyde (rectal), 41% Lorazepam (tablets), and 32% other. The majority of respondents play an active role in the implementation and management of rescue medication protocols. This includes devising rescue medication protocols (76%), renewing rescue medication protocols (76%), providing education/training to other professionals around rescue medication (41%), and providing education/training to families or care providers around rescue medication (56%).

3.1.4. Non pharmacological interventions 3.1.4.1. Epilepsy surgery. The majority (78%) of responders have access to and would consider epilepsy surgery for people with ID and epilepsy. A small percentage (6%) has access to epilepsy surgery but would not consider it for this population group. Less than 1 in 6 (15%) of responders do not have epilepsy surgery available but would consider it if available, and 2% would not consider it even if it was an available option. Those professionals who do not consider epilepsy surgery consist of general practitioners (GPs) with a special interest in epilepsy and learning disability nurses. 3.1.4.2. Vagus nerve stimulation (VNS). Nearly all responders (85%) have VNS available and would consider it for people with ID and epilepsy. A small number (7%) of responders do not have access to VNS but would consider it if they did. A minority of responders (6%) who have access to VNS would not consider it for this patient group, and 2% do not have access to VNS and would not consider it in any case. 3.1.4.3. Ketogenic diet. Less than one third (31%) of responders have access to implementation of a ketogenic diet and consider it as a management strategy. Less than one in five (19%) have access to a ketogenic diet service but do not consider it. About one-third of responders (35%) do not have access to the ketogenic diet but would consider it, the remainder (15%) do not have access and would not consider the use of a ketogenic diet. Included in respondents who would not consider ketogenic diet are specialists of different professions working in tertiary epilepsy centres.
3.1.4.4. Deep brain stimulation. Only a minority of clinicians involved in this survey (11%) 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, but 30% would if it were available.

3.2. 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 [12]. Respondents were asked to consider a number of common risks associated with epilepsy in people with an ID and whether they are actively involved in assessing and managing these risks. Nearly nine of every ten (87%) responders are actively involved in the assessment and management of sudden unexplained death in epilepsy (SUDEP), risk of drowning (83%), hospitalization (69%), side effects of medication (94%), observational devices and sensors (48%).

3.3. Broader impact on quality of life
Epilepsy impacts on all aspects of an individual and can have significant effects on quality of life. It is particularly important for people with ID 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 area including education (61%), employment (59%), social factors (83%), and family support (89%).

3.4. The views of respondents – options and solutions
As described the respondents provided detailed free text answers within the questionnaire. The total free text responses were then transcribed and analysed for themes (MK). Ten themes emerged which were agreed by the working group. Table 1 identifies these themes and provides direct quotations from respondents. The responses have not been further qualitatively analysed in order to preserve examples of the raw data providing ‘real world’ opinions from clinicians working with people with epilepsy and ID. This data has been used by the working group to help develop recommendations (Table 2).

4. Discussion
The British Branch of the International League Against Epilepsy (ILAE) Working Group on services for adults with ID and epilepsy identified key themes relating to care delivery and meeting complex needs. Importantly the findings in this report come from the response of the membership of the ILAE and other representative professional bodies in the UK. Adults with ID 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 ID, residing in adult neurology and primary care. Care of adults with an ID in the UK is shared between neurology, ID 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 provides the skills to meet the needs of people identified by the White paper [1]. There is evidence that care delivery is fragmented in some areas. This leads to significant disparity and inequality of care across the UK for adults with an ID. The British ILAE is working to promote collaboration between the key stakeholders and governing bodies involved in the delivery of care to this population. The development of care pathways will help ensure that the needs of people with ID and epilepsy are met and reasonable adjustments are made. Collaboration between professional groups will allow sharing of expertise to ensure that patients receive person centred care. There needs to be a specific focus on the complex needs of this population. Delivery of care will require the input of multiple professionals, however, there needs to be one recognised responsible team or specialist to co-ordinate care. Following the findings of this report the RCPsych ID faculty has proposed a strategy for clinicians to better support their patients with epilepsy [13]. A tiered competency model (Bronze/Silver/ Gold) is proposed to evidence competencies against the National Institute for Health and Care Excellence (NICE) outcome indicators for epilepsy and the Scottish Intercollegiate Guidelines Network (SIGN) guidance [12,14].
Table 1
Key issues in the care of people with epilepsy and ID.

The need for information about the individual with epilepsy and ID.

"Having treatment does not mean inadequate information is a reason to challenge.

"We rely heavily on engagement with family and carers to provide accurate information and observations during the assessment process."

"There is a lack of supporting tools for person-centered communication and a lack of evidence-based systems to ensure robust delivery of information.

"Coming to the epilepsy clinic with a carer who knows, nothing, poor records, modifying family, inaccurate notes regarding seizures and behaviours."

"More information and try to be available between appointments."

"Availability of easy read accessible information, training, and support for carers.

"Identification, specification with nursing homes and respite, providing assertive 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 is available and brings data to appointments would assist the practitioners' assessment, would be less supported by the community learning disability services."

"There should be strong consideration of implementing multidisciplinary team meetings, particularly for more complex cases of refractory epilepsy with neuropsychiatric disturbances. This will improve communication and ensure that all of the individual's needs are considered in planning patient-centred care."

"Individual care information can be very patchy, this is not only due to lack of interest/handover errors but can often be more so where the individual is concerned and caregivers who give their best opinion. Sometimes where recordings are present at clinics then it is inconsistent. The clinician to review them. Clinicians should recognise that it may take several appointments, liaison with ID colleagues, phone calls etc. to be sure about care information.

The challenges of investigation.

"Challenges getting the General Practitioner (GP) to refer for further tests/investigations."

"Not being able to request scans directly."

"Difficultly 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 for longer for investigations, well beyond the limits set by NICE."

"The NICE clinical guideline do not offer specific guidance on the assessment and treatment of people with intellectual disability and epilepsy."

"Informed, lack of understanding of needs, lack of reasonable adjustments. Lack of service for same under GP."

"Clinic based in the assessment and treatment of people with intellectual disability and epilepsy may need to refer referral pathways to ensure that investigations take place in a timely manner."

Special knowledge.

"Clinic staff 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 is a minimum level of standard/line teaching provided to all clinicians involved in the care of people with intellectual disability and epilepsy. This teaching should include a focus on the MCA 2005, working with people with intellectual disability, and epilepsy competencies."

"Courses in antiepileptic drugs and care for people with intellectual disability and epilepsy are needed to be developed and made available.

"Closer liaison between key bodies including the ILE, ESNA, AEEH, PWE 's, HSYN, INN, and other professionals who develop common guidelines must be established to ensure the needs of this population are met in medical guidelines."

"Integrated and accessible patient information, training and education for primary, secondary care and ID services.

"Further education for neonatologists, epilepsy clinical nurse specialists (CNSS) on behavioural issues and ID/CHONS in neurological issues to improve and maintain standards.

Fragmented care.

"Lack of clarity about who takes the lead in the delivery of care.

"Transition as a whole: a challenging issue.

"Open collaboration and communication between community and hospital-based services so that all professionals involved in an individual's care has access to the most recent clinical evidence and management plans."

"Intellectual disability services are still slow to monitor epilepsy and the effect it has on functioning and the quality of life (QOL). I don't know if ID professionals should act out of the chain of different medical teams managing a person. Likely many of the treatments are being adopted but there is a lack of research into the effect of epilepsy on the people's lives. The information would be helpful to patients and relatives to make informed decisions regarding treatment options."

"Lack of communication between hospital and community services.

"Longer waiting times in clinic and at hospital outpatient clinics. There is a lack of appointments and waiting times with no clear guidelines on how best to manage these people.

"A lack of continuity of care needed to be made available.

"A lack of communication between hospital and community services.

"Lack of information about special care for patients and carers there is a range of appointments and waiting times with clear guidelines on how best to manage these people.

"Need for additional training 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 and communication: the link between community-based ID services and Neurology services are often informal and intermittent. There are many models of delivering epilepsy services but it may vary there should always be a role of formal communication between professionals, eg, meeting, letters, supervision. I would prefer all epilepsy services to employ ID experienced clinical nurse members. (eg. Environmental nurse specialist) to help with the decision making process and formal pathways can be helpful to make appropriate referrals, documentation and disproportionate referrals, and improve access."

Fatigue issues.

"Side effects of antiepileptic drugs (AEDs) - "I have found that side effects of some of these AEDs are more common. Patients worried about underweight epilepsy (more likely when being on treatment) need support if the patient is over or underweight at all times, this can benefit carefully thought out (mediation based on weight) treatment guidelines to help the individual to balance the side effects and quality of life."

"Medication errors - in my experience the main medication errors are common at all stages of the patient pathway. As an example, a had a patient discharged from hospital with no knowledge that the medication was Adjusted and the GP practitioner did not know this up, and was 5 years later at my clinic that the error was noted. Patients are not given the word correctly, written correctly in medications, and the prescribing of the medicine in the current practice. There is no way of collecting the data for this as an unclear AED is there is no the comprehensive reporting system."

A lack of services.

"If that fails to give enough clinic time for these patients, they are given a routine to 2 minute follow-up after this, 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."

"In my experience the routine may not be suitable for patients with an ID and epilepsy."

"Making reasonable adjustments. Strategies to help ensure people with ID receive equitable access to healthcare."

"There is a lack of understanding of reasonable adjustments required for individuals with intellectual disability and epilepsy."
There are many areas for improvement and the Working Group has identified actions (Table 2). These offer a blueprint for change that could address the current inequalities in care provision for this important group of people with epilepsy.

Limitations of study

The overall response rate to this survey is low considering the number of potential responders from each stakeholder group surveyed. The views considered therefore represent only a small sample of the potential professionals involved in the care of people with epilepsy and ID. This raises concerns of bias and the views may represent those individuals with a keen interest in the field and not provide a true representation of care provision with generalizable results. We also have to consider that not all members of the organizations surveyed are currently in clinical practice. This potential bias is reflected in the recommendations made by the group which go beyond the findings of the survey which are largely positive.

Conflicts of interest

MK has received speaker’s honoraria from UCB Pharma and Eisai outside the submitted work. RS has received institutional and research support, and personal fees from LivaNova, UCB, Eisai, Special Products, Bial and Desitin outside the submitted work. RS is also key contributor and author in the development of the SUDEP and Seizure Safety Checklist working with SUDEP Action.

AC honoraria from Special Products outside the submitted work.

LW no conflict of interest.

MG no conflict of interest.

HAL no conflict of interest.

AR no conflict of interest.

CH no conflict of interest.

References


