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

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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 (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 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%), renew- ing 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 considers 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 areas 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 services 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.
"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."
"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' assessment, 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"
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.
"Challenges getting the General Practitioner (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 IAE, 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 clinical nurse specialist (CNS) esp. in behavioural issues and ID/ID CNS 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 is a challenging issue."
"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 Quality of Life (QoL). I don't think that ID 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 a straight forward 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."
"A set of good practice pathways need to be made available."
"Multidisciplinary team's (MDTs) for refractory patients with ID and 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 epilepsy nurse specialist. 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 Anti epileptic drugs (AED) - "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 comprehensive reporting system."
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 appointment (ID services) Transition in both primary and secondary care supports available to"
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"

Table 2
Recommendations in Response To The Challenges Highlighted In This Report.

High Priority	
An end to fragmented care	The ILAE should promote collaboration between the AIBN, 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.
Risk reduction	The ILAE should develop and recommend standardised risk assessments/check lists 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 specialist nurses. The ILAE should support research into the use of monitoring devices so there is robust evidence to support protocols around seizure/overnight monitoring
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 in collaboration with ESNA 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.
Working in generic services	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. 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 ID liaison nurses within secondary care to facilitate hospital admission, greater time for consultations or shared clinics/working between general and psychiatric services.

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.

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