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.

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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 neurodevelopmental 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 but not longer than 1 year (20%), with 9% of clinics 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 to 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%), 26% 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
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