



**GOOD PSYCHIATRIC PRACTICE**

**CR203**

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# Management of epilepsy in adults with intellectual disability

**COLLEGE REPORT**

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## College Report CR203

May 2017

Approved: April 2017

Due for revision: 2022

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# Foreword

The health inequalities often experienced by people with intellectual disabilities have been known of for many years. Poorer outcomes are often associated with late diagnosis, misdiagnosis, variations in access to appropriate investigations and treatment, and lack of robust implementation of reasonable adjustments. Epilepsy is common in people with intellectual disabilities, and it increases in prevalence as the level of disability increases. It is a serious comorbidity, in which behavioural and psychiatric presentations are common. Epilepsy is also a condition which often falls into the mind–body gap in terms of the way clinicians and services respond.

This tiered approach to a training and competency framework, developed for psychiatrists working in the field of intellectual disabilities, sets out the profession’s commitment to deliver a clinical infrastructure that can support care pathways, raise standards of care delivery and, ultimately, improve patient outcomes.

Jean O’Hara FRCPsych  
National Clinical Director for learning (intellectual) disabilities  
NHS England  
31 March 2017

# Executive summary

Epilepsy and its treatment not only influence behaviour, but also affect long-term mental and physical healthcare outcomes in this group. Therefore, awareness and management of epilepsy is essential for any psychiatrist working with people with ID.

There is a lack of clarity on training standards, pathways to achieve competency and expected roles. This is part of a larger problem: care pathways for people with ID and epilepsy are poorly defined, poorly regulated and poorly governed.

This initiative from the Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability proposes a competency strategy for its members to benchmark their competencies, develop them as required, and better support their patients with ID and epilepsy.

A tiered model (Bronze, Silver and Gold) is proposed to evidence the competencies of a psychiatrist working with people with ID. Each of these categories is benchmarked to National Institute for Health and Care Excellence (NICE) outcome indicators for epilepsy and Scottish Intercollegiate Guidelines Network (SIGN) guidance. The tiered model is a continuum rather than a definitive categorical structure. The expectation is that psychiatrists working with people with ID or training in the specialty of ID will, at the minimum, satisfy the criteria of a Bronze grade.

The Bronze grade requires competency in delivering four of the nine NICE outcome measures. The focus is on basic management of epilepsy, including awareness and mitigation of direct and indirect risk issues, non-complex diagnosis and treatment, and effects and side-effects of epilepsy treatments. Additional 'desirable' competencies include awareness of the relevant local pathways for a person with ID to access specialist epilepsy care, and joint working with specialist services.

The Silver grade requires psychiatrists to be familiar with NICE and SIGN guidelines and to deliver on all nine outcomes. The focus is on managing most people with ID and epilepsy directly. In complex cases, a recognised back-up system of a neurology service or other specialist epilepsy service is in place. There is an expectation that the ID services will have access to other specialist clinicians, such as an epilepsy liaison nurse and appropriate investigations services.

At the Gold grade, psychiatrists are likely to work very closely with tertiary care specialists. They will have a level of knowledge and skills in epilepsy which go beyond the NICE or SIGN guidance, and be able to manage all aspects of epilepsy diagnosis and treatment. All NICE quality standards will be applicable and these psychiatrists are likely to be involved in education and standard-setting for people with ID and epilepsy at a national level.

Clinical vignettes have been provided to aid understanding of the Bronze, Silver and Gold models and their application to psychiatrists and their local services, recognising that psychiatrists may have a mixture of skills which sit between categories. The strategy aims to engage such psychiatrists to consider other relevant skill sets which can support them to move forward definitively. It is hoped that the template will serve as a pathway for those currently at a Bronze level to move to Silver and Gold.

A structured pathway for epilepsy competency needs to be provided for psychiatry trainees in ID. An evidence-based framework, using the Learning Disabilities Core Skills Education and Training Framework commissioned by the Department of Health, is postulated to help incorporate epilepsy training into the curriculum.

Other suggestions include a tool modelled on the Department of Health's Green Light Toolkit for mental health for self-audit and assessment of local epilepsy services for people with ID, and for identifying what the local commissioning board should be aiming to achieve, including quality outcomes.

An Appendix is provided as a separate document, which includes a list and samples of currently used good practice tools relevant to people with ID and epilepsy, as well as a 'frequently asked questions' section on Epilepsy that would be of particular use to patients, families and carers.



# Introduction

Psychiatrists working with people with intellectual disability (ID; also known as learning disability) are, by definition, experts in comorbidity. This is most clearly seen in the case of mental illness and ID, and, to a lesser extent, when working with challenging behaviour. Epilepsy, despite being the most frequent chronic serious comorbidity in people with ID, has undoubtedly suffered from a lack of clarity regarding exactly what role the psychiatrist should have. This has led to some variation in the role of ID services, and great variation in psychiatrists' views of their own role. This, as evidenced by a recent International League Against Epilepsy (ILAE) survey – discussed at length on pp. 12–13 of this report – has added to a general confusion as to where patients with ID and epilepsy stand in terms of care delivery. To put it simply, who cares – the general practitioner (GP), the psychiatrist or the neurologist? However, existential debates by physicians on their care role do not help the patients. Patients should see professionals who have the skills and capacity to manage their illness to a high standard. Access to such care should be unambiguously signposted.

This long-awaited document offers an important step towards clarifying the role of the psychiatrist in ID in the management of epilepsy. The proposed tiered system of professional competency gives psychiatrists the option to identify their role in care provision and ensures a framework for training. It provides a structure from which a competency evaluation can be developed. The vision should be for all psychiatrists working with people with ID to have training and certification to one of the three levels of competency (Bronze, Silver and Gold). This is not an unreasonable aim: the Royal College of Paediatricians has achieved a similar standard with their paediatric epilepsy training courses. Our College has an opportunity to lead the training of psychiatrists in epilepsy competency, and thus to raise standards and save lives.

# Background

Epilepsy is a common condition in people with ID. The complex needs of people with ID and epilepsy – particularly in terms of physical and behavioural comorbidity – mean that they are frequent users of ID services. This complexity can also lead to difficulties in the delivery of neurological care in traditional settings. Within the UK, the strong presence of ID psychiatry with an interest in epilepsy has led to psychiatrists and ID teams managing the epilepsy alongside traditional neurological care. This is because there is a significant overlap between ID, psychiatric symptoms and epilepsy. The management of epilepsy by psychiatrists working with people with ID, although common, is not universal. Unfortunately, owing to this approach not being uniform, patients across the UK can sometimes receive fragmented care, depending on where they live – no one is certain as to who has primary responsibility. There is a postcode lottery, leading to difficulties for patients and carers in navigating the system. In many places, there are expectations that neurology services will deliver epilepsy care. However, neurology does not equate to epilepsy, as neurologists – like psychiatrists – subspecialise into diverse domains, and thus not all neurologists are epilepsy specialists. In services such as neurology, it is possible that the ID-specific elements of epilepsy – for example, environmental risk assessments, understanding of mental and behavioural side-effects, and person-centred communication – will not be formally undertaken. There is a growing expectation on the part of patients, their families and other stakeholders that psychiatrists and services working with people with ID should have the necessary skills to manage epilepsy. However, the requirements associated with this are not always clear. There is no clearly defined requirement for ongoing training in managing the condition once a psychiatrist is appointed to a consultant or career grade post.

The Royal College of Psychiatrists' Faculty of Psychiatry of Intellectual Disability have a role in setting standards for the profession. This report highlights the current problems encountered by people with ID who also have epilepsy across the UK, and provides recommendations to address these problems. We also aim to define the potential breadth of roles of ID psychiatry in managing epilepsy and thus help in the delivery of appropriately trained ID psychiatrists for the future.

# Current situation

## Intellectual disability

ID is characterised by impairment of skills manifested during the developmental period which contributes to the individual's overall level of intelligence – that is, cognitive, language, motor and social abilities. According to the ICD-10, which is the most widely used classification system, the levels of severity of ID can be divided, on the basis of IQ, into mild (IQ 50–69), moderate (IQ 35–49), severe (IQ 20–34) and profound (IQ less than 20) (WHO, 1992). Among those with a diagnosis of ID, about 85% have mild ID, 10% have moderate ID, 4% have severe ID, and around 1% have profound ID. Life expectancy in mild ID groups is no different from the general population (Patja *et al*, 2000). However, life expectancy is reduced in people with moderate or higher levels of ID, with moderate to profound IDs related to mortality three times higher than standardised rates (Tyrer *et al*, 2007). There is significantly higher mental (Harris, 2006) and physical (van Schrojenstein Lantman-De Valk *et al*, 2000) comorbidity in ID populations when compared with the general population. Again, the trend of comorbidities is related to the intensity of ID.

## Epilepsy

Epilepsy is the propensity to have recurrent seizures. Seizures are transient behavioural, emotional, motor or sensory symptoms or signs, with or without an alteration in consciousness, due to abnormal excessive or synchronous neural activity (Fisher *et al*, 2014). The ILAE state that epilepsy is a disease of the brain defined by any of the following conditions:

- at least two unprovoked (or reflex) seizures that are more than 24 h apart
- one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures occurring, over the next 10 years
- diagnosis of an epilepsy syndrome (Fisher *et al*, 2014).

Up-to-date details about seizure types and classifications can be accessed via the ILAE website ([http://www.ilae.org/Visitors/Centre/Definition\\_Class.cfm](http://www.ilae.org/Visitors/Centre/Definition_Class.cfm)).

In the general adult population, epilepsy is the second most common chronic neurological disorder after stroke (Prasher & Kerr, 2016). According to the National Institute for Health and Care Excellence (NICE, 2012), an accurate estimate of incidence and prevalence is difficult to obtain because of the difficulty in identifying and defining people who may have epilepsy. Epilepsy has been estimated to affect around 600 000 people in the UK. In addition, there will be an estimated further 5–30% of individuals who have been incorrectly diagnosed with epilepsy. The incidence of epilepsy in high-income countries is estimated to be 50 per 100 000 per year. The prevalence of active epilepsy in the UK is estimated to be 5–10 cases per 1000 (Sander & Shorvon, 1996).

Two-thirds of people with epilepsy can have their seizures completely controlled with anti-epileptic drugs (AEDs). Such management improves health outcomes and can also help to minimise detrimental impacts on social activities, education and employment. However, a third of people with epilepsy do not achieve complete seizure control despite trying multiple medications. Coexistence of epilepsy and ID in an individual poses unique challenges. Appropriate diagnosis (history, investigation, classifications and aetiology) and management of epilepsy are essential to reduce the considerable social impact, potential stigmatisation, secondary handicap and low self-esteem compounded by social exclusion as experienced by people with ID.

## Intellectual disability and epilepsy

Both epilepsy and ID may be caused by a range of pathological processes (Forsgren *et al*, 1990; Bowley & Kerr, 2000; Lhatoo & Sander, 2001). Among people known to ID services in the UK, the prevalence of epilepsy is about 20–30%, and this figure may be higher in the residual populations of long-stay institutions (Bell & Sander, 2001). The prevalence of epilepsy in ID is between 22% and 26%, and increases with increasing severity of ID (McGrother *et al*, 2006; Robertson *et al*, 2015a). The estimated prevalence for mild ID is around 10%, compared with 30% for those with moderate, severe or profound ID (Robertson *et al*, 2015b). Two-thirds of people with ID and epilepsy are considered to show a poor response to anti-epileptic medication (McGrother *et al*, 2006), and people with ID and epilepsy often have more physical impairments than those with ID but not epilepsy (Robertson *et al*, 2015a). However, although psychiatric and behavioural comorbidities are common in people with ID, rates are not necessarily higher than in those with ID without epilepsy (Robertson *et al*, 2015a). Concomitant epilepsy in people with ID is associated with high healthcare costs and increased mortality (Robertson *et al*, 2015a). In the UK, convulsions and epilepsy were found to be the most frequent cause of what were considered as potentially avoidable hospital admissions in people with ID, accounting

for approximately 6000 admissions per year, equivalent to 40% of all emergency admissions for ambulatory care sensitive conditions in adults with ID (Glover & Evison, 2013). This is representative of the problem worldwide (Balogh *et al*, 2010).

The coexistence of ID, drug-refractory epilepsy and neurological deficits is often associated with genetic/chromosomal abnormalities or structural brain pathology (either damage or maldevelopment of the brain) (Busch *et al*, 2014). The number of known single-gene mutations associated with ID and epilepsy is increasing; some of these are important for treatment strategies and so should always be considered. For example, *SCN1A* mutations are associated with Dravet syndrome, which is characterised by febrile and non-febrile seizures beginning in the first 12 months of life, episodes of status epilepticus, and initial normal development but intellectual decline in the second year of life. This syndrome can respond poorly to drugs that block sodium channels (e.g. lamotrigine, carbamazepine and phenytoin) (Catterall, 2012). On the other hand, tuberous sclerosis may respond well to vigabatrin; however, the serious specific side-effects of treatment with this drug need to be considered (Curatolo *et al*, 2001). GLUT1 deficiency, which is associated with seizures in the first 4 months of life, dystonia (in particular, exercise-induced dyskinesia) and ID, may respond particularly well to a ketogenic diet (Klepper *et al*, 2005).

Supporting people with ID and epilepsy, especially those with poorly controlled epilepsy, requires high levels of competence and confidence in staff in community settings (Kerr *et al*, 2014; Thompson *et al*, 2014). Seizures in people with ID are commonly of multiple types and are often resistant to single-drug treatment (Branford *et al*, 1998; Amiet *et al*, 2008; Matthews *et al*, 2008). This is especially true in severe and profound ID. Uncontrolled epilepsy can have serious negative consequences that affect both quality of life and mortality (Kerr & Bowley, 2001a,b). There are guidelines (Working Group of the International Association of the Scientific Study of Intellectual Disability 2001; Kerr *et al*, 2009) on the management of epilepsy in people with intellectual disability that cite the relevant evidence base; where this evidence base was found to be lacking, an international consensus group of epileptologists have come up with a consensus statement (Kerr *et al*, 2011).

The management of epilepsy is also particularly important because of the risk of sudden unexpected death in epilepsy (SUDEP). The incidence of sudden death appears to be 20 times higher in patients with epilepsy compared with the general population, and SUDEP is the most important directly epilepsy-related cause of death (Hesdorffer *et al*, 2011; Doran *et al*, 2016). People with drug-resistant epilepsy are at particular risk of SUDEP (Hesdorffer *et al*, 2011; Shankar *et al*, 2013; Doran *et al*, 2016). NICE (2012) in England and Wales, and the Scottish Intercollegiate Guidelines Network (SIGN, 2015) in Scotland, both recommend that patients, carers and families need to be counselled using information tailored to the patient's relative risk of SUDEP.

An evidence-based risk factor checklist to engage patients (including people with ID) in such a person-centred discussion has been developed (Shankar *et al*, 2013). There is evidence that a bespoke service, which takes into account current good practice for supporting people with ID and amalgamates it with good practice for managing epilepsy, can reduce deaths in ID (Shankar *et al*, 2014, 2016). This is further highlighted by a recent ILAE report (Kerr *et al*, 2016).

## Mental illness and behavioural symptoms

Making a diagnosis of epilepsy in people with ID may be confounded by the high prevalence of psychiatric disorders. The point prevalence of mental illness in this population is over 50%, with many individuals having more than one diagnosable psychiatric illness (Cooper *et al*, 2007). Furthermore, the ID population with active epilepsy are at greater risk of developing mental illness (Turky *et al*, 2011). This can have an impact on both the assessment and the treatment of epilepsy. There may be some confusion for clinicians about behaviours that are associated with epilepsy and its treatment, and those that are not. There needs to be consideration of the role of psychotropic medication that has epileptogenic potential (Kerr *et al*, 2011). Specific guidance on considering behavioural manifestations and neuropsychiatric management is available for this population (Kerr *et al*, 2011, 2016).

The semiology of a generalised tonic–clonic seizure does not mimic many other conditions, and the nature of these episodes is usually well defined. By contrast, the diagnosis of focal seizures is reliant upon a description from the individual and a witness. This may be further complicated by the presence of associated ictal or post-ictal automatisms. Differentiating these more complex seizure presentations from psychiatric disturbance or non-epileptic seizures can be very challenging, even in the general population. These presentations in the ID population are further complicated by the high prevalence of repetitive stereotyped motor behaviours (Paul, 1997), and a large proportion of patients referred to specialist epilepsy units have a misdiagnosis of epilepsy. Observable abnormal movements thought to be of an epileptic nature have frequently been found by neurophysiological testing to be non-seizure-related (Donat & Wright, 1990).

When considering a differential diagnosis, obtaining a detailed understanding of the observed behaviour and the context provides essential information. This may be aided by the use of relevant investigations, including video electroencephalography (video-EEG). More complex scenarios may require detailed functional analysis from other professionals within the multidisciplinary team.

## Current views and expectations of professionals

The British branch of the ILAE working group on services for people with ID and epilepsy recently surveyed the membership of key stakeholders involved in the delivery of care to this population (2016–2017) (M. Kerr, personal communication, 2017). The clinicians surveyed included a range of health professionals affiliated to the ILAE, the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists, the Association of British Neurologists, and the Epilepsy Nurses Association. The work setting of responders ranged from community ID teams to tertiary epilepsy centres. The level of experience and specialist knowledge in the clinical work varied significantly. The percentage of these professionals' workload spent treating epilepsy ranged from 9.3 to 29.6%. The percentage of case-load involving a person with a diagnosis of ID showed two distinct peaks: those with limited contact and those working only with the ID population. The survey focused on a number of key domains exploring diagnosis and medical treatment, delivery of service, risk assessment, and the broader impact on quality of life.

The time taken for individuals with ID and new-onset epilepsy to undergo routine investigation for epilepsy, such as EEG and magnetic resonance imaging (MRI), was commonly reported to be at least 1–3 months, far beyond recommendations made by NICE (2012). Similar waiting times were reported for investigations in the ongoing management of epilepsy. Individuals with ID often have other significant comorbidities alongside their cognitive deficits, including, for example, communication impairment. As a result, prolonged investigations may be intolerable without other interventions. It is often necessary for investigations such as MRI to be conducted under general anaesthetic. For individuals who lack capacity to make decisions about their health, such investigation must only be considered following a best interests meeting in accordance with the Mental Capacity Act 2005 (in England and Wales). Survey results demonstrate that this significantly increases the waiting time for necessary investigations, with the majority of patients waiting at least 1–3 months, some more than 6 months. The fact that a large proportion of clinicians treating this population group are unable to directly request such investigations (as they now fall within the ambit of neurology or similar mainstream services) is also likely to be a contributing factor. It appears that health services are not routinely putting reasonable adjustments in place to meet the needs of this population.

People with ID and epilepsy are more likely to present with treatment-resistant epilepsy. The results highlight that there are still a minority of clinicians who would not consider non-pharmacological interventions that have proven benefit for treatment-resistant epilepsy – including epilepsy surgery, vagus nerve stimulation (VNS) and ketogenic diet.

Almost universally, responders to the ILAE survey were actively involved in the assessment and management of key risk areas, including risk of drowning, admission to hospital and medication side-effects, as recommended by NICE (2012). Nearly 90% of respondents reported that they assess and discuss SUDEP, a significant improvement on previous assessments of clinical practice. There is still a need to disseminate information about the importance of assessing the need for nocturnal monitoring systems. Encouragingly, the majority of responders were actively involved in supporting people with ID and epilepsy and their carers in decisions around access to education, employment, and other social issues.

Following the results of this survey, the British branch of the ILAE working group for people with ID and epilepsy recommends that the ILAE (British chapter) works to promote collaboration between the key stakeholder governing bodies involved in the delivery of care to this population. The development of care pathways will help to ensure that the needs of people with ID are met and that reasonable adjustments are made. Such collaboration between professionals would also allow for the sharing of expertise to ensure person-centred care. A specific focus needs to be on the complex needs commonly found in this population, including psychiatric illness, neurodevelopmental comorbidity and physical health issues. Recognition of the complexity and diversity of treatment, management, emergency care, legal issues and quality of life is imperative. Delivery of care for a person with multimorbidity may require input from different professionals, depending upon their expertise; however, there needs to be a central responsible team or specialist to help coordinate the various aspects of care and provide governance and clinical assurance.

## Specific areas of concern

Kerr *et al* (2014) introduced a White Paper which built on the publication of the ILAE and International Bureau for Epilepsy report *Listening for a Change: Medical and Social Needs of People with Epilepsy and Intellectual Disability* (Kerr *et al*, 2013). This section has been developed using the White Paper as a benchmark for current concerns and practice.

Actions in four domains are indicated.

- 1 The development of standards and initiatives that would enhance diagnosis, pathways to investigation and treatment.
- 2 The development of guidelines for treatment, specifically best practice in the management of AEDs, including rescue medication.
- 3 The development of standards for primary care, multidisciplinary teamwork and clinical consultations, with an emphasis on the need to enhance communication and improve access to information.



- 4 The enhancement of links among different stakeholders, including medical services, educational establishments, employment services, organisations providing opportunities for social engagement, and family members (Kerr *et al*, 2014).

The authors also outlined four major areas of concern, of which two are directly relevant to this report. Specific areas of concern relevant to the scope of this report are summarised below.

### **Diagnosis and medical treatment**

- Key concerns exist around misdiagnosis given the complexity of comorbid presentation.
- There are particular concerns around poor communication during consultation.
- Challenges exist for accessing appropriate investigations.
- Medication issues, including side-effects and difficulties in ensuring treatment monitoring, are particular worries.
- There is a need for greater knowledge transfer to all stakeholders.
- There is a requirement for more accessible information sources.

### **Service delivery**

- There are major concerns regarding engagement of multi disciplinary team approaches.
- Manner and quality of consultations are cause for concern; in particular, they are brief and possibly ineffective.
- There is a lack of listening and involvement of key stakeholders, including family.
- There is a lack of expertise in primary care settings.
- Use of epilepsy nurse specialists in training carers is unsatisfactory.
- Standards of care delivery and service provision vary in different regions of the UK.

### **Special educational and family life**

- Specific concerns exist around the lack of a holistic model to support access across various social domains.

# Proposed framework

Kerr *et al* (2014) also outlined a proposed framework to enhance the delivery of support for people with ID who have epilepsy. Some of the specific recommendations from the paper have been reproduced in Box 1.

## Box 1 Recommended actions

### Investigations and diagnosis in individuals with complex needs

- Establish a working group to develop standards for the diagnosis of epilepsy in people with an intellectual disability (ID), both for adults and children; this should include measures to investigate aetiology, misdiagnosis and equitable access to treatment.
- Develop educational initiatives to improve clinician communication when an individual has impaired communication, and support the call for extended consultations to ensure sufficient time is afforded to patients with an ID.
- Establish a working group to identify a pathway to investigation for those with complex needs, to include a discussion of best interests and the use of anaesthesia or sedation.

### Medication (including rescue medication)

- Establish a task force to develop guidelines for the treatment of epilepsy in people with an ID.
- Produce a position statement establishing best practice for the identification and management of anti-epileptic drug (AED) side-effects in people with an ID. Specific attention is needed to address drug interactions owing to the increase in prescribing for comorbid conditions.
- Develop audit templates to ensure that all people with an ID who have epilepsy have had an assessment regarding rescue medication, that such medications are prescribed when appropriate, and that staff and family members have had adequate training in their administration.

### Enhancing medical services

- Develop guidance on standards of information exchange in clinic settings; these should identify the input from patients, caregivers, families and professionals.
- Develop guidance on the role of primary care services in the management of comorbid ID and epilepsy, and their interaction with specialist services.
- Ensure accessible information on all aspects of epilepsy management is made available within services.
- Explore mechanisms for improving communication in clinical situations, including shared decisions methodology and option grids.
- Promote the development of epilepsy specialist nurse provision, with a particular focus on those supporting people with an ID either in specialist epilepsy services or in services providing healthcare to people with an ID.
- Develop guidance, including minimum standards, on multidisciplinary team working for individuals with epilepsy and ID.
- Develop guidance on appropriate duration of consultations with people with complex communication needs.
- Develop training manuals to support non-specialist services managing epilepsy in community settings.

Adapted from Kerr *et al* (2014).

The key issues relevant to this strategy document were:

- 1 keeping people with ID who have epilepsy at the core of change, especially given that inclusion of this group tends to be hampered by the complexity of their treatment, which inadvertently contributes to their invisibility within mainstream epilepsy services
- 2 recognising that the evidence base for the effectiveness of interventions in mainstream care for this vulnerable population is weak
- 3 recognising that there is a clear need for the development of an appropriate clinical infrastructure to support the delivery of person-centred holistic care, taking into consideration both the ID and the epilepsy. The infrastructure will require consensus on standards and guidelines spanning a range of areas, including diagnosis and treatment across multiple stakeholders in primary, secondary and tertiary care. In secondary care, this would require contribution from specialists in ID and neurology, and nursing specialists in epilepsy.

The College's Faculty of Psychiatry of Intellectual Disability has taken this framework seriously, and this strategy document is an attempt to provide a view of a potential holistic approach. A critical analysis of its relevance is provided in Box 2.

Box 2 Strengths, weaknesses, opportunities and threats for the proposed model	
<p style="text-align: center;"><b>Strengths</b></p> <ul style="list-style-type: none"> <li>● Simple and uncomplicated</li> <li>● Addresses a major health concern</li> <li>● Provides clarity of roles and expectations</li> <li>● A coherent and measured response to concerns on the treatment and management of people with ID and epilepsy</li> <li>● Supported by Faculty and its members</li> <li>● Developed using a robust evidence base and tested using focus groups</li> <li>● No major changes proposed: cost neutral</li> </ul>	<p style="text-align: center;"><b>Weaknesses</b></p> <ul style="list-style-type: none"> <li>● Untested in any large geographical area</li> <li>● Tries to harmonise diverse working practices across various regions and countries, thus risking losing specifics in focus</li> <li>● Looks primarily at the role of the ID psychiatrist and not the larger system</li> </ul>
<p style="text-align: center;"><b>Opportunities</b></p> <ul style="list-style-type: none"> <li>● May serve as a template for other stakeholder organisations to develop their strategies</li> <li>● Improve care to people with ID and epilepsy</li> <li>● Improve training and service delivery</li> <li>● Could be adopted in other countries</li> </ul>	<p style="text-align: center;"><b>Threats</b></p> <ul style="list-style-type: none"> <li>● Lack of integrated response from other stakeholders</li> <li>● Inadequate resources locally</li> <li>● Lack of training opportunities and placements</li> </ul>

# Objectives and methodology

Our working group agreed key objectives and developed the current strategy document setting out how these would be addressed.

## Objectives

- Identify the general and specific needs and requirements of people with ID who have epilepsy, with particular focus on the impact of ID on epilepsy.
- Develop and deliver a matrix to evaluate current epilepsy care from an organisational and individual clinician perspective.
- Develop a competency-based framework for psychiatrists working with people with ID to be self-aware regarding their skills and their level of training, by using the matrix to highlight personal and organisational responsibility in delivering epilepsy care.
- Consider and suggest pathways for inclusion of epilepsy competencies in the 'Gold Guide' for postgraduate specialty training in the UK.
- Provide a template to open a dialogue at a national level with other key health professional stakeholders, including epilepsy specialist nurses, neurologists and GPs to provide a unified strategy for diagnosis and management of epilepsy in people with ID to help improve outcomes.
- Offer suggestions for continuing professional development (CPD) to psychiatrists working with people with ID to provide themselves, their patients and their employers with assurance of their skills and competences in epilepsy care delivery.

## Strategy document development

*16 June 2016*

A working committee was formed from the larger Faculty executive committee. The committee included psychiatrists whose primary job role is in ID but who had a range of expertise in epilepsy. Advisors to support the core committee were identified. The preliminary meeting set the proposed objectives and proposed framework. The executive committee unanimously agreed with the working committee proposal

that epilepsy needs to be 'core business for the Faculty' and that steps needed to be taken to enshrine epilepsy care in routine practice for all psychiatrists working in ID. Over the next 3 months, the working group collaborated via email and telephone. Best practice documents, including those from NICE and SIGN, and recent white papers about epilepsy and ID and current models of care (see the Appendix) were selected, reviewed and analysed.

### ***30 September 2016***

The findings were collated and presented to a focus group in the Annual ID Residential Conference 2016 as part of a break-out session. The focus group was well attended by a diverse group of practitioners. Clinical vignettes were used to gain insight to participants' skills, aims and wishes. Feedback was collected and assimilated into the developing document and plan.

### ***23 January 2017***

An update on the planned structure of the document was presented at the Faculty of Psychiatry of Intellectual Disability executive meeting. Approval was gained to continue in the direction identified and specific issues were highlighted.

### ***26 January 2017***

A strategy meeting brought together the working committee to identify and populate the core structure of the strategy document. Good practice tools were identified, discussed and considered as to their suitability for inclusion. The structure of the strategy document was finalised and agreed.

### ***15 February 2017***

All working committee members had contributed their pieces of work to the relevant sections of the document by this date.

### ***25 February 2017***

The first preliminary draft was developed and sent to the three members and advisors of the strategy who have a significant role in epilepsy and ID care.

### ***15 March 2017***

The report was circulated to all working committee members for comments and feedback.

### ***20 March 2017***

The report was submitted to College for consideration of stakeholder feedback.

# Identifying good practice

The recent ILAE survey highlighted expectations and current gaps in everyday practice. However, it is important to provide benchmarks for what should be considered good practice and safe care delivery for people with ID when accessing services for management of their epilepsy. This requires the amalgamation of current good practice guidance in both the epilepsy and ID sectors.

## NICE guidance

The NICE (2012) guideline *Epilepsies: Diagnosis and Management* (CG137) was originally written in 2004 and updated in 2012 to incorporate the results of the 2007 SANAD trial (Marson *et al*, 2007). In February 2013, NICE produced two accompanying sets of quality standards for epilepsy in adults and in children and young people (NICE, 2013a,b). The quality standards each consist of nine outcome indicators which allow for audit of services. These guidelines relate to care delivery in the NHS in England and Wales.

The NICE guidelines are relevant to people with ID who have epilepsy, with this population having a specific section. The guidance starts with a focus on person-centred care and then outlines key priorities for implementation in the areas of diagnosis, management, prolonged or repeated seizures, special considerations for women and girls of childbearing potential, and review/referral.

The guidance then outlines more details with respect to information sharing (including information about SUDEP), diagnosis, investigations, classification, management and review. There is a large section (pp. 23–39) on pharmacological treatment of the different seizure types and syndromes. There is a section on the need for referral to a tertiary specialist centre for complex or refractory epilepsy, including where there is psychological or psychiatric comorbidity. Finally, there are specific sections for women, people with ID, young people, older people and those from Black and minority ethnic groups.

A ‘specialist’ is defined as a medical practitioner with training and expertise in epilepsy. A ‘tertiary epilepsy specialist’ is an epileptologist who devotes the majority of their time to epilepsy, working in a multidisciplinary tertiary referral centre, and is subject to regular peer review.

The nine quality statements (NICE, 2013a) are as follows.

1. Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.
2. Adults having initial investigations for epilepsy undergo the tests within 4 weeks of these being requested.
3. Adults who meet the criteria for neuroimaging for epilepsy have an MRI scan.
4. Adults with epilepsy have an agreed and comprehensive written care plan.
5. Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.
6. Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.
7. Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.
8. Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.
9. Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

## SIGN guidance

SIGN, as part of Healthcare Improvement Scotland, has the task of developing and disseminating clinical practice guidelines based on current best evidence for the Scottish population.

The SIGN (2015) guideline *Diagnosis and Management of Epilepsy in Adults* (SIGN143) updated and expanded the previous 2003 guideline (SIGN70) to address issues that had arisen from developments in service delivery, diagnostic processes and therapeutic interventions, including new pharmacological agents. Like all SIGN guidelines, SIGN143 was created using a standardised methodology: establishing a multidisciplinary, nationally representative group, which conducts a systematic review of relevant literature and evidence and, after critically appraising the evidence, makes recommendations according to the supporting evidence.

As the title suggests, SIGN143 is concerned with the diagnosis and management of epilepsy in adults only. There is currently no SIGN guideline for epilepsy in children. SIGN143, similar to NICE CG137, dedicates a specific section to the management of people with ID and epilepsy, particularly emphasising equality of access with regard to assessment and treatment.

SIGN143 key recommendations relate to:

- diagnosis, which should be made by a specialist, with a clear history from the patient and an eyewitness as the mainstay
- treatment, including initiation of AED treatment after a first tonic-clonic seizure
- maintenance treatment
- EEG assessment and monitoring
- medication choices to treat prolonged seizures, including status epilepticus.

Key recommendations are also made in relation to specific populations, including women and people presenting with psychiatric comorbidity. Finally, mortality and SUDEP are highlighted, as well as models of care emphasising the importance of a structured management system and active chronic disease management.

Although there are clear overlaps between SIGN143 and NICE CG137 – as both are based on the same evidence – there are some differences. These include the definition of ‘specialist’. SIGN143 is more prescriptive in its definition of a specialist and the assessment process. It recommends: ‘The diagnosis of epilepsy should be made by an epilepsy specialist [...] An epilepsy specialist has been defined as a trained doctor with expertise in epilepsy as demonstrated by training and continuing education in epilepsy, peer review of practice and regular audit of diagnosis. Epilepsy must be a significant part of their clinical workload (equivalent to at least one session a week).’ SIGN also recommend that: ‘The diagnosis of epilepsy is most appropriately delivered in the setting of a dedicated first-seizure or epilepsy clinic.’ There are few, if any, psychiatrists working in ID in Scotland who satisfy this particular recommendation. Additionally, SIGN does not offer a system of quality standards. However, the principles set out in the NICE outcome measures are appropriate and could be applied in keeping with the SIGN recommendations.

## Intellectual disability

The NICE and SIGN guidelines state that a person with ID should have the same access to treatment for epilepsy as anybody else, and that if there are additional treatment needs, the most appropriate health professionals should meet those needs. Meeting these needs is easier said than done.

Epilepsy Action ([www.epilepsy.org.uk](http://www.epilepsy.org.uk)), in their work on good practice, aim to promote equality of access to quality care for all people with epilepsy. They have recognised that epilepsy is more difficult to diagnose in people with ID because of diagnostic overshadowing created by communication deficits, repeated behaviours and movement disorders which can be mistaken for epilepsy. For an epilepsy specialist to decide which symptoms are epilepsy and which are not



can be difficult without expertise in ID. Furthermore, people with ID may have additional needs, such as feeding and swallowing problems, constipation, repeated infections (with associated treatment) and pain. The Mencap (2012) document *Treat me Right!* reiterated the need for healthcare professionals to have appropriate training in ID to reduce the potential for incorrectly ascribing physical health needs to the ID.

Some of the associated concerns are highlighted by the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) (Heslop *et al*, 2013). This inquiry identified four long-term conditions that were significantly more prevalent among people with ID who had died: epilepsy, hypothyroidism, cerebral palsy and type 2 diabetes. Of these long-term conditions, epilepsy was the most likely to be the cause of death. CIPOLD reported that 43% of the study cohort of people with IDs had been diagnosed with epilepsy, and 72% of these had experienced seizures in the past 5 years. There were a number of people with a diagnosis of epilepsy who remained in treatment, although they had not had any known seizures in the past 5 years.

Weak spots were found in the epilepsy care pathway, despite the majority of individuals being identified, whether by themselves, family or paid carers, as being unwell. Of those identified by health services as being unwell, problems with investigations, referral to a specialist and misdiagnosis were among the top five barriers to access to standard care. CIPOLD recognised the need for a clear care pathway so that people receive optimal, evidence-based care for their conditions, and to ensure that people with ID and epilepsy have access to the same investigations and treatments as anyone else. It acknowledged that services may need to be delivered differently in different areas, based on demographics and local established services, to achieve the same outcome.

## Good practice guidance for ID

There have been numerous national developments in the past decade focused on improving health and social outcomes for people with ID. The majority of the health-related focus has been on mental and general physical health. While not directly focused on epilepsy, many of these documents provide a good framework which can be adopted to support the delivery of high-quality epilepsy care for people with ID. Most, if not all, psychiatrists working in the field of ID would be familiar with the documents that follow. This subsection is intended to help psychiatrists and policy makers to consider the wealth of evidence that has been established to help plan corresponding outputs and structures for people with ID and epilepsy.

The Green Light for Mental Health (National Development Team for Inclusion, 2013) is a toolkit developed to support mental health services in delivering the objectives of the National Service Framework for

mental health in people with ID in England. Using the checklist allows a provider to establish what is in place and working well for people with ID and mental health issues, as a first step towards improvement and development of local services. Using the self-assessment checklist at regular intervals allows the provider to track developments, celebrate achievements and move towards developing better services for people with ID, benchmarked against national guidance and expectation. Although it is not in use in other countries of the UK, it outlines a good model of care which can be adapted to develop a similar approach for epilepsy. This toolkit can be modified to help assess, monitor and develop quality epilepsy services for people with ID. A model is provided in the Appendix document.

## Improving access to care

Across the UK there have been many policies regarding how government services, including health and social care, are provided for people with ID to promote inclusion, choice and rights. These strategies, such as *Valuing People Now* (Department of Health, 2009) have allowed significant gains to be made, including the decommissioning of old long-stay hospitals, promotion of person-centred plans and the introduction of primary care-led annual health checks and health action plans. However, it was noted that after many years significant inequalities still existed in access to healthcare, and thus there was an attempt to emphasise the need for partnership working and recognition that people with ID will need support for the whole of their lives.

The Improving Health and Lives (IHAL, 2012) Learning Disabilities Observatory for England recognises that people with ID die younger than the general population and that they face avoidable significant health inequalities. The Equality Act 2010 places responsibilities on providers to make reasonable adjustments so as to improve access to care (Office for Disability Issues, 2011). Services should go beyond just providing quality care and ensure that their design allows good access for people with ID. IHAL recognises that good epilepsy services are likely to reduce the risk of seizures and the number of unplanned hospital admissions, and will thus save money. Reasonable adjustments include home visits where there is a reasonable chance of the patient getting distressed in a busy hospital environment, extended clinic appointments and pre-visits to see scanners.

There is other good practice in psychiatric care for people with ID which can be adopted or developed for the delivery of epilepsy care for these patients. *Stopping Over-Medication of People with Learning Disabilities* (NHS England, 2016) is a collaborative attempt, endorsed by the Royal College of Psychiatrists and others, to increase vigilance regarding excessive medication in those with mental health problems and challenging behaviour. Care of patients with comorbid physical health problems, including epilepsy, would require similar vigilance and management, in context and not in isolation. This specialist skill most likely sits within an ID psychiatrist's role.

It is important that the views of individuals with ID are considered when deciding what pathway best meets their needs, or when considering medication. The Mental Capacity Act 2005 requires an assessment of capacity in making such decisions. Where this is lacking, there is a requirement for the best interests of the individual to be considered, in collaboration with carers and families.

The Autism Act 2009 provides a legal requirement for the health and social care needs of autistic people to be met. The ID epilepsy strategy that we present in this document recognises the need for specialist provision for these individuals and the relationship between autism and epilepsy.

# Proposed model of competency

The current evidence suggests that the delivery of epilepsy care and access to epilepsy pathways for people with ID are fragmented and subject to geographical variations. It is imperative that the patient be at the centre of any services designed. Delivery of epilepsy care, given its complexity, needs to be ‘everyone’s business’ (as opposed to ‘someone’s business’) among all stakeholders. For the purpose of the Faculty to support psychiatrists working with people with ID, we propose a competency framework of Bronze/Silver/Gold to identify their skill set and the minimum expectations they need to have of their local service to provide their competency level of epilepsy care. The advantages and challenges of this model were summarised in Box 2 (p. 16).

We suggest that all psychiatrists working with people with ID have a minimum Bronze level skill set to provide assurance of basic safety. It is hoped that the template will serve as a pathway for those currently a Bronze to move themselves to Silver and Gold if they wish to do so. Each category has been developed to be benchmarked against the relevant NICE outcome indicators, and is also in line with SIGN143 recommendations. The linked NICE outcome standards for each category are provided in Box 3 (p. 27).

## Bronze

All psychiatrists working with people with ID should have a ‘Bronze’ level of skills. We recognise that these psychiatrists may or may not provide direct care for epilepsy, so the NICE quality standards may not all apply. However, they should still be familiar with the content of the guidelines and quality standards, or alternatively follow SIGN recommendations if appropriate. At Bronze level, the psychiatrist should have the following competencies.

- Be able to diagnose, assess and manage medication of epilepsy to a reasonable standard. This includes knowledge of the diagnostic process of epilepsy and non-epileptic attack disorder (NEAD); an understanding of investigations relevant to the condition; psychiatric side-effects of AEDs; and the psychiatric manifestations of epilepsy, including an appreciation of the associations between challenging behaviour, epilepsy and ID.

- Understand the precipitating, perpetuating, predisposing and protective factors for epilepsy in a person with ID.
- Know the risks associated with epilepsy and be able to complete and scrutinise risk assessments to ensure that their service delivers on mitigating SUDEP, as well as social and environmental risks.
- Understand epilepsy and its impact on psychiatric illness and behaviour.
- Be aware of AEDs and their interactions with other drugs (psychiatric drugs in particular).
- Ensure that risks are identified and appropriately mitigated, including, for example, that a rescue medication protocol is in place if necessary.
- Be familiar with local or regional pathway for epilepsy, either in general or specific to ID, including relevant clinicians in neurology or other epilepsy services, and the local area epileptologist.
- Be able to lead on a management level (although there will be overlap with other clinical staff, particularly nursing) to provide holistic and safe care.
- Be familiar with the best interests process for treatment of those who lack capacity, and the use of restrictive interventions as part of epilepsy management (helmets, braces, holds) to prevent self-injury.
- Lead on multidisciplinary team care planning, with epilepsy being part of a wider health plan with input into annual health checks, hospital passport etc.

## Silver

At Silver level, psychiatrists will be much more familiar with the specific content of the NICE and SIGN guidelines, as they will be managing epilepsy directly with the back-up of a neurology service or other specialist epilepsy service with which they have close links, as well as having access to services such as an epilepsy liaison nurse and appropriate investigations. At this level, the psychiatrist should be able to deliver all Bronze level requirements, in addition to the following.

- Be able to diagnose new epilepsy.
- Initiate, withdraw and titrate medication.
- Diagnose, address and treat any associated mental illness or challenging behaviour occurring alongside the epilepsy, by managing both the AEDs and psychiatric treatments.
- Manage SUDEP discussions with patients and carers, as well as risk mitigation.

# Gold

At Gold level, psychiatrists are likely to work very closely with, if not alongside, tertiary care specialists. They will have a level of knowledge and skills about epilepsy which goes beyond the NICE or SIGN guidelines and will be able to manage all aspects of epilepsy diagnosis and management. All NICE quality standards will be applicable, and these psychiatrists and their services are likely to be involved in education and standard setting for people with ID and epilepsy at a national level. At Gold level, the psychiatrist will practise all Bronze and Silver requirements, as well as the following.

- Identify and manage specialist conditions, including epileptic encephalopathy.
- Dedicate a significant part of their clinical work and CPD activity to epilepsy care.
- Support referral for epilepsy surgery assessment, including being able to refer patients for VNS or other specific epilepsy surgery.
- Review complex epilepsy in patients with autism and/or specific genetic conditions.

## Box 3 NICE outcome indicators associated with proposed models

### Bronze

- That adults with epilepsy have an agreed and comprehensive written care plan
- That adults with a history of prolonged or repeated seizures have an agreed written emergency care plan
- That adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services
- That young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services

### Silver

- That adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation
- That adults having initial investigations for epilepsy undergo the tests within 4 weeks of these being requested
- That adults who meet the criteria for neuroimaging for epilepsy have an MRI scan
- That adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews

The above are in addition to all Bronze level indicators

### Gold

- That adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral

The above is in addition to all Bronze and Silver level indicators

This strategy recognises that there may be ID psychiatrists who do not want to develop a Silver or Gold set of competencies in epilepsy, choosing instead to subspecialise in other areas based on their interest, the services in which they are working, and the available training. The expectation is that an ID psychiatrist will have a basic Bronze level of competency in ID to sit alongside the other core skills expected of them (Fig. 1).

There will be considerable overlap in the skills outlined in the different categories. A summary of how this could work in practice is provided in Fig. 2.

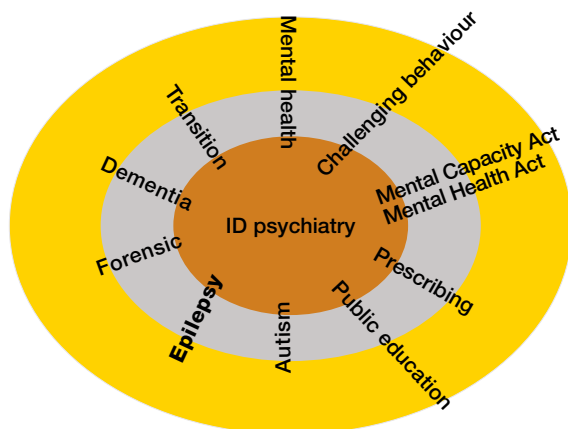


Fig. 1 Schematic showing how epilepsy would sit with other subspecialties.

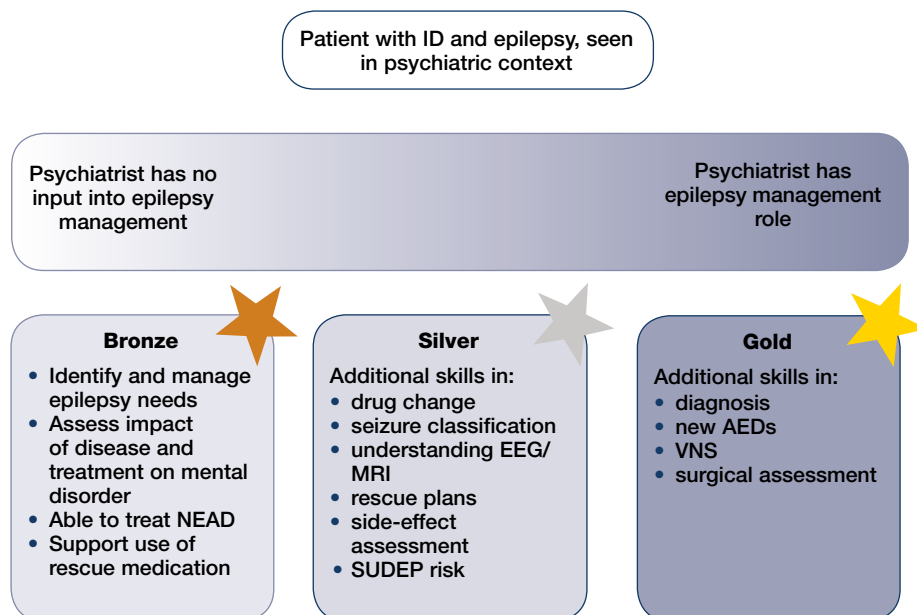


Fig. 2 The psychiatrist's role in epilepsy service delivery. AED, anti-epileptic drugs; EEG, electroencephalogram; ID, intellectual disability; MRI, magnetic resonance imaging; NEAD, non-epileptic attack disorder; SUDEP, sudden unexpected death in epilepsy; VNS, vagus nerve surgery. Figure adapted with permission from *Epilepsy in People with ID: Can we Reduce the Burden of Disease?* Keynote presentation by Professor Mike Kerr at the Faculty of Psychiatry of Intellectual Disability Annual Conference, 26–27 September 2013.

# What should services look like?

Although the scope of this document is primarily to identify roles, competencies and training issues for psychiatrists working with people with ID, this cannot be done without providing a brief overview of what the expectations should be of the larger care model to ensure a suitable working environment. The strategy aims to promote the idea that clinicians work in competent teams. Epilepsy care is a multidisciplinary field, and there is a need to have suitable access to a competent team. The psychiatrist should not work in isolation, as much of the risk assessment work and epilepsy training is done by nursing colleagues. There is also a role for allied health professionals, depending on the complexity and multimorbidity. Many psychiatrists might not see themselves as specialists on the Gold or even Silver level, but might consider that their teams were specialist enough on the basis of their shared skills and knowledge.

Here, we provide a summary of service delivery and a proposed audit tool. This constitutes a set of wishes more than recommendations. The hope is that providers of epilepsy care or psychiatrists interested in developing local services will use this list to assess and develop facilities. Those in bold are essential to any service delivering epilepsy care to people with ID, as opposed to those that are desirable.

Minimum – where all psychiatrists are certified as Bronze

- 1 Services should support written care plans and emergency care plans.**
- 2 Services should act as health advocates to support patients to access other specialist services for investigations and so on, if systems for these are already not in place.**
- 3 In cases of active or complex epilepsy, awareness and pathways need to be developed to identify outlets and referrals for second opinion if needed.**
- 4 All patients with epilepsy and ID should be identified, the team members to be involved selected and the source of medical support confirmed.**
- 5 For all such patients, services need to know when a review is required and, together with primary care colleagues, make a re-referral to specialist services as needed.**
- 6 From a research perspective, services could help identify and recruit to suitable studies.



- 7 **All individuals should have an epilepsy risk assessment.**
- 8 **There should be at least annual audit to ensure that all patients have risk assessment, management plans are reviewed and a referral pathway is sought.**
- 9 **Services should be able to support relevant stakeholders, including carers, and hold best interests meetings relevant to managing complex epilepsy.**
- 10 Services should support access to clinical investigations such as EEG and MRI.
- 11 **Services should be able to monitor their care delivery against NICE guidelines and outcome indicators.**
- 12 Services should ensure that individuals with epilepsy and their families are informed and provided with educational materials.
- 13 Services should support rescue medication plans with training.
- 14 Services should be able to support seizure recording, night-time monitoring and risk reduction.
- 15 There should be availability of or referral to epilepsy-specific psychological support.
- 16 There should be availability of or referral to NEAD psychological support.

Where psychiatrists are certified as Silver and Gold, all of the above, plus:

- 1 Have the support of an ID nurse specialist with expertise in epilepsy or an epilepsy nurse specialist with competencies in ID.
- 2 Have clear defined links with specialist neurology services, depending on expertise. This should include access to counselling on women's health issues, referral for surgery, support of VNS, and access to further investigation such as prolonged EEG.
- 3 Have established links to medical genetics and expertise in referral for genetic assessment.
- 4 Be able to support patients in drug choice, advise on diagnosis and seizure risk, develop risk plans, prescribe rescue medication, educate on rescue medication.
- 5 Support prescription of AEDs, monitor outcomes and side-effects.
- 6 Support the diagnostic process.
- 7 **Engage with other services to provide holistic and safe care, for example, managing a person with tuberous sclerosis and other genetic conditions with epilepsy phenotypes.**

An adaptation of the Green Light Toolkit has been proposed for evaluation of service status.

# Clinical vignettes

This section uses examples to highlight:

- the complexities of diagnosis of epilepsy in a person with ID
- expectations for delivery of the proposed Bronze/Silver/Gold model of care.

## Differential diagnosis of epilepsy

### Clinical vignette 1

Johnny is a 24-year-old man with moderate ID and autism. He lives in a care home with other people with autism and challenging behaviour. He has lived in the home for the past 3 years. He has regular contact with his family; he has a brother who also has autism and has epilepsy. He has been referred as a result of a collapse in the street on the way to the shop. No physical cause for this collapse could be found. There is also a concern that Johnny has been talking to himself in his room. Staff have struggled to hear what he is saying, but he sometimes seems to have a strange voice when doing this. There has been a recent violent incident in the home. One of the residents attacked another and the staff had to intervene. One of the staff members was injured in this process and so the police were called. As a result of the level of concern, the police took one of the residents away for assessment, as they were concerned that the situation in the home was unsafe. Things are still a little unsettled. Johnny has been biting his lip as a repetitive behaviour, thought to be due to his increased levels of stress; blood has been noted on his pillow.

Johnny attends clinic with a carer. He sits quietly during the interview twiddling a piece of string he has brought with him. Although approached, he does not answer questions; the staff member says this is not uncommon when he first meets a new person. He makes no eye contact. The member of staff that attends clinic today was, helpfully, the person that was with him when the event occurred. He explains that Johnny likes routine and that his normal routine has been a little disrupted owing to the incident with the police and the episode last week. He would normally have gone to a stable to help with mucking out on the day of the episode, but could not go as there was no driver that could take him there. In order to still offer him one-to-one time, the carer had explained to Johnny that there was no work as there was no driver and so, instead, they were going to go to the shop to do his personal shopping. They were walking to the shop when the event occurred.

Johnny got dressed and put on his coat to go to the shop, seemingly without too much difficulty. When they left the house, he seemed to be compliant and happy, vocalising that they were going to the shop. There were some roadworks *en route*, and so they had to cross over and walk a slightly different route. While on the new route, they heard the siren of a passing emergency vehicle, but couldn't work out what sort of emergency there was. Johnny stopped, seemed frozen, bit his lip, stared to one side, mumbled something to himself and then seemingly fell to the ground next to a car. While lying in the gutter, he seemed to have some 'odd movements', but these were not clearly tonic, clonic or coordinated. It did seem like his hands were 'scrunched up'. It was impossible to see his eyes as he was lying face down. He lay quite still for a number of minutes; the carer called for help, initially from the home. By the time another carer had arrived, Johnny was sitting up, seemed a little dazed and confused, had not been incontinent, had some blood coming from his lip and would not engage in conversation. They were able to make an emergency appointment with the GP. While in the waiting room, Johnny started talking under his breath while twiddling his string. The GP referred him to the community learning disability team (CLDT) for review.

In describing this case (you know that it is made up because the carer that attended was the carer who could give a first-hand account of the situation!) we have put together a number of possibilities in order to demonstrate the care that is required in trying to understand individual issues that may help with making the diagnosis.

- 1 Anxiety has a significant role in people with autism and in people with ID in general. Could Johnny be anxious about the changes that have taken place in the house? He might have a concern that the police have taken someone away and that he may be next. When he heard the siren, he thought they were coming for him and had a panic attack. His hands were 'scrunched up' owing to carpo-pedal spasm, and this is why he looked stiff in the gutter. It might also explain why he was dazed and confused afterwards.
- 2 Mental illness is more common in people with ID than in the general population. A diagnosis of schizophrenia is sixfold more likely. Johnny is 24 years old, an age at which psychosis may first appear. He has been talking to himself when there are no other people around. Has he been responding to voices? Could it be that he stopped on the walk because he was distracted, that the voices then said something that made him frightened and that he lay in the gutter to try to escape from them?
- 3 A significant feature of developmental disabilities is the need for routine. This is an important feature in the management of people with autism, in particular, but can be seen in all those with developmental disability. Adherence to routine makes the person feel safe and secure. The fact that Johnny was not able to attend his usual activity on the day would have made him a little irritated, as this was a deviation from his routine. The carer

explained to him that he wasn't able to do his routine on that day and that they were going to the shop instead. He usually goes to the shop on a Thursday, and this was Tuesday, so he was a little uncertain about what was going to happen on Tuesday and whether he was going to the shop on Tuesday as well. Then, on the walk, they deviated from the usual path and so this meant that they were now not going to the shop at all. Could Johnny have sunk to his knees and lain in the gutter as a protest against all of the changes in his routine and the inadequate explanation for the changes and what these meant?

- 4 Physical illness, and particularly pain, can present differently in people with ID. Autistic people, in particular, may have a high pain threshold. Without thinking about the person as a whole and considering all of the options, sometimes physical illness can be overlooked. Could it be that Johnny had put on his shoe without first checking that it had nothing in it? During the melee the other day, a jug was broken and a shard of glass fell into Johnny's shoe; he then put this on and went on his walk to the shop. He has a shard of glass in his foot that is causing him pain every time he walks on it and this has changed his behaviour. He fell to the ground as he was feeling faint from the pain associated with walking to the shop with this glass in his foot.
- 5 Epilepsy is common in people with ID and Johnny has a brother who has the diagnosis. He is therefore at risk of having seizures, and this diagnosis needs to be considered. It is important to piece together a 'video' of the event in one's own mind, to try to understand whether the event described is more likely to be epilepsy than anything else. Eyes deviating to one side, a distant look with the person being 'inaccessible', repetitive movements (lip smacking or picking at clothing) and abnormal movements that are synchronous and a recovery period afterwards would make this more likely to be a seizure. Blood on the pillow is also a common sign of nocturnal seizures. Is there sufficient information in this history to consider that Johnny may have had a seizure?

Any one of these diagnoses is possible and should be thought through. It is very important to have a first-hand account of the event and to be able to piece together the whole story.

Epilepsy remains a clinical diagnosis that is based on a good history. The results of investigations, if negative, do not mean that this individual does not have epilepsy. Equally, an EEG that is 'abnormal' but lacks the diagnostic spike waves is likely, so this result is potentially unhelpful. It is important to remain vigilant and to ensure that a good history is backed up by appropriate investigation and, if necessary, appropriate treatment.

# Modelling cases on to the proposed competency template

## Clinical vignette 2

An 18-year-old woman is transferred to the learning disability service from child and adolescent mental health services (CAMHS) for ongoing assessment and treatment of her mixed problem behaviours. She has a diagnosis of mild ID, autism and epilepsy.

She has been taking one anti-epileptic medication since her epilepsy diagnosis, at a middle therapeutic dose. She has complex partial seizures (CPS) and generalised tonic-clonic seizures (GTCS) which require rescue oral medication after the first one in order to prevent clusters. She has an average of one seizure of either type each month. She lives with her parents and siblings.

ID epilepsy competencies for clinical vignette 2	
<b>Bronze</b>	<ul style="list-style-type: none"> <li>• Educate the patient if appropriate, according to capacity, regarding her epilepsy and medication management to enable her to more actively participate in the monitoring of her epilepsy and medication effectiveness and side-effects.</li> <li>• Advocate for the patient with neurological and primary care services regarding her epilepsy needs.</li> <li>• Ensure that the patient and her family have a clear description of her epilepsy and the risks associated with the diagnosis, have appropriate mitigating factors in place and know what to do in an emergency within their home. If this is not in place, support a referral to secondary care services in conjunction with primary care.</li> <li>• Work with neurological and primary care services regarding the influence of the epilepsy or its treatment on the patient's mixed problem behaviours.</li> </ul>
<b>Silver</b>	<ul style="list-style-type: none"> <li>• Attend paediatric neurology clinic as part of transition from child to adult services.</li> <li>• Manage the epilepsy and its risks in conjunction with neurological services. This may include neurological services advising on and reviewing (at least every 6 months or sooner as deemed appropriate by the direct care team) the treatment plan, with the ID service undertaking treatment and risk management. Seek advice from neurological services if concerns arise between neurological appointments.</li> <li>• Engage in discussion regarding more effective anti-epileptic management in terms of benefits and potential adverse effects.</li> <li>• Ensure there are regular medical and nurse reviews regarding any medication changes, as well as reviews of the patient's needs using the care programme approach.</li> </ul>
<b>Gold</b>	<ul style="list-style-type: none"> <li>• As for Silver, but assess and manage without neurological support and advice.</li> </ul>

### Clinical vignette 3

A 45-year-old man with moderate ID and Down syndrome with whom the CLDT have been actively involved in the past year, assessing, diagnosing and supporting his residential home regarding his Alzheimer's dementia, cognitive deterioration and behavioural disturbance.

He has a first GTCS and recovers within 3 minutes, but sleeps afterwards. There is no personal or family history of epilepsy. He is refusing medications at the present time. He lives in supported living with 24h support.

ID epilepsy competencies for clinical vignette 3	
<b>Bronze</b>	<ul style="list-style-type: none"><li>• Work jointly with primary care to refer the patient to neurological services for diagnosis and treatment.</li><li>• Work with neurological and primary care services regarding the influence of the epilepsy or its treatment on behavioural and psychological symptoms of dementia.</li><li>• Provide advice to neurological services regarding the patient's capacity, the best interests process and decisions about medication, as the patient is currently refusing all medication.</li><li>• Ensure that the patient and the home have a clear description of his epilepsy and the risks associated with the diagnosis, have appropriate mitigating factors in place and know what to do in an emergency within the home. If this is not in place, support a referral to secondary care services in conjunction with primary care.</li></ul>
<b>Silver</b>	<ul style="list-style-type: none"><li>• As for Bronze, work jointly with primary care to refer the patient to neurological services for diagnosis and treatment.</li><li>• Actively manage the epilepsy and its risks following advice from neurological services.</li><li>• Refer back to neurological services if the epilepsy or the patient's situation changes.</li><li>• Engage in discussion regarding more effective anti-epileptic management in terms of benefits and potential adverse effects.</li><li>• Ensure there are regular medical and nurse reviews regarding any medication changes, as well as reviews of the patient's needs using the care programme approach.</li></ul>
<b>Gold</b>	<ul style="list-style-type: none"><li>• As for Silver, but assess, investigate, diagnose and decide on medication management within the community learning disability service, without support from neurology (except for seeking second opinion).</li></ul>

## Clinical vignette 4

A 40-year-old woman with severe ID has had a diagnosis of epilepsy since she was 3 years old. She suffers with multiple seizure types, which the home find difficult to accurately describe and differentiate – myoclonic, GTCS and CPS with secondary generalisation. She has at least one seizure a day according to the home.

In the past 2 years, she has suffered with two status epileptic episodes as a result of physical illness. She is taking valproate, lamotrigine and carbamazepine. The CLDT are involved as she has a deteriorating swallow and mobility. She lives in residential care.

### ID epilepsy competencies for clinical vignette 4

#### Bronze

- Advocate for the patient with neurological and primary care services regarding her epilepsy needs.
- Attend neurology reviews to ensure there is a joined-up approach with the swallowing and mobility difficulties.
- Ensure that the patient and care staff have a clear description of her epilepsy and the risks associated with the diagnosis, have appropriate mitigating factors in place and know what to do in an emergency within the home. If this is not in place, support a referral to secondary care services in conjunction with primary care.

#### Silver

- Attend neurology clinics to agree epilepsy treatment and risk management.
- Manage the epilepsy and its risks in conjunction with neurological services. This may involve neurological services advising on the treatment plan and reviewing 3–6 monthly, with the ID service undertaking the treatment plan and risk management on a daily basis. Seek advice from neurological services if concerns arise between neurological appointments.
- Engage in discussion regarding more effective anti-epileptic management in terms of benefits and potential adverse effects.
- Ensure there are regular medical and nurse reviews regarding any medication changes, as well as reviews of the patient's needs using the care programme approach.

#### Gold

- As for Silver but assess and manage without neurological support or advice.
- At some point, a diagnosis of Dravet syndrome is suggested following a case-based presentation at an academic meeting. The ID team involvement would then be to:
  - refer to neurological services to confirm the diagnosis, and then to initiate tertiary specialist treatment after discontinuing the carbamazepine and lamotrigine
  - agree with neurology ongoing involvement of ID services – similar to Silver level.

# Mapping clinical vignettes to competencies

The case vignettes highlight how to identify competencies of ID psychiatrists. However, relevant support services are also required to enable delivery of a good-quality service. Looking at competencies in a categorical way can provide a pathway for ID psychiatrists to move between competencies, keeping in mind what their local services provide. The service level expectations to support each level of competency are highlighted below, using clinical vignette 2.

## Bronze ID epilepsy competency

A Bronze ID psychiatrist would review the patient in line with NICE guidelines as identified earlier. They would educate the patient and/or carers and review the medications. Service clinicians would help in writing up a risk assessment and an epilepsy care plan. Finally, if the intervention needed an external professional, they would work in collaboration with neurology and GP services.

## Silver ID epilepsy competency

A Silver ID psychiatrist may work in a team with a good understanding of NHS procedures for epilepsy management, and have back-up from the local neurology or specialist epilepsy service.

There might be an established epilepsy nurse or an ID nurse with epilepsy competencies in place to review the patients, who would be able to order appropriate investigations. The psychiatrist would be able to look at the patient's epilepsy needs by working in conjunction with the neurology service to ensure that epilepsy is reviewed every 6 months. They would undertake risk assessments and treatment plans. They would discuss whether only one epilepsy medication is needed, or whether they need to add an additional AED to control the seizures. They may liaise with the neurologist to see if any neurological investigations, such as MRI, computed tomography (CT) or EEG, need to be done. If the patient's care is deemed to be complex enough, the patient would need to be on the care programme approach.

Finally, if the epilepsy issues are complex, the psychiatrist could refer to a neurologist and discuss treatment options.

## Gold ID epilepsy competency

A Gold competent ID psychiatrist would be able to do all the assessments expected at the Silver level; however, they would not require major input from neurology, and they would have the expertise to do all the investigations and management. They would provide a stand-alone service which has its own expertise along with a supportive team to diagnose, manage and investigate, without the need for a separate specialist team.



# Future proposals

As epilepsy is a common medical condition, it is important that there are sufficient appropriately trained professionals to ensure that people with ID are well supported to have the best outcomes possible for this long-term condition.

When there are no clearly defined roles and responsibilities, there is a risk that we may succumb to the 'bystander effect' (Darley & Latané, 1968). If no one has clear responsibility, each clinician involved thinks someone else is going to take charge of the situation and make the changes that are required. Epilepsy needs to be everyone's business, and we need to be sure that there are people with the appropriate skills to manage the condition, who are able to recognise when they need additional support, and who know where they should refer more complex cases.

There is significant variation in services across the UK (Robertson et al, 2015b). The best areas are those with well-defined and comprehensive services, where neurology and ID psychiatry have clear roles and responsibilities and an agreement on how to manage the workload; while some areas have a less clear arrangement but with clarity about which service has primacy in epilepsy management. Other areas have no clear pathway and an expectation that 'others' will manage the epilepsy rather than clarity of purpose.

The diversity of practice means that any future developments will be aspirational. It is important that the medical student curriculum includes adequate education on epilepsy diagnosis and management. It is also important to consider how the understanding of epilepsy and its management in primary care could be enhanced. There is a drive to ensure that, as part of the Directed Enhanced Service for primary care in England, epilepsy is reviewed by the GP and that there is a record in the health action plan as to whether the person is seen in primary care or secondary care for their epilepsy (and, if in secondary care, then a note as to whether this is the neurology service or the psychiatry service).

We can, of course, be far clearer about what should be in the curriculum for the training of psychiatrists. There are a number of opportunities for trainees. These can range from special-interest sessions in a neurology or neuropsychiatric clinic to direct and hands-on management in a clinical setting. There are additional opportunities for teaching on the various MRCPsych courses. There is an ID curriculum, which can include epilepsy management. This is an area that all psychiatrists of the future may benefit from. There are also formal

teaching opportunities for trainees through the ILAE, which has an annual conference and a biannual teaching weekend for trainees in neurology, paediatrics and psychiatry.

For consultants, there are similar opportunities, particularly the ILAE annual conference. There are often regional meetings on epilepsy, and it is important that consultants engage in ongoing CPD in epilepsy in order to maintain their skill set. Although this has not been explicitly laid down in our model of competencies, each consultant should look at their case-load and agree, as part of their appraisal and job plan, what ongoing training they may need to maintain their Bronze, Silver or Gold 'status'.

It is important to recognise that each level will have its own set of competencies. There might be a consideration of how a psychiatrist evidences these sets of competencies for each domain. For other professionals who work in the epilepsy field, there are not only competency frameworks but exams and accreditations. For example, epilepsy specialist nurses have medication prescriber courses and accreditation. Neurologists will have had basic epilepsy management training and validation for their Royal College of Physicians membership. Paediatricians have the Paediatric Epilepsy Training (PET) courses from the British Paediatric Neurology Association. It is also important that there are procedures in place to accredit those who move between levels, especially to a Silver or Gold level: these may involve standardised competency assessments, a semi-structured formative framework to be supported by peer groups or trainers, a minimum portfolio requirement, or all of these. Distance learning modules, either via the Royal College of Psychiatrists or other accredited bodies such as the ILAE, could be used to support the accreditation process. We suggest using the distance learning PET course (<https://www.bpna.org.uk/distancelearning/>) as a model. In order to develop this type of module, experts in the field need to facilitate the process, ensuring that best practice and standards regarding epilepsy and General Medical Council (GMC) regulations are kept in mind. Until such an initiative is supported, the individual psychiatrist should ensure that they work within their domains of competency as stipulated by the GMC, look to develop skills and competencies with peer supervision from their CPD or peer group, and use the Core Knowledge, Skills and Attitudes Framework described in the next section.

# Core Knowledge, Skills and Attitudes Framework

This framework is modelled on the Learning Disabilities Core Skills Education and Training Framework, which was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health, Skills for Care and Health Education England (Skills for Health, 2016), and may be read and utilised in conjunction with this document.

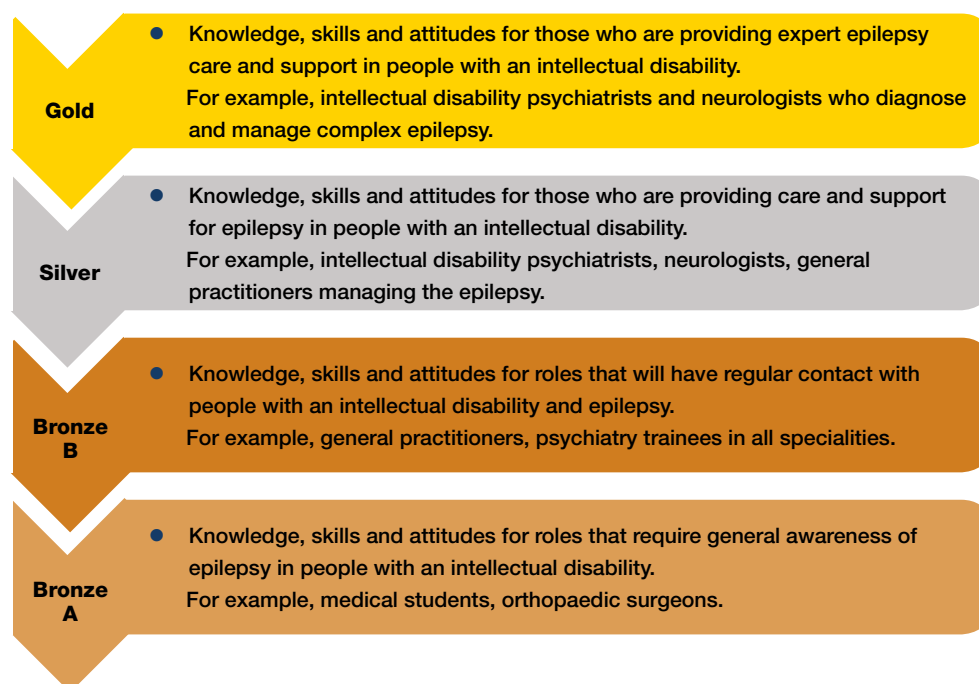


Fig. 3 The Gold, Silver and Bronze levels of the Core Knowledge, Skills and Attitudes Framework. The Bronze level is divided into two subcategories, Bronze A and Bronze B, depending on the level of contact the professional is expected to have with people with intellectual disability.

Outcome	Bronze A	Bronze B	Silver	Gold
Know what is meant by the term 'intellectual disability', common types, prevalence and causes				
Know what is meant by the term 'epilepsy', common types, prevalence and causes				
Be aware of the key legislation, policy and guidelines when working with people with an intellectual disability and epilepsy				
Be able to communicate effectively with people with an intellectual disability, their families and carers				
Know the importance of a person-centred approach and reasonable adjustments when working with people with an intellectual disability to maximise their quality of life, while minimising the effects of epilepsy and side-effects of treatment				
Be aware of the prevalence of epilepsy in people with an intellectual disability and the impact on their lives, and how this differs from the general population with epilepsy				
Be aware of the key legislation, policy and guidelines when working with people with an intellectual disability and epilepsy				
Be able to communicate effectively with people with an intellectual disability, their families and carers				
Know what health services are available and how to refer people with an intellectual disability to improve their biopsychosocial outcomes in relation to the epilepsy				
Devise and implement appropriate health action plans that meet the health needs of people with an intellectual disability and epilepsy				
Understand the health inequalities experienced by people with an intellectual disability and epilepsy				
Understand the complexity and comorbidity of epilepsy in people with an intellectual disability and support them to reduce health inequalities as a result of this complexity and comorbidity				
Develop and disseminate health promotion advice to people with an intellectual disability, their families and carers in relation to epilepsy				
Assess and manage risk related to epilepsy in people with an intellectual disability				

Take a history to gather information regarding whether the event is epileptic in nature, and if so the type of seizure, and differential diagnosis in people with an intellectual disability				
Identify, order and interpret investigations as part of the assessment, diagnosis and treatment of epilepsy in people with an intellectual disability				
Know the classification of seizures and be able to differentiate, through appropriate use of history taking and assessment tools, the type of seizure and syndrome				
Know and be able to consider the link between the epilepsy syndrome and the aetiology of the intellectual disability in order to more effectively manage the person's condition to improve their quality of life				
Have a working, day-to-day knowledge of current national guidelines in relation to assessment and treatment of epilepsy				
Be able to initiate, monitor and evaluate epilepsy treatment, including knowing the specific idiosyncratic effects in people with an intellectual disability and the need to take into account potential comorbidities such as dysphagia				
Be able to initiate and evaluate appropriate rescue medication				
Understand that people with an intellectual disability and epilepsy have greater health needs than the general population and are more likely to have respiratory disease, gastrointestinal reflux or osteoporosis which affects their epilepsy and treatment				
Be able to fully involve the person with an intellectual disability and epilepsy in the process of understanding and devising supports relating to their epilepsy				
Understand the important role families and carers have in supporting people with an intellectual disability and epilepsy and involve them appropriately in the care of the person				
Understand and refer when the support of a 'specialist in epilepsy' might be needed				
Be able to synthesise data to create a formulation for a person with an intellectual disability and epilepsy and devise appropriate care and support plans				
Understand that epilepsy may develop and present in different ways in people with an intellectual disability, and that the usual signs or symptoms may not be observable or reportable				

# References

- Amiet C, Gourfinkel-An I, Bouzamondo A, et al (2008) Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biological Psychiatry*, **64**: 577–82.
- Balogh R, Brownell M, Ouellette-Kuntz H, et al (2010) Hospitalization rates for ambulatory care sensitive conditions for persons with and without an intellectual disability – a population perspective. *Journal of Intellectual Disability Research*, **54**: 820–32.
- Bell GS, Sander JW (2001) The epidemiology of epilepsy: the size of the problem. *Seizure*, **10**: 306–14.
- Bowley C, Kerr M (2000) Epilepsy and intellectual disability. *Journal of Intellectual Disability Research*, **44**: 529–43.
- Branford D, Bhaumik S, Duncan F (1998) Epilepsy in adults with learning disabilities. *Seizure*, **7**: 473–7.
- Busch RM, Najm I, Hermann B, et al (2014) Genetics of cognition in epilepsy. *Epilepsy & Behavior*, **41**: 297–306.
- Catterall WA (2012) Sodium channel mutations and epilepsy. In *Jasper's Basic Mechanisms of the Epilepsies* (4th edn) (eds JL Noebels, M Avoli, M Rogawski). Oxford University Press.
- Cooper S, Smiley E, Morrison J, et al (2007) Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry*, **190**: 27–35.
- Curatolo P, Verdecchia M, Bombardieri R (2001) Vigabatrin for tuberous sclerosis complex. *Brain Development*, **23**: 649–53.
- Darley JM, Latané B (1968) Bystander intervention in emergencies: diffusion of responsibility. *Journal of Personality and Social Psychology*, **8**: 377–83.
- Department of Health (2009) *Valuing People Now*. TSO (The Stationery Office).
- Donat J, Wright F (1990) Episodic symptoms mistaken for seizures in the neurologically impaired child. *Neurology*, **40**: 156–7.
- Doran Z, Shankar R, Keezer MR, et al (2016) Managing anti-epileptic drug treatment in adult patients with intellectual disability: a serious conundrum. *European Journal of Neurology*, **23**: 1152–7.
- Fisher SF, Acevedo C, Arzimanoglou A, et al (2014) A practical clinical definition of epilepsy. *Epilepsia*, **55**: 475–82.
- Forsgren L, Edvinsson S-O, Blomquist HK, et al (1990) Epilepsy in a population of mentally retarded children and adults. *Epilepsy Research*, **6**: 234–8.
- Glover G, Evison F (2013) *Hospital Admissions that Should Not Happen*. Improving Health and Lives: Learning Disabilities Observatory.
- Harris JC (2006) *Intellectual Disability: Understanding Its Development, Causes, Classification, Evaluation, and Treatment*. Oxford University Press.
- Hesdorffer DC, Tomson T, Benn E, et al (2011) Commission on epidemiology. Subcommission on mortality combined analysis of risk factors for SUDEP. *Epilepsia*, **52**: 1150–9.
- Heslop P, Blair P, Fleming P, et al (2013) *Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)*. Final report. Norah Fry Research Centre.
- Improving Health and Lives (2012) *Confidential Inquiry into the Deaths of People with Learning Disabilities*. Interim report 2. IHAL.

- Kerr M, Bowley C (2001a) Evidence-based prescribing in adults with learning disability and epilepsy. *Epilepsia*, **42** (Suppl 1): 44–5.
- Kerr M, Bowley C (2001b) Multidisciplinary and multiagency contributions to care for those with learning disability who have epilepsy. *Epilepsia*, **42** (Suppl 1): 55–6.
- Kerr MP, Guidelines Working Group, Scheepers M, et al (2009) Consensus guidelines into the management of epilepsy in adults with an intellectual disability. *Journal of Intellectual Disability Research*, **53**: 687–94.
- Kerr M, Mensah S, Besag F, et al (2011) International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. *Epilepsia*, **52**: 2133–8.
- Kerr M, Linehan C, Thompson R, et al (2013) *Listening for a Change: Medical and Social Needs of People with Epilepsy and Intellectual Disability*. ILAE.
- Kerr M, Linehan C, Thompson R, et al (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**: 1902–6.
- Kerr M, Linehan C, Brandt C, et al (2016) Behavioral disorder in people with an intellectual disability and epilepsy: a report of the Intellectual Disability Task Force of the Neuropsychiatric Commission of ILAE. *Epilepsia Open*, **1**: 102–11.
- Klepper J, Scheffer H, Leiendecker B, et al (2005) Seizure control and acceptance of the ketogenic diet in GLUT1 deficiency syndrome: a 2- to 5-year follow-up of 15 children enrolled prospectively. *Neuropediatrics*, **36**: 302–8.
- Lhato SD, Sander JW (2001) The epidemiology of epilepsy and learning disability. *Epilepsia*, **42** (Suppl 1): 6–9.
- Marson AG, Al-Kharusi AM, Alwaidh M, et al (2007) The SANAD study of effectiveness of valproate, lamotrigine, or topiramate for generalised and unclassifiable epilepsy: an unblinded randomised controlled trial. *Lancet*, **369**: 1016–26.
- Matthews T, Weston N, Baxter H, et al (2008) A general practice-based prevalence study of epilepsy among adults with intellectual disabilities and of its association with psychiatric disorder, behaviour disturbance and carer stress. *Journal of Intellectual Disability Research*, **52**: 163–73.
- McGrother CW, Bhaumik S, Thorp CF, et al (2006) Epilepsy in adults with intellectual disabilities: prevalence, associations and service implications. *Seizure*, **15**: 376–86.
- Mencap (2012) *Treat me Right! Better Healthcare for People with a Learning Disability*. Mencap.
- National Development Team for Inclusion (2013) *Green Light Toolkit 2013: A Guide to Auditing and Improving your Mental Health Services so that It Is Effective in Supporting People with Autism and People with Learning Disabilities*. Department of Health.
- National Institute for Health and Care Excellence (2012) *Epilepsies: Diagnosis and Management* (CG137). NICE.
- National Institute for Health and Care Excellence (2013a) *Epilepsy in Adults* (QS26). NICE.
- National Institute for Health and Care Excellence (2013b) *Epilepsy in Children and young people* (QS27). NICE.
- NHS England (2016) *Stopping Over-Medication of People with Learning Disabilities* (STOMPLD). NHS England.
- Office for Disability Issues (2011) *Equality Act 2010: Guidance*. HM Government.
- Patja K, Livanainen M, Vesala H, et al (2000) Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, **44**: 591–9.

- Paul A (1997) Epilepsy or stereotypy? Diagnostic issues in learning disabilities. *Seizure*, **6**: 111–20.
- Prasher VP, Kerr MP (2016) *Epilepsy and Intellectual Disabilities* (2nd edn). Springer.
- Robertson J, Hatton C, Emerson E, et al (2015a) Prevalence of epilepsy among people with intellectual disabilities: a systematic review. *Seizure*, **29**: 46–62.
- Robertson J, Baines S, Emerson E, et al (2015b) Service responses to people with intellectual disabilities and epilepsy: a systematic review. *Journal of Applied Research in Intellectual Disabilities*, **30**: 1–32.
- Sander JW, Shorvon SD (1996) Epidemiology of the epilepsies. *Journal of Neurology, Neurosurgery, and Psychiatry*, **61**: 433–43.
- Scottish Intercollegiate Guidelines Network (2015) *Diagnosis and Management of Epilepsy in Adults: A National Clinical Guideline* (SIGN143). SIGN.
- Shankar R, Cox D, Jalihal V, et al (2013) Sudden unexpected death in epilepsy (SUDEP): development of a safety checklist. *Seizure*, **22**: 812–7.
- Shankar R, Jalihal V, Walker M, et al (2014) A community study in Cornwall UK of sudden unexpected death in epilepsy (SUDEP) in a 9-year population sample. *Seizure*, **23**: 382–5.
- Shankar R, Walker M, McLean B, et al (2016) A step to modify and prevent SUDEP: the validity of risk factors in the SUDEP and seizure safety checklist: a case control study. *Journal of Neurology*, **263**: 1840.
- Skills for Health (2016) *Learning Disabilities Core Skills Education and Training Framework*. Skills for Health, Skills for Care, Health Education England.
- Thompson R, Kerr M, Glynn M, et al (2014) Caring for a family member with intellectual disability and epilepsy: practical, social and emotional perspectives. *Seizure*, **23**: 856–63.
- Turky A, Felce D, Jones G, et al (2011) A prospective case control study of psychiatric disorders in adults with epilepsy and intellectual disability. *Epilepsia*, **52**: 1223–30.
- Tyrer F, Smith LK, McGrother CW (2007) Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of Intellectual Disability Research*, **51**: 520–7.
- van Schroyen Lantman-De Valk HM, Metsemakers JF, Haveman MJ, et al (2000) Health problems in people with intellectual disability in general practice: a comparative study. *Family Practice*, **17**: 405–7.
- Working Group of the International Association of the Scientific Study of Intellectual Disability (2001) Clinical guidelines for the management of epilepsy in adults with an intellectual disability. *Seizure*, **10**: 401–9.
- World Health Organization (1992) *The ICD-10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines*. WHO.



