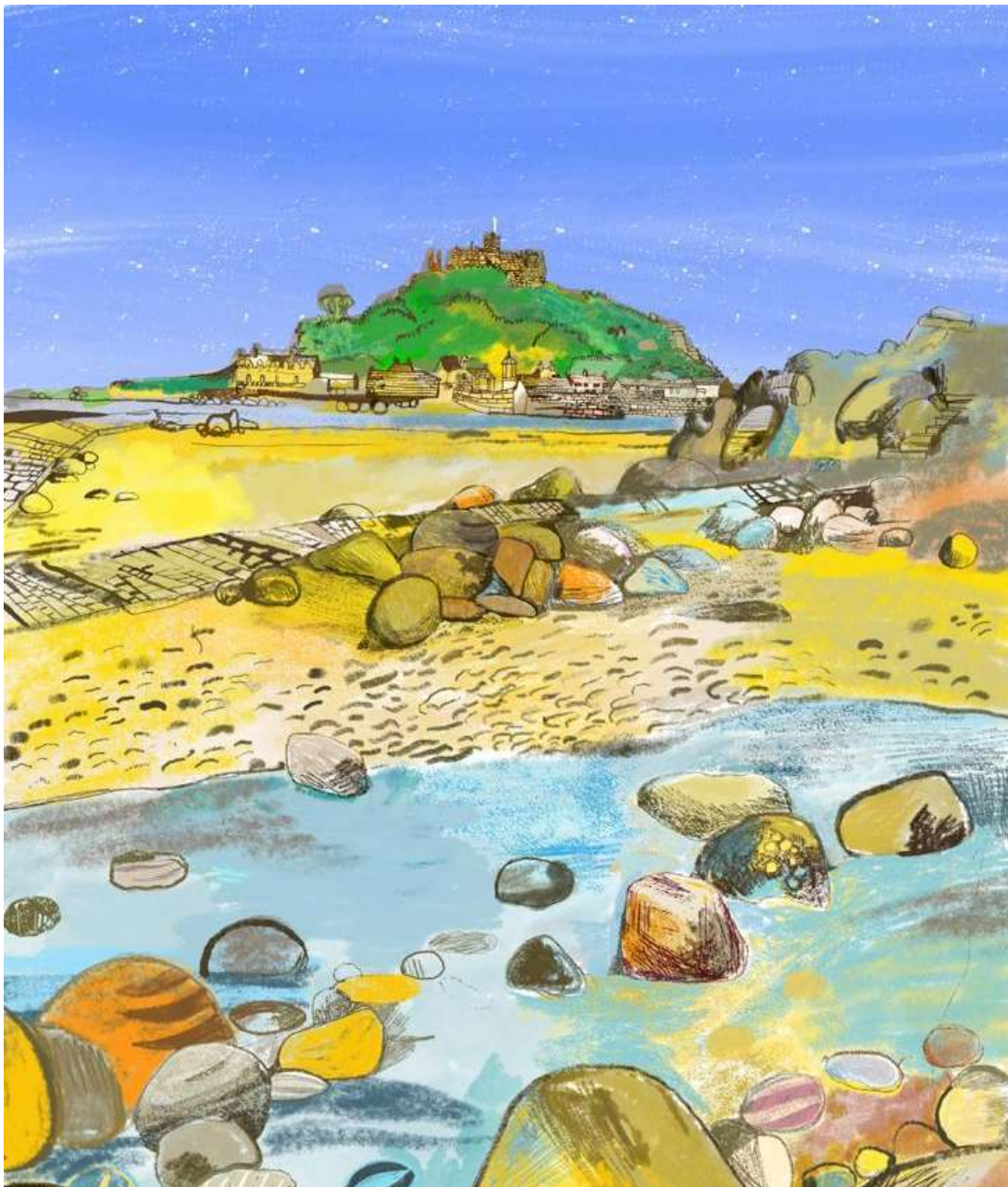


# Step Together

## Integrating Care for People with Epilepsy and a Learning Disability





The ROYAL  
SOCIETY of  
MEDICINE



Cornwall Partnership  
NHS Foundation Trust



Learning Disability  
Professional Senate



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### **Keywords**

Learning disability, intellectual disability, mental impairment, learning difficulties, intellectual difficulties, pervasive developmental disorder, autism spectrum disorder, autism, epilepsy, seizures, reasonable adjustments, commissioning

## Foreword

Epilepsy is more common in people with a learning disability and/or autism than the general population. It is more likely to be difficult to control. Seizures can have a profound impact on a person's ability to live and enjoy their life. It also impacts on their level of learning disability and functional interaction with others.

Poorly controlled epilepsy can also present as a huge burden of care and anxiety to family members and carers. Seizures are often distressing to witness, can require urgent intervention and can lead to injury or sudden and premature death. The recently published LeDeR report (2020) reminds us that too often people with learning disability and/or autism die many years sooner than they should and epilepsy is a frequently associated cause of this. We know that good seizure control for individuals with the most complex seizures often requires complex assessments and investigations e.g. telemetry, genetic testing, brain imaging etc. It may require trials of treatments that can come with side effects and interactions with other drugs.

With good seizure control, people's lives, both in terms of quality and length of life, can be transformed. It is absolutely right, therefore, that we should expect the highest standards of investigations, care and treatment for people with the most complex epilepsy irrespective of whether they have a learning disability and/or autism.

People with a learning disability and/or autism often have multiple professionals involved in their care and support for social care, health care and emotional and behavioural difficulties. Historically it has been quite complex and varied as to who the lead medical professional or team has been in managing a person's epilepsy. This has often depended on the history of service configuration and suitable clinical skill availability in localities. Specific interests and expertise of clinicians and local commissioning priorities have been instrumental in shaping local area services.

This guidance does not recommend that only one type of professional or a particular team can or should be involved in leading epilepsy care for people with a learning disability and/or autism. More importantly it recognises the standards of care that people and their families should expect and describes existing competency/skill frameworks (such as the bronze, silver gold levels suggested by the Royal College of Psychiatrists) and collects these across professions to suggest a way of recognising aggregated standards of care and describing the 'ideal service'. This should enable both commissioners of care and providers of care to recognise what is currently available to people and what could or should be available if their needs are going to be fully and satisfactorily met. It is clear more collaborative working between General Practice, Learning Disability Mental Health Services, Specialist Nursing Services and Neurology/Epileptology services is needed and this is a welcome recommendation.

This guidance should be used by commissioners of health care to audit and assure themselves that the services they are commissioning meet the needs of their population and that there is the correct aspiration to improve and provide access to 5\* services when needed. It should be used by clinicians in both primary and secondary care to recognise service gaps and build more collaborative models of working. Families and carers should also look at the services they receive and see if they measure up to what they need using some of the ideas provided here.

Whilst this guidance is specifically focussed on the needs of people with learning disability who have epilepsy there are many people with autism (without a learning disability) who also have epilepsy and the principles in this guidance should be equally applied to commissioning services for this group of individuals too.

Perhaps for me, the most important thing is the need to end any sense of futility or nihilism. For far too long there has been an attitude amongst some professionals that more complex epilepsies are intractable and fully resistant to treatment. This may lead them to think it is futile to keep trying to improve the situation or that it is not a commissioning priority. This is countered by stories of individuals whose lives have genuinely been transformed by opportunities to have 'fresh eyes' assess their epilepsy or try new treatments. In order to decrease premature and avoidable mortality and to improve quality of life for people and their families, we must use this guidance to transform services and be ambitious for good epilepsy management and optimum seizure control for people with a learning disability and/or autism.

Dr Rohit Shankar MBE, FRCPsych

## Executive Summary

Epilepsy is the tendency to have recurrent unprovoked seizures. Rates of epilepsy are reported to be significantly higher in people with a learning disability compared to the general population. A prevalence of 20% is reported among people known to learning disability services; likewise up to 30% of people with epilepsy are considered to have learning disability or difficulties. The existence of physical, mental and other developmental co-morbidities among people with a learning disability and epilepsy can present varying degrees of challenges requiring specialist approaches and collaborative working between different specialist healthcare settings.

A diagnosis of epilepsy can have worsening effects socially and psychologically for both the person with a learning disability and their family carers.

There is significant potential to improve care for adults and children with learning disability. Both learning disability services and epilepsy services deserve parity of care but, can encounter diagnostic overshadowing and thus higher risk of overall failure of care, increasing their chances of premature mortality and adverse impacts on their social well-being and access to community.

The recent Neurological Alliance – Public Health England report looking at trends of deaths associated with neurological conditions between 2001 -2014 emphasises the significant year on year increase in the number of deaths associated with epilepsy. Physical vulnerability and increased likelihood of multiple co-morbidities in people with a learning disability requires further careful consideration of these report findings.

This document will be of benefit to people and associations providing direct care to children and adults affected by epilepsy and a learning disability and those organisations which commission services for epilepsy or learning disability or both.

The document provides an understanding of the association, nature, overlap and complexity of the two conditions. It highlights a brief overview of the current patterns of clinical delivery for the two conditions and the possible problems faced by individuals who have both learning disability and epilepsy in accessing good standards of care. It argues for the need to have overlapping mechanisms of service delivery to reduce the current failings and post code lottery of care delivery to this vulnerable population.

The document sets out clear expectations of the roles and responsibilities of relevant stakeholder clinicians and commissioners. It argues for and sets out a basic and desirable set of competencies in the core skills of clinicians including paediatricians, neurologists, psychiatrists and nurses who are engaged in care provision to people (children, young people and adults) with learning disability and epilepsy. It provides insights into good practice already happening in many organisations to address the clinical and service gaps. It looks to provide a basic framework of measurement and benchmarking tools to assess and enable expected



standards of service delivery for commissioners and other key stakeholders including the person with learning disability and epilepsy, their family and their carers.

This document identifies core healthcare professionals who should be part of any local epilepsy service for people with a learning disability. Furthermore, the guidance proposes tools that can be utilised by commissioning organisations in testing the fitness of their local services to provide adequate epilepsy services. It proposes an integrated model of working and identifies core healthcare professionals and services that should be part of every area in the UK.

Where gaps in skills or competences are identified, the guidance outlines competency frameworks for core healthcare professionals that can be used to upskill individuals so as to provide an acceptable level of epilepsy service for their populations. By providing guidance to acceptable levels of epilepsy service delivery through benchmarking, the report seeks to help local areas achieve adequate services.

Acceptable standards of epilepsy care could be achieved by improving existing models of current care and practice. This guidance lays out some of the current problem within epilepsy services and the potential solutions which will need testing by local areas. Future improvements can be made as necessary using the presented frameworks.

This report is the first of its kind to address the variation in epilepsy service provision for people with a learning disability. It is of great pleasure to see the various clinical groups and organisations coming together taking this first step in improving epilepsy care for people with epilepsy and a learning disability.

# Improving Epilepsy Services for People with a Learning Disability

## Case for change

- 1. Rates of epilepsy are reported to be significantly higher in people with a learning disability compared to the general population.** People with a learning disability commonly have multiple seizure types and are often resistant to drug treatment. The management of epilepsy in people with a learning disability and in particular those presenting with complex mental health and physical co-existing conditions will often require specialist multi-disciplinary approaches.
- 2. There are wide variations in the provision of epilepsy services across the country with lack of benchmarking tools/ideas to assist commissioners in mapping the needs of their local population so they can provide the right care.**
- 3. Lack of expertise in learning disability and epilepsy and lack of national standards or guidance, are identified as limiting factors for safe and optimum care for people with a learning disability affected by epilepsy.**
- 4. People with a learning disability have a shorter life expectancy and a greater risk of early death than the general population. Sudden unexpected death in epilepsy (SUDEP) is also a particular risk particularly if epilepsy is poorly managed.** Premature avoidable deaths in people with a learning disability have been linked to problems with treatment plans and the lack of reasonable adjustments for better access and management of health conditions.
- 5. High rates of healthcare and social care usage.** Epilepsy is associated with high healthcare and social care costs. Convulsions remain the main cause for avoidable hospital admissions for people with a learning disability and currently account for 40% of all emergency hospital admissions for people with learning disability; approximately 6000 admissions annually in the UK.

## Recommendations / Key Standards

### What does this mean for commissioners of epilepsy services?

1. Across the UK the provision of local services for people with epilepsy and learning disabilities varies and where there are gaps in or between services, redesign or recommissioning may be appropriate.
2. Indicators of a need to review and redesign services for the population with epilepsy and learning disabilities may include:
  - evidence of high avoidable emergency attendances for seizures
  - evidence of premature avoidable deaths linked to the quality of care or of treatment plans
  - evidence of failures in communication between different health and social care services (perhaps from complaints or feedback from carers).
3. New approaches to collaborative commissioning and integrated care systems focusing on improving outcomes open up opportunities to innovate and better meet the complex needs of this population.
4. Service models incorporating care co-ordination and multidisciplinary team working offer potential benefits.
5. Using the 'Step Together Commissioning Guide' which provides a checklist of the components of a minimal service and beyond that a good service or a fully integrated service may improve standards of care.
6. Commissioners can initiate work with providers and patients to agree local care pathways, workforce competencies, training plans, and key performance measures to support implementation of new models and improved outcomes.

## What does this mean for those providing direct care to children and adults affected by both a learning disability and epilepsy?

1. The document seeks to remove the focus from treating epilepsy as a condition in people with learning disability to consideration of holistic care where epilepsy management needs to be part of the large formulation of well-being and safety.
2. The document integrates current best practice and informed views in learning disability and epilepsy held by the various clinical stakeholders
3. Learning disability and epilepsy management is provided on many occasions by multiple diverse professionals working in different services, to their ranges of competency and resource which at times creates service gaps and fails patients. This document looks to identify these gaps.
4. This document gives an opportunity to bridge those clinical service fissures by providing a clear competency framework to key professional groups of clinicians, streamlined to necessary service needs and expectations to help mitigate the risk of individuals falling through the gaps.
5. It supports the need to look upon epilepsy as a condition within a complex neurodevelopmental and neuro-disability framework.
6. The document helps clinicians to become self-aware of / their skills and how it would position within the large service delivery model. Where there is a gap in knowledge it prompts an opportunity and provides a pathway for interested professionals to upskill.
7. It looks to give a range of care models from acceptable to excellent and helps define the diverse range of ways to integrate epilepsy and learning disability care.
8. The document looks to provide a template for an open, structured, person-centred discourse for transition to enable the individual to be at the right place, in the right service for the right need on entering adulthood
9. Central to the document is the focus on clinical co-production and co-design of care involving the patients and where appropriate their parents / carers
10. It allows regions to be flexible in generating their local clinical pathways based on already existing structures by stipulating end expectations as opposed to prescriptive change in clinical delivery.
11. It is a document to facilitate consistent epilepsy clinical care to people with a learning disability in England, irrespective of their location or the service structure.



### **Art by Sammy de Courcy**

This is the first of 3 art pieces (1,2,and 3) by Sammy who lives on the south coast of Cornwall in a woodland area. He is 41 years old and has Downs Syndrome and Autism.

Sammy is highly creative young man with an innovative imagination and consistently works on his art work.

## Introduction

In spite of the overwhelming evidence of worse clinical outcomes, higher levels of mortality and increased expenditure of resources in emergency care; there is no structured UK wide plan to deliver a consistent, structured and person centred approach to the management of epilepsy in a person with a learning disability.

Up to 600,000 people in the UK have a diagnosis of epilepsy and many take antiepileptic drugs (AEDs). Worldwide, the prevalence of epilepsy is likely to be between 0.5 to 1% of the population [1].

Epilepsy is common in people with a learning disability, usually as an additional complication of the underlying condition [2, 3, 4]. Around one quarter of people with epilepsy have a learning disability and it can be more difficult to control than in people without a learning disability. A clinical learning disability includes the presence of [5]:

1. Significant impairment in intellectual function
2. Significant impairment in adaptive function
  - a) *Conceptual skills*: language; reading and writing; and money, time and number concepts;
  - b) *Social skills*: interpersonal skills, social responsibility, self-esteem, gullibility, naivety (i.e. wariness), following rules/obeying laws, avoiding being victimised, and social problem-solving;
  - c) *Practical skills*: activities of daily living (personal care), occupational skills, use of money, safety, health care, travel/transportation, schedules/routines, and use of the telephone.
3. These started in childhood

Learning disability (or intellectual disability) is also defined as a Full Scale Intelligence Quotient (IQ) of less than 70 [2, 6] but can be a catch all term to encompass learning disability (ICD 10 F70-73) and Pervasive Developmental Disorders (ICD 10 F84) such as childhood Autism [6].

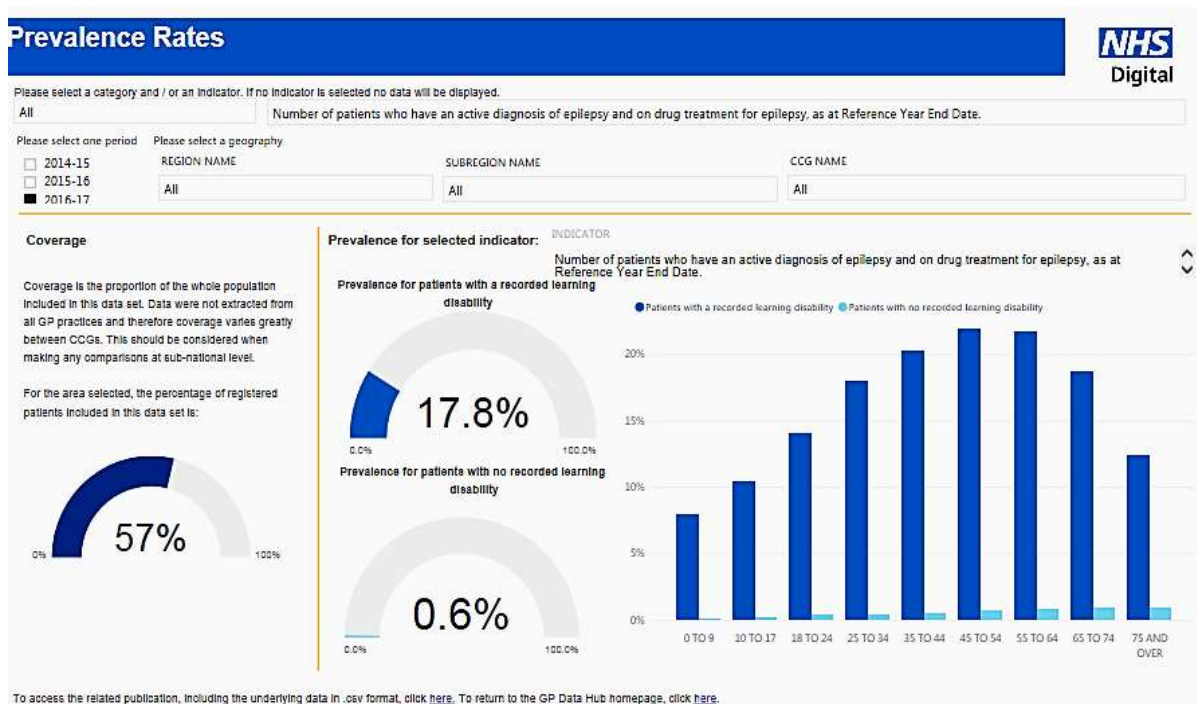
Epilepsy is the tendency to have recurrent unprovoked seizures, which are episodes of changes in movement or behaviour, the direct result of abnormal excessive neuronal activity in the brain [3, 7, 8]. Seizures usually manifest as transient disturbed behaviour, emotional, motor or sensory symptoms or signs with or without an alteration in consciousness.

Epilepsy and a learning disability may be caused by a range of pathological processes [9, 10,11]. Among people known to learning disability services in the UK, the prevalence of epilepsy is 20-30% and possibly higher in the residential populations in long-stay institutions [12].The prevalence of epilepsy in people with a learning disability is between 22 -26% and increased with increasing level of learning disability [13, 14]. The estimated prevalence of epilepsy for mild learning disability is around 10% compared to 30% for those with moderate, severe or profound learning disability [15].

NHS Digital 2017 [16] reported on the number of people who had an active diagnosis of epilepsy and on drug treatment for epilepsy as recorded by GPs in a report produced in collaboration with Public Health England. As expected, rates of epilepsy were significantly higher in people with learning disabilities. 17.8% of people with learning disabilities were recorded as having epilepsy and on drug treatment for epilepsy. The corresponding figure for people without learning disabilities was 0.6%.

Please refer to **figure1** below;

**Figure1. Number of patients who have an active diagnosis of epilepsy and on drug treatment for epilepsy 2016-2017**



Adjusting for the different age and sex profile, the number of people with a learning disability diagnosed as having epilepsy was 21 times the figure expected if general population age and sex specific rates had applied.

## Impact of Epilepsy in People with a Learning Disability

Learning disability is not a homogenous grouping, people with a learning disability have different underlying aetiologies, and different groups of co-existing conditions, therefore people's needs and ability to make informed choices are diverse. For the individual and those supporting them, a diagnosis of epilepsy can have both a physical and psychological impact resulting in significant care and support needs.

The presence of a learning disability has a number of potential influences on the prognosis of an individual's epilepsy and similarly epilepsy (and its treatment) can have a worsening effect on cognitive and social function in people with a learning disability. Both conditions individually are potentially disabling, longstanding and socially isolating. It may not be possible to separate the effects of an individual's epilepsy as opposed to their underlying learning disability on cognitive function; so considering the person as a whole is crucial. The epilepsy could be considered in many if not all instances to be part of the neurodevelopmental abnormality which contributes towards the learning disability and other co-existing conditions.

Epilepsy is associated with high healthcare costs and premature mortality [17]. It is known that people with a learning disability have a shorter life expectancy and a greater risk of early death than the general population of England and Wales. Many of these deaths are avoidable. The Confidential Inquiry into Premature Deaths of people with a learning disability (CIPOLD) revealed a dramatically reduced life expectancy - 13 years shorter for men and 20 years shorter for women - compared to the general population [18]. Forty three percent of the deaths in CIPOLD were considered to be premature, but 86% had a timely diagnosis of the event that led to their death: - 43% had epilepsy and 31% (of the studied population) had a seizure in the past 5 years. It is important to recognise that there is a potential sample bias to these rates of premature death as there are many more people with life limiting conditions associated with their learning disability than there are in the general population.

The inquiry reported that a greater proportion of those who had died in the learning disabilities group had inadequate or inappropriate accommodation for the person's needs; family or paid carers who did not feel they were listened to; problems in advanced health care and planning; problems in recognising the person's needs and adjusting care when needs changed; and poor adherence to the Mental Capacity Act 2005 [18]

The recent review to learn from deaths of people with learning disability confirms the issue of premature deaths among those with a learning disability remains unchanged [20]. It was identified that mortality rates for individuals with a learning disability increase with the severity of a learning disability and existence of co-existing conditions including epilepsy. There are three main causes of preventable death in people with a learning disability: sepsis, aspiration pneumonia and epilepsy or convulsions [20].

Convulsions remain the main reason for avoidable hospital admissions for people with a learning disability and currently account for 40% of all emergency hospital admissions, approximately 6000 admissions a year in the UK [21]. This is a worldwide problem [22].



## Management of Epilepsy

People with a learning disability and epilepsy have diverse needs with a higher likelihood of communication, psychiatric, behavioural and drug sensitivity problems that make it more difficult to be treated than those without a learning disability or with a milder disability [17]. Two thirds of people with a learning disability and epilepsy are considered to show a poor response to AEDs [14].

When developing a care plan for an individual with a learning disability and epilepsy, care and attention should be paid to the increased risk of adverse cognitive and behavioural effects of AED treatment [17]. Cognitive impairment and communication difficulties leave individuals at risk of making poor health choices and enhance the risk of poor choices being made for them [18]. There is a significantly higher representation of mental health and physical health co-existing conditions in people with a learning disability who often have complex health needs [23].

People with a learning disability commonly have multiple seizure types and are resistant to drug treatment [24, 25, 26]. This is especially true for those with severe and profound learning disabilities. Uncontrolled epilepsy can have serious negative consequences on both quality of life and mortality [27, 28]. There is a poor understanding and limited evidence base supporting suitable prescribing in this vulnerable population [29].

For people with a mild learning disability, treatment is mainly focused on adherence to treatment and understanding association of the epilepsy and its treatment to any challenging behaviour and mental health issues while trying to facilitate as much independence for the individual as possible. People with severe to profound learning disability have more complex needs, are more likely to have additional genetic conditions and structural brain damage and require higher levels of support. As up to 50% of those with severe to profound learning disability have epilepsy, their treatment is more focused on factors such as co-existing conditions (and complex health conditions), impact of medication, recognition of side effects, treatment resistance, and best interest and, when possible, informed consent [17, 30].

The management of epilepsy is also particularly important because of the risk of SUDEP (Sudden Unexpected Death in Epilepsy). The incidence of sudden death appears to be up to 20 times higher in people with epilepsy compared to the general population, and SUDEP is the most important directly epilepsy-related cause of death [31]. People with drug resistant epilepsy are particularly at risk of SUDEP [31, 32]. It is suggested that SUDEP rates can be as high as 42% in people who have over 15 years of pharmaco-resistant epilepsy. People with learning disability are over represented in this risk population [3, 4]. The National Institute for Health and Care Excellence (NICE) [33, 34] recommends that individuals, carers and families need to be counselled using information tailored to the individual's relative risk of SUDEP. There are now recommendations on consultation length and risk assessment in people with a learning disability, in particular regarding to SUDEP [30, 35]. Risk assessments are recommended to be person centred using semi- structured evidenced based tools such as the SUDEP and Seizure Safety Checklist (<https://sudep.org/checklist>) to evaluate change in risk and take appropriate measures where there is identified worsening of seizures [30, 35].

## The National Opportunity - defining the problem

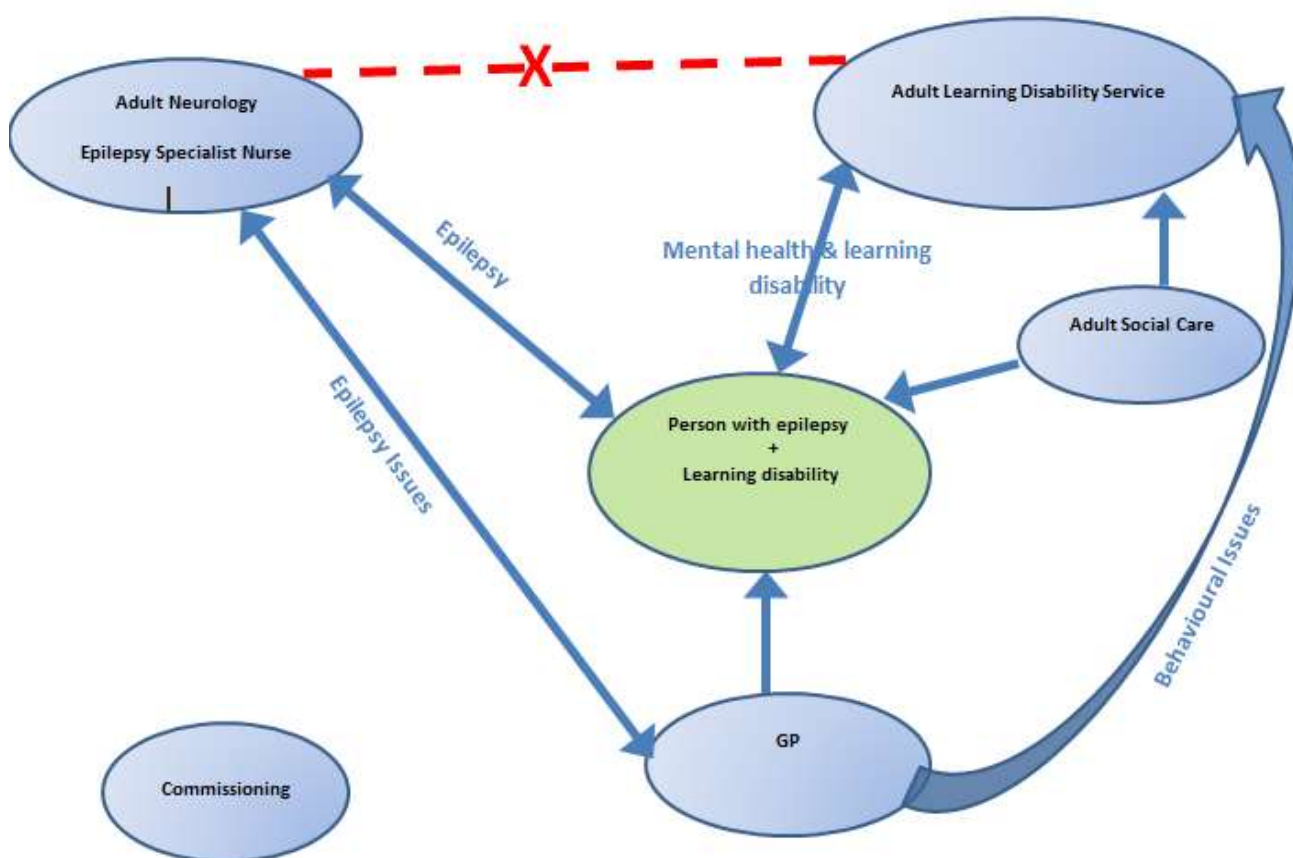
In the UK a mix of providers deliver care across the child–adult interface for learning disability and epilepsy.

Epilepsy care is fragmented with inadequate provision of specialist care being reported in many areas. The myriad range of professionals and differing competency sets have resulted in different service models meeting the epilepsy needs of children, young people and adults with a learning disability across the country.

There has been some work describing properly resourced paediatric neuropsychiatry and neuropsychology services for this population within NHS England including commissioned paediatric neuroscience service specifications [36 - 40] but there continues to be a lack of a coordinated and consistent approach to ensuring good quality standards and coverage of services across the country. The variation in service provision was also shown in the recent surveys and studies by the Royal College of Paediatrics [41], ILAE, British Chapter [42] and the Royal College of Psychiatrists Faculty of Intellectual Disability [43].

An example illustration of a current fragmented working practice model in epilepsy services for people with a learning disability is shown below; where there is a missing link between core healthcare professionals (**figure 2**).

**Figure 2: Fragmented working practice model**



In many areas there are Learning Disability Liaison Nurses to facilitate appointments in hospitals. A specialist multidisciplinary approach enables formulation of seizure events in the wider context of the mental and social care provision and behavioural change. It requires a service model able to provide individualisation in health care and reasonable adjustments such as more frequent, flexible and longer appointments [44, 45]. . Use of telephones or web based video conferencing could be a suitable alternative to fixed hospital appointments as the latter can cause distress to individuals with a learning disability.

A continued concern is the lack of a consistent commissioning structure for complex epilepsy. Services for complex epilepsy in children are via NHS England and when those same children transition to adult care, commissioning is taken over by CCGs. In general, epilepsy is commissioned through CCGs but specialist services e.g. paediatric neurology and epilepsy surgery happen through specialist commissioning. This often results in difficulties continuing certain specialist medications/therapies and also results in a fragmentation of care. Further consideration of provision of longer clinics as is suggested to support people with a learning disability and epilepsy might require consideration for novel tariff arrangements to be supportive of an inclusive and holistic model of care.

## Adults with Epilepsy and a Learning Disability

Epilepsy care for adults with a learning disability varies significantly based on geographical region, availability of specialised personnel, skills and competence of professionals either from a learning disability or a neurological background. A few areas have developed commissioned services for people with a learning disability and epilepsy.

At the basic level as with the general population the service delivery in **primary care** is via the **general practitioner (GP)**. Despite moves to improve the general health and well-being of people with learning disability, the uptake of these initiatives has been slow. People with a learning disability should be registered on the learning disability quality outcomes framework (QOF) register. Although the expected population in primary care should be around 2% of the population, the England prevalence of learning disability identified on QOF registers is 0.44% of the total population, meaning that the majority of people with a learning disability are unidentified to primary care. Those people on the QOF register are entitled to an Annual Health Check, which would include a medication review and possibly include an epilepsy review. The current target is for 65% of people on the QOF register to have an annual health check.

From this data, it seems clear that there are problems with identifying individuals with a learning disability, there will then be problems with identifying them to appropriate services and there is a concern that with limited resources, uncertain referral criteria and unclear pathways into secondary care, that there is significant unmet need in the primary care community. Primary care liaison nurses should be able help improve standards of care for people with learning disability and epilepsy to access their GPs for reviewing epilepsy needs, but they need to be well trained and up-to-date about epilepsy care.

At a **secondary and tertiary care** level clinical input is delivered by an eclectic mix of **psychiatrists** working with people with a learning disability and with an interest in epilepsy, **neurologists** with specialism in epilepsy and **nurses** with a range of competencies in learning disability and epilepsy.

In the **community care** setting, psychiatrists and Community Learning Disability Teams (CLDTs) often provide some form of epilepsy service, reserving the neurology advice for individuals with more complex needs. Over the past 20 years the rapid developments in AEDs, combined with the national policy towards service mainstreaming, have meant that a significant number of learning disability psychiatrists have left differing levels of epilepsy care to their neurology colleagues. There have been fluctuations at an operational and commissioning level where policy has been changed leading to certain Trusts withdrawing epilepsy care historically provided by learning disability services. Adult learning disability teams, even if supporting epilepsy care could lack expertise in neurodisability (disorders such as cerebral palsy) which is comorbid in a significant proportion of people with epilepsy and a learning disability. There is no parallel speciality in adulthood like neurodisability paediatricians in childhood though in some places local neurology or neurorehabilitation services have assumed this.

It has been recognised in a recent survey that in regions short of neurology specialist care, in predominantly rural areas, learning disability psychiatrists and local learning disability services have filled the gap [43]. A study comparing the two service types has found parity of care, but observed they tended to care for individuals with different needs [46].

In 2014, a white paper from the ILAE task force, commented that “The breadth of needs of this population is a challenge to the epilepsy world, spanning all the professional groupings, care providers, and the research modalities in epilepsy” [47].

In 2017 the Royal College of Psychiatrists brought together experts in epilepsy and learning disability from the three major stakeholder groups of neurology, learning disability psychiatry and epilepsy nursing to publish two College reports [17, 30] focused on aspects of epilepsy care provision and the role of the learning disability psychiatrist. The reports were well received by all stakeholders of the College Faculty [43]. It has now been proposed to be implemented thus ensuring that present and future learning disability psychiatrists meet a recognised basic competency.

It is recognised that nursing skills and availability ranges from nurses who work solely with people with a learning disability and have no specific epilepsy skills to nurses who work with people with epilepsy primarily in the general population and see people with a learning disability within the general population framework. In between, the spectrum can encompass learning disability specialist nurses with epilepsy interests and epilepsy specialist nurses with a learning disability interest. The Learning Disability Epilepsy Specialist Nurse Competency Framework takes account of this (48, 49).

Similar structures do not exist for neurologists who are expected, as part of their competency curriculum, to have a basic competence in epilepsy management. There is growing recognition that as there is increasing specialisation; neurologists might choose to keep up their skills in other areas of neurology and not necessarily epilepsy. Further there is no expectation of a neurologist to have an up to date understanding of learning disability related good practice. These issues can leave service level gaps in delivering epilepsy services to a person with a learning disability, as the focus might be on the epilepsy and not the individual who could have other complex learning disability linked health and social needs.

## Children with Epilepsy and a Learning Disability

Epilepsy care for children with epilepsy and a learning disability also varies significantly based on geographical region, availability of specialised personnel, competence and interest of professionals from a variety of backgrounds (general practitioners, paediatricians, school nurses, paediatric epilepsy specialist nurses, psychiatrists, paediatric neurologists) in managing this population. Few areas in the country have developed a specifically commissioned service for this vulnerable population.

As with adult services, there is a wide range of professionals who will be involved in the clinical delivery of epilepsy care for children and young people with a learning disability. These are:

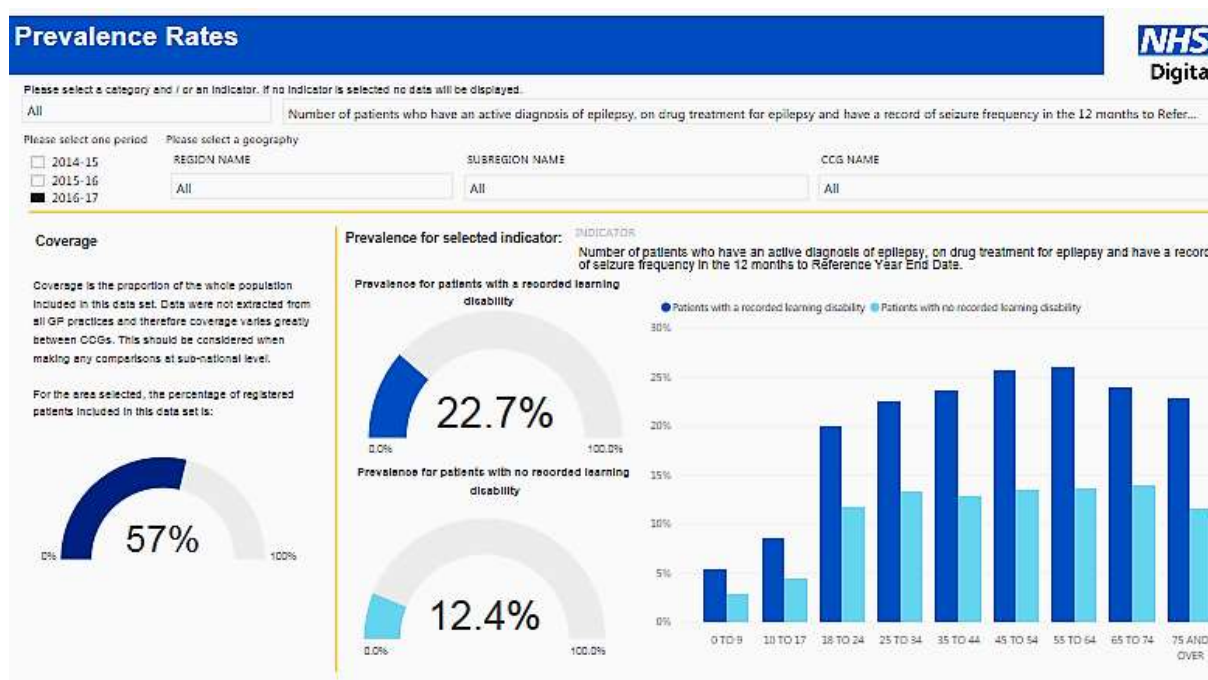
- a) **General Practitioners (GPs)** – a few children who have remission of their epilepsy, may be under the care of GPs. Otherwise, all children with epilepsy, irrespective of a comorbid learning disability, will be managed in secondary care by a Paediatrician and/or a Paediatric Neurologist.
- b) **Community Paediatricians and School Nurses** – many state funded special schools have large populations of children with a learning disability and associated diagnoses such as Autism Spectrum Disorder. Most special schools have a medical service that is staffed by Community Paediatricians and School Nurses. A number of children in special schools also have epilepsy and their anti-epilepsy medication may be advised on and monitored by the Community Paediatrician attending their special school. In collaboration with the School Nurse, the Community Paediatrician will also develop appropriate epilepsy management plans including rescue medication protocols. School Nurses are well placed to deliver education and training to education professionals in special schools. Community Paediatricians may also assess and review children with epilepsy and a learning disability in their community clinics. Lastly, there are a number of private special schools in the country, some of which are provided by large companies that deliver a number of special schools. Some of these schools will employ a combination of Paediatricians, Psychiatrists and Nurses who will be involved in the care of children with epilepsy and a learning disability, but there are no agreed standards and the competencies of these professionals will range greatly.
- c) **General Paediatricians including Paediatricians** with an expertise in epilepsy and specialist paediatricians in neuro-disability – most secondary care hospitals have identified general paediatricians with expertise in epilepsy and established links and referral pathways to paediatric neurology. There are also parts of the country that have specialist paediatricians in Neuro-disability who may also be the designated paediatrician with epilepsy expertise. Both these groups of Paediatricians will typically work in secondary care hospitals with access to investigations such as neuroimaging and EEGs, although direct access to a radiologist or neurophysiologist with specialist knowledge of paediatric neuroimaging and EEGs respectively, may be patchy. The curricular for core and specialist paediatrics all contain competencies with respect to epilepsy and some reference to learning disabilities [36]. All will be expected to have accessed the BPNA standardised

Paediatric Epilepsy Training ([www.BPNA.org.uk](http://www.BPNA.org.uk) ), and work within an OPEN UK (Organisation of Paediatric Epilepsy Networks) tertiary led network for childhood epilepsy/paediatric neurology.

- d) **Paediatric Epilepsy Specialist Nurses** – The Royal College of Nursing has published guidance recommending that every paediatric epilepsy service must ensure that children and young people are seen by an epilepsy specialist nurse who has competencies in both paediatric epilepsy and learning disabilities [37]. The same guidance also emphasises competencies related to the communication and mental health needs for these children and young people.
- e) **Psychiatrists** – depending on the degree of learning disability, children with epilepsy and learning disability may be assessed by psychiatrists working in Child & Adolescent Mental Health Services (CAMHS), life-span learning disability services or specialised CAMHS-LD services. These will be psychiatrists trained in the curricula developed by the Royal College of Psychiatrists in either Child & Adolescent Psychiatry or the Psychiatry of Intellectual Disability; or a combination of the both. Both these curricula specify competencies in epilepsy and learning disabilities [38]. Even though a Royal College of Psychiatrists report [17] relates to the management of epilepsy in adults with learning disability, the proposed model of competency can apply equally to psychiatrists involved in the management of mental health and challenging behaviour in children and young people with learning disability.
- f) **Paediatric Neurologists** – any complex issues related to the assessment, diagnosis and management of paediatric epilepsy will be referred to the attention of Paediatric Neurologists, as per NICE Guidelines [34]. The competency curriculum for Paediatric Neurology established by the Royal College of Paediatrics and Child Health also details an understanding of the impact of having a learning disability [36]. Much of the training for Trainee Paediatric Neurologists in the UK is supplemented by training courses in paediatric epilepsy and distance learning organised by the British Paediatric Neurology Association [39, 40] – both these training formats include specific competencies about learning disabilities.

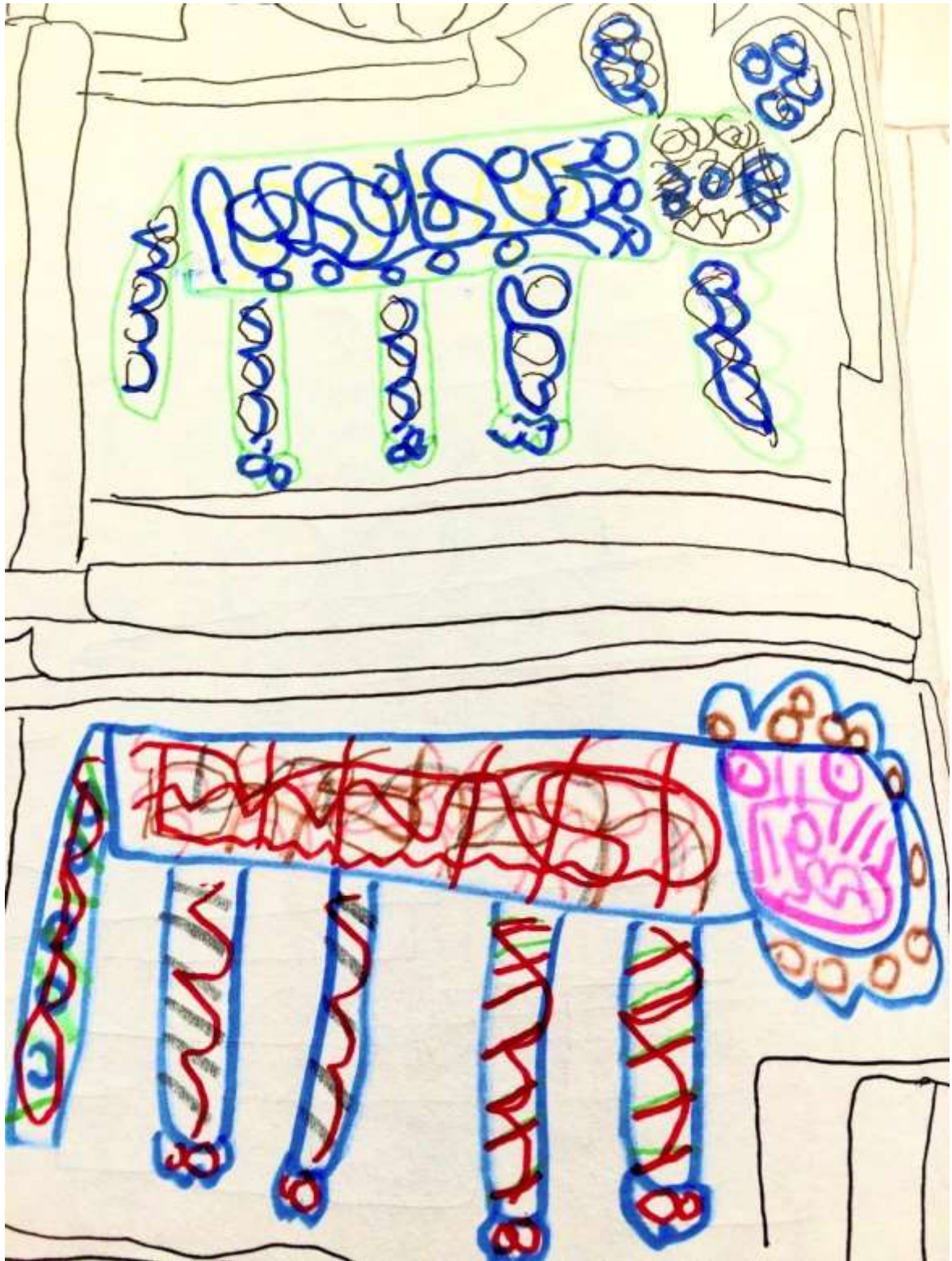
There is growing awareness of the variations in epilepsy service provision for people with a learning disability. The variation in epilepsy management particularly for the younger groups was also seen (see **figure3**) where records of seizure frequency had been recorded for both those with a learning disability and those without [16]. In both groups, rates were much lower for children and young people aged under 18 with epilepsy but reasonably consistent across adult age groups. This may reflect primarily differences in local arrangement for epilepsy management.

**Figure3. No of patients who have an active diagnosis of epilepsy and have a record of seizure frequency in the 12 months 2016-17**



It is felt that good practice where evidenced, irrespective of who the principal service drivers are i.e. paediatricians, neurologists or psychiatrists, needs to be consolidated and systemised. Guidance is needed for commissioners to measure the fitness of the local service delivery to people with a learning disability and epilepsy to ensure consistent care across England. Where gaps are found solutions based on local service provisions, practices, resources and competences need to enable a basic framework of consistent and good care. Commissioning guidance will reduce the risk of failing any individual with epilepsy and a learning disability in England. NHS England has produced an epilepsy best practice tariff to support trusts in England who have services configured to meet best practice criteria. However this is not currently designed to support services based on block contracts and in these circumstances such criteria should be considered within the service specifications.





2

## The Epilepsy Pathway Guidance

This report looks to collate and provide an overview of epilepsy diagnosis and management and the current good practice on its applicability to people with a learning disability. It takes into account the needs of those with a learning disability and how best current evidence, management principles and reasonable adjustments can be pragmatically used to deliver comprehensive care to not just achieve better outcomes in epilepsy but to have overall positive health and social benefits for the individual.

It provides guidance on what constitutes minimum standards of good care to people with a learning disability, how it could be evidenced and what people with a learning disability and epilepsy could expect to have as basic epilepsy care from local service providers. It attempts to bring together the voices of a diverse group of people including people with a learning disability and epilepsy, family carers, care providers, healthcare professionals and organisations supporting people with a learning disability. This guidance supports the delivery of local pathway frameworks which should be owned by local commissioners of epilepsy and learning disability services across the country.

### Methods

Four types of consultation workshops were carried out with the following groups of participants between September and November 2017:

- Expert by experience – people with a learning disability and epilepsy
- Family carers of people with a learning disability and epilepsy
- Care providers of people with a learning disability and epilepsy
- Professional experts – a range of healthcare professionals working in the field of epilepsy with expert knowledge on the health needs of people with a learning disability

A webchat was conducted for family carers to enable further participation from all regions. Consultation workshops for the first 3 groups were conducted in South West England and London whilst the professionals group represented a range of organisations and trusts (as acknowledged). The purpose of the workshops was to have greater understanding of the experiences of the different groups with epilepsy and their local epilepsy services.

### Discussion summaries

#### **Experts by Experience - People with a Learning Disability and Epilepsy**

The participants expressed a general lack of understanding of the causes and treatments of epilepsy. There was lack of knowledge on the side effects of medication; also some of the social and economic implications of having epilepsy. The majority of participants reported similar post seizure experiences particularly feeling generally tired and sleepy. Where others could relate to the metabolic implications of anti-epilepsy drugs; they talked about the effects of medication resulting in weight gain and mood swings. Participants expressed their reliance on their supporters in medication administration and in maintaining safety. For the few that were self-medicating they found dossett box systems very useful.

The impact of epilepsy on day to day activities was a common challenge, individuals reporting 'missing out' on activities they enjoy following seizures. The following was deemed to be working well in the management of their epilepsy;

- Having overnight support
- Support in attending appointments
- Support in maintaining relationships with respect on privacy

However it was recognised that this good practice might be a regional as opposed to a national practice.

### **Family Carers Participant Group**

Delayed, unclear and misdiagnoses were common themes among family carers. Early recognition and diagnosis of epilepsy was seen to be hindered by the inconsistency with the definition and understanding of learning disability among healthcare professionals. Being proactive with video recording of seizures to enable a diagnosis was an important part played by most family carers. Challenges faced by family carers are shown in Table 1 below. It has been recognised that many if not all the challenges are equally applicable to those from the general population.

**Table 1**

<b>CHALLENGES FOR FAMILY CARERS</b>
<ul style="list-style-type: none"><li>• No clear identification of professional roles within epilepsy services</li><li>• Accessibility to records hindered by lack of integrated systems</li><li>• Maintaining safety at night time</li><li>• Lack of information for young people</li><li>• Transition into adult services</li><li>• No availability of Out of Hours epilepsy service contacts</li><li>• Longer waiting times for specialist input in tertiary services</li><li>• Changing needs of carers particularly with aging</li><li>• Limited access to leisure activities – no positive risk assessments</li><li>• No clear prescribing for females</li></ul>

Family carers commonly faced challenges with many of the tests and investigation with reports of lack of reasonable adjustments at these tests resulting in termination or incomplete procedures. Other challenges included unavailability of specialist professional roles within local epilepsy services, also lack of information and understanding on:

- Treatment options
- Drug interactions
- SUDEP

The following (**Table 2**) were good experiences reported by family carers:

**Table 2**

<b>WHAT WORKS WELL (FAMILY CARERS GROUP)</b>
<ul style="list-style-type: none"><li>• Timely referrals from paediatrics to neurology</li><li>• Co-ordinator role important</li><li>• Good integrated epilepsy care plan</li><li>• Epilepsy annual review also as part of the Annual Health Check</li><li>• Regular medication reviews (GP seen as critical particularly in adult epilepsy)</li><li>• Having an epilepsy nurse specialist</li><li>• Good discharge planning</li><li>• Good record keeping including use of technology (e.g. Apps)</li><li>• Being vigilant and risk assess home environment</li><li>• Having an Education Health Care Plan (EHCP)</li><li>• Epilepsy training for health/social care and school staff</li><li>• Support networks and organisations such as Young Epilepsy and SIBS</li></ul>

Families related to the social impact of epilepsy on the wider family and home life. Having epilepsy considered a barrier to an individual's happiness, with the condition still carrying a stigma in society. This could lead to isolation and emotional breakdowns in the whole family. In some families non-verbal communication and a learning disability meant families played an advocacy role in the care and management of their loved one's epilepsy.

Those supporting an individual with epilepsy were regarded to be an important aspect of every decision making process; and ensuring continuity of family life transitions post 18yrs.

## Care Provider Participant Group

Care providers were concerned with poor assessments prior to admissions and the unavailability of health records making the transition process a difficult one. Participants widely shared the idea of the importance of providing an individual with a learning disability with the most suitable placement with better planning particularly when an emergency placement was required. Care providers are not always aware of epilepsy services that are available locally to them and at times unclear on the roles of health professionals within these services. Good relationships with families were important in meeting an individual's needs. The following are further examples of what care providers see working well for individuals with epilepsy and a learning disability.

### WHAT WORKS WELL (CARE PROVIDERS GROUP)

- Having access to a learning disability liaison role
- Responsive epilepsy services with out of hours access
- Epilepsy training in provider settings
- Confidence in managing seizures - avoiding unnecessary hospital admissions
- Empowering individuals with epilepsy by respecting their choice of community activities and supporting access to these
- Better funding – facilitating recruitment and retention of support staff

The three participant groups shared some common themes evolving from their discussions.

Common challenges included:

- Lack of understanding of behaviour and mental health issues and the impact on epilepsy and vice versa
- Lack of clear referral pathways

Commonly shared good practice examples included:

- Person centred approach
- Good communication between and within services
- Reasonable adjustments at appointments for tests and investigations

A full list of cross-cutting issues is shown in **appendix 1**.

## **Professional Experts – Epilepsy Services for Children with a Learning Disability**

The full focus groups discussion and summary transcripts are provided in **appendix2**.

**Conclusion: a working model for a children's service would be to have one or a combination of the following:**

- A Specialist Paediatric Epilepsy Team commissioned jointly by paediatric and learning disability commissioners with all necessary components of epilepsy and learning disability care across the age-span, whilst ensuring a biopsychosocial approach.
- Child and Adolescent Mental Health Services (CAMHS) for children and young people with a learning disability, with access to epilepsy expertise from Community/General Paediatrics, Paediatric Neurodisability and/or Paediatric Neurology
- Special schools with access to specialist CAMHS (including a service for children and young people with a learning disability), and with access to epilepsy expertise from Community/General Paediatrics, Paediatric Neurodisability and/or Paediatric Neurology
- A Community Paediatrics or Paediatric Neurodisability Service with a specialist interest in paediatric epilepsy, and supported closely by specialist CAMHS (including a service for children and young people with a learning disability)
- ALL epilepsy services to have linked child psychology

**A good service and pathway needs to have the following in place for an effective transition:**

Suitable diagnostic assessments such as neuro imaging, genetic screening, neurophysiology, support for monitoring and recording seizures and access to more complex assessments involving telemetry and more advanced imaging when needed.

It needs to follow NICE guidelines on optimal evidence based treatments but look to include trials of other up to date management when conventional treatment fails e.g. novel AEDs, diet therapies, epilepsy surgery etc. Generally when looking after people with a learning disability there needs to be an element of flexibility towards imaging and EEG. It is, however, relevant in certain situations particularly to diagnose epilepsy syndromes where it facilitates access to rarer treatments and pathways. Suitable guidance needs to capture these issues.

The pathway should be in sections considering

1. Initial assessment and diagnosis
2. Evidence based treatment and when to consider referral for novel or rarer treatment options
3. Good transition to adult services

It needs to:

- Include good transition information including hospital passports
- Consider the needs of those with communication difficulties, and with English as a second language
- Consider technology to allow young persons and their families to access appropriate care information
- Identify roles of key stakeholders and have a seamless design such as the same age of eligibility between different health providers
- Revisit all health needs and ensure there are identified providers earmarked to take over care including the GP
- Identify locally what systems are in place in general neurology and learning disability
- Align the child or young person to one of the pathways at least 12 months prior to transition. locally ensuring there is a pathway for those who have active epilepsy, and other physical and cognitive challenges
- Consider a holistic reevaluation where appropriate based on individual complexity particularly during transition. Undertaken jointly with all stakeholders to taking into account types of resources and services that are available within the adult landscape locally
- Avoid a 'cliff edge' for children with complex needs at 18yrs by allowing known paediatric services to continue with their support until it is clear which adult services meets their needs

There needs to be good data collection from commissioners locally on access to services and on outcomes for children with learning disability and epilepsy. With comparators to the local population with epilepsy who don't have a learning disability, so that there are reliable metrics for charting adherence to an agreed and standardised pathway and continuous quality improvement.

## **Professional Experts – Epilepsy Services for Adults with a Learning Disability**

The full focus groups discussion and summary transcripts are provided in **appendix 3**.

**Conclusion:** A working model for adult services would be to have one or more of the following:

- A Specialist Epilepsy Team commissioned by liaison of adult, learning disability and physical health commissioners with all necessary components of epilepsy care, and learning disability care across the life span ensuring a biopsychosocial approach (gold standard)
- Adult Learning Disability Service with epilepsy input sourced from neurology
- A Neurology Service with learning disability specialism sourced from learning disability services
- Joint learning disability and epilepsy services
- Good links with specialist centres in tertiary care services for rapid assessment and treatment of complex needs including availability of epilepsy surgery

A good service needs to have the following in place:

- Good transition arrangements based on eligibility, a clear process for individuals and their supporters ensuring awareness and transparency of local policies and commissioning of local services. This should be done well in advance for smooth transition
- Every person with a learning disability and epilepsy and their supporters will have a clear understanding of the care plan and services available for routine and emergency care
- Clear ownership of specific pathways and whose responsibility it is to interlink between the pathways
- An agreed measure of how different pathways, services and systems work to ensure consistency in each region
- It is imperative that as a minimum the NICE guidance for epilepsy and best practice for people with a learning disability be met. Either the learning disability or the neurology service needs to take a lead based on resource, skill availability and interest
- Good engagement with commissioners to ensure there is no service gap for people with a learning disability in a commissioned region
- Good links to speciality centres for consideration of epilepsy surgery

There needs to be good data collection from commissioners locally on access to services and on outcomes for people with learning disability and epilepsy with comparators to the local population with epilepsy who don't have a learning disability, so that there are reliable metrics for charting adherence to an agreed and standardised pathway and continuous quality improvement.



## Discussion

To implement good practice the 4 different clinical groups: Neurology, Psychiatry, Paediatrics and Nursing (with the GP central to all) could consider who can demonstrate the respective competencies and how they can work with each other based on competencies to deliver a safe service.

### Psychiatry Competencies

As described earlier the Royal College of Psychiatrists have developed and suggested implementation of a competency framework [17, 30]. This approach would identify the skill set of psychiatrists working with people with a learning disability. This would include the minimum expectations about what their local service needs to provide and their competency level of epilepsy care. The framework which can serve as a pathway to a Gold standard suggests that all psychiatrists working with people with a learning disability have a minimum Bronze level skill set to provide assurance of basic safety. The Bronze/Silver/Gold categories were benchmarked against the relevant NICE outcome indicators, and are also in line with SIGN143 recommendations [34, 50]. The linked NICE outcome standards for each category are provided in the Box which has been taken from the Royal College Report [17].

#### 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 diagnoses 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 neuro-imaging 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

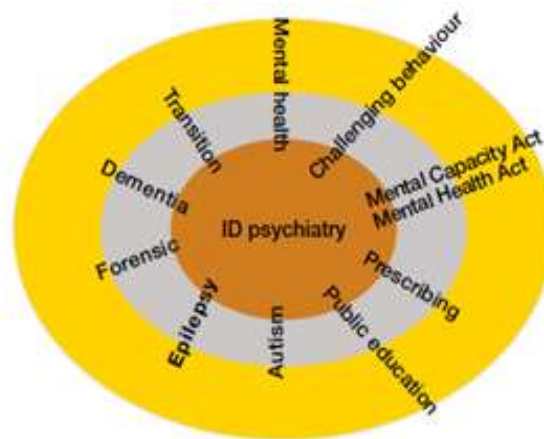
- That adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral

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

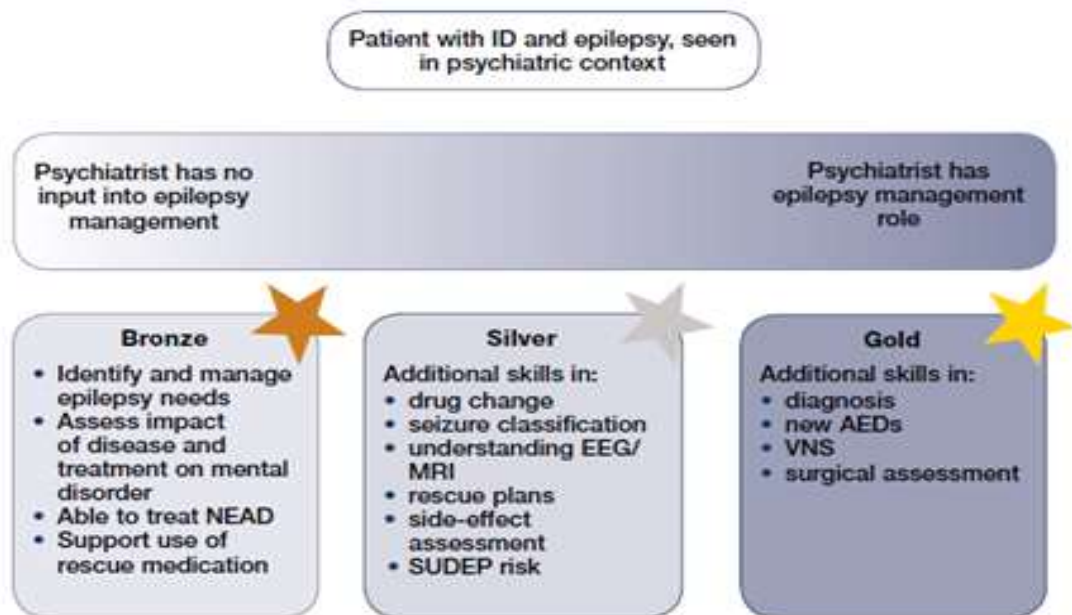
The framework however acknowledges that psychiatrists may or may not provide direct care for epilepsy so the NICE quality standards may not all apply. Under this approach psychiatrists are however expected to be familiar with the contents of the guidelines and quality standards or alternatively follow SIGN recommendations if appropriate. There may also be learning disability psychiatrists who do not wish to develop to a Silver or Gold set of competencies in epilepsy, choosing instead to subspecialise in other areas based on interest, based on services in which they work and the available training.

The expectation is that a learning disability psychiatrist will have a basic Bronze level of competency in epilepsy to sit alongside the core skills expected of them (figure 1 below – taken from RCPsych CR203 [17])

There will be overlap in the skills outlined in the different categories. A summary of how this could work in practice is provided (figure 2 below – taken from RCPsych CR203 [17])



**Fig. 1 Schematic diagram 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.

## Paediatric Competencies

The General Medical Council (GMC) has approved a new curriculum developed by the Royal College of Paediatrics and Child Health entitled RCPCH Progress, for delivery from 1<sup>st</sup> August 2018. The syllabus for General Paediatrics states a learning outcome for Paediatricians to be able to coordinate and lead the care of children and young people with complex conditions (including seizures, abnormal behaviour and delayed/disordered development) which may include liaison with other community and hospital specialists, such as Psychiatry and Paediatric Neurology. The syllabi for the sub-specialties of Community Child Health, Paediatric Neurodisability and Paediatric Neurology [36] further expand on learning outcomes and key capabilities in epilepsy and learning disabilities (as well as associated conditions of pervasive development such as Autism and Hyperkinetic disorders). The RCPCH has developed a SPIN (Specialist Interest Module) framework to facilitate competences for paediatricians with expertise in epilepsies. This includes a comprehensive curriculum and training including pre-CCT and post-CCT pathways. The British Paediatric Neurology Association also delivers a 3 tier Paediatric Epilepsy Training (PET) and distance learning course structure [39, 40] which mirrors the Bronze, Silver and Gold structure of the Psychiatric competencies. PET1 is directed at Paediatric professionals providing acute or community care. PET2, PET3, and distance learning module in epilepsy are directed at Paediatric professionals managing epilepsy in secondary care, and the expert to expert PET course held every two years is directed at Paediatric Neurology professionals working in tertiary care. PET3 covers the epilepsies in older children and adolescence. It has been recently designed so that it would be suitable for any adult physicians, neurology/psychiatry/learning disability involved in transition of care.

## Neurology Competencies

The Association of British Neurologists (ABN) in collaboration with the Royal College of Physicians (RCP) should define the care standards for people with a learning disability and epilepsy, and the competencies within the training curriculum required for management of these individuals. The Neurology Curriculum 2010 currently deals with epilepsy in one competency (2.6) and learning disability as part of psychiatry in another (3.8). We suggest this should be adjusted so that learning disability with epilepsy is a specific field of sub-competency. This proposal has strengths and weakness. While on one hand there would be more competent subspecialised neurology professionals managing people with learning disability and epilepsy. Possible negatives are that it could lead to a polarization of this population from mainstream neurology or even learning disability services.

Service models of delivery will vary throughout the UK, depending on geography and the services currently in place, but we would recommend identification of the current expertise and pathways. Then modelling care along suggested standards involving learning disability, adult Neurology/epilepsy services, therapy streams and tertiary service availability.

We propose criteria setting out what we consider are the essential and desirable elements for the neurologists and neurology led services. Service components that should be considered essential are as a minimum: a consultant with epilepsy and learning disability interests and

competency, access to a learning disability MDT, and an epilepsy nurse. The service should have clear guidelines for management of emergencies with appropriate shared access to information such as a Health Passport, and the flexibility to take in to account changing service provision in agreement with commissioning groups. The table below sets out the skills required of a neurologist managing people with a learning disability. The suggested components of a desirable service are set out in our final conclusions.

### Neurologist who sees people with a learning disability\*

Essential Components**
<ul style="list-style-type: none"> <li>• Awareness of recent relevant legislation such as Mental Capacity Act 2005, Equality Act 2010, Social Care Act 2012, Accessible Information Standards</li> <li>• Professional Developmental Plan identified CPD in learning disability and epilepsy appropriate to the work in learning disability being undertaken</li> <li>• Knowledge of major psychiatric co-morbidities such as depression, psychosis, anxiety and interactions between commonly prescribed psychotropic and antiepileptic medication</li> <li>• Knowledge and awareness of local pathways to refer for learning disability specific issues</li> <li>• Links with learning disability experts e.g. learning disability liaison nurse</li> <li>• Able to make reasonable adjustments as required by the person with a learning disability. Adjustments may be required for effective communication by providing easy read material in particular when planning for appointments.</li> </ul>

\*It has been recognised that many areas and secondary care providers lack an epileptologist. Services are provided by general neurologists. Where there is an identified epileptologist there would be an expectation that they have basic competencies in managing people with learning disability. Where there is a generic neurology service local discussion needs to occur on whether one neurologist looks to support all people with learning disability or it is 'everyone's business'.

\*\* It is recognised that many of the skills suggested will overlap with the general core competency framework of a general neurologist

## Nursing Competencies

The Epilepsy Nurses Association (ESNA) is a professional body in the UK representing the interests of all nurses working with people who have epilepsy. In 2012, ESNA produced epilepsy competency frameworks, ratified by the Royal College of Nursing (RCN), covering the subspecialties of adults (49), and learning disability (48), with the RCN itself producing a further document covering paediatrics a year later (37). The learning disability and adult competencies clearly set out the attributes of nurses working at novice, competent and expert levels (the equivalent to the medical Bronze, Silver and Gold standards discussed above). There are several core dimensions set out in the documents. These cover a wide range of personal and clinical skills, from the clinical diagnosis and management of epilepsy, through the impact of the condition, to the personal and professional development of the nurse. The learning disability competencies were designed in order to facilitate two core principles. Firstly, there was a need to allow learning disability nurses, working with people who have epilepsy, to identify their level of competence and then work towards the higher competent or expert levels in specific areas, according to their roles and professional needs. Secondly, epilepsy specialist nurses, with or without a learning disability background, needed to identify the competencies required to manage the care of a person with epilepsy and a learning disability. Some examples of the competencies are shown in the table below.

Table adapted from Section A of the learning disability epilepsy specialist nurse competency framework (48).

<b>EXAMPLE COMPETENCY: Diagnosis of epilepsy</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>To identify routine investigations that may be completed during diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>To identify and understand the relevance of each investigation and possible outcomes</li> </ul>	<ul style="list-style-type: none"> <li>To identify and request appropriate investigations, interpret each investigation and its outcome, and identify the need for referral to an appropriate specialist. Is actively involved in the diagnostic decision-making within the MDT.</li> </ul>

<b>EXAMPLE COMPETENCY: Diagnosis of epilepsy</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>To recognise the existence of non-epileptic attack disorder (NEAD) and is aware of conditions that commonly associated with differential diagnosis.</li> </ul>	<ul style="list-style-type: none"> <li>To establish appropriate monitoring/recording tools to support the classification of NEAD and differential diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>To evaluate and interpret evidence from investigations and assessment to assist in differential diagnosis and NEAD.</li> <li>To contribute to evidence-based practice relating to the diagnosis and understanding of epilepsy.</li> <li>To make referral to specialist tertiary services as required.</li> </ul>

<b>EXAMPLE COMPETENCY: Assessing and managing seizures</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>• To utilise appropriate assessment tools to gather information on:               <ul style="list-style-type: none"> <li>- seizure type</li> <li>- triggers for seizures</li> <li>- seizure severity (type, pre/post ictal)</li> <li>- seizure frequency</li> <li>- seizure pattern</li> <li>- injuries</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• To use formal assessment tools to interpret information including:               <ul style="list-style-type: none"> <li>- triggers for seizures</li> <li>- severity (pre-/post ictal)</li> <li>- seizure frequency</li> <li>- seizure pattern</li> <li>- injuries</li> <li>- management plans</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• To utilise formal assessment tools to allow for the development of individualised, complex management plans and protocols.</li> <li>• To create individualised monitoring tools to obtain specific information surrounding more complex issues.</li> <li>• May initiate the use of video monitoring to support seizure and syndrome classification.</li> </ul>

<b>EXAMPLE COMPETENCY: Assessing and managing seizures</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>• To understand the difference between generalised seizures and focal seizures.</li> <li>• To implement and evaluate seizure description forms</li> </ul>	<ul style="list-style-type: none"> <li>• To use epilepsy specific expertise to obtain a clinical history and assess seizure frequency and severity.</li> <li>• To document and communicate a clear and holistic epilepsy history, whilst understanding the difficulty of receiving information from a third party.</li> <li>• To understand how diagnosis of syndrome, and seizure type, can lead to specific medicines management.</li> </ul>	<ul style="list-style-type: none"> <li>• To be aware of all treatment options and can consider those individuals who may benefit from vagal nerve stimulation or surgical assessment.</li> <li>• To lead an innovative approach to practice in epilepsy and behaviour, and differential diagnosis.</li> </ul>

<b>EXAMPLE COMPETENCY: Anti-Epileptic drugs</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>• To understand the effect of a learning disability on how individuals may respond to medication.</li> <li>• To demonstrate an understanding of how individuals with a learning disability may respond differently to treatment and may be unable to articulate side-effects.</li> </ul>	<ul style="list-style-type: none"> <li>• To identify and observe potential side-effect profiles, and understand how to take a case history from people with a learning disability and their carers to pre-empt side-effects.</li> </ul>	<ul style="list-style-type: none"> <li>• To manage and lead the review of treatment, recommending treatment options and taking into consideration appropriate formulation of medication acceptable to the individual.</li> <li>• Is aware of the reasons for and limitations of biomedical investigation.</li> </ul>

<b>EXAMPLE COMPETENCY: Emergency Medication</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>• To collect and collate records of rescue medication usage and outcomes appropriately.</li> <li>• Refer to relevant specialist for review and modification of treatment plan</li> </ul>	<ul style="list-style-type: none"> <li>• To assist the prescriber in the formulation of a treatment plan.</li> </ul>	<ul style="list-style-type: none"> <li>• To review and evaluate records of rescue treatment administration, consider the appropriate merits and uses of available rescue treatments, including efficacy, the practical considerations, to meet the person with a learning disability needs.</li> <li>• To review, evaluate and recommend changes to individualised rescue medication protocols and treatment plans.</li> </ul>

<b>EXAMPLE COMPETENCY: Assessing and managing linked health conditions</b>		
<b>Novice Nurse (Bronze)</b>	<b>Competent Nurse (Silver)</b>	<b>Expert Specialist Nurse (Gold)</b>
<ul style="list-style-type: none"> <li>• To discuss recognised learning disability conditions and syndromes linked to epilepsy</li> </ul>	<ul style="list-style-type: none"> <li>• To discuss recognised epilepsy syndromes and potential impact on learning and development</li> </ul>	<ul style="list-style-type: none"> <li>• To assess and record the impact of syndrome specific features.</li> <li>• To assess and respond to the relationship between epilepsy and co-morbid conditions.</li> </ul>

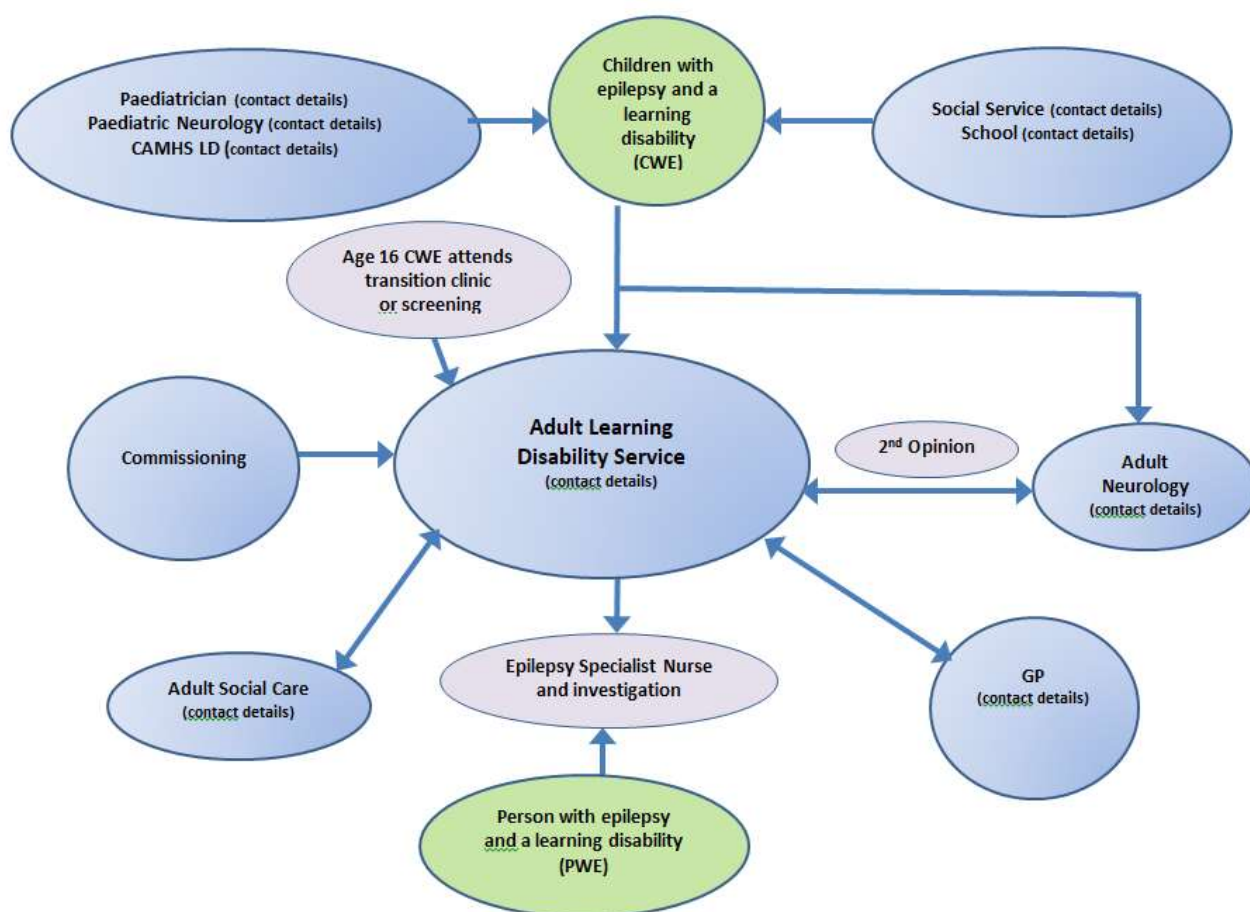
# Proposing a New Model in Epilepsy Care for People with a Learning Disability

In the current environment people with a learning disability who require seizure management that is often complex, are vulnerable to a lack of provision of holistic care.

There are pockets of good practice where areas have developed safe and efficient structures of care delivery for this vulnerable group. Where there is holistic care it is usually due to the professional interest of an individual professional or a specialist group. There has not been sustainable/skilled or easily implementable guidance for epilepsy and people with a learning disability to date.

To this end this project proposes the following model of integrated working (**Figure 4**) which identifies clear pathways for epilepsy care in children and adults with a learning disability. This can be viewed as the plan for a person with a learning disability identifying services and healthcare professionals taking them through the journey of epilepsy care.

**Figure 4. Proposed integrated working model**



Furthermore; the project’s view is to provide recommendations on a two pronged approach supporting the above working model in order to provide a consistent and holistic framework of care; i.e. *commissioning* and *clinical levels*



## Commissioning Level

Commissioning of epilepsy care services for people with a learning disability is widely varied across England. There is currently a lack of systematic approaches with commissioning dependent on availability of clinicians and ability, interest and competence. The current environment suggests lack of clear pathways and commissioning responsibilities for this small but complex group of individuals. This then splits a vulnerable individual's needs into conditions that is commissioning epilepsy and a learning disability separately instead of looking at this together.

### **Specialist Commissioning**

The commissioning of specialised services is a prescribed direct commissioning responsibility of NHS England. NHS England is responsible for commissioning £16.6 billion of specialised services to meet a wide range of health and care needs. Specialised services are those provided in relatively few hospitals, accessed by comparatively small numbers of patients but with catchment populations of usually more than one million. These services tend to be located in specialised hospital trusts that can recruit a team of staff with the appropriate expertise and enable them to develop their skills. To enable greater health outcomes, there will be much closer collaboration between NHS England and local commissioners on specialised service commissioning, as well as between commissioners and providers in the design and delivery of services. This new approach, to be reflected in all 44 Sustainability and Transformation Plans (STP's) and will complement various national priorities that include learning disability. Where available, Integrated Care Systems (ICS) [51] will provide much closer collaboration between NHS organisations, local councils, local charities and community groups to help people to live healthier lives for longer, and to stay out of hospital when they do not need to be there. Therefore integrated commissioning through STP's and ICS's will be of benefit to local populations in improving health outcomes, including for people with a learning disability who are affected by epilepsy.

NHS England has reconfigured epilepsy surgery services for children to further centralise specialised surgery into four national centres of excellence. These changes will ensure that all children with epilepsy have access to a range of appropriate and high quality treatment options.

In 2018/19, The footprints of Sustainability and Transformation Plans focused on implementation of collaborative commissioning arrangements covering at least one of the following priority service areas: Cancer, Mental Health and Learning Disabilities [52].

## **Clinical Commissioning**

It is recognised that commissioning can only be successful if there is suitable competent clinical resource. There is a need to support provider and workforce development. The complexity lies in recognising what roles each of the core clinical stakeholder groups possess and can deliver in a particular region. With regards to epilepsy and a learning disability, it is expected that all groups should have basic levels of competencies in epilepsy and learning disability. A model service would have:

- An expert or competent professional in epileptic seizures and seizure disorders also with expertise in learning disabilities
- A learning disability specialist with expertise in epilepsy, working in a joint service with dedicated clinics
- A team of specialised therapists and psychologists
- Clear pathways of care including young person's clinics and joint transition clinics from paediatric to adult services
- An immediate access to high quality Neurophysiology and epilepsy surgery

At present this model exists only in some Tertiary Centres however what is currently aspiration for many places could become realistic if developed at ICS level as is the direction of travel for health and social care in England.

## **Social Care Commissioning**

Commissioners of social care could include the following requirements as part of their contracting arrangements.

- Ensure that staff supporting the person are trained in basic epilepsy awareness, and have a good understanding of how epilepsy affects each individual they support. This includes basic understanding of the need for the person to rest post seizure, the interaction of alcohol on medication if the person drinks, the basics of a possible relationship between behaviour and some forms of epilepsy.
- Providers of social care should ensure that support staff have good links with specialist health staff and are able to provide information about the person that help with assessment and review of treatment.
- Ensure that staff supporting the person are helpful in arranging and facilitating attendance at appointments at clinics hospitals or GP practices, including getting an annual health check. Ensure they follow the health action/care plan and knowing how to respond in an emergency is important.
- Providers should be aware of the medication prescribed for people, and it is likely that people they are supporting will be taking medicines to help manage their epilepsy. However, vigilance about over medication is also important. There is a national pledge

that social care providers can sign up to as part of the “Stopping the over medication of people” who have a learning disability or STOMP.

<http://www.vodg.org.uk/campaigns/stompcampaign/>

- Finally social care providers can help the person by understanding how best to manage the environment the person is in to minimise any epilepsy triggers (e.g. sleep disturbance, hunger, infections etc.). This could reduce the ambient stressors people may experience on an ongoing basis.

### **Paediatric Commissioning**

Commissioners of children and young people’s services could consider the following approaches:

- Support the secondary providers within England on payment by results tariffs to ensure they are achieving or working towards epilepsies best practice tariff services. The best practice framework includes a comprehensive set of criteria designed to optimise quality and value of secondary epilepsies care and pathways to adult, neurodisability, neurology and mental health services. The 2017-2019 tariff for example included for all children with epilepsy:
  - Follow up to be delivered by a paediatrician with expertise and an epilepsy specialist nurse in defined epilepsy clinics
  - Appointments to be at least 20 minutes duration
  - Service to have defined pathways to neurology, neurodisability and adult services
  - Comprehensive care planning
  - Full participation in Epilepsy12 National Audit
- NHS Services on block contract or not in England can still be supported or contracted to deliver services fulfilling epilepsy best practice criteria
- That children with complex epilepsy have access to appropriate paediatric neurology and neuroscience services at tertiary level via specialist commissioning
- Recognise that children with complex epilepsies still require high quality primary and secondary shared care alongside the tertiary specialist paediatric neurology and Children’s Epilepsy Surgery Services
- Establish links with OPEN UK regional networks to support identification and action around local themes requiring quality improvement and to support benchmarking between component trusts and health boards
- Review and analyse ongoing Epilepsy12 National reports [41] describing gaps and variations in care, key findings and recommendations and results at regional and trust/health board level

## Clinical Level

Clinical groups need to have ownership of delivering evidence based practice and according to NICE guidelines for epilepsy. To help identify suitable benchmarks different stakeholder groups have to put together frameworks of competency with regards to meeting the epilepsy needs of someone with a learning disability.

Should a Sustainability and Transformation Plan's footprint not be the most suitable vehicle presently for a region, high quality services could be provided with the following minimum key components;

- A neurologist with expertise in epilepsy
- A psychiatrist with an epilepsy interest
- Specialist nursing support
- Appropriate psychology and therapy services
- Transition services
- Access to 2nd opinions and tertiary services, with clear pathways and lines of responsibility

The suggested desirable elements of a learning disability and epilepsy service are set out in the table below:

<b>Desirable Service Components</b>
<b>Medical Service</b>
<ul style="list-style-type: none"> <li>- Learning disability Psychiatrist (or Child &amp; Adolescent Psychiatrist) with epilepsy interest &amp; Neurologist with learning disability interest*</li> <li>- Neurologist with learning disability interest</li> <li>- Learning disability Psychiatrist (or Child &amp; Adolescent Psychiatrist) with epilepsy interest</li> </ul>
<b>Clinics</b>
<ul style="list-style-type: none"> <li>- Dedicated joint epilepsy &amp; learning disability clinics *</li> <li>- Dedicated clinics for people with learning disability in general neurology epilepsy, or epilepsy dedicated clinic in learning disability or CAMHS-LD setting</li> <li>- Adequate time to inquire into epilepsy issues in learning disability clinics</li> </ul> <p>It needs to be noted that there are risks as well as benefit to creating separate clinics for people and children with learning disability and epilepsy. Concerns on ensuring delivery of standards of care in both epilepsy and learning disability needs to be assured. There is a risk of exclusion for learning disability.</p> <p>It is also worth considering using video or tele-consultation to facilitate joint clinical participation of epilepsy and learning disability professionals.</p>
<b>Nursing Service</b>
<ul style="list-style-type: none"> <li>- Learning disability nurse with epilepsy interest*</li> <li>- Epilepsy nurse with learning disability interest*</li> </ul>

<b>Multidisciplinary Team</b>
Consisting of Occupational Therapy, Physiotherapist, Psychologist, Speech and Language Therapist, Dietitian & Social Worker
<ul style="list-style-type: none"> <li>- Dedicated team for epilepsy *</li> <li>- Learning disability based with neurology access</li> </ul>
<b>Epilepsy Surgery</b>
<ul style="list-style-type: none"> <li>- On site*</li> <li>- Link to tertiary centre</li> </ul>
<b>Paediatric to Adult Transition</b>
<ul style="list-style-type: none"> <li>- Joint clinic*</li> <li>- Young peoples' epilepsy clinic</li> <li>- Learning disability or neurological clinic</li> <li>- Agreed pathway</li> </ul>

\*ideal service components

There needs to be recognition that delivery of services to people with epilepsy and learning disability is complex and usually cannot be provided by local learning disability services, neurology services and nursing in epilepsy services meeting their own individual essential criteria. There has to be leadership from one or more of these services extending themselves to ensure **ALL** current good practice issues are met. This would require one or more of these services/professions taking on a more skilled role. To help provide guidance a table providing different permutations and combinations between the three professions has been created and the overall picture rated with a star rating. It is suggested that an acceptable model of care should be a three star service or above.

**Table showing star ratings of combined services**

Neurology Service	Learning Disability Service	Specialist Epilepsy Nurses	Star Rating
E	1	1	1*
E	1	2/3	2*
E	2/3	1	2*
D	1	1	2*
D	1	2/3	3*
D	2/3	1	3*
E	2/3	2/3	4*
E	2/3	2/3	4*
D	2/3	2/3	5*

**Key:**

**Neurology**

E = Essential Requirements in learning disability

D = Desirable Requirements in learning disability

**Learning Disability Service and Epilepsy**

1 = Bronze

2 = Silver

3 = Gold

**Specialist Epilepsy Nurses**

1 = Novice

2 = Competent

3 = Expert/specialist

To help illuminate the concept and use of the table 2 examples have been provided.

**Example 1 –**

A county has two learning disability psychiatrists trained in epilepsy management to satisfy a silver/gold competence and work in a learning disability MDT. There is one epilepsy nurse specialist who has learning disability competencies satisfying silver criteria for nursing. The Neurologists in the area and their service would be of an essential standard. This would total to a star rating of 4 as per the table highlighting that satisfactory delivery of services to people with epilepsy and learning disability. In a three year period one learning disability psychiatrist retires and the other moves elsewhere. They are replaced by one learning disability psychiatrist who satisfies a bronze level of competence and a locum. The epilepsy nurse goes on long term sick and resigns. She is replaced by a nurse with basic epilepsy competency. The nurse is moved to co-locate with the neurologists and all people with epilepsy and learning disability are transferred to neurology. This then leads a 4 star service downgrading to a one star service thus leading to gaps in holistic care. To meet standards of care of at least a 3 star the region's commissioners would either need to encourage and fund one or two of the service providers to enhance their skill set to cover the gap.

## Example 2 –

A county has a Neurologist and a neurology service which meets the desirable criteria. They tend to deliver joint clinics alongside a 'bronze' qualified learning disability psychiatrist. There is an epilepsy nurse who works independent to the joint clinic with silver level competencies. This would be a 3 star service delivering acceptable care. The Neurologist retires and is replaced by another who has essential criteria. This would lead to a reduction in star rating to 2. However if the nurse is introduced into the joint clinic with the learning disability psychiatrist it would again assume a 3 star rating.

The grid while not perfect would help showcase how changes to roles in different service providers could impact on service delivery. It could help make adjustments in available resources to optimise service delivery. As an example of good practice in mapping the fitness of local epilepsy services, other areas have utilised the Purple Light Tool Kit (PLT) (Appendix 6) [17].

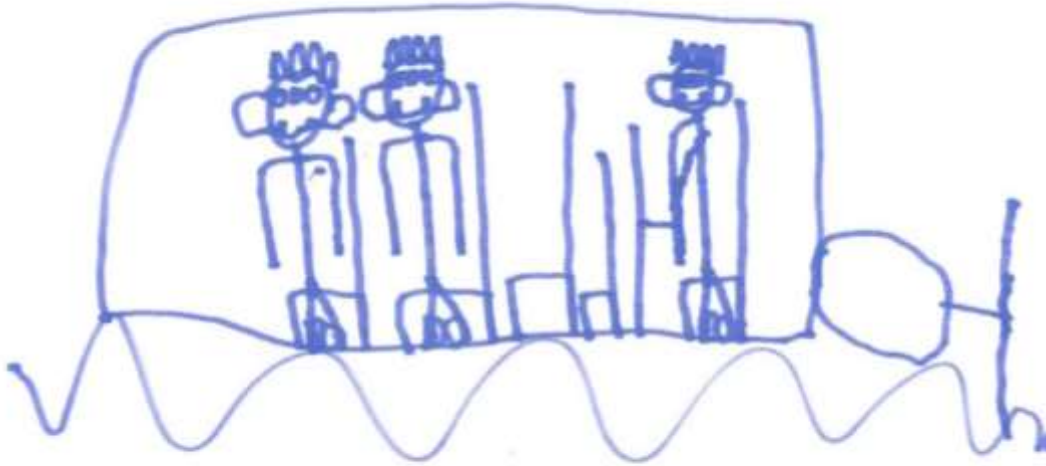
## Benefits of Integrated Epilepsy Care

Addressing variations in epilepsy care for people with a learning disability not only improves outcomes for those affected by the condition but has many other benefits as outlined below;

Individual Outcomes	Clinical Outcomes	Resource Outcomes
<ul style="list-style-type: none"><li>• Reduced epilepsy related deaths, for example SUDEP</li><li>• Reduced unnecessary hospital admissions</li><li>• Reduced A&amp;E attendances</li><li>• Reduced GP visits</li><li>• Addresses polypharmacy leading to safer treatments</li><li>• Better understood care plans</li><li>• Best interest oriented, working closely with families and carers</li><li>• Healthier and more fulfilled lifestyles</li></ul>	<ul style="list-style-type: none"><li>• Reduced clinical emergencies</li><li>• Professional role clarity</li><li>• Consistency of care in local areas</li><li>• Clear pathway deliverables leading to improved efficiency</li><li>• Provides a seamless service that improves referrals to tertiary care services</li></ul>	<ul style="list-style-type: none"><li>• Reduction of costs resulting from streamlined prescribing</li><li>• Reduction in costs related to emergency admissions and ambulance call outs</li></ul>



3



4



### Rene Parr

Rene lives in Cornwall and one of his favourite things to do is to go out on a boat which makes him happy and feel at ease. He does like going really fast and looking for marine life. Art work 4



## Appendix 1 - Detailed group discussions

Themes shared by expert by experience, family carers and care providers groups.

Common Themes
<p><b>Challenges</b></p> <ul style="list-style-type: none"><li>• Lack of understanding of behaviour and mental health issues and the impact on epilepsy and vice versa</li><li>• Lack of clear referral pathways</li><li>• Lack of information about medication</li><li>• Lack of information about medication and its side effects</li><li>• Inability to understand complexity with other underlying conditions and presentation</li><li>• Unclear about emergency plan</li><li>• Lack of training regarding rescue medication</li></ul> <p><b>What works well</b></p> <ul style="list-style-type: none"><li>• Person centred approach</li><li>• Good communication between and within services</li><li>• Epilepsy and learning disability and 1<sup>st</sup> aid training for health, care and school staff</li><li>• Multidisciplinary working</li><li>• Reasonable adjustments at appointments for tests and investigations</li><li>• Knowledge of mental capacity act (Consent, Best Interest)</li><li>• Local venues for epilepsy clinics</li></ul>

### Quotes from family carers

“Asked to attend test, EEG, waste of time as we knew my daughter could not tolerate it, hospital did not listen to me earlier, so myself and my son were both stressed”

“My son has a type of pacemaker (vagus nerve stimulator (VNS)) you swipe during a seizure and it makes it end sooner. Really good”

“Peers aren’t educated about conditions and bully. People don’t understand. They stare”.

“We had a really positive experience in Berkshire. Doctor understood learning disability and made reasonable adjustments. He told us to bring our dog to the appointments so that the focus would be on the dog, not on the test”.

“The LD Liaison Nurse is good; before appointment she will send a picture of the room the appointment will be in, the Doctor involved and any equipment that will be used. She also arranges a quiet room to wait in and tries to ensure appointment is on time”.

“Good for Doctors to talk to son like any other 16-year-old”.

“Epilepsy has been a barrier and the more of a major issue than the LD and took over everything”.

### **Quotes from service users**

“Liaison Nurse, B..., is brilliant”.

“CLD Nurse is helpful. Little things like making sure the sides are up on the bed”.

## Appendix 2 - Paediatrics

### Group round table discussion summaries

There is a post code lottery based on local availability as to whether an individual will sit with purely a CAMHS service, a paediatric service or a paediatric neurology service. If there is a significant learning disability such as moderate to profound learning disability, a CAMHS-LD service may be involved although the availability of a specialist service like this is uncertain in most places.

Services for children with learning disability would not exclude children due to their epilepsy. However there are some CAMHS services which will exclude children with learning disability (irrespective of epilepsy) as they believe they do not have the relevant skill sets.

Many CAMHS-LD psychiatrists will encounter children with learning disability and epilepsy, as the co-morbid rate of mental disorders is high. There is a postcode lottery with some areas having no or little resources for a child with learning disability and Epilepsy. Example – “I actually spoke to the CAMHS -LD Team who consists of two people who said they only deal with severe mental health problems and not behavioural problems and refused a referral for a child with learning disability, attention deficit disorder, challenging behaviour and severe epilepsy”.

Having severe epilepsy and a co-morbid psychiatric disorder and learning disability using the association of the Isle of Wight and more recent similar studies are as high as 60%. This is still an under diagnosis as these studies would not have considered ‘Challenging Behaviour’ as a diagnosis.

Some Paediatric services, CAMHS or CAMHS-LD services will focus on the child’s mental health but not their epilepsy. This has the potential to fail individuals as common mental disorders in children have medications which lower seizure threshold. Some mood disorders may also require AEDs as mood stabilisers, so optimising an existing AED might be better than introducing a new drug.

“I can quote quite a lot of examples to back up the point that mental health and epilepsy is so intertwined that actually it would be very unlikely that you would have a service that would say that’s an epilepsy need so off you go to a different service”.

Much of childhood epilepsy it’s unclear if the child has learning disability, what impact it can further have to their overall functioning. In most cases in the learning disability and the non-learning disability population, Epilepsy management ideally in all should be by a paediatrician with an expertise in epilepsy. It would be good for CAMHS to plug into specialist epilepsy services i.e. a paediatrician with expertise in epilepsy or a paediatric neurologist.

A challenge is having access to specialist epilepsy services especially if not near centres of excellence. There are four Children’s Epilepsy Surgery Centres across the UK who gets lots of referrals nationally.

Another problem is the nature and type of commissioners. There are gaps between delivery mechanisms of social care and health. Another challenge is that there are some good schools and private health providers which have set up local in-house expertise. It is hoped that the Transforming Care programme can help realign these pathways.

Services range from residential special schools built on the foundation of epilepsy which take complex people with epilepsy and learning disability (around 66% at the national Young Epilepsy school have a learning disability) and have MDT input. However, it remains unclear what are the referral pathways to specialist paediatric epilepsy services for these children in specialist residential settings, for example – “we had a student that was presenting with what could have been epilepsy or it could have been a side effect of his medication and we had to go through the psychiatrist and then through the GP to refer to a neurologist.” This is the required referral pathway by commissioning, if already under a psychiatrist they cannot refer directly to paediatric neurologist. This is an example which highlights the procedural barriers for good, swift effective care.

### Summaries of the brief statements of the round table discussions

Services for children and young people with learning disability and epilepsy are patchy across the country in terms of the types of services that has been commissioned. Part of that is because some services are within the NHS, some private sector and some within Social Care.

Lots of parts of the country have specific Social Care commissioning for behavioural support nurses specifically for children and young people with learning disability and /or epilepsy but may sometimes exclude epilepsy within the commissioning.

Within the private sector there are lots of private residential schools in the country that either specialise in learning disability and/or autism but usually have a large group of children that have comorbid epilepsy.

In terms of the types of service within the NHS there is a postcode lottery. Children with predominant mental health issues and learning disability are supported by CAMHS but not if they have epilepsy in many cases. Specific CAMHS -LD services are not widespread across the country. In either case good operational links to specialist epilepsy services are rare.

Investigations are a big challenge as there is a lack of clear care pathways for this and NICE is insufficient to encapsulate all relevant scenarios.

Competency frameworks for practitioners in the area of children with learning disability and epilepsy are at best ambivalent. There is good training through the British Paediatric Neurology Association and a lot of community paediatricians are skilled up that way but then to understand how that translates to commissioning a clear service around the individual is unclear especially taking on board the psychiatric issues.

Another challenge is around transition. Good transition is the systematic process of disseminating good information that is contained within the bio-psycho-social formulation to all relevant adult stakeholders of care.

## **Good examples of working include –**

CAMHS - LD services joint working with paediatric neurology

CAMHS - LD services joint working with community paediatrics that have a special interest in epilepsy

Good transition to adult neurology exists but can be patchy, for example this may be because one particular adult neurologist has a special interest in learning disabilities. However it raises questions of sustainability of the model. Many need to go to neurologist with epilepsy expertise, but the neurologist may not take individuals with associated learning disability.

An ideal system is a plan made two years prior to transition based on locally available services and identifying the most appropriate services. For example, if the individual's needs are predominantly epilepsy with minimal learning disability needs, then possibly the general adult neurology service. If there is a significant learning disability need in the form of challenging behaviour or impairment, then possibly the learning disability services. For those with concerning epilepsy, multiple physical and/or mental health co-morbidities, there needs to be a specialist service skilled in managing epilepsy and learning disability, although it would be important to acknowledge that not every part of the country will have a sufficient population to justify a specialist service. A re-evaluation of epilepsy and other needs should happen during transition to assist decisions as to where the management should be primarily organised and who takes the lead. Then a robust transition pathway should encapsulate all aspects of regular and emergency care.

It should be a recommendation that every person with epilepsy deserves to have a care plan worked out and robustly arranged with facilities available locally dependent on the service commissioned taking into account the speciality interest and competence locally. Children and people with learning disability should have equity of access to everything that is available to people without learning disability.

Another aspiration is that a cliff edge of transition at 18 years be avoided and be used more as a guidance than a rule. This can help a small number of people with complex needs in which it is not clear which services is suitable to have a more gradual and person centred transfer to adult services.

Ideally there should be no debate of a psychiatry based service or a more neurology based service because if it was an epilepsy based service one could prescribe the components of that to include psychiatry and neurology. Not just psychiatry and neurology but psychology, nursing, dietetics, support worker, social work, play therapist etc. The challenge to this model would be resource and commissioning. Children's mental health / learning disability and physical health are all commissioned differently and have different challenges and horizons in any given time. However knowing the eligible population it should be achievable to describe and commission between the three a suitable specialist team. However the political and financial climate is possibly adverse to this.

## Appendix 3 – Adults

### Group round table discussion summaries

Ideally there needs to be a number of different levels of assessment, treatment, management and advice. A problem is people get referred but are not discharged and the neurology model is likely to be a medical model with the focus on epilepsy but not necessarily on the needs of the person with learning disability.

It is not important to set boundaries for learning disability and epilepsy as it is important to realise that the presenting profile of epilepsy is a function of a variety of conditions of the brain including the developing brain, the maturing brain, quiescent brain conditions and the degenerative brain. This can then lend itself to a polymorphic presentation of mental and neurological presentations. Thus the clinical team that will be involved will be interactive with the active presenting symptomology and looking to provide holistic care.

A major gap is the manner in which neurology and psychiatry trainees especially in learning disability are trained. In neurology there is a move to reduce specialism and increase generalists thus reducing the focus on epilepsy. However the possible advantage could be more awareness of psychiatric morbidity. It is important to ensure there is ongoing CPD to keep focus on such complex co-morbid conditions such as learning disability and epilepsy. Training is important for the unique challenges posed in diagnosis and management in people with learning disability.

The short term strategy should be a flexible and complimentary pathway incorporating current practices ensuring basic standards of care irrespective of the provisions or systems of care.

The long term strategy should be for the four Royal colleges with a direct stake i.e. Royal college of Paediatrics, General practice, Physicians and Psychiatrists to develop a consensus statement and ratify a basic competency framework and a minimum standard pathway for a person with learning disability and epilepsy.

There needs to be a single information pack or care plan located preferably with the patient/carer to help transfer information between community settings, acute settings and primary care settings. The pack could include basic safety information about SUDEP, carers with basic and essential clinical advice possibly an epilepsy care plan. Hospital passports could be strengthened to become health passports. A standardised approach can be developed with elements of person centred input. It is important that there is one recognised lead for a local pathway i.e. a psychiatrist or a neurologist who can take responsibility for an integrated care package for a person with learning disability. This will ensure consistency around community care, emergency care, telemedicine, medication policy and surgical referrals. Better communication and clarity of role can lead to fewer emergencies and hospital admissions.

## Summaries of the brief statements of the round table discussions

This represents the feedback of professionals in adult services; psychiatry, neurology and learning disability. There are areas where there is good integration of learning disability and Neurology services to deliver epilepsy care to people with learning disability but it is not seen by others. The fault lies in dividing up the services into psychiatry, neurology, learning disability, general practice, and each seems to act independently from each other with a lack of uniformed thinking. Thus a proposal is each of these different Colleges should be presented with a template, a plan for how the different Colleges should interact with one another and a training and competency framework. Colleges need to endorse basic requirements. This could be done via the Academy of Royal Colleges.

There should be better access to tertiary services. The tertiary services see disproportionately smaller numbers of people with a learning disability. Similarly, disproportionately lower numbers of people from ethnic minorities. There appears an inbuilt prejudice against referring people in those groups. This should be redressed by more awareness. Amongst the powerful drivers to commissioning for these groups are the differing death rates and other morbidity indicators in these populations.

Individuals and families/carers need clear information systems which should be packaged together, held by an individual or their representative to share across the different agencies and environments a person with learning disability accesses.

There needs to be inter-region learning of what works well and what not so well. There needs to be clear ownership of who delivers any pathway/practice related to people with learning disability. The question “who’s in charge – the psychiatrist, the GP, the neurologist – who?” needs to be clearly defined. Each individual, each carer and professional group should have an identified lead that takes ownership of care plans and makes sure the information is disseminated appropriately.

Psychiatrists in learning disability have a range of skills in epilepsy and similarly neurologists with regard to epilepsy. Further it is unlikely for Neurology to have specific awareness of learning disability related clinical issues such as mental illness and challenging behaviour. Equally there is likelihood for a knowledge gap within psychiatrists leading to misdiagnosing ictal behaviours as psychosis, or over attributing behavioural/mood change to AEDs. Adult pathways thus need to be shaped based on resource availability, pragmatism and ensuring NICE and good practice guidance. The guiding principal is the overcome the variability of the resources and commissioning to ensure equality of access through out England. Where there is a lack of clarity or skill deficit a case needs to be made for one or the other service to upskill itself to ‘bridge the gap’ and take responsibility for ensuring models of care are suitably equipped for epilepsy care for people with learning disability.

**Conclusion: A working model for adult services would be to have one of the following –**

- A specialist epilepsy team commissioned by liaison of children, learning disability and physical health commissioners with all necessary components of epilepsy and learning disability care across the life span ensuring a biopsychosocial approach (gold standard)
- Adult learning disability service with epilepsy input sourced from Neurology
- A Neurology service with learning disability specialism sourced from learning disability services
- Joint learning disability and epilepsy services
- Good links with centres of excellence for rapid assessment and treatment of complex cases including availability of epilepsy surgery. As with any PWE, a flexible/responsive network, so people can move between primary, secondary and tertiary services when they need to, and back again without losing continuity

**A good service needs to have the following in place –**

- Good transition arrangements based on eligibility with a view to inform individuals and families on the process ensuring awareness and transparency of local policies and commissioning of local services well in advance preferably work up done for smooth transition.
- Every individual and their care stakeholders will have a clear understanding of the care plan of services needed to be accessed for routine and emergency care.
- There would be clarity of who 'owns' specific pathways and whose responsibility it is to interlink between the pathways.
- There needs to be an agreed measure of how different pathways, services and systems work to ensure consistency in each region.
- It is imperative that as a minimum the NICE guidance for epilepsy and best practice for learning disability be met. Either the learning disability or the neurology service needs to take a lead based on resource, skill availability and interest to ensure there is no service gap for people with learning disability in a commissioned region and where necessary engage with commissioners to bridge it.
- There has to be good links to centres of excellence with epilepsy surgery provisions for consideration of epilepsy surgery



## Appendix 4 - Expert Consultation Group

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Mr Nory Menneer, Kernow Clinical Commissioning, Programme Manager for Learning Disability in Cornwall

Mr Phil Tittensor, Royal Wolverhampton NHS Trust, Lead Epilepsy Nurse Specialist Chair – Epilepsy Specialist Nurse Association

Dr Robert Winterhalder, Oxleas NHS Foundation Trust, Consultant Psychiatrist in ID

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Dr William Howie, St George's NHS Trust, Consultant Psychiatrist in ID

## **Appendix 5 - Consultation Organisations**

Royal College of Paediatrics

Royal College of Psychiatrists (ID Faculty)

Workforce Innovation - Skills for Care

Autistica

Epilepsy Action

Epilepsy Society

Generate

MenCap

SUDEP Action

Young Epilepsy

## **Appendix 6 - The Purple Light Toolkit**

An adaptation of the Green Light Toolkit has been proposed for evaluation of service status. The Green Light for Mental Health [53] is a toolkit developed to support mental health services in delivering the objectives of the National Service Framework for Identifying good practice mental health in people with learning disability in England. Using the checklist allows a provider to establish what is in place and working well for people with learning disability 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 learning disability, benchmarked against national guidance and expectation. Although it is not in use in other areas of the UK, it outlines a good model of care which can be adapted to develop a similar approach for epilepsy. This toolkit was modified by the Royal College of Psychiatrist ID faculty epilepsy working party and proposed as a good practice tool [17]. It requires field testing for epilepsy and learning disability.

## Significant Other Individual Contributions:

### **Mrs Sharon Hambly**

in her role as Speech & Language Technician, Cornwall Partnership NHS Foundation Trust, for all her work on the Easy Read insert

### **Mr Christopher Tate**

for allowing us to feature his art on the cover and back of this report

*Christopher dealt with severe asthma and dyslexia in his time at school. After studying at Truro College he read for a degree in Illustration at Falmouth University, graduating in 2004.*

*Christopher has a distinctive style and vision with a particular interest in architecture and the built environment, using coloured inks inspired by reportage styles. As well as painting in Cornwall he has painted a number of towns and cities including Venice, Paris, Rome, London and Cambridge.*

For more works by Christopher:

<https://www.landergallery.co.uk/artists/57-christopher-james-tate/overview>



### **Natasha Green**

Natasha is a young lady who lives in North Cornwall who loves being creative and is currently enjoying working with clay to produce wall hangings such as the one above which features bluebells from her walk in the wood.

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