

Integrating care for children, young people and adults with epilepsy and learning disability

A summary guide



# I. Epilepsy and learning disability: the need for guidance

# I.I What people need to know about epilepsy

Epilepsy is a neurological condition which causes seizures. There are many different types of seizures with different triggers and treatments including anti-epileptic drugs, surgery and diet. The focus of treatment is for the individual to become seizure-free, or to have the number of seizures reduced. Achieving seizure control reduces the risk of early death, which is higher in this group than the general population.

However, optimal treatment can be difficult to achieve. People with drug-resistant epilepsy are particularly at risk of sudden unexpected death in epilepsy (SUDEP) especially if their epilepsy is poorly managed. For people with learning disabilities (clinically defined as intellectual disability) and epilepsy, treatments can be less effective than in the general population. Epilepsy treatments can interact with other treatments leading to unwanted side effects and behavioural issues.

Epilepsy can have a physical and psychological impact on people with learning disabilities, resulting in significant care and support needs. They may experience communication, psychiatric, behavioural and drug sensitivity problems that make establishing optimal treatment more difficult than for people without a learning disability or with a milder disability. It may not be possible to separate the effects of an individual's epilepsy from the effects of their underlying learning disability on their ability to function. In some cases, epilepsy and its treatment can have a worsening effect on cognitive and social function and quality of life.

Epilepsy is associated with high healthcare costs and premature mortality. 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, which is approximately 6,000 admissions a year in the UK.

Around 1% of the general population have epilepsy, but this rises to 20% in those with a learning disability. Around 30% of the people with epilepsy who receive care in any setting will have a learning disability. Up to 50% of those with severe to profound learning disability have epilepsy.

# 1.2 Why people with epilepsy and learning disabilities are a priority group

Men and women with learning disabilities have a shorter life expectancy than the general population (14 years for men and 18 years for women). For people with epilepsy and learning disabilities the number of premature and avoidable deaths can be reduced. Mortality rates for people with a learning disability increase with the severity of learning disability and the existence of comorbidities including epilepsy. Epilepsy is the third most recorded associated condition after sepsis and pneumonia, and 43% of people with a learning disability who died had seizures during the last five years of their life.

People with epilepsy and a learning disability are more likely to be taking a higher number of drugs, including psychotropics, and have increased multimorbidity, including higher rates of challenging behaviour and mental illness associations. Sixty per cent have seizures that are treatment resistant. This group is the most prevalent in using emergency rescue medication such as Midazolam.

Avoidable emergency attendances are five times higher in people with learning disabilities than the general population and the most common cause is Seizures. Redesigning services and improving care pathways will help avoid emergency attendances and admissions (at a cost of £2,500 per admission) and improve quality of life.

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. Other limiting factors include lack of expertise in learning disability and epilepsy matters, clinical training gaps, availability of resources and time.

Many people who have epilepsy and a learning disability do not receive the holistic care they need. They often have many professionals involved in their health and social care. The lead professional managing their epilepsy care depends on the local services and professional skills available, which may have evolved historically rather than resulted from a needs assessment, active commissioning priorities or contract specifications.

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To date, there has not been easily implementable guidance on the provision of services for people with epilepsy and a learning disability. There have been examples of poor care and deaths that may have been avoided if care plans had been agreed, shared and implemented. An objective of commissioning a quality service is to reduce the risk of failing any individual with epilepsy and a learning disability.

Providing holistic care, increasing seizure control, and implementing guidance on the provision of integrated services, will transform services and ensure vulnerable individuals receive the care they need.

# 1.3 Epilepsy Integrated Care Pathway Guidance

Healthcare professionals have expressed concerns about lack of clear referral pathways into and between services for people with epilepsy and a learning disability.

The 'Step Together' guidance was developed with input from professional bodies, healthcare professionals, people with a learning disability and epilepsy, families, carers and third sector support organisations. It aims to ensure there is no service gap for people with a learning disability in an integrated care system. This guidance may also be useful when considering the needs of people with epilepsy and autism.

The full guide is available here: <a href="https://www.bild.org.uk/ldsenate/">https://www.bild.org.uk/ldsenate/</a>

# 1.4 New commissioning approaches and integration of care

New approaches to collaborative commissioning between national and local commissioners offer a way to develop and promote integrated care pathways across primary, secondary, and specialised care. Commissioners and providers are involving people with health conditions and carers in the design of service models and pathways of care and increasingly using patient experience to inform improvements. This new approach is reflected in the streams set up to deliver the NHS 10-year plan.

Where they have been established, Integrated Care Systems (ICS) 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 will benefit local populations in improving health outcomes, including people with a learning disability who are affected by epilepsy.

Clinicians and families previously expressed concerns about the lack of a consistent commissioning structure for complex epilepsy, for children transitioning to adult care. This often results in difficulties continuing certain specialist medications or therapies, leads to a change of approach to clinical management and also results for many in a fragmentation of care. Developing integrated pathways of care offers opportunities to join up care and improve the patient and carer experience.

## 1.5 About this guide

This guide describes the elements of a good quality integrated service for people with a learning disability and epilepsy. It enables commissioners and providers to audit what is available for their population and assess the extent to which needs are currently met. It offers examples of ways to increase collaboration, improve services and consistency in epilepsy provision, and reduce unwarranted variation.

It will help identify the extent to which services are working well together to deliver good care.

It will enable commissioners to ask questions and encourage provider cooperation, quality improvement and workforce development. This will involve reviewing the expertise and capacity of the workforce. Where gaps in provision or quality are identified, new or enhanced services could be commissioned.

Alternatively, pragmatic provider development solutions could be facilitated as part of integrated care work streams, clinical audit programmes or quality improvement objectives. A local care pathway could be documented, and protocols/practices agreed to deliver consistent and good care. Professional competency frameworks and resources exist to support skills and knowledge development and role extension.

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# 2. Where we are: commissioning and provision

### 2.1 Current service provision

A variety of providers deliver care for children and adults with learning disability and epilepsy. Different models of care have evolved locally often based in the organisations employing clinicians skilled in the care of people with learning disabilities or people with epilepsy. Some epilepsy services were not specifically commissioned and, as a consequence of service reviews, adult epilepsy services have been withdrawn from some learning disability service providers to the detriment of some patients.

The management of epilepsy in people with a learning disability requires a specialist multidisciplinary team skilled in formulating seizure events in the wider context of mental health and social care provision and behavioural change. It requires a service model able to provide health care that meets the needs of individuals through reasonable adjustments such as more frequent and longer appointments. In England there are now recommendations about consultation length and epilepsy risk assessment for people with a learning disability, in particular a focus on SUDEP.

#### 2.1.1 Services for adults

Epilepsy care for adults with a learning disability varies significantly with only a few areas developing commissioned services for people with a learning disability and epilepsy.

In primary care, people with a learning disability should be registered on the Learning Disabilities Quality Outcomes Framework (QOF) register. The average registered population in England for 2018 is 0.5% of all registered patients. The actual England prevalence of learning disability is thought to be nearer to 2%. This means that the majority of patients with a learning disability are not identified and may not be invited to attend an Annual Health Check, which should include a medication and epilepsy review. It is possible that there is significant unmet need and that optimal epilepsy treatment is not achieved. The absence of clear referral pathways from primary care into secondary care and community services has been noted by professionals and families.

In hospital-based secondary care, clinical input is often delivered by neurologists who may be specialists in epilepsy. Additional input is variably delivered by psychiatrists working with people with a learning disability and with an interest in epilepsy, and nurses who have a range of competencies in learning disability and epilepsy.

In secondary community care, psychiatrists and Community Learning Disability Teams (CLTDs) often provide some form of epilepsy service, with nurse input. Over the past 20 years treatment options have increased, new epilepsy drugs have been developed, and national policy has encouraged access to mainstream services for people with learning disabilities. This service model has been in decline, though a recent survey found that in areas short of neurology specialist care in predominantly rural areas, learning disability psychiatrists and local learning disability services have filled the gap.

In 2017, a study found no difference in seizure severity and epilepsy-related quality of life between those adults with learning disabilities whose seizures were managed by a neurology service and those whose seizures were managed by a community learning disability team.

This guidance does not recommend either type of service but does clarify the components and competencies that should be commissioned from a single provider or a partnership.

Clinicians working in tertiary neurology services, report that disproportionally smaller numbers of people with a learning disability are assessed and treated. Integrated commissioning and clear pathways of care could help to address any potential health inequalities.

#### 2.1.2 Services for children

Epilepsy care for children with a learning disability varies significantly, as does the workforce of specialised personnel, competence and interest of professionals managing this population, including General Practitioners, Paediatricians, School Nurses, Paediatric Epilepsy Specialist Nurses, Psychiatrists, Neuro disability Paediatricians and Paediatric Neurologists. Few areas in the United Kingdom have developed a specifically commissioned service for this vulnerable population.

Very few children are managed in primary care. Community paediatricians and school nurses often support children attending special schools ensuring appropriate care plans are in place including emergency medication protocols. There are no relevant agreed standards or competencies for this workforce. The curricula for core and specialist paediatrics all contain competencies with respect to epilepsy and some reference to learning disabilities. 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.

Any complex issues related to the assessment, diagnosis and management of paediatric epilepsy should be referred to the attention of Paediatric Neurologists, as per NICE Guidelines. 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. Psychiatrists are trained in the curricula developed by the Royal College of Psychiatrists in either Child and Adolescent Psychiatry or the Psychiatry of Intellectual Disability, or a combination of both. And both these curricula specify competencies in epilepsy and learning disabilities.

There are examples of good practice in the delivery of services by teams of these professionals, however, the evidence base needs to be consolidated and systemised.

NHS England has produced an epilepsy best practice tariff to support trusts in England who have services configured to meet best practice criteria. This is not currently designed to support services based on block contract and in these circumstances such criteria should be considered within the service specifications.

Existing transition arrangements often mean clinicians in children's services have to make pragmatic decisions about best use of locally available resources. For example, if the individual's needs are predominantly epilepsy with minimal learning disability needs, then transition to the general adult neurology service is considered. If there is a significant learning disability need in the form of challenging behaviour or impairment, then possibly transition to learning disability services is considered.

If there is 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 is important to acknowledge that not every part of the country will have a sufficient population to justify a specialist service.

# 2.2 What patients, families and carers say good care should include

People with a learning disability and epilepsy, their families and carers attended focus groups to share and discuss their experiences and ideas about what is working well, what needs to improve and what good care should include. Here is a summary:

	240		
	What patients, families and carers say good care should include		
1	Support in medication administration		
2	Support in maintaining safety, for example, having overnight support if needed		
3	Clear information about the roles of professionals		
4	Health professionals with knowledge of learning disability, and social care and education professionals having knowledge of epilepsy		
5	All professionals being able to see care records		
6	Access to a care co-ordinator role		
7	Out of hours access to epilepsy service contacts		
8	A good integrated epilepsy care plan		
9	Having risk assessments of home environment that also make it clear how they can safely participate in leisure activities		
10	Having an epilepsy annual review as part of the Annual Health Check and regular medication reviews		
Ш	Good discharge planning		
12	Support networks and organisations such as Young Epilepsy and SIBS		
13	Support in attending appointments		
14	Reasonable adjustments to enable access to tests		
15	Accessible information to give them understanding of treatment options, drug interactions and SUDEP		
16	Having input from an epilepsy specialist nurse		
17	Planned transition into adult services and good information for young people		
18	Short waiting times for accessing specialist input in tertiary services		
19	Carer needs assessments		
20	Informed decision making or use of best interest process to highlight prescribing issues such as teratogenicity in using valproate in women of child bearing age		

# 3. Stepping forward together: the options

## 3.1. Planning adult services

Potential service models for adult care include:

- i. A specialist epilepsy team commissioned by liaison of adult, 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)
- ii. Adult learning disability service with epilepsy input sourced from neurology (meeting minimum standards for safe care below)
- iii. A Neurology service with learning disability specialism sourced from learning disability services (meeting minimum standards for safe care below)
- iv. Joint learning disability and epilepsy services (meeting minimum and good service components below)

Models ii, iii and iv would need good links with specialist centres in tertiary care services for rapid assessment and the treatment of complex needs including the availability of epilepsy surgery. Workforce capacity issues have emerged in local areas these can leave service level gaps in delivering epilepsy services to people with a learning disability. It is not always possible to recruit experienced professionals from all disciplines so the four service models are suggested as options with potential to ensure that the focus of local provision is not just on the epilepsy but rather on the individual who could have other complex learning disability linked health and social needs.

As with the treatment of any person with epilepsy, a flexible/responsive network is necessary, so people can move between primary, secondary and tertiary services when they need to, and back again, without losing continuity of care.

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The following service components are needed to achieve seizure management and to avoid unnecessary hospital admissions in adults.

#### A minimum service

The components that should be considered essential for safe care are as a minimum:

- **a.** A consultant with epilepsy and learning disability interests and competency
- **b.** Access to a learning disability Multidisciplinary team
- c. Access to an epilepsy nurse
- **d.** Clear guidelines for management of emergencies with appropriate shared access to information
- **e.** A neurologist with expertise in epilepsy
- **f.** A psychiatrist with an epilepsy interest
- g. Specialist nursing support
- **h.** Appropriate psychology and therapy services
- i. Transition services
- j. Access to second opinions and tertiary services, with clear pathways and lines of responsibility

It is imperative that as a minimum the NICE guidance for epilepsy and best practice for people with a learning disability is met. Commissioners can use the following NICE outcome indicators in service specifications or to monitor provider quality:

- i. Adults with epilepsy have an agreed and comprehensive written care plan
- **ii.** Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan
- iii. Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services
- iv. Adults presenting with a suspected first seizure are seen by a specialist in the diagnosis and management of epilepsy within two weeks
- Adults having initial investigations for epilepsy undergo the tests within four weeks
- vi. Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews

### A good service

A good service would have all of the minimum components and the following in place:

- a. Good transition arrangements based on eligibility with a view to inform individuals and their supporters on the process ensuring awareness and transparency of local policies and commissioning of local services. This should be done well in advance for smooth transition
- b. 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
- c. Clear specific pathways and clear workforce responsibilities to interlink between specific primary, secondary and tertiary services
- d. Agreed measures and monitoring of how well different pathways, services and systems are working to ensure consistency of care in each area

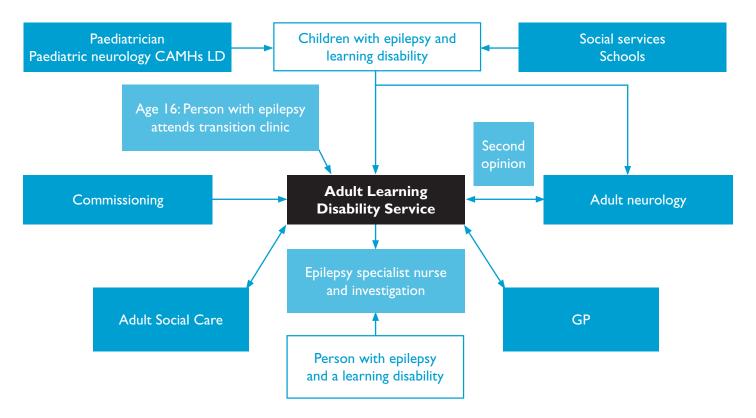
### A fully integrated service

An integrated service implementing best practice would also have:

- a. An expert in epileptic seizures and seizure disorders also with expertise in learning disabilities
- **b.** A learning disability specialist with expertise in epilepsy
- **c.** Learning disability nurse with epilepsy interest
- **d.** Epilepsy nurse with learning disability interest
- e. Dedicated joint epilepsy and learning disability clinics
- f. Provision of longer clinics
- g. Use of telephones, web-based applications such as Skype could be a suitable alternative to fixed hospital appointments which in itself can cause distress to individuals with a learning disability
- h. A team of specialised therapists and psychologists able to give input as required, consisting of Occupational Therapy, Physiotherapist, Psychologist, Speech and Language Therapist, Dietitian and Social worker
- Learning disability Psychiatrist (or Child and Adolescent Psychiatrist) with epilepsy interest and Neurologist with learning disability interest\*
- j. Neurologist with learning disability interest
- k. Learning disability Psychiatrist (or Child and Adolescent Psychiatrist) with epilepsy interest
- I. For some people to achieve diagnosis or to agree treatment options immediate access to high quality Neurophysiology and epilepsy surgery is necessary. At present this model exists only in some tertiary centres.

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The service model below has been produced by clinicians to show the linked components that would be present in a desirable or high quality integrated service.



It is recognised that a fully integrated service might be aspirational and resourcing this could require new service specifications or novel tariff arrangements. There are risks to creating dedicated joint clinics (separate from mainstream epilepsy services) for adults

and children with learning disability and epilepsy. Ensuring delivery of standards of care in both epilepsy and learning disability is key to positive outcomes. Integrating care for children, young people and adults with epilepsy and learning disability

## 3.2 Benefits of integrated epilepsy care

Based on the experiences of services which have implemented more integrated models of care and the benefits they have realised, it is anticipated/predicted that 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
Reduced epilepsy related deaths, for example SUDEP  Reduced unnecessary hospital admissions Reduced Accident and Emergency attendances Reduced GP visits  Addresses polypharmacy leading to safer treatments  Better understood care plans  Best interest oriented, working closely with families and carers  Healthier and more fulfilled lifestyles	Reduced clinical emergencies  Professional role clarity  Consistency of care in local areas  Clear pathway deliverables leading to improved efficiency  Provides a seamless service that improves referrals to tertiary care services	Reduction of costs resulting from streamline prescribing Reduction in costs related to emergency admissions and ambulance call outs

#### Sample adult services pathway

## Initial assessment and diagnosis:

- Identify and manage epilepsy needs making reasonable adjustments to ensure effective communication. For example, providing easy to read materials
- Identify investigations needed. For example, EEG and MRI
- Formulation of diagnosis and seizure classification based on history
- Assess impact of disease and treatment on mental health disorder
- Support use of rescue medication

# Evidence based treatment and when to consider referral for novel or rarer treatment options:

- Medical management prescribing and review side effect assessment
- Discussion of SUDEP risk
- Surgical assessment

## Ongoing management of care:

- Care lead or co-ordinator can take responsibility for an integrated care package
- 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 with basic and essential clinical advice, and possibly an epilepsy care plan

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## 3.3 Planning children's services

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

**3.3.1** 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 suggests that all children with epilepsy:

- Follow up to be delivered by a paediatrician with expertise and an epilepsy specialist nurse in defined epilepsy clinics
- **b.** Appointments to be at least 20 minutes duration
- Service to have defined pathways to neurology, neurodisability and adult services
- d. Comprehensive care planning
- e. Full participation in Epilepsy 12 National Audit

- **3.3.2** NHS Services on block contract or not in England can still be supported or contracted to deliver services fulfilling epilepsy best practice criteria.
- **3.3.3** That children with complex epilepsy have access to appropriate paediatric neurology and neuroscience services at tertiary level through specialist commissioning.
- **3.3.4** 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.
- **3.3.5** Establish links with <u>OPEN UK regional networks</u> to support identification and action around local themes requiring quality improvement and to support benchmarking between component trusts and health boards.
- **3.3.6** Review and analyse ongoing Epilepsy 12 National reports [41] describing gaps and variations in care, key findings and recommendations and results at regional and trust/health board level.

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

Model children's service

 All epilepsy services to have linked child psychology

- 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)

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It has been suggested that a care pathway should include:

#### 1. Initial assessment and diagnosis:

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 if, and when, needed.

## 2. Evidence based treatment and when to consider referral for novel or rarer treatment options

Follow NICE guidelines on optimal evidence-based treatments but look to trial other up to date management when conventional treatment fails, for example, novel AEDs, diet therapies, epilepsy surgery. There needs to be flexibility where suitable and

evidenced through imaging and EEG, especially for certain epilepsy syndromes, to benefit from earlier exposure to certain rarer treatments and the pathways should provide guidance as to when that should happen.

#### 3. Good transition to adult services

- **a.** Identify and prepare the child or young person at least 12 months prior to transition.
- **b.** Provide good transition information including hospital passports.
- **c.** Technology to allow young people and their families to access appropriate care information.
- d. Revisit all health needs and identify providers to take over care including the GP. Consider a holistic revaluation with all stakeholders where appropriate based on individual complexity.
- e. This requires a seamless design with systems in place triggered at same age of eligibility between different health providers.

- f. An established local referral system to ensure the individual needs of those who have active epilepsy and other physical and cognitive challenges are met taking into account types of resources and services are available within the adult landscape locally.
- g. Avoid a 'cliff edge' for children with complex needs at 18 years by allowing known paediatric services to continue with their support until it is clear which adult services meets their needs.

#### 4. Pathway monitoring data

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.

## 3.4 Commissioning social care

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

**3.4.1** Ensure that all staff supporting people with epilepsy are trained in basic epilepsy awareness and have a good understanding of how epilepsy affects each individual they support. This includes being able to access the care plan and know what to do for the type of seizure, a basic

understanding of the need for the person to rest postseizure, the interaction of alcohol on medication if the person drinks, the basics of possible relationship between behaviour and some forms of epilepsy.

**3.4.2** 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 helps with assessment and review of treatment.

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- **3.4.3** Ensure that staff supporting the person are helpful in arranging and facilitating attendance at appointments, clinics, hospitals or GP practices, including getting an Annual Health Check. After this, following the health action plan, and knowing how to respond in an emergency is important.
- **3.4.4** Providers should be aware of the medication prescribed, 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, supported by NHS England, 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 available at vodg.org.uk/campaigns/stompcampaign/
- **3.4.5** 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 (for example, sleep disturbance, hunger, infections). This could reduce the ambient stressors people may experience on an ongoing basis.

# 3.5 Commissioning: examples of good practice and support tools

#### 3.5.1 The Purple Light Toolkit

An adaptation of the Green Light Toolkit for Mental Health has been proposed for evaluation of service status. Using self-assessment checklists at regular intervals allows providers to track developments, celebrate achievements and move towards developing better services for people with learning disability. Although it is not in use in all 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 Intellectual Disability faculty epilepsy working party and proposed as a good practice tool. It requires field testing for epilepsy and learning disability.

Using this tool, a model of integrated working to meet the needs of adults and children with a learning disability and epilepsy has been developed in Cornwall.

#### **3.5.2** Workforce competencies

In 2017 the Royal College of Psychiatrists brought together experts in epilepsy and learning disability from neurology, learning disability psychiatry and epilepsy nursing to consider the competencies psychiatrists needed to deliver safe and effective epilepsy care that met NICE guidance. They proposed a tiered bronze, silver, gold approach. Bronze is the minimum standard expected of all psychiatrists working with people with a learning disability.

They also offer a grid enabling commissioners and providers to consider the impact of a skill mix of disciplines. This incorporates the Royal College of Nursing Epilepsy learning disability nurse competencies. It enables a star rating to be generated by mapping the existing staffing or considering the impact of recruiting additional posts.

## 3.5.3 Cornwall Partnership NHS Foundation Trust Intellectual Disability Specialist Epilepsy Service

An operational policy was agreed between the commissioning CCG and the provider: the service offered, eligibility criteria, referral pathway, discharge process, record keeping, quality standards and outcome indicators. The key performance measures included:

- **a.** 100% of people receiving care from the service being provided with a copy of their care plan
- **b.** All referrals acknowledged within 5 working days of receipt
- **c.** 100% of clinic letters are typed and sent out within a maximum of 5 working days of receipt of dictation.
- **d.** 100% of people have their care plan reviewed annually as a minimum
- **e.** 100% of people prescribed rescue medication have an emergency rescue medication protocol in place which is reviewed yearly
- **f.** To monitor the number of deaths due to epilepsy and identify any modifiable trends
- g. To measure active clinical caseloads
- h. Quality of Life survey
- i. Service Feedback using meridian surveys
- i. NICE audit
- k. Training feedback

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Philip Lee, Chief Executive, Epilepsy Action

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