

Improving epilepsy care for children and young people: an integrated approach

Full report



Acknowledgements

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This report summarises collaborative work involving the organisations below. The project team was made up of:

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Young Epilepsy

Young Epilepsy is a national charity with over 100 years expertise working exclusively on behalf of children and young people with epilepsy. It operates an internationally renowned research programme and offers a unique blend of specialist services for over 200 students on its Lingfield campus, providing education and healthcare for children and young people with epilepsy, autism and other neurological conditions. The charity provides support and information for parents and the 112,000 children and young people with epilepsy across the UK.

Institute of Child Health (University College London)

Together with its clinical partner Great Ormond Street Hospital for Children (GOSH), ICH forms the largest concentration of children's health research in Europe. The inspirational mission of the joint institution is to improve the health and well-being of children, and the adults they will become, through world-class research, education and public engagement.

Whittington Health NHS Trust

Whittington Health provides general hospital and community services to 500,000 people living in Islington and Haringey as well as other London boroughs. As one organisation providing both hospital and community services, it is known as an "integrated care organisation". Key to their approach is partnering with patients, carers, GPs, social care, mental health and other healthcare providers.

UCLPartners

UCLPartners is an academic health science partnership with over 40 higher education and NHS members, and a central team providing operational support and clinical academic leadership through a not-for-profit company. Together, its member organisations form one of the world's leading centres of medical discovery, healthcare innovation and education. Its purpose is to translate cutting-edge research and innovation into measurable health and wealth gain for patients and populations - in London, across the UK and globally.

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Executive summary

Epilepsy is a common long-term condition amongst children and young people in the United Kingdom, and the most common neurological disorder, with 112,000 affected. Unfortunately, it is widely acknowledged that the services for this group have been inadequate. Despite efforts aimed at addressing some of the perceived issues, the gap between where we are, and where we want to be, has persisted - as confirmed by national audit figures. In essence, this has been a failing system for some time.

This report aims to answer the following questions:

- why are current services not up to scratch, and how can we close the gap?
- what's stopping us from achieving national guidelines for epilepsy services?
- how can we improve outcomes for children and young people with epilepsy?

The work utilises a range of sources in a scoping review of the evidence; this includes peer-reviewed studies, grey literature, guidelines and standards. The other components of the report use qualitative data gained from group interviews with parents, completed questionnaires from young people and perspectives from a multi-professional forum (which included commissioners, healthcare professionals, education and social care representatives amongst its numbers).

The report provides key findings which look beyond the often-quoted statistics, to identify the real barriers and enablers to providing better care. In its key recommendations, it provides a proposed set of shared goals towards the aim of improving epilepsy services for children and young people. Policy-makers and commissioners must take these recommendations and work together - in collaboration with professionals and with children, young people and their parents - in order to achieve lasting and transformational change. It is only through this process that the type of service that children and young people with epilepsy deserve can be delivered.

Recommendations

- 1 Establish a registry of children and young people with the epilepsies**
This would allow professionals to learn about and map the needs of their population - informing the design and structure of services, and enabling crucial research.
- 2 Create an individualised plan for every child and young person**
This plan (Education, Health and Care Plan) must reflect their needs across a full range of professional services.
- 3 Develop a patient-held (or parent-held) electronic record**
As well as enabling better integration across different service organisations, this would empower young people to take greater control of their condition allowing the use of helpful self-management strategies.
- 4 Design a 'year of care' tariff for the epilepsies**
This would better reflect complexity and heterogeneity of the condition and would allow commissioners to take a condition-wide view, encompassing the broad associations that are unique to the epilepsies (such as the impact on education and mental health).
- 5 Audit annual review of relevant outcomes for each child and young person**
These should be a mix of health-related, quality of life, functional and experience measures. It is imperative that regular national audits continue.
- 6 Commission economic evaluation of good epilepsy care**
A robust economic analysis would better map out the advantages of an integrated approach, and enable many of the other recommendations of this report.
- 7 Improve and expand networks**
Regional professional networks (reflecting all relevant professional agencies) aid integration by allowing regular liaison allowing them to communicate with policymakers with a collective voice. The organisation of young persons' and parents' groups should also take place on a similar basis.



Introduction

Epilepsy is a common long-term condition amongst children and young people. According to the most reliable published numbers more than 1 in 200 children and young people under the age of 25 have epilepsy, with a total in the United Kingdom of over 112,000. Rates of incorrect diagnosis of epilepsy have historically been high, with figures ranging between at least 20 to 30%. Similarly, 40% of children referred to specialist clinics eventually transpire not to have the condition, having often been diagnosed and usually on drug treatment by this point. At the other end of the spectrum there are a significant number of children who are not being adequately treated, with estimates that up to 70% of people with epilepsy could be free of seizures if appropriately managed (JEC 2011, House of Commons 2010).

However, epilepsy is not purely a health condition. One thing that sets it apart from diseases such as asthma and diabetes is the wider functional impact it has on a child, with effects on mental health, learning and behaviour - and all at a crucial time of development. Epilepsy also has an immeasurable impact on families, whether the child has well-controlled seizures or multiple seizures per day. This latter group is most often affected by a broad range of other health conditions. Any child with epilepsy may require input from a combination of agencies, encompassing physical health, mental health, social care and education.

Unfortunately, outcomes for children and young people with epilepsy are far from optimal. This is not new - numerous reports, over many years, have suggested the same. Though attempts to improve have been made (with mostly local service improvements), the overall picture has not progressed as hoped. Indeed, most of the issues identified 15 to 20 years ago remain today. Robust data from repeat rounds of national audit confirms that services for children and young people continue to fall short of what is desired (RCPCH 2012, RCPCH 2014).

However, in terms of seeking to improve services, opportunity knocks. A combination of recently-passed legislation, NHS objectives and an apparent increase in political will, all mean that the time is now right for meaningful, positive change to occur (Children and Families Act 2014, DoH 2013). In order to do this, a cogent strategy needs to be developed, and the design of this must involve all relevant agencies.

This piece of work brings together professionals from all backgrounds - along with the ever-important voice of children, young people and their parents - in order to identify the issues underlying inadequate performance of paediatric epilepsy services and to offer solutions for transformational change. It aims to answer the following points:

- why are current services not up to scratch, and how can we close the gap?
- what's stopping us from achieving national guidelines for epilepsy services?
- how can we improve outcomes for children and young people with epilepsy?

Methodology

Three distinct approaches were utilised to inform the content of this report.

Scoping review

A scoping review of relevant literature was carried out. Initially, a literature search was performed using Medline, PubMed and Google Scholar. As part of this, health services research databases such as HMIC and CINAHL were used in order to capture grey literature. Organisational websites were searched for relevant documents; these included third sector epilepsy organisations (such as Young Epilepsy and Epilepsy Action), health and epilepsy-related bodies (e.g. RCPCH, ILAE), guideline-producing organisations (e.g. NICE and SIGN) and health think-tanks (e.g. The King's Fund, The Nuffield Trust, The Health Foundation).

Parents' and young persons' viewpoints

Perspectives from children, young people and parents were sought; questionnaires relating to experiences with epilepsy services were sent out to parents and young people in Islington and semi-structured group interviews were held in Islington and at Young Epilepsy in Lingfield.

Multi-professionals' forum

A multi-professional forum was held at The King's Fund on 1st December 2014, with representation including consultants (from across community, secondary and tertiary care), epilepsy nurse specialists, commissioners, education and social care delegates, psychologists and psychiatrists. Representatives from NHS England and NICE also attended the day. In total there were 55 delegates at the forum and they were divided into three facilitated discussion groups.

The purpose of this overall approach was firstly to examine the history of paediatric epilepsy services in the United Kingdom, and to define the standards to which epilepsy services should aspire. Next, the aim was to identify barriers and enablers that would enable change and the closing of this gap. Lastly, the goal was to establish a set of recommendations that could be taken forward as a strategy to improve outcomes.



Results

Scoping review

Seminal reports - shining a light on children's epilepsy services

Epilepsy services for children and young people came under the spotlight in the early 2000s, with the publication of the Leicester inquiry (BBC 2003, The Guardian 2001). This was a widely-publicised report into the practice of a paediatrician who ran children's epilepsy services at Leicester Royal Infirmary. Covering several years, the report demonstrated many of the inherent difficulties in diagnosing epilepsy in children and, in particular, the issue of over-diagnosis and the subsequent overprescribing of anti-epileptic drugs. Its findings reported multiple failings, not only in the clinical assessment of individuals, but of the system as a whole (White 2001).

Another influential report, the National Sentinel Clinical Audit of Epilepsy-Related Deaths, examined the medical care of a large group of patients in whom the cause of death was attributed to epilepsy (Hanna et al 2002). The findings acted as a wake-up call to the entire medical community. For example, it found therapeutic management to have been inadequate in almost half of children, and a startling 59% of child deaths were adjudged to have been avoidable. The report identified multiple deficiencies in the system, notably in the areas of access, quality of care provided and communication. The report recommended these deficiencies be directly addressed in the redesign of paediatric epilepsy services.

One important response to this came from the British Paediatric Neurology Association (BPNA 2003). It acknowledged the inherent difficulties in accurately diagnosing epilepsy and, given the reliance on good clinical assessment, it stated that non-specialists should not be involved. It also found that poor communication and a variation in access to investigations existed and that resources and technology were not being optimally utilised. The report also recognised that closer links with education and social care were vital. It proposed a healthcare pathway across primary, secondary, tertiary and quaternary care. This model contained a greater function for epilepsy nurse specialists (at both secondary and tertiary care levels), and a new role; the paediatrician with 'an expertise in epilepsy'. The report also recommended better access to specialists and appropriate investigations, better selection of patients whose epilepsy could be amenable to surgery, earlier intervention by social care and education and better support for clinical networks. One tangible output was the conception of the Paediatric Epilepsy Training (PET) courses, which became the standard healthcare professionals training in epilepsy.



Guidelines and standards

Further developments came with the publication of national guidelines (NICE 2004, SIGN 2005). These again reinforced concerns with epilepsy services, in line with those stated in earlier reports. Both documents made mention of the different elements needed for a 'good' epilepsy service such as mental health provision, agencies such as education and social care, and also that the third sector also had an important role to play. In essence, there was an acknowledgement that a whole system approach was needed. However, due to the remit of both SIGN and NICE at the time, this did not form part of the resulting guidance.

In 2013, a Quality Standard for the epilepsies in children and young people was published (NICE 2013). This comprised nine specific statements towards which services should aspire. Drawing on the existing NICE guidance, the aim of this report was to describe particular areas of high priority. This influential document also espoused an integrated approach as 'fundamental to the delivery of high-quality care', though stopped short of a practical method of achieving it.

Recent publications

In the same year, a detailed report was published which examined case reviews of children with epilepsy who had died, or had serious morbidity (RCPCH 2013). This was the first study examining avoidable deaths from epilepsy for over ten years (Hanna et al 2002). Amongst the 18 key findings of the report was the familiar mantra of poor communication (both between professionals and with families), a need to improve assessment and classification, and further acknowledgement of the fragmented nature of services. The requirement to follow national guidelines was also emphasised and the need for clear clinical pathways (e.g. Desitin 2014). Suggestions for improvements included a named paediatrician to better coordinate care, the need for clear care plans, and involving families more in management of a child's condition. One key recommendation was to develop an 'epilepsy passport', in order to aid communication across agencies.

The wider impact of epilepsy on children and young people on learning, already known to be higher in children with epilepsy, was further emphasised in 2014, with the publication of the Children with Epilepsy in Sussex Schools study (Young Epilepsy 2014). This report demonstrated the high levels of behavioural difficulties and problems with cognition that children with epilepsy experience, often with an impact on academic performance. Such difficulties were shown to be unrecognised without proper assessment. Equally, even children whose seizures were well-controlled were found to have these problems. This indicated, therefore, that many children may be experiencing issues that negatively impact on their ability to fulfil their potential. The study's authors recommended that guidelines be updated to reflect these associations and that epilepsy ought to be considered a special educational need, in order that needs are met.

National audit

The recurring concerns about the quality of epilepsy care (specifically around misdiagnosis, poor communication, variation in care and fragmentation of services) have been reinforced by national audit data. The first round of Epilepsy12 confirmed deficiencies in all of the areas previously mentioned (RCPCH 2012). The second round found small improvements yet, overall, the problems were still found to be prevalent (RCPCH 2014).

One illustration of this is that only 46% of paediatric epilepsy units had an epilepsy specialist nurse in 2012. This figure has increased to 59%, yet the fact remains that in over one-third of units across the country, children and young people still do not have access to an epilepsy specialist nurse. This is despite it being something which all of the guidelines and standards make clear is imperative. It is clear that efforts to date have not achieved the necessary improvement.

Integration

Every child with epilepsy requires a unique mix of disparate services, from different organisations and bodies. Whilst an integrated approach has been suggested in previous influential reports, significant work has never been carried out to try to reduce the fragmented way in which different services interrelate. This is somewhat surprising, given the growing importance attached to integrated care in healthcare policy (NCICS 2013). One of the clearest definitions of integration is 'a means to overcome perceived fragmentation of care within and between organisations that provide healthcare and associated services' (BAACH 2012). Essentially, this simply positions integration as the opposite of fragmentation.

Successful examples of integration can be found with chronic conditions such as diabetes, and so an integrated model appears to suit a condition-specific service that requires good coordination of care and a holistic approach, of a certain defined population (Ham 2008, Rosen and Ham 2008). Such an approach would certainly appear to fit the epilepsies in children and young people well. Integration is no magic bullet, however, and for it to be successful requires several components including: strong leadership, a culture of collaboration, shared financial incentives and joint accountability (Ham and Smith 2010). Perhaps the overarching driver for successful integration, therefore, is a shared will for integration to occur.

Current levers for change

Excitingly, levers have emerged recently that could be used to bring true integration to epilepsy care for children and young people. New legislation for children with disabilities was passed last year - with specific mention of epilepsy - bringing with it a legal obligation for education, social care and healthcare to work together and a requirement to make joint commissioning arrangements (Children and Families Act 2014). During this process, the presence of non-partisan political will, calling for the need for greater integration became apparent (Hansard 2014). Alongside this, there is a drive in NHS policy to tackle long-term conditions with particular mention of a need to reduce unplanned hospital admissions for young people with epilepsy (DoH 2013).

It seems that now is the time for the different agencies involved in epilepsy care to come together and form shared objectives in order to improve services.



Parents' and young persons' viewpoints

The following themes were apparent through interviews and questionnaires with young people and parents.

“It’s still really difficult as these services are not integrated...”

“You have no control as the parent... it’s not coherent, it’s not joined up in any way”

Difficulties in navigating system

These were common, with a widespread feeling that agencies tend to work separately and that the system as a whole is too fragmented to work effectively.

“We were expected to cope, and that’s what parents do - we just cope until it just gets too much”

“I tried literally everything, I wrote tons of letters, and they fell on deaf ears...and it wasn’t until I went to the local MP, and he spoke to somebody in government, and then it all changed”

The effect of this seemed to be that parents find the system **complex and hard to navigate**, with little signposting. Several parents mentioned that they had to find novel ways to circumvent this. One parent expressed his concern that, whilst he and his family had found ways to navigate the system, many may not be able to do so.

“What bothers me is that the people in this room are quite articulate and know how to fight their case...there’s a whole raft of people out there - perhaps English isn’t their first language, they don’t have the mental capacity to fight these cases...they’re just slipping through the net”

Many participants had experienced **difficulties in accessing an appropriate professional**, specifically in healthcare, even if their child was well-known to them.

“I didn’t have a specialist nurse until sixth form. I could really have used one in the run-up to my GCSEs, as they could have helped me deal with problems at school”

“If you change an appointment twice, you cannot have that appointment, and the consultant might strike you off. When you try to point out the difficulties and why, they’re not interested. I was told that I was threatening the health of my son, as I tried to change the appointment”

Many children and young people had also found contacting professionals difficult, but found that when access was clear and simple (for example to an epilepsy specialist nurse), that the positive impact could be felt throughout different aspects of their lives.

Resources

Another common theme brought up by parents was that of **funding**. Most parents interviewed had personal experience of difficulties in getting what they perceived to be the best care for their child and often felt that this was due to funding constraints.

“...although everybody recognised that our daughter needed this extra support, they weren’t prepared to give it to us for a financial reason”

“It seemed to be about budgets to keep him there, even when everybody said he needed special school”

Many parents felt this was not always directly due to a lack of funding, but finances were often misdirected, believing that the money spent on certain processes would be better served going directly to the care of children. This was widely felt to derive from a short-sighted approach. Most felt that providing appropriate care for a child - rather than denying them certain services - could save money overall.

“...they’ll spend money fighting us... They may as well have taken the money they’d spent fighting 5 or 6 parents, and put that money into a school that can specialise in epilepsy within the county”

“An OT joined after the last one left, and said “I’ve read his notes and he’s not getting what he needs”. In 3 months, she’s fixed it for us. That person has done an amazing job at saving them money”

Not hearing the voice of children and families

Most parents found the decision-making process around their child to be somewhat shrouded in secrecy. This seemed to engender a feeling that the priority of authorities is to deny funding. Some parents felt this was a deliberate ploy employed by certain agencies, typified by examples of misinformation which were felt to have delayed their children accessing appropriate services. The overall consensus was that **the voice of children and their families is not heard enough**.

“It’s always the people who make the crucial decisions - who you never get to meet, who never meet your child”

“These panels that make decisions about your child’s future: you’re not allowed to go, you’re not allowed to read what went on”

“...you get...to people who actually control budgets, but will never speak to you - you never get to speak to them, it’s always their PA, their secretary”

“If anyone has a child in their late teens, they need to do this (become the welfare deputy). My Local Authority told me not to do that. With my cynical hat on, I think “they don’t want me to do that, as I’ll throw my weight around”

Most parents interviewed said that they would relish the opportunity to be more closely involved. Without this, many felt there was often no adequate advocate for their child and, specifically, no way for professionals to view what life is like for their child.

“we took the iPad, and they saw that person on the iPad...totally different. Because you can't describe our children in black and white”

“When they're good they're good, when they're bad, you can't put it down in words... it's better to give a video”

A solution to this, used by some parents, was the ability to share videos of their child. This proved a popular suggestion, as participants felt that their child's needs would be more accurately represented.

“If you could show these individuals who're making a decision about your child a video of a seizure - I don't know what their impression of epilepsy is....”

“Our children don't fit the boxes on their forms”

Communication

Unfortunately, many parents and young people were able to give numerous examples of **poor communication**.

“I had this really condescending sister say “what's the matter dear? Are you frightened of epilepsy?””

“No-one had told us what form epilepsy would take”

However, there were also examples of the difference that good communication can make.

“You need to be given some sort of clue as to what could happen...one time, I went into his room and he was face down on his pillow. Why didn't they tell me that could happen? That's an avoidable accident.

“The reasons for starting each medication, and changing the doses, were explained well. We were always asked if we wanted to do these things - rather than this is what we are going to do. She is the only person through all of that who we felt listened to us”

Skills and training

Several parents and young people discussed instances where both healthcare and non-healthcare professionals displayed a **lack of appropriate skills or training**.

“We called NHS direct, then an ambulance, and by the time they got there he was up and walking around. They didn’t take it very seriously, they thought I’d got them out on a false alarm and weren’t particularly gracious about it”

“My husband got arrested having pulled our daughter out of the road after she’s had a seizure”

“My school did not understand epilepsy. I had absences, so if I had one at school I felt fine afterwards and could have continued on at school, but they would call my mum and ask her to collect me. I’ve worked it out, and that meant that over 5 years at that school I missed 60 days of schooling.”

However, there was also an appreciation of individuals’ efforts and the system constraints under which they have to work.

“They’re trained, they want to help people, and they probably get worn down from having to firefight”

A tailored approach

All parents called for services to be more flexible, **dependent on the specific needs of their children**. Whilst all gave examples of where this would be useful for their child, most also felt this could make assessments more efficient and hence be beneficial for professionals - and the system - in the long-term.

“It’s a one size fits all approach, which is wrong”

“My child refuses to get out of the car when we attend hospital, we go in to the department and say is there another way this can be done, can you come and see us?”

“Every time she goes to A&E, they spend 2 hours going through her medical history. “What was your pregnancy like?” ...with a 16 year old! The longer she’s kept there, the more anxious she gets and the less she’ll cooperate”

“We need more time than the average patient for outpatient appointments. You cannot have your standard 20 minutes”

Multi-professional forum

Barriers

Inherent to epilepsy

Epilepsy is unquestionably a complicated condition, and it was widely felt that this inherent **complexity** can often itself act as a barrier to optimal care. Whilst other long-term conditions may demonstrate a natural, and relatively simple, pathway of care that can be followed in a logical fashion, the nature of epilepsy - with its co-morbid associations and related problems - was not felt to easily lend itself to such a design.

“It’s so much more complex than diabetes in terms of the range, the spectrum of the epilepsies, and the types of people that it affects...it’s perhaps not surprising, is it, that it is difficult to get it coordinated, because of that complexity?”

The impact of chronic illness on mental health is well-documented; members of the forum reinforced the psychological and psychiatric associations with epilepsy.

“Epilepsy is different to the other long-term conditions, being a brain illness - in terms of the cognitive, education and learning, mental health facets...I mean those are all true for all long-term conditions, but probably 5 times more so for epilepsy”

“I think lots of teachers don’t actually understand that children with epilepsy do have learning and behavioural difficulties, and that’s actually part of the whole picture”

Similarly, participants confirmed the impact that epilepsy can have on a child’s education, over and above the effect one would find with other long-term conditions.

Likewise, another inherent characteristic of epilepsy mentioned as an obstacle to providing a suitable service was the spectrum of seizure types and epilepsy types that exist (indeed, having the same umbrella term of ‘epilepsy’ for such a range of children and young people was also viewed as a barrier, with all feeling ‘the epilepsies’ to be a more appropriate description). Many felt that this **heterogeneity**, meaning that no one child with epilepsy can be treated the same as another in terms of their needs, presents a difficult challenge for those seeking to provide adequate provision, across a range of different professional agencies. An example was the contrast between the input required for a child with infrequent seizures to that needed by a child with intractable epilepsy.

There was also specific mention of the changing nature of the impact of epilepsy on children - that is, needs will vary even for the same child over time.

“...it’s more the heterogeneity of it, so you can’t see one child and say “oh that’s the solution we need”

“What we want to be training them to do is how to pick up these other difficulties, how to notice the child who - at the age of 8 or 12 suddenly begins to start having difficulties in all these areas”

“...children with epilepsy change, epilepsy can come on at any age, and their learning issues and behavioural issues can come on at any age. They always say “right, well we assess them between 2 and 3, so they go into school, they’ve got their label and everything will be fine”

Resources

The inherent difficulties in providing a simple specification for the epilepsies was thought to, at least in part, account for an issue that was repeatedly mentioned; that of inadequate **funding** and finance. A condition like diabetes was acknowledged as lending itself well to being commissioned in the way it now is, with a best practice tariff that fits to a particular specification. It proved much harder to envisage the same for the epilepsies, in particular when seeking a unique coordination across health, social care, education and other professional agencies. Yet the consensus was that continuing to shirk a challenge like this, on account of its size and complexity, was unacceptable.

“With a young person with epilepsy, where it might be really helpful - as an example - to have neurodisability, neurology...in a joint clinic arrangement, that can be really difficult, because of different departments vying for different budgets”

“What we find with the parents who are trying to get education and health joined up is that they might get agreement from education, or they might get agreement from health, but getting health education and social care to agree a package of funding for a young person is very very complex and very very difficult, and our parents are having a very difficult time”

“Commissioning, particularly around epilepsy nursing, is very borough ring-fenced, and also for us to link in with schools, again it seems every borough ring-fenced”

“I think - at the moment in the sort of economic situation that we’ve got - money talks. And unfortunately epilepsy hasn’t got the money attached to it at the moment”

A related barrier raised in the forum was that of the epilepsies being viewed as a **‘Cinderella condition’** (a term used to describe the fact that the epilepsies are perceived to have been relatively ignored by policymakers and commissioners), and hence the necessary money has not followed. This raised a ‘chicken and egg’ scenario: has the necessary funding not been forthcoming because the epilepsies have not been prioritised, or have they not been prioritised because the current model of funding does not encourage this? Most felt the reality to be a mix of the two and that therefore the solution is one that addresses both simultaneously.

A **lack of human resources** was mentioned by many participants as a major barrier to achieving good care. Two areas in which this appeared to be most obvious were in the provision of epilepsy nurse specialists (with none in some boroughs in which participants worked) as well as psychology and psychiatry services. The former surprised some in the forum, given that national guidelines and standards state that access to an epilepsy nurse specialist is a vital component for a high quality epilepsy service.

“Everybody thinks that everybody else is just not taking their calls or not answering, but actually we’re all running around after our tails, trying to deal with everything”

Reasons offered for these deficiencies centred on a lack of funding and the need to push epilepsy up the agenda, in order that these resources are prioritised. Particular discussion took place around mental health provision which is not a problem unique to epilepsy. Yet, as pointed out by the psychiatrists and psychologists present, an under-appreciation of the marked association between epilepsy and mental health disorders significantly contributes to the lack of priority given to mental health provision as part of an overall epilepsy service.

Lack of data

A clear message from those present, whatever their professional background, was that not enough is known about the population of children and young people with epilepsy. It was widely felt that collating data and having access to this would have multiple benefits, not least that mapping the needs of children and young people in a given area would enable services to be designed and commissioned far more appropriately, accounting much better for the complexity and heterogeneity outlined earlier. Another advantage was thought to be the ability to learn from the data in terms of meaningful research.

“...how difficult it is to plan for a population when the people who’ve got the budget for the services can’t even look at the data!”

Participants argued that the problem of **lack of data** did not just reflect the need to know which children have epilepsy, but also to collect information pertaining to meaningful outcomes. Thinking in a condition-specific way, across a spectrum of professional agencies, forum members felt this should include health-related indicators (e.g. seizure control, hospital admissions), but importantly should also include educational measures (such as school days missed, performance) and a range of other relevant indicators (e.g. quality of life indices, experience measures). Participants believed that collecting such information would better enable system-wide planning and, with regular auditing, allow accountability, transparency and a measure of performance to be obtained. Importantly, such an ‘annual review’ would also allow an individual’s progress to be tracked and help enable a tailored service.

“...parents want the information shared, children want the information shared - it’s very rare for them to say “oh no, don’t share””

“On an individual basis, I think at every level - primary, secondary, tertiary level - we’re a bit of afraid of engaging, and of other people not engaging”

“The other question about systems and working together is how we communicate. ...we rely on faxes and letters, which often get lost, and we’re not allowed to email each other easily”

Communication issues

A significant barrier noted by participants working in the system was that of **poor communication**, something which has been a recurring theme in numerous previous reports looking at paediatric epilepsy care.

“It’s about how do we integrate the hospitals and the community better to care for these children? Because if you’ve got an epilepsy nurse in the hospital - well, what about the children who aren’t in the hospital? And if you’ve got one in the community, what about the ones in the hospital?”

A major contributor to this was thought to be **organisational barriers**, something which is well known as a problem within healthcare, but which was felt to occur even more frequently when considering all the relevant agencies in epilepsy care.

Skills and training

Many had experienced poor communication with schools and felt this was due to a **lack of training** amongst staff in education, and those from healthcare wished they had more opportunities to teach the necessary skills. However, several people mentioned specific difficulties they had with certain schools, and what they perceived as an unwillingness to engage with the need to learn these skills if the school had pupils with epilepsy.

“(Teachers) see the child as different and treat them medically, whereas actually often the seizures are the easiest bit in school to look after and it’s all the other sort of knock-on implications”

However, others acknowledged the competing demands on teachers, and found many schools had engaged well, instead offering **fear** of seizures and the potential need to administer rescue medication as reasons.

“We do these care plans for all of these children...and they’re only as good as the team that’re going to implement them”

“I went to a nursery to do training for a young boy who needed rescue medication, and when I got there they just outwardly said to me “well, we’re not giving that, we can’t give medication, it’s not in our job description...when I asked “do you give epi-pens?”, they said “yes””



Training issues were reported with all professional agencies, including social care who, despite often acting as an important link for families, were felt to not be equipped with the necessary training about the condition.

“I think they’re fearful...as soon as you mention the word epilepsy there’s a kind of a big barrier that goes up, because they don’t know what they’re dealing with”

“I think in instances where there are good referral pathways, and good links, these situations don’t usually arise, and I would like to think that it’s more that people don’t realise...and maybe that is an education thing”

Within healthcare, those professionals present thought that knowledge and skills were often not good enough - exacerbated by silo-style working between community services, secondary care and tertiary hospitals. The issue of ‘when to refer’ was mentioned repeatedly, despite the criteria for this being specifically laid out in guidelines and standards.

Guidelines and standards

Several members of the forum who worked in hospitals reported that, whilst guidelines and (NICE) Quality Standards were overwhelmingly a good thing, interpretation of them may have **unintended consequences**, acting as an unexpected barrier. An example given was that of children requiring hospital admission not always getting the same initial input when admitted under colleagues who did not have an ‘expertise in epilepsy’, who may instead wait for this particular consultant to decide on management. This was felt to be leading to unnecessary delays for patients to have investigations and management decisions they would previously have had promptly, regardless of which consultant first saw them.

“I think people are stepping back a little bit because they’re aware that these children should have input from a paediatrician with a special interest, but as a result they’re now not really getting any sort of service initially...”

Difficulties in navigating system

Many participants, in particular those who worked on a day-to-day basis with families, perceived the system as **unnecessarily complex and difficult to negotiate**. As a consequence, many felt that families who are not experienced (or with issues such as a lack of health education or a language barrier) can struggle to cope in a poorly signposted system.

“...parents have got directories of 15-20 professionals that they’re working with, and pretty much it’s a full time role”

“If you talk to parents, they’ll say to us that they’re always in constant fight mode, because everything they need they have to fight for...and until we get more integrated, and we understand better, it’s never going to get better for them, or their children”

Service users not involved

There was widespread acknowledgement that **the voice of the child and young person is not heard enough**, with an overwhelming consensus that to have this would have a positive effect on service improvement. Another recurring theme was that children and young people are often **not adequately engaged**, with the two very much entwined.

“Depending on the individual child or young person, some people want the whole school to...whereas another person will say “I really don’t want my friends knowing”, “I don’t want my teacher knowing””

“...we’ve just run some self-management training for young people, lots of young people came to it, with their families - of all different ages, teenagers as well as young people”

This was shown during the forum itself as, after participants heard testimony from a young person who had experience through the system (from birth through to transition to adult services), many referred back to this when giving their own feedback (i.e. hearing a young person’s perspective helped to pinpoint specific areas in need of improvement).

Attitudes to epilepsy

Many participants had found the prevalence of **cultural attitudes** to be an important barrier, such as certain beliefs that seizures were related to evil spirits, for example.

“I think education of the public is probably on important - and particularly culturally sensitive education”

“Historically it’s been almost a demonic, satanic connection... the brain is a very complex dynamic to try and understand”

“A young person wanted to go to scouts - they’d always wanted to go to scouts... and he was allowed to go to scouts, as long as he took his mother. Needless to say, he didn’t go to scouts”

Nearly all delegates had experiences where **stigma** towards epilepsy had been apparent. This seemed to be pervasive across all cultures in society and often appeared to relate to a **fear and lack of understanding** about the epilepsies - whether from individuals, sections of the community, or even whole organisations.

Enablers

When asked “what would help?”, delegates offered many suggestions, which fitted into the categories below:

Improving communication

All made clear the importance of **good inter-professional relationships**, both within their own organisations and across different organisations and disciplines. There was specific mention of the positive impact of **networks** (though experience of these seemed to be solely healthcare-based), with advantages including the sharing of good practice, a greater appreciation of different professional structures and the discussion of complex cases.

“What’s also important that people mentioned is relationships, and networks. You can cross institutional, and funding boundaries, if we all sit together like we are here today, and we talk we shouldn’t let our own institutional barriers and funding boundaries stop us actually improving care”

“The value of those relationships and knowing people on an individual basis...is incredibly valuable”

Participants said they would value **greater connectivity** between professionals, with a specific example being the sharing of videos of seizures (or suspected seizures) being difficult with available technology within the NHS. Forum members viewed such a potential resource as aiding timely, accurate assessment and diagnosis - therefore any means to facilitate this was welcomed.

“An electronic record...which is based on what young people want and they manage their own condition”

“...young people owning their own information and sharing that with others - rather than us being the leaders, they’re the leaders of their own healthcare and information”

A specific suggested improvement was for a **patient-held (or parent-held) record**. Such a tool was felt to have several advantages, not least as a means to help overcome fragmentation present across different agencies. Additionally, it was believed that the empowerment this could engender in the young person (or parent) could help increase engagement, compliance and allow for self-management strategies in the older child or young person.

This concept was thought to offer a way to help achieve better integration, in conjunction with **good pathways** which encompass all agencies involved in the care of children and young people with epilepsy.

“...people don’t realise the trigger points, so they go through a year and then end up reaching a crisis or 5 years and reaching a crisis...it’s knowing how to look at the whole journey, and knowing which are the trigger points”

Greater engagement with children and young people was also a focus, with a call for the formation of well-supported **young persons' and parents' groups** that would enable service users' voices to be heard, and their perspectives utilised to help shape services.

Better data

It was strongly felt that **accessible data** was key to helping improvement of services, with particular support for the continuation of **national audit**. However, most believed that what is also needed is a means of collecting data pertaining to one's population, with such mapping helping to enable the better tailoring of provision in a given geographical area. As such, the concept of an **epilepsy registry** proved popular, with perceived benefits to patients, families, commissioners and providers.

“It's just one way of drawing research, clinical activity and audit together if we can get an epilepsy registry”

A tailored approach

There was a unanimous call for a **new model of care** to be used in order to achieve greater integration between agencies, and to improve outcomes. Various elements for this were proposed: joint clinics, co-located services and outreach clinics all offered as potential solutions. Terms such as a 'wrap-around service' were also used to describe this envisaged model, all towards a way of taking into account the individual's unique needs and incorporating this into any such redesign.

“I think - to a certain extent - we need to move away from this pathway model, and see the services come to the child, so they don't feel they need to navigate anything, and so the health service wraps around them, and that we do the work and find out what fits for that child, rather than leaving the child or the parent to get lost in a complex system”

“...you have got to facilitate and promote teamworking around the child... that actually is just using the resource you have in a different way, and trying to make sure people are able to do their work around that goal, around that child in a cohesive and inter-related way”

“...coming back to the EHCPs, that is a real opportunity to sit round with the parents and child and talking about what outcomes are we looking for”

A big enabler for this type of provision was felt to be the **measuring of relevant outcomes**, relating to various indicators across all agencies.

These measures (e.g. experience measures, health outcomes and educational indicators) had in common that they reflected the many possible effects of this complex condition on a child's life and, when reviewed regularly, could be used to measure the progress of each and every child.

"...outcomes should be clinical outcomes, but they should also be functional outcomes...If every child with epilepsy, in our area, had an annual review reported on quality of life, patient experience and clinical measures, and that was reported year in year out - so you could actually compare with the child's previous year - then you will begin to see, I believe, improvement"

It was also acknowledged that recent legislation (Children and Families Act 2014) could be effectively leveraged using this type of model, with specific use of **Education Health and Care Plans (EHCPs)**.



Strategy

The forum acknowledged that all of the enablers mentioned required a **whole-system approach** and that central to this was the need for **strategic planning and leadership**. Many felt a large contributor to the 'silo-style' working and the organisational barriers that accompany it, has been the perceived competing interests of the different bodies involved in the care of a child with epilepsy.

“Epilepsy is only ever considered in a fragmented way, and what we’re recognising now is it needs to be not just health, but education, mental health as well...so really, the solution is going to be integrated beyond just health, but encompassing those other domains as well”

“...the strategic vision and push...that’s what we’re missing”

“We need to look at the whole population, and the whole pathway, otherwise we’re going to get it wrong - we’re going to make one area better, at the expense of other areas”

To break down these barriers, all felt there must be a realisation that these different organisations must work effectively together and not oppose each other. In essence, a shared goal of improving outcomes for children and young people must be prioritised above all else.

The forum felt that, historically, a major block to this joint working has been financial, with different organisations having separate budgets. All felt that a robust **health economic analysis** is needed to help prove the benefits and so encourage greater integration across the spectrum.

“When you’re trying to prove money saving, it’s family cost, it’s child cost, it may be education cost - which may not be recognised to the same degree as health cost...they’re all different bits of the package”

“...there probably would be a saving and improvement if one actually delivered care well in that cohesive and joined-up way”

Specific examples were given where interventions and benefits often do not occur within one domain: for example, the benefits of seizure control may result in savings in education, as well as healthcare itself; input from mental health services may enable greater educational achievement and arguably a much wider economic benefit when that young person reaches employment age.

“...talk of integration, and health and social care and education coming together seems to be an ideal opportunity to think about new models of funding”

“CCGs were brought in because they’ve got clinical leads, and actually, what’s driving the money should be about what clinically needs to be done”

“...actually, if you do it right, and you do it really well, it’ll be the cheapest in the long run, because of the return for that young person, and their future lives, and their ability to work, and their ability to be educated”

Summary

It has long been acknowledged that epilepsy services for children and young people are below-par. The reasons for this have been attributed to poor clinical assessment, inadequate communication and a lack of training - to name just a few of the commonly mentioned themes. However, despite some good efforts, the gap between where we are and where want to be, has persisted. In essence, this has been a failing system for some time. If we were considering a rare illness, then this would be enough of an indictment. In fact, we are discussing one of the common long-term conditions of childhood, with both serious short and long-term repercussions. The urgency to improve is clear. This report seeks to ascertain what has been holding back the system from getting better, what can help to drive lasting change, and how this can be best achieved.

Epilepsy can affect both physical and mental health, has an impact on education and behaviour that we are still getting to fully understand and often means that social care are needed to provide support. Given that some, or all, of these elements may be issues for any child with epilepsy, and that the relative mix of these will form a unique set of needs, it is surely imperative that all of the relevant agencies liaise well. However, in the experience of many children and young people, parents and professionals, the opposite has been true. The system is instead fragmented and organisations within it remain disparate. A new, clear strategy, borne from an integrated approach, must be the way forward. This report was developed to start this process, and ensure that all key stakeholders were involved in a unique collaboration. The key findings and recommendations are summarised overleaf.

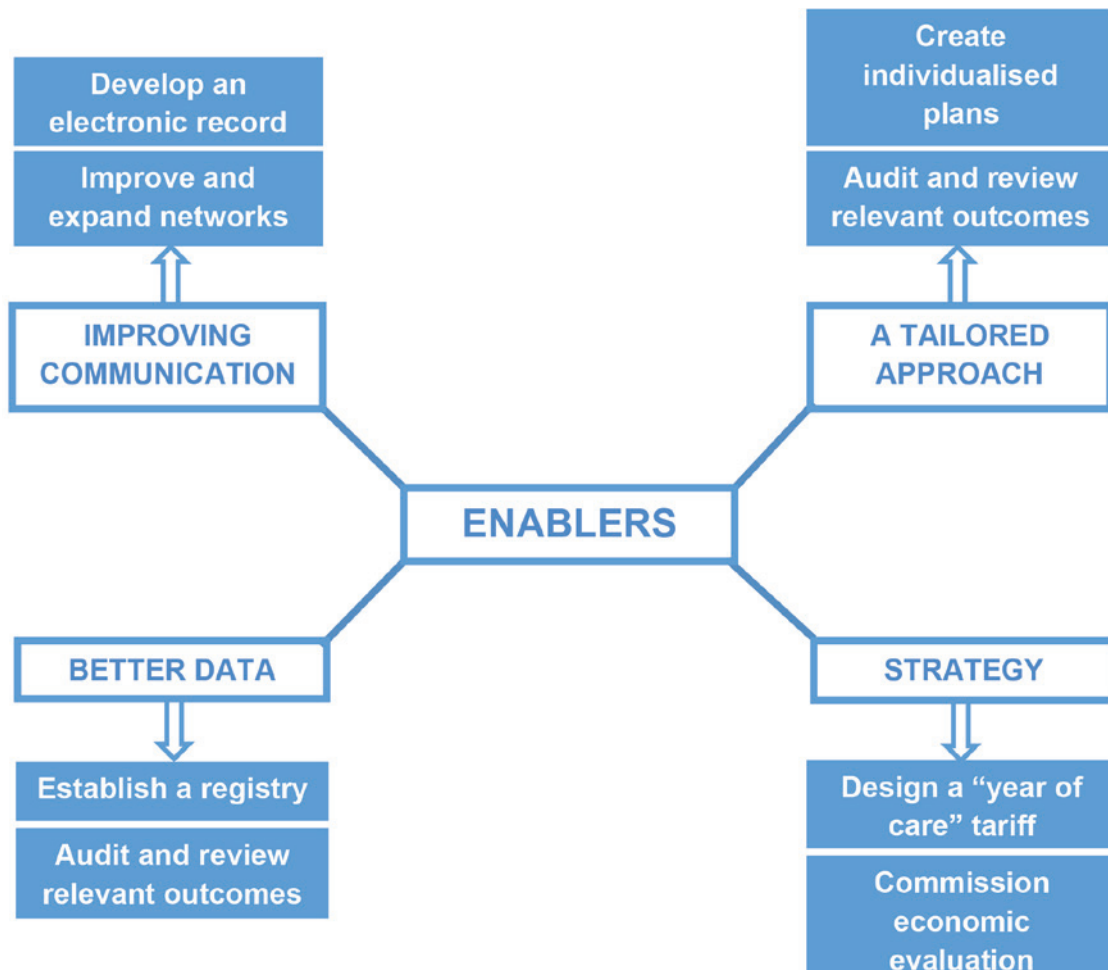


Key findings

- 1 Epilepsy care for children and young people continues to be inadequate, relative to clear consensus and national guidelines.
- 2 Previous attempts to improve epilepsy care have relied largely on local service improvement efforts, and hence any progress has been patchy.
- 3 It has long been accepted that the needs of children with epilepsy, along with the many professional agencies required to provide input, necessitates a multi-agency, systemic approach - but progress is simply not evident.
- 4 Any continued fragmentation of care will perpetuate poor care for children and young people.
- 5 Despite these barriers, professionals, young people and parents are all keen to see integration occur.
- 6 There are several enablers which would facilitate improvement in epilepsy care, and allow the gap between current services and desired standards to be closed.

Recommendations based on enablers

Any recommendations must be achievable. This analysis has attempted to align what needs to be done to the perceived enablers within the system.



Recommendations

- 1 Establish a registry of children and young people with the epilepsies**

This would allow professionals to learn about, and map, the needs of their population - informing the design and structure of services, and enabling crucial research.
- 2 Create an individualised plan for every child and young person**

This plan (Education, Health and Care Plan) must reflect their needs across a full range of professional services.
- 3 Develop a patient-held (or parent-held) electronic record**

As well as enabling better integration across different service organisations, this would empower young people to take greater control of their condition, and allow the use of helpful self-management strategies.
- 4 Design a 'year of care' tariff for the epilepsies**

This would better reflect complexity and heterogeneity of the condition and would allow commissioners to take a condition-wide view, encompassing the broad associations that are unique to the epilepsies (such as the impact on education and mental health).
- 5 Audit annual review of relevant outcomes for each child and young person**

These should be a mix of health-related, quality of life, functional and experience measures. It is imperative that regular national audits continue.
- 6 Commission economic evaluation of good epilepsy care**

A robust economic analysis would better map out the advantages of an integrated approach, and enable many of the other recommendations of this report.
- 7 Improve and expand networks**

Regional professional networks (reflecting all relevant professional agencies) aid integration by allowing regular liaison, and allowing them to communicate with policymakers with a collective voice. The organisation of young persons and parents groups should also take place on a similar basis.

Conclusion

This report can only be the first step in the improvement of epilepsy services for children and young people. Its findings and recommendations are a proposed set of shared goals towards this aim. Policy-makers and commissioners must take these recommendations and work together - in collaboration with professionals and with children, young people and their parents - to achieve lasting and transformational change. It is only through this process that we can deliver the type of service that children and young people with the condition deserve.



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