

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



# Introduction

Epilepsy is a common long-term condition amongst children and young people, affecting more than 1 in 200 in the UK. Epilepsy is far from purely a health condition; it has a wider functional impact. A child with epilepsy requires input from a combination of agencies to provide for the complex nature of their needs, including physical health, mental health, social care and education. Outcomes for children and young people with epilepsy are far from optimal. The systemic issues identified 15 to 20 years ago remain problems today. A combination of recently-passed legislation, NHS objectives and an increase in political will, all mean that the time is now right for meaningful, positive change to occur. In order to do this, a cogent strategy needs to be developed and the design of this must involve all relevant partners.

## Aims

This work brings together professionals from all backgrounds, along with the all-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?

**“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 five times more so for epilepsy.” – Professionals forum**

## Methodology

The report includes:

- A scoping review – encompassing peer-reviewed papers and grey literature from many relevant organisations and bodies
- Perspectives from children, young people and parents – via interviews and questionnaires
- Perspectives from professionals across all relevant agencies – this took the form of a professionals forum, with representation from healthcare (including mental health), education, social care, commissioners and health bodies.

The purpose of this approach was to:

- Obtain background and context from the history of services in the UK
- Define the standards to which epilepsy services should aspire
- Identify barriers and enablers that would enable lasting change, and the closing of this gap
- Establish a set of recommendations that could be taken forwards as a strategy to improve outcomes.

# Results

## Scoping review

Previous seminal reports have identified recurring themes around systemic deficiencies, which can broadly be summarised as:

- Unacceptable levels of misdiagnosis
- Inadequate communication
- A variation in care
- A fragmentation of services

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

It appears that - rather than representing a timeline of progress – the chronology of epilepsy care for children and young people has instead been somewhat circular. As such, despite efforts, little has been seen in terms of real improvement – with national audit data reinforcing this lack of progress. Only small steps have been taken in areas that required big leaps forward.

All sources acknowledged the importance of agencies in the system working together. However, no practical recommendations towards an integrated approach were found.

## Parents and young persons viewpoints

Thematic analysis of data from the interviews and questionnaires revealed the following themes:

### Difficulties in navigating system:

Services are complex and are hard to understand. Families often experience difficulties in accessing an appropriate professional.

### Resources:

Funds are scarce, but even those available are not always used appropriately.

### Skills and training:

Both healthcare and non-healthcare professionals need greater training in epilepsy, including the impact on children and families.

### Not hearing the voice of children and families:

Important decisions are made without involving children and families. Parents want the opportunity to be involved more, and to be able to advocate for their child.

### Communication:

Parents want clear information about their child from professionals, including what could happen in the future. Parents value good communication highly.

### A tailored approach:

A flexible system is needed, taking into account the specific needs of each child.

**“...you can’t describe our children in black and white. They can’t get their head around it. Our friends who’ve know her since she was born cannot understand what life is like 24 hours a day.”** – *Parents group interview*

## Multi-professional forum

Thematic analysis of the professionals forum revealed the following barriers and enablers:

### BARRIERS

<b>Inherent to epilepsy:</b> <ul style="list-style-type: none"><li>• Its complexity and heterogeneity</li></ul>	<b>Skills/training issues:</b> <ul style="list-style-type: none"><li>• Lack of training</li><li>• Fear amongst some professionals</li></ul>
<b>Resource issues:</b> <ul style="list-style-type: none"><li>• Lack of funding and human resources</li><li>• Perceived as a 'Cinderella' condition</li></ul>	<b>Guidelines and standards:</b> <ul style="list-style-type: none"><li>• Interpretation of these can actually lead to gaps in care</li></ul>
<b>Communication issues:</b> <ul style="list-style-type: none"><li>• Poor communication between professionals, exacerbated by organisational barriers</li></ul>	<b>Difficulties in navigating system:</b> <ul style="list-style-type: none"><li>• Unnecessarily complex and difficult to comprehend</li></ul>
<b>Lack of data:</b> <ul style="list-style-type: none"><li>• Relevant outcomes not available</li></ul>	<b>Service users not involved:</b> <ul style="list-style-type: none"><li>• Voice of the child and young person is not heard enough</li><li>• Not adequately engaged</li></ul>

### ENABLERS

<b>Improving communication:</b> <ul style="list-style-type: none"><li>• Good inter-professional relationships</li><li>• Networks</li><li>• Greater connectivity</li><li>• Patient-held (or parent-held) record</li><li>• Good pathways</li><li>• Young persons and parents groups</li></ul>	<b>A tailored approach:</b> <ul style="list-style-type: none"><li>• A new model of care</li><li>• Measuring of relevant outcomes</li><li>• Education Health and Care Plans (EHCPs)</li></ul>
<b>Better data:</b> <ul style="list-style-type: none"><li>• Accessible data</li><li>• National audit</li><li>• Epilepsy registry</li></ul>	<b>Strategy:</b> <ul style="list-style-type: none"><li>• Whole-system approach</li><li>• Strategic planning and leadership</li><li>• Health economic analysis</li></ul>

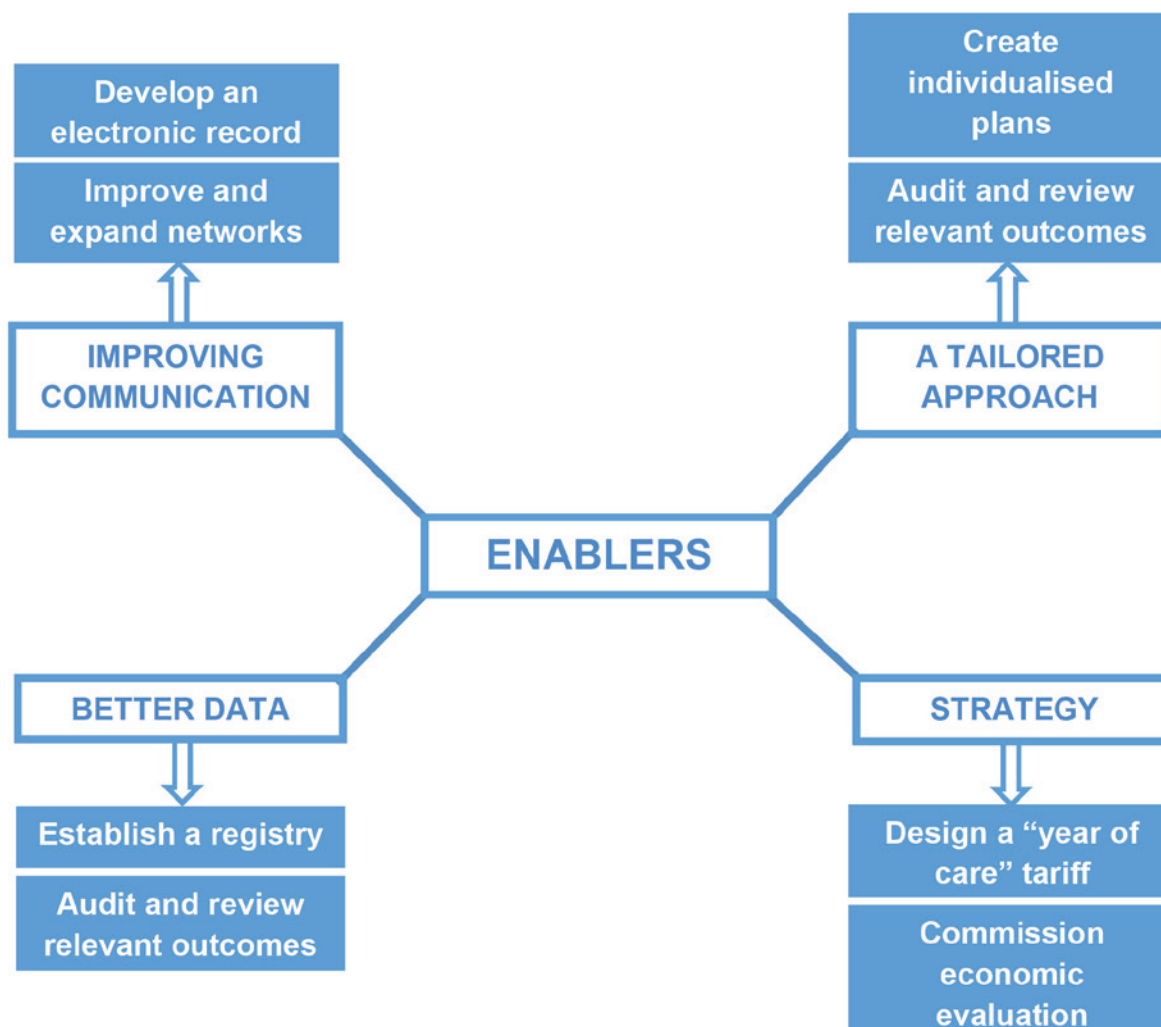
**“It’s usually when it hits a crisis that the child gets looked at as a whole, rather than being pro-active.” – Professionals forum**

## 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.

**“It’s a one size fits all approach, which is wrong.”** – *Parents group interview*

## 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).

**“Our children don’t fit the boxes on their forms.”** – *Parents group interview*

## 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.

**“...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.”**  
– *Professionals forum*

**“There probably would be a saving and improvement if one actually delivered care well in that cohesive and joined-up way.”** – *Professionals forum*

## 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.

**“...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.”**

– *Professionals forum*

# Summary

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.

## Acknowledgements

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- **Professor Helen Cross** (*The Prince of Wales's Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology, UCL-Institute of Child Health, Young Epilepsy*)
- **John Cowman** (*Director of Operations, Young Epilepsy*)
- **Professor Monica Lakhanpaul** (*Programme Director - Integrated Children, Young People and Maternal Health Programme, UCL Partners; Professor of Integrated Community Child Health, Population, Policy and Practice, UCL-Institute of Child Health*)
- **Dr Kerry Robinson** (*Consultant Paediatrician, Whittington Hospital*)
- **Dr Amit Bali** (*Darzi Fellow*)

### 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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