



Lack of mental health support real concern for children with epilepsy – new audit

- RCPCH reveals areas in England and Wales with best and worst paediatric epilepsy services
- RCPCH lists twelve recommendations for Health Boards and Trusts to improve upon
- Epilepsy charities highlight key improvements, but raise concerns over a lack of dedicated support services for mental health care

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Many children and young people with epilepsy in England and Wales are not getting enough mental health support, or receiving comprehensive, routine care planning.

This is according to the latest national audit report released by the Royal College of Paediatrics and Child Health (RCPCH). The 'Epilepsy12 National Audit' is designed to measure epilepsy care for children and young people against national guidelines and standards set by the National Institute for Health and Care Excellence (NICE). The last Epilepsy12 National Audit Report was published in 2014.

The report raises key issues around access to mental health provision, as well as poor referral pathways from childhood into adulthood.

- Established research shows that children with epilepsy are four times more likely to experience a mental health problem than their peers. The Epilepsy12 report found however that almost 90% of Health Boards and Trusts do not facilitate mental health provision within epilepsy clinics.
- More than a quarter of Health Boards and Trusts do not have an agreed referral pathway to adult services.

There were also concerning figures around care planning, with almost a quarter (23%) of all Health Boards and Trusts failing to provide routine and comprehensive care planning for children and young people with epilepsy.

However, there are promising signs in other areas. Whilst almost a quarter of Health Boards and Trusts are still unable to provide any access to Epilepsy Nurse Specialist support for their children, the overall number of Epilepsy Nurse Specialists employed across England and Wales has increased significantly since 2014.

These Epilepsy Nurse Specialists provide key information and support for children and young people and their families, including rescue medication training for parents and schools.

With the Epilepsy12 report key findings in mind, epilepsy charities are encouraged to see a positive progression towards better provision of epilepsy services for children and young people. However, they still see obvious gaps across Health Boards and Trusts within regional paediatric epilepsy networks which need to be filled.

In the report, **Professor Anne Greenough, the RCPCH Vice-President in Science and Research**, writes:

“This report highlights some improvements in areas of paediatric epilepsy service provision. More, however, needs to be done to address the variation in care between regional paediatric epilepsy networks.”

Mark Devlin, Chief Executive of Young Epilepsy, which was part of the Epilepsy12 Project Board, says that:

“Every child and young person with epilepsy should have access to the best levels of care, but sadly there are still too many areas of the UK where children living with epilepsy are not getting the range of services they need. Focus on getting this right is vital.

Whilst we welcome the audit evidence that some positive progress has been made nationally in children with epilepsy getting the right support, there is still much work to be done.”

Philip Lee, Chief Executive of Epilepsy Action which is also represented as a key stakeholder organisation on the Epilepsy12 Project Board, said:

“It is encouraging to see that clear improvements have been made in some areas of children’s epilepsy services. Despite this, there are still too many children and young people with epilepsy whose health, wellbeing and safety is being put at risk. There needs to be a strong focus on good care plans and support between appointments to improve epilepsy services and outcomes for young people.

The report does a good job of highlighting best practice in this area and provides an opportunity for those services that are still lagging behind to step up. We hope that this report, together with the NHS’s recently announced plans to create clinical networks to improve the quality of care for children with epilepsy, will provide an incentive for improvements across the board. Acting on the recommendations in this report and sharing best practices would represent an important step towards reducing health inequalities and improving the lives of children and young people with epilepsy.”

-ENDS-

NOTES TO EDITORS:

Link to Epilepsy12 Audit: <https://www.rcpch.ac.uk/resources/epilepsy12-national-organisational-audit-report-2018>

Regional stats are available upon request. Please contact any media contact below to arrange compilation, or download the Audit, along with the 12 recommendations by clicking on the link below.

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