



Child Health and
Wellbeing Network
North East and North Cumbria

Epilepsy Project 2:

Exploring Mental Health and Psychology Support for CYP with Epilepsy

Executive Summary

October 2022

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Background

The Child Health and Wellbeing Network (CHWN) supports the delivery of the Children and Young Person's (CYP) Transformation Agenda and Improvement for services for CYP with long term conditions, including epilepsy. This report baselines current services to identify good practice and inequity in our region.

This improvement programme of work runs simultaneously with Epilepsy Project 1, which focusses on the referral pathways and access to tertiary services/surgery, transition and variation in care based on the analysis of the Epilepsy 12 indicators and soft intelligence gathered from each of the NHS Foundation Trusts in the NENC footprint.

The project was undertaken between October 21 and April 22 and represents example of close collaboration between primary, secondary and tertiary care and also the inclusion and involvement of wider stakeholders including education partners.

Findings and Recommendations

The scoping and exploration exercise has highlighted some areas of good practice and good intentions and a clear willingness amongst professionals working with CYP across the system to improve the availability and quality of the mental health support they provide to CYP with epilepsy. Key positive findings are:

- Education Mental Health Support Teams are becoming established across the geography to **improve the offer** in school settings.
- Most education and primary care professionals, Epilepsy Specialist Nurses (ESNs), clinical leads and mental health leads **recognise the correlation** between epilepsy and mental health needs and epilepsy and cognitive needs.
- Most professionals felt **confident in identifying mental health needs** but were less confident when CYP had multiple or profound needs.
- **ESNs continue to provide a pivotal role** which, with improved resource and oversight could be enhanced to provide further mental health support/appropriate co-ordination, colleagues are well placed to be able to provide support to CYP and families.
- The **importance of screening is recognised** amongst all professionals but a local consistent use of setting specific/appropriate evidence-based screening tool is lacking.
- **ESNs and clinical leads attempt to support parents and carers** and spend significant time giving this support.

However, the project has revealed some critical gaps and variation identified are in relation to availability and access to mental health and psychological support. These are summarised below:

- There is **significant variation in relation to the mental health services available**, referral pathways and eligibility criteria in each of the different localities in the NENC footprint. Further work is required to articulate this at locality level
- **Very few epilepsy services have access to health psychology** as part of multi-disciplinary epilepsy clinics
- There is **variation and significant limitations in relation to communication** and interaction between school and hospital clinic-based teams

- There is no **commonly agreed screening tool** appropriate for use in each setting
- Workforce across the system would benefit from **further training** about mental health needs and cognitive problems in CYP with epilepsy
- There are **variations and limitations in relation to the pathways and processes** for referral for more specialist mental health support where lower-level interventions are ineffective or the mental health needs are beyond the expertise of the practitioner
- There is **inequality of access** for CYP with epilepsy to ESN and limitations to the training support and oversight for the ESN role
- There is **inequality of access to appropriate mental health assessment, screening and support** and workforce and interdisciplinary arrangements may need further review.
- **Information available for CYP and families is limited and inconsistent**
- There is **limited involvement of CYP and families** in relation to the service improvements required

This report identifies a series of recommendations for the improvement in paediatric epilepsy services and care which include development to multi-agency systems and processes to improve mental health assessment, screening and support, remove or reduce variation and to improve experience and outcomes for CYP and their families.

The areas for improvement fall broadly into the following categories which are the areas of focus that have been identified nationally.

- 1) **Mental health screening and access to psychosocial support**
- 2) **Access to tertiary services including surgery**
- 3) **Transition from paediatric to adult epilepsy services**
- 4) **Variation and inequality of epilepsy care**

The main vehicle to progress this work will be through the development and establishment of the strategic relationship between the Paediatric Epilepsy Network, North East and Cumbria (PENNEC) and CHWN. A key part of this will be to ensure that PENNEC has the necessary representation and lines of influence, as well as prioritising the recommendations of the report through this forum.

Following the further development to accountability and governance arrangements within PENNEC their role will be to support to develop service improvement plans and operationalise relevant recommendations. This work is planned and underway with the support of the Chair of PENNEC

For more information and to read the full report click [here](#)

To become involved in the continuation of this work or for further information please contact the team at england.northernchildnetwork@nhs.net