

# Epilepsy12 Quality Improvement Case Studies 2023

## Cambridgeshire Community Services NHS Trust

We wanted to improve attendance at epilepsy clinics and reduce the burden associated with hospital appointments, particularly for children with specialist educational provisions.

We recognised that children and young people with autism spectrum disorder and learning disabilities have higher rates of epilepsy than the general population. Children with early onset refractory epilepsy often have developmental needs and many of these children are in special education settings and are looked after by support workers while at school.

Hospital attendance for children with additional developmental needs can be challenging for children and families and results in both being out of education or work. These children often have multiple hospital visits and families incur much cost of travel and loss of work. Furthermore, parents of children with neurodisabilities frequently have their own learning needs and face increased financial constraints.

The team felt that delivering epilepsy care in schools would:

- Allow clinicians to gain holistic picture of a children's needs between home and school.
- Minimise miscommunication and help schools support children with epilepsy.
- Be financially viable due to the numbers of patients co-located in a single setting.
- Reduce cost and carbon miles for families.
- Allow community paediatricians providing epilepsy reviews to identify and support relevant comorbidities for the child, family, and school.

Cambridge University Hospital NHS Trust supported a service level agreement for two community paediatricians with an interest in epilepsy to deliver outreach epilepsy care in school as part of the secondary care epilepsy team. We also provided an epilepsy specialist nurse to support the outreach clinics.

70 children were identified from the secondary level epilepsy service that attended three SEND schools in south Cambridgeshire. Children were grouped together and outreach clinics in school were arranged. The children were seen in school with the paediatrician and epilepsy specialist nurse. The class teacher or teaching assistant accompanied the child to a clinic space in school. Parents were given the option to attend in person or virtually. Parents were also given the contact details for the epilepsy specialist nurse.

## **Outcomes**

As a result, better links were made between schools, teachers and community paediatricians, with better support offered for non-urgent care plans. Overall, clinicians were provided with a more holistic picture of the children.

Children spent less time out of school and were more relaxed, as were parents, it was possible to observe children in their own environment. Parents found it easy to attend and liked the option of virtual assessment, meaning they did not have to take time out of work or arrange childcare for siblings. Parents liked the new approach, as did the schools and teachers, attendance was better than in-hospital clinics.

Schools were able to contribute to the picture and assessment of seizure burden in school. Education providers participated in management decisions and gained more insight and confidence in epilepsy care. They were able to support parents with changes in medication or emergency plans and could reinforce any discussions.

Involving the community paediatricians was helpful in identifying additional comorbidities. The ESN was able to support schools and families outside of clinic time. The children seen in outreach clinics had easy access to the extended epilepsy team as and when needed.