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Topic: Epilepsy: Diagnosis and Investigations

Content English

Title: CHECC (Child and young person Epilepsy Concerns Checklist) to identify wider needs of epilepsy patients

Objective: CHECC was sent to certain families and education providers for children and young people with epilepsy. These were seen in a DGH epilepsy clinic supported by a neurodisability epilepsy paediatrician and epilepsy nurse. CHECC aims to facilitate information sharing between education and epilepsy services to identify concerns relating to epilepsy, neurodevelopment and mental health. It also allows professionals to confirm support that is in place such as special educational needs provision. CHECC also serves to highlight areas that require further evaluation such as intellectual (learning) disability (LD), autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) and developmental coordination disorder (DCD).

Methods: CHECC was developed with input from parents, epilepsy charities and professionals including paediatric neurologist, neuropsychiatrist, psychologist, epilepsy nurse, general and neurodisability paediatrician . Three different versions of the checklist were created (parent/carer, education and young person version). Different questions were included in each version. All checklists had a specific space to set their top three goals. Checklists were received from education professionals for 41 patients.

Results: The main areas of difficulty identified by CHECC related to the following: mood and behaviour 20 individuals; attention and concentration 32; communication and social interaction 25; learning and intellectual development 29. 16 Individuals had additional SEN (special educational needs) support. In 22 cases there were clear areas for evaluation, support and goal setting stated. Following or accompanying the CHECC, more focussed information gathering and evaluations were completed. These were associated with the following outcomes: 5 formal cognitive assessments confirming LD and 2 awaiting outcome; 5 ASD, confirmed, 2 in progress. 6 individuals diagnosed ADHD/ADD and 2 individuals diagnosed with DCD

Conclusions: This pilot study indicates that CHECC is an efficient and effective way of enabling education providers to highlight any broader concerns to the epilepsy team, without the need for multiple screening tools. We aim to develop the project further with online versions of each checklist.

Keywords: Epilepsy, neurodevelopment concerns, ASD, ADHD, DCD, Learning disability,

Conflict of Interest Disclosure

I (or a member of my immediate family) have/has not received any benefits by a commercial company or institution.