

Submission
No 431

INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

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EPILEPSY ACTION
A U S T R A L I A

Submission to the NSW Legislative Council
General Purpose Standing Committee No.2

*Inquiry into the provision of education to students with
a disability or special needs*

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1. Summary and Recommendations

Epilepsy is a disability which is associated with much stigma and misunderstanding. Misunderstanding and lack of education about the impacts that epilepsy can have on learning have led to many children missing the school support required to assist them to achieve to their capacity. Some of the neurological effects on cognition can be subtle or be misinterpreted as 'day dreaming' or 'poor behaviour'. Lack of early identification and support for these learning needs can have profound consequences on the student's learning as well as on the social and emotional experience of school.

Learning can be impacted by:

- Neurological location of the seizure activity
- Type of seizure
- Frequency, duration and age of onset of epilepsy
- Reduced learning opportunities
- Side effects of anti-epileptic medication
- Disability in association with epilepsy
- Psychosocial impacts of epilepsy

Following consumer consultation, interviews with subject experts and review of international best practice, EAA makes the following recommendations:

- Inclusion of epilepsy as a category in the Department of Education and Training (DET) Disability Criteria (school sector)
- Development of an Individual Education Plan for every student with epilepsy – to be developed alongside the already compulsory Individual Health Care Plan
- Access to specialist learning assessment by a neuropsychologist or paediatrician
- Interagency collaboration
- Case Management
- Teacher training

2. Background to Epilepsy

*It is doubtful if there is any other medical condition so universally neglected, due to a combination of social stigma, low profile and lack of resources.*ⁱ

It is estimated that over 440,000 people in Australia will be affected by epilepsy during their lifetime, with more than 140,000 of these children and adults residing within NSW. Although exact figures about the number of children with epilepsy in NSW schools is difficult to measure, predictions of incidence suggest up to 26,000 children aged between 0 and 14 years in NSW will be diagnosed with epilepsy at some time in their lifeⁱⁱ. Epilepsy is a disorder characterised by spontaneous, recurrent seizures and can affect any one at any time, regardless of age, gender, level of intelligence, culture or background.

There are many types of epilepsy and seizures can range from a brief loss of awareness (absence seizures), or altered awareness producing a vague, confused or dreamlike appearance with inappropriate random and repetitive behaviour (complex partial seizures) to a complete loss of consciousness with involuntarily jerking movements of the limbs (tonic clonic seizures) causing the child to experience a period of confusion and drowsiness after the seizure.

Epilepsy can be severely disabling for some people impacting their capacity to live a meaningful, independent life. While advances in anti-epileptic medications have assisted a large number of people, around 30% of people with epilepsy will not respond completely to medication and many have more than 20 seizures per day.

3. Impact on learning

Two-thirds of children and young people with epilepsy in mainstream schools underachieve academically in relation to their intellectual skillsⁱⁱⁱ.

Studies have shown that up to 50% of children with epilepsy require additional support at school.^{iv}

The impact of epilepsy on a student's learning and independence varies due to multiple factors. Generally however, students can be classified in one of the following ways:

- Some children with epilepsy experience no difficulty with cognition and learning and make good academic progress in mainstream classes without any special supports^v.
- Many children with epilepsy experience fluctuations in cognition and learning as a result of seizures or as a consequence of treatment for epilepsy. These children would benefit from additional support to ensure they do not fall behind their peers.^{vi}
- Others experience permanent impairments to memory and thinking ability which require ongoing and specialised support.^{vii}

It is the experience of EAA that the category of children with permanent impairments or additional disabilities is well supported within the school systems. The category of children, however, with fluctuating impacts on cognition and function is not so well understood and these children often miss vital support and learning opportunities.

3.1. Causes of learning difficulties

3.1.1 The neurological location of the epilepsy

The impact of seizure activity on cognition and learning is different for each individual depending upon type and location of the seizure activity. Evidence-based research has enabled the following generalisations to be made:

- students with left temporal lobe seizures may have difficulty with verbal processing, including comprehension, rote learning and memory

- students with right temporal lobe seizures may have difficulty with independent work, sequencing tasks and visuospatial ability
- temporal lobe epilepsy is associated with poor memory function
- frontal lobe epilepsy impacts on executive skills, such as planning and organising.^{viii}

Clearly, from the above examples, students with epilepsy may have difficulty with a range of classroom tasks including mathematics, reading, spelling and comprehension, speech and language, memory tasks, perceptual abilities, speeded tasks and tasks requiring complex information processing, concentration and attention, numeracy and problem solving.^{ix}

3.1.2 Seizure Type

The various types of seizures can impact a student's learning in a variety of ways for example:

- Seizures which result in a loss of consciousness, such as tonic clonic (grand mal) seizures, can disrupt cognitive functioning and alertness for several days
- Tonic-clonic seizures are often followed by a period of tiredness and inattentiveness
- Generalised seizures (seizure activity involving both hemispheres of the brain) can impair sustained attention.
- Partial seizures (seizures involving one hemisphere of the brain) can impair selective attention, memory, psychomotor speed and word finding ability
- Seizures and epileptiform discharges occurring during sleep can disrupt brain function and cause tiredness which effects learning ability the next day.^x

3.1.3 Frequency, duration and age of onset of epilepsy

The frequency of seizures can vary from multiple times per day to rarely. This variation will significantly affect the impact of the seizures on learning. For example absence seizures can occur multiple times per day. They may not be apparent and are often misinterpreted as day dreaming, inattentiveness, poor concentration or hearing problems.^{xi}

The age of onset of epilepsy also has an impact on learning. For example, early onset partial epilepsy is often associated with poorer language skills.^{xii}

Fluctuating levels of functioning, also common among children with epilepsy, have a major impact on learning.^{xiii} Regression of skills can also be experienced as a result of seizure activity in the brain.^{xiv}

3.1.4 Reduced learning opportunities

He can lose understanding of words for hours at a time. When not affected by seizures, he is considered gifted academically. This makes it harder for people to believe he has epilepsy^{xv}

Children with epilepsy can fall behind in learning as a result of the cumulative effect of missed learning opportunities. Children with epilepsy often experience a period of drowsiness and

tiredness following a seizure and take time to recover.^{xvi} For this reason lost opportunities for learning not only occur during the seizure but for a period of time following.

Seizures may also result in increased absence from school. As well as the seizures themselves, medical appointments are a cause of absenteeism. Children may also try to miss school to avoid activities where they may need to explain why they can't participate, because of anxiety about having a seizure in public or as a consequence of bullying or feelings of isolation.^{xvii}

3.1.5 Side effects of anti-epileptic medications

Even the successful treatment of epilepsy may have long term effects on quality of life, with some medications having serious side effects, such as memory impairment, visual disturbance, altered behaviours, reduction in bone density and unrelenting weight gain.

Other common side effects of anti-epileptic medications include fatigue, dizziness, nausea, irritability, restlessness, sleep disturbances, hyperactivity and drowsiness.^{xviii} These side effects affect attention, concentration and information processing. Side effects vary among different medications and between individuals.

3.1.6 Disability in association with epilepsy

Children with epilepsy may have other intellectual, physical and sensory disabilities. Common comorbidities include autism, cerebral palsy, Angleman Syndrome and Down's Syndrome.^{xix}

Attention deficit hyperactivity disorder (ADHD) is more common among children with epilepsy than children in the general population.^{xx} Symptoms of attention deficit hyperactivity disorder (ADHD) are reported in up to 40% of children with epilepsy.^{xxi} Hermann et al (2008) found deteriorating executive functioning over a two year period among children with epilepsy and ADHD. This deterioration was caused by poor attention and concentration. This contrasted with control groups which showed considerable cognitive development during this time.^{xxii}

Evidence suggests there is a strong relationship between epilepsy, which is difficult to control medically, and learning disabilities. Around 15% of people with epilepsy have a learning disability while around 30% of people with learning disabilities have epilepsy.^{xxiii}

3.1.7. Psychosocial impacts of epilepsy

There are various reasons why epilepsy is often associated with increased levels of anxiety and depression including:

- The unpredictable nature of seizures. One parent expressed that *'at any time my child could have a life threatening episode'*. Many children and their siblings share this fear.
- Fear of embarrassment from having a seizure in front of peers.
- Bullying or harassment as a result of the diagnosis or after having had a seizure in public. The Joint Epilepsy Council of Australia (2007) reports that than half of Australians with epilepsy experience discrimination, most commonly in the workplace or in education.

- Psychological distress, reduced self esteem and non-participation related to drug induced obesity.
- Misunderstanding by teachers about the impact of epilepsy and the supports required.
- Sense of isolation if the student is avoided by peers at school or excluded from group activities such as school excursions, overnight camps, swimming or other physical activities.

Children with epilepsy have approximately double the rates of behavioural and psychiatric disorders compared to the general population.^{xxiv} Anxiety disorders and depression are common, although they may remain undiagnosed and untreated. Ott et al (2003) found approximately 60% of children with epilepsy had a psychiatric diagnosis. The majority of these children (more than 60%) had not received any mental health treatment.^{xxv}

Discrimination and stigma associated with epilepsy contribute to emotional and adjustment difficulties. Poor self perception and self esteem of the child can impact on motivation to learn and willingness to attend school, and can lead to behavioural problems that impact on learning.^{xxvi}

In a study of children with epilepsy and 'normal' IQ, Sabaz et al (2001) found that, compared with their peers, children with epilepsy are more likely to have emotional and behavioural problems and to be less competent in socialising and school performance.^{xxvii} Neville found that at least half of the children with epilepsy had problems with school progress or behaviour.^{xxviii}

4. The NSW education system - experiences of children with epilepsy and their parents

Parents report varying levels of understanding and different approaches among teachers and schools to the needs of their children with epilepsy.

Consumer consultations conducted by Epilepsy Action in 2009 revealed that one of the main concerns of parents was finding an appropriate school. Parents' experiences were that schools differ markedly in their ability to accommodate children with epilepsy. It was difficult to identify the 'good' schools.

"It is absolutely overwhelming to know where to start to look for a school. I would need to be counselled through the decision"

"There is no one to assist with finding a school. I don't understand the different systems and levels of support – what does it mean my child would actually receive?"

"I would like to know what a particular school has to offer, I wish there was an easy way to find this out, rather than us having to go around and ask everything"^{xxxix}

Common challenges for the school and student include:

4.1. Understanding the specific nature of epilepsy

Lack of understanding can result in misinterpretation of learning and memory problems. A child may be blamed for not remembering instructions and for being disobedient, and this may result in inappropriate and unfair treatment of the child.^{xxx}

“Before he got the diagnosis, he was labelled as ‘bad behaviour’. Some teachers still don’t fully believe he is not always in control of his behaviour.”^{xxxvi}

When I went to school it was actually not recognised as being epilepsy, it was just me basically staring into space and the teachers never sort of picked up on it, they just used to comment, or I got bullied at school by other kids who said, “Oh, she’s staring at me. Why?”^{xxxvii}

4.2 Responding to student needs

Frequently parents find it difficult to know where to turn for help:

“I was told there is no money available to get him help at school. Sometimes I wish he had an additional disability then at least he’d be eligible for some support at school.”

“You have to learn how to play the system – no one helps you understand what supports are available. I know I have to exaggerate his other disabilities, additional to epilepsy, to get more support”.

*“I was told my child **only** has epilepsy so there is no help. **Only** epilepsy! He needs support”^{xxxviii}*

“..... I asked for special consideration for my exams. My teacher said that I didn’t need it, I should just study hard and I would be OK. I got tired and anxious and I had a seizure during the first exam. I didn’t sit any more [exams] and didn’t complete [school] that year. Later I had neurosurgery and I no longer have seizures but it was a long time before I got to uni.”^{xxxix}

4.3 Expectations of children with epilepsy

Students with epilepsy can be incorrectly stereotyped as poor learners, resulting in lower levels of academic achievement and reduced life opportunities.^{xxxv}

4.4 Overprotective approaches

Overprotective approaches can increase feelings of isolation and episodes of peer avoidance or bullying if children with epilepsy are excluded from activities.^{xxxvi}

“One of his schools would not let him do anything for safety reasons. The school he goes to now includes him in everything. The level of inclusion is very dependent on which school you go to”.^{xxxvii}

5. Support within the NSW education system

The challenge for the education system is to recognise and respond in a timely manner to the varied and changing needs of individual children with epilepsy.

Because of the varied manifestations of epilepsy, the support needs of students with epilepsy are difficult to predict based on diagnosis alone. DET NSW clearly recognises the medical aspect of epilepsy and makes it compulsory that every student with epilepsy has an 'individual health care plan' outlining actions to be taken in event of a seizure. Unfortunately, the requirement for learning support for children with epilepsy is not routinely assessed. Currently children with epilepsy would need to have an additional disability such as autism or intellectual disability to automatically be considered for integration support funding. The other avenue for support within NSW DET is for children to have evidence that their condition is 'impacting greatly on educational outcomes'^{xxxviii} before they would be considered for additional support.

It is the belief of EAA that if we are to prevent another generation of children with epilepsy from failing to achieve their full potential, we need to provide timely support to prevent them from falling behind, rather than waiting for evidence that there is a great impact on their educational outcomes.

DET's commitment to each student is to 'provide the knowledge, understanding, skills and values for a productive and rewarding life'^{xxxix}. EAA believes that early detection of the support needs of students with epilepsy is crucial in enabling the school system to honour this commitment.

6. International Experience

The National Centre for Young People with Epilepsy (NCYPE) states that in the United Kingdom, epilepsy is not currently recognised as a special educational need despite having a devastating effect on children's education^{xl}. The UK All Party Parliamentary Group fully endorsed the adoption of the Code of Practice for Children with Epilepsy^{xli} which would see all students with epilepsy routinely monitored for learning within the education system.

In contrast to the approach taken in NSW and in the UK, epilepsy is recognised as a disability in the United States under the *Individuals with Disabilities Education Act (IDEA)*^{xlii}. This Act enables children with epilepsy to gain special education and support services. IDEA states that limited alertness as a result of epilepsy is recognised as an impairment which can adversely affect educational performance.^{xliii}

7. Recommendations - Educational support needed by children with epilepsy

7.1 Inclusion of epilepsy as a category in the (DET) Disability Criteria (school sector)

Inclusion of epilepsy as a category would ensure students with epilepsy are automatically considered for programs such as the Integration Funding Support Program. Schools would be supported to cater for students with epilepsy through programs such as the School Learning and Support Coordinator Initiative (November 2008), which provided positions and training for schools to cater for students with conditions such as autism and physical disabilities.

Under the Integration Support program, funding should be provided to assist children with epilepsy where this is indicated by the child's functional ability, or as an intervention recommended by a clinical psychologist or paediatrician. Although EAA advocates a functional assessment to determine levels of support required, by having epilepsy included as a disability category, every child would be assessed for the required level of support.

It is noted that provision of a scribe and tutorial support are advocated by the NSW TAFE system (TAFE NSW Teacher Consultant).^{xliv}

7.2 Development of an Individual Education Plan (IEP)

Although every child with epilepsy does not require additional support, it is recommended that an IEP is developed in conjunction with each child's individual health care plan to ensure any necessary learning and support needs are identified early.

Early recognition of academic and behavioural problems and timely intervention is the key to achieving improved educational outcomes for children with epilepsy. The academic progress and behaviour of all children with epilepsy should be regularly reviewed to identify any changed needs.^{xlv} The NCYPE recommends six monthly reviews. EAA also recommends a further review if there is a change in medication or seizure activity.

IEP's are also recommended for all children with epilepsy by both the National Centre for Young People with Epilepsy UK and the All Party Parliamentary Group, UK.^{xlvi}

7.3 Access to specialists for assessments

Neuropsychologists or paediatric neurologist should be accessed to provide comprehensive epilepsy and cognitive assessments for any child with unresolved academic or behavioural problems.

When academic or behavioural problems are identified and existing intervention strategies have not been successful, the child with epilepsy should have access to a Neuropsychologist for cognitive assessment particularly of their executive skill functioning as well as the child's intellectual abilities (IQ), processing speed, attention, learning and memory, language skills, visual-spatial skills, academic abilities and behaviour. Neuropsychology is a specialised field that provides much greater sensitivity when assessing executive skills than general educational psychological tests in children over six years of age.

Testing of executive skill functioning is particularly important in children with epilepsy due to the nature of the condition as the cognitive impacts of epilepsy varies widely according to the area of the brain that is affected, the type of epilepsy, age of onset and medications being used.

Executive skill functioning refers to a set of cognitive processes that allow us to meet challenges in our environment and accomplish our goals by deciding what activities we will attend to and choose to do (Hart and Jacobs, 1993). Through the use of our executive skills we can plan, organise and complete complex tasks, develop and change strategies, evaluate information to make decisions, respond to unexpected situations and adapt to new situations. Executive skills enable us to use feedback to monitor and regulate our behaviour and emotions.

The Professional assessments can identify the nature of specific cognitive and executive functioning problems and suggest tailored intervention strategies.^{xlvii}

7.4 Interagency Collaboration

The Disability Policy and Planning Team, within NSW DET Disability Programs Directorate, is committed to interagency collaboration and supporting agencies which are funded to deliver various NSW government health initiatives such as the Department of Aging Disability and Home Care (DADHC) funded NSW Stronger Together Better Together program.

EAA has been unsuccessful in securing any ADHC funding specifically for the development of a specialised program for children. It is recommended that DET collaborate with EAA in the provision of services for students with epilepsy and the sourcing of funding. This would be in line with the specific objective of the DET Disability Action Plan aimed at improving service delivery through collaboration across government departments and agencies.^{xlviii} This collaboration could enable a Case Management approach to be offered to students with epilepsy between the school, home and community sectors.

7.5 Case Management

The family of a child with epilepsy should be offered a Case Management service to assist with coordinating the multiple services required for the child and to assist with the transition and integration into school. Funding should be provided so that this Case Manager could come from a community agency such as EAA to ensure all environments of the home, school and community are considered for the child and family. EAA is not currently funded to undertake a case management role for children.

The Case Manager should liaise with the child's pre-school and school regarding the future transition of the child to school, including the development of an individual plan addressing transition, the provision of training to staff, the coordination of additional support if needed and, if agreed to by the child, the education of peers. As stated by the Joint Epilepsy Council UK, the Case Manager should be in close contact with the child, the family and the child's school throughout the first year of schooling to ensure integration is successful.

7.6 Teacher Training

Every school where a child with epilepsy is enrolled should undertake training in awareness of epilepsy, emergency medication and seizure first aid. These training programs, some with RTO accreditation, are offered by EAA.

Teaching staff would also benefit from education about the impact of epilepsy on learning, strategies to assist with learning and the importance of inclusive practices. Training should increase awareness of potential problems with skills regression, failure to progress and behavioural problems so that they can identify problems and seek support early if needs arise.^{xlix} Without training, teaching staff can often interpret the symptoms of cognitive problems (e.g. failure to follow instructions) as disobedience.^l

End Notes

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