Submission
No 17

INQUIRY INTO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS IN NEW SOUTH WALES SCHOOLS

Organisation: Epilepsy Action Australia
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EPILEPSY ACTION
AUSTRALIA

Submission to the NSW Legislative Council

General Purpose Standing Committee No.3

Inquiry into the provision of education to students with a disability or special needs in government and non-government schools in NSW.

Submitted by:

Epilepsy Action Australia

January 2017

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January 2017

The Hon Natasha Maclaren-Jones MLC
Deputy Chair
General Purpose Standing Committee 3
NSW Legislative Council
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Ms Maclaren-Jones,

Inquiry into the provision of education to students with a disability or special needs in government and non-government schools in NSW

Thank you for your invitation to make a submission to the Committee regarding the provision of education to students with special needs. As the CEO of Epilepsy Action Australia (EAA), my submission presents the needs of students with epilepsy and other seizure disorders.

Epilepsy Action Australia previously made a submission to the General Purpose Standing Committee No.2 in 2010. We welcomed the recommendations made following the 2010 inquiry, in particular those in relation to implementing a model of Functional Capacity to inform decisions about support. While students with epilepsy remain ineligible for support based on their diagnosis alone, the implementation of a functional assessment approach was a victory for many families of children with epilepsy.

There have been some positive changes since the previous inquiry. About a quarter of the NSW students with epilepsy who require support have noticed an improvement since the implementation of the ‘Every Student, Every School’ policy. Most (86%) of the children who require support are receiving some assistance. However, for about half of those students the support is not adequate[i].

I welcome this opportunity to provide the Committee with details of the experiences of students with epilepsy in the NSW school system in relation to the terms of reference of the inquiry.

If you have any queries regarding the contents of this paper or would like to speak in more detail about the needs of students with epilepsy, please feel free to contact me directly.

Yours sincerely,

Carol Ireland

Chief Executive Officer

Epilepsy Action Australia

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1. Summary and Recommendations

Epilepsy is condition associated with much misunderstanding. The varied manifestations of epilepsy can mean some seizures are so subtle they are misinterpreted as 'daydreaming' while other seizures demonstrably interrupt the classroom and can lead to social isolation for the student. Any support provided must be individually tailored to the student's needs. The supports required for a child to fully integrate at school can include curriculum modification, behaviour support and support for social inclusion.

Epilepsy is not classified as a 'disability' under the department of education's disability criteria; therefore, students with epilepsy do not automatically qualify for support. Epilepsy Action Australia welcomed recommendations from the 2010 Parliamentary Inquiry for the inclusion of a Functional Capacity Assessment in addition to the disability criteria. Since this recommendation, and the introduction of the 'Every Student, Every School' policy, over a quarter (27%) of EAA's clients have noticed an improvement in the support their child receives at school.

According to Epilepsy Action Australia's NSW clients, up to three quarters of students require support at school. The majority (86%) of those do receive support; however half (48%) believe the support provided is inadequate. The reasons for this inadequacy range from lack of understanding about epilepsy (66%), insufficient support time provided (48%) and a general lack of support from the school (28%).

This report provides information about the impact that epilepsy can have on learning as well as detailed analysis of the responses from parents of children in the NSW school system as they relate to the terms of reference of the inquiry.

While some parents have experienced positive changes since the 2010 Parliamentary Inquiry, Epilepsy Action Australia makes the following recommendations to further enhance the inclusion of every student with epilepsy in the NSW school system:

- Provision of easy access to allied health assessment such as occupational therapy and psychology and neuropsychology
- Development of an Individual Education Plan for every child with epilepsy – to be developed alongside the already compulsory Individual Health Care Plan
- Increased usage, and knowledge of, Functional Capacity Assessments
- Increased knowledge of epilepsy through teacher training
- Review of the block funding model of support in favour of providing support directly to the eligible student
- Enhanced communication between the school and family about the assessment and support process
- Enhanced interagency collaboration between the school system and specialist services such as Epilepsy Action Australia
- Systemic approach within the department of education to promote inclusive attitudes and behaviours

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. [ii]

Epilepsy is a disorder characterised by spontaneous, recurrent seizures. It can affect anyone at any time, regardless of age, gender, level of intelligence, culture or background. It is estimated that over 800,000 people in Australia will be affected by epilepsy during their lifetime, with more than 263,000 of these children and adults residing within NSW[iii]. Although the exact figure is difficult to measure, it is estimated that 18,795 children and youth aged between 0-19 years in NSW are currently living with epilepsy[iv].

There are many types of epilepsy and epilepsy syndromes. Seizures present in many different ways depending upon where in the brain the seizure activity is generated and spreads. Seizures can range from absence seizures, characterised by a brief loss of awareness, to generalised tonic clonic convulsions or the more common, but less recognised, focal seizures where the person has a loss of awareness and demonstrates confusion, inappropriate actions and responses. Depending upon the type of seizure activity, the person may remain confused and drowsy for a period of time after the seizure.

Epilepsy can be severely disabling for people in its impact on a person's capacity to live a meaningful, independent life. While advances in anti-epileptic medications have assisted a large number of people, around 35% of people with epilepsy have medication resistant epilepsy where they will continue to experience frequent seizure activity or intolerable unwanted side-effects; a smaller percentage will experience more than 20 seizures per day.

3. Impact of Epilepsy on Learning

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

Studies in the UK have shown that up to half of children with epilepsy require additional support at school.[vi] Epilepsy Action Australia's client survey reveals that up to three quarters of school aged children in NSW require support at school[vii].

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[viii] .
- 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.[ix]

- Others experience permanent impairments to memory and thinking ability which require ongoing and specialised support.[x]

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.

The causes of the learning difficulty for a child with epilepsy can be varied, with multiple reasons compounding to impact on a student's functioning at school.

These causes may include:

1. The neurological location of the epilepsy[xi]
2. Seizure type[xii]
3. Frequency, duration and age of onset of epilepsy[xiii]
4. Reduced learning opportunities[xiv]
5. Side effects of anti-epileptic medications[xv]
6. Disability in association with epilepsy[xvi]
7. Psychosocial impacts of epilepsy[xvii]

The above causes are further outlined below.

3.1. Neurological location of the epilepsy

The involvement of different parts of the brain in seizure activity causes varied impacts on cognition and learning.

Some examples follow:

- 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.[xviii]

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.[xix]

3.2. 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 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 can impair sustained attention.
- Focal seizures 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.[xx]

3.3. Frequency, duration and age of onset

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.[xxi]

The age of onset of epilepsy also has an impact on learning. For example, early onset focal epilepsy is often associated with poorer language skills.[xxii]

Fluctuating levels of functioning, also common among children with epilepsy, have a major impact on learning.[xxiii] Regression of skills can also be experienced as a result of seizure activity in the brain.[xxiv]

3.4. Reduced Learning Opportunities

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.[xxv] 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.[xxvi]

3.5. Side effects of anti-epileptic medication

Side effects of anti-epileptic medication vary between different medications and between individuals. They can include impaired cognitive processes such as problems with memory, concentration, information processing and attention.

Other common side effects of anti-epileptic medications include fatigue, dizziness, nausea, irritability, restlessness, sleep disturbances, hyperactivity and drowsiness.[xxvii]

3.6. 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.[xxviii]

Attention deficit hyperactivity disorder (ADHD) is more common among children with epilepsy than children in the general population.[xxix] Symptoms of attention deficit hyperactivity disorder (ADHD) are reported in up to 40% of children with epilepsy.[xxx] 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.[xxxi]

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.[xxxii]

3.7. Psychosocial impacts of epilepsy

Children with epilepsy have approximately double the rates of behavioural and psychiatric disorders compared to the general population.[xxxiii] Anxiety disorders and depression are common, although they may remain undiagnosed and untreated. Ott et al 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.[xxxiv]

In a study of children with epilepsy and 'normal' IQ, Sabaz et al 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.[xxxv]

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.
- 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 swimming or other physical activities.

4. Response to Terms of Reference for the General Purpose Standing Committee No. 3

To inform this submission to the General Purpose Standing Committee No.3, Epilepsy Action Australia (EAA) conducted a voluntary online survey of families who have a child attending school in NSW.

The survey targeted the following terms of reference of the inquiry:

- Developments since the 2010 inquiry by General Purpose Standing Committee No. 2
- The impact of the Government's 'Every Student Every School' policy
- Complaints and review mechanisms within the school's systems

4.1. Support for Students with Epilepsy Survey 2016

In total there were 101 responses to the survey. Over the past three years EAA has provided service to nearly 400 students with epilepsy in NSW; the response of 101 is considered to be a strong response and indicative of the importance families place on their child's education.

Nearly three quarters (72%) of families who responded to the survey had a child in primary school (K-6). Of those who had a child in high school the majority (66%) were in years 7 or 8. Therefore the results from the survey are more indicative of the experiences of students in the years between K-8.

Respondents to the survey had children attending all school types including department of education schools (65%), Catholic schools (13%) and Independent/ Private schools (11%). This spread is considered representative of the general Australian population where 65% of students are educated in the government school sector[xxxvi].

4.2. Survey Findings

4.2.1. Summary of Findings

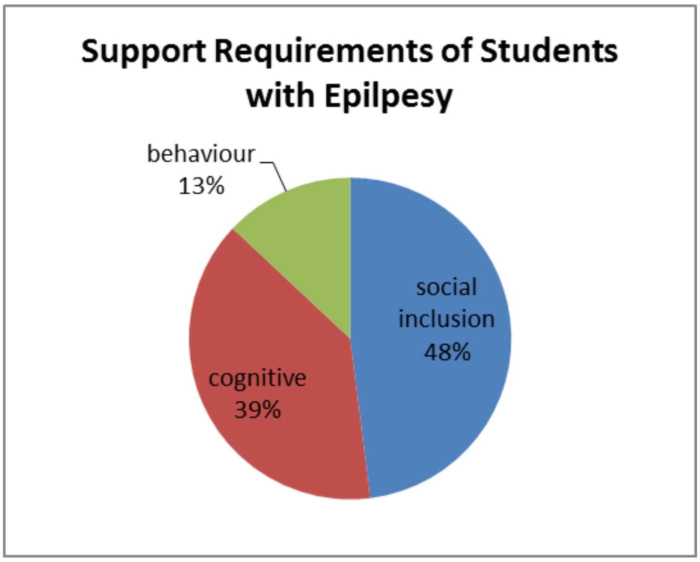
- Three quarters (76%) of all respondents state that their child requires support at school.
- The three main reasons for which they need support are:
    - Social support and inclusion in the playground and on excursions (48%)
    - Learning and cognitive function in the classroom (39%)
    - Challenging behaviour (13%).
- Of those who state their child requires support, the majority (86%) are receiving support
- In applying for support at school, three quarters (76%) required assessment reports from professionals outside the school system; most commonly occupational therapy (44% of students) and psychology or neuropsychology (45%).

- Of those receiving support almost two thirds (65%) have an Individual Education Plan; about a third (32%) has undergone a Functional Capacity Assessment.
- Of those receiving support, almost half (48%) say the support provided is not adequate to meet their child's needs.
- The three main reasons given for the support being inadequate include (note that families could indicate more than one option for this question):
  - Lack of knowledge about epilepsy in the school (66%)
  - Insufficient support time provided (48%)
  - School generally not supportive of student's needs (28%).
- Over a quarter (27%) of families whose child receives support have noticed a positive impact since the introduction of the 'Every Student Every School' Policy; half (55%) have not noticed a positive change for their child.
- The majority of respondents (77%) have not made a complaint to the school. Of the quarter (23%) that has made a complaint more than two thirds (69%) did not feel the complaint was handled to their satisfaction.

4.2.2. Detailed Findings

Just over three quarters (76%) of the students with epilepsy, whose families responded to the survey, require extra support at school. The areas in which they require support are displayed in Figure 1.

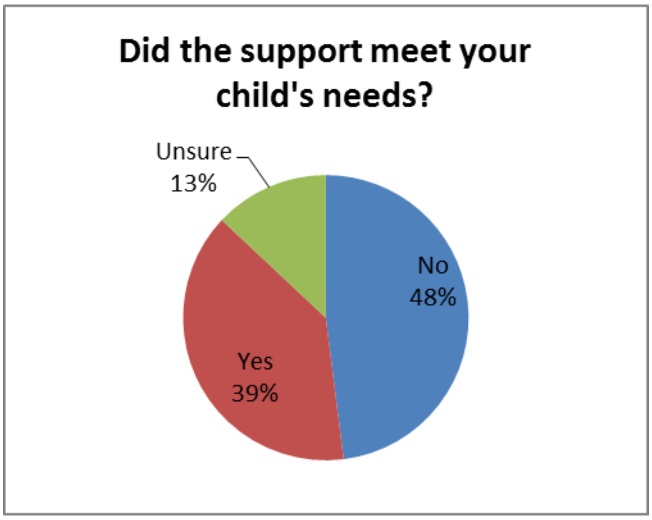
Figure 1 Support Requirements of Students with Epilepsy



It is very pleasing to note that of the children that require support at school, the majority (86%) do receive support. Only a small number (10% n=8) do not receive support even though their family feel support is necessary at school; three respondents were unsure.

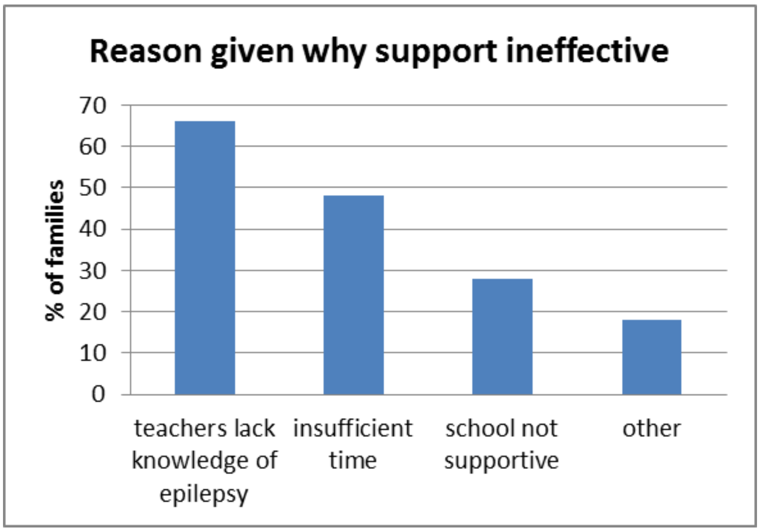
Families whose child receives support at school were asked if the support provided met their child's needs over the past year. The responses are displayed in Figure 2.

Figure 2 Effectiveness of Support



Those families who responded that the support their child receives does not meet their needs were asked why. The reasons given are displayed in Figure 3.

Figure 3 Limitations of Support Provided



Lack of Knowledge about Epilepsy

Lack of knowledge about the impact that epilepsy can have on learning is a key factor in the challenge of providing appropriate learning support for students with epilepsy.

Some schools are welcoming of Epilepsy Action Australia attending the school to provide training.

> *Staff invited a trainer/ expert to come into the school and train teachers and support staff about epilepsy and the administration of Midazolam. (Matthew, father of Malachi aged 7)*

Epilepsy Action Australia is committed to providing education about the impacts of epilepsy. Currently EAA offers online courses for teachers wanting general information about epilepsy as well as two online courses designed for primary school children. Individualised education sessions are also available from EAA for any school with a student who has epilepsy.

EAA takes seriously its responsibility in helping to educate the school system about the impact of epilepsy on learning. As part of this responsibility, in 2017 EAA will apply to the Board of Studies, Teacher Education and Standards (BOSTES) for endorsement as a provider of Quality Teacher Council (QTC) Registered Professional Development for NSW teachers.

Insufficient Time

Almost half of all families that stated their child did not receive adequate support at school reported that this was because insufficient time was made available.

> *We have a great aide; just not enough aide time. Teacher can't possibly deal with 30 kids plus my son at the one time and I often have to collect him early to save her from having to. (Sharon, mother of James aged 10)*
>
> *The school is fabulous but I feel they are restricted by the fact that epilepsy is not very well funded by the Department of Education. They do their best to support her but it is not enough. (Cindy, mother or Amity aged 12)*

Many families expressed frustration that the block funding model was not necessarily in the best interests of their child (refer to parent quotes below).

> *School does try its best - but funding is used up by severe cases - even if you get funding for your child there is no guarantee it goes to your child…Funding gets directed away from (children with epilepsy) when they are not having lots of seizures or not in crisis (name withheld).*
>
> *Due to the schools lack of support Individual students miss out on the support they need as they allocate resources to the students they feel have the greater need (Gary, father of Isaac aged 12).*
>
> *It's my understanding that public schools use whatever funding is allocated to children with additional needs on various children, not just the specific child who has brought the funding into the school! I think this is disgusting! (name withheld)*
>
> *We received some support for a term or two when my son was in year one for his handwriting as he was suffering a tremor in his hand as a side effect of the sodium valproate. This was a couple of hours a week and very soon we saw the teacher just use it as an extra resource for the class rather than dedicating it to our son's needs. (Rebecca, mother of Harry aged 8)*

Other families made comments that the school system does not allocate funding for their child; however the school itself has made funding available to support the student's learning and inclusion.

> *After much fighting for funding from the district, the school fund extra support themselves and are wonderful (Meg, mother of Bailey, aged 8).*

Inclusive Attitudes

Families commented that the amount of support received often depends on the individual attitude of the principal and class teacher. Some families reported that their child's current class teacher was very supportive, however previous teachers had not been. They find it difficult to anticipate the level of support for each new school year.

A number of families commented that they had removed their child from unsupportive schools and found schools where the principal and teachers were more supportive.

> *……the way they provide a no stress environment and the understanding they have for my son's needs is exceptional. I wouldn't change a thing for him. He did however change schools because the previous school was the total opposite. (Kerry, mother of Jai aged 14)*
>
> *It was very heart breaking to see that my daughter was already being excluded (at enrolment). My daughter is now attending (another) public school in which the staff are absolutely wonderful and very supportive. (Carly, mother of Natalia aged 6)*
>
> *In public primary we received zero assistance …….. We privately funded an aide to assist in class and outsourced all reading recovery until eventually moving to the private system. The public system was an incredibly negative experience (Cat, mother of Jan).*
>
> *No support provided at all by the school. They have failed my son and as a result he is changing schools in 2017. (Kristin, mother of Sean aged 15).*

Epilepsy Action Australia is pleased to note that the NSW Department of Education Disability Inclusion Action Plan 2016-2020 aims to address inclusive attitudes systemically under Focus Area 1: Developing positive community attitudes and behaviours. Without looking systemically at inclusive attitudes, families will continue to have vastly different experiences of inclusion depending on the attitude of the principal and teachers at their chosen school.

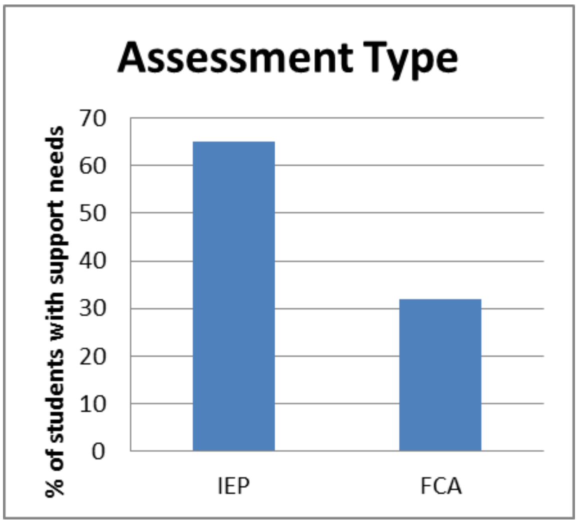
Assessment Type

In applying for support, three quarters (76%) required assessment reports from professionals outside the school system to support the application and planning. While it is no surprise that most students required a neurology assessment; almost half also required an occupational therapy (44%) and/ or psychology or neuropsychology assessment (45%).

The cognitive impacts of epilepsy vary widely according to the area of the brain that is affected, the type of epilepsy, age of onset and medications being used. Professional assessments can identify the nature of specific cognitive problems and suggest tailored intervention strategies.[xxxvii] Families commented on the expense related to obtaining these assessments.

Of those children whose parents feel they need support, almost two thirds (65%) had an Individual Education Plan (IEP) and about a third (32%) had undergone a Functional Capacity Assessment (FCA).

Figure 4 Assessment Type



Of those that had received a Functional Capacity Assessment the majority of families were informed about the outcomes (only two indicated they were not). While some parents were unsure about the types of assessments their child had received, there was more uncertainty around the Functional Capacity Assessment with 34% of families unsure if their child had this assessment type versus 17% who were unsure about the IEP.

4.3 Developments since the 2010 Inquiry

The following section responds to specific recommendations made by the General Purpose Standing Committee Number 2 following the 2010 Inquiry.

> *Recommendation 6:* *That the Department of Education and Training move rapidly towards the development and application of a functional assessment tool which has been independently monitored and assessed. This tool should be used to inform decisions about access to disability funding and to further enhance educational outcomes for students with disabilities and special needs.*

Epilepsy Action Australia made a submission to the 2010 inquiry on behalf of students with epilepsy and their families. In the 2010 submission EAA recommended that epilepsy be included in the disability criteria for funded support. While this was not a recommendation of the General Purpose Standing Committee from that inquiry, the recommendation to implement a Functional Capacity Assessment Model in addition to disability criteria was welcomed.

The Functional Capacity Assessment Model is considered to be a fairer assessment for students with epilepsy who may not qualify for support based on their diagnosis; however have demonstrable challenges with curriculum or social skills when measured with a functional assessment tool.

There are still some schools not aware that a Functional Capacity Assessment (FCA) is appropriate to use for a student with epilepsy.

> *The school didn't do the FCA as they said it didn't apply to Gracie as she only has epilepsy. I got the school counsellor to do an assessment which said she had a mild disability but didn't qualify for school funding or learning support. It took nearly 20 months to get them to apply for an individual grant with my external paper work and an assessor from education department came to school to observe and told them to apply (Nicola, mother of Grace aged 8).*
>
> *Recommendation 5: That the Department of Education and Training investigate ways to communicate the outcome of the disability funding assessment process to families, carers and schools in a manner that is clear, timely and sensitive.*

Of the children who had been assessed for their support needs, two thirds (66%) felt that they had not been informed about the process and outcome of any assessment; a third (34%) felt they had been informed.

> *We have found the process he went through to be very secretive and have had no feedback or explanation from it (Stephan, father of Jayden).*
>
> *Recommendation 13: That the Department of Education and Training require all mainstream NSW Government schools to establish or be resourced by a school learning support team.*

More than three quarters (78%) of the survey respondents stated that their child’s school has a Learning Support Team; most of the remaining respondents were unsure (17%).

> *Recommendation 15: That the Department of Education and Training publish guidelines on the functions and outcomes of school learning support teams, including the role of parents in these teams, for distribution to school communities.*

Despite not feeling informed about the assessment process and results, nearly two thirds of all respondents (60%) felt they were part of the team that manages their child’s support needs. When this question is analysed for school type it is clear that families whose child attends a school for specific purposes or attends a special class in a department of education school feel included as part of the team which makes decisions about their child; only three families did not feel included. The results were similar for Catholic and Independent schools with very few in either system feeling they are not included. For children attending a mainstream department of education school just over half (54%) feel included.

4.4 Impact of the ‘Every Student Every School’ Policy

Families were asked whether they had felt the impact of the ‘Every Student Every School’ policy introduced into the NSW Department of Education school system. A quarter of the families whose child requires learning support stated that they had noticed a positive impact of this policy in relation to increased support.

> *This has been a positive for us. Previously I have had to fight the Department of Education to get support needed in relation to his Epilepsy needs. This included making a complaint to the Human Rights Commission against the Department Education NSW. (Chantelle, mother of Isaiah aged 10)*
>
> *I am thankful for this (new policy) as it has allowed my daughter to receive the help she needs finally after 4yrs of begging (Natisha, mother of Sharyn aged 10)*

Half (55%) of the families whose children require support stated they had not noticed an improvement in support for their child since the introduction of the 'Every Student Every School' policy. One in five (19%) is unsure if there has been a change since this policy was introduced.

> *For 6 years we have struggled to get extra help for my son with his learning needs. ….. His individual learning needs have been assessed over many years with poor results but still did not receive any extra funding to get him a teacher's aide. It seems to be a diagnosis is the way they still assess for extra funding and not individual learning needs or my child would have had that help by now (Karen, mother of Alex aged12).*

4.5 School Complaints and Review Mechanisms

Almost half (49%) the respondents were unsure if their child's school has a complaints process. Of the remaining respondents who answered the question about the complaints process three quarters (75%) agreed the school had a simple complaints process and a quarter (25%) disagreed. The majority (77%) of respondents has never made a complaint to the school and a quarter (23%) has. Of those that had made a complaint (n=26) more than two thirds (69%) did not feel the complaint was handled to their satisfaction and almost one third (31%) felt it was handled satisfactorily.

> *Every time we have issues it is a fight, never a simple process….. Unless you are strong enough to stand your ground no complaint is ever taken seriously even escalating it to the Department area office you get given the run around. (Kelly, mother of Alexander aged 10)*
>
> *Previous school Principal didn't take complaints seriously or follow up until such time as I put a complaint against them to Human Rights Commissioner with the support of a Disability Advocate. (Chantelle, mother of Isaiah, aged 10)*
>
> *I am not aware of a simple complaints process however we have requested many meetings with the principal when we have felt that the needs of our son have not been met. We are met with a wall of school employees, and usually the teacher in question, which makes frank discussions difficult. Also the actions which the school has agreed to implement have not in many cases been undertaken - so it wears you down after a while and you start to wonder whether being a squeaky wheel assists your child in the school community.(Rebecca, mother of Harry, aged 8)*

> *I spoke to my child's teacher and the acting principal about my concerns however do not feel they really know how to respond so just never get back to you. (Gary, father of Isaac, aged 12)*
>
> *The principal makes it clear he supports his teachers and backs them with all issues raised ....we do not feel comfortable or welcome to make comments re issues (Michelle, mother of Jack aged 11)*
>
> *Principal did not take complaint seriously; only when I threatened to take it higher did anything happen (Kaili, mother of Aisha aged 10).*

Other parents have had very positive experiences:

> *I have direct contact with the LaST and if I have any concerns I take it straight to them (Sandra, mother of Georgia-Brooke aged 17).*
>
> *Any complaints made by us are immediately handled by the Principal (Theresa, mother of Isabelle aged 7)*

5. International Experience

Epilepsy is recognised as a disability in the United States under the *Individuals with Disabilities Education Act* (IDEA)[xxxviii]. 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.[xxxix]

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.

Individual Education Plans are recommended for all children with epilepsy by the National Centre for Young People with Epilepsy UK and the All Party Parliamentary Group, UK.[xlii] The academic progress and behaviour of all children with epilepsy should be regularly reviewed to identify any changed needs.[xliii] The NCYPE recommends six monthly reviews.

6. Interagency Collaboration

Epilepsy Action Australia (EAA) is committed to promoting optimal living for people with epilepsy. As part of this vision EAA is open to interagency collaborations to optimise life experiences for people with epilepsy.

EAA does not currently receive any government funding for teacher training or assessment and case management services for students with epilepsy in NSW.

It is recommended that the Department of Education collaborate with EAA in the provision of services for students with epilepsy and the sourcing of funding. This would be in line with Focus Area 2 of the NSW Department of Education Disability Inclusion Action Plan 2016-2020. This collaboration could enable a Case Management approach to be offered to students with epilepsy between the school, home and community sectors.

7. Recommendations

Following analysis of responses from clients within NSW, as well as considering international recommendations, Epilepsy Action Australia makes the following recommendations:

- Provision of easy access to allied health assessment such as occupational therapy and psychology and neuropsychology
- Development of an Individual Education Plan for every child with epilepsy – to be developed alongside the already compulsory Individual Health Care Plan
- Increased usage, and knowledge of, Functional Capacity Assessments
- Increased knowledge of epilepsy through teacher training
- Review of the block funding model of support in favour of providing support directly to the eligible student
- Enhanced communication between the school and family about the assessment and support process
- Enhanced interagency collaboration between the school system and specialist services such as Epilepsy Action Australia
- Systemic approach within the department of education to promote inclusive attitudes and behaviours

8. End Notes

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[i] Epilepsy Action Australia (2016) Support at School for Students with Epilepsy, client survey.
[ii] World Health Organisation
[iii] Epilepsy Action Australia (November 2015) Lifetime Incidence of Epilepsy by State Statistics
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