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## *Epilepsy, individual resilience and teacher professional sustainability*

Noelene Weatherby-Fell<sup>1</sup> & Brian Kean<sup>2</sup>

1. University of Wollongong

2. Southern Cross University

Email: [noelene@uow.edu.au](mailto:noelene@uow.edu.au) & [brian.kean@scu.edu.au](mailto:brian.kean@scu.edu.au)

### Abstract

A diagnosis of epilepsy is all encompassing. It affects the ability of the individual to be considered as a worthy, risk free, member of society. The continued use of the labels of 'disease' and 'handicap' evidence the reality of stigma and discrimination that with the label of epilepsy is all pervasive. Resilience is necessary for developing coping strategies for children and adults with epilepsy to survive and function in society.

Despite concerted campaigns designed to inform and change the attitudes of society, many children are misunderstood and handled inappropriately. Studies today confirm that up to 30% of teachers in some countries still associate epilepsy with insanity. For many, the concept of fear leads to prejudice which flows on to stigma and discrimination. This situation is unacceptable in contemporary times.

Where can we, as a society and a community of learners learn the attitudes and behaviours that disable those who are disempowered by virtue of a diagnosis, and then learn to accept and appreciate those with epilepsy? The answer may be found in our schools – the places long understood and accepted to be venues for learning, academic knowledge and preparation of the young to take their place as citizens in our world.

Teachers are increasingly viewed to be leaders, with accreditation and registration bodies setting expectations through explicit professional teaching standards. It is vital that teacher preparation both empowers and enables a positive difference, and to eliminate injustices that result from miscommunication and ignorance.

A critical social research methodology is used to structure the review and interrogation of an *Epilepsy Action* (Australia) DVD exploring the thoughts and voices of adolescents diagnosed with epilepsy. This analysis informs recommendations for teacher education and teacher action, and the need for broader education and understanding in public sphere.

As with all great teachers, his curriculum was an insignificant part of what he communicated. From him you didn't learn a subject, but life... Tolerance and justice, fearlessness and pride, reverence and pity, are learned in a course on long division if the teacher has those qualities. William Alexander Percy (1941, p. 83).

## **Introduction**

Epilepsy is one of the more common serious neurological conditions. Data indicate that 1% of the world's western population is diagnosed with some form of seizure disorder, with a higher incidence in young children and those of older age. Epilepsy has also been described as one of the most stigmatising of neurological conditions (Sirven, Drawkowski & Noe, 2007).

The most troublesome side-effects of an epilepsy diagnosis are noted to be the long-term psychological ones (Holdsworth & Whitmore, 1974). Today, epilepsy is associated with significant behavioural and psychiatric symptoms, which may be partly attributed to the chronicity of the disease (Blumer, Montouris, & Davies, 2004; Caplan, Siddarth, Gurbani, Ott, Sankar, & Shields, 2004; Rodenburg, Stams, Meijer, Aldenkamp, & Dekovic, 2005). In the psychological context, significant consequences include increased anxiety, depression and poor self-esteem (Baker, 2002; de Boer, Mula & Sander, 2008).

Stigma associated with epilepsy has a profound impact on quality of life in both developed and developing regions (Baker, Jacoby, Buck, Stalgis, & Monmet, 1997; Baker, Brooks, Buck, & Jacoby, 2000; Jacoby, Snape & Baker, 2005; Kleinman, Wang, Li, Cheng, Dai, Li, & Kleinman, 1995; Morrell & Pedley, 2000). Exclusion, restrictions, overprotection and isolation also contribute to the epileptic condition (Fisher, van Emde Boas, Blume, Elger, Genton, Lee & Engel, 2005).

Despite concerted campaigns to inform and change the attitudes of society, many children with epilepsy are misunderstood and handled inappropriately. Studies show that up to 30% of teachers in some countries still associate epilepsy with insanity (Hsieh & Chiou, 2001). For many, the concept of fear leads to prejudice which flows on to stigma and discrimination.

Management of seizures predominates scientific and educational literature in the field and is central to discrimination and stigmatisation of those who are diagnosed with epilepsy. A number of studies have shown that children's perceptions of control and self-efficacy for seizure management as well as attitudes towards epilepsy are associated with depressive symptoms (Austin & Huberty, 1993; Austin, MacLeod, Dunn, Shen, & Perkins, 2004; Caplin, Austin, Dunn, Shen, & Perkins, 2002; Dunn, Austin, & Huster, 1999). Stores (1978) compared children with epilepsy with those without, describing those with epilepsy to be significantly more socially isolated, inattentive, overactive and anxious. As a group, they were also found to be emotionally dependent on their mothers, with the boys being more affected than girls.

The continued use of labels that include 'disease' and 'handicap' evidence the reality of stigma and discrimination that still endures. There is great reliance on the medical model of the disorder. On investigation of 'epilepsy', we are referred to a scientific-

medical model of neurology linked with implications related to cognitive impairment or limitation. Discussion of drugs and medical intervention are prioritized, with the goal of eliminating seizures. However, the psychosocial effects, which have the potential to affect social, educational and medical outcomes for both the individuals with epilepsy, and those who support the them, are not recognised as a priority, and instead become secondary.

### **Teachers, schools and inclusion**

Individual and societal attitudes and beliefs, in combination with laws and organisational guidelines, affect and impact on the way those with epilepsy, are supported. Over the past twenty years the *United Nations Educational, Scientific and Cultural Organization* (UNESCO) has produced a series of reports and policies that have consistently argued for inclusive practices in schools. For children and young people with epilepsy, schools that focus on learning and understanding, rather than social competition and comparison, are likely to be more supportive in meeting their educational and social needs. (McDougall, DeWit, King, Miller, & Killip, 2006).

Laidlaw & Laidlaw (1984) raised the issue that too many teachers, as a result of not understanding the needs of the individual with epilepsy, “treat him as much more stupid than he is” (p. 157), and are hindered in their ability to provide the support required. Kuester (2000) maintained that the aspect of attitude, both by teachers towards students and student self-concept, is a key variable in determining the success of effective inclusion of students with epilepsy.

The school has been described as the second most important social environment for the child after family (Bishop & Slevin, 2004), and has the power to better future life opportunities or create disadvantages (Campbell, 2007). Burden and Schurr (1976) found that three out of four children with epilepsy attend ordinary schools, so it is likely, as Dunkley, Waldron, Ahmad, and Whitehouse (2003) note, that schools have the potential to play an important role in minimising the impact or stigma that a diagnosis of epilepsy may have on the life of the child.

Epilepsy is frequently encountered in school children. However, teachers may possess negative attitudes or feel unprepared to deal with the children and the situation (Bekiroglu, Ozkan, Gurses, Arpaci, & Dervent, 2004). Rogan (1986) stated the “intellectual abilities of epileptic children fall within the normal distribution range” and that it is “essential for teachers and parents to recognize this fact so that epilepsy is not accepted as an excuse for low attainment, bearing in mind that underlying brain disorder could be the cause of low attainment as well as the epilepsy in some children” (p. 25).

Deficit discourses contribute to a negative attitude in teachers potentially resulting in a belief that students meeting certain criteria are impaired or unable to be taught (Comber & Kamler, 2004). In this way, students with epilepsy are then seen as lacking in ability, and are usually referred to by a label. As a further consequence, these students are given less attention and fewer opportunities based on these labels and discourses, and prejudiced ideas are promoted among teachers and school communities (Smyth, 2004).

## **Methodology**

The methodology for this investigation was framed using a critical social research paradigm. Guba (1990) described the epistemology underpinning a critical research project as subjective, where values mediate the inquiry. Harvey (1990) noted that critical social research is developed from a critical-dialectical approach that deconstructs the foundations of historically oppressive social structures. The critical research tradition recognises that hegemonic grand narratives function as oppressive mechanisms of control and are used to legitimate dominant ideologies (Harvey, 1990). Sarantakos (1998) noted that the critical paradigm reframes sociological analysis with the assumption that “humans are perceived as creative and compassionate yet they are often enslaved in a system of false beliefs” (p. 37). From this perspective critical analysis research can free people from oppression of ideas and false belief systems.

In structuring the analysis of the investigation within critical theory, the aim is to go beyond the hegemonic model of epilepsy to restructure false beliefs and construct a transformative approach to understanding the educational and social implications for adolescents with epilepsy. A deconstruction of the narratives of adolescents and their experiences of living with a diagnosis of epilepsy is undertaken. Their voices, giving insight into their thoughts and their feelings are explored, and that which is not voiced, the silences within their narratives, are considered.

The data presented in this paper reports on a section from a broader study by Weatherby-Fell (2010).

## **Data analysis – Adolescent Perspectives**

The findings presented here are an analysis of comments made by several adolescents with epilepsy in the *Epilepsy Association (Australia) DVD (2004) entitled Through Adolescent Eyes*. Its purpose was to explicitly investigate the thoughts, feelings and experiences of a group of adolescents living with epilepsy. The title provokes thought – so often it is the visual reality of a seizure that both alerts and alarms individuals. We may not be able to ‘walk in their shoes’, but we can certainly listen and thereby understand. By seeing what epilepsy means through their eyes, we become aware not only of how things are, but of how we can make things better.

This video presentation was designed to allow individuals to respond freely to focus questions and statements, allowing a view through the window of their reality. After introducing themselves, the adolescents stated their age and their interests or hobbies, and also classified themselves as simply having epilepsy or further describing the types of epileptic seizures they experience. The analysis was organised by aggregation of comments of each individual in the video collage. The five students included in the data are Amanda, Anita, Todd, Danielle and Leigh. Amanda, aged fourteen, enjoys drawing, reading and “hanging out with friends”. Anita, aged sixteen, lists animation, drawing, French and web- design as her interests, admits to a dislike of maths, and relies heavily on the support of her parents. Todd, aged fifteen, describes himself as interested in hockey, cooking and soccer. Danielle lists her interests as netball and swimming, and is sixteen years old. Leigh is fifteen years old,

turning 16 soon and lists his interests as tennis and cadets.

A number of Amanda's challenges occur at school with teachers, their attitudes and actions, stating:

*It's just really annoying, if they treat you like you're stupid!*

The term 'stupid', defined as slow to learn or understand, and marked by a lack of intelligence, is derogatory and yet is reminiscent of earlier historical perceptions of people with epilepsy being considered slow to learn.

Anita agreed, saying:

*Yeah, don't you hate it when teachers fuss over you too much, and things like that? It's happened a couple of times, because there are teachers who fuss over me, and they always make sure I've got everything down, but it makes other people call me the teacher's pet – that's happened to me.*

Anita is sharing her experiences with Amanda, but also re-living these experiences – her manner is thoughtful, although visibly relieved and motivated to be sharing similar journeys. Amanda continues to say:

*I've got a teacher, and he, because I've got this, epilepsy, he assumes I am going to miss every single thing that happens and so he goes over everything like, oh, about eight or ten times.*

Again, Amanda appears frustrated – in both manner and speech, but then provides a contrary experience:

*One teacher is just so brilliant – he is like a friend and a teacher all rolled into one, if you know what I mean (Anita agrees) – he's very understanding, and he doesn't single you out.*

This is a crucial point - it is disturbing that the teacher who treats Amanda as an individual, worthy of respect and is inclusive of her rather than exclusive of her as a result of her epilepsy, is described as being 'brilliant' – indicating that he is the exception rather than the norm.

Todd described himself as interested in hockey, cooking and soccer, aged 15 years:

*...and I have epilepsy.*

Todd then recalls a specific experience at the age of nine years:

*When I was back in primary school my Year 4 teacher, he kept on ripping me off about how I fluttered my eyes ... he kept fluttering his eyes, like I do, I felt like he was making fun of me, because I had epilepsy.*

This event is evidence of cruel and manipulative behaviour by the teacher. It is also evident that this memory has remained as a focal point during Todd's life. Further, it is unclear how this has affected his confidence in teachers and other significant persons in his life in addition to his own self-esteem and perception of value. Mimicry

of the actions of individuals, particularly those who are victimised by the system, has occurred throughout history, and the appropriateness of such has never been validated.

Danielle tells that:

*my PE teacher, he actually told the whole class and then it just spread around the whole grade and people started making up stuff, so, I think its better if they (the teachers) don't tell the students and they leave it up to you – stay with your friends and they can usually look after you and eventually it doesn't get to the stage where it spreads everywhere.*

Similarly, teachers cannot be expected to be knowledgeable about all handicaps, thus they need support and education about the nature of epilepsy.

Leigh shares his experiences and relates:

*My mum actually contacted teachers and just told them about some of the side effects I was having and yeah, all my teachers, they were really good about it, they just accepted it, they weren't overprotective, they offered – do you need more time on this, or they asked me if I needed fresh air or needed a drink, and they did it discreetly, and so everyone, they didn't sort of shout it across the room, they just kept it quiet....*

It would appear that these teachers could be considered good role models. However, although Leigh appears to appreciate their attention within the class, would Amanda and Anita view this same attention differently? Where one individual may perceive this care and concern positively, others may describe it as being 'babied' or being 'fussed over'. Are the reactions of boys different to those of girls? Is there a difference in the way that teachers interact with boys?

As a focus for the future, Amanda cautions parents, carers and teachers, saying:

*“don't be overprotective – it can be so annoying...**Have you done this? Don't go there! Don't do that!** ... You just want to be normal”.*

## **Discussion**

Australia's *Epilepsy Action* gives on-line guidance and provides related resources for both teachers and students. Teachers are explicitly warned about their reactions to students with epilepsy, and the flow on effects from their classmates. The following statement alerts us all to the consequences of inappropriate and uninformed actions: “Negative reactions from peer groups and teachers to epilepsy can adversely affect the child with a seizure disorder” (Epilepsy Action, 2007). *Epilepsy Action* stresses the importance of teachers possessing a general understanding of the disorder in its various forms, including likely seizure triggers, and the possible causes of difficulties with memory and concentration, both of which are crucial for effective learning. These include the side effects of medication, seizures and psychosocial issues.

The analysis of the DVD supports many issues documented within *The Living History*

*Project report, produced by the Victorian Equal Opportunity and Human Rights Commission (in Australia) in December 2004. These include concerns related to the attitudes of teachers and staff towards youth who are labeled as 'disabled'. The data supports developing a more sustainable support system for children with epilepsy in schools through more emphasis in teacher education and professional development*

When significant others, including teachers, peers and other parents either do not understand or are fearful of children with epilepsy, further difficulties arise. When others may perceive a 'change' in the individual, there is no foundation to their being considered 'strange'. Communication barriers result, that may create further misunderstanding, isolation and discouragement for the individual.

The data described in this paper combined with the more comprehensive analysis in the study by Weatherby-Fell (2010) lead to the development of the following recommendations for sustainable inclusive practices in school education.

### **Recommendations for Educational Practice: What Teachers Need to Do!**

- Be understanding and accepting of all children, looking beyond the deficit discourses, as reflected with epilepsy, concerning labels and seeking to support and promote their individual strengths and gifts;
- Exercise a leadership role within the school community in the promotion of holistic care – care of the individual, taking into account their physical, cognitive, and social and emotional needs;
- Give genuine praise, not patronage and empathy/sympathy;
- Promote staff development in schools for all staff – teaching and non- teaching – involving the following aspects:
  - Protocols for enrolment process for children with epilepsy – supportive and based on knowledge of the disorder;
  - Need for appropriate medical information including anti- epileptic medications and potential side-effects regarding learning and psychosocial factors;
  - Be able to identify and understand the different types of epilepsy, for diagnosis and ongoing monitoring;
  - Be able to 'deal with' an epileptic seizure, be calm and unflustered whilst supporting the child, and provide a positive role-model to students and colleagues;
  - Awareness of safety in physical activities, in conjunction with appropriate occupational health and safety guidelines;
- Recognise importance of relationships between child/youth and teachers based on mutual respect and agreed goals;
- Encourage children/youth with epilepsy to willingly share information, and allow an opening for conversations to occur;
- Ensure effective communication between home and school, reducing teacher anxiety concerning duty of care, and enabling parents and carers to feel acknowledged and accepted as a part of the triangulation model of effective schooling (student, teachers and parents/carers).

## **Recommendations for Teacher Education**

- Develop an awareness and deconstruction of media image to move towards positive inclusion and support of students in schools who may have other health impairments;
- Attitudes and perceptions of teachers have a great influence, and have the potential to overturn the deficit discourses, and correct negative misconceptions and prejudices (Martin, Hooper & Snow, 1986). Hence, knowledge of the specific as compared to the general is necessary as a foundation;
- Promote recognition of social and emotional well-being in students and effects on learning and behaviour. Children and adolescents may already experience high stress in school environments – bullying and exclusion are evidenced in school communities, and have the potential to raise the risks to the child with epilepsy exponentially;
- Mandatory first-aid training – a tool in empowering people and therefore eliminating the fear factor associated with epilepsy.
- Contact can humanise the condition so that the person is seen as an individual, not an illness. People may avoid associations with a person with epilepsy as a result of fear – lack of knowledge of what to do in the event of a seizure;
- Current Australian texts in special education are heavily focused on the concept of inclusion and yet without knowledge of the diversity of children and their needs, it would seem a challenge to adequately and appropriately support the child;
- Promotion of the leadership role of teachers within the school community, and fostering links with family and carers in the promotion of care of the child or adolescent, and their development in physical, cognitive and social and emotional contexts.

## **Concluding Comments**

Those with epilepsy, their families and those who care for them have the potential to recognise the risks and harm that negative perceptions, attitudes and behaviours have on their being. However, without the ability to ‘walk in their shoes’, can we, who are situated on the sidelines, move from empathy to full realisation and knowledge of the loved experience? Families, friends and teachers have demonstrated their inability to comprehend and understand, and as a consequence deflect issues and concerns back onto the child or adolescent with epilepsy.

Currently there is a recognition that resilience, as an entity, is a skill to be developed and fostered in school communities, and beyond into society. This has the potential to promote positive outcome in a variety of contexts.

Current trends in education towards mainstreaming and inclusion provide meager opportunity for issues concerning a child’s adaptations to the adversity of epilepsy. Knowledge of epilepsy may have taken the place of ignorance, but superstition and stigma remain. Meanwhile, the process of changing attitudes and behaviours is difficult and challenging, and where there are instances of positive change and exemplars of effective educational practice, the task remains immense.

The findings of this study and similar others are highly congruent with the literature related to the field, and indicate that stigma, myth, fear and discrimination still exist in

relation to a diagnosis of epilepsy. This is despite the fact that the majority of persons with such a diagnosis have the symptoms well controlled, in that seizures are controlled and prevented by medication and other medical treatments.

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