Submission
No 35

INQUIRY INTO SERVICES PROVIDED OR FUNDED BY THE DEPARTMENT OF AGEING, DISABILITY AND HOME CARE

Organisation:	Epilepsy Action Australia
Name:	Ms Carol Ireland
Position:	Chief Executive Officer
Telephone:	1300 88 68 94
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EPILEPSY ACTION
AUSTRALIA

Submission to the NSW Legislative Council
Standing Committee on Social Issues

Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care

Submitted by:

Epilepsy Action Australia
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Phone: 1300 37 45 37
Address: Suite 8, 44-46 Oxford Street, Epping NSW 2121
Fax: 1300 88 68 94
Email: cireland@epilepsy.org.au
Web: www.epilepsy.org.au

6 August 2010

The Hon Ian West MLC
Committee Chair
Standing Committee on Social Issues
NSW Legislative Council
Parliament House
Macquarie Street
Sydney NSW 2000

Dear Mr West,

Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care

Thank you for your invitation to make a submission to the Committee regarding services provided or funded by Ageing, Disability and Home Care for Australians with epilepsy and other seizure disorders.
I would like to take this opportunity to address terms of reference 1a. 'the historical and current level of funding and extent of unmet need'.

Epilepsy is the world's most common serious brain disorder and yet epilepsy is a misunderstood condition, with a broad range of myths adding unnecessary and damaging stigma around those Australians who live with the condition.

Epilepsy Action Australia (EAA) provides services throughout Australia which aim to equip people with epilepsy to live confidently, despite seizures. EAA is funded primarily by a combination of private and corporate donors and private trusts and foundations, with a very small proportion of government funding. The funding received from Ageing, Disability and Home Care contributes, but far from covers, the services provided for people in NSW who require EAA services to live confidently despite seizures.

Epilepsy Action Australia has identified significant unmet need for people with epilepsy and we are currently redesigning our service approach to most effectively and efficiently expand our reach of service. Without additional financial support EAA is unable to provide the scope and reach of services which are vital to assisting people with epilepsy to lead productive and independent lives.

If you have any queries regarding the contents of this paper or would like to speak in more detail about the needs of people with epilepsy, please feel free to contact me directly on my office line 02 9856 7087 or mobile 0425 269 312 or my email is cireland@epilepsy.org.au.

Yours sincerely,

CA Ireland

Carol Ireland

Chief Executive Officer
Epilepsy Action Australia

1. Summary

- Epilepsy Action Australia is committed to minimising the barriers to full community engagement often experienced by people with epilepsy. EAA would welcome opportunities to partner with government in promoting broad community awareness of epilepsy.
- The complexities associated with a chronic condition such as epilepsy are often poorly understood. EAA would appreciate closer working relationships with government to align the service needs of people with epilepsy with the parameters of government funded programs.
- Recurrent funding is vital in building a sustainable base for the delivery of service. EAA would appreciate recurrent government funding to bridge the gap between the current level of funding and the real cost of service delivery.

2. Background to Epilepsy

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. 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[i].

There are many types of epilepsy and seizures can range from absence seizures, characterised by a brief loss of awareness, to grand mal and complex partial seizures where the person becomes unconscious, moves involuntarily and 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 30% of people with epilepsy will not respond completely to medication[ii] and many have more than 20 seizures per day.

The incidence of seizure disorders including epilepsy is highest in children and the elderly. As Australia’s population ages, more people will live with the impact of seizures. Epilepsy Action Australia is working to ensure we respond appropriately to the growing demand of our ageing population and to maintain our position as a leader in the provision of services to those people affected by epilepsy.

3. Impact on Quality of Life

Epilepsy is not simply a medical diagnosis; it can severely diminish the capacity of people to live meaningful, independent lives.

While the majority of people diagnosed with epilepsy are medicated in a bid to manage seizures, reactions to the medication are common[iii]. These can include problems with memory and behaviour, depression, visual disturbance or reduction in bone density as well as living with the constant fear of breakthrough seizures. These side effects frequently compromise the ability of Australians with epilepsy to actively engage in their community.

As a result, many people with epilepsy report poor quality of life[iv]. More than two thirds of people with epilepsy report high levels of psychological distress compared with just 13% in the general population[v]. Anxiety disorders and depression are common[vi]. Suicide rates among people with epilepsy are 12 times higher than in the general population[vii]. People with epilepsy often live in fear. Not knowing when and where a seizure will occur is a major cause of that fear. This leads some people with uncontrolled epilepsy to become socially isolated, as they avoid large public venues and situations where they will be alone among strangers. Loneliness can be a significant problem for people with epilepsy.

Fear of prejudice and discrimination is another cause of psychological distress. Many Australians with epilepsy experience discrimination, most commonly in the workplace. To avoid this social stigma, some people with epilepsy hide their condition from employers, friends, colleagues and even family members and in some cases effectively cutting themselves off from access to treatment.

This stigma has a significant impact on children with epilepsy, who are more likely than children without epilepsy to have emotional problems and behavioural difficulties. Children with epilepsy are more likely to experience bullying and social isolation at school. In fact, they are twice as likely to be bullied compared to the general population with 42% likely to experience some form of bullying[viii]. Family members are also at greater risk of psychological and emotional difficulties. Parents report that many teachers have lower expectations of children with epilepsy, resulting in lower levels of academic achievement and reduced life opportunities[ix]. It is also a challenge for family members of people with epilepsy to lead ‘normal’ lives. Many parents are unable to work, as they deal with a child who requires 24 hour care. With little or no respite, this ongoing situation can cause sibling rivalry, financial difficulties and even family breakdown[x].

4. Services Provided by Epilepsy Action Australia

People with epilepsy respond to the condition in a multitude of ways, many of which compromise their ability to effectively contribute to society and be engaged in the community. These barriers to social and economic participation are compounded by a lack of understanding by the broader community about the condition. The reality is that people suffering from epilepsy need more than just reactive medical support. To improve their integration with the community and improve social inclusion, a broad range of community based services need to be available in a way that is easily accessible

To effectively manage their epilepsy, people with epilepsy often require education about the condition, access to counselling, employment advice and wider support networks.

Epilepsy Action Australia provides information, counselling, epilepsy first aid, public education, and professional training and support services to help people with seizure disorders. EAA's team of highly qualified registered nurses, educators and social workers are equipped with a rich base of technical expertise, enabling the organisation to fulfil its vision and mission to assist people to live confidently despite seizures.

While proud of its heritage, EAA constantly challenges itself to improve and better respond to people with epilepsy. Epilepsy Action Australia is working to reach more people and tailor its services to meet their specific needs. This is only possible with increased support from the community and government.

5. Unmet Need

Over 2009/2010 Epilepsy Action Australia provided support and service to over 2500 people. When considering the prevalence of epilepsy there must be a significant number of people with epilepsy who are not currently receiving support from EAA.

EAA is grateful to the Department of Ageing, Disability and Home Care for the contribution of $97,852 in the financial year 2009/ 2010 towards the outreach program. With the total annual cost of providing service for people with epilepsy in NSW in excess of a million dollars, it is clear that the majority of funding for services is supplemented from community based funding and philanthropic activities. EAA is aware that these revenue streams are not an ideal base for building sustainable service delivery and seeks a greater proportion of recurrent funding.

Data based on the Australian population stats from the Australian Bureau of Statistics (ABS) *http://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0* (September 2008 Key figures)

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[x] Epilepsy Action Australia Findings from National Consumer Consultation 2007