Productivity Commission Inquiry into Long Term Disability Care and Support Scheme

Joint Epilepsy Council of Australia and Epilepsy Australia

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INTRODUCTION

The Joint Epilepsy Council of Australia (JECA) is the Australian member of the International Bureau for Epilepsy (IBE) and speaks nationally on behalf of all people with epilepsy. Epilepsy Australia (EA) is the coalition of the state-based organisations including South Australia and the Northern Territory, Western Australia, Australian Capital Territory, Queensland, Tasmania and Victoria. Epilepsy Australia has its head office in New South Wales and offers services to that state. Epilepsy Australia meets its commitment to Australians with epilepsy through providing services and information to people with epilepsy, their carers and the broader community. JECA and EA welcome the review of disability services currently being undertaken.

BACKGROUND

Many of the people the JECA/EA represent have moderate to severe impairments as a result of their epilepsy. However many people with epilepsy have it well-controlled by medication while others go through periods of time when their health is relatively stable. For many people with epilepsy, even those with good control through medication, the unpredictability of seizures means they find it very difficult to live normal everyday lives. It is concerning for people with epilepsy that public views of epilepsy are also outmoded and need to be addressed as a matter of public policy.

JECA/EA recognises that people with disabilities and their carers are the most disadvantaged in Australia with low incomes and low employment rates. A national disability insurance scheme would assist in providing a more flexible funding model which in turn would create greater opportunities for both people with disabilities and their carers, thus leading to better quality of life and opportunities to contribute to the community.

The Productivity Commission’s focus on the most severe disabilities, including children who are born with a disability, and those arising from accidents in people under 65 years of age, means that an unknown proportion of people with epilepsy related to genetic conditions and trauma will be included but also that there is a strong likelihood that many people with epilepsy will miss out. These are people with idiopathic epilepsy and those who are not so severely impaired they require full time care.

We would agree that those with the greatest impairment should be the greatest beneficiaries of such a scheme. However this should not mean that those with lesser impairments are left out. All people with needs should receive support proportional to their impairment. Thus those with greatest impairment are the greatest beneficiaries, but those with lesser impairment receive benefits according to their impairment so that early intervention would minimise transition to greater impairment.

We recognise that those who have severe uncontrolled epilepsy are likely to be part of the proposed scheme. However, there is a danger that those with less severe epilepsy or even well-controlled epilepsy will be left out and suffer accordingly. This is because the lack of community understanding about epilepsy and the consequent stigma affects the ability of people with epilepsy to participate fully in their communities. This creates a level of impairment of its own. We know that people with epilepsy, even when their epilepsy is controlled, have trouble:

- attaining employment;

- having reasonable incomes,
- forming relationships and,
- participating in community activities.

This is a level of impairment that is socially bestowed and leads to unnecessary and humiliating dependence on family, carers, governments and not-for-profits. We would argue that timely care and intervention in epilepsy through appropriate disability services would lead to benefits for people with epilepsy and would be cost-effective to the health and disability systems.

PRINCIPLES OF THE SCHEME

JECA/EA suggests that to meet the needs of people with epilepsy and their carers the following principles are:

a) Based on need

JECA/EA supports a scheme that is based on need so that those with the greatest need would be ensured of having access to the services they need. Such needs should be judged across physical, intellectual and social impairment. Services would be coordinated rather than case managed and the emphasis would be on optimising people's well-being regardless of how that impairment was contracted.

b) Timely intervention promotes wellness and ability

While those with the greatest impairment should be the greatest beneficiaries of such a scheme it should not mean that those with lesser impairments are left out. All people with needs should receive support proportional to their impairment. Thus those with greatest impairment are the greatest beneficiaries, but those with lesser impairment receive benefits according to their impairment which should minimise the transition from lower impairment to higher impairment where a condition is progressive and/or limit increased impairment due to a lack of intervention. There is evidence that people with epilepsy have a significantly higher risk of depression and anxiety. Timely intervention by services as early as possible will mean that in some cases where depression plays a role, many years of dependency can be averted.

c) Encouraging community participation, education and employment

Many people with epilepsy find it very hard to become employed or to retain a position following a diagnosis of epilepsy. People with epilepsy are often able to work and could do so with support and flexible arrangements. Younger people with epilepsy may also fail to complete their education. Far more support is needed in the community, schools and employment to ensure that both younger people with epilepsy and skilled workers who develop epilepsy later in life are able to participate as long as possible in the lives of their communities at a productive level.

d) An infrastructure program

Infrastructure to assist people with epilepsy to retain employment and complete their education is required.

To our knowledge there have been no purpose-built facilities developed to take care of younger persons with disabilities including serious Acquired Brain Injury and epilepsy that cannot be managed in the community. Accordingly they are often placed in nursing homes designed for older people that may be inappropriate to their physical and psychological needs.

There does not appear to be a structured approach to half-way houses within this process of care of younger persons with serious disabilities.

We recommend the inclusion of a budgeted capital works program providing expenditure to permit the development of purpose-built facilities for all young people with serious disabilities.

All people with disabilities and chronic illnesses are severely disadvantaged by the lack of suitable transport, leading to enforced isolation and inability to work and complete education. People with epilepsy are among the most disadvantaged in this respect. There is little reason to believe that any infrastructure program will fix this in the near future so that the Inquiry should consider other means to assist all people with disabilities to a better level of mobility and independence, such as improved half price taxi schemes and mobility cards.

e) People first, funding models second

JECA/EA is concerned that funding models will reflect the current trend to privatise services as was done with disability employment services some years ago. Private providers are concerned with profits rather than providing high quality labour intensive services. Any model should take into account that many not-for profit organisations have been providing services for a very long time, often with charitable money and often in straitened circumstances. Where those services are already good or where funding would assist to improve them, those not-for-profits should be supported to continue rather than having to compete with private providers.

A national disability insurance scheme would assist people with epilepsy in providing a more flexible funding model which takes into account episodic illness and the unpredictable nature of seizures and provided more assistance so they could continue working or continue to participate in the lives of their communities.

Funding models that ensure equitable and timely access to services should mean that over time the costs to Government through both health and disability services will be reduced as people with epilepsy will be able to improve their quality of life, their health and well-being. This in turn will be reflected in their level of community participation, including employment.

f) A complaints mechanism and quality framework

An easily accessible complaints mechanism which is separate to those providing services is required. Such a mechanism should have the power to investigate and address complaints immediately for the individual. However, a complaints mechanism should exist within a quality framework to ensure that systemic problems are continually rectified.

A Consumers and Carers Steering Group should exist within this quality framework as well as consumers and carers being represented on any advisory group for the overall work of the new scheme.