



Epilepsy Waikato Charitable Trust (EWCT)
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Submission by Epilepsy Waikato Charitable Trust for the “Charities Act Review Bill”

About Epilepsy Waikato Charitable Trust: EWCT is a non-government-funded organisation supporting and helping people living with epilepsy, their families, work associates and communities, to enable them to improve their holistic wellbeing. Such support includes help and advocacy on an individual basis through to hosting social events. Based in the Waikato region, EWCT also aims to promote a better understanding of epilepsy and its impacts in the greater Waikato region, and beyond, through education, such as by presentations (training sessions) to schools or community living groups, by publishing information on its website and Facebook, by publishing four books, and via displays at regional expos. EWCT was formed as a stand-alone organisation in 2011 and is not associated with Epilepsy New Zealand. [Charities Services registration number CC46715, website www.ewct.org.nz]

1) Will the committee of 10 elected people have a fair understanding of all disabilities including epilepsy?

There are a number of ‘hidden conditions’ that are under-represented in the context of a disability, epilepsy being one of them. Not all people are disabled by epilepsy but many face the challenges of having it.

Having epilepsy is by far one of the most insidious conditions there is. Firstly, it is a complex medical condition that requires a dedicated team of medical professionals to diagnose and treat; and, secondly, it is a very much a ‘hidden’ condition that conjures up fear, prejudice, and stigma by society at large. Epilepsy has a low and misunderstood profile within government systems because many people, including health professionals, have little or no understanding of how epilepsy affects people and indeed, from my experience, most are reluctant to even attempt to understand the condition. It is often seen erroneously as ‘simply’ an episodic event with no apparent impact. Instead, however, the condition can have very substantial and enduring impacts on the lives of many who have the condition, and on their family members, caregivers, and workmates. Currently, many in the epilepsy community, especially those with uncontrolled seizures that are medication-resistant (intractable epilepsy), experience intolerable failures and roadblocks in government systems¹.

In 2015, Aotearoa New Zealand signed a WHO resolution aimed at ensuring that people with epilepsy would receive timely treatment and benefit from educational and occupational opportunities². By giving visibility to those living with epilepsy, people will experience improved social and health outcomes.

What is epilepsy and what are its impacts?

Epilepsy is a complex neurological disorder – specifically a disease of the brain and the central nervous system – that is characterised by recurrent and unpredictable seizures. Moreover, epilepsy is considered a spectrum disorder because there are at least 40 different seizure types and 25 syndromes, which vary in severity, have many causes, and require different treatment options. It affects people in many different ways. Some people live well with little, or no, impact from having epilepsy. Others are greatly affected by it throughout their lives. At least 30% of people living with epilepsy are deemed to have intractable epilepsy and have no seizure control at all with medications that are available to them being ineffectual¹.

There are many challenges facing approximately 50,000 New Zealanders living with epilepsy¹ and the condition can impose immense burdens on individuals, families, and society. The elderly and children are more likely to develop epilepsy than the general population, and Māori will feature more prominently than non-Māori because of inequities in health and welfare.

The economic burden of epilepsy in Aotearoa New Zealand has not been measured but a Deloitte's economic study³ in Australia 2019-2022 estimates that the cost to that nation of people living with active epilepsy is \$12.3 billion/year. Using that figure, the estimated cost in Aotearoa New Zealand pro rata would therefore be about \$4.14 billion/year.

The Deloitte study looked at (a) the medical costs of epilepsy, e.g., hospital costs (pathology and imaging) and medication; (b) financial costs to the individual carer and society as a whole in productivity losses (absenteeism and premature mortality), transport, welfare costs, deadweight loss of taxation; and (c) the burden of epilepsy itself.

2) Will the committee enhance accountability and co-ordination across the Public Service and Government to progress accessibility issues?

Will this committee and the Accessibility Bill redress the many inequities currently facing many people living with epilepsy? Or will epilepsy remain in the shadows as a hidden and difficult condition?

Judging by the sample of comments made below by public servants and government ministries, there is a very distorted view of what epilepsy is and its impacts. There is also a severe disconnect between what is agreed in principle and reality.

- a) MSD case manager: "We don't have to understand epilepsy but manage the law."
- b) From a MOH funding stream: "Your client doesn't meet the disability support services criteria with a diagnosis of epilepsy." The community care model has never supported those with epilepsy.
- c) From MOE: "Children with epilepsy comprise only 2.5% of the recipients of the SHHN funding compared with children with type-1 diabetes who comprise 38% of recipients of SHHN." Children living with epilepsy are excluded from receiving learning support under the MOE criteria for receiving that help despite at least 20% of children having a learning disability. A further 32% of children at least will have a mild to moderate learning disability. Approximately 40% of children with autism will have epilepsy and/or ADHD⁴. Many children face stand-downs at school because of the difficulties managing seizures and behaviour.
- d) From a government-funded employment service: "Your client has epilepsy and is not entitled to be here because you can't guarantee that he will be able to finish the course because he has seizures." Many people with epilepsy are unemployed and underemployed.
- e) "I have received more help through ACC [for a medical-accident-related epilepsy condition] than I ever did when my child was deemed 'just' to have epilepsy."

- f) “Your client will not be seen by the mental health services.” (It is not uncommon for people with epilepsy to experience depression, anxiety or to sometimes feel suicidal. Some people may even develop personality disorders and psychosis. In fact, it is so common, that the overall rate of people with epilepsy experiencing a mood disorder stands at 25-50% higher than that of the general population.)⁵
- g) Housing insecurity remains a huge problem, e.g., “You have this week to vacate your room as the motel wants it back for the summer trade. Okay?” A phone call from an MSD case worker who didn’t have a plan B for the client being ‘evicted’ from her emergency housing. Plan C became a hurriedly arranged stay at a hostel where, after an epileptic seizure, the client was asked to leave. “It is not fair that others should have to witness your seizures. It is scary.”

Many laws are designed to protect people with disabilities but, perversely, they can be used against people living with epilepsy, for example with “health and safety” laws in employment. As one employer said, “We are a business, not a charity.” Another government-funded business (ironically championing itself as a bastion of fairness for its disabled clients) unfairly and probably illegally stood down an employee for three months after a seizure as a misguided grand gesture towards making “reasonable accommodations” as set out by the Human Rights’ Act 1993. The employee felt needlessly punished and humiliated, and lost wages, as a result.

Stigma, prejudice, and fear towards a person with epilepsy exist here in Aotearoa New Zealand with its entrenched and irrational views of what epilepsy is and how it affects many people’s lives. The challenges faced by many go beyond those at a bureaucratic level and extend to society in general.

Although many people with epilepsy have near-normal lives, a substantial number carry the burden of their condition daily in many different ways. For example, they may have difficulties in education, employment, financial constraints, mental health disorders, finding safe and affordable housing, and social isolation^{1,6,7}.

3) Will the Accessibility Bill build knowledge and awareness about the importance of addressing accessibility barriers? Or will it divide the wider disability community and cause disunity between the groups because of the complexities involved in understanding what those barriers are?

The Accessibility to New Zealanders Bill has to be truly inclusive to all people living with disability and it must remove the current barriers surrounding those with epilepsy. Aotearoa New Zealand adopted the UN Disability Convention definition of “disabled people” which includes those with sensory impairments but somewhere in the process of understanding what a disability is, epilepsy has been overlooked or deemed to be too difficult to handle⁸.

Recommendations to the success of this bill:

The bill has to be truly inclusive for all people living with disability and, specifically, it must remove the current barriers and ignorance surrounding those with epilepsy and its ongoing impacts. The Bill must:

- 1) Genuinely embrace the desire to make improvements in all people’s lives and avoid paying lip-service to goals which are unachievable and unrealistic. The Bill has to be sustainable and fair.
- 2) Listen to those who work at grass root levels and/or have lived experience with epilepsy to understand the many barriers facing people living with the condition. By listening to those in our epilepsy community, guidelines can be developed based on facts, and not ignorant opinions of

what epilepsy is and its impacts. Hopefully, this information would then influence government and professional practice and shift the balance of power back to the people.

- 3) Develop a 'social model of disability'. The Bill needs to de-stigmatise all disabilities so that society is able to change and not the disabled person. What makes someone disabled is not their medical condition but the attitudes and structures of society. (Although epilepsy is a complex medical condition, it impacts on the social and emotional aspects of one's life. People with epilepsy are not epileptics. They are people who happen to have epilepsy.)
- 4) Leverage better funding models that will take into account the needs of all people with disabilities. Presently the threshold for achieving any funding for a person living with epilepsy is impossible unless there is a significant co-morbidity or identifiable accident-related seizure present. Better accessibility to funding would enable many people living with epilepsy to enjoy a better quality of life and possibly independence.

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on behalf of Trust Board, Epilepsy Waikato Charitable Trust (EWCT)

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References

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- ² Ministry of Health 2019. *Living well with epilepsy: A service improvement plan for people with epilepsy in New Zealand*. Ministry of Health, Wellington.
- ³ Deloitte Economic Access 2020. *The economic burden of epilepsy in Australia, 2019-2020*. deloitte-audae-economic-burden-of-epilepsy-260220.pdf
- ⁴ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6406948/>
- ⁵ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4631862/>
- ⁶ <https://ewct.org.nz/living-challenges-epilepsy/>
- ⁷ <https://ewct.org.nz/we-are-removing-stigma-fear-and-prejudice-around-epilepsy/>
- ⁸ Ministry for Social Development 2016. *New Zealand Disability Strategy 2016–2026*. <https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf>