

Oral submission February 28th 2023

Maria Lowe on behalf of EWCT

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[Oral submission 28 Feb 2023 by Epilepsy Waikato Charitable Trust for the “Accessibility to New Zealanders Bill”](#)

Kia Ora kotou katoa

Thank you for listening to this submission on what it means to live with epilepsy in Aotearoa

New Zealand. Our key aim is that epilepsy will be given disability status.

In New Zealand epilepsy is not yet acknowledged to be a disability. I hope that through my voice and the voices and vision of those experiencing the challenges of the condition will be heard for the first time.

Aotearoa New Zealand signed a resolution of the World Health Organisation in 2015 which was aimed at ensuring that people living with epilepsy would experience improved social and health outcomes free from stigma and discrimination. By 2020, at least 80% of those countries that signed the resolution were also improving legislation with a view of promoting and protecting the human rights of people with epilepsy. Is Aotearoa New Zealand one of those countries? Will the human rights of people living with epilepsy be honoured by the Accessibility Bill?

Epilepsy is an episodic event in the truest sense of the word. Seizures happen without warning and, depending on the severity of them, they can have a devastating effect on how well a person lives.

Whilst at least 70% of people living with epilepsy have seizure control, 30% do not.

Approximately the fifty thousand people who live with epilepsy in Aotearoa New Zealand, including those most severely disadvantaged with no seizure control, face daily challenges that go well beyond

the impacts of seizures to dealing with the stigma and common misunderstandings around epilepsy. Seizures involve challenges in education, uncertainties about social and employment situations, limitations on driving, mental health issues and questions about independent living. For some people, epilepsy is a childhood disorder that seemingly goes into remission whilst for others it is a lifelong burden.

In my written submission, I pointed out the systemic failings that people with epilepsy face. I see a huge gap in services and funding for people living with epilepsy simply because it has a low priority in many health and other social systems. Epilepsy is unfairly seen as an episodic event and, as such, it is dismissed as a disability. This ignorant view and the associated stigma are pervasive within bureaucracies, and people with epilepsy and their families continue to experience discrimination because of the misconceptions and negative attitudes that surround the condition. These discriminatory attitudes lead to human rights violations and social exclusion.

Our requirement is that the Bill will be truly inclusive of all disabilities, including those living with epilepsy, and that it will have some guiding principles that will ensure that the social, economic and educational needs and freedoms of persons and families affected by epilepsy are promoted, prioritised and protected.

To achieve this inclusivity, there needs to be more epilepsy awareness at all levels of society, including among government representatives and agencies. More epilepsy awareness will change the major structural and attitudinal barriers to achieving positive outcomes that ultimately will reduce stigma and discrimination and thus promote human rights and improve the quality of life for many people.

Epilepsy has to be integrated and mainstreamed in national policies, legislation and guidelines if it is

to promote and protect the rights of people with epilepsy with respect to issues found in education and employment and transport for example.

The Bill must also have accountability by setting up mechanisms to monitor and evaluate the implementation of policies and legislation to ensure compliance with the Convention of the Rights of Persons with Disabilities.

Speaking with you today on behalf of the Epilepsy Waikato Charitable Trust and all those we support in our region, and elsewhere, my advocacy is part of a global push by the International League Against Epilepsy and the World Health Organisation to improve the quality of life for those living with epilepsy and their families by 2031. The Accessibility Bill must be the mechanism for that to happen here in Aotearoa New Zealand.

Thank you for listening.

Mauri ora