

Juliana Carvalho submission Accessibility for New Zealanders Bill

About me

I had a healthy life until May 2001 when one day I felt unwell, after a week I went to hospital and 48 hours later I was totally paralyzed. It started with pins and needles in my legs, then my arms, then nothing, I just could move my head. I was dying in the Intensive Care Unit. The doctors tried everything and prepared my family for the worst. I survived. But it took a long time until I got a possible diagnosis: transverse myelitis caused by Lupus. TM incidence is 1.34 in a million but caused by lupus there are fewer than 100 cases described in the medical literature. In plain English, I had a massive inflammation in my spinal cord caused by an autoimmune disease.

I remember asking the doctor, how long am I going to stay here? I have uni and work... 3 days, she said. After 37 days I went home. My first reaction was to cry. There was an overwhelming pain in my heart. Nothing could change the reality that surrounded me: I was 19 years old, was in a wheelchair and could not move or feel $\frac{3}{4}$ of my body.

As you can imagine, the road to recovery was not easy, but slowly through intensive physiotherapy and exercise I managed to recover the movement of my arms and hands. I've learnt how to live independently in a wheelchair. With the support of my family and friends, I got my life back on track.

I pushed myself very hard for 8 years fiercely pursuing my goal to walk again. And truly believing that I would recover a 100% and overcome the biggest challenge of my life I decided that I would achieve whatever I dreamed about. I finished my studies and graduated from university in Communication Studies. I created TV show named Make a Difference and I ran it for four years until I moved here. I produced and presented it with the help of a great team. Its main goals were to give disabled and underprivileged people a voice and also shed light on difficult subjects like discrimination, human rights abuse and inequality.

In 2010, my autobiographical life journey, before and after becoming paraplegic, was published. The book (In my chair or yours?) was a best-seller and the Ministry of Education in Brazil distributed it to public schools. As you can see, I had a well-established career in the disability and communication sector. I started doing inspirational speeches, I won awards for the best true story. Everything was possible.

After the book I received an email of a mother of a girl called Bruna. She was 9 years old and she was in a wheelchair. Her mother asked if we could meet, so Bruna would have a successful woman in a wheelchair to be a role model for her daughter. And that changed everything.

If you have a disability the message everywhere, is you can't, you are less, you are a burden. A lot of kids with disability grow up believing that they are less because of the message we as society are communicating all the time. I realise to walk again wasn't that important. All the energy, passion, drive and focus I had to walk again I could now direct into something else. To fight for the rights of people with disabilities.

Coming to New Zealand

Then at the beginning of 2012 I came to NZ on holiday to visit my siblings. As a tourist I travelled all over NZ and there were always accessible restaurants, places, things to do. I thought I could live in a country that was perfect and would never ever again have to fight for disability rights. I was wrong. You see, access barriers are an indirect form of discrimination. In terms of upholding disability rights, New Zealand is behind Brazil. Shocking, right?

After nearly 10 years living in New Zealand, here are some of my personal experiences and the impact of access barriers when trying to take part in society (please, read the news articles linked to each experience):

- [Barrier to get into a brand-new ANZ Branch](#), but the [problem was solved by kids](#). 2013
- [Systemic barrier in the immigration system. The acceptable standard of health policy directly discriminates against people with disabilities. It took me 7 years of legal battle to be granted residency via Ministerial intervention](#). 2014-2020
- [Barriers to transport. I was called by Auckland Transport and told I should no longer take the ferry because it was not accessible. I was relying on staff and sometimes other passengers to get in the boat](#). 2015
- [Barrier to accessible housing, situation that left me having to shower in the porch for half-year](#). 2022

Advocating for my basic human rights all the time is exhausting. Government needs to create the conditions which lead to an accessible Aotearoa where people with disabilities can live and participate.

Position on the Bill and recommendations

I **oppose** the Accessibility for New Zealanders Bill as it is currently drafted but I support the introduction of accessibility legislation based on the following recommendations:

- That the Bill is rewritten involving a genuine co-design and co-production process with the disabled community, including whānau hauā tangata whaikaha and Pasifika
- That the Bill is designed to honour Te Tiriti as guided by whānau hauā and tangata whaikaha
- That the (rewritten) Bill mandates the creation of an independent crown entity with statutory responsibility and powers to develop, review and enforce accessibility standards. We recommend that this be a disability commission led by disabled people.
- That the Bill clarifies that the scope of enforceable standards should extend beyond central government to cover all facilities and services open or provided to the public, including those delivered by local government and private entities.
- That the Bill mandates the creation of an accessible, free and well-resourced complaints and dispute resolution process for accessibility barriers.
- That the bill guarantee accountability by law, not by the Minister in charge.
- In addition to guaranteeing rights directly associated with accessibility, that the Government, in line with its obligations under the disability Convention, work closely with disabled people and disability-led organisations to co-design and implement legislation ensuring access to all of the human rights disabled people have under the disability Convention.