

Hon Louise Upston - Minister for Disability Issues

*By email*

6 June 2024

Tēnā koe Honourable Louise Upston,

The Enabling Good Lives (EGL) Waitaha Regional Leadership Group would like to welcome you as the Minister for Disability Issues.

In your role, it is important you have a good understanding of the principles and approach of Enabling Good Lives and that this should be the experience all disabled people in Aotearoa have when accessing disability support services - regardless of their impairment, funding or contracting arrangements.

In Ōtautahi, Christchurch, we have been part of the government response to the EGL approach via a piloted approach to funding and commissioning – EGL Personal Budgets for young people (14 and over) with Ongoing Resourcing Scheme (ORS) funding have been in place since 2013. This accounts for about 1000 disabled people in Waitaha, with around 100 new young people eligible each year. There are approximately 8000 disabled people accessing disability support funding in Christchurch in total.

We have included below for your information, the letter we had previously sent to the members of the Whaikaha Senior Executive Team, Doug Funnell also of Whaikaha, and the previous Minister for Disability Issues Penny Simmonds regarding the 18 March 2024 announcement.

As stated in our letter we are concerned not only about the changes made on 18 March 2024 but also about how these changes were communicated, the contradictions and lack of clarity in the information provided, and the sheer volume of muddled details that people are now required to sift through to find answers.

Alongside these is the concern about the need for meaningful consultation with informed community leaders. It is disheartening to see that disabled people and their families are being treated as passive recipients rather than partners in decision-making processes.

This has again been demonstrated by the lack of disabled input into the terms of reference, and the selection of panel members to review the disability support system.

We appreciate and note your comment on 30 May 2024 that 'It's important we provide disabled Kiwis with ongoing support that meets their needs and helps them lead a good life.' Key to achieving this is ensuring that the voices of disabled Kiwis, the families/whānau and

service providers who also support them, are heard and listened to at every stage of a change process so to this end we will be contacting the panel members inviting them to meet with us.

We would like to invite you, or a representative from your office, to meet with our Regional Leadership Group to discuss and observe how the Enabling Good Lives approach and funding works in Waitaha. We meet on the last Tuesday of each month.

Ngā mihi

Waitaha Enabling Good Lives (EGL) Regional Leadership Group

Waitaha EGL Disabled Core Group

Waitaha EGL Family and Whānau Core Group

Waitaha EGL Providers Core Group

Letter to Penny Simmonds, 6 April 2024 by email

Tēnā koutou,

We write to you today to express our profound disappointment and concern regarding the recent changes to the purchasing rules announced via social media on 18 March 2024.

Our previous engagement with Whaikaha, including the meeting with Paula Tesoriero on 13 November 2023, left us with a sense of optimism and a belief in the possibility of a genuine partnership towards positive change for disabled people and their families. However, the recent developments have shattered this optimism and reinforced our concerns about the future.

The changes implemented by Whaikaha not only signify a step backward from the already slow progress towards a truly transformed disability system but also represent an abandonment of the fundamental principles of Enabling Good Lives. Whaikaha's understanding of disability and its commitment to enabling disabled individuals and their families to lead good lives appears to be even more lacking than we had previously imagined.

We are concerned not only about the changes made on 18 March 2024 but also about how these changes were communicated, the contradictions and lack of clarity in the information provided, and the sheer volume of muddled details that people are now required to sift through to find answers. Alongside these is the concern about the need for meaningful consultation with informed community leaders. It is disheartening to see that disabled people and their families are being treated as passive recipients rather than partners in decision-making processes.

Sadly, we are also left questioning the intent behind these changes. It is difficult to tell whether this has been executed in ignorance and genuine naivety or if it is a deliberate attempt to sow confusion and undermine the progress towards genuine inclusion and autonomy for disabled individuals.

Furthermore, we are deeply troubled by the lack of trust shown towards disabled people in managing the funding allocated to them. The insistence on maintaining control over resources instead of enabling individuals to make choices that best suit their needs and 'good life' goals opposes the principle of self-determination and is most certainly not mana-enhancing.

As a leadership group committed to bringing about societal change through the Whanau Ora framework and EGL approach and principles, we are not interested in simply begging for a return to what we had before 18 March 2024 - it was never fit for purpose and continued to fail so many.

However, returning to the purchasing rules that were in place before 18 March 2024 would be appropriate temporarily while working towards something better.

This means working in genuine partnership with disabled people and whānau to transform the system in alignment with the Enabling Good Lives principles the government has committed to.

We urge you to uphold the principles of Te Tiriti o Waitangi and the UN Convention on the Rights of Persons with Disabilities by prioritising the voices and agency of disabled individuals and whānau.

In closing, we reiterate our profound disappointment with the recent actions and reaffirm our goal of seeing disabled people and their whānau leading valued lives of their choice within their community.

Ngā mihi nui,

Waitaha Regional Leadership Group (WRLG)