

## Submission to the Disability Support Services Consultation ending 24 March 2025

### About us:

Waitaha EGL Regional Leadership Group (WRLG) exists to lead societal change in Waitaha through the Whānau Ora framework and the Enabling Good Lives Approach and Principles. We lead change in Canterbury, consistent with the EGL Approach, so that disabled children and adults and their families have greater choice and control over their supports and lives.

Within this WRLG, we have a number of groups that support this vision and approach in different ways. One of these groups is the Waitaha Regional Leadership Group – Whānau/Family Core Group- and that is who we are.

### Our submission:

Changes to disability support system should:

- be guided by:
  - Enabling Good Lives Approach and Principles. We know it works. It has been demonstrated that it works. Appendix Four – evaluation of EGL demonstration sites to inform the national implementation of the EGL approach
  - Aotearoa New Zealand's obligations under the Rights Under the UN Convention on the Rights of Persons with Disability (UNCRPD) to which we are a signatory
  - Te Tiriti o Waitangi
  - Code of Health and Disability Services Consumers' Rights / Health and Disability Commissioner Act 1994
- aim to work meaningfully with disabled people and whānau to enable them to live a good life
- acknowledge that individuals, both disabled and whānau, have different and changing requirements
- be a high trust model that empowers disabled people and their whānau to have choice and control over the supports they use

The current DSS system does not align with these – and we submit that the Consultation document is seeking to amend a system that is fundamentally broken.

Disabled people have operated in a system that has forced many of them to be passive, believe that they are a burden, and that they should have to justify their spending. The changes to the system since 18 March 2024 have served to reinforce this belief and this has had a devastating effect on their wellbeing.

We urge you to reframe your thinking about disability supports aligned with the above vision and to recognise that disabled people and their whānau deserve the same power over the way they manage their lives as everyone else. They are the only group who are being forced to justify the way they choose to live.

We have intentionally focused on just some of the questions in the submission to help frame this thinking in a more practical way.

In those areas where EGL has been implemented it has been life-changing for disabled people and whānau, offering flexibility and meaningful support.

**Question 2:** What information does the assessment tool need to gather about you and your circumstances to ensure it can identify the support you need?

**Some disabled people do not need ‘assessing’ - they are the experts about what they need to live their good life.**

We challenge the use of the word tool and instead want to look at the overall system that should be focused on disabled people and their whānau living a good life.

- Any assessment **system** needs to be aligned with:
  - EGL Approach and Principles
  - UNCRDP
  - Health and Disability legislation and Code of Rights
- For those who are looking for support to imagine and live a good life, the system should empower them to do so. This should align with EGL and Te Whare Tapa Whā model
- Assessments should be guided by disabled people and parents, not just assessors/professionals. People should be given the option to edit or even write their own assessments if they wish as this means errors or misunderstandings can be rectified
- The assessment process should be transparent. People should be given information and a chance to review it before their assessment appointment.
- The need for supervisory support should be formally assessed, recognising that caring is a 24/7, on-call role.

- Many caregivers support multiple people and do significant unpaid work. Individualised Funding (IF) and the paid care component provide essential relief, but the system should not deny support by assuming “natural supports” will fill the gap.
- Disabled people and their whānau should have access to trained professionals to help them develop their vision of a good life, and what supports they need to achieve that. These trained professionals need to understand rights, how to envision a good life, and who are able to gather and incorporate cultural differences into the vision
- Be accessible to all people and have an outcome that matches people's vision and rights – not just what they have been able to justify

**Question 3:** Do you support the needs of carers being specifically assessed alongside those of the disabled person? Why/Why not?

- The whole whānau’s needs and circumstances need to be considered together with the individual's needs. Families do not operate in silos – they are systems that are interconnected
- Everyone in the whānau should be able to live a good life so need to considered what will enable each individual as well as the whole whānau to live a good life
- Key disability-related needs, including trauma of both disabled people and their whānau are often ignored in assessments. Early intervention is crucial to prevent families from reaching crisis points. People are frustrated at falling through the cracks between government departments due to bureaucratic silos. A holistic approach is needed - assessments should not force people into rigid categories while overlooking their most pressing concerns.
- Any assessment should be flexible enough to absorb the ever-changing needs of whānau ie they should be wide enough to absorb the normal flex of life
- Important to look at long term needs of whānau eg planning for transitions as needs change
- Assessments should acknowledge share caregiving responsibilities rather than assuming a single primary carer
- Carers should have access to their own support pathways eg respite, training, financial recognition
- The whole system should be whānau led and strength based and support the whole family in ways that uplift everyone's well-being
- Recognise Māori and Pacifica model of care which emphasises collective responsibility and interdependence. It shouldn't be geographical

- The needs of carers are currently commonly overlooked. Some disabled people require 24/7 supervision and if this occurs within the whānau environment, a significant portion of this is unpaid and not acknowledged through any assessment. Needs Assessments commonly focus personal care support ie one hour a day, along with occasional respite breaks across a month, but they fail to address the constant oversight required for certain individuals. This high-level supervision is a major part of caregiving, yet it is rarely discussed or considered in NASC assessments. For example, assumptions are often made that all children sleep through the night or do not require ongoing supervision. This neglects the reality that many children with disabilities require overnight monitoring, behavioural support, or medical intervention, which is a 24/7 responsibility for family carers.

Recommendation - high-level supervision is formally recognised and factored into the allocation of disability support. This would ensure that the full scope of caregiving responsibilities—especially for continuous supervision—is appropriately acknowledged and supported.

**Option 1 – Link flexible funding to the person’s plan, with oversight of how it is used**

**Option 2 – Adjust current lists of what can and can’t be funded using flexible funding.**

**Question 9:** Do you prefer Option 1 (link flexible funding to the person’s plan, with oversight of how it is used) or Option 2 (adjust current lists of what can and can’t be funded using flexible funding)? Why?

**Option 1:**

- A step backwards to link funding to a persons plan as it risks undermining flexibility, autonomy and the core proposition of Enabling Good Lives as it makes disabled people / whānau accountable to funders rather than empowering them as decision makers
- Individual and whānau plans need to align with:
  - EGL Approach and Principles
  - UNCRDP that Aotearoa New Zealand is a signatory to
  - Health and Disability Code of Rights
- Any plan needs to be owned by the disabled person / whānau and should be a living document
- A plan should be a vision and not a set of measurable goals

- Any plan should be subject to Privacy Law requirements ie who has access to it should be restricted
- Plans should allow for flexibility, self-determination and be based on trust and respect for the disabled person and their whānau to manage a budget

#### Option 2:

- Do not want a list as this contradicts the entire purpose of flexible funding as it:
  - Reduces choice
  - Reinforces inequities
  - Risks being used to justify funding cuts
  - Does not empower disabled people to live good lives

#### Option 3 – our proposal

- Have flexible funding that aligns with EGL approach and principles
- All individually funded people should have the same access to EGL
- ‘Assessments’ are key – they need to be:
  - Voluntary
  - Person-centred
  - Self determined
  - Robust assessments by skilled and experienced professionals who have expertise in disability eg psychology, OT, PT or SLT etc recognising that for many, they are the expert in their own needs

**Question 11:** Do you support the introduction of criteria for receiving flexible funding? Please let us know why, or why not?

Other than being disabled, having ‘criteria’ means funding is not flexible so no we do not agree, and we urge you to understand that this question is therefore meaningless.

Choice and control is key – the vast majority of disabled people and their whānau know what supports they need to live their best lives on an ongoing basis. These are who the system should be designed for.