

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 – Disabled Core Group - and that is who we are.

How we gathered input for this submission:

The complexity of the Consultation document and the number of questions is inaccessible for many.

We held a hui for our community of disabled people and chose some of the questions or main themes to discuss. We have collated those responses below along with examples of how the current system is broken, as well as suggestions for a design feature of a better future.

Summary

The current system is broken and any tweaks to it will only disadvantage disabled people more while reinforcing an idea that disabled people must justify their right to choose how they live a good life.

Supports that disabled people need to live a good life do not exist in silos created by how government departments are designed ie supports run across Education, Health, and individual business units within MSD. A whole government approach is needed.

Assessments and plans

- We do not agree that everyone needs assessments. Some disabled people know exactly what they need to live their good life while others might want to have some help envisaging a good life and what they need to live that
- We do not understand why we are singled out because we are the only beneficiaries who are obliged to be 'assessed' and then justify our spending and introducing criteria only serves to exacerbate that
- How can a disabled person who uses a wheelchair 16 hours a day require an assessment for what sort of wheelchair they need? They know what they need. No one else can know better than them
- Some of us need supports such as connectors/navigators - but that's ok. That is part of that person's needs. Just because some do doesn't mean all do. Or that the disabled person and their whānau always will. Over time those needs will change
- Having an agreed plan to support the outcomes identified in the plan and measuring outcomes does not work for individuals because there are so many personal and external variables. The risk is that should measurable outcomes not be met, then that funding would be withdrawn.
- We are part of the community, and we need to be invested in just like anyone else and you will be amazed at what we can contribute
- An assessment 'tool' misses a lot of information and is often loaded with 'judgement' by people who are not the experts in how our life is or should be.
- There should be a collaborative discussion around what a good life could look like (many disabled people do not even know that they can imagine a good life)
- Meaningful respite for parents/caregivers is essential

Reviews

- Currently the yearly (or less) reviews by the NASC are problematic:
 - In order to retain what we have we are obliged to make things seem work
 - We are not told of entitlements/options and only find out about them through networking which not everyone is able to do
 - It is a them and us approach not collaborative
- Alternatively, we are asked if everything is ok and that is the scope of it
- There should be a collaborative discussion around what a good life could look like (many disabled people do not even know that they can imagine a good life)
- Meaningful respite for parents/caregivers is essential

Flexible funding and criteria

- How are you defining flexible funding? If you are putting criteria and lists that tells us how to spend it, then it is not flexible
- Are the broader health and wellness needs included?
- Justifying our spending is a cost – in fact many of us are obliged by the system to pay third parties eg Manawanui to gatekeep our spending. How is it that a third party somehow knows better than us what we need to be able to live a good life? Eg Nintendo Switch - it might seem on the surface that this is not essential however in fact might allow parent to be able to go out and about in the community, carry out their essential daily tasks with their child who is regulated, calm and content
- Criteria and lists of products and services that flexible funding can be used for (and cannot be used for) leads to scenarios like we have currently where earmuffs are 'allowed' while ear buds are not. How much is spent deciding on these criteria and then gatekeeping this? Why is the cost of that not monitored like an individuals spend is?
- How about things like non foaming toothpaste – this is a need based on some people's disabilities, but do we really need criteria, administration and gatekeeping around a whānau purchasing this?

- Criteria assumes that people and disability can be put into boxes however each individual and whānau are unique. This leads to people falling through the cracks between the boxes because they are not the 'right' type of disabled
- Disabled people and their whānau would be able to do more if they had true flexible funding – they would manage that budget creatively and resourcefully just as they do their wider budget/finances

General

- Enabling Good Lives has been designed and tested by the disabled community – why has this not been mentioned anywhere is the consultation?
- GP's need more leeway to be able to support disabled people and their whānau as they are the ones who have the regular and ongoing relationship. This could take away the need for disabled people to constantly having to prove they are disabled eg on MSD form, NASC, home help, Hapai card
- It would be great to have an app to help understand terminology and what supports are available
- There is currently a stark rural / urban divide with rural people lacking access to resources
- Having bulk funded carer service providers will not work as disabled people and their whānau need to be able to choose who comes into their home. Carers and disabled people need to have a trust relationship that goes both ways as this directly relates to the quality of care provided
- There is great concern that the agencies can't deal with the work load they have now so many people would not get the care they need because the agencies don't have the staff. Also having new people coming in the home all the time is upsetting for some disabled people and having someone who is known and consistent works best eg. family. There's are also times of the day/night and week that a support person wouldn't be available so whānau would end up doing more for no recognition
- Carers need access to support and development opportunities

A better way

- We are a diverse community, so we need to have a system that works for us all
- That system should be high trust and recognise that disabled people and their whānau are able to be resourceful and make the right decisions
- Rather than monitoring individual/micro spending, a better system would be to allow disabled people and their whānau to manage a budget and then measure the outcomes at a macro level eg how have the levels of engagement in the community increased, what has happened to the usage of the health system, what has happened to engagement and success in the education system? These are the true measures of investment in disabled people.
- The overall wellness and good life of anyone is intersectional and it is no different for disabled people. We need an 'all government' approach as opposed to the silos of health, education, disability supports and other MSD functions. Planning a good life incorporates all these things.
- We need the system to understand that it is not a them and us scenario
- We want a collaborative approach that acknowledges that disabled people are valuable and are just as entitled to be able to live a good life as everyone else