Submission to the Disability Support Services (DSS) Consultation – Have your say on further improvements to Disability Support Services

Waitaha Enabling Good Lives Regional Leadership Group
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Email: admin@eglwaitaha.org

About the Waitaha Enabling Good Lives Regional Leadership Group

The Waitaha Enabling Good Lives (EGL) Regional Leadership Group represents disabled people, tāngata whaikaha Māori, Turi Māori, tagata sa'ilimalo, family/whānau/aiga, providers and other members of the disability community across Canterbury. Our work is guided by the Enabling Good Lives (EGL) Approach and Principles, which recognise that disabled people and their families are the experts in their own lives and should have choice and control over the supports they receive.

We appreciate the chance to submit feedback on the Disability Support Services Consultation on improvements, and to take part in the in-person hui held at Sudima, Christchurch on 30 July 2026. Eight WRLG members attended, helping to ensure our community's voice was heard. It was also great to connect with Al and the rest of his team.

We have split our submission into 2 parts:

Part 1 – General feedback on the Submission content and process

Part 2 – Our Submission

Part 1 – General feedback on the Submission content and process

- We already know the way forward –our community has designed a new way of doing things called Enabling Good Lives. This Vision, supported by Principles, Key Characteristics, and Elements for System Change.

- We know that EGL works - DSS's goal should be to return to rolling out EGL nationwide and as part of that, champion EGL across all government departments

- We are pleased to see that the EGL vision and principles are listed at the top of 'The Laws and Principles that guide our work' however note that the principles are not used as a framework for guiding change. Using EGL references inside the existing service system in isolation of the whole Vision and Approach is meaningless.

- Because most people have not yet experienced EGL, they cannot imagine what life can be like using this Approach. Their responses are likely to be around ‘tweaking’ the system rather than describing a true transformation. Centring the EGL principles would go some way to eliciting responses that make a positive step towards more choice and control.

- There is compelling evidence that the current system that is being amended is broken.
    - From Data to Dignity (IHC, 2026): people with intellectual disability are being left behind across most areas of health and wellbeing, including a 17-year life expectancy gap. Daily life compounds into life outcomes.
    - The Cost of Exclusion (IHC, 2025): New Zealanders with intellectual disability are twice as likely to live in hardship or severe hardship; nearly half cannot pay an unavoidable bill within a month without borrowing; children with intellectual disability routinely miss out on food, school events and ordinary childhood participation because of cost.
    - NZ Health Survey 2024/25: disabled adults report poorer health, more unmet mental health need, more psychological distress and loneliness, and lower family wellbeing; disabled children face higher unmet mental health need and greater household food insecurity. Tāngata whaikaha Māori and tagata sa'ilimalo report even greater disparities.
    - A Window on Disability (HQSC, 2026): disabled people experience poorer access to and quality of health care across the life course, die from treatable conditions at five times the rate of non-disabled people - for tāngata whaikaha Māori this rate is ten time higher - and remain largely invisible in major health datasets.
    - HDC complaints report (2026): complaints about disabled people's experiences of health services identify failures in person-centred care, reasonable accommodations, communication, informed consent and coordination between health and disability systems.

- ‘Everyday Life’ is not an ‘Ordinary Life’ - the Consultation document refers to everyday life. We are aware that the words ‘everyday life’ has been used in the EGL Principle however to use it taken out of that specific context is a move away from use of ‘ordinary life’ - a concept that is grounded in the history of enabling full citizenship, participation, and autonomy. The change to ‘everyday life' lowers expectations and reframes support as a limited contribution rather than an investment in participation, citizenship, and human rights.

  Disabled people should be supported to live ordinary lives with the same opportunities as everyone else to learn, work, participate in and contribute to their

communities and pursue their aspirations. This is consistent with EGL and the UNCRPD. Anything less would be in breach of these.

- We have heard that there has been low engagement in this Consultation process. This is not because people are happy with the system – it is because there is a lack of trust. Our community has engaged in the previous consultation in good faith however this has been reframed against us in kōrero at the introduction of the DSS Bill. This has further eroded trust and created more fear and uncertainty.

  It is also because not enough was done to inform the community about the workshops - promotion efforts were lost in the 'noise' around the DSS Bill.

  Not enough was done to ensure that the community knew the workshops was not about the DSS Bill. Explaining that to the people in attendance does nothing to engage the people that didn't come because they thought it was about the Bill.

  Not enough was done to ensure the workshops were safe, accessible or welcoming to attend. The 'run your own workshop' model used previously could have been a successful additional option if the community wasn't exhausted and disengaged.

- We are being asked to provide feedback on 'further improvements' to a revised system that we have not yet experienced in terms of the new NASC / OBIR process and resulting changes to Host processes. This was reflected at workshops where the focus of attendees continued to roll back to sharing where the system has been failing.

- We are being limited to providing feedback on two of the outcomes - daily living and safety - but the needs assessment process includes others.

- Disabled people are required to supply significant amounts of personal information not only to DSS but also to agencies acting on your behalf. While we are being reassured that the OBIR application is secure we have no such assurance from these external agencies. Further we have no visibility of the mechanism behind the OBIR application ie how our information has been interpreted and used to determine support provision. Access to this information is vital for self-determination, ensuring ordinary life outcomes and also has significant privacy implications ie if we understand what is happening in the back end, we can choose what is relevant to share instead of the current situation where we are repeatedly forced to divulge sensitive information where no ongoing relationship exists. EGL Connectors are part of the solution.

Part 2 – Our Submission

Topic 1: Outcomes that matter for disabled people

We are pleased to see that the EGL Vision and Principles are listed at the top of 'The Laws and Principles that guide our work.' This means that disability supports must support the whole person and not be split into silos. Separating Daily Living and Safety from 'wider benefits' does not support being able to live a good life. EGL was never only a values list. It was a whole change approach that enabled a real transfer of authority toward disabled people and their families.

We do not understand Daily Living as a narrow category of tasks, personal cares, and routines. Daily living is life, experienced daily compounded over a lifetime. A person's daily life is not just whether they were washed, fed, transported, supervised, or kept occupied. It is whether each day gives them more or less autonomy, dignity, belonging, contribution, connection, confidence and control over the direction of their own life.

Safety must never be used to justify smaller lives: good support creates safety with freedom, not safety through segregation, surveillance or restriction. As we have outlined in the research findings in Part 1 above, a 17-year life expectancy gap, deaths from treatable conditions at five to ten times the rate of non-disabled people, loneliness, hardship and family stress are not separate from daily living, they are what daily exclusion becomes when it compounds. Any redesign of safety must also carry the memory of the Royal Commission of Inquiry into Abuse in Care and the promises made as a result.

The value of support from DSS lies in what it makes possible, and we reject any approach to this consultation that positions disabled people and their whānau as mere consumers, transactions, liabilities, statistics, or survey responses. Disabled people have rights and are not defined by their use of services.

Being asked to rank 'wider' benefits is abhorrent, and inconsistent with the requirements of all 'The Laws and Principles that guide our work' (DSS Consultation Page 6).

DSS Consultation Page 9 – How will we know when we are making a difference?

We know support is working when the person's world gets bigger, not smaller: more people know them, more places welcome them, more roles become possible, more choices are genuinely theirs, and fewer parts of life depend on crisis response or exhausted family labour. And we would know it at system level too: fewer avoidable hospitalisations, better primary care access, less unmet mental health need, less loneliness, improved family wellbeing, better food security and reduced hardship over time.

Outcomes that are measured by mining data about people's everyday lives on how they spend support funding are meaningless because if outcomes are not achieved (which can happen for a range of valid reasons ranging from external to internal factors) or achieved outside of that immediate funding year, the risk is that is interpreted as a failure and funding for that withdrawn. This does not reflect real life.

EGL has already described how you will know that you are making a difference – it is when you are able to report on on disabled people and their whānau being able to say:

I have choice and control over:

- I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
- I have real choices about the kind of support I receive, and where and how I receive it.
- I can plan based on my strengths and interests.
- I am in control of planning my support, and I have help to make informed choices if I need and want it.
- I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
- The level of support available to me is portable, following me wherever I move in the country.
- My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
- My family, whānau, and friends are recognised and valued for their support.
- I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
- I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed

Topic 2 – A more proactive approach to support

Being able to respond to change as needed is vital – this contrasts with a system that only responds to a crisis, features annual inaccessible reviews and constant justification.

We support DSS becoming proactive however this must mean co-designing a robust system that does not require constant changes and instead can flex as people's lives change. Being able to respond early to challenges or opportunities, instead of waiting for crisis-level thresholds, is one of the clearest markers of a proactive system.

In addition to asking for better services now, disabled people and their whānau are asking for a system that includes succession planning. Our community experiences a lot of worry

and fear about the future. The new system needs to include access to practical support that helps disabled people, whānau, support teams, providers and community partners plan for the future. This means planning with the person, supported decision-making, communication access, recruiting and leading support teams, safeguarding without containment, using budgets flexibly, building relationships, navigating transitions, and understanding rights. It should be available early, before crisis, and last a lifetime.

An easy-to-use process for things like supported decision making, wills, trusts, welfare guardianship and financial planning is also essential.

Topic 3 : Feedback and complaints processes

People complain because they want change to the system however the current complaints process is not working. Disabled People's | Tāngata Whaikaha Experiences of Health Services: Report on complaints to HDC — Health & Disability Commissioner shows that disabled people and whānau report failures in reasonable accommodations, inaccessible communication, inadequate engagement with family and support people, and poor coordination between systems. Trust is not created by slogans. It is created by systems that listen, repair and change.

An effective complaints system must:

- include timely decisions with clear solutions, a process to confirm that the solution has been implement and the effectiveness of this.
- be mana enhancing, easy to use and free from reprisals
- be trauma-informed and culturally safe
- safeguard the disabled people that need to engage with the system for their own disability related support needs while also supporting other disabled people to navigate and access supports
- written decisions with reasons, clear timeframes, review and appeal rights, and remedies as opposed to verbal decisions, shifting rules and invisible rationing.
- have a feedback loop that outlines the outcome and the changes that have been implemented
- have independent monitoring of the system including identifying patterns and systemic failures is essential.

With respect to monitoring service quality, formal disability services, including residential care, should be independently monitored and publicly reported on (the ERO reports in education are an example of this). Families and disabled people, as the consumers of these services, could then make informed decisions about which service is right for them and represents good value, based on an unbiased account of a service's true performance and its

alignment with EGL Approach and Principles. The services and the system should be scrutinised, not the disabled people and families who use them. Quality monitoring and feedback tools must never become tools for monitoring how disabled people live, or for auditing whānau.

Topic 4: Better support for carer respite and breaks.

We are aware that a 'Carer Support Package' is currently being developed in isolation from the carer and disability community however, genuine co-design includes consultation from the beginning.

We know that Carer organisations are responding to this DSS Consultation with detailed information and want to tautoko their mahi. We also want to amplify that consulting after design has started makes people feel the decisions have already been made, and creates fear that whatever we say will be ignored, watered down, or used to justify choices already locked in.

For any consultation to be meaningful, disabled people and whānau must be able to speak freely, raise their own priorities, shape the direction as opposed to responding to responding to a series of questions designed in isolation. A closed feedback loop on how this has been incorporated is essential.

Whānau/Family carers should be seen as skilled and valuable partners who are worthy of and entitled to support, training, respite (time away from their role), development and opportunities just like any other working person. They are not a resource to be exhausted before other supports are available. Being part of a whānau must never be an excuse for systemic neglect.

When systems under-support disabled people, the pressure does not disappear, it shifts to extended whānau, frequently at the cost of health, income, relationships, rest and future security. Over time this damages the very relationships disabled people most need protected. Disabled people have the right to be a valued and contributing member of their family/whānau and community and not a drain on resources and hence become a burden. Disabled people have the right to have disability support needs met in a dignified way and they should not have to forfeit familial relationships to maintain eligibility or access to the funded disability support they need.

Caregiving for disabled children and adults is skilled, complex, and continuous work. If disabled people choose whānau/family to be their support workers, they must be recognised financially for the work they do. Paying family carers strengthens families, reduces reliance on benefits, and acknowledges the real labour involved. Flexibility must also extend to siblings and extended family members, who should be free to flourish in their own lives and choose how involved they want to be without guilt or financial penalty.

Carer support should not be framed only as a break instead it is an opportunity to support whānau create a life they do not constantly need to recover from. Survey data shows us that families experience financial pressure, food insecurity, reduced family wellbeing and care strain. When whānau are depleted, the disabled person's life becomes more fragile. Whānau sustainability is a safeguard, not a side benefit.

It is increasingly difficult to get good support workers, and this means we are often forced to employ support staff who are not ideal or go without hence increasing the burden on family/whānau. Exercising our right to choice and control with support worker agencies raises the risk of being seen as difficult and having this service withdrawn. This is a particular issue in rural areas. It would be great to see cross department support (DSS, wider MSD, Immigration, Education and Health) to develop a skilled, valued support worker workforce.

Training would include access to information around being an employer, how to manage staff, how to train staff, and how to retain staff.

Topic 5 – More choice and control in DSS services

The EGL Vision is about increased choice and control. The only way to truly increase choice and control in DSS services is to implement the EGL Vision.

The services that DSS supply must have EGL embedded in their design, staff training, systems and processes.

Funding processes that are easy to use, supported by access to a Connector, would reduce the number of people who choose to subcontract managing their budget. For those who choose to not fully self-manage, an option that is independent, mana-enhancing and person centred is essential.

Full transparency about how services are funded both by the user and DSS is essential for building trust. This includes any payments from DSS to Hosts.

Inherent in any system is capability building - one source of accurate and up to date information about how to employ, how to manage, how to train, how to retain. Also, when employing direct the cost of training is significant.

Topic 6 – Improving DSS information and advice

We need a system that is single one-stop resource that:

- Focuses on increasing capability not enforcing compliance
- Is holistic and centered around the person and/or whānau
- Is accessible (multiformat), accurate and consistent across the whole system (including DSS, Health, Education etc)

- Features clear, plain language but also goes from simple through to the detail. Some people need to understand the whole funding mechanism in order to operate the system
- Includes a process to ask questions and clarify information needs to be easy to use, one on one, and mana enhancing.
- Respects the role of whānau in this process
- Gives real life examples
- Has multiple options for direct communication channels where disabled people and whānau can ask questions and get real answers and can initiate topics rather than only respond to predetermined questions.
- Is staffed by people trained in EGL-aligned, mana-enhancing communication, and communication channels co-designed with disabled people and whānau, including Māori-led approaches.
- Flags changes early and provides advance training and information about the forthcoming change

We look forward to continuing to contribute to this transformation and stand ready to work alongside DSS as the changes take shape.

Tēnā koe i tō wātea mai / Thank you for your time,

Waitaha Enabling Good Lives (EGL) Regional Leadership Group

Waitaha EGL Disabled Core Group
Waitaha EGL Family/Whānau Core Group
Waitaha EGL Providers Core Group