FERNZ
Foundation for Equity and Research New Zealand

Introduction

This submission is made on behalf of the Foundation for Equity and Research New Zealand (FERNZ) Wellington Region Community Action Groups (CAGs). It reflects discussions from a CAG-wide discussions and written feedback from CAG members throughout late July 2026. The views presented are drawn from the lived experience of Disabled People and Tāngata Whaikaha Māori in response to the Ministry of Social Development's consultation on further improvements to Disability Support Services.

FERNZ is a kaupapa Māori-governed charitable trust that works alongside communities to identify inequities, build disabled leadership and support systems change. Through our Community Action Groups, Disabled People identify issues that matter to them, gather evidence from lived experience, develop community-led solutions and advocate for positive change.

Across every discussion there was one consistent message.
Disabled people want a disability support system that works alongside them, responds to their changing lives, and trusts them to make decisions about what matters most.

Throughout this submission we refer to the principles of Enabling Good Lives. These principles recognise that disabled people are the experts in their own lives and should have choice and control over the decisions that affect them. Our members consistently told us they want to see these principles reflected throughout Disability Support Services.

Topic 1: Outcomes that Matter to Disabled People

The proposed outcomes are a useful starting point, but they do not yet reflect what disabled people told us matters most.

One issue came up repeatedly throughout our discussions. Disability Support Services should not define what a good life looks like. Disabled people should.

What matters most will differ depending on a person's age, stage of life, disability, aspirations, and circumstances. There is no single set of outcomes that will be right for everyone. The framework needs to recognise this diversity rather than expecting disabled people to fit within a prescribed model.

Across our CAGs, members consistently identified self-determination, choice, and control as the foundation of good disability support. Disabled people want to decide what autonomy looks like for them, not have it defined by Government or by the disability support system.

Members also questioned why Daily Living and Safety are the only two core outcomes. Both are essential foundations, but they should not represent the limit of the system's ambition. Disability Support Services should provide the right support at the right time so disabled people can pursue education, employment, culture, recreation, whānau and community life in ways that reflect their own goals and aspirations.

Another important discussion centred on participation. Members felt the consultation sometimes blurred the difference between participation, connection, and contribution. A person may never develop broad social connections but still participate meaningfully in their community. Likewise, contribution looks different for everyone. The important question is not whether someone contributes in a way recognised by the system, but whether they are living a life that is meaningful to them.

Success should be measured against each person's own aspirations, not against a standard set of outcomes. For some people, success means increasing independence. For others, particularly those with progressive conditions, success means maintaining independence, wellbeing, and quality of life with the right supports as their needs change.

Disability Support Services should not decide what success looks like.
Disabled people should.

Topic 2: A More Proactive Approach to Support

Across our discussions, CAG members people welcomed the idea of a more proactive approach. However, they were equally clear that proactive must not become another way of directing people's lives.

A recurring theme was that disabled people often must wait until their situation deteriorates before additional supports are considered. CAG members described having to repeatedly explain or justify their needs as their lives changed. This creates unnecessary stress, contributes to advocacy fatigue, and places pressure on people who are already navigating complex lives.

Planning needs to recognise that people's circumstances change throughout life. Moving through education, starting work, becoming a parent, ageing, changes in health or the progression of a disability can all create new support needs. Those needs may be temporary, but they may also become permanent. Disability Support Services should respond to what people need, not what the system assumes should happen.

CAG members also highlighted the opportunities created by advances in assistive technology. New technology can significantly improve independence and participation, but only if people have timely access to it. Reviewing equipment and technology should become part of proactive planning rather than being treated as a one-off decision.

Just as important was the role of assessors, service coordinators, and navigators. CAG members want staff who listen, understand their circumstances and work alongside them to plan for the future. Their role should be to help people navigate the system, not to act as gatekeepers to it.

A proactive system responds to people's lives as they change. It does not wait until they reach crisis point.

Topic 3: Feedback and Complaints

Disabled people should be able to raise concerns knowing they will be listened to, treated fairly and not disadvantaged for speaking up.

Throughout our discussions, one issue came up repeatedly: the power imbalance between disabled people and service providers. Many disabled people rely on the same provider/ support team every day. CAG members told us they worry that making a complaint could affect the support they receive or damage important relationships. Unless people feel safe to speak honestly, the system will never receive an accurate picture of how services are performing.

CAG members also described complaints processes as difficult to navigate, time-consuming and lacking transparency. Many questioned what happened after a complaint was made, whether anyone was held accountable and whether anything actually changed. Feedback should not become another barrier that disabled people have to navigate.

Quality cannot be measured simply by whether a provider has delivered the services outlined in a contract. CAG members told us they know they have received a quality service when they have achieved the outcomes that matter to them, feel respected, are genuinely listened to and receive the support they need.

Feedback and complaints processes need to be accessible, available in multiple formats and designed around the diverse communication needs of disabled people. Short surveys may have a place, but they should provide opportunities for people to explain their experiences rather than simply rating a service on a scale. Just as importantly, disabled people need to know that their feedback has been heard and has led to meaningful improvement.

Disabled people should never have to choose between raising a concern and protecting the support they rely on.

Topic 4: Better Support for Carer Respite

Family members told us that having respite funding available does not always mean they have access to respite that meets their needs.

They described a lack of suitable respite providers with the skills, knowledge, and confidence to support disabled people safely. This leaves families with little real choice and often means carers continue without a meaningful break because the available options simply do not work for them. Emergency respite was also identified as a significant gap, particularly when unexpected situations arise.

CAG members questioned whether the current range of respite options is flexible enough. Every family is different, and respite should reflect that. Some families may benefit from in-home support, while others may need community-based options or flexible funding that can be used in ways that genuinely provide relief. A one-size-fits-all approach does not recognise the realities of caring.

Supporting carers is not separate from supporting disabled people. When carers are well supported, disabled people are more likely to receive stable, sustainable support that enables them to continue living the lives they choose.

Better information and navigation are also needed so families understand what respite options exist, how they can be accessed and what support is available when circumstances change.

Respite should fit around families' lives, not expect families to fit around the respite system.

Topic 5: More Choice and Control in Disability Support Services

Choice and control need to sit at the heart of Disability Support Services. Without them, supports become something that is done to disabled people rather than with them.

Throughout our discussions, CAG members consistently spoke about unnecessary restrictions, inconsistent decision-making, and gatekeeping. While many valued the flexibility offered through some funding models, they also described uncertainty about what funding could be used for and inconsistent decisions across the country. This creates confusion and undermines confidence in the system.

CAG members want clear information about the options available and to be trusted to make informed decisions about their own supports. The system should begin from a position of trust, recognising that the overwhelming majority of disabled people use supports responsibly to achieve the outcomes that matter to them.

Many CAG members highlighted the importance of independent advocacy and navigation. Genuine choice is only possible when people understand their options and have someone alongside them if they need support to make informed decisions.

Family members spoke about the importance of recognising the knowledge and experience of parents and whānau, particularly when supporting children and young people. At the same time, decisions should increasingly reflect the wishes, aspirations, and growing independence of the young person themselves.

Every disabled person's circumstances are different. Disability Support Services need to be flexible enough to respond to those differences rather than expecting everyone to fit within the same rules or pathways.

Choice and control only exist when disabled people are trusted to make decisions about their own lives.

Topic 6: Improving Information and Advice

Good information does more than explain what supports are available.
It gives disabled people the confidence to make informed decisions about their lives.

CAG members told us they receive information from many different places, including Disability Information Centres, disability organisations, government agencies, providers, and peer networks. While these sources are valuable, the information is often inconsistent, difficult to understand or focused on what services exist rather than how to access them.

A recurring theme was that information alone is not enough. People often need support to understand what they are entitled to, work through application processes and navigate an increasingly complex disability support system. Too often information is provided without any follow-up to check that it has been understood or whether additional assistance is needed.

CAG members also emphasised the importance of information being written by and with disabled people. It should be available in a range of accessible formats, culturally appropriate and supported by well-trained staff who can answer questions and provide practical guidance. Navigation services can play an important role, provided they are focused on helping people access supports rather than creating additional barriers.

The disability support system has become increasingly complex. Disabled people should not have to become experts in funding streams, eligibility criteria, or government structures simply to access the support they need. Better coordination between agencies, clearer information and stronger navigation would make the system easier to understand and more responsive to people's lives.

Good information gives disabled people confidence.
Great information gives them choice.

Contact:
Pip McLean
Lead Community Coordinator
Foundation for Equity and Research New Zealan
pip.mclean@fernz.org.nz
021 217 1151