Disability Support Services

March 2025

New Zealand Council Of
Christian Social Services

Tirohanga Whānui | Overview

The New Zealand Council of Christian Social Services (NZCCSS) welcomes the opportunity to provide feedback on this phase of work on Disability Support Services (DSS). We support the kaupapa to stabilise the system that disabled people rely on to enable good lives. Our members engage with those who rely on Disability Support often and have excellent experience on how the various services and policy supports have evolved over the years. We welcome this opportunity to amplify their voices and we also extend the offer for further targeted discussion as this work progresses.

Kaupapa | Purpose

We express concern that this is a small piece of work that must exist within a larger and more comprehensive ecosystem of supports to be effective. While we support this particular cog being corrected, if the machine is not addressed then the system will continue to be as much a barrier as a support those who engage with it.

We strongly recommend that the Ministry consider the following points:

1. Disabled people and their advocates are supportive of movement in this space.
2. Aspiration must be at the core of any support system.
3. Funding levels should be determined in partnership with providers based on the costs of service delivery.
4. Carers are critical components to the safety and success of DSS.
5. Current funding models are preventing disabled people from being able to live well in their chosen community
6. Disability support exists alongside other supports that require context and integration.

These points will be followed by specific answers to the questions in the discussion document.

Whakaaro | Discussion

Item One – Disabled people and their advocates are supportive of movement in this space.

Members we spoke to who have worked in this space for many years expressed their exasperation that these questions are still being asked. The timeline of advocacy and policy correction as it relates to disabled people seen in “A brief history of disability in Aotearoa” (Stace and Sullivan, 2020) illustrates how long these same questions have been asked, throughout the period of mass institutionalisation up until 1973 through to the development of the Enabling Good Lives principles in 2011. Members we spoke to expressed disappointment for themselves, as advocates and professionals who have invested their time and resources into supporting previous processes, and for their clients for whom there has been little positive movement. They also expressed hope that, this time, their words prompt real change. There is optimism in the sector that with appropriate prioritisation that the Enabling Good Lives model can provide real change for disabled people and their whānau, and that this time their words will be the trigger to bring us closer to that aspirational future for disabled people.

Recommendation 1: We support a commitment to action that honours the efforts and voices of disabled people and their advocates.

Item Two – Aspirations must be at the core of any support system.

The Enabling Good Lives principles are centred around a core idea – support systems must have aspiration at their core to make a life ‘good’. The United Nations Convention on the Rights of Persons with Disabilities defines a disability as “any long-term physical, mental, intellectual or sensory impairment which, *in interaction with various barriers*, may hinder the full and effective participation of disabled people in society on an equal basis with others.” The key element here is that it is interaction with various barriers that make a disability, not the impairment itself. A person is disabled by a system that does not support and enable them, which comes from failing to take an aspirational approach to what a good life looks like. The Enabling Good Lives framework can be the lens through which aspiration can be at the core of any system that truly supports disabled people towards that ambitious goal of a good life.

Recommendation 2: We suggest ensuring that any changes to the system are focused on enabling an aspirational vision for the lives of disabled people.

Item Three – Funding levels should be determined in partnership with providers based on the costs of service delivery

A significant and ongoing issue noted by our members in this space is a mismatch between the understanding of the situation from funders and providers. Members noted that current funding models do not align with the practical costs of service provision. This results in insufficient funding for providers to deliver services. A significant example of this was funding increases that failed to account for pay parity increases. Providers want to work from an understanding of what it *does* cost to provide services, enabling them to commit to providing these services at the highest level. To do this would require rectifying historic miscalculations to bring sector funding up to a more realistic level with commitment to fund this in the future. This shared understanding and expectation will ensure a more collaborative relationship between funders and providers, allowing each to do the core work of supporting disabled people.

Recommendation 3: We support prioritising a shared understanding between funders and providers on funding requirements and expectations, with better and more consistent service provision as a goal.

Item Four – Carers are critical components to the safety and success of DSS.

Without family carers, the over 672.2 million hours of care that is provided in a year would need to be delivered by professionals (Grimmond, 2014). This would have to be funded by government if not provided by whānau carers and in 2014 this care was estimated to have a value of approximately $10 billion. How much this has increased in the intervening decade can only be speculated. Carers must be well supported to live their own good lives to enable them to care for others and deserve to be prioritised through the Mahi Aroha strategy to give them a central and distinct place to advocate for their own needs. We believe the strategy of support for carers and the support system for disabled people must be treated as part of a system wide view and complementary.

Recommendation 4: We support continued action on Mahi Aroha to enable carers to live their own good lives.

Item Five – Current funding models are preventing disabled people from being able to live well in their chosen community

Current models for individual support payments may allow disabled people who live remotely the financial means to access services, but current commissioning models do not support these services to exist outside of main centres. There is a significant disconnect between the planning, operational, and policy spaces in this sphere that force individuals to choose between receiving support from their own communities and moving to where they can access support from service providers. The models currently do not allow for smaller organisations to provide what is needed, as they rely strongly on a bulk-funding model scales poorly outside of large centres. Those who live in smaller communities deserve access to services in the same way as those who live in cities.

Recommendation 5: We suggest ensuring commissioning models enable people to access support where they live instead of being forced to choose between community and provider access.

Item Six – Disability supports exist alongside other supports that require context and integration.

Disability exists as facet of a lived experience or a living potential for all of us. There are services that benefit disabled people that are accessed by those who are not disabled, and there are disabled people who access services of support that fall outside the disability space. The lines drawn between these supports can make it difficult for people to access the support services they best need. A key example of this are the clear demarcations made between disability support and mental health support, where the interplay between mental health and disability is not supported or uplifted to ensure holistic care for the individual. We are also encountering more overlapping complexity in the older person's space. While there is an understanding that many people will acquire disability as they age, through illness or frailty, we are for the first time encountering a much larger cohort of people who are aging while disabled. Medical advancements now support disabled people, including those with intellectual disability, to live much longer, and as a result we are now encountering many more people who need to access both the supports of the DSS space and the Aged Care space. These cannot exist in isolation, and to ensure that all individuals can access the support they need, we need to ensure that the barriers between these streams of support are addressed.

Recommendation 6: We suggest ensuring DSS is integrated in the approach to ageing and mental health to ensure that the best support is available for people who cross multiple streams of need.

Tūtohutanga | Recommendations

1. We support a commitment to action that honours the efforts and voices of disabled people and their advocates.

2.We suggest ensuring that any changes to the system are focused on enabling an aspirational vision for the lives of disabled people.

3. We support prioritising a shared understanding between funders and providers on funding requirements and expectations, with better and more consistent service provision as a goal.

4. We support continued action on Mahi Aroha to enable carers to live their own good lives.

5. We suggest investigating commissioning models that enable people to access support where they live instead of being forced to choose between community and provider access.

6. We suggest ensuring DSS is integrated in the approach to ageing and mental health to ensure that the best support is available for people who cross multiple streams of need.

Hua | Answers

Q1

Partnerships for care must be prioritised and the assessment tool and process must be the vehicle for this relational approach. People are the experts in their own lives and so if we seek to establish systems that would enable these lives to be ‘good’, we must centre the person experiencing that life. Th system, specifically mechanisms for assessment, are paternalistic and demeaning, reducing willingness to engage and efficacy of outcomes

The solution must be support provided to truly enable a good life for the person being served, not support provided to drive down budgets or direct the individual’s choice towards preselected options. Flexible funding is key to this, rediverting agency to the individual. This also extends into assessment, with frameworks being co-created alongside the individuals and their whanau to ensure that the purpose of the assessment and the method by which it is conducted is genuine, respectful, and uplifting. Navigating to a social model of support, removing DSS from the sphere of the medical model of support, would be key to this.

Q2

A social model of support is critical for success in the disability space. Supports cannot be constructed with a deficit-based perspective on disability. As the strategy is named, it is about enabling good lives, working in a strengths-based framework to enable individuals to meet their needs and reach their goals. Needs assessments must come from an aspirational vision of where each individual wishes their life to go.

Q3/Q4

Carers are critical to the support network that enables an individual, and we support any and all interventions that also ask the carer what a good life looks like for them, not just the person they are supporting. We support the maintenance and progression of the Mahi Aroha plan as a specific space for advocacy for carers to progress, but support specific policy centred around DSS to retain the disabled person as the priority. We strongly believe that policy can create space for all of these needs to be addressed.

In response to the carer procurement issues in 2024 which causes significant service disruption, we want to ensure that purchasing guidelines are always provided with the full suite of supports and documentation, including accountability information to ensure transparency for carers.

Q6/Q7/Q8

Relational approaches that are client-directed will address these issues.

We recommend that assessments should be come about when a person encounters a threshold. This can be a negative threshold, such as a degradation in mobility or sight that they need more support to navigate, or positive, such as what supports can be provided to enable the individual to study or get married. Life changes that are deemed significant by the individual should be the trigger for assessment.

Regularity is not the answer. Cyclical assessments may stymie responsive and proactive assessment to meet changing need, especially when there is a significant delay in the ability to access assessments. Needs can change rapidly, and regimented cyclical systems discourage a response to this.

Q9/Q10

While the discussion document outlines the definition of a plan as a document that "sets out the outcomes sought and the support needs of the disabled person, how the flexible funding will be used, and why it is the best option to address the support needs to help the person live a good life', we encourage this to be a set of iterative and relational guidelines, based on principle-based decision making. If this is a rigid, inflexible document, then this impacts the ability to access services in a damaging way. Criteria are often arbitrary, unhelpful and paternalistic, and providers often find that the 'rules' that are put in place are often immediately adjusted, malleated, or outright broken to meet the specific needs of the individuals in their care. Rigidity and prescriptivism just don't work, but under a relational approach then Option One is the preferred choice.

For a relational and responsive plan to be effective, frontloading education and support is key. Host organisations have found incredible success in their 'coaching' spaces, where individuals are supported to understand their entitlements and responsibilities, such as payment and accountability requirements. The funding for these roles, however, has not kept pace with need and as a result they are severely limited in their ability to support in this more specific way. With consideration that much of what would be considered 'fraud' from individuals that our members support occurs through a lack of understanding and education – for example, an individual not understanding that they were responsible for paying care providers and spending the money available to them on games and treats – these roles are key to not only providing support for individuals and whānau to understand their rights, but also for them to understand their responsibilities.

Q11/Q12/Q13

Agency is key. Personal autonomy is key. Individuals should have control over the aspirations they have for their own 'good lives' and the vehicle that can move them towards it.

Individualised funding is not for everyone, nor was it designed to be. The work that was happening regarding flexible disability supports through the Enabling Good Lives Trials must be progressed, allowing for variable levels of management where individuals cannot have full independence. A continuum of options is key to ensure that everyone can have and make choices with the right level of support for them and their whānau.

Accountability is difficult to do well without being overly scrutinous and paternalistic. Without the coaches mentioned in previous answers there is no scaffolding in place for education on how money can and should be spent, and instead only judgement and punishment for those who do it 'wrong'.

Ngā Tohutoro | References

Grimmond, D (2014). The economic value and impacts of informal care in New Zealand. Carers NZ, the Carers Alliance, and Infometrics. https://carers.net.nz/wp-content/uploads/2020/11/The-economic-value-of-informal-care-in-New-Zealand-Final-copy-5.pdf

Stace, H. & Sullivan, M. (2020). A brief history of disability in Aotearoa New Zealand. https://www.whaikaha.govt.nz/assets/Guidance-and-resources/History-of-Disability-in-Aotearoa-NZ-final.pdf

The United Nations (2007). The United Nations Convention of the Rights of Persons with Disabilities. https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles

Ko wai tātou | Who we are

NZCCSS has six foundation members; the Anglican Care Network, Baptist Churches of New Zealand, Catholic Social Services, Presbyterian Support and the Methodist and Salvation Army Churches.

Through this membership, NZCCSS represents over 100 organisations providing a range of social support services across Aotearoa. Our mission is to call forth a just and compassionate society for Aotearoa, through our commitment to our faith and Te Tiriti o Waitangi.

Further details on NZCCSS can be found on our website - www.nzccss.org.nz.

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