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Wellington Regional Community Action Groups
Foundation for Equity and Research New Zealand
By email, care of info@fernz.org.nz

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Ministry of Social Development

By email, care of DSS_submissions@msd.govt.nz

Tēnā koe Chris

Please find attached a submission on the DSS consultation on consistent and transparent assessment and allocation tools and fairer more consistent flexible funding.

This submission is on behalf of the members of our five Wellington Region Disability Community Action Groups, which have membership from disabled people / tāngata whaikaha from Wellington, Porirua, Kapiti, the Hutt Valley, and the Wairarapa.

While we have followed the submission form provided by the Ministry of Social Development, our overarching concern is that consultation's apparent assumption that increasing transparency and reducing variation will necessarily make DSS more fair. But not all variation is unfair, especially where variation reflects an appropriate response to different needs.

In fact, a one size fits all approach, which may be transparent and consistent, can create more unjust and unfair differences. Both nationally and internationally there is a body of work looking critically at this one size fits all approach, which highlights that it leaves people behind, especially where multiple and intersecting inequities exist (as is often the case for disabled people/tāngata whaikaha).

Our overarching feedback is that the DSS assessment process and allocations need to be flexible so that they can truly meet the needs and aspirations of disabled people/tāngata whaikaha.

The proposals set out in the consultation document give inadequate attention to DSS being person-centred, mana-enhancing, and easy to use. Instead, there is a disproportionate focus on financial accountability and reducing costs, and on rules and criteria, when the focus should be on aligning with the Enabling Good Lives (EGL) principles.

We expect many of our concerns will be shared by others. We trust that these will be taken seriously by the Ministry of Social Development in your ongoing work to improve services for the 50,000 disabled people / tāngata whaikaha and their whānau who receive essential disability support.

If you have any questions about this submission, you can contact our Wellington regional community coordinator in the first instance at pip.mclean@fernz.org.nz.

Naku noa, nā

Assoc. Prof. Tristram Ingham KSO ONZM
Executive Chairperson, FERNZ
On behalf of the Wellington Regional Community Action Groups

Topic 1: Improving the way the needs of disabled people are assessed, and how support is allocated

This covers proposed changes to the way peoples' needs are assessed and how decisions are made about what supports they receive.

It includes assessments through a Needs Assessment Service Co-ordination (NASC). Enabling Good Lives (EGL) assessments are not included.

Make sure there is a consistent approach to needs assessment

Question 1: What changes can you suggest that would ensure the assessment tool and process is fair, consistent, and transparent? You might for instance wish to suggest it is: done in a different place; in person, or not; that it be supported differently; or that you receive different information about it before or after the assessment occurs.:

The ideal needs assessment process would be driven by the question **"what do you need for a good life?"** and would be undertaken by a disabled person / tāngata whaikaha. The underlying assumption appears to be that non-disabled people will be leading an assessment. This is highly insulting. Ensuring more people are involved as assessors is something that must be addressed by MSD.

The assessment needs to be done where it is convenient for the person and where appropriate for their family/whānau.

Collectively we have also experienced or heard that in some instances the current assessment process is not fit for purpose. The issues primarily stem from the wrong questions being asked and the lack of disabled people leading the needs assessment.

Other issues we have observed include:

- Reduced focus on outcomes (assessment, even by NASCs, had been moving towards an outcomes focus but this stopped in March 2024).
- Overly long and complicated assessment tools.
- Narrow focus on working within funding limitations rather than addressing and meeting needs. At the moment assessors cannot say identified needs will be met, due to funding barriers.

Improve how the assessment tool reflects the diversity of disability

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?

As outlined in the previous response, a useful assessment will start with the question "what do you need for a good life?". Such a question reduces the likelihood of assumptions being made by the assessor on what is best for the disabled person / tangata whaikaha. A persons age, type and stage of impairment (and if there are multiple it is important to understand the combined impacts rather than looking at them separately), and current circumstances/context (including so called 'natural supports') would also be necessary for a full assessment. The approach taken with EGL gives a sense how this can work effectively. Assessors also need to be knowledgeable about the variables in the particular area the person lives in (for example, is it rural or urban) in order to be able to ensure the person is getting appropriate and realistic supports.

Assess the needs of family/whānau and carers

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

Question 4: What considerations in respect to a carer's situation should be taken into account in order to link them to, or provide, the support needed

Collectively we agree the needs of carers need to be taken into account and met, but we emphasise that the needs of carers should be assessed *in addition to* the needs of the disabled person *not in place* of the needs of the disabled person.

There is a risk that a joint assessment could be used to reduce the support available to a person if the assessment is designed to illicit the ability of a carer to deliver more for less or where it leads to an assumption that a whānau/ family will take on additional carer duties. We are also concerned that in some situations it is necessary and appropriate to have separate assessments for example where a carer is also a family member (from both the perspective of the disabled person and the carer there could be good reasons they want to keep the assessments separate) or where a disabled person states that they do not want their carer or whānau/family involved in an assessment. Once again, the approach will depend on the person's circumstances.

We also note that having this question, posed in this way, contributes to an unhelpful discourse that pits the needs and aspirations of disabled people / tāngata whaikaha against those of carers.

Lastly we support a broader range of supports being provided to carers where appropriate (other than just respite).

Make sure the services and support a person receives continues to meet their needs

Question 5: How often have your needs and services / supports been reviewed or reassessed?

Question 6: What changes to your circumstances do you think should mean a review or reassessment of your services / supports would be needed?

Question 7: How often do you think your services / supports need to be reviewed or reassessed? (For instance, every year, every two years, every three years, or every five years.)

We tend to support a review every two years, or on request. This is already what some of us experience. But we note it is dependent on the person and their circumstances. Relevant changes in circumstances might be in living situation, leaving school, changes in impairment, or changes in overall health and wellbeing.

We are concerned that an rigid approach (for example, where circumstances that trigger reviews is prescribed) would cause unnecessary reviews, wasting time for assessors and causing stress for disabled people / tāngata whaikaha and families. Again, there needs to be options for varied review or assessment periods, depending on the person.

On the assessment process, we note those of us in aged residential care do not have our needs properly assessed. One consequence is that we are unable to access supported living, even though it may be of great benefit. Similarly those of us who have had Zoom or other online reviews found them inadequate and impersonal and led to their needs not being properly identified.

Helping you access support that isn't available through DSS

We propose that NASCs identify supports that are available through other agencies and provide guidance on how these can be accessed.

This will help ensure that DSS is only used for the supports that are not provided elsewhere.

Question 8: What information or support might NASCs provide that will help you access the services, beyond DSS, that you might be eligible for?

This question appears to assume that disabled people can easily access a range of funded services from other agencies and that the main barrier to accessing this is a lack of information.

We know that NASCs often already identify other, non-DSS, supports that might be available for a person, but NASCs do not have the mandate to ensure a person has access to the supports, nor are they always aware of the rules and assessment processes of other agencies.

More often than not, people find out that they are not in fact eligible for a service the NASC has suggested, that the services are not available (especially outside of main centres), or that somebody (either the person or someone important in their life) must do battle to make it happen.

An improved, person-centred, approach would allow a single assessment to unlock a range of supports so that people only have to tell their story once. In our discussion on this question we shared examples of having to repeat stories to doctors, providers, and other government-funded services. And of having to advocate for months to get basic supports. This is in contrast to what we understand of the EGL approach where connectors / kaitūhono work with a disabled person / tangata whaikaha to explore together the supports that meet the person's needs and aspirations.

Topic 2: Accessing flexible funding, and how it can be used

There are two options for changing how flexible funding can be used:

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?

We believe there should be a third option where a person receives an agreed funding sum and is trusted to use this, as in the UK.

Of the two options, we prefer option 1, if it involves a good, outcomes focused, plan. However, we are cautious about what "oversight" might involve. Who does the oversight? And what information might the oversight be based on? We are not supportive of approaches that leave people feeling like they're subjected to surveillance in the name of transparency.

We do not support option 2. Our reservations about option 2 are based on past experiences, including action in the 1990s taken against ACC on its list of what supports its clients could and could not have.

We also have concerns about a list of agreed or funded supports because it ignores the fact that what a person needs will vary on that person and their circumstances (and such a prescriptive approach makes flexible funding inflexible). We also know that where something is on an approved list that it becomes open to exploitation by suppliers who could double or triple their prices in response – creating more costs for the system and reducing the funding available to a person for no additional benefit.

Question 10: Do you have any suggestions on how flexible funding can be used to allow disabled people and carers as much choice, control and flexibility as possible, while still providing transparency and assurance the funding is being used effectively, and is supporting outcomes?

The solution to this appears to be full EGL implementation, or as close to it as you can get.

If there is a good plan, based on the central question of "what do you need for a good life?", then this should provide sufficient transparency. Seeking more transparency will come at the cost of choice, control, and flexibility.

In preparing our submission, we had a conversation about the concept of "supporting outcomes". In general we recognise that the aim of any plan should be to achieve a set of outcomes. But this is not a linear process. For many of us, there are circumstances beyond our control (and outside of what might be funded by flexible funding) that will affect the likelihood of achieving outcomes. This can include changes within our families/whānau, to our living situation, to our carer's circumstances, to our health, and so on. The approach to flexible funding cannot lead to the unjust situation where people are routinely denied or given restrictions to their support because of a perceived lack of progress against outcomes.

Introduce criteria to access flexible funding

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

The only criteria for receiving flexible funding should be if a person has some sort of impairment and that they or other important people in their lives (like a family member, carer, or flatmate) are capable of managing the flexible funding arrangement.

We note that when it comes to managing the fund we have concerns about fund holders top slicing and reducing the funding available to the person, while at the same time offering services that are not accessible to disabled people / tāngata whaikaha.

It is important that flexible funding is made available where it is the best option for the person. Any more specific criteria will lead to a rigid or prescriptive approach that gets in the way of being person-centred. Our responses to question 12 should be read in light of this overarching view.

Question 12: Which of the following criteria for receiving flexible funding do you agree or disagree should be included and why? (Choose all that you think should apply.)

12a. Use of flexible funding is part of an agreed plan and linked to a specific need.

Agree/Disagree

Why/Why not?

As above, we agree that a plan can be a helpful part of flexible funding. But we are cautious about what it means to have a “specific need”. Who decides what a specific need is? How does this relate for example to needs that arise from multiple impairments but is not specific to any single impairment?

12b. Disabled people and/or their family / whānau / carers are able to manage the responsibilities of flexible funding.

Agree/Disagree

Why/Why not?

As above, we consider that flexible funding should be managed by the disabled person/tangata whaikaha or an important person in their lives (like a family member, carer, or flatmate).

12c. Flexible funding will be used to purchase a service or support that DSS provides through its contracted services/supports, that will address a person's disability-related support, and there is an advantage to using flexible funding to purchase it (such as greater flexibility for scheduling, it is closer to where the person lives etc).

Agree/Disagree

Why/Why not?

We do not agree with this proposed criteria. Limiting services to contracted providers has issues for the person and the provider.

12d. Flexible funding will address a service gap, where the service is not otherwise available, or suitable for the individual.

Agree/Disagree

Why/Why not?

We do not agree with this proposed criteria

12e. The cost of the support or service that will be funded is not more expensive than other ways to get that support.

Agree/Disagree

Why/Why not?

We do not agree with this proposed criteria

12f. The flexible funding will enable the person to purchase or access a service that is expected to reduce a person's future support needs.

Agree/Disagree

Why/Why not?

We do not agree with this proposed criteria

Question 13: Can you suggest other criteria for accessing flexible funding in addition to, or instead of, those above? If you have suggestions, please explain why you think they will be helpful for those who are accessing flexible funding.

Refer to our answer for question 11 and 12a and 12 b.