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Tēnā koutou,

Aotearoa Disability Law Submission on the Disability Support Services Community Consultation

1. Please find below the submission of Aotearoa Disability Law on the Disability Support Services Community Consultation.

Introduction

2. Aotearoa Disability Law is the only community law centre in Aotearoa New Zealand specialising in disability law. We provide free legal services to Deaf and disabled people when they have a legal issue related to their disability. We also run free seminars to educate the Deaf and disabled community, their whānau and supporters, and professionals working in the sector about disability-related legal topics.
3. We appreciate the opportunity to contribute to the Disability Support Services Community Consultation. Disability Support Services are important in many of our clients' lives, and we support the goals of making these services fairer, more consistent, more transparent and sustainable into the future.
4. The comments we make in this submission are informed by the experiences of our clients, feedback we get from the community when delivering legal education, and the advice of our ADL governance group, who are all members of the Deaf and disabled community.
5. Whilst we will be answering the questions raised in the discussion document, we do wish to note that the nature of these questions means there is limited opportunity to provide feedback on the more substantial changes that are needed to ensure that Disability

Support Services are fair and sustainable. We – and our clients – would appreciate the opportunity to contribute to a less constrained consultation process that truly allowed the community to say what they want the Disability Support Services of the future to look like.

6. In particular, we are concerned that the goal of the Disability Support Services Taskforce is to stabilise Disability Support Services within current funding levels. Disability Support Services are currently inadequate and difficult to access, and this is largely the result of the system being underfunded. To truly make Disability Support Services fair and sustainable, the amount of funding available needs to be raised to meet the needs of the community.

Consultation Question One:

What changes can you suggest that would ensure the assessment tool and process is fair, consistent and transparent?

7. The assessment process needs to retain its current flexibility to be done in a way that works for the disabled person and their whānau / carers (if relevant). All disabled people are different, and it wouldn't be fair to insist that all assessments take place in the same location (for example, to require that the assessment always takes place in the person's home). People should retain the ability to choose where they would prefer to do the assessment – at home, at the NASC office, somewhere in the community, online etc.
8. People should be asked ahead of the assessment about what support they might need during the assessment. Disabled people have a variety of different needs, and the easiest way to meet any individual's needs is simply to ask them what they need. Options could be provided (e.g., providing assessment documents in alternate formats, providing documents before the assessment so that the person can prepare), but assessors should also be prepared and able to provide other supports that the person asks for during the assessment.
9. The assessment process should start with two key questions – 'what does a good life look like for you?' and 'what support do you need to live that life?'. Most disabled people can identify what their needs are, and if they cannot do this themselves their whānau can identify these needs. Starting with these two questions allows the process to be led by the person and their whānau, and aligns with the Enabling Good Lives principles of being person-centred and mana enhancing. The assessment tool could certainly include examples of common supports to prompt people if they are struggling to identify what supports they might need, and for people and whānau who cannot identify their support needs a more thorough assessment process could then take place. However, for most disabled people, simply asking them to identify what their support needs are will be enough and no further assessment should be required.
10. If the disabled person has whānau / carers who are taking part in the assessment, the assessor should have the opportunity to speak with the whānau / carers without the disabled person in the room (provided that the disabled person and / or their whānau / carers are happy for this to happen). Whānau / carers need to be able to speak frankly

about the disabled person's needs – including what they cannot do – during the assessment process, and if this conversation takes place in front of the disabled person there is a risk that whānau / carers will avoid talking about the more difficult aspects of supporting the disabled person. This can mean that the disabled person's support needs do not get identified.

11. Alternatively, if the assessment tool were oriented around the questions 'what does a good life look like for you?' and 'what support do you need to live that life?', the assessment process could be more aspirational, and support needs could be identified without people having to focus only on the things they can't do or on the negative aspects of their disability. This approach would be more in line with the Enabling Good Lives approach, and particularly with the principle of being mana enhancing.

12. Putting NASCs and EGL sites under budgetary pressure means they feel pushed to create overly optimistic assessments that won't meet the person's needs and will put them at risk. It is an unfair conflict to put the NASC/EGL staff under. Their assessments should be about need, not about meeting budgets.

13. The assessment process doesn't align with Te Tiriti o Waitangi and Te Ao Māori. The Enabling Good Lives approach does, and that is the approach that should be used for assessment. This has been communicated for over 10 years with supporting data.

Consultation Question Two:

What information does the assessment tool need to gather about you and your circumstances to ensure it can identify the support you need?

14. The assessment tool must be able to identify what support should be being provided by other government departments, whether the person is actually able to access that support via that other government department, whether they need any assistance to access that support, and what the impact on the person's life will be if the responsible government department refuses to provide the required support.

15. Many of our clients have complex needs and are navigating multiple government systems and also NGO's, which they find confusing, frustrating and time-consuming. For example, some clients are unable to work due to their disability or their care responsibilities and therefore have to navigate the WINZ system; some clients are told that certain needs would be better met by education, health or ACC, rather than Disability Support Services. Our clients have described feeling as though they are stuck in the middle of a circle of agencies all pointing at each other and saying that another agency needs to provide the support, resulting in the client feeling like they are constantly fighting the system and not getting the support they need.

16. Our clients have pointed out that it costs the government more to constantly deny support and refer the person to another agency than it would cost to simply pay for the needed support when it is first requested.

17. It is important that the assessment tool captures all the support needs a person has. When there are needs or entitlements that are the responsibility of another agency, it should be recorded in the assessment tool;

    a) whether the person needs support to navigate that other agency's process,

    b) whether the person is able to access the support via that other agency in a timely manner, and

    c) what the impact on the person's life will be if they are unable to access the support will help ensure that all disability support, from all agencies, is well coordinated.

    The result of the assessment needs to ensure that people don't go unsupported simply because every government department thinks the person's needs are not their responsibility.

18. People should be able to have their voices heard regarding preferences without fear their current service will be withdrawn. One example we have experienced is a person who lives alone and received additional funding for a service they do not need or use. They DO need additional 1:1 support for matters like showering and toilet assistance. But they fear that if they request the funds be shifted to the service they actually need, the current funds will be withdrawn and they will have no ability to negotiate regarding those funds. They do not want to raise the mismatch of their current funding vs what they actually need for fear their entire funding package will be revoked leaving them without support at all. All disabled people want those funds to be used for what they actually need.

19. As discussed in our answer to question two, identifying whether a person needs support to navigate other agencies' systems is important, because the system is complex and many disabled people do not know what support they might be entitled to, or they have trouble accessing supports that they should be entitled to receive. If a person needs support to navigate this complex system, this should be a support that Disability Support Services can pay for. This will make the system much easier for disabled people and their whānau / carers to use, as the NASC or EGL site will then become a 'one-stop shop' where people can come for support accessing all their entitlements, even those that Disability Support Services does not end up paying for, or is not directly responsible for. This will lead to people's needs being met earlier (as they will not have to fight to access the supports they are entitled to), which both aligns with the Enabling Good Lives principle of beginning early and is likely to lead to lower overall costs, as people get support before they reach crisis point. Identifying what other supports the person should be receiving in the person's assessment, and following up to see whether they were actually able to access that support from the responsible agency, will also lead to better coordination across the system as a whole. By including the whole system (not just Disability Support Services) in each person's assessment, it will be possible to identify what gaps exist and make improvements across government, leading to a simpler system that meets people's needs early.

20. It is important that the assessment tool captures what the impact on a person's life will be if they are unable to access a support that should be funded by another agency, and to follow up to establish whether the person was ultimately able to access that support via the other agency or not, because this will allow the assessment tool to capture whether the system as a whole is supporting the person to lead a good life. If the assessment tool identifies that a person needs a support that is normally provided by another agency, and the person is unable to access that support via the other agency in a timely manner, Disability Support Services should be able to pay for that support to fill the gap. This will likely reduce overall costs to government, as it will help stop people from reaching crisis point.

Consultation Questions Three and Four:

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

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

21. Yes, we support the needs of carers being specifically assessed alongside those of the disabled person. Carers have specific needs of their own related to their caring role – in particular, carers need opportunities for respite in order to be able to provide safe care for the disabled person. We are concerned that there is significant risk of potential harm, either to the carer or to the person they care for, if these respite needs are not met. Specifically assessing the needs of the carer and providing Disability Support Services funded supports to address these needs is an easy way to reduce these risks.
22. Carer's respite-related needs should therefore be one of the key things covered by the assessment. In particular, attention should be paid to what supports carers have within their existing networks and how easy it is for them to utilise those supports. For example, if there is a friend or family member who is able to care for the disabled person while the main carer takes a break, Disability Support Services should support the carer to use these natural supports, for example by covering the costs of thank you gifts to friends and family who serve as respite carers, covering the travel costs for a friend or family member to come from out of town to provide respite care, or covering the costs for the main carer to have a night away so the disabled person can stay at home. Supporting people to use their natural supports, where these are available, in this way is more flexible for the whānau, less disruptive for the disabled person (who can be cared for at home by someone they trust, rather than having to go into a respite care facility), and is likely more cost-effective overall.

23. As noted in point 11 above, many of our clients have complex needs and need support to navigate the various government systems they interact with to ensure they get all the support they are entitled to. In some cases, it is the carer, rather than the disabled person, who is responsible for doing this system navigation. Carers have told us they spend significant time doing this – they have to follow up on enquiries and repeat their story to

multiple different people. This burden has increased significantly since the changes to purchasing rules last year. For example, one carer has told us that, since the changes to the purchasing rules announced on 18 March 2024, they have had to spend 5 hours per week arguing for the supports that the disabled person they care for needs, when previously all they had to do was send a one-sentence email with the receipt. If the carer is the person navigating the system on behalf of the disabled person, their needs related to system navigation should be assessed. For example, in some cases the carer might need support to navigate the system. In other cases, the carer might need compensation for the time they spend navigating the system on behalf of the person they care for.

Consultation Questions Five, Six and Seven:

How often have your needs and services / supports been reviewed or reassessed?
What changes to your circumstances do you think should mean a review or reassessment of your services / supports would be needed?
How often do you think your services / supports need to be reviewed or reassessed?

24. Disabled people are diverse, and therefore different people will need review or reassessment at different time intervals. For example, someone whose condition is expected to change quickly may need reviews every 6 months, whereas someone whose condition is not expected to change may only need an assessment every 5 years. People going through significant life changes – such as young people transitioning into adulthood – may need more regular reviews than people who have established routines that are not expected to change. Therefore, there should be no standard interval for review or reassessment. Rather, as part of the assessment the person and the assessor should discuss what an appropriate interval for review should be. This agreed-upon review date should be written into the assessment as the date that the next review or reassessment needs to happen by.
25. As identified in point 8 above, disabled people and their whānau know what their needs are and can therefore identify when there has been a change in their circumstances that warrants a review or reassessment. Disabled people and whānau should be trusted to identify when they need a review or reassessment and to ask for one. Guidance about the types of circumstances that might trigger the need for a review or reassessment could be provided, but these should not be binding – every whānau is different, and therefore it would be inappropriate to suggest that there are any circumstances that always warrant a review.

26. Having flexibility to determine when a reassessment or review is needed, as detailed in points 17 and 18, aligns with the Enabling Good Lives principles of self-determination and being person-centred, as this approach puts disabled people in control of their lives.

Consultation Question Eight:

What information or support will help you access the services, beyond DSS, that you might be eligible for?

27. As detailed in points 11 and 12 above, the disability system in Aotearoa New Zealand is complex, with supports provided by a variety of different agencies. Disabled people and carers often need support to navigate this system and to access the supports they are entitled to – without this navigation support, they can end up feeling like they are standing in the middle of a circle of agencies who are all trying to pass responsibility for funding the support on to each other, with the result that the disabled person either does not get the support at all, or they only get support after a significant delay.
28. Therefore, Disability Support Services should be able to support disabled people and whānau to navigate the system. In some cases, this might involve simply writing into the assessment what other supports the person should be eligible for, and the person or their carers will then feel confident following up to access those supports. In other cases, the person or their carers may need someone to help them access these supports, for example by assisting them to contact other agencies or contacting other agencies on their behalf. This system navigation support should be covered by Disability Support Services funding.

29. There needs to be aggregate data for analysis regarding what entitlements people receive from Disability Support Services funding and elsewhere, plus what additional service they need from Disability Support Services. The analysis will inform future provision to support disabled people to live good lives. This will stop people from reaching crisis point by enabling them to access the support they need when they need it. By aggregating and analysing this data, Disability Support Services will be able to have an overview of how the whole system is working to support disabled people to live good lives. This will allow Disability Support Services to identify where improvements are needed at a system level. This data could potentially be passed to Whaikaha for analysis, as the function of having oversight of the whole disability support system and working across government to improve it may be more within their remit. However, Disability Support Services is the agency that is best placed to gather this data on behalf of Whaikaha.

Consultation Questions Nine and Ten:

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?
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?

30. We prefer Option 1 (linking flexible funding to the person's plan). This approach is more in line with purpose of flexible funding, which should empower disabled people to spend their funding on whatever they believe will support them to live a good life. This approach is also more aligned with the Enabling Good Lives approach, and particularly the principles of self-determination, being person-centred, being mana enhancing and being easy to use.
31. We do not support Option 2 (adjusting the purchasing guidelines) because constraining what flexible funding can be used to purchase in this way undermines the purpose of flexible funding. Disabled people are diverse and have a variety of needs related to their disabilities, and it would be impossible to write purchasing guidelines that fully accounted for this diversity.
32. In addition, Option 1 is likely to be less stressful and time-consuming for disabled people and carers than Option 2 is. As identified in point 16 above, following the changes to the purchasing guidelines on March 18 last year, disabled people and carers are now having to spend significant amounts of time each week justifying purchases. This situation is likely to continue if the purchasing guidelines are merely adjusted, whereas Option 1 would be similar to the situation prior to March 18 2024 – any purchase aligned with needs identified in the plan could be quickly approved with a simple email, reducing the administrative burden on disabled people and carers. And, presumably, reducing the administrative burden on MSD staff.
33. Keeping to the flexible funding budget a person has been given each year should be all the transparency that is needed. People should be able to use flexible funding for anything that supports them to live a good life, and requiring people to constantly justify their purchases is intrusive and time-consuming. If a person is frequently spending all of their budget and finding that they need more support, this should trigger a review to ensure that the amount of funding provided is sufficient and being spent well. However, if people are keeping to their budgets no more accountability should be needed. Again, this approach aligns with Enabling Good Lives, especially the principle of self-determination.
34. The funding amount provided to the person should also be the full amount, without any part of it being skimmed off by organisations set up as host providers of Individualised Funding. This is a major problem, the money needs to go to the person, not the middlemen.

Consultation Questions Eleven, Twelve and Thirteen:

Do you support the introduction of criteria for receiving flexible funding? Please let us know why, or why not?
Which of the following criteria for receiving flexible funding do you agree or disagree should be included and why?

a. *Use of flexible funding is part of an agreed plan and linked to a specific need.*
b. *Disabled people and / or their family / whānau / carers are able to manage the responsibilities of flexible funding.*
c. *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 of scheduling, it is closer to where the person lives etc.).*
d. *Flexible funding will address a service gap, where the service is not otherwise available, or suitable for the individual.*
e. *The cost of the service or support that will be funded is not more expensive than other ways to get that support.*
f. *The flexible funding will enable the person to purchase or access a service that is expected to reduce a person's future support needs.*

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.

35. We believe the option to use flexible funding should be available to any disabled person who wants it, as this approach aligns with the principles of Enabling Good Lives. Therefore, the only criteria for flexible funding that we agree are appropriate are **a** (use of flexible funding is part of an agreed plan and linked to a specific need) and **b** (disabled people and / or their family / whānau / carers are able to manage the responsibilities of flexible funding). The other criteria unnecessarily constrain what flexible funding can be used for. Introducing these other criteria (c-f) would undermine the purpose of flexible funding by making it significantly less flexible, and would therefore go against the principles of Enabling Good Lives.
36. We particularly disagree with criterion f (the flexible funding will enable the person to purchase or access a service that is expected to reduce a person's future support needs). Expecting that a person's support needs will be reduced in the future is not reasonable for all disabled people – many people will always have support needs related to their disability. It would be unfair to prevent these people from accessing flexible funding simply because having reduced support needs in the future is an unreasonable or unattainable goal for them.

37. Thank you for taking the time to read through this submission.