

Waitaha Regional Leadership Group
Via email

Thursday 18 May 2024

Dear Amanda Bleckmann,

We are the Leadership Group for Waitaha writing in response to the recent updated version of the Purchasing Guidelines. Our group is made up of disabled people, family members of disabled people and providers of services for disabled people. We have been discussing how the purchasing guidelines and the system around them demonstrates the Enabling Good Lives Principles. We would like to give our feedback on this with some suggestions for adjustments.

Disabled people and whanau are mindful the funding is available to break down barriers to participation, to enable in a disabling world, and to support us to live our good beautiful ordinary lives. The review of the purchasing guidelines includes examples on the application of the guidelines and some rewording for clarity, but fails to address the experience of the disabled person and whanau in accessing their funding through Host services.

Our disabled person and whanau community experiences:

- Exhaustion over the amount of effort required to keep on fighting to use the funding that has already been allocated to us/our family member to help enable our good life.
- A loss of choice and control when required to complete the exercise of writing and explaining our justification for using the funds in the way we had in mind. For some of us, writing and justifying using the forms set out by the hosts is not possible.
- Threats from fund holders/hosts that we will be caught out misusing funding in the audit process.
- Being shut down when we are explaining about our individual situation by being redirected to a process that is not easy to use/individualised.
- Confusion about the principle 'ordinary life outcomes' as some fundholders refuse to allow any ordinary life expenses even if that expense relates to an ordinary life outcome.
- Rules created by the fund holder about using funding to help the disabled person/family experience an ordinary life outcome. When questioned about this, fund holders say it is a direction or rule that has been communicated from the Ministry. These rules change depending on who you talk to.

We are unclear which hosts disabled people and families are finding these negative issues with. We would like to be involved in leading the change in our region but if it is a widespread issue then we would appreciate the involvement of Whaikaha to show leadership for change. Some of our group have had the mana enhancing and person centered experience of a needs assessment that includes hearing the disabled person / family voice and making the decisions on the types of things that the funding would be spent on at the time of doing the plan/assessment. This reduces the need to have to justify things every fortnight and gives plenty of time for disabled people and families to focus on living their good life. The current system has a gap in the planning section.

As a group, we have had some lively discussions as the disabled people and families have listened to providers about what the experience of holding funds has been like for them. In particular, the providers said that there has been no communication regarding the guidelines and no rules that have been given as a directive.

We are concerned that the Guidelines are based on a medical model of disability. We understand that disabled people and family were involved in the process to update the guidelines. Our society has a long way to go in moving from a medical model of disability to a social model and we are all learning to think in a different way. We have been wondering what the purchasing guidelines would look like if they were written by disabled people and families. We see this would only be successful if the document was rewritten, rather than asking for feedback on the guidelines / editing / being consulted, on an existing document.

It is of great concern that we are missing out on building the capacity and capability into disabled people and families by having a funding process that does not demonstrate the EGL Principles. We would appreciate the opportunity to be involved in finding an outcome for this.

To improve the experience of the disabled person, whanau and provider, we believe the investment in planning the purpose the funding is trying to achieve for a family has not been addressed. We believe this would fundamentally change the experiences of all parties. As the leadership voice for disabled people, whanau and providers, we are aware some of the planning can be delivered by connectors in the EGL space, at other times there is enough capacity and enrichment of experience (vs poverty of experience) from the family and disabled person that they can work directly with the Host.

To this end our suggestions are:

1. Working from a high trust model, inline with the principals of enabling good lives, meaning that hosts are not imposing their values upon individuals or caregivers around their goals..
2. Provide opportunities for people to connect with someone who could assist them making a plan, if they choose. This could be built into funding allocations. Currently this is done locally and whilst local knowledge is important, variance nationally becomes an issue.

3. Having easy access to easy to read, information or guidance from diagnosis, assessments, purchasing, employment, housing, employing support workers etc, currently each host or system manages this differently giving inconsistent information throughout Aotearoa. This system would also be a mechanism to alert Whaikaha of trending patterns or challenges within a community and able to respond rather than poor practice becoming established.

Yours sincerely,

The Waitaha EGL Leadership Group