**Enabling Good Lives National Leadership Group (NEGL)**

**Points to consider when making a response to the Whaikaha announcement on the 18th March 2024**

The Enabling Good Lives National Leadership Group (NEGL) recognises the confusion created by Whaikaha’s unilateral announcement on Monday 18th March 2024 via Facebook. NEGL also recognises that many disabled people and families have already made their views known to Whaikaha and Ministers. NEGL notes the strong support for EGL-based change (choice and control).

NEGL believe the changes to the purchasing guidelines restricting self-determination do not align with the EGL approach and potentially the governments' obligations to the UNCRPD and the NZ Disability Strategy. NEGL encourages disabled people and families to individually and collectively make their voices known at this time.  We suggest that you express your thoughts to both Whaikaha, Ministers, MPs and to the community.

NEGL suggests you potentially send your views to a variety of decision makers. This should include Ministers. For example:

Penny Simmonds, Minister for Disability Issues @ P.Simmonds@ministers.govt.nz

Nicola Willis, Minister for Social Investment @ N.Willis@ministers.govt.nz

Louise Upston, Minister for Social Development and Employment @ L.Upston@ministers.govt.nz

Key Whaikaha decision makers include:

Ben O'Meara - Deputy Chief Executive, Whaikaha - Policy, Strategy and Partnerships @ ben.o'meara001@whaikaha.govt.nz

Amanda Bleckmann - Deputy Chief Executive, Whaikaha - Commissioning, Design and Delivery @ amanda.bleckmann001@whaikaha.govt.nz

You may want to consider the following points:

* flexibility via choice and control makes things better
* the reduction of flexibility will bring about additional challenges and the impact this will have on personal and/or family well-being.
* the Enabling Good Lives National Leadership Group (NEGL), as the advisor to officials on the EGL approach, can confirm it was not involved in the changes announced
* there are already EGL, UNCRPD and Te Tiriti informed leadership networks who have experience and expertise with partnership. Whaikaha needs to use them
* there has been overwhelming support for EGL-based change. People who have experienced choice and control and flexibility do not want to return to a far less effective approach
* The change of criteria for Equipment and Modification Services is not mana-enhancing because it encourages disabled people to be at their worst to be prioritised.
* there are disabled people and families with the expertise, insights, strategic ability and experience with working in partnership regarding challenging and sensitive issues. Use the EGL, UNCRP and Te Tiriti informed leadership networks
* are we giving priority to the "old" and institutional approaches to the point where new innovations (flexibility) are being potentially eroded
* NEGL believes that there will have been other cost saving alternatives more consistent with an EGL-based change process
* Individual and family funding must be based on their unique circumstances and aspirations
* NEGL needs to experience partnership between EGL-informed community leaders and Whaikaha to be confident Whaikaha is committed to implementing the EGL approach described in cabinet papers
* NEGL appreciates there are times when challenging decisions must be made. NEGL expects disabled people and their families are recognised as being able to fully contribute to the processes around making these decisions
* all decisions must be strategic and made on the basis of EGL, Te Tiriti and the UNCRPD as they are key foundations for both current practice and future changes
* Whaikaha was set-up with the expectation that they would do things differently. The decisions released on Monday 18th March are not strategically aligned to positive change, EGL informed or reflecting a partnership process
* the messaging about the changes unfairly demonises disabled people and their loved ones to the general public
* disabled people and families must not ‘pay the price’ for things that relate to political and bureaucratic actions, inactions and misunderstanding
* the EGL approach is about try – learn – adjust. It is time to make adjustments based on the feedback from the community
* we need to see bold and constructive change emerging from this unfortunate situation that demonstrates Whaikaha understanding and commitment to EGL
* support for the announced “review” providing EGL, UNCRPD and Te Tiriti informed leaders (disabled people and families) are involved in the design, implementation and recommendations associated with the “review”

NEGL is really frustrated by this situation. At the moment there are some great initiatives that will progress positive change as well as we know many individuals and families have experienced better lives through flexibility. This is a huge and unnecessary situation that is causing fear and confusion. NEGL wants to get on with positive change and wants people to continue to experience flexibility. There has been considerable political attention related to this situation. Now is the opportunity to describe to decision makers how partnership and positive change can be achieved

NEGL is making our thoughts known to decision makers and we encourage those of you who have not yet taken this opportunity to do so.

The Enabling Good Lives approach was developed by disabled people and families and has been demonstrated for a decade. It works for disabled people and families. It is time for the Enabling Good Lives approach to be experienced throughout New Zealand.

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