

A SUMMARY OF COMMUNITY VOICES

This document contains key repeated messages in response to the Whaikaha announcement on the 18th March 2024

Process:

- NEGL provided an opportunity for disabled peoples and family networks to respond to the change announced on the 18th March 2024 by Whaikaha.
- Key themes and direct quotes were collated in this document.

Note: There are multiple similarities in comments received from disabled people and families and so single quotes have been used to describe responses that came from multiple submissions

Response:

Eleven (11) responses were received.

Note: Some of these responses came from national networks that had directly received 300+ comments from impacted community members

Quotes:

Quotes have been extracted from all eleven responses. Typically, only one quote has been used as an example of many repeated statements. *Quotes are in italics.*

i. RESPONSE TO THE WHAIKAHA ANNOUNCEMENT

Question

1. What were the responses when people heard the news about the cuts (thoughts, emotions etc)?

Responses

a. Emotional distress

“Utter confusion, shock, despair, rage, cheated, humiliated, targeted unfairly, genuine fear that their lives would take a turn for the worse, shame and guilt about

needing respite and support for their own wellbeing as a carer because of the derogatory statements made by the Minister.”

“Whanau and people with disability on the ...x... are horrified. They don't know how they will manage to have a good life with the restrictions on travel and purchases”

b. Targeted

“Families felt personally targeted, and deeply disappointed in the lack of consultation...”

“Carers/Family felt violated by the way the Minister talked about misuse of funding”

“People felt that they were being picked on.”

c. Anger that partnership mechanisms with community had not been used by Whaikaha

“Anger about ignoring the partnerships that were in place”

d. Loss of trust

“There is a loss of trust that people in Whaikaha know what they are doing, why are people being drip fed the details about the changes in what funding can be spent on, it seems chaotic and disorganised. The callous way carers have been spoken about by the very decision-makers who are meant to be knowledgeable and aware of the needs and situations of carers beggars belief.”

e. Poor communication

“Disappointment in the way it was communicated – facebook and website only. Still many IF users have not received any official letter of changes, so there will be many people who still don't know about the changes. Not disability friendly (sign, easy read etc)”

f. A belief this is pushing people into services

“Pushing people into services – residential care because families are at breaking point. Trust is broken with Whaikaha.”

g. A failure of Whaikaha to educate and challenge the Minister

“Loss of trust that Whaikaha had not challenged the Minister to represent the disabled people and families”

“There is worry as people face their new reality with expenditure restrictions and how they will manage the emotional, mental and physical stress that may well come with their changed living situations. This same community and providers, for several years, have raised the issues surrounding underfunding, the growth in demand for disability support, the need for more flexibility so people can make decisions that best suit their needs, and the slowness of systems transformation – so there is a feeling that not only have we not moved forward but we are going backwards.”

h. Lack of recognition

“Carers/family upset that there was no recognition of the unpaid labour, just made to look like a bunch of bludgers”

i. Loss of progress

“Disgusted and disempowered, felt like the work of generations before us was carelessly discarded and disregarded.”

j. No recognition of the concept of family well being

“Realisation that Whaikaha and the Minister of Disability Issues do not recognise the interdependence of disabled children/people and their families”

ii. POTENTIAL IMPACT

Question

2. How might these changes impact on people in your networks?

Responses

a. Increased risk

“Higher risk of burnout, isolation, mental health breakdown and issues like depression and anxiety”.

“Increased risk of violence and harm due to frustrations and inability for the disabled child to regulate through a preferred item gadget or toy.”

“Serious risk to health and life when life saving gadgets that support monitoring of health vitals aren’t allowed.”

b. Stress on families

“Fracturing of the family unit and more strain on relationships within the family unit.”

“Added stress, time and effort trying to clarify claims and processes here on.”

c. Reduced choice and control

“The disability community will have less choice and control and independence. Their mana has been stomped on. It will be hard for people to live close to their family and many people are thinking residential care is the only option”

“Angry – daily routine and activities were being removed after weeks, months or for some years of trying, learning and adjusting strategies to enable life to be ‘good’.”

d. Mana trampled on

“... the way the announcement came out and the wording and confusion made me feel like I was worthless and my life and how I lived my life was worth zero The fact that it was announced and the change was from that day not even given time to process made me feel like our community is worthless to society, that even though I stay within the rules and guidelines we are told to access the funds that I am been punished for something I have no control over.”

“Pissed off – because flexibility and EGL had been attacked – felt like a stab in the back”

“Hurt – people were happy to take a funding cut to retain flexibility. As always it’s not how much rather how it can be used.”

“One of my youth group members didn’t come to youth group as he was too anxious and unsettled ...”

e. Restricted opportunity

“Financial inability to continue accessing activities, therapy or items that provide for some respite and ensure carer wellbeing, especially for single mothers who have been forced to give up their work/careers due to caregiving responsibilities for their disabled child”.

“Long term impact of ‘pausing’ something like a therapy – makes disabled persons’ progress go backwards”

“Families unable to use their funding as they are not skilled in employing or training workers”

f. Reduction of supports

“No more breaks for parents whose children refuse to leave home or are unable to due to high and complex medical needs.”

“Concern that some disabled people might not have the support they need to travel to meet employment obligations, does this mean their employer needs to pay for support workers? Can immediately see that this is a disincentive to employ disabled people!”

“No respite for those who are rural or can’t find carers due to a shortage of carers.”

iii. NEXT STEPS

Question

3. What do you think should be done now?

Responses

a. Full apology

“Community engagement to listen to the community, address and apologise for the hurt and harm caused.”

“I think the minister of disabilities should announce a formal apology and stand down from her role”

b. Develop and implement a shared decision-making approach

“Push for shared decision making models not consultation with Whaikaha.”

c. Reinstate choice and control

“Reinstate the prior guidelines immediately and start personal budgets for all”

“Overturn the decision and make cuts through other avenues – not targeted at families. Work with community for solutions. Ensure the information with Minister is receiving is correct and backed up with actual evidence.”

d. Action a formal complaint

“A complaint made to the Ombudsman’s office for the appalling way this change was announced and disseminated along with the lack of work that had gone into the changes, for example, a change stating no domestic travel will meet the criteria and then a couple of days later, oh no, travel in your locale is ok. An internal review of the situation cannot be tolerated. The lack of accessible information and it is still not available because the information was too unstable for the translators to use. The communications strategy used by Whaikaha leaves a lot to be desired – was there any strategy at all.”

e. Strategies to unite disabled people and families (Collective Independent Voice)

“Disabled people and Carers/Family unite to progress change (various groups working hard but still not working together as well as they could)”

f. Ensure EGL is embedded in all work

“Feedback on new Disability Strategy must include EGL as a pillar”

g. Increased understanding of a personalised approach

“Whaikaha and Government need to find an effective way to come and discuss with the Disabled community and host providers in a way that is an even field of play, to work out the rules for accessing flexible funding, noting that each person's daily life is different and the funding is needed for different reasons depending on the individual”

h. Ensure any ‘Wellbeing’ Strategy (respite strategy) meets the unique needs of all parties

“Families need a Respite/Wellbeing Strategy that is additional to disabled persons respite (as was made obvious with the withdrawal of any support for families)”

i. Increase the availability of personal budgets

“The rollout of Enabling Good Lives personal budgets nationwide over the next 18 months to reestablish faith and trust.”

“Cut costs and save on unnecessary monitoring mechanisms for small budgets”

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j. Increase the development of EGL-based leadership

“Whaikaha needs to pro-actively reach out to EGL, Te Tiriti and UNCRPD informed leaders in the tangata whaikaha Maori, Pacific, disabled and family communities and begin deep discussion on a way forward. The current approach to budget management decisions obviously hasn’t worked, a radically different EGL informed process needs to be used.

The expectation when Whaikaha was stood up was that it would work in partnership with community, this did not happen. Community members feel there has been a significant regression to an extremely draconian way of making decisions, totally disempowering for disabled people and their families.”

“Resource community to stand up EGL leadership groups ASAP.”

“Full system transformation through a EGL lens in partnership with EGL informed community partners.”

k. Better communication

“When the shit hits the fan ‘more’ comms is needed not ‘less’”

“Whaikaha improve their communication and use the partnerships they have established to bring about change”

“I hope that there will be a real analysis of the work underway and that the key actions will be taken forward so momentum on this important work is not lost.”

l. Increased focus on informed positive change

“Minister and government need to step up the system transformation and resource it better.”

“Review the budgeting and resourcing for Whaikaha and clarify the stewardship role with clear and robust outcomes that uphold disabled people and family rights.”

“Aotearoa has been so slow at moving to the EGL way, Australia have been operating NDIS across disability for several years - why cant we do the same, stop meddling at the edges. Fund and resource real change and value the people in the sector”

“Use the research, networks and people available in the community, ultimately this “free” resource has been more than forthcoming with information and solutions -both in health and education, but action doesn’t match the input provided. The reality is lived experience and whanau are the most valuable members of this community and should be valued as such.”