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"A Different Light"

A Different Light – 30^h March 2024 – “Come on Minister Simmonds, we need a champion of our people – not champion of covert hatchet”

Beware the Ides of March! Okay, it's a couple of days out but the announcement about changes to Disability Services on 18th March was foreboding to say the least!

Out of the blue, Whaikaha the Ministry of Disabled People proclaimed changes to the Purchase Rules for Individualised Funding. The reason given was, that “Whaikaha has a fixed amount of funding. Growing demand has meant they are already forecasting an overspend in this financial year and to manage these demands and to ensure that disability funding is directed to those that need it the most, Whaikaha has made some difficult decisions”.

The changes target Flexible Funding. This funding has enabled disabled people and their whanau to be self-directed about the services they access through mechanisms such Individualised Funding where they can manage their own allocated budget by hiring people or buying goods or services they need. This meant that disabled people have been able to hire a friend or a family member, or someone else they have connected with and who has an understanding of their needs. This self-determination is articulated by the Enabling Good Lives (EGL) approach, a foundation and framework to guide positive change for disabled people, promoted by...Whaikaha.

The news sent shockwaves throughout the Disabled Community, instantly raising a multitude of questions. Where was the consultation, given “the true partnership the Disability Community, Maori and Government” Why didn't the current or past Minister of Disability Issues advocate for additional funding to address increased demand? How do these changes in Flexible Funding contribute to the EGL Approach and the much hyped System Transformation?

The decision to implement restrictions to disability supports strikes at the very core of Whaikaha's principles. It not only undermines the progress made in enhancing the quality of life for people with disabilities but also threatens to unravel the fabric of inclusivity and partnership that Whaikaha sought to weave.

One of the key pillars of the EGL approach is self-determination. By empowering individuals to make decisions about their own lives and support needs, Whaikaha aimed to foster independence and dignity. However, the funding cuts jeopardize this fundamental principle, forcing individuals to navigate an already complex system with fewer resources and support structures.

Since the announcement, we have been repeatedly told that individual allocations will not be cut, but rather that the criteria around the flexibility will be tighter and clearer. But hang on, isn't the catalyst for these changes a budget blow out, which requires some significant savings to address the budget shortfall? Oh I get it: by tightening the criteria on Flexible Funding, some disabled people and whanau will not be able to spend all their allocation because the criteria doesn't give options that work for them! They have no respite facilities for their disabled whanau member to utilise- maybe they are in Tai Tokerau where external respite providers are close to zilch? Where the only way dog tired carers can get a break is to book into the local motel, while a carer steps into their worn out shoes for a weekend and ...sleep! In my conversations with such 24/7 carers this uninterrupted sleep through the night is the main goal. If they were getting a massage for an overworked back dealing with the lifting, positioning, toileting and dressing of their loved one - well, good on them! But, not any longer... Bingo! No cuts in allocations, but Hey Presto - reduced costs. Clever but pernicious. Some whanau are already struggling to navigate the intricacies of Individualised Funding and cannot use their full allocation right now, without imposing a list of exclusions which is ambiguous at best and cryptic at worst.

Respite options are included in the changes in criteria, with the ability to purchase items that would contribute to relieving carers of continual attention to their loved ones such as the provision of electronic devices or recreational equipment like trampolines (which can be very therapeutic for some Autistic children) are for the chop. Yep- the same Ministry that has spent the past 18 months convincing whanau that they can be creative and flexible, to work

around the glaring systemic gaps in provision for disabled people is unfortunately having to sing to a different piper.

Surely the Minister of Disability Issues, Penny Simmonds should have known about these demand pressures. She is not new to these issues. The Southland Times on 31 Mar 2022 as MP for Invercargill quoted her : “as the National Party’s disability spokesperson, I’ve been working hard to achieve improvements for carers and to get a commitment from the Government on the provision for extra support. Respite care payments are a major stumbling block. They are capped at \$80 a day, after a disappointing \$5 increase from the Government last year. They fall well below the minimum wage and make it virtually impossible for carers to attract people to these roles, unless they top up the funding themselves”.

Come on Minister Simmonds - we need a champion of our people- not a champion of the covert hatchet - put your money where your mouth is and get in there and advocate to your cabal of colleagues. After all, the measure of a civilised society rests with how it treats its most vulnerable members.

Jonny Wilkinson is the CEO of Tiaho Trust - Disability A Matter of Perception, a Whangarei based disability advocacy organisation