

Refocusing on Community-based Support

In a surprising turn of events, it seems that Whaikaha, the Ministry of Disabled People, has implemented policies that are causing quite a stir among those who rely on community-based supports. This move seems to contradict the principles of empowerment and inclusivity, which are essential to supporting the disabled community and their families.

Here's what's happening: Disabled individuals and their families, who depend on tailored, community-based support systems, are now facing significant limitations on how they can use their funds. These restrictions include:

No More Respite through Purchases Buying items that provide a break or relief (known as respite) for caregivers and disabled persons is no longer allowed. This could range from simple pleasures like a new book or a day out to more significant purchases.

Restrictions on Non-Essential Spending Spending on anything considered non-essential for the direct support of the disabled person is now off the table. This means no funds can go towards activities or items that, while not essential, significantly contribute to the well-being and happiness of those involved.

Self-Care Services Cut Services aimed at self-care, such as massages, pedicures, or other forms of therapeutic and appearance care, are no longer covered unless they directly benefit the disabled person.

Gifts and Recognition Limited Providing gifts or tokens of appreciation for voluntary support, a practice that acknowledges the invaluable help provided by volunteers, is no longer permissible.

Travel and Accommodation Costs Covering travel-related costs for disabled individuals, their families, or support workers, including accommodation, both overseas and domestic travel, and food, is now restricted.

Interestingly, these restrictions do not apply to individuals and agencies managing group homes. These homes, despite being criticised and even labeled as institutions by the United Nations, now seem to have the most freedom in how they can allocate their funds. They are, at least theoretically, allowed to spend on any of the above, should they choose to.

This disparity raises important questions about fairness and the value we place on different forms of care. Why are community-based supports, which align closely with the values of the Enabling Good Lives approach, being restricted, while institutional settings are given more leeway? This approach seems to be at odds with the EGL principles, which focus on self-determination, the enhancement of Mana &

Community building.

The focus should be on creating policies that support all aspects of a disabled person's life, including their mental and emotional well-being. Community-based supports that align with the principles of the Te Tiriti o Waitangi the UN Convention on the Rights of Persons with Disabilities, and empowerment should not be "punished" or restricted. Instead, they should be celebrated and supported for the crucial role they play in the lives of disabled people and their families.

The EGL approach has been tested, refined and proven to be a replacement for legacy services (the status quo). It is heartwarming to note the massive support for EGL in the life stories people have been sharing recently. It is time for bold action where disabled people, families, service providers and officials work together on a tangible plan to transform "business as usual:" in line with the three pou of Whaikaha.