12 years in Court and still fighting

Disabled adults and their carers deserve better

Kathy Spencer

The primary focus of government-funded social services should be to support the most vulnerable members of society. Something has gone badly wrong when severely disabled adults and the family members who care for them have been battling in court for more than 12 years to be treated fairly.

The first 12 years in Court

In 2000, a small group of families with adult disabled children lodged a complaint about the Ministry of Health's policy on who could be paid to provide care to disabled adults. The policy excluded family members from being paid carers.

It took a 12-year process, involving appeals to the High Court and Court of Appeal by the Ministry of Health, to finally confirm that the policy was indeed discriminatory.

Funded Family Care

After losing the case, the government introduced *Funded Family Care* to pay family carers for their work. Care would be paid for at the minimum wage for a maximum of 40 hours per week and be available only to those with high or very high needs.

The scheme was predicted to benefit 1,600 family carers and their disabled adult children, but more than 4 years after its introduction, only 354 people are being paid. The government spent only $8.8m on the scheme last year, well short of the $23m originally budgeted.

Why are so few people using Funded Family Care?

Bearing in mind that all clients have high or very high disability-related needs and 50% of the clients have an intellectual disability, the requirements of the scheme are onerous to say the least. Even the Ministry's own document on *Funded Family Care* acknowledges:

"The requirements of the FFC arrangement are quite extensive and complex and understanding the obligations and responsibilities of being an employer in this arrangement can be quite daunting."

The disabled person first has to make an informed choice to use the scheme. But many of those most likely to benefit from the scheme are unable to make that choice. In the Ministry's 2015 evaluation of the scheme, one family member said:

"He doesn't talk. He can point with a finger … His disability is such that he couldn't make any choices himself in regards to things like that."

The disabled person is then required to formally employ their family carer. Here are just a few of the 21 responsibilities assigned to the disabled person:

- employing the family carer
- paying the family carer
- complying with all laws as an employer

- ensuring that payments are made for replacement care when the family carer is unable to provide funded family care
- notifying the Ministry of any change in the disabled person's circumstances that makes them not eligible for funded family care.

Another family member, quoted in the Ministry's 2015 evaluation, said –

"Disabled people who are very high needs and severely disabled don't have the ability to be an employer. It's not in their psyche. It's not something they can get their heads around, you know?"

Before any funding can flow, the disabled person has to open a bank account from which s/he can pay their family carer. This would be quite straightforward for many people, but less so for someone with a severe intellectual disability. As one carer said:

"It was a classic catch 22 situation. We needed to open a bank account for him which could have direct debits taken from it so it needed to be a cheque account. I couldn't open it in my name, I couldn't open it as a trust account. So we were at a brick wall, really, because he couldn't sign his name which was the prerequisite to having an account like that…."

Still in Court

Unfortunately 12 years to establish discrimination has not been the end of the fight. A number of families are alleging that the Ministry of Health discriminated against them by refusing to pay family caregivers. And earlier this month, the Court of Appeal ordered a reassessment of the 17 hours a week funded under the scheme for a 51 year old severely disabled man.

Changes needed

The scheme may be delivering choice and control for a small group of disabled people who can deal with the requirements of being an employer. However, it needs to work for a much wider group. Other options should be available to suit people with a range of disabilities and preferences about their care.

For example, some families may prefer to be paid by the Ministry under a simple contract for services. ACC funds care for some of its clients in this way, offering to pay either the disabled client or their carer. Another option is for the carer to be paid an allowance by the Ministry.

Discrimination against family carers also needs to be addressed in the following areas:

- the rate of pay for family carers should be the same as for other carers
- spouses/partners should be able to be funded carers
- those with family members as carers should not have to demonstrate a higher level of need than others to get funded care
- the number of paid hours needs to be realistic to support the person in their home.

A good start would be to see **at least** the $23m originally budgeted actually being spent – the funding is there to improve lives, not to fight in Court.

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