



CCS
disability action
Including all people

TE HUNGA HAUĀ MAURI MŌ NGĀ TĀNGATA KATOA

Briefing to
Hon Julie Anne Genter
The Associate Minister of Health
Disability Support Services

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Contents

Executive summary	2
Recommendations	3
Introduction	4
About us.....	4
Disabled New Zealanders do not get a fair go	4
Outcomes for people receiving disability support services.....	5
Consolidating the new direction	5
Recommendation	6
The underfunding of disability support services needs to end	6
Recommendation	6
Unfair choices and the impact on ethnic inequalities	6
We must not leave people in residential services behind	7
Recommendations	8
Flexibility and time	8
Recommendations	9
Societal barriers	9
Recommendation	10
Personal budgets	10
Recommendations	11
The System Transformation Project and demand pressure.....	12
Recommendation	13
Thank you	13
Bibliography	14

Executive summary

- We need a disability support system that is based on disability rights and that gives disabled people and their whānau choice and control over their supports and lives.
- Since the early 1990s, significant increases in funding for disability support services have been rare and funding has simply not kept up with inflation. As a result, many organisations providing disability services such as ours are now underfunded by the government around 10% to 15% on average.
- Cultural groups that prefer more family-based options are deeply disadvantaged by the current focus on segregated options.
- The ongoing lack of resourcing for family-based and community-based options is forcing people into unfair choices and driving inequality between different groups.
- It is vital that the System Transformation Project improves the situation of people in residential services. Wherever possible, we should be supporting people to move out of residential services into true community living.
- Inflexible and inefficient supports can severely limit choices and possibilities for disabled people.
- You need to keep challenging the Ministry of Health to demonstrate that they are making the system more flexible and reducing time costs for disabled people and their whānau.
- No matter how effective disability supports are, they will never give disabled people and their whānau a good life unless there are wider societal changes too.
- People should be able to choose, and alter later, their involvement in managing their budget. A person-directed budget should not be seen as a binary one-off decision, but a sliding scale of control that can be flexible based on each person's wishes.
- It is important that the government does not rely solely on personal budgets to transform disability support services. The government will need to fund some services centrally, particularly more intensive and crisis-based supports. It is vital that a safety net is maintained for people who cannot currently manage their budgets and/or are facing a crisis.
- It is important that you safeguard the success of the System Transformation Project by ensuring adequate investment is available. We need to be realistic about the possible increase in demand; otherwise, we risk budget blowouts and punitive funding cuts, which will harm people receiving support.

Recommendations

That as the Associate Minister of Health you:

- Support the System Transformation Project.
- Direct the Ministry of Health to investigate providing an immediate 10% increase to all contracts for disability supports to, partially, address the significant underfunding of these contracts.
- Direct the Ministry of Health to make sure the System Transformation Project benefits people in residential services, including supporting them to move out of residential services.
- Direct the Ministry of Health to roll out Choice in Community Living nationwide.
- Direct the Ministry of Health to measure the time costs the disability support system imposes on people receiving support and their whānau.
- Direct the Ministry of Health to demonstrate that the disability support system is being made more flexible and is increasing the amount of free-time disabled people and their whānau have available.
- Direct the Ministry of Health to consider how the System Transformation Project can address societal barriers.
- Direct the Ministry of Health to ensure that there is a safety net of centrally funded supports for disabled people and their whānau, particularly intensive and crisis response supports.
- Direct the Ministry of Health to plan for the possible increase in demand the System Transformation Project may cause, including planning for the fiscal impact.

Introduction

Congratulations on being appointed Associate Minister of Health with responsibility for disability support services. This is an exciting time for disability support services. We are on the cusp of major changes that could give disabled people and their whānau far more choice and control. We are supportive of the System Transformation Project and are optimistic that it can deliver a positive change for people receiving support services.

We urge you to ensure the Project remains on track and true to the Enabling Good Lives Principles as well as its high-level design.

About us

CCS Disability Action is a community organisation that has since 1935, supported disabled people and advocated for their inclusion in the community. As of May 31 2017, we were providing support to around 4,000 children, young people and adults through our 17 branches, which operate from Northland to Invercargill. Our support focuses on breaking down barriers to participation. We receive a mixture of government and private funding.

Disabled New Zealanders do not get a fair go

Too often disabled people do not get a fair go. They do not get the same opportunities as non-disabled people.

The issues affecting disabled people are complex and the government alone cannot solve all the issues. The government, however, has a key role to play. Government funded services play a major role in the lives of disabled people. Considerable money is spent on disability related services and supports, but there is often poor outcomes for disabled people.

In the 2013 Disability Survey, disabled people compared to non-disabled people:

- were less likely to report a high level of life satisfaction;
- were less likely to feel safe at home or in their neighbourhood;
- were twice as likely to be the victim of violent crime;
- were more likely to report being discriminated against and more likely to be discriminated against more than three times over a twelve month period;

- were more likely to have no qualification and less likely to have a bachelor's degree or higher;
- had higher unemployment and lower labour force participation;
- were more likely to have lower incomes and live in lower income households.

Outcomes for people receiving disability support services

The outcomes for people receiving disability support services are even worse than for disabled people as a whole. This is because people who use support services tend to have higher support needs and face more barriers in society. They are less likely to have any qualifications and only about 5% received their main income from work. They are more likely to have had a finding of abuse and/or neglect (Office for Disability Issues, 2016).

Consolidating the new direction

Disability services have undergone radical shifts in direction in recent decades. The old state paternalism of large scale institutions has moved to a focus on individual choice and community living. This change has mirrored different approaches to disability and impairment.

There has been a growing focus on equal opportunities and rights for disabled people as well as encouraging and embracing leadership by people with disabilities. The Convention on the Rights of Persons with Disabilities, the New Zealand Disability Strategy and the disability action plans are evidence of this new direction (Convention on the Rights of Persons with Disabilities) (Office for Disability Issues, 2014) (Office for Disability Issues, 2016).

The revised New Zealand Disability Strategy uses a Social Model of Disability. This model emphasises that disability is primarily the result of environmental and social barriers people with impairments face because society is built in a way that does not take into account their needs (Office for Disability Issues, 2016).

There has also been a range of service reforms, under the New Model for Disability Supports, Individualised Funding and Enabling Good Lives. There has been progress and initiatives like Choice in Community Living are giving people more options and control over

their lives (Ministry of Health, 2013). The System Transformation Project is our chance to consolidate these changes and overhaul the whole system. We need a system that is based on disability rights and that gives disabled people and their whānau choice and control over their supports and lives.

Recommendation

- That as the Associate Minister of Health you support the System Transformation Project.

The underfunding of disability support services needs to end

Since the early 1990s, significant increases in funding for disability support services have been rare and have not kept up with inflation. While there have been some increases, they have tended to focus on specific areas, such as the recent “pay equity” settlement or the “sleepovers settlement”. As a result, many organisations providing disability services such as ours are now underfunded by around 10% to 15% on average. This has made it harder and harder to deliver services at the level of quality disabled people need. There is a funding crisis in the disability sector which is getting worse every year and comes at a time when we need our service organisations to invest in new ways of supporting disabled people and their families. This will simply not happen with so much pressure on “bottom lines”.

Recommendation

- That as the Associate Minister of Health you direct the Ministry of Health to investigate providing a 10% increase to all contracts for disability supports.

Unfair choices and the impact on ethnic inequalities

Too often disabled people and their families are faced with unfair options and are effectively pressured into decisions. Currently, some options are better resourced or easier to access than others. There can be more support available if people choose a segregated option, such as a special school or residential services. Resourcing for independent living or family-based options can be far less. Resourcing of supports outside of segregated options is generally contributory or subsidy based (such as Carer Support), rather than providing full funding. Other family-based supports such as Funded Family Care are very difficult to access.

Unequal resourcing can also result in inequality between cultural groups. Cultural groups that prefer more family-based options are deeply disadvantaged by the current focus on segregated options. For example, Pacific peoples make up 6.2% of all people receiving disability support services. Yet they make up only 3% of people receiving residential services, which are generally the highest funded option for support. By comparison, Europeans make up 77% of people receiving residential services, despite being only 67% of people receiving disability support services (Ministry of Health, 2017, pp. 10, 38).

Pacific people make up 8% of all people receiving Carer Support, which is, as mentioned, only partially funded. By comparison, European only make up 59% of people using Carer Support. The lower level of support for family-based options is likely to increase poverty rates among Pasifika families who have a family member with a disability. Pasifika people who use disability support services are the mostly likely cultural group to live in deprived areas. Fifty three (53%) per cent of Pasifika people who use Ministry of Health disability supports are in deprivation deciles 9 or 10, which have the highest levels of deprivation (Ministry of Health, 2015, p. 14). The ongoing lack of resourcing for family-based and community-based options is forcing people into unfair choices and driving inequality between different groups.

We must not leave people in residential services behind

It is vital that the System Transformation improves the situation of people in residential services. Wherever possible, we should be supporting people to move out of residential services into true community living. Choice in Community Living is one model for how to do this and should be expanded. We should also be increasing the amount of choice and control people have within residential services.

Preventing people from needing expensive segregated services, such as residential services, will be vital to ensuring the sustainability of disability support. In the long-run, segregated services are likely to be inefficient compared to preventative and investment approaches. The government will need to invest in disabled people and communities to ensure disabled people are included in society. This will, hopefully, reduce demand for segregated services.

Recommendations

- That as the Associate Minister of Health, you direct the Ministry of Health to make sure the System Transformation Project benefits people in residential services, including supporting them to move out of residential services.
- That as the Associate Minister of Health, you direct the Ministry of Health to roll out Choice in Community Living nationwide.

Flexibility and time

Some disabled people rely heavily on the availability and flexibility of supports in order to live independent lives and participate in society. This means that the government and providers have a large impact on, and therefore control over, their lives.

Inflexible and inefficient supports can severely limit choices and possibilities for disabled people. They can reduce, or eliminate, their opportunities to participate in employment and social life. Disabled people report that one of the biggest barriers they face is a lack of time (Wilkinson-Meyers, et al., 2014, p. 1547). If accessing support takes a lot of time or waiting around for inflexible support takes a lot of time, this creates opportunity costs for people with disabilities. How we choose to spend our time is one of the most important decisions we make for our wellbeing (Dalziel & Saunders, 2014, pp. 22-24).

Research we commissioned has found that inflexible supports that rely on set schedules leave little chance for spontaneous activities or meeting strangers. This leads to isolation, which can have profound negative social, economic and quality of life consequences (Milner & Mirfin-Veitch, 2012, pp. ix-xi, 22-26, 54-62).

The System Transformation Project should lead to more flexible support and reduce the time costs complex application and eligibility processes forced on disabled people and their whānau. It is important that you make sure this happens. You need to keep challenging the Ministry of Health to demonstrate that they are making the system more flexible and reducing time costs for disabled people and their whānau.

Recommendations

- That as the Associate Minister of Health you direct the Ministry of Health to measure the time costs the disability support system imposes on people receiving support and their whānau.
- That as the Associate Minister of Health you direct the Ministry of Health to demonstrate that the disability support system is being made more flexible and is increasing the amount of free-time disabled people and their whānau have available.

Societal barriers

For disabled people, however, a lack of time is not the only problem. The costs imposed by societal barriers are important too. This is where a second concept called conversion costs is important. Conversion costs is an idea the wellbeing economist Wiebke Kuklys developed based on Amartya Sen's capability approach (Sen, 2010, pp. 291-296) (Kuklys, 2004). Disabled people often require more resources (time and/or income) to achieve the same wellbeing as non-disabled people, these extra costs are called conversion costs (the costs could be due to a person needing a support worker, equipment or just needing more time to complete a task or everyday activity).

From Kuklys' research in the United Kingdom, assessed just on income, 23.1 per cent of individuals in families with a disabled family member were below the poverty line. If you apply conversion costs to adjust the poverty line, the percentage of families with a disabled family member under the poverty line jumps to 47.4 per cent. The concept of conversion costs is similar to the concept of the extra costs of disability, but conversion costs are better suited to assessing equality of opportunity. This is because conversion costs attempt to measure what resources disabled people need to have a good life, rather than just measuring their current spending. Effectively conversion costs act as a multiplier of the resources needed to achieve equivalent levels of wellbeing, rather than being fixed costs.

The costs are mainly caused by societal barriers, particularly inaccessible transport, infrastructure, housing, mainstream services and public buildings as well as negative public attitudes towards disability. The issues people with disabilities face are not primarily

individual issues, but are environmental and social issues (Sherlaw, Lucas, Jourdain, & Monaghan, 2014, p. 449).

As a result, no matter how effective disability supports are, they will never give disabled people and their whānau a good life unless there are wider societal changes too. For example, a lack of accessible housing can cause people to go into, and stay in, residential services, especially as people's needs change over time (Saville-Smith & Saville, 2012, pp. 22-24). Without addressing the current lack of accessible housing, efforts to reduce residential services may fall short. The revised New Zealand Disability Strategy highlights some of the changes that are needed (Office for Disability Issues, 2016).

The System Transformation Project will need to consider both how it can help bring about these wider changes as well as link to and reinforce other government initiatives.

Recommendation

- That as the Associate Minister of Health you direct the Ministry of Health to consider how the System Transformation Project can address societal barriers.

Personal budgets

A key part of the System Transformation is the move to personal budgets. Person directed budgets give people more choice, control and responsibility over their supports. Both Individualised Funding and Enhanced Individualised Funding are forms of person directed budgets (Ministry of Health). Both have proven effective at letting people take more control of their lives. The System Transformation plans to expand the range of support that can be incorporated into person directed budgets.

Person directed budgets are not silver bullets, however, and not everyone will want to fully manage their budget at all time. It is important that the government does not rely solely on personal budgets to transform disability support services. The government will need to fund some services centrally, particularly more intensive and crisis-based supports. It is vital that a safety net is maintained for people who cannot currently manage their budgets and/or are facing a crisis.

Research from the United Kingdom suggests that person directed budgets still rely on adequate funding levels to be effective and may not be able to deliver better outcomes for less money as has been previously asserted (Slasberg, Beresford, & Schofield, 2012, p. 1033).

Other research from the United Kingdom suggests that sometimes people find it difficult to self-manage budgets. In times of emotion distress, people can find it particularly difficult to make choices (Baxter & Glendinning, 2013, pp. 447-449). Sometimes people may want full control of their supports, other times they may want less control because they lack the time or energy. They may also sometimes want more time to focus on other aspects of their life such as family, employment or education. Also, some people may need to develop the capability over time to take control over their support.

It is also important to consider the impacts of time and emotional costs with person-directed budgets. Managing budgets and especially employees can be time consuming and stressful. Sometimes these costs might outweigh the benefits. Such costs on individuals need to be acknowledged, measured and evaluated. If health & safety or employment issues happen, it can even end-up financially costing disabled people and their whānau.

People should be able to choose, and alter later, their involvement in managing their budget. A person-directed budget should not be seen as a binary one-off decision, but a sliding scale of control that can be flexible based on each person's wishes. There also will continue to be a need for non-government organisations that people can turn to for advice and support. There is also a potential issue between moves to person directed budgets and the dependency of outcomes for a person on wider social change. Approaches focused on individuals may be ineffective at creating wider change. (Sherlaw, Lucas, Jourdain, & Monaghan, 2014, p. 449).

Recommendations

- That as the Associate Minister of Health you direct the Ministry of Health to ensure that there is a safety net of centrally funded supports for disabled people and their whānau, particularly intensive and crisis response supports.

The System Transformation Project and demand pressure

Research carried out in Canada, the United Kingdom and the United States found that officials had widespread concerns about the future of person-directed budgets in disability support services. Officials believed there were a large number of disabled people currently relying on unpaid help from family and friends. If these people started accessing government-funded services, funding would soon run out (Power, 2014, p. 839).

Officials talked about trying to decrease people's expectations of services and there seemed to be a conflicting situation emerging. Officials were attempting to improve the quality of government-funded supports through reforms (including by moving to person-directed budgets), but were conscious and very concerned that inevitably, this would increase demand (Power, 2014, p. 839).

Officials expressed similar fears during the paid family carers court and tribunal cases. During the cases, the Ministry of Health described its supports as just being there to meet gaps in unpaid support. The Ministry said most support should be met through unpaid support from family and friends and that the government-funded system was only available as a back-up (Atkinson and others v Ministry of Health, 2010). The Ministry had similar fears as overseas officials about a cost blow-out occurring if people switched to government-funded services, should these become more available/attractive.

Currently, some people who are eligible for disability support services do not access this support or underuse support because the available options are so unappealing. This is likely to contribute to the poor outcomes disabled people experience as well as significant ethnicity and gender inequality. As mentioned, for example, Pacific disabled peoples tend to prefer underfunded family-based support, rather than the more significant support available through segregated options, such as residential services.

Any increased demand for support should be seen as a sign of success. It is likely to reflect that the quality of support is improving. If the demand can be met, more people will get support that actually works for them and can help them participate in society. Over the medium to long-term there is likely to be benefits both to people's lives and to wider government spending from people getting the support they need. The System Transformation Project should also reduce demand for expensive segregated options,

such as residential services. In the short-term, improved support may put a strain on fixed budgets.

Overseas officials have recognised that a widespread move to person-directed budgets might decrease the advocacy power of people receiving support, through diluting their effective bargaining strength. They might then become vulnerable to funding cuts. Individual people might have less power to oppose funding cuts relative to providers (Power, 2014, pp. 837-838). It is important that you safeguard the success of System Transformation by ensuring adequate investment is available. We need to be realistic about the possible increase in demand; otherwise, we risk budget blowouts and punitive funding cuts, which will harm people receiving support.

Recommendation

- That as the Associate Minister of Health you direct the Ministry of Health to plan for the possible increase in demand the System Transformation Project may cause, including planning for the fiscal impact.

Thank you

Thank you for taking the time to read this briefing. We are always happy to offer advice and analysis.

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