

Cabinet Social Policy Committee

CHOICE IN COMMUNITY LIVING FOR PEOPLE WITH DISABILITIES

Proposal

- 1 This paper asks the Cabinet Social Policy Committee to note decisions taken by the Minister of Health and Associate Minister of Health (Hon Tariana Turia) to demonstrate “Choice in Community Living”, which is an alternative to residential services for people with disabilities.

Executive Summary

- 2 In 2010/11, the Ministry of Health purchased community residential support services (residential services) for about 7,000 people with intellectual, physical and/or sensory disabilities. Despite service specifications and monitoring arrangements that seek to promote and protect the rights of residents many people consider that residential services unreasonably limit residents’ choice and control over the supports they receive and the lives they lead.
- 3 Choice in Community Living is an alternative to current residential services which will increase disabled people’s choice and control. It will involve, for example, the Ministry of Health contracting with providers for the delivery of support (such as a person who provides personal care) only, rather than contracts combining support and living costs.
- 4 These types of changes will enable people with disabilities who would otherwise live in residential services to:
 - a have the same housing options as other people;
 - b have increased choice about which provider supports them and the way in which they are supported; and
 - c be eligible for a wider range of social welfare benefits, as other people are.
- 5 People who wish to take up Choice in Community Living will have access to independent facilitation-based support to assist them to build a life like other New Zealanders that is more connected to natural supports and the wider community.
- 6 We strongly support the movement towards people living in, and being connected to, the community. We anticipate demonstrating ‘Choice in Community Living’ in Auckland and Waikato for up to 150 people over a three year period ending in October 2014.
- 7 The Ministry of Health will lead the demonstration, and will work with the Ministry of Social Development on issues related to social welfare benefits and (where necessary) with the Department of Building and Housing and Housing New Zealand Corporation.
- 8 The intention is that the introduction of Choice in Community Living will be fiscally neutral. The Ministries of Health and Social Development will gather information to determine whether Choice in Community Living is fiscally neutral across Votes: Health and Social Development. If the demonstration shows that this is not the case, consideration will be given to the options for addressing the additional fiscal costs.

Background

- 9 In 2010/11, the Ministry of Health purchased community residential support services (residential services) for about 7,000 people with intellectual, physical and/or sensory disabilities, at a total cost of about \$460 million and an average cost of \$66,000 per person. Residential services are purchased through contracting and funding arrangements that have the following key characteristics:
- a Residential service providers' contracts with the Ministry of Health cover both living (such as rent, food and electricity) and support costs, with providers either owning or leasing the premises. In 2010/11, the Ministry of Health contributed approximately \$400 million towards the cost of residential services out of the Ministry of Health's National Disability Support Services non-Departmental Appropriation.
 - b People eligible for a main benefit (e.g. Invalid's or Sickness) or New Zealand Superannuation are required to contribute their main benefit or superannuation, less a personal allowance, towards their accommodation and living costs. These contributions amounted to about \$60 million in 2010/11. The most common situation is that of people with an intellectual disability who receive an Invalid's Benefit of \$251.73 (net) per week, of which they contribute \$191.05 and receive a personal allowance of \$60.68 per week.
 - c People in residential services are not eligible for some financial assistance from Work and Income, such as the Accommodation Supplement, because the costs covered by this other financial assistance are covered by the residential services contract. Since 2006, however, they have been eligible for the Disability Allowance to meet some expenses that are not covered in the residential services contract.
- 10 The use of residential services reflects a view that they are often seen as a more cost-effective way of supporting people who require support 24 hours a day than supporting them individually in their community. Residential services also guarantee people a basic standard of living by providing them with a warm furnished house, food, power, and other basic necessities. These are things that some of these people may struggle to afford if they do not live in residential services.
- 11 Despite service specifications and monitoring arrangements that seek to promote and protect the rights of residents, the Social Services Select Committee's 2008 Report on its "Inquiry into the Quality of Care and Service Provision for People with Disabilities" found that residential services unreasonably limit residents' choice and control over the supports they receive and the lives they lead. For example, in many cases, people living in residential services have little actual choice over who they live with. Further, because only disabled people live in residential services, living with non-disabled people, including family or friends, is usually not an option. These limits contribute to a desire by many disabled people and their families to move to arrangements that enable the disabled person to live an everyday life in the community.
- 12 In recent years, an increasing number of people have successfully moved from residential services to live in the community or have chosen not to enter residential services. This trend has been facilitated through such changes as making home and community supports more flexible and the introduction of a supported living service that works alongside the person to help them develop the skills to become independent.

CHOICE IN COMMUNITY LIVING

- 13 The New Model for Supporting Disabled People (CAB Min (10) 23/4A refers) focuses on supporting people to live everyday lives through increasing the choice and control they have over the support they receive and the lives they lead. Increasing the range of community living choices that are available to disabled people with relatively high support needs is part of implementing the New Model. Developing and implementing the full range of options will take some years as this will involve fundamental changes to existing arrangements.
- 14 Consultation with disabled people and their families and whanau, and with disability support providers, has led to the development of Choice in Community Living, which will be a new option under the New Model. Choice in Community Living is an alternative to current residential services that will increase people's choice and control and can be implemented relatively quickly. Choice in Community Living involves several changes to the residential services' contracting and funding arrangements:
 - a The Ministry of Health's contracts with providers will only cover the cost of support, rather than the cost of support and living. [Note: contracts will reflect current Government policy, such as that relating to the payment of family caregivers].
 - b People will have the same housing choices that are available to other people (such as being an owner or tenant), and will be able to choose which of several contracted organisations provides them with support, independent of any decision around accommodation. As with other supports, the number of contracted providers a person can choose between may vary throughout the country.
 - c People who wish to take up Choice in Community Living will have access to independent facilitation-based support to assist them to build a life like other New Zealanders that is more connected to natural supports and the wider community.
 - d Funding for support will be able to be used more flexibly as people with disabilities (with support if necessary) will be able to negotiate with the provider the particular support that is delivered, as long as it fits within guidance provided by clear rules on what funding can and cannot be used for (rather than the specific rules contained in current contracts).
 - e People can receive the full amount of their main benefit in the same way as other members of the community, and are then responsible for their own living costs (e.g. housing, food and utilities).
 - f People may be able to access the full range of supplementary assistance available through Work and Income such as the Accommodation Supplement, the Disability Allowance and Temporary Additional Support. The extent of financial assistance that people would be eligible for will depend on things such as what assistance they receive through Vote: Health (under the New Zealand Public Health and Disability Act) where they live, what allowable costs they have, and any other income they may have.

Comment

- 15 The movement towards people with disabilities living in, and being connected to, the community is consistent with the National and Maori Party 2008 Manifestos, the New Model for Supporting Disabled People (CAB Min (10) 23/4A refers), and alternatives to residential services in other countries including the United Kingdom, United States of America and Australia. The international evidence shows these improved outcomes can be achieved at costs that are no higher on average than the costs of more traditional models of support. In some circumstances, the costs may even be lower.
- 16 At a practical level, Choice in Community Living will enable disabled people to:
- a choose the area they live in and what food to buy;
 - b have ordinary housing choices, such as renting or owning their home and deciding who they live with;
 - c choose who provides them with support from among several contracted providers and have control over how and what support is provided (note: the choice of provider may be limited in some areas);
 - d have better linkages with, and support from, family and whanau; and
 - e take more part in normal, everyday activities.
- 17 Family and whanau are also expected to benefit. For example, the Choice in Community Living approach eliminates the cumbersome requirement under current residential services contracts for families who own or buy houses that their disabled family member can use, to lease them to a contracted residential services provider before the provider can deliver services. The Appendix describes a real-life example of the types of possibilities that Choice in Community Living could lead to.

NEXT STEPS

- 18 We have decided to demonstrate Choice in Community Living to determine whether it is a cost-effective option that effectively supports disabled people and their families and whanau to live better lives and, if so, the most effective ways of implementing it. The Ministry of Health currently anticipates that the demonstration will take place in Auckland and Waikato for up to 150 people over a three year period ending in October 2014. Limiting the scale of the demonstration reflects the expectation that it will take time for people to decide if they wish to take advantage of Choice in Community Living, and to plan for and put in place their preferred living and support arrangements. The focus on individuals and families and whanau deciding what works best for them means it will take time to plan individual support arrangements with providers. Limiting the scale of the demonstration will also allow government agencies to learn about how to effectively implement this change, including managing any risks that may emerge.
- 19 This demonstration will still, however, be relatively significant. That is because 150 people living in residential services would, on average, currently receive funding from the Ministry of Health of about \$10 million per annum. The demonstration will be led by the Ministry of Health, which will work with the Ministry of Social Development on issues related to social welfare benefits and (where necessary) with the Department of Building and Housing and Housing New Zealand Corporation.
- 20 Ongoing evaluation will enable affected government departments to learn about the benefits, issues and risks of the proposed approach, including how it impacts on people's lives. It is intended that the evaluation will inform decisions on whether Choice in Community Living will be rolled out nationally.

- 21 We will report back to Cabinet Social Policy Committee in 2014 prior to decisions being taken on the national roll-out of Choice in Community Living. That report will include consideration of how effective Choice in Community Living is at improving the lives of disabled people and their families and whanau, whether the initiative is fiscally neutral and how it fits with the Government's overall social policy directions. During the demonstration, the Ministry of Health will make progress reports to the Ministerial Committee on Disability Issues.
- 22 If a decision is made to roll out Choice in Community Living nationally, the Ministry of Health anticipates that, over say 10 to 15 years, it could be taken up by up to around 20% (1,400) to 25% (1,750) of the 7,000 people who are currently in residential services, as well as other people who elect to not enter residential services. The actual take up will, however, depend on factors such as the degree of interest from individual disabled people, the degree of support they receive from their family and whanau, and the range of support options that are available (for example, the Ministry of Health is currently developing a broader individualised funding scheme that may be more attractive to some people).
- 23 If a decision is taken that Choice in Community Living should be discontinued, the Ministry of Health will work with any affected disabled people and their family and whanau to put in place suitable alternative arrangements (such as supported living) or continue the arrangements they have developed under Choice in Community Living. The Ministry of Health will also support them to move to any agreed alternative.

Financial implications

- 24 The overall intention is that the introduction of Choice in Community Living will be fiscally neutral. It is, however, unclear what the net effect will be. There are two main issues:
 - a There is a risk that Vote: Social Development's expenditure will increase as a result of more people becoming eligible for the Accommodation Supplement and Disability Allowance, plus some additional expenditure for hardship assistance and the Domestic Purposes Benefit for the Care of the Sick or Infirm. The Ministry of Social Development estimates that this impact could be in the range of between \$0 and \$0.7 million over the three-year demonstration period. MSD will also incur some additional operational costs. It is possible, however, that the actual fiscal impact will be towards the bottom of this range as most people who take advantage of Choice in Community Living would have moved from residential services in any event or have never lived in residential services.
 - b The Ministry of Health intends to fund the demonstration from within its baseline funding for disability supports. While the Ministry expects it will be able to achieve this, its current funding allocation process was not designed for the sorts of arrangements envisaged by Choice in Community Living. This creates a risk that allocations will, on average, be higher than it can afford. To manage this risk, the Ministry is developing a more robust funding allocation process.
- 25 It is not clear what the net effect will be on Housing New Zealand Corporation. Some people may move from Community Group Housing (which is owned by the Corporation and leased to providers) to other state housing, or to other housing owned by community organisations or the private sector. Some people may also seek to take over leases for Community Group Housing. Doing this, however, may affect current delivery models for Community Group Housing as the current relationship is between the provider and the Corporation. These issues would need to be worked through should people seek to make such a change.

- 26 One of the purposes of the demonstration is to understand the fiscal implications, particularly across Vote: Health and Vote: Social Development. The report back to Cabinet Social Policy Committee prior to decisions being taken on a national roll out will include information on the fiscal costs and the options for addressing them.

Consultation

- 27 The proposals in this paper were developed through discussions with a range of people with disabilities and people from the sector, including contracted providers. The Ministry of Social Development, including the Office for Disability Issues, the Department of Building and Housing, Housing New Zealand Corporation and the Treasury were consulted during the preparation of this paper. Their comments have been incorporated. The Department of Prime Minister and Cabinet was informed about the paper.

Publicity

- 28 The Ministry of Health has received positive feedback on Choice in Community Living from the disabled people and providers it has discussed this proposal with. The Minister and/or the Associate Minister of Health (Hon Tariana Turia) will make public announcements on Choice in Community Living at suitable times. To aid public awareness of this work, the Associate Minister of Health (Hon Tariana Turia) intends to release this paper after Cabinet has made decisions on it.

Human rights, Bill of Rights and gender implications

- 29 The proposals in this paper are not inconsistent with the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993. There are no gender implications associated with this paper.

Disability perspective

- 30 The proposals in this paper are consistent with the directions set out in the United Nations Convention on the Rights of Persons with Disabilities, the New Zealand Disability Strategy, the recommendations of the Social Services Select Committee's "Inquiry into the Quality of Care and Service Provision for People with Disabilities", and the New Model for Supporting Disabled People. These directions are consistent with approaches that many disabled people and their families and whānau have sought in recent years.

Legislative implications and Regulatory Impact Analysis

- 31 There are no legislative implications associated with this paper and a Regulatory Impact Analysis is not required.

Recommendations

- 32 We recommend that Cabinet Social Policy Committee:
- 1 **note** that the Minister of Health and the Associate Minister of Health (Hon Tariana Turia) have decided to demonstrate "Choice in Community Living", which is an alternative to residential services for people with disabilities;
 - 2 **note** that the demonstration project will be led by the Ministry of Health, which will work with the Ministry of Social Development on issues related to social welfare benefits and (where necessary) with the Department of Building and Housing and Housing New Zealand Corporation;
 - 3 **note** that Choice in Community Living is part of implementing the New Model for Supporting Disabled People (CAB Min (10) 23/4a refers);

- 4 **note** that the overall intention is that Choice in Community Living will be fiscally neutral;
- 5 **note** that the Ministry of Health will provide reports on progress with Choice in Community Living to the Ministerial Committee on Disability Issues;
- 6 **invite** the Minister of Health and the Associate Minister of Health (Hon Tariana Turia) to report back to Cabinet Social Policy Committee in 2014 prior to decisions being taken on the national roll-out of Choice in Community Living;
- 7 **note** that the report back will include consideration of how effective Choice in Community Living is at improving the lives of disabled people and their families and whanau and whether the initiative is fiscally neutral; and
- 8 **note** that, if Choice in Community Living is discontinued, the Ministry of Health will work with affected disabled people and their families and whanau to either put in place suitable arrangements or continue their existing arrangements.

Hon Tony Ryall
Minister of Health

Hon Tariana Turia
Associate Minister of Health

APPENDIX: A REAL LIFE EXAMPLE OF THE POSSIBILITIES

This appendix describes a real example from the United States of the possibilities opened up by Choice in Community Living.

MAN WITH DOWN SYNDROME WAS ABLE TO GET HIS OWN DIGS, WITH HELP FROM A PERSONALIZED SECURITY SYSTEM IN HIS HOME.



On a recent tour of his home, Jeremy Collins showed off his kitchen, his chair, his bed, his new shower.

It's a dream come true for the 31-year-old who has Down syndrome, and who had lived in group homes all of his adult life. Since April, he's lived on his own in a Coon Rapids townhouse, with a web of support that includes his parents, his caregivers and landlords, Anoka County and a technology company that all work together to help him be safe and continue to grow in independence and confidence.

The benefits go beyond what's good for Collins. Like other people with disabilities, he receives state and federal support to help cover the costs of his care. Right off the bat, he was able to spend more time without the help of a personal-care attendant; the shift from constant supervision to being independent 25 percent of the week meant an immediate 10 percent reduction in the costs borne by taxpayers. The percentages don't match up because group home residents shared staffing costs.

For the most part, Collins' 1,100-square-foot townhouse looks like any other in the Mary T. Villas Sand Creek development, a mixed community of single-level residences occupied by people with and without disabilities. But a closer look reveals a sensor on the front door that's activated if it's opened after 11 p.m., a security keypad required to turn on the stove, a motion sensor in the bathroom to give the alert if he's in there and motionless for more than 20 minutes, signaling a possible fall. There also is a sensor under his mattress, to detect a fall out of bed,

and one in the cedar box where he keeps his medications, to alert his family if he forgets to take them.

The system is monitored round-the-clock by Mendota Heights-based Sengistix; an alert triggers a phone tree that, depending on the situation, could go to Mary T. Inc. maintenance staff or to Collins' parents, Dennis and Brenda, who live in Ham Lake, or on down a list of family and friends until someone can confirm the call and check in with Collins by telephone.

There have been several false alarms, triggered, for example, when he opened the door to watch a late-night lightning storm. But it's been easy to check in by phone, his parents said.

Sengistix has similar contracts in place in several Minnesota counties, wiring single- and multiple-unit dwellings to help people with a variety of disabilities who are overserved in a group home but need some help to live independently, said account executive Drew Beaulieu.

The arrangement was only possible with buy-in from all parties -- Collins' family, Mary T. Inc., Sengistics, Anoka County and Collins' caregivers, through St. David's Center. Anoka County Commissioner Carol LeDoux met recently with Collins and his family.

"Initiatives like this are the types of things we should be pursuing for valid health care reform," she said, calling it an "innovative and visionary project."

During 10 years in a group home, Collins was safe, his parents said. But he had few opportunities to use the life skills he has mastered so far, or to make decisions about how to spend his time and the money he earns at his part-time food-service job at Medtronic.

Now, he writes out the checks for utilities and rent, which he hand-delivers (usually early) to the Mary T. Inc. office. He helps with grocery planning and keeps his home neat.

He continues to learn and grow.

"He has risen to some of the issues that used to be problematic for him," his father said. For example, he used to be afraid of storms. Now, he knows how to monitor weather reports on his phone, and he knows that a siren means he should head for shelter in the bathroom.

"This promotes more independence for him, which is a win-win," his father said.

His family hopes that his independent time will grow, as his skills grow, to as much as 50 percent. Long-term, his parents hope that when they're gone their son will continue to be secure and not be too reliant on his three older siblings. The signs are good, so far.

"It's nice," Brenda Collins said. "When he was born, most people talked gloom and doom for his future. Living here, you can see the next level of independence."

Source: Minnesota Star-Tribune, 9 August 2011.