

Appendix Three: Disability Support System Transformation

Introduction

- 1 This Appendix outlines lessons about transforming systems that the Ministry of Health has learnt to date from its experience with transforming the disability support system.
- 2 The key differences between this approach and transforming the mental health and addiction system is the scale and level of control that the Ministry of Health has (Disability Support is funded directly by the Ministry).

Background

- 3 The Ministry of Health's current approach to supporting disabled people was developed during disability reforms of the mid-1990s. Those reforms introduced the needs-based Disability Support Services (DSS) Framework to allocate support services and manage costs within the disability support system (the framework is described further below).
- 4 For some years, disabled people have expressed concern that the disability support system unnecessarily limits their choice and control over their support and their lives. Those concerns stem from the following aspects of the existing system:
 - a multiple eligibility, assessment and planning processes for accessing different types of support from several government agencies;
 - b being allocated existing contracted services, not necessarily what works best for them; and
 - c disability services becoming the 'hub' of their lives, rather than helping them to connect to support available to everyone in the community.
- 5 There are also other concerns:
 - a Disabled people (especially those supported by DSS) experiencing poorer outcomes than New Zealanders generally in a range of areas (e.g. health status, education, employment, income and housing).
 - b Ongoing high rate of increases in DSS' costs, with increases have primarily resulted from cost pressures, rather than improved life outcomes or more people accessing support.
- 6 Initially, the responses to these concerns were developed primarily by officials, primarily from the Ministry of Health. Since 2011, however, they have been co-governed and co-designed by the disability community and officials, and based on the Enabling Good Lives (EGL) vision and principles that were developed by a working group from the disability community (see below).
- 7 To date, relatively small scale initiatives have been implemented – with each supporting around 250 people –and have led to improved outcomes for many disabled people. Cabinet has now agreed to implement a prototype of a transformed disability support system in the MidCentral region (based around Palmerston North) on 1 October 2018.
- 8 The initial focus of the transformation is on people who are eligible for support funded through DSS. Consideration will, however, be given to inviting other groups of people into the transformed system in the future. In addition, a 'try, learn and adjust' approach will be taken to improve the prototype over time.

Prototype design

- 9 The transformation involves re-thinking the entire disability support system based on the EGL vision and principles. Key features of the prototype design are the following:
 - a People are welcomed into the system in multiple ways, and can then be provided with information, linked with a Connector, peer network, government agency or disability organisation.

- b Access to Connectors who can walk alongside disabled people and whānau if they choose, to help them identify what they want in their lives, how to build a life that is connected to the community, and access funded support where to help live their life.
- c Easy to use information and processes that meet the diverse needs of disabled people and their whānau.
- d Seamless support across government, with Government Liaison supporting people in the background to access other government services (e.g. benefit applications), and to build positive relationships with other parts of government (e.g. learning support in school).
- e A straightforward process for accessing funding, with a focus on the purpose that people want funding for, and flexibility about what can be purchased and how it can be administered, and easy reporting on how funding has been used.
- f Capability funding for disabled people and whānau with decisions made by the Regional Governance Group
- g Greater system accountability to disabled people and their whānau which leads to disabled people and whānau being involved in monitoring and evaluating the system, and making recommendations to Ministers about system changes.

Impacts of the new approach

- 10 Overall, we are expecting that the transformation will lead to improved lives disabled people and their whānau, and improved cost-effectiveness. Examples of the benefits we anticipate from the transformed system are the following:
 - a The question that the system asks shifts from ‘what support do you need?’ to ‘what’s a good life for you?’. This changes the conversation from its current focus on what the system considers important (‘needs’) to the desired experiences of disabled people and whānau.
 - b The Connector will provide invaluable support through being an ‘ally’ who provides a listening ear who helps the disabled person and their family to understand and resolve the issues they face. This means they do not have to face the additional challenges of living with disability alone. It contrasts with people feeling they have to fight the current system alone.
 - c There is a strong emphasis on the Connectors understanding disabled people and the real issues they face, and supporting them to develop bespoke responses that are appropriate for them. Funding those bespoke responses contrasts with the current system in which people are allocated pre-determined services that are not necessarily appropriate.
 - d There is a focus on addressing issues as soon as they are identified, and providing support from the time disability is first recognised, rather than only providing support when a person meets a ‘need threshold’. This is expected to increase up-front costs, but reduce the unresolved issues and family breakdown that lead to people entering residential care.
 - e There is a shift from assuming that family and other natural networks will provide unpaid support, to creating wider natural networks around people and building up existing natural networks. It also recognises that there are limits to freely provided support, and that there is real value from disabled people having friends and family members who are not over-burdened by caring roles.

What we have learned

- 11 The process of transforming the disability support system is leading to ongoing learning by everyone involved. We anticipate that we will learn considerably more in the first 12 to 18 months after the prototype is implemented in the MidCentral region. Some things are, however, already clear:
- a There are substantial advantages from adopting a co-design approach over the more usual approach of officials consulting on a design they had developed. Those advantages include greater ownership within the community, and a design that reflects an in-depth understanding of the diversity of the population and the wide range of personal, family and whānau, and community factors that impact on people lives. Without the input of people with that lived experience, the design the narrower perspective of officials, which was likely to challenge the assumptions underpinning the current system.
 - b Developing an understanding of the dynamics of the current system can support the case for change. For example, providing most support to people with the highest need likely drives avoidable and ongoing increases in the costs for people who do receive support. That is because issues are not addressed when they are first recognised and, in most cases, easiest to address, meaning that higher cost interventions are subsequently required because people have more complex issues.
 - c Understanding that the purpose of the system is to improve people's lives, and to support them to resolve the very real issues that they have, challenges many of the assumptions that underpin the current system. Those assumptions include the assumption that the systems should respond to the 'needs' that it recognises, and in the way that it considers appropriate, and that some people should be excluded from support through eligibility policies.
 - d A focus on government funded services and support alone – or, even more narrowly on funding within a single government agency - is not sufficient. Rather, an effective response requires a cross- -government agency approach that is connected to the wider community. Furthermore, being connected to the community e.g. doing the same things that other people do, and having supportive friends and family - are likely to be more important on an ongoing basis than government funded services and support. This broader emphasis frees up services to do what they do best, which is to complement the support that is available in the community.
 - e Transformation takes a considerable period of time and effort. Bureaucratic processes themselves can be difficult to change, especially as the underlying assumptions are built into all elements of the current systems (e.g. including IT and financial systems). But, real transformation requires change from everyone involved – the people who are supported, their family and other natural supports, providers, health and other professionals, and the wider community. When those changes are driven by the person, and what they consider to be important, they are more likely to be genuinely transformational than if the wishes of other parties predominate.

End notes

DSS Framework

- 1 The essence of the current DSS Framework is the following:
- a needs assessment determines the level of unmet need that a person has;
 - b service coordination services determine which particular services will be allocated to a person to meet their prioritised needs;
 - c the services which people are allocated are purchased from providers who are contracted to the Ministry of Health (the 'purchaser-provider' split).

- 2 Under the DSS framework, the main levers for controlling costs are:
 - a specifying high-level eligibility criteria that people must meet before they can be assessed for funded support (the definition of disability);
 - b prioritising the needs that will be met, with those with the highest need receiving proportionately more support;
 - c limiting the 'needs' that are responded to by the system to those that:
 - i allow the person to live safely at home;
 - ii can be met by contracted services; and
 - iii which cannot be met by unpaid 'natural supports', which includes family carers in most situations.
 - d specifying strict eligibility and access criteria for particular services;
 - e closely specifying the type and quality of the services that can be delivered;
 - f controlling the prices that will be paid for services and specifying the inputs that will be used to deliver them;
 - g specifying the volume of services that can be delivered, with providers prioritising who can access that service when there is excess demand;
 - h maintaining clear boundaries between what DSS and other funders are responsible for; and
 - i managing within annual budgets, with no explicit mechanisms for managing longer-term costs.

Enabling Good Lives Vision and Principles

- 3 The EGL vision is that, in the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.
- 4 The EGL principles are: *Self-determination; Beginning early; Person-centred; Ordinary life outcomes; Mainstream first; Mana enhancing; Easy to use; and Relationship Building.*