

In Confidence

Office of the Minister for Disability Issues  
Office of the Associate Minister of Health

Chair, Cabinet Social Wellbeing Committee

## **Transforming the disability support system: Approval to commence MidCentral Prototype**

### **Proposal**

- 1 This paper seeks your agreement to start the prototype of a transformed disability support system in the MidCentral District Health Board (DHB) region<sup>1</sup> (the MidCentral prototype) on 1 October 2018. The Minister of Health is seeking agreement to spend the tagged budget contingency for the MidCentral prototype in a separate paper 'Transforming the disability support system: Approval to spend the tagged contingency'.

### **Executive Summary**

- 2 Approval is sought to implement a prototype of the transformed cross-government disability support system for about 1,600 disabled children, young people and adults in MidCentral from 1 October 2018. The objectives of transforming the disability support system ('system transformation') are to give disabled people and their whānau more options and decision making authority about their supports and lives, to improve their outcomes, and to create a more cost-effective disability support system.
- 3 Disabled people, whānau, providers and officials have been co-designing the prototype over the last year. Key features include people being welcomed into the system in multiple ways, access to a Connector, easy to use information and processes that meet the diverse needs of disabled people, streamlined funding and allocation processes, access to a personal budget that can be used flexibly, seamless support across government, capability funding for disabled people and their whānau, and greater system accountability to disabled people and their whānau. Work continues on funding allocation and accountability arrangements and workforce issues.
- 4 A 'try, learn and adjust' approach will be taken for the MidCentral prototype to refine and finalise the model for rollout across New Zealand. Disabled people and their whānau will be involved in governance arrangements, monitoring and evaluation. Advice will be provided to Cabinet on the final model and expanding the transformed system beyond the MidCentral region in late 2020.
- 5 Officials will work with a working group involving disabled people and whānau representatives to develop recommendations for organisational arrangements for the transformed disability support system.
- 6 A further policy paper will come to Cabinet in June 2018 with a progress update on the MidCentral prototype, advice on funds in scope, funding allocation and accountability arrangements, and other policy issues.
- 7 The Minister of Health is seeking agreement to drawdown the funding of \$23.842 million from the available Budget 2017 tagged contingency [CAB-17-MIN-0185.12 refers] in a separate paper.

---

<sup>1</sup> The MidCentral DHB region (MidCentral region) includes Palmerston North, Horowhenua, Manawatu, Ōtaki and Taranaki districts.

## Background

- 8 The cross-government disability support system supports disabled people to overcome the barriers created by society. The cross-government disability support system includes support funded through the Ministry of Health (Disability Support Services and DHBs), Ministry of Social Development (e.g. the disability allowance, income support, employment support, community participation, social housing), Ministry of Education (e.g. learning support), Oranga Tamariki (e.g. disabled children in care), ACC, and the Ministry for Transport (e.g. the total mobility scheme).
- 9 There are about 33,000<sup>2</sup> people receiving Disability Support Services (DSS) in New Zealand. This includes children, young people and adults with physical, intellectual and sensory disabilities and/or high and complex needs that arise before they turn 65 years and who need ongoing assistance. The ongoing support averages about \$30,000 per person per year but ranges from less than \$100 to more than \$500,000 a year.
- 10 Disabled people experience poorer outcomes in a range of areas (e.g. health status, education, employment, income and housing). Māori and Pacific peoples experience a disproportionate level of disability than the general population.<sup>3</sup> Māori and Pacific peoples are also less likely to know about and access the disability support system. People supported by DSS have significantly worse life outcomes than New Zealanders generally, as outlined in Table 1 below.

**Table 1: Indicators of differences in life outcomes (primarily sourced from Integrated Data Infrastructure)**

| Indicator   | All New Zealanders | All people with disabilities | DSS Clients   |
|---|--------------------|------------------------------|---------------|
| Employment of working age people                  | 72%                | 45%                          | 10%           |
| Proportion with incomes below \$30,000            | 45%                | 65%                          | Not available |
| Proportion with school or tertiary qualifications | 85%                | 67%                          | 18%           |
| Findings of abuse or neglect before age 17        | 8%                 | Not available                | 19%           |

- 11 Disabled people and their whānau<sup>4</sup> have sought changes to the disability support system for some time, including the 2008 cross-party *Report of the Social Services Select Committee's Inquiry into the Quality of Care and Services Provision for People with Disabilities*.
- 12 Concerns about the current disability support system include: multiple eligibility, assessment and planning processes; people being allocated existing contracted services (not what works best for them); lack of options and decision making authority for disabled people, and disability services becoming the 'hub' of people's lives.
- 13 In 2011, a group of people from the disability community prepared a report for the Minister of Disability Issues - *Enabling Good Lives* (EGL). The report included a vision for a transformed disability support system that: *"In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make*

<sup>2</sup> Some people also receive one-off support, e.g. equipment and modifications, but do not receive ongoing support.

<sup>3</sup> After adjusting for population age profiles, Māori (32 percent) and Pacific peoples (26 percent) have higher rates of disability than the general population (24 percent).

<sup>4</sup> 'Whānau' covers the diverse range of family (kinship-based – both immediate and extended; and kaupapa/subject-based - a shared common bond other than descent, with similar values as kinship-based). 'Whānau' also serves reasonably to refer to the Pacific values and family structures of 'aiga and kainga.

*more use of natural and universally available supports”* (see Appendix 1 for full description). Two small-scale demonstrations of the EGL vision and principles were undertaken in Christchurch (2013-2016) and Waikato (2015 – now).<sup>5</sup>

### **The previous government agreed to a co-design process to transform the system**

- 14 In February 2017, the previous government agreed that the Ministries of Health and Social Development would work alongside the disabled community to design a process for a nationwide transformation of the disability support system starting with the MidCentral DHB region [SOC-17-MIN-0007 refers]. The initial scope for system transformation was for people eligible for ongoing support through Disability Support Services (DSS) funded through the Ministry of Health.
- 15 The high level design was developed through a co-design process with a group involving disabled people, whānau, providers and officials (see Appendix 2). Detailed design was developed with a range of working groups involving at least a third disabled people on each group. While there has been extensive involvement from disabled people, it has been challenging to include the voices of disabled children and disabled people with high and complex needs such as challenging behaviours, communication challenges (e.g. non-verbal) and people in residential care.
- 16 In July 2017, Cabinet noted the high level design and invited the Minister for Disability Issues and Associate Minister of Health [SOC-17-MIN-0085 refers] to report back in February 2018 on the design of the transformed disability support system and high level implementation plan for the MidCentral region.
- 17 In February 2018, Cabinet agreed to extend the expiry date of a Budget 2017 tagged contingency Disability Support Services – Enabling Good Lives from 1 February 2018 to 3 April 2018 [CAB-18-MIN-0021 refers]. The Cabinet Business Committee minute noted that the February 2018 report back would be delivered a month later than previously agreed by Cabinet to enable officials to fully brief and engage with Ministers on the proposal [CBC-18-MIN-0018 refers]. On 28 March 2018, the Cabinet Social Wellbeing Committee agreed to extend the expiry date for the tagged budget contingency until 30 July 2018 [SWC-18-MIN-0026].

### **Approval is sought for the MidCentral Prototype to start on 1 October 2018**

- 18 A prototype for a national transformation of the disability support system is proposed for the MidCentral DHB region, starting on 1 October 2018. A ‘try, learn and adjust’ approach will be taken. It was initially planned to launch the prototype on 1 July 2018 but the amount of work required to design and plan the prototype, the time taken to use a co-design process, and the need to ensure all elements are in place at the start, means that more time is required.
- 19 On 1 October 2018, there will be a new disability support system in the MidCentral region. Disabled people and whānau will continue to receive the support they were receiving on 30 September 2018 until they contact a Connector or disability information specialist to explore change. Alternatively, a Connector will engage with disabled people and whānau on their regular review date. The key features of the new system are set out below and described further in Appendix 3 (a visual representation) and Appendix 4:

---

<sup>5</sup> Although the Christchurch demonstration ended in 2016, the EGL approach has continued to be provided through the Ministry of Health.

- 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 their life, and the range of supports available to 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 flexibility about what can be purchased and how it can be administered, and easy reporting on how funding has been used. The intention is for this to integrate multiple sources of funding from across government following Cabinet consideration in June 2018
  - 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** so that disabled people and whānau are involved in monitoring and evaluating the system, and making recommendations to Ministers about changes to the system.
- 20 The Ministry of Health is working with its Oranga Tamariki and Ministry of Education partners to strengthen a joined-up view to delivering effective responses to disabled children and their whānau. The aim is to ensure that disabled children and young people with complex needs are supported by holistic and integrated supports and services.
- 21 As part of developing the detailed design for the new system, officials have also undertaken design work with the sector on several underpinning elements including: network building, safeguarding<sup>6</sup>, market stewardship, provider capability and analysis, responsiveness to Māori, implications for people with high and complex needs, equipment and modifications, and how the interfaces will work with different government agencies.
- 22 Decisions on the detailed design of the funding allocation, accountability for funding, and financial risk management will be sought from Ministers in June 2018.

### **There are benefits and risks with the transformed system**

- 23 A change of the size and complexity of the disability system transformation will have impacts for a range of people and groups including: disabled children, young people and adults and their whānau, Māori, Pacific peoples, providers, workforce, Needs Assessment and Service Coordination (NASC) organisations<sup>7</sup>, and government agencies. Appendix Five describes what system transformation means for various groups.

---

<sup>6</sup> Safeguarding is about enabling disabled people to take the same opportunities as other people without being at greater risk, and protecting disabled people from harm.

<sup>7</sup> NASCs are the regional organisations currently providing access to DSS through detailed support assessments, packages of appropriate services and support plans.

24 The benefits include:

- a better outcomes for disabled people and their whānau in all aspects of their lives, such as employment, education and overall wellbeing
- b improved quality of life for disabled people and their whānau, but also an increase in economic contribution by disabled people and their whānau with increased employment participation and greater levels of education and training
- c potential to reduce some government costs through beginning early with disabled people and their whānau to support them to achieve in education, employment, and remain in the community, and preventing negative outcomes such as interactions with the justice system
- d disabled people and their whānau will have greater options about the supports they use to live the lives they want and greater autonomy over their lives
- e disabled people and their whānau will have a better experience of the disability support system. There will be real opportunities to create higher levels of trust with government agencies while reducing the stress of disabled people and their whānau
- f reduction in compliance costs for disabled people, whānau, providers, and government agencies
- g more flexible and individualised support options are likely to be attractive and result in higher demand for support from people who have not been using the current services, and requests for higher levels of support.

25 The risks include:

- a increased demand from people who have not been accessing services may mean that more funding is required
- b there may be tensions between increasing flexibility and choice for disabled people and their whānau and safeguarding existing working conditions for workers
- c providers may not be able to continue providing the same range of supports in an environment where they are funded by individuals rather than through bulk contracts
- d disabled people and whānau may not use their funding for the purpose intended
- e disabled people and their whānau in other regions may be frustrated as they cannot access the transformed system sooner
- f cost-shifting may occur as a result of the transformed system being easier to access and more flexible than other government systems
- g some groups of clients (e.g. high and complex clients or disabled children living in challenging family situations) may not be able to access support from providers that works flexibly for them
- h the extent of the resources for the change management process to assist and facilitate change of this scale may be underestimated.

### **Organisational arrangements for the prototype**

26 As an interim and pragmatic step ahead of decisions on future organisational arrangements for the transformed disability support system, two teams will be established for the MidCentral prototype and located in the MidCentral region:

- a The **Disabled People and Whānau** supporting team will be a new team established within the Ministry of Health comprising Connectors and Network Builders, reporting to a manager who will be given the authority to operate as if they were the manager of a separate organisation within the new system
  - b The **System Enabling** team will be delivered through a contract with Enable (the existing MidCentral NASC) following a reorganisation of the existing team to establish and fill new roles. The new team will be made up of a mix of current employees and new staff recruited into the team.
- 27 The disability sector may be concerned that using the existing NASC and infrastructure (including buildings, fleet, IT systems and website) as the basis for the System Enabling team will undermine the intention of the transformation and reduce change. We think this risk can be managed through:
- a National and Regional Enabling Good Lives Leadership group representation on recruitment panels and involvement in induction of key roles
  - b governance arrangements over the prototype with a strong voice from disabled people and their whānau
  - c a relationship-based contract between the Ministry of Health and Enable that sets out expectations, outcome measures, processes for decision making and includes the voice of disabled people and whānau, and ensures regular feedback is provided
  - d close working relationships between the managers of the two teams with shared responsibilities for vision and goals, measures, and integrated teams
  - e frequent and timely feedback through monitoring and evaluation about the experience of disabled people and whānau
  - f an independent and accessible complaint mechanism.

### **Governance for the MidCentral Prototype**

- 28 A range of governance and advisory groups have been put in place to ensure that a wide range of perspectives are heard and taken into account in the design of the new disability support system and implementation of the MidCentral prototype. The voices of disabled people and whānau are part of each governance and advisory group.
- 29 A subgroup of the MidCentral Regional Leadership Group, the MidCentral Regional Governance Group (the Governance Group), will make decisions relating to, for example, the two new teams and the detailed implementation and operation of the MidCentral prototype. To satisfy the Ministry of Health's (the Ministry) accountability requirements, the Governance Group will be formally advising the Ministry, although with a strong expectation that the Ministry will follow its advice.
- 30 Consistent with the co-design approach taken to date, if the Ministry and the Governance Group cannot agree on how to approach an issue, Ministers will be asked to make a decision after considering the advice from both the Ministry and the Governance Group. The Minister for Disability Issues and Associate Minister of Health will approve the terms of reference for the Governance Group.

### **The transformed system will be monitored and evaluated**

- 31 Successful system transformation requires monitoring and evaluating throughout the entire transformation process. This includes a baseline study, outcomes evaluation, impact

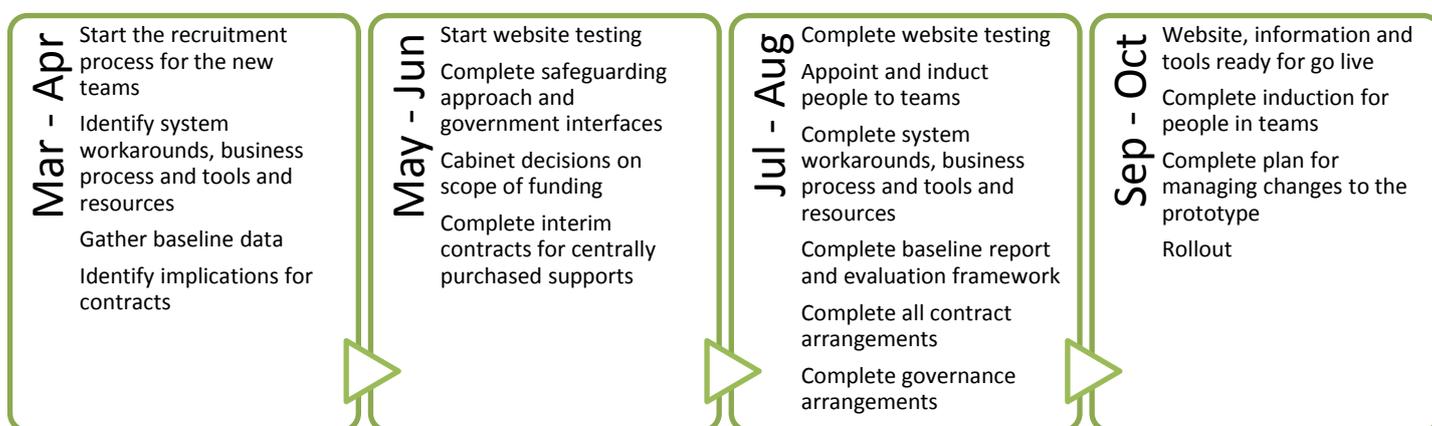
evaluation, system-level evaluation and cost benefit analysis. Disabled people will be involved in the evaluation.

- 32 The purpose of the evaluation is to help us understand:
- a if the transformed system leads to improved life outcomes for disabled people and their whānau (including health and wellbeing, physical and financial security, relationships, social inclusion, self-determination, and self-fulfilment)
  - b where improvements are needed
  - c if and how the approach should be expanded.
- 33 A Developmental Evaluation approach will also be used to provide frequent information and insights to affirm or inform meaningful change in the prototype. This approach is appropriate for evaluating innovations in complex and dynamic systems where the path to successful outcomes is emergent and developing. Opportunities will be sought to align the evaluation with the New Zealand Disability Strategy (2016-2026) outcome indicators.

**The high level implementation plan for the MidCentral prototype has been developed**

- 34 Following Cabinet decisions on the rollout of the MidCentral prototype, and alongside further policy work, the focus will shift from a prototype design phase to an implementation phase. Communication, engagement and change management strategies will continue throughout the implementation phase. Appendix Six shows the high level implementation plan for the rollout of the MidCentral prototype. A summary of the implementation phase leading up to rollout is in Table 2:

**Table 2: MidCentral Prototype Implementation phases**



**Funding for the MidCentral Prototype**

- 35 Additional funding is required for several purposes in the MidCentral prototype, and to continue the EGL demonstrations in Christchurch and Waikato. The Minister of Health is seeking agreement to spend the tagged budget contingency for this purpose in a separate Cabinet paper. These additional costs can be met from within a Budget 2017 EGL tagged contingency [CBC-18-MIN-0018 refers] and are summarised in Table 3 on the next page.

**Table 3: Proposed use of Budget 2017 contingency funding**

| <b>System Transformation: Estimated Additional Expenditure (\$ million)</b> |                |                |               |
|---|----------------|----------------|---------------|
| <b>Expenditure category<sup>8</sup></b>                                     | <b>2018/19</b> | <b>2019/20</b> | <b>Total</b>  |
| Additional direct support   | 2.939          | 3.546          | 6.485         |
| Additional indirect support   | 3.118          | 3.055          | 6.173         |
| Infrastructure  | 1.329          | 0.576          | 1.905         |
| One-off transitional and implementation costs                               | 3.907          | 2.772          | 6.679         |
| Continuation of existing EGL demonstrations                                 | 1.300          | 1.300          | 2.600         |
| <b>Total</b>  | <b>12.593</b>  | <b>11.249</b>  | <b>23.842</b> |

**Advice will be provided about expanding beyond the MidCentral region in late 2020**

36 Given the scale of the change, and the impact on disabled people, whānau, providers, workforce, and government agencies, it is critical to take the time to get the model right. After the new disability support system model has been refined using a ‘try, learn, adjust’ approach, decisions on the final model, informed by the ongoing monitoring and evaluation, and expansion beyond MidCentral will be sought from Cabinet in late 2020. At that stage, work will commence on developing the required IT systems.

**Financial implications of nationwide transformation**

37 Any additional funding for a nationwide rollout of the transformed system would be sought through subsequent Budget processes. There are a large number of uncertainties and assumptions that need to be tested through the prototype including benefits from early investment, numbers of Connectors, and the number of additional people who may access the transformed system. Initial estimates are \$140-\$160 million a year, plus provision for an updated nationwide IT solution and transitional costs for organisational and governance changes, but this does not include any benefits from early investment or savings across government.

**Future policy work**

- 38 Developing and implementing a transformed system creates a wide range of policy and operational issues to be addressed. Policy work is underway or planned on:
- a **Potential inclusion of disability support funding from across government.** This is in addition to Vote Health’s National Disability Support Services Non-Departmental Appropriation. Officials and representatives from the disability community are considering whether a range of disability support funding from Votes Social Development and Education should be moved to the transformed system
  - b **Income aspects.** Inland Revenue is considering the appropriate tax treatment of disability support funding paid to disabled people and whānau. Once decisions are made on this paper, it will seek Ministerial approval to consult on this issue, prior to the Minister of Revenue providing advice to Cabinet on possible changes. Any changes agreed by Cabinet would be included in the next available omnibus taxation bill to give disabled people and whānau certainty over the tax treatment. In addition, the Ministry of Social Development is considering changes to its regulations on exempt income, so that personal budgets for disability support are not treated as chargeable income or cash assets for the purpose of determining eligibility to a benefit, supplementary assistance or social housing

<sup>8</sup> Described further in paper from the Minister of Health for approval to spend the tagged contingency.

- c ***To the extent feasible, determining how to bring the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2001 into line with the transformed system***
- d ***Further developing safeguarding arrangements.*** While safeguarding arrangements must be developed with each person (often led by Connectors), those arrangements can be more effective when they are complemented by:
  - i community and contractual safeguarding arrangements, and quality monitoring, that reflect the EGL principles;
  - ii effective safeguarding arrangements across the wide range of government agencies that disabled people interact with (e.g. police, health and education services); and
  - iii supportive legislation, which could lead to proposals for amending health sector legislation (e.g. the Health and Disability Services (Safety) Act 2001) and legislation administered by other agencies (e.g. the Protection of Personal and Property Rights Act 1988)
- e ***Developing a response to the differential impact that GST will have within the transformed system.*** Disabled people who purchase disability support themselves cannot claim 'input GST' from Inland Revenue in the way that a provider can when buying support on their behalf. This means that the purchasing power of people's budgets is reduced by up to 15 percent.
- f ***How to implement the government's approach to paying family carers within the transformed system.*** This will include how to implement the funded family care policy settings through the new system elements e.g. personal budgets and new accountability arrangements and ensuring disabled people and whānau understand the full range of options and have made an informed choice
- g ***Eligibility.*** Developing options to streamline entry, where a lack of timely diagnosis limits or delays access to the disability support system
- h ***Means testing.*** Access to some DSS supports are means tested (e.g. household management). These financial thresholds are reasonably low, and may mean that some clients receive little financial benefit from entering employment. We will provide advice on options to bring current means testing requirements into line with the transformed system.

### **Machinery of government review**

- 39 Underpinning the transformed system is a transfer of decision making authority to disabled people and whānau. Consistent with this approach, consideration needs to be given to what sort of governance arrangements will recognise the transfer of decision making authority at a system level. Transferring some decision making authority to disabled people and whānau by involving them in governance will also serve to promote and protect the EGL principles. This reflects the community's direct interest in how well the disability support system operates in practice.
- 40 We propose initiating a machinery of government review (MOG Review) to investigate, and advise Ministers on, the benefits, costs and risks of different options, including potential structural changes, for involving disabled people and whānau in the governance of the disability support system. The options may include, for example, a Departmental Agency or a new organisation, either of which would be supported by one or more advisory groups.

- 41 The MOG Review would be led by a Working Group consisting of officials from the State Services Commission, Ministry of Health, Ministry of Social Development, Ministry of Education, Treasury, and representatives from the disability community. It is envisaged that there will be consultation with the wider disability community generally as part of the review.
- 42 The Working Group would report to the Ministers of State Services, Disability Issues, Associate Minister of Health (Hon Julie Anne Genter), Social Development, Education and Finance. Those Ministers would approve the Terms of Reference for the MOG Review, and report to Cabinet as necessary during the Review, such as when seeking approval to consult with the wider disability community. It is envisaged that final advice on the MOG Review will be provided to Cabinet in late 2020 alongside advice on the final model and expansion beyond MidCentral.

### **Consultation**

- 43 The groups and organisations consulted for this paper are described below and include statements they have prepared for inclusion.

#### ***MidCentral Regional Leadership Group***

- 44 The MidCentral Leadership Group is dedicated to the transformation process. We are enthusiastic about the possibilities, acknowledge there will be challenges associated with the change process and offer strong regional leadership. We support the Enabling Good Lives vision, the Enabling Good Lives principles and the intent of this Cabinet paper. As a diverse leadership group, we are excited about the potential of this change and will be paying particular attention to: the impact of eligibility criteria on people, safeguarding, monitoring progress, capability building and the attitudinal change required for this to be successful for disabled people, their families and whānau.

#### ***National Enabling Good Lives Leadership Group***

- 45 National EGL Leadership Group (NEGL) support the general direction of this paper. We wish to emphasise that we see the proposed organisational structure as an interim solution to facilitate prototype implementation while work continues to consider final organisational form. NEGL supports the co-development approach taken in prototype development and the movement towards disabled people and families holding governance as well as leadership roles. We will continue to contribute to the System Transformation process and monitor development for alignment with the EGL vision and principles.

#### ***System Transformation Co-Design Group***

- 46 The Co-design group greatly appreciate the leadership of the System Transformation team and the progress made on the MidCentral prototype. However, we are very uncomfortable with the short-term involvement of the NASC and it cannot become the template for a national rollout. We reiterate the need for strong governance by disabled people and whānau, to safeguard quality support for disabled people – and the rights of workers. We note that some government agencies have been reluctant to shift funds to a central budget and are concerned that the System Transformation could become a DSS transformation only. Finally, we urge the Government to take this opportunity to address systemic shortfalls in policy and funding settings affecting disabled people, who have experienced decades of poverty, social exclusion and discrimination.

#### ***New Zealand Needs Assessment and Service Coordination Association (NZ NASCA)***

- 47 As the national network of assessment and co-ordination services (NZ NASCA) across disability, mental health, chronic health and services for older people, one of our objectives is that people with acquired and life-long disability receive support that is meaningful to

them, and in ways that are simple, consistent and equitable. NASCA fully supports the Enabling Good Lives principles and we want to see these converted into genuine action, rather than sitting at a strategic 'guiding' level. NASCA has been a strong advocate for system changes that bring practical and real benefits to all disabled people, in a financially sustainable manner, and we have already given effect to some such outcomes. NASCA remains particularly concerned for people who have complex and significant needs; who continue to be underserved and whose voices continue to be under-represented in the current proposals. When considering the current proposals, we ask Ministers to investigate improvements that are already available but need to reach people with high and complex needs, and others who may face inequalities, such as people with autism, Māori and people in residential support.

### **Unions**

- 48 The Council of Trade Unions Te Kauae Kaimahi (CTU) is engaged in consultation with the Ministry of Health on the proposed changes, together with two affiliate unions, the Public Service Association (PSA) and E tū, both of which have significant membership in the disability support sector. Unions support the Enabling Good Lives (EGL) vision and principles. The goals of creating a person-centred system of disability support that enhances the self-determination of disabled people and their whānau are in line with long-standing union values. For the system transformation to be sustainable, it will also need to maintain and enhance the working conditions and security of the workforce, including support workers.
- 49 Unions have concerns about the impacts on workers of the proposed changes, which are summarised in Appendix Five. Given the predominantly female workforce in disability support, any workforce impacts also have gender implications. Unions welcome the creation of a working group to address issues for the workforce in the system transformation process and make recommendations to maintain and improve working conditions. Unions are committed to working with disabled people's organisations, government, and employers to reach agreement on a mutually acceptable model for support work in the system transformation process. Feedback and recommendations from this working group will be included in subsequent Cabinet papers.

### **Government departments**

- 50 The following government departments were consulted in the development of this paper and views incorporated: The Treasury, State Services Commission, Ministry for Social Development, Ministry of Education, Oranga Tamariki, Inland Revenue, Te Puni Kōkiri, Ministry for Pacific Peoples, Office for Disability Issues, Ministry of Youth Development, Ministry of Health, Accident Compensation Corporation, Ministry for Women, Ministry for Business, Innovation and Employment, Department of Corrections, Housing New Zealand, Statistics New Zealand, Ministry of Transport, New Zealand Police, Ministry of Justice.
- 51 The Department of the Prime Minister and Cabinet has been informed.

### **Human Rights**

- 52 The decisions sought in this paper are consistent with the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993.

### **Legislative Implications**

- 53 There are no immediate legislative implications arising from the proposals outlined in this paper. Proposals for legislative change may emerge from some of the ongoing policy work.

## Impact Analysis

54 An impact analysis is not required for the proposals outlined in this paper.

## Gender Implications

- 55 There are several gender implications for disabled people and their whānau and support workers:
- a Women continue to contribute the majority of the unpaid labour for disabled people depending on whānau for support. Relying on partners for support can strain relationships and lead to a loss of independence that can mainly affect women, including disabled women. The transformation should help to ease this situation.
  - b For support workers, any changes to employment resulting from the proposed changes will need to be carefully managed to maintain pay, conditions, and employment security of the mainly female disability support workforce. This includes maintaining the benefits of the Care and Support Workers' Equal Pay Settlement, the In-between Travel Settlement, and the Sleep-over Settlement.
  - c At 31 January 2018, about 700 disabled women and young girls receiving DSS services in MidCentral are likely to benefit from the transformation in the prototype. It will also bring benefits for women in terms of their role in caring for a disabled whānau member and their wider whānau care and leadership roles.

## Disability Perspective

56 The objective of this paper is to seek approval to transform the disability support system to give disabled people and their whānau more options and decision making authority about their supports and lives, to improve their outcomes, and create a more cost-effective disability support system. The disability sector is very interested in, and supportive of, this work. This paper reflects the co-design process and describes the close involvement with disability groups. Several of these groups have provided a statement for inclusion in this paper, provided above.

## Publicity

57 There will be ongoing communications including Ministerial announcements about the decisions in this paper.

## Recommendations

- 58 The Minister for Disability Issues and the Associate Minister of Health recommend that Cabinet Social Wellbeing Committee:
- 1 **Note** that the sector developed the Enabling Good Lives vision and principles for transforming the disability support system in 2011;
  - 2 **Note** that in response to calls from the disabled community, the previous Cabinet directed the Ministries of Health and Social Development to work alongside the disability community to co-design a nationwide transformation of the disability support system [SOC-17-MIN-0007 refers];
  - 3 **Note** that in Budget 2017, the Government agreed that \$23.842 million would be set aside in a "Disability Support Services – Enabling Good Lives" tagged contingency over the years 2017/18 to 2019/20 to support system transformation and to fund the transformation of the MidCentral region disability services [CAB-17-MIN-0185.12 refers];

- 4 **Note** that in July 2017 the Government invited the Minister for Disability Issues and Associate Minister of Health to report back in February 2018 on the detailed design of the transformed disability support prototype for MidCentral and the high level implementation plan [SOC-17-MIN-0085 refers];
- 5 **Note** that Cabinet agreed to extend the Disability Support Services – Enabling Good Lives tagged contingency from 1 February 2018 to 3 April 2018 [CAB-18-MIN-0021 refers];
- 6 **Note** that the Cabinet Social Wellbeing Committee agreed to extend the Disability Support Services – Enabling Good Lives tagged contingency from 3 April 2018 to 30 July 2018 [SWC-18-MIN-0026 refers];
- 7 **Endorse** the Enabling Good Lives Vision and Principles for transforming the disability support system;
- 8 **Note** that officials have worked in partnership with the sector to co-design a transformed disability support prototype for MidCentral region over the last year;
- 9 **Agree** to implement the MidCentral prototype of the transformed disability support system in MidCentral from 1 October 2018;
- 10 **Note** that the key features of the design of the MidCentral prototype are:
  - a people are welcomed into the system
  - b access to Connectors
  - c easy to use information and processes
  - d seamless support across government
  - e a straightforward process for accessing funding
  - f capability funding for disabled people and whānau
  - g greater system accountability to disabled people and their whānau;
- 11 **Note** that the MidCentral prototype will use a ‘try, learn and adjust’ approach to refine and finalise the model for rollout across New Zealand;
- 12 **Note** that as an interim and pragmatic step, two teams will be established to deliver the new disability support system for the prototype:
  - a Disabled People and Whānau supporting team will be established within the Ministry of Health
  - b System Enabling team will be delivered through a contract with Enable (the existing NASC) following a reorganisation of the existing team;
- 13 **Note** that there are a range of governance and advisory groups with disabled people at every level to ensure that a wide range of perspectives are heard and taken into account for the design of the new disability support system and implementation of the prototype in the MidCentral region;
- 14 **Note** that the Minister for Disability Issues and Associate Minister of Health will approve the terms of reference for the MidCentral Regional Governance Group;

- 15 **Note** the formation of a working group to address workforce issues, with representatives of disabled people's organisations, Ministry of Health, unions, and employers;
- 16 **Note** that in a separate Cabinet paper, the Minister of Health is seeking decisions on the use of the Disability Support Services – Enabling Good Lives tagged contingency to cover the costs of implementing the MidCentral prototype of the transformed disability support system and to continue with the Enabling Good Lives demonstrations in Christchurch and Waikato;
- 17 **Note** that there will be ongoing monitoring and evaluation for the MidCentral prototype;
- 18 **Note** that advice will be provided to Cabinet in late 2020 about expanding the transformed disability support system beyond the MidCentral region;
- 19 **Invite** the Minister of Revenue to report back to Cabinet separately on the appropriate tax treatment of the proposed disability support payments;
- 20 **Invite** the Minister for Social Development to report back to Cabinet separately on any proposed changes to legislation to exempt personal budgets as chargeable income or cash assets, for the purpose of determining eligibility to benefits, supplementary assistance or social housing;
- 21 **Agree** to initiate a machinery of government review to advise on the benefits, costs and risks of different options, including potential structural changes, for involving disabled people and whānau in the governance of the disability support system;
- 22 **Invite** the Minister for Disability Issues and the Associate Minister of Health to report back to Cabinet by the end of June 2018 on:
  - a policy proposals to support System Transformation
  - b progress with the MidCentral prototype, including funding allocation and accountability arrangements.

Authorised for lodgement.

Hon Carmel Sepuloni  
Minister for Disability Issues

Hon Julie Anne Genter  
Associate Minister of Health

## Appendix One: Enabling Good Lives (EGL) Vision and Principles

### Vision

1. 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.
2. Disabled people and their families and whānau, as appropriate, will be able to say:
  - a. I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
  - b. I have real choices about the kind of support I receive, and where and how I receive it.
  - c. I can make a plan based on my strengths and interests.
  - d. I am in control of planning my support, and I have help to make informed choices if I need and want it.
  - e. I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
  - f. The level of support available to me is portable, following me wherever I move in the country.
  - g. My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
  - h. My family, whānau, and friends are recognised and valued for their support.
  - i. I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
  - j. I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.
3. The government will get better value for the funding it provides because:
  - a. the new approach will generally provide better quality of life outcomes for disabled people and their families and whānau (based on international evidence);
  - b. less money will be spent on providers premises and more on support;
  - c. government agencies will work more closely together, for example using shared way to determine support needs, integrated funding and contracts.

### Acknowledging the Relationship between Māori and the Crown under the Treaty of Waitangi

4. The Treaty relationship as set out in the New Zealand Disability Strategy, and the Māori Disability Action Plan, will continue to be core to this future vision. It will be based on three key principles of participation at all levels; partnership in delivery of support, and the protection and improvement of Māori wellbeing.

### Principles

- *Self-determination*: Disabled people are in control of their lives.
- *Beginning early*: Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.
- *Person-centred*: Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

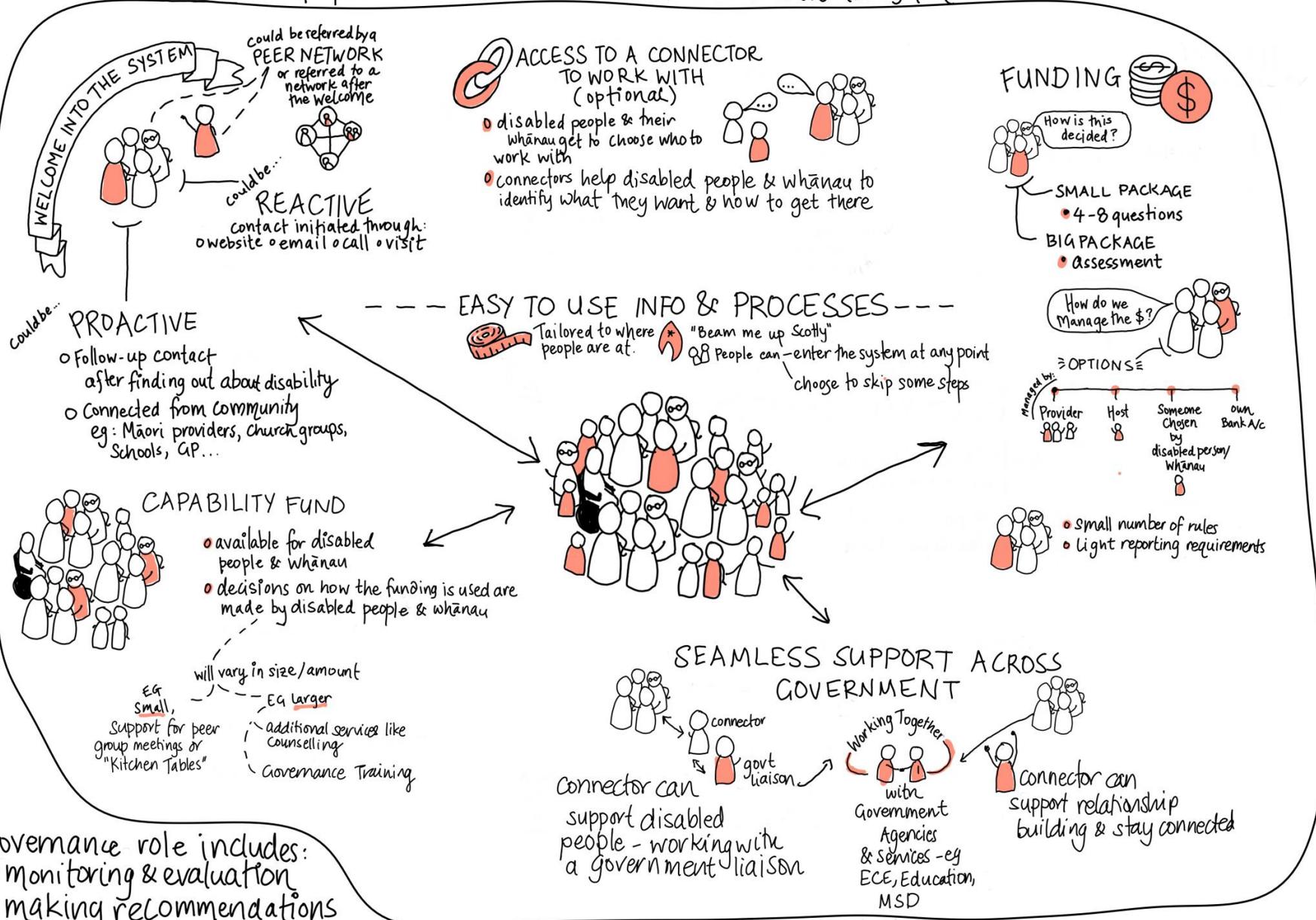
- *Ordinary life outcomes:* Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life.
- *Mainstream first:* Disabled people are supported to access mainstream services before specialist disability services.
- *Mana enhancing:* The abilities and contributions of disabled people and their families and whānau are recognised and respected.
- *Easy to use:* Disabled people have supports that are simple to use and flexible.
- *Relationship building:* Supports build and strengthen relationships between disabled people, their whānau and community.

## Appendix Two: High Level Experience of the Transformed System

| Enabling Good Lives Principles: self determination, beginning early, person-centered, ordinary life outcomes, mainstream first, mana enhancing, easy to use, relationship building |   |   |  |  |  |   |   |
|--|---|---|--|--|--|---|---|
|  | 0.0 Catalyst  | 1.0 Awareness<br>I/we know what support and assistance is available   | 2.0 Entry<br>I/we are listened to and respected  | 3.0 Immersion<br>I/we develop my aspirations and an approach   | 4.0 Transitioning<br>I/we enable my aspirations  | 5.0 Extension<br>I/we live my aspirations   |   |
| Overview   | A person finds out they, or a family member, have an impairment and want to know more   | It is easy to find out about disability support and there is widespread awareness at whānau, community and the system level   | There are proactive and responsive entry points for everyone   | The Enabling Good Lives team provides a space for thinking about possibilities, and responds in a way that enables the life that the disabled person and whānau wants  | The Enabling Good Lives team assists the disabled person and whānau to put support in place that works for them  | Disabled people continue to live the lives they want, have new experiences and connect with others  |   |
| Gateway  | I am looking for information and support  |   | I would like someone to assist me  | I am ready to talk about what I want in my life  | I know what I want to achieve and how to get there   | I have the support to do the things I want  | Things have changed – I might need something else |
| Disabled Person  | "Something has changed or I could have more in my life."  | "I know there is support for me and I know there is someone to walk alongside me and help me work things out, on my terms."   | "I am listened to, respected and responded to in a way that works for me."   | "I'm making decisions about my life and I'm supported to do this in a way that builds the life I want. I have mana."   | "I am in control of my supports and am connected with people and places I enjoy."  | "I am continuing to build the life I want and have flexible support to assist me"   |   |
| Whānau   | "We are facing some challenges or life could be better for us."   | "We know there is support for our whole whānau. I know who to talk to about getting support."   | "We are listened to, respected and responded to in a way that works for all of the whānau."  | "Our whānau know where we are heading and have supports in place to build the life we want together."  | "We are in control of our support, and our disabled family member, along with our whānau, are stronger."   | "We know that if things change for our whānau and disabled family member our supports are flexible and can change with us."   |   |
| Other People   | "I can see someone might benefit from some information or support."   | "I know what support, resources and information is available and am going to offer this. I know what my role is, I'm confident and capable. I'm going to actively help."  | "I have the time, skills and the resources to truly listen and respond in a way that works for you and your whānau."   | "I'm there to assist you and your whānau, work out what you want to achieve and how to get the supports and resources you need to make this a reality. I'm the 'support crew' while you are in the driving seat."  | "I am alongside to assist as you manage your supports, try new experiences and deal with difficult times".   | "I reflect and learn from the opportunities I have to support disabled people and their whānau".  |   |
| Critical System Shifts   | <ul style="list-style-type: none"> <li>Strengths-based social awareness</li> <li>The EGL team reaches out to people</li> <li>Support is available to ensure equity of outcomes</li> </ul>   | <ul style="list-style-type: none"> <li>Support is directed by the person, builds trust, reflects manaakitanga and is culturally responsive</li> <li>Support is available to cover an immediate crisis</li> <li>Disabled people are welcomed with warmth and respect in a way that matches where they are at and what they want</li> <li>The EGL team is pro-active in supporting disabled people and their whānau and connecting those who don't have someone in their lives</li> <li>When support is needed from other places, communication is open and transparent with the disabled person deciding what information is shared</li> </ul> | <ul style="list-style-type: none"> <li>The EGL team takes the time to listen and get to know each person and learn about what is happening and what is important in their lives</li> <li>The EGL team invests the time needed to build trust with disabled people and their whānau</li> <li>Disabled people and whānau own and can access their records, and decide who else can see them</li> <li>The intensity and type of support provided changes quickly in response to what the disabled person and their whānau need at the time</li> </ul> | <ul style="list-style-type: none"> <li>Disabled people and their whānau are in control and direct their support and lives</li> <li>EGL practice is informed by disabled peoples' lived experiences and uses these learnings to continually develop better ways of working</li> <li>There is flexibility in how resources are used at a system and an individual level</li> <li>The disabled person's aspirations drive the conversation, not the funding</li> <li>Support across government is seamless to the disabled person and whānau</li> </ul> | <ul style="list-style-type: none"> <li>Control over support has shifted from the system to disabled people and their whānau</li> <li>Each disabled person's Enabling Good Lives proposal is flexible and changes with them as they do</li> <li>Disabled people and their whānau have choices about their support with very few rules</li> <li>The EGL team trusts that disabled people will use their funding for the purpose it was intended (and doesn't require much detail about expenditure in return)</li> <li>Disabled people and whānau have a range of options for managing their support and can be reimbursed for costs if they take on administration</li> </ul> | <ul style="list-style-type: none"> <li>Each disabled person's support is flexible and changes with them as they do</li> <li>The EGL team keeps in regular contact to see how things are going for people</li> </ul> |   |
| System Building Blocks   | <ul style="list-style-type: none"> <li>Investing in disabled people and whānau capability</li> <li>Self-managed information and resources</li> <li>Tools, resources and processes to support the Enabling Good Lives journey</li> <li>The Enabling Good Lives team and investing in system capability and capacity</li> </ul> |   |  | <ul style="list-style-type: none"> <li>Multi-channel disability information</li> <li>Self determined pathways and support, tailored to the disabled person and their whānau</li> <li>Funding allocation (including funding model, allocation and processes)</li> </ul>   |  |   |   |

# Appendix Three: Visual Representation of the MidCentral Prototype

Disabled people & Whānau involved in  $\geq$  GOVERNANCE  $\leq$  over the System \*



\* Governance role includes:  
• monitoring & evaluation  
• making recommendations for change

| Disabled people and whānau make decisions about their lives and supports  |  |   |  |  |  |  |
|---|--|---|--|--|--|--|
|   | People are welcomed into the system  | Connectors  | Seamless support across government   | A straightforward process for accessing funding  | Capability funding   | Greater system accountability to disabled people and their whānau  |
| Disabled people and whānau will:  | <p><b>be welcomed in multiple ways</b><br/>with information that is easy to use, and have access to:</p> <ul style="list-style-type: none"> <li>o a Connector</li> <li>o peer networks</li> <li>o disability organisations</li> </ul>  | <p><b>have access to someone who can walk alongside them</b><br/>to help them to identify what they want in their lives, and what supports are available to achieve this</p>  | <p><b>be supported by government liaison</b><br/>who will work in the background to access other government services (e.g. benefit applications), and to build positive relationships (e.g. learning support in schools)</p> | <p><b>have the ability to make decisions about what can be purchased</b><br/>and how it can be administered, and easy reporting on how the funding has been used</p>   | <p><b>have the opportunity to develop skills</b><br/>through a fund to help develop leadership and community capability</p>  | <p><b>be involved in monitoring and evaluation, and making recommendations to Ministers</b><br/>about changes to the system</p>  |
| The system will have:   | <ul style="list-style-type: none"> <li>• someone to talk with face-to-face, on the phone, online</li> <li>• an accessible website with useful and accurate information</li> <li>• self-directed pathways through the system based on where an individual is</li> <li>• an outreach function to connect with disabled people and whānau when they first learn about an impairment</li> <li>• outreach to communities and groups who have not had contact with disability support services</li> </ul>  | <ul style="list-style-type: none"> <li>• connectors employed by the Disabled People Supporting organisation</li> <li>• a simple process for people to be validated as a connector</li> <li>• contracts with organisations (that do not provide disability support services) to provide connectors e.g. Whānau Ora</li> </ul>  | <ul style="list-style-type: none"> <li>• processes with government agencies on how they work together</li> <li>• a transparent, easy to use process to access government funding for whole of life</li> </ul>                | <ul style="list-style-type: none"> <li>• a clear process to make an application for funding</li> <li>• transparent purchasing guidelines</li> <li>• a simple funding allocation process</li> <li>• clearly stated monitoring requirements</li> <li>• range of options for other people to manage the personal budget</li> <li>• processes for:                             <ul style="list-style-type: none"> <li>o getting the funding into a disabled person's bank account</li> <li>o monitoring the funding</li> </ul> </li> </ul>                                       | <ul style="list-style-type: none"> <li>• pool of funding for disabled people capability building</li> <li>• pool of funding for whānau capability building</li> <li>• criteria for funding applications</li> <li>• transparent process for making funding applications</li> <li>• clear and multiple ways to inform people about the funding</li> <li>• clear communication process about funding decisions</li> </ul> | <ul style="list-style-type: none"> <li>• a monitoring and evaluation framework</li> <li>• multiple ways for disabled people and whānau to give their views about what is working and what needs to be improved</li> <li>• a Governance Group with 60% disabled people</li> <li>• a process for the Governance Group to communicate its decisions to the disability sector</li> </ul> |
| <p>Disabled people and whānau will have tools and resources</p> <p>These will be in multiple formats, languages and easy to use</p> | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• welcome pack and orientation</li> <li>• the Enabling Good Lives principles and approach</li> <li>• information about:                             <ul style="list-style-type: none"> <li>o what government support is available and how to access it</li> <li>o local and national service providers (disability and universal)</li> <li>o community-based activities such as sports, recreation, clubs</li> </ul> </li> </ul> <p><b>Tools</b></p> <ul style="list-style-type: none"> <li>• who to contact with any concerns or feedback</li> </ul> | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• the role of connectors – what they can and cannot do</li> <li>• profiles of connectors</li> <li>• stories from disabled people who have worked with a connector</li> <li>• Code of Ethics</li> </ul> <p><b>Tools</b></p> <ul style="list-style-type: none"> <li>• validation process for connectors</li> <li>• how to contact a connector</li> </ul> | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• information about what supports are available</li> </ul>  | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• information about what funding is available</li> <li>• purchasing guidelines</li> <li>• how to request a review of a decision about funding allocation</li> <li>• how to manage a personal budget (rights and obligations)</li> <li>• how to employ or contract support people (including health and safety, taxation, training)</li> <li>• options for someone else to manage a personal budget</li> </ul> <p><b>Tools</b></p> <ul style="list-style-type: none"> <li>• funding allocation tool</li> </ul> | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• simple, clear and easy to use funding application</li> <li>• some examples of funding applications</li> <li>• information about the process for making decisions, including timeframes</li> </ul>   | <p><b>Resources</b></p> <ul style="list-style-type: none"> <li>• training and support for the Governance Group</li> </ul>  |

## Appendix Five

### What system transformation will mean for key stakeholder groups

#### *Children and young people*

- 1 There are about 400 children and young people (aged 0 to 17 years) currently receiving Disability Support Services (DSS) in MidCentral (of about 12,000 children and young people receiving DSS nationally). Some disabled children and young people may not be eligible for DSS but will be accessing other government funded support. Families may be connected to the disability support system through health and educational professionals. The new disability support system needs to be responsive to children, young people and their whānau, including disabled children and young people living with their whānau, with other kin or non-kin caregivers, in foster care or in residential facilities.
- 2 The transformed system will improve outcomes for children and young people through:
  - a ***Providing early support to families with a disabled child*** - Connectors will assist parents to get the right supports for their child at the right time, connect them to positive people and nurture those relationships, and to get the services and supports the whānau needs to be resilient and grow its confidence and skills to support the child. The transformed system will also ensure that children whose whānau face complex mixes of social, mental health and cultural needs do not miss out on these protective factors. Early support also includes timely access to assessment and diagnosis for holistic, integrated specialist supports and services for disabled children and young people with complex needs. The system transformation will work with the Ministry of Education and Oranga Tamariki to improve engagement and responses to these groups of disabled children and young people and their whānau.
  - b ***Ensuring the voice of disabled children and young people is heard within the system*** – The current system can exacerbate differences in interest between whānau and their disabled members. This can especially be the case for disabled children. We expect that the Connector role, and particularly supported decision-making processes, will help ensure that the voices of disabled children and young people are heard and their views and preferences taken into account.
  - c ***Reducing fragmentation in specialist supports for developmental and behavioural needs*** – Health and Education fund specialist supports for behavioural and developmental needs for disabled children and young people. Fragmentation between services leads to multiple assessments and reassessments, different plans for similar needs for the same child, and increased complexity when accessing services. The transformed system will reduce the complexity that families experience in trying to access and maintain the different supports and services for their child. Officials are going to trial moving these services closer together through taking a person/child-centred approach in the prototype. This will better manage resources to improve access and outcomes for children.

#### ***People with high and complex needs***

- 3 Within the cross-government disability support system, there is a group of high and complex clients comprising:
  - a people with complex medical issues, challenging behaviours, multiple impairment, alternative forms of communication and/or complex living situations whose support is coordinated by the NASCs

- b people who receive support under the High and Complex Framework through the National Intellectual Disability Care Agency. This includes people who are in compulsory care under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2001.
- 4 The first group is initially the priority group for the prototype. They require more specialised and intensive support to enable them to live a good life. They may be living within the community or within residential options. There has been lots of feedback from whānau members about current levels of stress for families, the need for more specialised options, sustainability of support arrangements and the requirements for the workforce to be qualified to work with this group.
  - 5 Within the MidCentral prototype, there will be:
    - a some contracted capacity for providers to work intensively with this group to develop tailored and sustainable support for their specific situation, in addition to the other system features that will be available to other disabled people
    - b a commitment to recruiting connectors who have experience working with these groups and ensuring there is someone to contact outside business hours
    - c supported decision making and formal advocacy options.
  - 6 Within the prototype, we will be monitoring the outcomes for this group closely, including uptake of Connectors, how the information and processes meet the needs of this group, the availability of support options, and workforce.
  - 7 Further work is being completed to consider the implications for people receiving support under the High and Complex Framework including those under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2001. This will be included in the June 2018 Cabinet paper.

***People with Autism Spectrum Disorder (ASD)***

- 8 There are approximately 220 people in the MidCentral region who have an autistic spectrum disorder (ASD). People who have ASD may have a fear of change and are concerned about the system being transformed because it would be disruptive and challenging to their routines and way of life. Some people will not know or understand the changes and they and their support network will need support to understand what the changes are, the possible impacts of change and how this would be managed. People with ASD and their whānau will need time to get used to the prospect of change.
- 9 Those who support disabled people with ASD, may have reservations about change, as it was not until recently that the Ministry of Health accepted people with ASD service access. Service development for people with ASD has not been rapid, and some still believe there is a significant gap, and that the range of support services are inadequate.
- 10 Socialising change for people with ASD is a skill and it needs to be individualised. There may be a need to access behaviour support services to assist with communication. Some disabled people with ASD may need assistance to:
  - a Understand any communication
  - b Read any messaging/letters
  - c Make decisions that affect how and where they live or how they can use support
  - d Access or understand how to use technology

- 11 The new system will:
  - a Have Connectors who understand autism to work with people with ASD
  - b Support what works for people with ASD and their whānau
  - c Help people to continue to get all their current support and, if it is working well, they don't have to change if they don't want to
  - d Have opportunities to change supports if people want to
  - e Make changes at a pace that suits people, including trying something and having options if it doesn't suit.

### **Māori**

- 12 The objectives of system transformation are aligned with the goals and outcomes in *Whāia Te Ao Mārama*, the Māori Disability Strategy.<sup>9</sup> That Strategy is based on the principles of te Tiriti o Waitangi (the Treaty of Waitangi). The objectives are also consistent with New Zealand's obligations under the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Declaration on the Rights of Indigenous Peoples.
- 13 Disability is an important issue for Māori with disabilities (tāngata whaikaha) and their whānau. Māori have a relatively high disability rate for a population with a relatively young age structure. In the 2013 Disability Survey, 26 percent of the Māori population (176,000 people) self-reported as being disabled (compared with the other main ethnic groups: European – 25 percent; Pacific – 19 percent; Asian – 13 percent).<sup>10</sup> After adjusting for differences in ethnic population age profiles, Māori would have had an even higher disability rate of 32 percent.
- 14 Māori, particularly in low socioeconomic areas, experience poorer health and are more likely to be living with a disability than other New Zealanders.<sup>11</sup> Despite Māori having higher rates of disability, Māori are more likely to have unmet needs relating to specialised equipment and consultations with health and disability professionals.
- 15 In 2016, 17.5 percent of national Disability Support Service (DSS) clients (5,920) identified as Māori and half were aged under 23 years. There is a significant Māori presence in the MidCentral region, about 20 percent of the region's population. About 11 percent (175 people) of the DSS clients in MidCentral identify as Māori.
- 16 The design of the MidCentral prototype reflects tāngata whaikaha and whānau experiences and perspectives. The co-design process involved around 20 empathy interviews and observations with tāngata whaikaha and whānau, health and disability contributors and kaupapa Māori providers in MidCentral. It also involved a wānanga (educational seminar) at Te Hotu Manawa o Rangitāne marae to support a kaupapa Māori co-design process.
- 17 The co-design process highlighted that Māori feel marginalised, invalidated and stigmatised by the current system. The development of the MidCentral prototype included a specific focus on how the design aligns with Māori values, concepts and

---

<sup>9</sup> *Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services*. Wellington: Ministry of Health.

<sup>10</sup> Statistics New Zealand. 2015. He Hauā Māori: Findings from the 2013 Disability Survey. URL: [www.stats.govt.nz/browse\\_for\\_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey.aspx](http://www.stats.govt.nz/browse_for_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey.aspx).

<sup>11</sup> Higher rates of disability among Māori contribute to poorer socioeconomic outcomes. Key issues include low income, poor housing quality and discrimination. Māori have higher rates of moderate impairments, which relate to environmental factors such as ill health, poor housing, or injury from hazardous occupations.

practices to support Te Ao Māori being weaved into the operational design, rather than having a separate system for Māori.

- 18 The MidCentral prototype will support tāngata whaikaha and whānau to be empowered to make more decisions and have more options around their supports and lives. This could include strengthening relationships with whānau, hapū and iwi or support for whakawātea (healing) processes. The MidCentral prototype includes capability funding options that can directly support Māori aspirations and rangatiratanga (self-determination).
- 19 The co-design process highlighted the importance of information accessibility and appropriate support to navigate the system. The MidCentral prototype includes the role of a connector who will be available to walk alongside tāngata whaikaha and whānau to help them identify what they want in their lives, how to build that life, and the range of supports available to live that life. The recruitment and induction process for the new teams will specifically include cultural responsiveness expectations and cultural competency-based induction and training modules.
- 20 System transformation is all about enabling tāngata whaikaha and whānau to have more options and decision making authority about their supports and lives, including the option to use kaupapa Māori providers. The approach is complementary to, and supportive of, the intent of kaupapa Māori approaches such as Whānau Ora. Further work is underway to co-design the interface between a transformed system and Whānau Ora.
- 21 The evaluation approach for the MidCentral prototype will focus on a number of important groups, including Māori. This will provide a deep understanding of how the transformed system is working for Māori and opportunities to improve how the system supports Māori values, concepts, and practices.

### **Pacific Peoples**

- 22 Effective disability support services need to be responsive to the needs of Pacific peoples and their 'aiga.<sup>12</sup> System transformation will contribute to the priority outcomes and actions of *Faiva Ora 2016-2021 National Pasifika Disability Plan*.<sup>13</sup>
- 23 In the 2013 Disability Survey, 19 percent of Pacific peoples self-reported as being disabled (compared with the other main ethnic groups: European – 25 percent; Māori – 26 percent; Asian – 13 percent). After adjusting for differences in age profiles, Pacific peoples would have had an even higher disability rate of 26 percent.
- 24 About 3 percent (48 people) of the DSS clients in MidCentral identify as Pacific peoples. Despite this being a comparatively lower figure than that for Māori, the MidCentral prototype will offer useful information and experience about meeting the needs of Pacific peoples to assist the wider rollout.
- 25 The design of the MidCentral prototype reflects Pacific peoples' experiences and perspectives, and has been developed with the assistance of:
  - a Three Pacific members on the National Enabling Good Lives (EGL) Leadership Group, Pacific people taking part in the Co-Design group which developed the high-level design for the transformed system, and Pacific 'aiga members attending

---

<sup>12</sup> 'aiga - extended family

<sup>13</sup> *Faiva Ora* sets out the priority outcomes and actions to support and improve the lives of Pacific disabled people and is aligned with all health and disability strategies and the United Nations Convention on the Rights of Persons with Disability (UNCRPD)

- Regional Leadership Group (RLG) meetings in MidCentral while they determine who is going to represent them on the RLG.
- b Through a Pacific member of the National EGL Leadership Group, a number of meetings have been held in Palmerston North and Levin to inform and engage Pacific disabled people and their aiga about System Transformation, and further forums are planned.
  - c The System Transformation lead has also started to engage with Le Va (a Pacific disability information advisory service) and Vaka Tautua (a charitable organisation providing disability support services for Pacific peoples) in Auckland.
- 26 Pacific peoples require the appropriate time to connect and build the "va" i.e. the relationship. Trust from Pacific peoples is not automatic, and is pinned to many factors, e.g. humility, service, reciprocity, honour, guardianship, obligation and duty.
  - 27 Whilst there is a small proportion of Pacific peoples in MidCentral, there are much larger populations in other major centres, including Auckland and Wellington. We will be engaging with Pacific communities in both cities to test the prototype and ensure the model works for Pacific 'aiga across the country.
  - 28 The principal support people for Pacific disabled people are their 'aiga, who sometimes struggle to navigate the disability system and, as a result, feel isolated. Disabled Pacific peoples and their 'aiga are comparatively low users of disability support services (DSS) funded through the Ministry of Health.<sup>14</sup>
  - 29 While Pacific peoples use the carer support subsidy and home and community support services, they do not generally use community residential services, supported living and day programmes. Reasons for this include: a lack of awareness of available supports; a preference to care for disabled 'aiga (family) members at home; and the limited number of Pacific peoples' disability provider organisations, particularly for home and community support services and respite services. Pacific 'aiga have expressed the need to access Pacific relief carers.
  - 30 A greater Pacific peoples' disability support service workforce would enable Pacific models of support and better outcomes for Pacific disabled peoples and their 'aiga. System transformation will need to address the support required for potential disability support providers, particularly providers for Pacific peoples. There will be a need to increase the cultural capability of non-Pacific service providers to ensure they are able to interact successfully with Pacific peoples. Disabled people will have the option of talking to people about the prototype in multiple languages, including Pacific languages.
  - 31 This Cabinet paper includes funding for a series of EGL Lives workshops nationally to build awareness and start to prepare disabled people, families and providers for change. The proposal includes funding for workshops for Pacific Peoples.
  - 32 The prototype includes the role of a Connector who will be available to walk alongside disabled Pacific peoples and 'aiga to help them identify what they want in their lives, how to build that life, and to explain the range of supports available. This role will have an outreach role to educate Pacific Peoples about the system.
  - 33 Evaluation of the prototype will also help to prepare for the later transformation of systems in regions with significant populations of Pacific peoples such as Auckland and Wellington.

---

<sup>14</sup> 5.9% of service users, relative to the national Pacific peoples' population of 7.4% (295,941 people)

### ***People from a refugee and migrant background***

- 34 Disabled people from a refugee or migrant background have a wide range of experiences that can affect the way in which they make decisions whether or not to engage with the health system and access disability support.
- 35 Important factors relate to: language, culture, nature of background to arrival in New Zealand, physical location in New Zealand and broader whānau and community supports (particularly engagement with people from a similar cultural background).
- 36 It is difficult to determine actual numbers of people accessing or eligible to access disability supports. The MidCentral region has about 2,000 people from a diverse refugee and migrant background including Asia, Africa and the Middle East.<sup>15</sup> However, the numbers accessing DSS in MidCentral are extremely low and there is likely to be unmet need.
- 37 There are a number of reasons why people from a refugee background, and to some extent other migrants, don't access disability support. This includes:
- a issues of communication – having no or limited English can complicate communications on many issues
  - b lack of knowledge of existing disability supports and eligibility (complicated further for some having come from countries where there is no or limited support for disabled people and so would expect it or look for it)
  - c disabled people being looked after at home by the whānau
  - d feelings of embarrassment or shame about disability for some cultures
  - e vulnerability – some people may have left countries and situations where they had been extremely vulnerable. Examples include escape from repressive regimes and harrowing experiences of a mental and physical nature. For this reason, some people are naturally cautious or even highly distrustful or frightened of any communication or person from any official source, including government organisations. Despite being well-intentioned, an enquiry about personal circumstances can be sensitive.
- 38 Some people will need time, care and culturally appropriate assistance to:
- a understand any communication
  - b read any messaging/letters
  - c make decisions that affect how and where they live
  - d access and use technology

### ***Workforce***

- 39 Transforming the disability support system will:
- a bring change for the existing workforce supporting disabled people and their whānau, including changes to jobs, organisations, terms and conditions of employment, and job descriptions and requirements

---

<sup>15</sup> Myanmar [Burmese & Rohingya], Afghanistan, Palestine, Congo Brazzaville, Democratic Republic of Congo, and Rwanda

- b create new opportunities for the existing workforce and people who are not currently providing disability support, including the creation of new jobs and types of job.
- 40 Through engagement with the unions and other stakeholders, a number of workforce issues have been identified. Actions that need to be taken to ensure good outcomes for disabled people and their whānau, as well as for workers, include:
- a ensuring that changes to give flexibility and choice to disabled people and their whānau also safeguard working conditions including for support workers
  - b clarifying the status of workers, including how support workers will be employed or engaged, and how current terms and conditions of work and employment will be maintained and improved
  - c designing appropriate structures of incentives and support to ensure that change in the form or structure of employment does not result in support workers and the wider workforce becoming fragmented and isolated in individual employment or contracting arrangements
  - d maintaining and improving capacity for workforce development and planning, including the promotion of appropriate training and qualifications for support workers, alongside efforts to retain and recruit quality staff
  - e supporting disabled people and their whānau who are employers, to understand their rights and fulfil their responsibilities and obligations
  - f clarifying and supporting the respective roles of government and providers in engaging workforce about the transformation
  - g investigating up front, and in the course of ongoing monitoring and review of system transformation, whether the current regulatory framework is sufficient to protect disabled people and workers.
- 41 A workforce working group of disabled people, unions, providers and government officials has been established to work through these and any other issues arising during system transformation. This group will also identify the best mechanism for, and oversee, workforce engagement for the proposed changes.

***Needs Assessment and Service Coordination (NASC) organisations***

- 42 NASCs (regional organisations providing access to DSS) will be directly affected by system transformation, initially with the MidCentral prototype.
- 43 NASCs are supportive of the direction of change sought through system transformation and have members contributing experience and advice on working groups and virtual testing groups.
- 44 NASCs have altered their systems and processes where possible with broader system and policy changes and with the different demonstrations that have been based around NASCs (e.g. flexible purchasing guidelines and enhanced individualised funding in Bay of Plenty). The insights of disabled people and their whānau have been an important part of the process for the changes overseen by NASCs.
- 45 As noted in the discussion of organisational changes for the MidCentral prototype in the Cabinet paper, the current MidCentral NASC (Enable) will be directly affected by the prototype. The System Enabling team of the MidCentral prototype will be delivered through a contract with Enable following a reorganisation of the existing team to

establish and fill new roles. The new team will be made up of a mix of current employees and new staff.

- 46 NASCs and the umbrella New Zealand Needs Assessment and Service Coordination Association (NZ NASCA) will be keenly interested in the 'try, learn and adjust' approach of the MidCentral prototype, the change process, operation and outcome. During this time, NASCs throughout the country will be continuing their work including the management of relationships with disabled people and their whānau, providers and government agencies.

## Appendix Six

### High level implementation plan for the MidCentral prototype

Alongside ongoing communication, engagement and change management strategies, the following table shows the high level implementation plan leading up to the rollout of the MidCentral prototype:

| <b>Information and support</b>   | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
|--|-----|-----|-----|-----|-----|-----|-----|-----|
| Finalise website content and functionality                                       |     |     |     |     |     |     |     |     |
| Welcome pack and orientation modules   |     |     |     |     |     |     |     |     |
| Website testing phase  |     |     |     |     |     |     |     |     |
| Website ready for go live  |     |     |     |     |     |     |     |     |
| <b>MidCentral teams</b><br><i>Disabled People and Whānau and System Enabling</i> | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| Recruitment process  |     |     |     |     |     |     |     |     |
| Support for change process for MidCentral DHB staff                              |     |     |     |     |     |     |     |     |
| Final appointments made  |     |     |     |     |     |     |     |     |
| Induction phase  |     |     |     |     |     |     |     |     |
| <b>Operational tools, processes and policies</b>                                 | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| IT system workarounds identified and managed                                     |     |     |     |     |     |     |     |     |
| Business processes developed and finalised                                       |     |     |     |     |     |     |     |     |
| Tools and resources developed and finalised                                      |     |     |     |     |     |     |     |     |
| Safeguarding approach complete   |     |     |     |     |     |     |     |     |
| Government interface processes complete  |     |     |     |     |     |     |     |     |
| Market development plan complete   |     |     |     |     |     |     |     |     |
| Governance arrangements in place   |     |     |     |     |     |     |     |     |
| <b>Funding</b>   | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| Cabinet decisions on scope of funding  |     |     |     |     |     |     |     |     |
| Funding application process complete   |     |     |     |     |     |     |     |     |
| Capability funding framework complete  |     |     |     |     |     |     |     |     |
| <b>Provider contracts</b>  | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| Implications for MidCentral contracts finalised                                  |     |     |     |     |     |     |     |     |
| Interim contracts for centrally purchased supports complete                      |     |     |     |     |     |     |     |     |
| Signed changes to all MidCentral contracts                                       |     |     |     |     |     |     |     |     |

| <b><i>Workforce engagement</i></b>                                     | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
|--|-----|-----|-----|-----|-----|-----|-----|-----|
| Working group makes initial recommendations for safeguarding workforce |     |     |     |     |     |     |     |     |
| Support for change process for staff employed by providers             |     |     |     |     |     |     |     |     |
| Safeguarding approach for workforce finalised                          |     |     |     |     |     |     |     |     |
| <b><i>Evaluation plan and process</i></b>                              | Mar | Apr | May | Jun | Jul | Aug | Sep | Oct |
| Gathering baseline data  |     |     |     |     |     |     |     |     |
| Monitoring and evaluation framework complete                           |     |     |     |     |     |     |     |     |
| MidCentral baseline report complete                                    |     |     |     |     |     |     |     |     |
| Plan for managing changes to the prototype complete                    |     |     |     |     |     |     |     |     |