



Implementation evaluation of Mana Whaikaha system transformation



ALLEN+CLARKE

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GLOSSARY

Manaakitanga	Hospitality, kindness, generosity, support – the process of showing respect, generosity toward others.
Tino rangatiratanga	Self-determination, sovereignty, autonomy, self-government, rule, control, power.
Whānau	Extended family, family group, a familiar term of address to a number of people – the primary economic unit of a traditional Māori society.
Whakawhanaungatanga	Process of establishing relationships, relating well to others.

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EXECUTIVE SUMMARY

This report presents findings from an evaluation of the implementation of Mana Whaikaha. Mana Whaikaha is a prototype of a transformed disability support system that was introduced in the MidCentral DHB area from 1 October 2018. Mana Whaikaha is based on the Enabling Good Lives (EGL) vision and principles and aims to give disabled people and their families and whānau more choice and control over their lives and the supports they receive. It also aims to improve their life outcomes.

The Ministry of Health contracted *Allen + Clarke* to undertake an evaluation of the implementation phase of Mana Whaikaha. The purpose of this evaluation is to understand:

- what has been implemented
- to what extent Mana Whaikaha has been implemented as intended
- what is working well and what is working less well (from different perspectives)
- where improvements are needed.

The evaluation supports the Try, Learn and Adjust approach being adopted for Mana Whaikaha and the intention of ongoing development.

The evaluation involved qualitative interviews, focus groups and small group interviews with a wide range of stakeholders (123 participants) including disabled people and their families and whānau, the MidCentral Governance Group, members of the core groups, Mana Whaikaha staff¹ providers and government officials from the Ministry of Health, Ministry of Education and Ministry of Social Development and the MidCentral DHB.² Surveys were sent following focus groups with Kaitūhono/Connectors and providers, and a survey was also sent to support workers. The surveys provided open-response questions, and the intention was to allow people to respond individually and to gather further qualitative data.

The data collection for this evaluation took place between August 2019 and November 2019, and the evaluation focuses on the implementation of Mana Whaikaha from 1 October 2018 to November 2019. The evaluator was involved in meetings following the data collection period, and updates on changes since the data collection point in time have been included in this report.

KEY FINDINGS

Unanimous support for the vision and principles of Enabling Good Lives

All evaluation participants support the core principles and aims of giving disabled people and their families and whānau more choice and control over their lives and the supports they receive and to improve their life outcomes.

¹ Mana Whaikaha comprises two teams: the Kaitūhono/Connectors team and the Tari/System team.

² The evaluator had intended to interview Oranga Tamariki staff. However, this could not be coordinated within the fieldwork timeframe.

Challenging role for the Connectors and recognition they are doing their best

The role of the Connector is to be the disabled person's ally – to walk alongside them to support them to work out what they want in their lives and what supports are available to support them to achieve their goals. This role is challenging and ambitious.

Connectors rely on their personal connections to support disabled people to access support that will enable the disabled person to realise more choice and control over their lives. This means that the outcomes were uneven as not all Connectors have the same personal connections or the same skill sets for engaging and creating new connections across a number of systems. There is a consensus that the Connectors are doing their best and acknowledgement that it is a very demanding role.

Success stories with Connectors and disabled people improving choice and control

There are success stories where Connectors and the disabled person together have realised change and improvements in the daily lives of the disabled person and their family and whānau. Given the short timeframe since implementation commenced, the success stories should be kept centre of mind as they are an outcome of the commitment of those in the Kaitūhono/Connectors and Tari/System teams.

Emphasising “lived experience” of disability

According to Mana Whaikaha staff, the experience of being disabled and/or having experience of living with disability is central to the design of the prototype and the organisational culture. This is a move away from clinical assessment of disability towards engagement that is empathetic and without judgement. Most disabled people and their families reported that they had been treated with empathy and without judgement by Mana Whaikaha.

Different kinds of knowledge

One of the unintended outcomes of stressing lived experience over clinical assessment, however, is that clinical and other forms of knowledge were, at times, disrespected and relationships were damaged as an outcome. Māori and health professionals at the DHB reported this and stressed that this is an impediment to successful implementation.

The challenges of implementing a new system and taking on clients at the same time

Mana Whaikaha staff experienced a range of challenges and commonly described the implementation period as one that was like “flying while still building the plane” – exciting but stressful. There were a range of practical problems that needed to be resolved, including setting up processes and practical administrative tasks while implementation was under way.

Unexpected demand on the day of the launch

On 1 October 2018, the day of the launch, the Mana Whaikaha workforce was inundated with people wanting this new service, and the outcome was a 400+ waiting list of disabled people. According to Mana Whaikaha management, this unanticipated number meant that the planned ratio of approximately one Connector to 45 disabled people (1:45) was now more like one Connector to 100 disabled people (1:100). There is insufficient resource to address the high demand. An important outcome has been that the Kaitūhono/Connectors have been overwhelmed by the higher than anticipated number of people they now need to work with and require greater support. The long waiting list has caused frustration and stress for the workforce and the disabled people and their families and whānau who are waiting.

Learning to think and do things differently

The transformation has involved people having to learn to think differently and do things differently. Disabled people and their families and whānau are learning to think in terms of choice and control. This process will take time, and it is still very early in the implementation phase.

Leaving the old system behind and working in a new system

Mana Whaikaha is co-located with Enable New Zealand (Enable NZ). Enable NZ is a division of the MidCentral DHB that provides disability services in New Zealand. It is contracted by the Ministry of Health to provide shared functions and support for Mana Whaikaha. This co-location was troubled by factions arising from the provider organisation (Enable NZ) and the staff of Mana Whaikaha. There is a consensus that having separate accommodation would allow Mana Whaikaha to develop a new culture and identity and a more positive working environment. Having a shop front would also help with having a presence in the community and a place from which to establish networks.

Formal and informal communication

Informal communication (gossip) was the dominant form of communication between the Kaitūhono/Connectors team and the Tari/System team. Strengthening formal communication, where all teams receive the communication at the same time with the same content, is currently being implemented. The dominance of informal communication undermines teams and morale.

Lines of command and communication

Participants from Mana Whaikaha think that lines of command are a reason behind weak formal communication. There is consensus that having one line of command would be better than having two directors and two managers. The suggestion is one director and two managers. There is also a need for a communication strategy that could be applied internally and externally.

The need for information for disabled people and their families and whānau

There are information needs for disabled people and their families and whānau that have not been met consistently, and this is largely because of accessibility. This means those less able to navigate the system were confused and uncertain about what was available to them. Overall, those who were good at navigating the previous system were good at navigating the new, and those who were less able to navigate and who had weak social networks were disadvantaged. Those who navigated well had planned and were prepared to join the new system. Those who were less able to navigate did not have access to information about the new system and were not able to plan. They were subsequently not ready to join the new system on 1 October 2018 and instead joined a waiting list.

Government liaison roles enabled simplified access to services for disabled people

The government liaison roles are a success. Internally and externally, these roles are central to establishing networks and bringing about change that made the lives of disabled people and their families and whānau easier. There were a range of success stories shared by participants involving a range of government departments, including the Inland Revenue Department, Ministry of Education, Ministry of Social Development and Oranga Tamariki. These successes involved making access easier, simplifying access for disabled people and their families and whānau, joining up different services to meet the choices being made by disabled people and their families and whānau and enabling more control and dignity.

Connectors treating disabled people like persons, not numbers

Analysis of the experiences of disabled people and their families and whānau found disabled people's experience of Connectors was more positive than that of families and whānau. Generally, they spoke highly of their Connectors and the role they had played in helping them develop goals and to have a plan. Most families and whānau also spoke highly of the Connectors, describing them at times as heroes and now members of their family. Disabled people spoke of being treated like a person instead of a number and how much this meant to them. Many also spoke of having choice and of being heard for the first time. This is the transformation the prototype intended to bring about.

The new system is a better system, but there is a need to address mental health in the disabled community

Most thought the new system was better than the old system as it treated disabled people and their families and whānau with greater respect. However, many also stressed the need to support the parents and the families and whānau of disabled people, and while the new system was considered better, many felt that it needed to address mental health in the disabled community.

Greater engagement with Māori is necessary

There was a consensus that greater engagement with Māori is necessary. The experience of Māori was mixed. Some Māori had better connections than others, and this had impacted on their ability to access the system. Some had found engaging with the system as “not mana enhancing”. Some stressed the need for the new system to address their cultural world view. Most thought the new system was better than the old, and they now no longer had to “beg” for support.

FINDINGS AGAINST THE KEY EVALUATION QUESTIONS

KEQ1: Who was involved in the design process?

The evaluative judgement is that considerable effort went into the design process and the collaborative and co-design process was optimal as it ensured the prototype was an outcome of many viewpoints and was not something that was being imposed on the sector.

KEQ2: Are the core principles of the transformed disability support system being realised in practice?

There was unanimous support for the core EGL principles and a will to see them manifest in practice. The evaluative judgement is that the core principles have been put into practice, if unevenly, and have not been fully realised. It would not be reasonable to expect full realisation of this in a 12-month period.

KEQ3: What has been the experience of those implementing the prototype?

Based on the data collected from Mana Whaikaha staff and those outside of the organisation, the evaluative judgement is that the experience is mixed. The process of implementation has been challenging not least because of resource constraints and a demand to access the new system that was not anticipated.

KEQ4: What has been the experience of disabled people and their families and whānau?

The evaluative judgement is based on the qualitative data collected by SAMS and *Allen + Clarke*. The prototype has started the move towards putting disabled people at the centre of the system. This is significant progress for an implementation period of just 12 months.

KEQ5: What role have individuals played in the implementation of the prototype?

The evaluative judgement is based on the qualitative data, and the narrative around implementation. Individual behaviour shaped the implementation and the culture of the organisation. Individual behavioural change took place over the implementation period, and this was strongly shaped by the nature of the prototype and the principles underpinning it and the desire to make it work and to be a part of the new system.

KEQ6: What works best?

Based on the qualitative data and the experience of those involved in the implementation and unanticipated outcomes, the evaluative judgement is that the following issues are important for the ongoing successful implementation of Mana Whaikaha:

- Before the implementation of Mana Whaikaha, there was a readiness for change in the disabled community. This is a positive condition for the implementation of a new system.
- It is necessary to have the right people in the right roles.
- Forward planning and being prepared for anticipated change are necessary if staff are to be able to respond effectively.
- A clear and simplified line of command was important to many staff, and this was expressed in terms of the need to have one line of command.
- The need for role clarity and a well-defined scope for roles is best practice, and after some role confusion, role clarification and scope change processes are under way.
- Many staff thought having an independent building was important, although all acknowledged this would require resourcing.
- It was agreed that there is a need for strong and clear communication to assist the development of a healthy workplace culture. To this end, there has been an increased focus on communication following the evaluation period.
- There was a need to have formal communication channels in place internally and externally, and management are now working on developing these channels.
- An external communication strategy is necessary to formalise engagement between Mana Whaikaha and external stakeholders.
- Developing teams that are made up of people performing different functions from across the organisation (now established).
- Providing ongoing/further training and education and nurturing a learning culture for Mana Whaikaha staff.
- Having the right people in the government liaison roles (achieved).
- Having adequate engagement with Māori (under way).

- Acknowledging that the disabled community is made up of people with a wide range of disabilities and addressing choice and control will need to be as varied as this community.
- Providing easily accessible information and support to families and whānau.
- Raising awareness of disability.
- Focusing on those who are most likely to be overlooked.
- Addressing mental health.
- Adequate resourcing for a system transformation.

SUGGESTIONS

Suggestion 1

The Ministry of Health and Mana Whaikaha continue to promote the core EGL principles within their organisations and raise awareness of these principles for those in the community generally.

Suggestion 2

Those who are not able to access or navigate the system need to be targeted and provided with greater assistance.

Suggestion 3

The Ministry of Health and Mana Whaikaha provide further education on the Treaty of Waitangi and ensure that staff are aware and sensitive to Māori needs and cultural perspectives.

Suggestion 4

Ensure resourcing meets the demands being placed on the prototype and is adequate so the core principles are not undermined.

Suggestion 5

The Ministry of Health needs to address resource issues – in particular, the ratio between Connectors and disabled people.

Suggestion 6

Mana Whaikaha needs to be housed in a separate building and have its own shop front so it is a visible separate entity.

Suggestion 7

There needs to be greater social media coverage of the prototype and a social awareness campaign so that the wider community is aware of the issues and the need for a system of this type for disabled people and their families and whānau.

Suggestion 8

Information needs to be made available for disabled people and their families and whānau in an easily accessible way, and there needs to be transparency over what is possible and what is not.

Suggestion 9

Greater engagement with disabled Pasifika people is necessary so their needs can be understood and addressed.

Suggestion 10

Mana Whaikaha staff, particularly Connectors, need to be trained to engage appropriately with Māori.

Suggestion 11

Ongoing adequate resourcing is necessary to allow the prototype to embed successfully.

Suggestion 12

Stronger engagement between Mana Whaikaha staff and providers.

1. INTRODUCTION

1.1. Background

At various times over the last 30 years, concerns have been expressed about the disability support system not working well for disabled people. More recently, new approaches to disability support have been developed, both locally and internationally, with the aim of empowering disabled people to have greater choice and control over their lives and the support they receive.

In March 2017, Associate Minister for Health and Disability Issues Hon Nicky Wagner announced a three-month co-design process with the disability sector to begin a nationwide transformation of the disability support system. Central to this transformation was recognition that disabled people and their families should have greater control over their lives as well as the support they receive from government. The Ministry of Health with the Ministry of Social Development led the work to establish a change leadership team. This team's role was to implement the co-design process and establish a co-design group that included disabled people, Māori and Pasifika (disabled and family members), family representatives and providers.

The high-level co-design group met on 11 April 2017, and a series of nine meetings were held between then and June 2017. Following the high-level co-design process, there were detailed design working groups. The transformation was to focus on those receiving Ministry of Health-funded Disability Support Services in the MidCentral DHB region for two years. The design was based on the Enabling Good Lives (EGL) vision and principles, and at this time, it was envisaged that the new system would include:

- access to independent facilitation to assist people to be aspirational and feel connected to their community
- a strengths-based assessment process
- a personal budget for disability support with funding from multiple government agencies
- flexibility and choice about how to use the personal budget and a range of options to assist its management
- capacity building opportunities for disabled people and their families, as well as the sector and providers
- referrals to other agencies for additional services including learning and income support, with the new system streamlining the process for disabled people.

The high-level co-design group and the detailed design working groups were aware that they would have to work through many issues to enable system transformation.

1.2. Mana Whaikaha – vision and implementation

On 4 April 2018, Cabinet agreed to implement a prototype of the transformed disability support system – Mana Whaikaha – in the MidCentral DHB region on 1 October 2018. The agreed approach to implementation was a Try, Learn and Adjust approach, which would allow iterative adaptation of the prototype as required.

Mana Whaikaha is designed to support disabled people and their families and whānau to have the best possible lives.

The vision is that, in the future, disabled people and their families and whānau will have greater choice and control over their lives and supports and will make more use of natural and universally available supports. The implementation of this vision would enable:

- generation of opportunities for disabled people and their families and whānau to envisage a personally meaningful future
- promotion of individual choice for people to lead lives that are both purposeful and aspirational
- empowering people with choice, opportunity and the confidence to create and realise their aspirations
- supporting the development of competencies that will in turn enable disabled people to acquire valued roles in the community
- supporting communities to more confidently include disabled people in all aspects of community life.

Mana Whaikaha is a responsive person-centred approach that involves engagement that enables self-determination and self-management of supports and services, allowing people to maximise their potential.

1.2.1. The role of Mana Whaikaha

The role of Mana Whaikaha involves walking alongside disabled people and their families and whānau and supporting them to hold a vision of what is possible in their lives and to connect them to the people, resources and opportunities that will best enable them to develop the skills necessary to pursue their life potential and aspirations.³

Mana Whaikaha comprises two teams: the Kaitūhono/Connectors team who are employed directly by the Ministry of Health and the Tari/System team who are employed by Enable New Zealand, which holds a contract with the Ministry of Health.

Kaitūhono/Connectors team – function and roles

The team comprises a director, a manager, Kaitūhono/Connectors and a Network Builder/Community Development team. The director leads the Kaitūhono/Connectors team and ensures that Connectors are of service to disabled people and their families and whānau. The director provides strategic leadership and works closely with the director of the Tari/System team and the MidCentral Governance Group to deliver the transformed disability support system. Both directors lead the culture change of moving power and control from the system to disabled people and their families and whānau. They also oversee its financial management.

The manager of the Kaitūhono/Connector team supports the director. The manager also plays a key role in providing support for the Kaitūhono/Connectors so they can be of service to disabled people and their families and whānau. The key role of the Kaitūhono/Connectors is to establish and maintain trusting relationships with disabled people and their families and whānau. The Network Builder/Community Development team within the Kaitūhono/Connectors team works with disabled people and their families and whānau to develop their networks.

³ Mana Whaikaha Enabling Good Lives service transformation practice model.

Tari/System team – functions and roles

The team comprises a director, a manager, a Disability Information team, administrators, funding specialists, government liaison roles and a business insights specialist. The Tari/System team director works in partnership with the Kaitūhono/Connectors team. The manager supports the director to ensure disabled people and their families and whānau can access all features of Mana Whaikaha. Information specialists in the Disability Information team may be the first point of contact in Mana Whaikaha for disabled people and their families and whānau – face-to-face at the hubs, on the phone, via online chat or in response to emails. Administrators in this team provide administrative support for the functioning of both the Kaitūhono/Connectors and Tari/System teams.⁴

Funding specialists make decisions and provide advice about the funding proposals from disabled people and their families and whānau. They allocate funding and ensure it is transparent, equitable and responsive to the needs of disabled people and their families and whānau. The government liaison roles within the Tari/System team support Kaitūhono/Connectors to assist disabled people and their families and whānau to access other government services. The business insights specialist is responsible for analysis and reporting on the prototype and, in conjunction with the directors, provides information and insights to the MidCentral Governance Group and to support the Try, Learn and Adjust approach.

Funding philosophy and the Tari/System team

The approach to funding undertaken by the Tari/System team considers:

- mainstream first
- what is fair and equitable
- investment in starting early
- investing in ordinary life outcomes.

The Kaitūhono/Connectors team works with people to define supports and to respond to available resources and budget, including paid and unpaid supports.

1.2.2. The core principles underlying Mana Whaikaha

1. Self-determination

Disabled people are in control of their lives and of the services and supports designed to support their life aspirations and opportunities.

2. 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.

3. Person-centred

Disabled people have supports that are tailored to their individual needs, goals and life aspirations and that take a whole-of-life approach.

⁴ Documentation provided by the Ministry of Health.

4. 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.

5. Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

6. Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected.

7. Easy to use

Disabled people have supports that are simple to use and flexible.

8. Relationship building

Supports, builds and strengthens relationships between disabled people and their families and whānau and community, reducing dependency on paid supports in their lives.

1.2.3. Service and support goals

What is required for best possible outcomes to be achieved (see Figure 1):

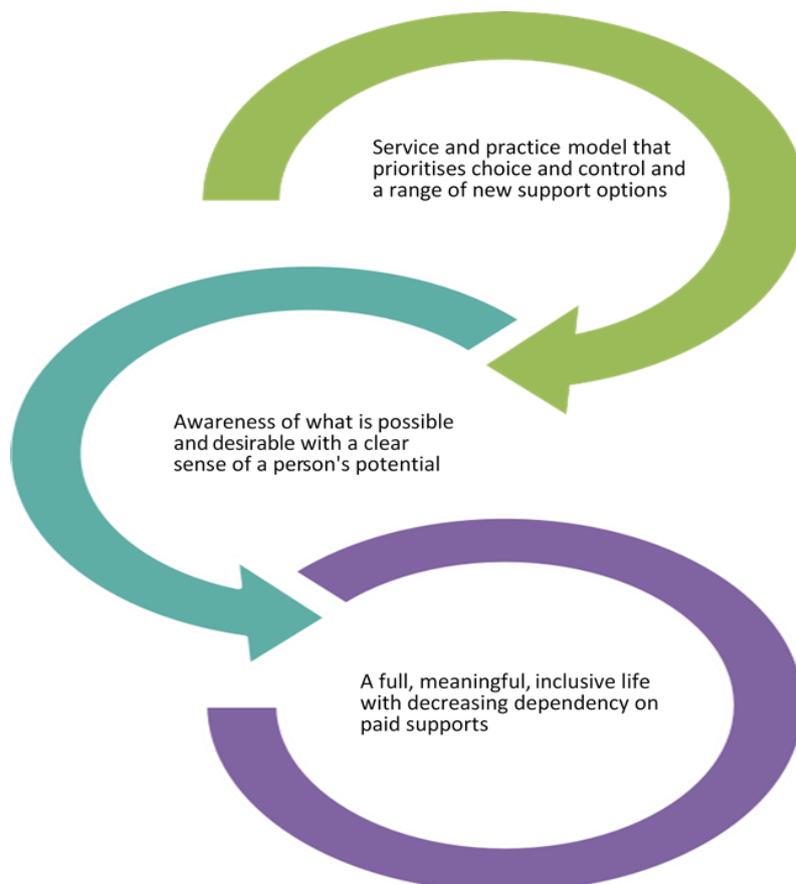


Figure 1: Service and support (Source: Ministry of Health)

- People need to be aware of and understand what options are available and how they can be accessed, developed and delivered.
- Clarity around what is possible and desirable in disabled peoples' lives.
- The establishment of a clear sense of a person's potential to work and engage in the community.
- Working with each person to develop a full, meaningful and inclusive life with decreased dependency on paid supports.⁵

The prototype rests on these core principles. The implementation of the prototype draws on these core principles, and action is directed by these principles. These principles, if acted on, would be empowering for disabled people. The following sections provide the findings of the evaluation while bearing in mind these core principles, the target population and the service and support goals.

Figure 2 depicts the structure of the prototype at the organisational level as at 1 October 2018. However, the core principle of mainstream first and accessing existing services means that the organisation has links with a range of government entities and community services – there are arms of connectedness that span out from the organisation.

1.3. Governance

The MidCentral Governance Group provides advice and support and strategic oversight of the Mana Whaikaha prototype and makes recommendations to the Ministers on what improvements could be made. The directors of the Kaitūhono/Connectors and Tari/System teams report to the MidCentral Governance Group, which also make decisions around capacity funding. The MidCentral Leadership Group is made up of elected representatives from disabled people, families and whānau and provider core groups.

The Try, Learn and Adjust working group was established to:

- identify the options and rationale of the focus for each Try, Learn and Adjust cycle – except for the first cycle
- engage in workshops, led by the evaluators, to make sense of what the data, information and insights are suggesting about what is working and what could be improved in Mana Whaikaha
- develop evidence-based advice for the MidCentral Governance Group about what improvements could be made to Mana Whaikaha.

The Try, Learn and Adjust working group has representatives from the MidCentral Governance Group and MidCentral Leadership Group to ensure their contributions to the sense-making workshops reflect the diversity of MidCentral's disability community, which they represent.

⁵ Mana Whaikaha Enabling Good Lives service transformation practice model.

1.4. Evaluation purpose

The Ministry of Health contracted *Allen + Clarke* to undertake an evaluation of the implementation phase of Mana Whaikaha. The purpose of this evaluation is to understand:

- what has been implemented
- to what extent Mana Whaikaha has been implemented as intended
- what is working well and what is working less well (from different perspectives)
- where improvements are needed.

The evaluation supports the Try, Learn and Adjust approach being adopted for Mana Whaikaha and the intention of ongoing development.

This implementation evaluation involved engagement with the Try, Learn and Adjust working group, the MidCentral Governance Group and the core groups and extensive data collection involving disabled people and their families and whānau, the Kaitūhono/Connectors and Tari/System teams, government liaison and various Ministries.

Allen + Clarke's role included:

- planning and implementing data collection (interviews, focus groups, small group interviews)
- working with Standards and Monitoring Services (SAMS)⁶ on data collection tools and analysing the results
- collating and analysing data from multiple sources
- preparing insights and inputs for sense-making sessions with the Try, Learn and Adjust working group
- working with the Try, Learn and Adjust working group to develop advice for the MidCentral Governance Group on recommendations for change
- producing an interim Cycle 1 evaluation report.

The data collection for this evaluation took place between August 2019 and November 2019, and the evaluation focuses on the implementation of Mana Whaikaha from 1 October 2018 to November 2019. The evaluator was involved in meetings following the data collection period and updates on changes since the data collection point in time have been included in this report

⁶ SAMS works in partnership with disabled people and their families and whānau to improve community services.

2. EVALUATION METHODOLOGY

This section covers the key evaluation questions (KEQs),⁷ the evaluation methodology and data sources. The evaluation used an interpretive methodology, interviewing a wide range of stakeholders with the aim of understanding their perceptions and experiences of the implementation of Mana Whaikaha.

Table 1: Key evaluation questions (KEQs)

Evaluation focus areas	Evaluation questions and sub-questions
Design (intervention source)	<p>Who was involved in the design of the prototype?</p> <p>What were the perceptions of prototype design?</p>
Implementation (system-level change)	<p>Are the core principles for the transformed disability support system being realised in practice?</p> <ul style="list-style-type: none"> • What are the enablers? • What are the barriers?
Mana Whaikaha	<p>What has been the experience of those implementing the prototype?</p> <ul style="list-style-type: none"> • What has worked well? • What has worked less well? • What factors have contributed to success or otherwise?
Disabled people and family and whānau experience	<p>What has been the experience of disabled people and their families and whānau?</p> <ul style="list-style-type: none"> • What has worked well? • What has worked less well? • What have the challenges been? • Has the implementation been experienced consistently for all disabled people?
The role of individuals	<p>What role have individuals played in the implementation of the prototype?</p> <ul style="list-style-type: none"> • What has been the interplay between individuals and the organisation within which they work? • Has individual behaviour change occurred because of the prototype?
What works best?	<p>Under what conditions could the prototype work best?</p> <ul style="list-style-type: none"> • What structures, approaches and programme components can provide the greatest benefit?

⁷ The evaluation framework, the Consolidated Framework for Implementation Research (CFIR), is expanded on in Appendix 1.

	<ul style="list-style-type: none"> • What components should be sustained, scaled up, adopted and adapted to areas outside of MidCentral? • How could the prototype be improved from a disabled person’s perspective? For families and whānau? For Mana Whaikaha staff? For providers? For existing service providers?
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2.1. Methods and data sources and methodology

Qualitative methods of data collection were employed for this implementation evaluation.

2.1.1. Contextual review

The Ministry of Health provided the evaluation team with a range of 20 documents for contextual review. The review provided the context behind the development of the prototype and the broader social, economic and political environment within which reform of the disability system was first advocated and then manifest in the directive to design a transformative prototype named Mana Whaikaha. The Ministry also facilitated access to the Kaitūhono/Connectors team, the Tari/System team, the Try, Learn and Adjust working group, the MidCentral Governance Group and members of core groups who had been involved in the design phase and working groups.

2.1.2. Face-to-face semi-structured interviews with individuals, small groups and focus groups

Ethics approval was sought from the Health and Disability Ethics Committee, and no approval was considered necessary. Participation in the evaluation was voluntary and all participants provided their informed consent.

The evaluation included in-depth individual face-to-face semi-structured interviews, focus groups and small group interviews involving a total of 123 participants.⁸ The breakdown of interview type is as follows:

- Face-to-face in-depth interviews with 14 people, including mana whenua, members of the prototype design team, management of the Kaitūhono/Connectors and Tari/System teams, members of the MidCentral Governance Group, the Ministry of Education and the Ministry of Social Development. Most of these interviews were conducted at the Enable NZ premises in Palmerston North. The Ministry of Education interviews were conducted in its Palmerston North offices and in Wellington, and one interview was conducted by telephone.
- Face-to-face interviews with 10 disabled people and 10 members of a disabled person’s family and whānau. These interviews were conducted by SAMS and analysed by *Allen + Clarke*.
- Disabled persons focus group (15 attendees) and families and whānau focus group (9 attendees). These focus groups were conducted by SAMS and analysed by *Allen + Clarke*.

⁸ Methodological rigour in qualitative research (evaluation) is measured by the concept of saturation. Saturation is reached when interviews are no longer revealing anything new. The large number of participants for this evaluation is an outcome of inclusion rather than seeking saturation. Saturation was reached at 24 interviews.

- Focus groups with the Ministry of Health Systems Transformation team, the MidCentral Governance Group, Kaitūhono/Connectors and the core provider group.
- Small-group interviews with funding specialists and government liaison personnel and administrative personnel in the Tari/System team.
- Three surveys, comprising open-ended questions with comment boxes provided, allowed participants an additional opportunity to provide feedback on experiences. Responses were received from support workers and providers, and the data was thematically analysed. There was no response to the Kaitūhono/Connectors survey.

The interviews were audio recorded, with one interviewer and one note taker present for all. Themes were identified across the qualitative dataset, and these were then analysed using the Consolidated Framework for Implementation Research (CFIR) as the evaluative framework.⁹

The evaluators undertook not to reveal the identity of disabled people and their families and whānau. Participants from Mana Whaikaha have not been named in this report. However, they are identifiable through their role.

Participants in this evaluation also had different levels of knowledge and understanding and were more or less able to articulate their views and experiences.

A limitation of this evaluation is that the qualitative data collection using focus groups, small group interviews and interviews (all carried out face to face) allows an understanding of the process of implementation, however, there was no baseline data collection prior to the implementation of the prototype, and it was therefore not possible to measure change against a baseline.

⁹ The CFIR framework and concepts are outlined in Appendix 1.

3. CONTEXT

3.1. Design of the prototype, engagement and input

KEQ1:

Design (intervention source)	Who was involved in the design of the prototype? What were the perceptions of prototype design?
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3.1.1. High-level design

The development of the prototype involved a high-level co-design group, comprising members of the disability sector, public servants and disabled people, who were responsible for developing the high-level design for Cabinet.

3.1.2. Co-design and working groups

The high-level co-design group work for the prototype was followed by a detailed design process initially involving 21 working groups where a third of each group comprised disabled people. The high-level co-design working group composition was informed by the vision guiding Mana Whaikaha – that the new disability system would be responsive and person-centred, involve engagement that enabled self-determination and self-management of supports and services and allow disabled people to maximise their potential. There was an awareness amongst Ministry of Health staff that concerted engagement was necessary, that it be genuine and not tokenistic, that the design process must involve disabled people and that the prototype had to be disabled person centric. Members of the working groups were remunerated for their participation and in recognition of their expertise.

The working groups and meetings associated with these groupings were shaped and driven by a values-based approach that was informed by the core principles underpinning Mana Whaikaha. The main objective is that disabled people and their families and whānau will have greater choice and control over their lives and supports and will make more use of natural and universally available supports. This was an intensive and lengthy engagement process that required considerable commitment from Ministry of Health staff. As well as contributing to the design process, the workshops provided a forum for disabled contributors to voice their dissatisfaction with the previous system and the frustration, negative experiences and traumatic events in their lives as disabled people. This engagement was genuine, and the involvement of such a wide range of stakeholders in the detailed design process added to the legitimacy of the source of the prototype, which is central to buy-in and successful implementation of an intervention.

On reflection, it was noted that engagement with Māori could have been stronger. Early in the co-design stage, a company was contracted to manage the design process. However, the engagement with Māori was seen to be not enhancing the mana of the co-design partnership because:

- the company representatives were unknown to participants
- their approach was to “take or get something from you”.

There were also issues around the mana of the mana whenua sub-leadership group and disquiet from mana whenua about who had been selected. Some did not accept they had adequate mana

or could speak for Māori. This is about challenging the idea that one representative can speak for all Māori. The workshops more generally had their own internal politics.¹⁰

One of the key challenges to designing this prototype for transformative system change is that the disabled community is not homogeneous. There are a wide range of disabilities and associated abilities.

The disabled community also includes a range of ethnicities and a range of living circumstances and socio-economic characteristics.

The legitimacy of the prototype was questioned by Treaty partners Māori as engagement had not been as successful with some Māori, and some Māori thought they had not been represented by those involved in the co-design.

The sector is diverse in terms of perceptions and experience, and the politics during the co-design phase is not remarkable given this diversity.

It should be noted that this evaluation did not address the co-design process. This has been included as context rather than a finding of the evaluation. It is therefore not possible to comment on whether the prototype implemented the key content coming out of the co-design process.

3.1.3 The intervention¹¹

From the high-level co-design phase to the detailed design working groups, the intention was to be collaborative and inclusive and to maintain the value of having disabled people at the centre of the system transformation. The engagement process for the detailed design phase was intensive in terms of focus and extensive in terms of coverage, and while there were differences in opinion, disappointments and unanticipated interactions that were emotional and at times heated, this can be anticipated with co-design processes that are attempting to transform a system.

Mana Whaikaha is a complex system-level intervention. It is multi-faceted and has adaptable elements, which allows for structures and systems within the system to be adapted (through Try, Learn and Adjust). Modification of this intervention need not alter the integrity of the intervention and the values and principles that underpin it. The perception of a range of stakeholders was that the prototype had been developed collaboratively, it had legitimacy and that this system-level transformation was long overdue and welcome.

The values and objectives underlying this prototype have also been applied elsewhere, for example, the three-year National Disability Insurance Scheme trial in Australia provides evidence through an evaluation of a very similar system transformation prototype. Some successes and challenges could be anticipated for the Mana Whaikaha prototype. Mana Whaikaha has the advantage of being a prototype tested in a contained area – the MidCentral DHB region – and is therefore more easily adaptable. The Try, Learn and Adjust approach is built into the prototype and allows ongoing adaptation as required.

¹⁰ The politics of representation are an issue for Māori, just as it is for all social groups. The workshops more generally also had their own internal politics, where people had different agendas and, at times, conflicts of interest.

¹¹ This section refers to the intervention source issues outlined in the CFIR model and draws on the evidence that underpins this.

KEY FINDINGS

4. MANA WHAIKAHA – DISABILITY SUPPORT SYSTEM TRANSFORMATION

4.1. Implementation of the prototype

KEQ2:

Implementation (system-level change)	<p>Are the core principles for the transformed disability support system being realised in practice?</p> <ul style="list-style-type: none"> • What are the enablers? • What are the barriers?
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This section provides the evaluation findings relating to the implementation of the prototype. The findings are structured by KEQ and summarised by the key themes. Each thematic area is then analysed using the CFIR framework (see Appendix 1).

4.1.1. Getting ready for the launch

In the months prior to the implementation, a large recruitment drive took place to appoint the Mana Whaikaha staff. MidCentral was chosen as the area for implementation. The MidCentral DHB region includes the following districts: Horowhenua, Manawatu, Palmerston North City, Tararua and the Ōtaki ward of the Kapiti Coast. The region is predominantly rural, and workers in skilled service roles make up a very small proportion of the labour pool. Recruitment was challenging because of the small pool of labour with these skill sets. With respect to the Kaitūhono/Connector roles and in keeping with the core principles, wherever possible, these were to be filled by people with lived experience of disability. Those responsible for recruitment agreed that it was challenging given the labour market constraints and the skill sets required, particularly for the Kaitūhono/Connector roles. Some of the roles were filled by Enable NZ staff/employees, whose contracts allowed deployment when the NASC system gave way to Mana Whaikaha.

The prototype was launched on 1 October 2018.

4.1.2. Connections, networks and Connectors

Disabled person representation was sought and achieved for key roles in the organisation, the core groups and the governance bodies. These representatives brought with them a range of networks, most of which were connections to other disabled people in the community. These were personal networks relying on personal cultural capital rather than organisational networks where there were direct formal links to other organisations and other systems.

Interview participants raised several issues. Not having a shop front and stand-alone premises compromised the connection to the community. With no shop front, Mana Whaikaha lacked visibility and credibility as a new and separate system. Sharing a building with Enable NZ linked them to the old system as Enable NZ was the NASC provider for MidCentral. Most also stressed that the decision not to have premises and a shop front was a decision driven by resource constraints.

There was a consensus that networking across such a wide range of potential services in the area was and would be a challenge for the Connectors. While specific government liaison roles had been formed to address the need to network and align government services, the community

connections were by and large expected to be made by the Connectors. As discussed in the next section, this presented challenges. Developing and sustaining strong community networks requires a skill set that typically falls to people with a community development background. The Connectors, in the main, did not have this skill set, and this is largely because the local labour market was constrained with respect to this kind of employment skill and availability. Nonetheless, it was clear that all appreciated that people were doing their best to link into existing services, were wholly committed to the core principles and, over the first year, that Connectors had started to build networks outside of their own personal networks.

There are success stories where Connectors have linked into existing services (clubs and associations), with Ministry of Social Development and the Ministry of Education being the two most commonly mentioned government agencies, and have established links to enable the realisation of disabled people's plans (and goals). As one participant noted:

"There is still a lot to do, and to be honest we are not there. We do tend to focus on what is not working well, and don't celebrate successes enough." (Mana Whaikaha)

4.1.3. Networking across systems

Without formalised networks established and a services-mapping exercise, networking within and across systems was initially limited to the social networks of Connectors. Some Connectors had stronger networks than others, and there was variance in cultural capital, where those with mana and high capital were more easily able to navigate within and across systems. The success stories – where the disabled person has remained centre and mainstream services have been wrapped around them so they can realise their plans and life goals – demonstrate the importance of knowing and being able to easily access networks within and between systems. It is also central to realising the principles of mainstream first and achieving ordinary life outcomes.

A reliance on Connectors' social networks highlights a potential limitation. However, it is important to note that the prototype has only been operating for a year, and it would be surprising for a new system to immediately have strong external-facing networks and for a new organisation to have the cultural capital to attract others to network with them. Over time, however, adopting a formalised strategy for networks and inter and intra-system engagement will mean that the core principles could be realised more quickly for disabled people.

4.1.4. Launching Mana Whaikaha

The launch on 1 October 2018 and the interest in Mana Whaikaha demonstrates that there was readiness for change amongst disabled people and their families and whānau. By the end of the first day of implementation, there was a 400-person waiting list – an unanticipated response that had implications for the workforce and disabled people. The workforce was overwhelmed, some disabled people and their families and whānau achieved access to the new system and some had to be put on the waiting list. This means that, from the first day, there were inequities over accessing the new system. Those who were in early knew about the new system, and those who were not aware initially were slower to respond and were placed on the waiting list.

4.1.5. Transformation and maintaining system connections: the health system and lived experience

Some attitudes and behaviours damaged system relationships. Specifically, the move away from the dominance of biomedical definitions of disability towards a focus on the lived experience of

disability represents a shift from biomedical knowledge to subjective knowledge. This shift is a fundamental challenge to historical power dynamics, where biomedicine has held considerable power and the subjective experiences of disabled people less power. The shift has damaged relationships between Mana Whaikaha and people in the medical system. The shift has concerned clinicians and other health professionals that there was a risk to disabled people if those making decisions failed to understand that medical intervention was necessary.

Placing lived experience at the heart of the organisational culture has meant that, in some instances, there has been a perception of disrespect towards other knowledge systems, both in terms of biomedical knowledge and culturally defined knowledge systems. This perceived disrespect has damaged relationships.

It was noted by several allied health professionals at the DHB, who operate within a funding system that has explicit and publicly available criteria, that, while the rules may not be fair, the criteria are applied fairly. There was concern that a lack of transparency about the criteria for funding (for both services and equipment) meant that funding may be given in a less than systematic way and that there would be inequity as a result.

Some DHB staff were concerned that people were requesting services they wanted (rather than needed), and if the DHB could not deliver, they went to Mana Whaikaha to access funding.

There was a consensus from most participants that the Connectors should be separated from the funding stream. The connection to funding had raised concerns about the absence of formal accountability and that this could put the disabled person, their family and whānau and the Connector at risk.

There was complete support for the shift in philosophy from those at the DHB, who are familiar with a version of being person-centric with patient-centric services, with a focus being on those they serve. They were unanimous that change had to take place, but they were increasingly concerned about the disrespect some Connectors showed towards health professionals. In these instances, the lived experience was being applied to guide disabled people towards a plan, and if the Connector had had a bad experience with the health system, they were steering disabled people away from this in the plan. The concern was that what might be wanted or nice for a person in terms of choices might not always be safe. Value was seen in lived experience potentially contributing to greater empathy with disabled people, but when it became the driver for choices, these choices were potentially constrained by the Connector's lived experience, which may be narrow or inappropriate. Participants from the DHB, the public sector and Mana Whaikaha expressed these views.

In addition, other parts of the system started to experience increasing demand (for example housing) when there were almost one-third more referrals than expected. The increase was in part because people moved to the region to access the prototype, and those who previously could not access help increasingly sought help from the prototype. Delays with connecting with Connectors had led to longer hospital stays. It was acknowledged that some of the Connectors were doing a very good job, and the view was that this was because they had a professional background in a health or allied health role.

Communication between the DHB and Mana Whaikaha was described as weak. DHB participants contended that there would be better outcomes with greater collaboration.

“Having support from us [health professionals] would make their lives easier. Also, their “lived experience” – there is an anti-professional swing – where we aren’t regarded as key stakeholders. Our experience has been devalued in an ideological clean sweep.”

“They are working around us, in isolation.”

“We thought there would be more liaising, that we would work with them actively – but there is no collaboration, they are so busy with aspirational goals ... no one ever mentions budgets. I sat on a Core Group and said: “Who will pay for this?”

Collaboration between the DHB through the government liaison roles was considered effective. Overall, however, they wanted greater communication and collaboration between the DHB and Mana Whaikaha to realise system change. Without collaboration, it was observed that the disabled person was in the middle, and the situation was divisive.

5. THE IMPLEMENTATION WORKFORCE – KAITŪHONO/CONNECTORS AND TARI/SYSTEM TEAMS

KEQ3:

Workforce	<p>What has been the experience of those implementing the prototype?</p> <ul style="list-style-type: none"> • What has worked well? • What has worked less well? • What factors have contributed to success or otherwise?
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5.1.1. Mana Whaikaha was often described by the metaphor “flying while still building the plane”

The implementation experience common to the Mana Whaikaha workforce was expressed metaphorically in a number of ways, most commonly using “flight” as the key metaphor and usually invoking both the thrill and the fear of either an absence of landing gear or inhabiting a craft that was still under construction while in mid-air. This conveys aptly how many felt: rushed, excited and apprehensive as they embarked on the implementation of the prototype. There were several specific issues that participants raised that contributed to this.

The newly formed teams responsible for the implementation of the prototype all looked forward to their new roles and the launch on 1 October 2018. The participants spoke of being excited about the change and about having a role in this change. All participants were committed to the vision and the core principles of the prototype.

While many things had been prepared, some processes and functions were still under development. There had been a miscalculation about the number of people who would access Mana Whaikaha on 1 October 2018 and the days following. From day one, Mana Whaikaha started with a 400-person waiting list. This had an impact on the Connectors as there was no time for management to work with the Connectors to build capability. Not surprisingly, the Connectors’ role changed over the first few months, and it was not what they had envisaged. They struggled with funding and administrative processes that were still being developed, and they went from the planned working ratio of approximately one Connector to 45 disabled people (1:45) to a ratio more like one Connector to 100 disabled people (1:100) with no increase in resourcing.

With the number of people wanting to access Mana Whaikaha exceeding expectations, Mana Whaikaha staff were inundated with work, with little time to address processes and practical aspects while simultaneously dealing with the demand.

Mana Whaikaha staff said they had “tried, learned and adjusted” frequently over this time period, with many also thinking that some things should have been ready before the launch, such as templates that could have been developed in the planning stage and prior to implementation. For some of the workforce, the perpetual change was very stressful, and others experienced role confusion, which was also stressful. Given the scale of the change, these obstacles and experiences should probably not be unexpected. The interesting thing is that all these participants still agreed change had to happen, and they continued to embrace the core principles and underlying philosophy driving this change. There was demonstrated readiness for change amongst these participants.

5.1.2. Moving from the old system to the new

The transformative nature of the change and breaking with the past was embraced by most, but there was an interesting meaning attributed to this. Many interpreted breaking away from the past to mean that, for the system to be transformed, the past would have to be left behind and everything needed to start afresh.

For some, this meant that only then would new and positive experiences for disabled people be possible. For others, this meant that nothing from the old system (NASC) could be employed or used in a practical way within Mana Whaikaha. Some participants felt that former NASC employees were treated badly because of this interpretation and “shamed” for being an active part of the former system. Others noted that it had recently been acknowledged that some of the past processes and practical aspects could have been transferred and rebranded and would have made the first few months of responding to great demand a lot easier and more efficient.

“In a sense we threw the baby out with the bath water with the old NASC, but some of it still could be used, even if the old system was done away with.”

While the prototype included personal budgets as a central component and while some had chosen to have personal budgets, they were not a central focus in most interviews.

5.1.3. Learning to think differently and learning to do things differently

Many observed that transforming a system is really a 10-year process.

“It is really just a big thing to undertake. It is really 10 to 15 years like our children now won’t think of residential care ... they will try to connect in with the existing community support services e.g. community law, budget service, citizens advice, IRD small business advisors etc. There are so many resources out there.”

The length of time involved in developing a plan for the disabled person is in part connected to both the disabled person and their family and whānau having to learn to think differently. They had to unlearn fearing the system and learn to believe that they can have goals for themselves and their parents could support their children to have goals. Developing trust was critical. Time was also needed to build a relationship with the Connector.

“[Disabled people] have been socialised to be defined in terms of what they are not.”

“There was this big thing, what is a good life, for you? But many had not been asked that before, never had the opportunity to think about what a good life would be for them.”

There has been a lot of work happening at the community level addressing parent capability and providing workshops on how to create family goals and learning about what goals look like, for example, through the workshops provided by capability funding and called “Now or Never”. There are multiple levels of change required, and there is clear evidence that there are several sectors and many people involved in helping disabled people and their families and whānau to learn to think and do differently.

5.1.4. The inner dynamics of the Mana Whaikaha workforce

The structural characteristics of Mana Whaikaha are depicted in Figure 2 above. The nature of the social architecture is also important. The Ministry of Health employs the Kaitūhono/Connectors team and has a contract with Enable NZ to provide the Tari/System team and shared services. As

a new configuration, it is immature, and as might be expected, there have been issues with the division of labour internally, largely because they were overwhelmed by the number of people wanting to access the prototype. Processes were not established, and it took time to develop and embed processes and practical administrative responses.

Issues around role confusion and scope creep have more recently been addressed by reconfiguring the teams so that they focus on specific age groups and comprise members from Kaitūhono/Connectors and the Tari/System teams. This new configuration has also been promoted as having teams that are self-managing. This change is still in its early stages, but it has democratised the division of labour and evidence suggests that this is an effective model for strengthening workplace relations and supportive innovative interventions.

There is also widespread agreement that the physical architecture has not been conducive to an effective or happy working environment. Initially, there was an exclusionary politic between those linked to the old system (NASC) and the arrival of the Connectors. Hot desking had not been successful and, for most Connectors, led to “not desking” in the open-plan space. The more stable a team is and the more they feel at home in their environment, the more likely it is that successful implementation will occur.¹² Some Connectors no longer go to this space, and they operate from out of their cars. This also means that they operate in isolation. These structural aspects have led to a myriad of interactions between personnel, some of which have been positive and some less so. Participants spoke of a “toxic culture”. The inner dynamics shaped by the physical architecture and informed by “new arrivals” and “established incumbents” have had the potential to undermine the implementation of the prototype.

Communication was a significant issue for those working for the organisation. In the absence of regular formal and integrated communication, informal communication had flourished, with “the grapevine” and gossip being the main vehicle to finding out what was happening. There was a sense that things were pulling in opposite directions. Since the data collection, there have been efforts to provide clearer and more formal communication across the organisation so that this becomes the main vehicle rather than informal communication “making up” the gaps. Clear and frequent communication is central to good implementation, and the informal communication had contributed to factions between teams.

There was a consensus among all participants that they should be working as one team, where the Kaitūhono/Connectors team is joined with the Tari/System team with a single line of reporting. This was a means of reconnecting the Connectors. All of the participants from the Mana Whaikaha workforce were wholly supportive of the core principles, but the establishment of “this is how we do things around here” had been slow and the ‘forget the past’ norm had also undermined the ability to do practical things when under pressure.

Despite a clear willingness to change, there were a number of issues that emerged. Evidence suggests that there are six constructs that contribute to a positive implementation culture: willingness to change, compatibility, relative priority, organisational incentives and rewards, goals and feedback and learning climate.

The data suggests participants were ready for change. Issues were around compatibility for change, such as organisational culture, process issues and implementation issues. There was

¹² From the evidence that informed the development of the CFIR framework.

consensus that it was a priority, but in some instances, contradictory communication around goals and informal communication led to a lack of professionalism.

There was an uneven learning environment and diverse and large discrepancies in skill sets across the organisation. Since this data collection, efforts have been made to improve the learning culture to acknowledge fallibility and the need to learn from this and to ensure that it is safe to share failure.

The data also demonstrates that, for much of the last year, things have been done at speed because of the large numbers of disabled people wanting to access the prototype and resourcing constraints. People felt under pressure to deliver quickly. The key issue here for implementation is the need for managerial patience and taking the long view. This seems counter intuitive, but evidence from implementation science suggests that if the “service” is slowed, the intervention will take hold and embed more effectively.

There was a consensus that the directors and the managers cared about and were committed to the prototype and that they worked hard in trying circumstances. There was consensus that “taking off while the plane was being built” was stressful. This is a major transformation, and learning on the go is acknowledged as being a cost-effective and time-efficient form of practice. However, maintaining a long-term view and slowing at times is beneficial for embedded implementation and the wellbeing of a workforce. There was also consensus that the Connectors were under considerable pressure and strain and required greater support as they were constantly playing catch-up. The Connectors, however, demonstrated considerable support for each other in their focus group session. Given how stressed some of them were, they appeared to be a strong team and were there for each other. There were also concerns that the prototype lacked cultural sensitivity and that there had been no inclusion of observing tikanga for Māori.

5.1.5. Government liaison – linking systems within systems

The government liaison positions were considered a success, both within and outside the organisation. They were playing a key role in linking the organisation to government systems and supporting Connectors to have the right connections within the government sector. Those in these roles had a good understanding of system change and understood that they were one system operating in relation to many. Having a role both within the organisation and outside and developing relationships between both has been a very successful role and function within the Tari/System team. Examples of how changes had been made so that the new system was easy to use for disabled people and their families and whānau include success with Work and Income in streamlining processes and removing the necessity to go into the Work and Income office, which many disabled people found intimidating, the new Ministry of Education programme for children, which is being developed through a collective impact process and with which Oranga Tamariki is also involved, liaison with the MidCentral DHB and the Ministry of Social Development making the pathway smoother. While not uniform, it was evidently working well, and there was increasing cross-agency collaboration for improving services for families with children with disabilities (aged 0–8 years).

5.1.6. Access to information and knowledge

Access to information and knowledge was a barrier for disabled people and their families and whānau. It was also a barrier for those within the organisation. It was not easy to access information and knowledge, and at times, people were unsure how to translate this into work

tasks. Ongoing training was constrained because of work intensification and demand, and there were challenges with computerised information systems. Many spoke of a persuasive culture of resisting expert knowledge and challenging expertise externally. For many, lived experience was considered a higher form of knowledge. Concern was expressed by some participants that this was a naïve take on the world, and it could put people at risk. The clear theme was the tension between valuing lived experience over clinical expertise. This tension undermines collaboration between those with lived experience and clinicians and potentially puts disabled people at risk.

6. EXPERIENCE OF DISABLED PEOPLE AND THEIR FAMILIES AND WHĀNAU

KEQ4:

<p>Disabled people and family and whānau experience</p>	<p>What has been the experience of disabled people and their families and whānau?</p> <ul style="list-style-type: none"> • What has worked well? • What has worked less well? • What have the challenges been? • Has the implementation been experienced consistently for all disabled people?
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6.1. What has been the experience of disabled people?

In this section, the experience of disabled people is covered. Interviews were conducted by SAMS with 10 disabled people in MidCentral. Some had contact with Connectors, and one participant had not had any contact as they had only recently moved to Palmerston North.

The depth of response to the structured interview was variable, with some participants providing in-depth responses to the questions and others, challenged because of their disability, providing very brief or no responses to some questions. In these instances, either a family member or a support worker helped. This is a finding in as much as it demonstrates the diversity within the disability sector. With a range of challenges, some disabled people cannot navigate the system alone.

6.1.1. Feeling supported

Being supported was an important value and aspect of their relationship with their Connector – being supported personally and being supported in their choices and requests and around what they wanted to achieve.

“She was very supportive of what I wanted to achieve.”

“If I’m honest I just wanted to feel as if I’m being supported and I wanted to be provided some direction and some ideas as to goals.”

6.1.2. Knowing the principles and living by them – walking the talk

“... it’s very important from my perspective and speaking on behalf of other people the connectors really take on the principles and they understand what that means, they understand what the principles mean, and they themselves, in regard to their people or their clients and even in their personal lives, they apply them.”

Connectors were considered by many to be people who understood and lived the principles.

6.1.3. Connection and Connectors

The importance of being connected to the Connector was also expressed by participants. Not all participants chose their Connector, but most connected well with the Connector they had.

“If the connector is on the same page or is open minded to be on the same page as the person that they are working with time will not be wasted, resources will not be wasted, and money will not be wasted. So, it’s very important that we encourage people to pair up with the right connector. And I love the fact that if they do have problems, we have every right to turn around and say, “look, I’m sorry but this connector isn’t a good fit for me. That’s brilliant. That’s something the old system, you never got a choice.”

Wanting more connection was also raised by some participants. For some, it was difficult to arrange changes in their care, and they felt that they needed more support and a greater level of contact with their connector. Contact ranged from several hours a week to telephone contact during the week or an hour a week in person. For some, they waited for their Connector to arrive, and sometimes they didn’t arrive. For some, there was confusion over the role of the Connector, specifically whether they were only there to give advice or there to help do things with the person.

One participant expanded on what the implications are of not having a good fit with the Connector:

“If the people aren’t really a good fit it’s a lot of what seems to happen now, with some of them, they get these people that they’re not happy with, but they haven’t got enough confidence to say I want to change or I want somebody else. One of the support people who comes to me, he’s actually really good at helping people get the changes. One of the things I’ve noticed is that the people who aren’t confident enough to say that this person doesn’t fit, are often the people who start to miss out on things or they have a problem with sorting the funding. But once they have somebody that’s on their side it all seems to fit together. It’s a great ... it’s a good system as we can choose the people we have and the time.”

This participant went on to explain that a good fit is about having somebody you feel comfortable talking to, knowing that they are listening to you and that they follow through with what they have promised to do. With Mana Whaikaha, this participant said there was follow-through and that, when they didn’t have an answer, they found out. This demonstrated to her that they “actually care”. Being able to talk about health issues and knowing they would be kept in confidence was also valuable to participants.

While some wanted to have more time with their Connectors, others were happy with the amount of time they had and felt they could get assistance or ask for help when they needed it. After having things set up, they had become increasingly independent and felt comfortable about freeing up the Connector to work with other people.

“I mean if there are others who need more help than I do, then I can work out a lot of it for myself, then there is no real point in getting all that support from her. But knowing that I can, that is important. That’s the important part.”

6.1.4. Having a map to help direct the achievement of goals

“If I can look at my map up there, I have achieved about 3 or 4 of the small goals that we set and I am still waiting to achieve some of the other ones.”

The role of the Connector in helping establish goals and realising them was key for the participants.

“Although she was pushing me to achieve small goals which ended up adding up into a big goal, I didn’t feel like I was being forced to do them. It was more encouragement all the time to, sometimes strong encouragement, but that’s all a part of it. It’s one of the things I’ve found

about being a bit crook, you get a bit down on yourself and don't feel like doing a lot and she [the Connector] has been very good with that too, just understanding that sometimes you don't feel 100%."

Encouragement was central to goal setting, doing new things and developing confidence. One participant had the goal of getting out more.

"That was one of those goals where we set it up, so that I'm not sitting at home all the time. I'm coming down and keep using the facilities at the library. It's a great place here and to come in and make use of it, once they get the café back in here it will be brilliant."

6.1.5. On being heard and being a person and having choice

Having choice was appreciated and novel for some. The role of the Connector was key to helping people think about choice and direction in their lives. It was about being treated as a person, person to person.

"She was very accepting and open, and she also gave me direction that I couldn't see for myself, as suggestion."

"As I said, I'm not just a number anymore. I am a person. And yeah, that's all I can say. I'm not tick box anymore. I don't have just two options and that's that. We'll give you two options and that's your choice. I am regarded as an individual, whereas, I grew up where disability was ... people were uneducated on disability, you were seen as different, you were classified, you were almost unhuman and Mana Whaikaha is breaking down those, that stigma that really nasty systemic stuff that [has] surround[ed] disability, for decades. So that's what is different."

Having goals, being able to set goals and achieving them was also a positive change that had occurred. Others spoke of having options, more options and being able to think about what would work for them personally.

One participant compared her experience with Mana Whaikaha and interaction with a large government department.

"To some extent, it is a bit like going into Work and Income and you don't feel they really care, you're just a number ... but with Mana Whaikaha I haven't had that feeling there. Which is great. It is positive. It makes me feel great communicating with them."

6.1.6. Disabled peoples' views on providers

"I think more ... need to take on and be educated by the principles. I believe the Ministry can be a bit more thorough in who they choose to employ in their criteria, that those employees must meet."

"Some of the workers need to be stuck in a wheelchair for a day to see what it feels like."

Being able to contact providers and support people was an issue for some, and others felt that they needed to improve their communication with each other internally and that they should call back when messages have been left.

While several participants highlighted issues they had with their providers, there were positive experiences, usually after changes were made with a support worker who the disabled person

was not happy with or, in one case, when they moved towards having control over their funding. This provider was considered supportive and encouraging, and the people they employed were people who cared.

“And, it can be nice knowing that there is somebody out there that does care about what you are doing, because sometimes it can get quite lonely.”

For some, their support people were good, but they felt the company they worked for was bad. Some thought that, if providers are receiving funding for providing a service, the service should be good and reliable.

6.1.7. Disability and mental health – an important issue

“... frankly, I think that health should be a basic human right and also, personally I believe that ... personally I don't know if this is going to make a change, but I will put it out there, it needs to be known that a percentage of us that have a physical disability also have a level of mental health unwellness and mental unwellness needs to start being seen for what it is. It's a form of disability itself and it needs to start being talked about, recognised, and people need to be supported, educated in how best to support people who not only have physical challenges but also have mental challenges as well.”

Wellbeing and mental health were raised by several participants. The new system and having the power of choice was central for some to their enhanced wellbeing.

“It makes me feel better essentially. I have control of what goes on and that makes me feel good. And, if I feel good, then long term it keeps the doctor happy, keeps the cardiologist happy. Being happy is a good thing for your health.”

6.1.8. The new system was viewed as being better than the old system

There was a consensus that Mana Whaikaha was better than the old system and that this was because it provided greater choice and freedom. Participants had enjoyed having a Connector, but many had not changed their support plans since engaging with Mana Whaikaha. Not all participants chose their Connector. Those that did knew the person prior to Mana Whaikaha or knew people that could put them in touch with Mana Whaikaha. There was a consensus that Mana Whaikaha was easier to use and access than the former system.

Describing their engagement with Connectors, one parent who participated in the disabled person's interview because they were not always able to answer the questions described Mana Whaikaha as “life-saving” and she added that she was happy the system was changing from the old system.

Demonstrating that the system cares is what makes the new system great for many.

“I would say that compared with some other experiences I've had in working with big departments and organisations, it's been a positive experience ... I thought the idea was good. To actually have something like that and help people look after themselves and help. I mean It's something I've found with my health issues that I still want to be independent as far as I can and Mana Whaikaha seems to encourage independence. Which is good. If people can be independent and do things for themselves then you feel a lot better about yourself.”

Having support, encouragement and being able to trust the Connector was also key to a positive experience with Mana Whaikaha.

There was support for Mana Whaikaha as the new system. It was viewed as a positive change. There were several things that were appreciated.

“... the ease of contact, the staff are good to talk to, you get a good response. A lot of that I think comes back to having people who care in a team. I can see, there’s people I’ve dealt with, over time, I could see they would not be a good fit in a place like that. And, if they were I don’t think the people they’re working for have a good feeling about it ... coming down to those people and just getting a positive feeling, positive feedback when you’re dealing with them, is the thing, for me, that makes the difference.”

Under the new system, some participants had already achieved personal goals, and some were making greater connections in the community, for example, through joining existing clubs and taking on voluntary work. These changes in interaction were, according to these participants, helping them to be more independent, leading to greater confidence and less social isolation.

6.1.9. Understanding that the new system is not just about having access to money

“I would like Mana Whaikaha, right from recruitment, to educate the families and individual that the money is the last resort and encourage them to form networks outside of that funding. And, also to become educated on their budgeting, how they spend that funding.”

Participants had been introduced to new activities, and some had joined new groups. Personal budgets had made a difference for some who stressed it had given them flexibility, options and access to activities. People had chosen personal budgets as they wanted to have the freedom to choose and have control of their choices. However, not all had sought personal budgets. The need to educate families about budgeting was a theme that emerged from participant interviews generally.

6.1.10. Support the disabled person and understand the parents

“Unfortunately, parents with a child with a disability, they face a lot of pressure, so it’s very important, I know that it is person-centred, yes, but it’s very important for Mana Whaikaha to become fairly involved with the parents of the individual ... I think it is very important for Mana Whaikaha to come up with an individual support plan not only with the said individual, but with their parents, as much as they can, and let those parents know they are supported. And that may take a lot of pressure off the parents. Because at the end of the day, parents are individuals too, they struggle with their own challenges, getting through their own days – things like that. And at the end of the day you want to enjoy being a parent. And let’s face it, I’m going to be brutally honest, when you have that job 24/7 caretaker, sometimes that enjoyment is clouded because there is so much financial stress, physical stress, emotional demands, you know, challenge and that sort of stuff ... their role is to be a parent, not a 24/7 caretaker because at the end of the day they will become stressed, burnt out, relationships can become strained – it is a direct result of feeling unsupported by the system.”

One mother, assisting her disabled son during the interview, said Mana Whaikaha had been easy for her. This experience of the new system was her experience with the Connector.

“I mean, cos we sat and had a good chat and it was helpful knowing here was another mother who had children with issues and just understood. I would say with what we have been through, I don’t want your sympathy, I want your understanding.”

Help with paperwork was also noted by several participants and this help from Connectors “made it easy”.

“It added a bit of calm to my house ... she just became part of the family for my sons.”

Communication was key to support. Being able to text, email or call the Connector was mentioned by most participants as a good thing, having one point of contact and having a Connector who was a good listener.

Securing support, whether it be for meal making, cleaning or helping with specific tasks, was an important issue for the participants and particularly having the right kind of support from the right person and being able to change support workers if they were not right for them. For those who sought personal budgets and wanted to direct the support, set the parameters and direct what days it would be provided, this was empowering.

“So, one of the things I could do, was get a full list of what they were asked to do under that funding and just divide it up and make sure the work gets done. So, effectively, I’m their employer. If we’re employing them, we need to ensure the work is being done. Talking with a couple of people I know, they feel quite good that they’re somebody’s boss. It makes them feel good that they’ve got a bit of power for a change.”

6.1.11. The process is a bit slow

For some, the process was slow, and there had been delays around funding. There was, however, an appreciation that the Connectors were often busy, and others observed that no system is perfect.

6.2. What has been the experience of disabled people’s families and whānau?

SAMS interviewed 10 family and whānau members who were not matched to the disabled participants. Their experiences with the new system are different from disabled people’s experiences. Overall, families and whānau had a less positive take on the new system, which is perhaps not surprising given they interact and intersect with the system in a different way and are often advocating for their disabled child, not all of whom are able to do so for themselves.

6.2.1. Experience of Mana Whaikaha

Not all experiences were favourable. One described their contact with Mana Whaikaha as “fragmented, sparse and limited”. Some had found it difficult to access the kind of support they wanted and had thought that the Connector would do this for them. The interaction was described as “not straightforward” by one participant, and they had assumed that people with lived experience would be more sensitive to the needs of their disabled family member.

Conversely, there was also a positive attitude towards the new system. Most looked forward to working with Mana Whaikaha and saw it as a positive change for disabled people and their

families and whānau. Here, the positive attitude is towards the principles that underpin the new system.

However, once connected to a Connector, some felt let down and felt they should have been given more time and have received proper and timely responses to their questions.

6.2.2. Support for the families

Some participants felt unsupported by Mana Whaikaha and the Connector they had been assigned. These family members wanted to have things established so their child could be independent so that they will be alright when the parent is no longer alive. For these participants, there was a sense of not being kept informed or knowing where things were at. There was a high level of anxiety connected to not having things sorted out for their children before the parent dies

There were different expectations about what the new system would provide families and whānau. Some had thought that the Connector would take control of everything and they would be able to get things done for them by a certain date.

Some had experienced difficulties finding options for their adult disabled family member and accessing respite care.

6.2.3. The previous system compared with Mana Whaikaha

For some, dealing with the previous system had been easier, and they felt that they knew where things were at. They contrasted this familiarity with their experience of the new system where they felt that Mana Whaikaha had not kept them well informed and there was an absence of official information. One participant thought that Mana Whaikaha was not easier to use and that they needed to have somebody managing their child's affairs independently of her family, but she also thought that having "individualised funding" (personal budgets) was a very good development.

"I'm just totally disappointed as I thought they would be empathetic to our circumstances. Not us being empathetic to Connector's circumstances. We should get copies of agreements, be kept informed regularly ... have discussion about our choices and alternatives."

While some participants expressed frustrations with the new system, they also found it a positive change in that it was more interactive than the old system and that Mana Whaikaha had opened choices for their disabled family members. Others noted that it had taken a crisis for any response under the old system.

One participant heard of Mana Whaikaha through the church and family meetings. They thought the system sounded inviting and reassuring. They were "excited" and this was "the revolution".

6.2.4. Understanding what the new system means

For some families, the change to the system was confusing. They found the name Mana Whaikaha confusing. They did not have concerns about the new entity but simply found the process of change confusing.

Others learned about Mana Whaikaha through community and church meetings and became involved. When they first heard about Mana Whaikaha, they thought that it was "great" and that they would be able to do things differently. They would have flexibility around funding and were excited at the prospect that their child would be able to choose the things they wanted to do, yet

there was also cynicism about the change and a suspicion that “gut feeling, save money” might be the underpinning motivation.

6.2.5. Connectors – understanding the disabled family member

For most family and whānau members, the experience with the Connector was positive, and they felt that they guided their family member well. They had a positive experience of the interaction and had been provided with proactive ideas about choices available. Some stressed how “great” the Connector had been and how it had been a great experience working with Mana Whaikaha.

“I don’t know where I would have ended up if I didn’t have the support, just having a plan every week. I can now go to work and don’t worry.”

There are range of issues that impact on how a person engages with the system, and not all could be anticipated by Mana Whaikaha. Some general examples include moving into an area, having other health issues or family issues. One experience that came through from disabled people was that the link to Mana Whaikaha and its responsiveness and understanding was crucial to feeling supported. Understanding Connectors was central to this. Comments like “the Connector gets it” illustrate the relief that some felt when engaging with the new system. Some spoke of the new system giving their family choice and respite.

The changes in the funding options has led to “greater freedom, more control, not waiting, no forms”. Overall, there was a feeling of more choice and control. Participants noted the things their family or whānau member wanted to achieve and that they had achieved some of these already and some were a work in progress.¹³

There were concerns expressed by one participant about the communication skills of their Connector, who spoke to her, not her daughter, and that the Connector was relying on the family to do this communication. The Connector had not seen her daughter and had not connected with her daughter. This participant attributed this to the Connectors being overworked, yet this participant also described the Connector as good – that they were open and it felt good, that they listened and were non-judgemental and respectful. The Connector understood and respected needs and wanting to try other ways. This participant, as with others, thought that the Connector would have a more active role and organise her daughter’s life with support workers. As with others, this mother is concerned that, if she were to die tomorrow, nobody would know what to do with her daughter. While observing that Connectors were overworked, more time was wanted for the Connector to engage with her daughter and plan what she wants. She described her family as “just living day by day”.

Several family and whānau participants expressed concern about Connectors being overworked or there not being enough Connectors. They felt that the Connectors were doing their best.

6.2.6. Frustrations and stress for disabled families and whānau

Some of the frustrations were around process, delays and the staff of Mana Whaikaha all being new and not being prepared. They felt time was wasted because of this and that some information was addressed multiple times. While they had experienced frustrations initially, they were

¹³ The details for what they had chosen have been excluded to protect the identity of the participants.

currently happy with their arrangements and they reported positive relationships with the Connectors.

Funding arrangements were confusing, and participants noted delays and a lack of consensus over what could or could not be done.

Others noted that, while things were frustrating at the beginning, things had improved, there had been positive changes, new activities had been introduced and their family member was being helped to have a good life.

“Now in an environment where she is challenged to live her life the way she wants to.”

Some thought that what they had been led to believe and what can actually be done were two different things. Waiting for answers was very stressful for parents. Most of this stress was around funding.

Several suggestions were made for improving Mana Whaikaha including improving the funding approval process and providing greater transparency around what is possible in the new system. They wanted greater balance where the system helped and where the onus is not always on the family of disabled people.

6.2.7. Respite care – what is needed for families and whānau to have a good life

Respite care was an issue for some families and whānau, as accessing respite care had been confusing and challenging. Being able to have a break and know that there will be a certain number of respite care days available was central for many to have a “good life”. Focusing on the wellbeing of just the disabled person overlooks the fact that no person is an “island unto themselves”, and this is very much the case for people with complex needs.

6.2.8. Providers making changes

With the new system, providers had also made changes that were appreciated. Participants (parents and disabled people) thought there were more choices now. Support workers were also supporting greater interaction with others (family and friends) for the disabled person.

6.3. Whānau

One participant included a typed sheet outlining their experience and addressed what could be done better. They stressed the need to address the needs of Māori and whānau. In addition, they thought that awareness of Mana Whaikaha amongst Māori was not strong and that more whānau needed to know about Mana Whaikaha and what this new system means for them. This participant thought that Mana Whaikaha was making a difference but also experienced some confusion over Ministry of Health directives and how Mana Whaikaha aligns with them. They also raised their concern about the office space provided for Mana Whaikaha staff, particularly the lack of private space for Connectors and clients, and noted it seemed to be at odds with the kaupapa of Mana Whaikaha.

6.3.1. Teamwork – shifting from “Can we do this?” to “How can we do this?”

This participant was impressed by the teamwork within Mana Whaikaha and across other government agencies. The two Connectors they had worked with had “thought outside of the square” and worked with whānau to develop solutions. The participant’s Connector worked on

solutions with other professionals when the participant was too tired to do so. Mana Whaikaha represented a culture shift from “Can we do this?” to “How can we do this?” The system change had exceeded their expectations. The Connector provided support and looked at the wider whānau and was supportive of what they were doing. The engagement with the Connector had been positive, empowering and non-judgemental, and they felt listened to. Things have been held up because of wait lists and the roll-out taking so long.

6.3.2. In the old system, it was necessary to “beg”: there is now greater choice and control

For some in the old system, there was an experience of having to “beg” when there was a need. These participants felt that, with Mana Whaikaha, the Connector was an advocate on their behalf. The outcome was far greater choice and control.

Another participant was assigned their Connector and thought the experience was good and the Connector had provided suggestions, listened and worked out what was possible. They would have liked more time to work out solutions for greater independence and would have liked greater follow-up. Communication with the Connector was good, and the Connector understood.

6.3.3. Mental health

When mental health issues were also a factor, many did not feel supported by the system – or any system.

6.3.4. Other systems and becoming part of the family

Connectors played a key role in connecting families to other systems, such as the education system or the justice system. Connectors were described as “part of my family now”, and this reflected the level of trust that had been built up with Connectors and was also an outcome of implementing their suggestions and experiencing improvements in their daily life as an outcome, for example, having “more calm” in the household. Changes in the funding also helped some to be able to utilise personal budgets to bring about changes that improved the disabled person’s quality of life, which also had a flow-on effect for the rest of the family.

“(Name of Connector) – great Connector. He’s just so non-judgemental – there just to support me and family. Huge trust.”

6.3.5. Many challenges¹⁴

Dealing with the disability sector involved lots of challenges, and there were many “hiccups” on the way. Seeing Mana Whaikaha, a Māori name, gave some hope that this new system would be responsive to Māori need and values. Having a Māori Connector was not essential:

“She was Māori, but I would have been ok with a European if they came with the same approach. I’ve met many Europeans who come with a great understanding of our Māori values. Being Māori, we prefer Māori, the trust we’ve had growing up ... the cool thing is because we did manaakitanga with her, she’s not just a worker she’s part of our support network. When she’s finished with this organisation, she’s built a relationship, she actually

¹⁴ The themes identified from this point have been drawn from further interviews with whānau carried out by the Allen + Clarke team.

cares for us. Not just about giving us what we want. Sometimes just about being heard ... she provided a lot contacts."

This Connector helped arrange some respite and provided links to local services. The respite gave the couple a chance to reconnect and to establish new routines. The Connector addressed the whole whānau wellbeing.

While Mana Whaikaha is a new system, it is still linked to funding from government agencies where the whānau have previously had bad experiences. The system is new, and it will take a while for trust to be built. The cultural side to this engagement remains a challenge, where intersecting with the wider system often involves a lack of understanding about a Māori world view.

"We don't just want to be rolled into the European system without having our native indigenous rights protected and our sovereignty as guaranteed by the Treaty."

If the new system is to be empowering for Māori, it must embrace a kaupapa approach. A kaupapa approach has an underpinning principle of social justice. The new system should empower all disabled persons, including Māori. A kaupapa approach works towards building capability and capacity for Māori communities. The core standpoint is tino rangatiratanga, defined as sovereignty, self-determination, governance, autonomy and independence. All resonate strongly with the principles underpinning Mana Whaikaha.

Good health means balancing the spiritual, mental, social and physical dimensions, and individual wellbeing is linked to the wellbeing of the wider Māori collective. These participants raised mental health as a concern and one that was not effectively being address. They also raised not having access to cultural resources and that the old and new system need to understand that a secure Māori identity is fundamental to good health.

The new system had not been as easy as they had hoped, but it had offered some flexibility.

"We love that we can implement koha, we love that, we can feel their value and how much we are able to give depends on how we feel, with koha if you feel very appreciated you feel you can give more. When you ask for \$, that is not koha, because you stated it."

There is a need for respite so that couples can maintain their relationships.

"Good solid consistent respite that keeps us balanced and well."

The new system is not clinical, Pākehā, in its approach. There is, however, a need for information sharing, and this is not happening as well as it could. There is a lack of transparency around funding. Some people know about them and some do not. There needs to be a clear process. Depending on the disability, it is not often possible for the disabled person to be included and it is often not financially possible.

6.4. Pasifika

Only one Pasifika family member was interviewed by SAMS. They were positive about the support provided by the Connector and trusted them. The family had multiple needs. There were mental health issues, and they were trying to access services through the DHB but were turned away, despite suicide attempts and evidence of self-harm.

"They made me feel like the enemy, they were no help."

The relationship with the Connector was good, they felt listened too and they trusted them. The Connector was trying to facilitate employment for one of the family members. The greatest concern for this family member was the lack of support for mental health issues in the MidCentral DHB.

The family member wanted mental health to be addressed through Mana Whaikaha.

6.5. Hopes around the new system

"[I] was hopeful and positive [that Mana Whaikaha] would give us more voice to speak to the process that was happening, and give our experience and feedback so in future those things that happen to us don't have to happen, there are avenues or training or education in place so all these families can understand all the areas available to them, and especially Māori. Being Māori there's a feeling that we live under a ... in a country we are imprisoned by another culture and nation, and we feel that because we see British immigrants all the time and choose to live here, we can't just go there and choose to live there, we feel second class in our own land. Many of us want to feel we have a sovereign right in our own mana, want to feel strong in our own whenua and families. For us, it was a positive start, it has been a positive start."

6.5.1. Confusion around funding and the focus on individuals

The new system was also confusing, particularly around funding – what could or could not be done with the funds. For those from a large whānau, providing opportunity for their disabled child and new experiences is not easy. Other children can miss out, or they simply cannot afford to accompany their disabled child.

"We didn't want it to be that we pay for ourselves and her but the rest of the whānau miss out – don't want her to think she is different and is going to be treated differently, and didn't want the family to think they get to do things without her – my older daughters don't like it."

The focus is on the individual in the new system, not on the whānau. Again, the nature of the disability impacts on what can be done and how funding might be spent, and there is a lack of clarity about what funding can be used for.

"If there are guidelines about spending money, it has to be broader or more specific, so you have the luxury of spending on what you know will help your family. There is contradictory advice out there. I talked about how I could buy movie tickets, but my other friends weren't told they could do that. I was told I could only use money to support her, not for her."

6.5.2. Moving from the old system and to the new

Having a child with complex needs and adapting to the old system and the new is challenging for some.

"I'm kind of disheartened – do I really want to go through the rigmarole? I feel like I'm repeating the same journey as a few years ago. Her needs are so complex, I've learnt to deal with them now. Not sure I want to fight the battle anymore. I could potentially spend the money how I want to, but don't want to be forced to pay it back if I got told this is not how I can spend it."

There is a feeling that whānau and caregivers are overlooked.

“I know friends with depression and anxiety because they are restricted by what they have, stuck at home with their special needs kids. We forget about our personal lives – my husband should be able to relax too; he shouldn’t have to do everything, he works hard.”

Some Māori have better connections than others, and their whānau appear to be better connected with the new system. There are also reservations about always taking and not being able to give back.

“I don’t want to be the person who just wants to take. Also, I have more in the hand than most Māori families – lucky that husband has a decent job, own home, we struggle, but compared to other Māori, I think they deserve these services more than I do – don’t want to take away from them who can take more from it than I can. There are those people who just take and take, and I don’t want to be seen as just taking – I want to be able to give back too.”

6.5.3. Building relationships and being failed by the system

Building a relationship with the Connector takes time. One participant had two Connectors who both stopped coming, which had an impact on not only the mother but on the disabled child too.

“[Child’s name] was miffed that [Connector’s name] wasn’t coming back – [child’s name] just saw this person take all of our information and then leave – after building up rapport and trust. This was disappointing.”

The Connector was inconsistent, and this parent felt that, in the end, they were only interested in serving Mana Whaikaha and themselves, not whānau. The experience “was not mana enhancing, let’s put it that way”. Losing the Connector in these circumstances has had an impact for this parent.

“I don’t know where to get this help [for after-school support] – all my whānau are in Wellington, because of her needs I’m anxious, vulnerable, gullible – I’m protective of my [child] – need someone trustworthy – could Mana Whaikaha help me connect with someone like this? I don’t know where to look. You can look online, get bios, pick a person or create a profile and people might apply – I don’t want the stress of interviewing 20 people – this is something Mana Whaikaha could do – still a nightmare, very fresh. I felt failed by the system.”

7. THE CHARACTERISTICS OF INDIVIDUALS WHO MAKE UP THE MANA WHAIKAHA WORKFORCE AND THE PROVIDERS

KEQ 5:

The role of individuals	<p>What role have individuals played in the implementation of the prototype?</p> <ul style="list-style-type: none"> • What has been the interplay between individuals and the organisation within which they work? • Has individual behaviour change occurred because of the prototype?
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The implementation of the prototype was impacted by the role of individuals and the dynamics in the workplace at Mana Whaikaha. At the individual level and also at the team level, there was uneven knowledge about how to make this prototype work. Some individuals were uncertain how to translate the core principles into practice, and this is evident in the inconsistent approach towards some disabled people and their families.

7.1. The face of the organisation

The Connector became the “face of the organisation”, whether this was intended or not. In the absence of a separate dwelling and shop front, Mana Whaikaha was represented by the Connectors. With the pressure of having more people to work with than was anticipated, some Connectors became overwhelmed and some sought support from the families they were supporting. What this meant is, for some, the “face of the organisation” lost face. Despite the pressures on all and particularly the Connectors, they remained committed to the philosophy. The reliance on lived experience meant that some people received advice that was limited to the Connector’s advice and experience, not necessarily the best advice for the disabled person or their family and whānau.

Across the Mana Whaikaha workforce, some workers felt they were able to bring about change. These people came to their roles with a professional skill set. This was not consistent across the workforce. There were individuals who did not have strong faith in their own capabilities and were challenged when it came to driving change or implementing the core principles in practice. These people felt overwhelmed and stressed about their work. As would be expected given the recruitment challenges and the nature of the local labour market, there were a range of stages of change, with some being skilled, enthusiastic and able to sustain behaviour that was consistent with the prototype and others being only at the very beginning of a stage of change – precontemplation. The degree of commitment, largely because of the stress of heavy workloads, and being in a constant state of change and flux meant that some had become disenchanted. There was also mixed embracing of organisational identity – organisation citizenship. There were mixed views on organisational justice, with some questioning procedural fairness. Overall, many thought they personally could be doing a better job, while others thought they were doing their best. An outcome of this was that levels of job satisfaction were variable.

Emotional exhaustion was evident for some, particularly the Connectors. The ratio of Connectors to disabled people is more than double what was planned and anticipated, and Connectors are under considerable strain. They are aware that they have become the face of the organisation, and

this adds to the burden when they feel they are not able to do justice to their role. The Connector role is under-resourced, and resourcing for pastoral care appears to be a very real need.

7.2. Providers

Learning to think and do things differently has also been a change for the providers in the sector.

“We have had some really good and significant responses from providers ... some wanted to know how to get on board with the new system, usually community-based providers and some of the bigger providers were slower to come on board, because they cannot make changes locally ... has to be signed off elsewhere.

Providers who participated in the focus group wanted to know more about what they could be doing to change and wanted more frequent communication and transparency around recommendations being made by Connectors. Providers thought that the system transformation had not been as transformative as they would have liked. They thought the power remained with the funding bodies and not with disabled people. There was a concern that Connectors would just become the new gatekeepers (replacing NASC assessors).

Providers wanted more collaboration and to be treated as partners, “not enemies”. They were concerned that referrals from Connectors were shaped by who they knew, and there was role creep into service delivery instead of guidance. They also raised the issue of accountability and thought that there needed to be some clear ethical guidelines in this new system. The slow processing of funding requests had an impact on the market, and bottlenecks led to some reduction in services for some providers. There was discussion around the transformative aspects being oversold and the funding being constrained. Greater communication with the providers would help with implementation.

Providers expressed concerns that, while some plans conformed to the philosophy that disabled people should have greater choice and control over their lives, other plans were “tokenistic” due to the nature of the disability. An example was provided where a disabled person wanted to be a dog walker, but they were physically not able to hold the leads of the dogs, so the plan was for the disabled person to walk alongside the dog walker. Others in the provider group stressed how diverse the disability sector is and that having ordinary life outcomes was shaped by the severity of the disability.

7.3. Process using the Try, Learn and Adjust method

In terms of process, the Try, Learn and Adjust method was working and employed, but many felt that there had been insufficient time to reflect and not enough time to settle on one approach. The barriers to implementation were widely seen as not being ready on 1 October 2018 with basic administrative tools and clear processes to follow. There had been insufficient time to induct the Connectors and provide training. Overall, the narratives of change stressed that there was an absence of a systematic approach to implementation and adjustment.

7.3.1. Planning prior to the launch

Considerable effort went into the co-design process and planning prior to launching, but some things were not implemented. Key was the communication strategy – most participants were unaware that there had been a communication strategy developed. For many, communication

internally and externally was a concern. There was a desire to understand how they were progressing to realise goals and milestones.

The rush to implement was also a key theme. Some thought that it might have been more effective to implement components of the prototype incrementally instead of the all-at-once approach, which many found overwhelming.

There were a range of contextual factors that impacted on implementation, not least competing politics and interests within the organisation and across the disability sector. In some instances, there were undeclared conflicts of interest raised by participants and informal capture of resourcing routes and pathways, referred to as those in the know sharing with those closest to them – family. This has implications for equity. The need for transparency in terms of processes and what people are entitled to was stressed by many participants across a wide range of roles and amongst disabled people and their families and whānau.

7.3.2. Limited social marketing, education and training after the launch

On implementation, there was limited social marketing, education and training in MidCentral, and it was some months before this could be addressed. The awareness of Mana Whaikaha in the community would have been stronger with social marketing. This could also have helped ensure that people had equal access to information about the new system.

7.3.3. First users of the new system

Connectors engaging with the first users of the new system had mixed results, ranging from very successful to less than successful. This was an outcome of variability in service from Connectors and variable expectations from the disabled people and their families and whānau. There is evidence that early users can more readily adopt a new practice if they share things in common with those promoting the new system, in this instance, if the disabled person or their family and whānau had something in common with the Connector such as experience of disability, similar education background or socio-economic status. However, it is equally the case that, for system-level change, it is necessary to have a range of skills to navigate the range of contexts where connections need to be established (education system, health system and so on).

Establishing connections is challenging for disabled people, and not all are challenged in the same way. Connectors need to be able to navigate effectively on their behalf, and there was variability in this skill amongst Connectors.

7.3.4. Opinion leaders and people driving change outside of the new system

Over the course of a year, there has been evidence of opinion leaders in the sector, and there are external change agents from other agencies (for example, Ministry of Education and Ministry of Health). There has also been the emergence of informal leaders who are viewed variably, largely because they are perceived to be representing a faction rather than the sector or a particular social or ethnic group.

7.3.5. Execution of the implementation

The execution of the implementation was organic, and many experienced it as a huge rush without formal planning and felt that this challenged successful execution. Some thought that the rush compromised the prototype, particularly the unexpected demands on Connectors. These demands

had meant that Connectors were not able to sustain long-term relationships with disabled people and their families and whānau, as they had to work their way down the waiting list and their list of clients became unmanageable. Sustained engagement is very resource intensive, and the prototype is resource constrained. Connectors' increased workloads impacted on the quality of service delivery, and all were concerned about timeliness, particularly the waiting list and confusion around funding.

7.3.6. Reflecting and evaluating

The constant Try, Learn and Adjust approach precluded time for reflecting and evaluating. The need to work at a fast pace to meet demand also undermined time for people within the organisation to reflect and pace their response to new demands.

8. WHAT WORKS BEST?

KEQ6:

<p>What works best?</p>	<p>Under what conditions could the prototype work best?</p> <ul style="list-style-type: none"> • What structures, approaches and programme components can provide the greatest benefit? • What components should be sustained, scaled up, adopted and adapted to areas outside of MidCentral? • How could the prototype be improved from a disabled person’s perspective? For families and whānau? For Mana Whaikaha staff? For providers? For existing service providers?
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Participants made a number of suggestions about what they thought could be improved, what had worked best, what needed to change and how the prototype could be improved. These suggestions are measured against the framework used for analysis (Appendix 1) and have been included when there is evidence that supports these suggestions.

8.1.1. Readiness for change and support for the core principles

The sector is ready for change, and this provides an ideal climate to introduce the prototype. There is support for the principles that underpin the prototype. Having widespread buy-in to this new system will enable implementation to take place with little resistance to the core principles or the long-term aims of transforming the disability system. It is reasonable to expect unevenness of the implementation as this is an outcome of it being transformative, new and having only been implemented over the last 12 months.

8.1.2. Having the right people in the right roles

Having the right people with the right skill set in the right roles will be important for the implementation to become embedded. Connectors and government liaison roles require a range of skills that enable working within the system and outside of the system with other systems.

8.1.3. Being ready for greater demand

It would be ideal to have a good understanding of the disability sector in the given region, to allow for people migrating to take advantage of this system and to allow for changes in the definition of who is eligible for services. Ideally, there would be time given to this forecasting and planning for the organisation to be able to respond effectively to changed circumstances.

Before implementing in other regions, it would be necessary to understand the context, the nature of the local labour market, what services exist, who are providing services and social and cultural factors that may enable or serve as a barrier to accessing the system.

It is unlikely that one size will fit all contexts. The prototype would need to be shaped to fit the region. Barriers and enablers should be anticipated (for example, poor service provision, sparsely populated area, weak labour market). Mapping exercises would assist with knowing the context.

8.1.4. One line of command

The structure of the organisation was questioned by some participants largely with respect to management and the perceived need to have one line of command. The Kaitūhono/Connectors team and Tari/System team took time to work collaboratively, but functionally, it made sense to have the two teams and to have funding separate from the Connector role, although this in practice didn't happen when people were under pressure. Many felt there should only be one director and two managers. The original structure may need to be reconsidered.

8.1.5. Role clarity and scope

The role of the Connector needs to be more clearly defined, and there needs to be transparent processes around this role, who is being connected with and its relationship to funding. Having a risk management strategy in place for Connectors would also help address their safety and the safety of others.

8.1.6. Independent architecture and a shop front

Providing a separate building and a shop front with which the prototype could be associated would have helped remove some of the pressure placed on Connectors, who soon became the sole face of the organisation alongside an already broad role.

Having a separate building allows for the development of an organisational culture and citizenship, assists in building a culture that all identify with and protects workers when under pressure.

8.1.7. Team membership includes people across functions and structures

Teams should comprise members from across the organisation, preventing silos, and work in a matrix style.

8.1.8. Providing training, education and a learning culture

It is important to educate the workforce about the new system and acknowledge that there is a past and not all aspects of past practices are bad.

8.1.9. Implementing a communication strategy

Having a communication strategy in place at the beginning and having people in this role to manage communication internally and externally is key.

8.1.10. Ensuring there are the right people in liaison roles

The government liaison role should be retained, as it has been central to linking the systems within systems, and expanded to include people who can link in this way with the community and with local bodies.

8.1.11. Ensure adequate engagement with Māori

Engagement with Māori should be scaled up prior to implementation and during implementation, and the organisation and Connectors should receive adequate cultural training.

8.1.12. Acknowledge that disability is heterogeneous

It is very important that the disability sector is understood as heterogeneous, that there are a wide range of disabilities and that this has implications for what is possible and what is not. This does not mean that people are not equally valued, but it does mean that some people will not be able to engage in the same way as others. If they are forced to conform to those that have high functionality, tokenism can be resorted to and there is a risk their real needs will be overlooked.

8.1.13. Provide information and support to families and whānau

Disabled people and their families and whānau need information about what they are entitled to under the new system, information on the role of the Connector and greater transparency over funding. The prototype focuses on the disabled person, but many stressed that the families of disabled people need support and access to information on what support is available to them from existing services.

8.1.14. Have formal communication channels in place

Communication channels need to be formalised, and there needs to be greater communication with service providers, carers, community groups and existing mainstream services.

8.1.15. Raise awareness of disability

An awareness campaign would assist with implementation.

8.1.16. Include those who are most likely to be overlooked

The system works for those who are high functioning and well connected, less so for those who are not. This inequity could be addressed through consciously targeting those who do not have connections. An awareness campaign and wider provision of information in the community could help with targeting.

8.1.17. Address mental health

Consideration needs to be given to whether mental health is included as a disability and/or has a place in the prototype. Mental health was an issue raised by many parents of disabled children.

9. CONCLUSIONS AND SUGGESTIONS

This section sets out our conclusions related to each of the key evaluation questions and provides a summary of the key evidence on which the conclusions are based. The judgements are informed by the CFIR (see Appendix 1) and the evidence base that underpins this framework.

It is important to stress that this prototype has been running for a very short time in MidCentral. At the time of data collection, it had been running for less than 12 months, so it would be unrealistic to expect that things would have been implemented seamlessly. Within this short timeframe, there are clearly many wins for disabled people and their families and whānau, and when things have not been working, the Try, Learn and Adjust approach has been applied. There have also been many challenges, which the Kaitūhono/Connectors team and Tari/System team have met and are responding to along the way.

9.1. KEQ 1: Who was involved in the design process?

This question relates to understandings of the intervention source. The intervention (the prototype) was co-designed initially at a high level for Cabinet approval and then through detailed design working groups. The process was collaborative, inclusive, extensive, not always happy and at times very challenging.

The evaluative judgement for KEQ1 is that considerable effort went into this process, and according to intervention and implementation science, the collaborative and co-design process was optimal as it ensured that the prototype was clearly an outcome of a range of viewpoints around the table and not something that had been imposed on the sector.

9.2. KEQ 2: Are the core principles of the transformed disability support system being realised in practice?

The core principles include:

- self-determination
- beginning early
- person-centred
- ordinary life outcomes
- mainstream first
- mana enhancing
- easy to use
- relationship building.

There was unanimous support for the core principles and a will to see these manifest in practice through the implementation of the prototype in MidCentral.

The evaluative judgement is that the core principles are manifest in practice, if unevenly, and not fully realised. The core principles underpinning Mana Whaikaha are evident in the success stories told by disabled people and their families and whānau. There is evidence that the organisation has

worked towards these principles being put into practice. Given that the prototype has only been in place for 12 months, it would be expected that there may not yet be evidence of these principles being realised.

There is evidence that those who were previously good at navigating the system are good at navigating this system. There are some who are not experiencing the new system in this way – they are not high functioning and do not have good networks that can assist them to navigate the system.

There is evidence that, for some, the experience of engaging with the prototype has not been mana enhancing.

The organisation has focused on children (beginning early) and worked on systems to try and improve easy use. Relationship building is starting, and there are efforts to be mainstream first. The system has been person-centred, and over time, it would be expected that there will be greater evidence of self-determination. Sustainability at this point is potentially undermined by under-resourcing. Under-resourcing was perceived by some participants as evidence that the prototype was a cynical exercise in not providing additional funding to the sector and that mainstream linking was a means to cut costs.

Suggestion 1

The Ministry of Health and Mana Whaikaha continue to promote the core principles within their organisations and raise awareness of these principles for those in the community generally.

Suggestion 2

Those who are not able to access or navigate the system need to be targeted and provided with greater assistance.

Suggestion 3

The Ministry of Health and Mana Whaikaha provide education on the Treaty of Waitangi and ensure that staff are aware and sensitive to Māori needs and cultural perspectives.

Suggestion 4

Ensure resourcing meets the demands being placed on the prototype and is adequate so the core principles are not undermined.

9.3. KEQ3: What has been the experience of those implementing the prototype?

The evaluative judgement is based on the data collected from the workforce and management and those outside of the organisation. The experience was mixed. There was complete endorsement of the core principles, and the process of implementation had been challenging. Given the shift in demand and resourcing constraints, the workforce and management worked with what they had and adapted as they had to.

Most Connectors felt challenged at times to meet demand. Implementation was fast, and processes and practical tools were not developed prior to implementation. Try, Learn and Adjust was used to adjust and adapt as necessary, but the pace of this was stressful for most and there needed to

be more time to reflect before adaptation was made. This is a very complex intervention, and it would be unrealistic to expect that this would have been implemented smoothly without problems over a 12- month period.

Some of the challenges could have been anticipated with adequate mapping of the context. Some of the relationships could have been formally established prior to implementation and roles assigned to managing specific relationships across the sector and between sectors.

There were skill issues for the Connector workforce, and they were suddenly overwhelmed by the demand. The government liaison roles worked well.

There had been workplace issues, and breaking with the past did impact on some workers who had worked in the old system. Learning to think differently and to do things differently was a challenge for workers and for the sector.

The social architecture of the organisation needed to be developed more fully before implementation, and it would have benefited from being housed in a separate building with its own shop front. Communication within and outside of the organisation was an issue, and the implementation of a communication strategy would have helped address misinformation, gossip and people being confused about what was being done or how things could be done.

Improvement to access to information and knowledge is needed for those in the organisation and the disabled people and their families and whānau.

Suggestion 5

The Ministry of Health needs to address the resource issues – in particular, the ratio between Connectors and disabled persons.

Suggestion 6

Mana Whaikaha needs to be housed in a separate building and have its own shop front so it is a visible separate entity.

Suggestion 7

There needs to be more social media coverage of the prototype and a social awareness campaign so that the wider community is aware of the issues and the need for a system of this type for disabled people and their families and whānau.

9.4. KEQ4: What has been the experience of disabled people and their families and whānau?

The evaluative judgement is based on the interviews conducted by SAMS and additional interviews conducted by *Allen + Clarke*. The prototype has started the move towards putting disabled people at the centre of the system. This is significant progress for an implementation period of just 12 months.

For the disabled participants, there was generally a positive response to the new system and being engaged with Connectors. For families, the response was mixed, and many stressed the need to address the needs of families and whānau.

There was evidence of disabled people putting plans into practice and of feeling accepted and acknowledged. A number spoke of no longer being treated like a number – rather, they were now treated like a person. Mental health was raised by both disabled people and their families and whānau. They stressed that mental health was overlooked and that the “system” needs to address this as currently it is not clear where support for mental health issues can be accessed. Additionally, some expressed concern that mental health was disregarded for disabled people.

Some of the families navigated the new system well, others did not. Some struggled to understand the new system and wanted more information about it and for this information to be easily accessed. Many had experienced stress and frustration navigating support from the disability sector over a number of years. Some felt that the new system was also stressful and frustrating. There was confusion over what the role of the Connector should be amongst these families and whānau.

The experience of Māori was also mixed, with many feeling they had not been engaged with well and that the new system did not address their cultural world view or what is important to them. However, some felt that the new system was better as they no longer felt like they needed to beg for support.

The representation of Pasifika was poor in this evaluation. A number of reasons were offered including that the number of Pasifika is small in MidCentral and that they are not as far on the journey to accessing help. Therefore, we are not able to meaningfully comment on Pasifika experiences.

Suggestion 8

Information needs to be made available for disabled people and their families and whānau in an easily accessible way, and there needs to be transparency over what is possible and what is not.

Suggestion 9

Greater engagement with disabled Pasifika people is necessary so their needs can be understood and addressed.

Suggestion 10

Mana Whaikaha staff, particularly Connectors, need to be trained to engage appropriately with Māori.

9.5. KEQ5: What role have individuals played in the implementation of the prototype?

The evaluative judgement is based on the qualitative data, and the narrative around implementation. Individual behaviour shaped the implementation and the culture of the organisation. Individual behavioural change took place over the implementation period, and this was strongly shaped by the nature of the prototype and the principles underpinning it and the desire to make it work and to be a part of the new system.

9.6. KEQ6: What works best?

Based on the qualitative data and the experience of those involved in the implementation and unanticipated outcomes, the evaluative judgement is that the following issues are important for the ongoing successful implementation of Mana Whaikaha:

- Before the implementation of Mana Whaikaha, there was a readiness for change in the disabled community. This is a positive condition for the implementation of a new system.
- It is necessary to have the right people in the right roles.
- Forward planning and being prepared for anticipated change is necessary if staff are to be able to respond effectively.
- A clear and simplified line of command was important to many staff, and this was expressed in terms of the need to have one line of command.
- The need for role clarity and a well-defined scope for roles is best practice, and after some role confusion, role clarification and scope change processes are under way.
- Many staff thought having an independent building was important, although all acknowledged this would require resourcing.
- It was agreed that there is a need for strong and clear communication to assist the development of a healthy workplace culture. To this end, there has been an increased focus on communication following the evaluation period.
- There was a need to have formal communication channels in place internally and externally, and management are now working on developing these channels.
- An external communication strategy is necessary to formalise engagement between Mana Whaikaha and external stakeholders.
- Developing teams that are made up of people performing different functions from across the organisation (now established).
- Providing ongoing/further training and education and nurturing a learning culture for Mana Whaikaha staff.
- Having the right people in the government liaison roles (achieved).
- Having adequate engagement with Māori (under way).
- Acknowledging that the disabled community is made up of people with a wide range of disabilities and addressing choice and control will need to be as varied as this community.
- Providing easily accessible information and support to families and whānau.
- Raising awareness of disability.
- Focusing on those who are most likely to be overlooked.
- Addressing mental health.
- Adequate resourcing for a system transformation.

SUGGESTIONS

Suggestion 1

The Ministry of Health and Mana Whaikaha continue to promote the core principles within their organisations and raise awareness of these principles for those in the community generally.

Suggestion 2

Those who are not able to access or navigate the system need to be targeted and provided with greater assistance.

Suggestion 3

The Ministry of Health and Mana Whaikaha provide further education on the Treaty of Waitangi and ensure that staff are aware and sensitive to Māori needs and cultural perspectives.

Suggestion 4

Ensure resourcing meets the demands being placed on the prototype and is adequate so the core principles are not undermined.

Suggestion 5

The Ministry of Health needs to address resource issues – in particular, the ratio between Connectors and disabled people.

Suggestion 6

Mana Whaikaha needs to be housed in a separate building and have its own shop front so it is a visible separate entity.

Suggestion 7

There needs to be greater social media coverage of the prototype and a social awareness campaign so that the wider community is aware of the issues and the need for a system of this type for disabled people and their families and whānau.

Suggestion 8

Information needs to be made available for disabled people and their families and whānau in an easily accessible way, and there needs to be transparency over what is possible and what is not.

Suggestion 9

Greater engagement with disabled Pasifika people is necessary so their needs can be understood and addressed.

Suggestion 10

Mana Whaikaha staff, particularly Connectors, need to be trained to engage appropriately with Māori.

Suggestion 11

Ongoing adequate resourcing is necessary to allow the prototype to embed successfully.

Suggestion 12

Stronger engagement between Mana Whaikaha staff and providers.

APPENDIX 1: CONSOLIDATED FRAMEWORK FOR IMPLEMENTATION RESEARCH

The Consolidated Framework for Implementation Research (CFIR) was employed for analysis because it provides an evidence-based framework for evaluating intervention implementation and is a useful framework for understanding interventions aiming for broad-scale system change.¹⁵ In addition, and importantly, the CFIR offers a wide-ranging set of constructs and provides a means to expedite the analysis and synthesis of a large body of qualitative data such as that collected for the formative process evaluation of Mana Whaikaha.¹⁶

The initial coding structure was developed thematically and then the analysis of the themes was informed by the CFIR constructs because they allow strong coverage of wide-ranging themes and the capture of key factors that are important to implementation. The application of this framework also allowed for the development of recommendations that are data driven and further informed by an evidentially based and pragmatic framework.

The CFIR is composed of five major domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved and the process of implementation. The framework and the five major domains are illustrated in Figure 3. Within these five domains are evidentially informed constructs.

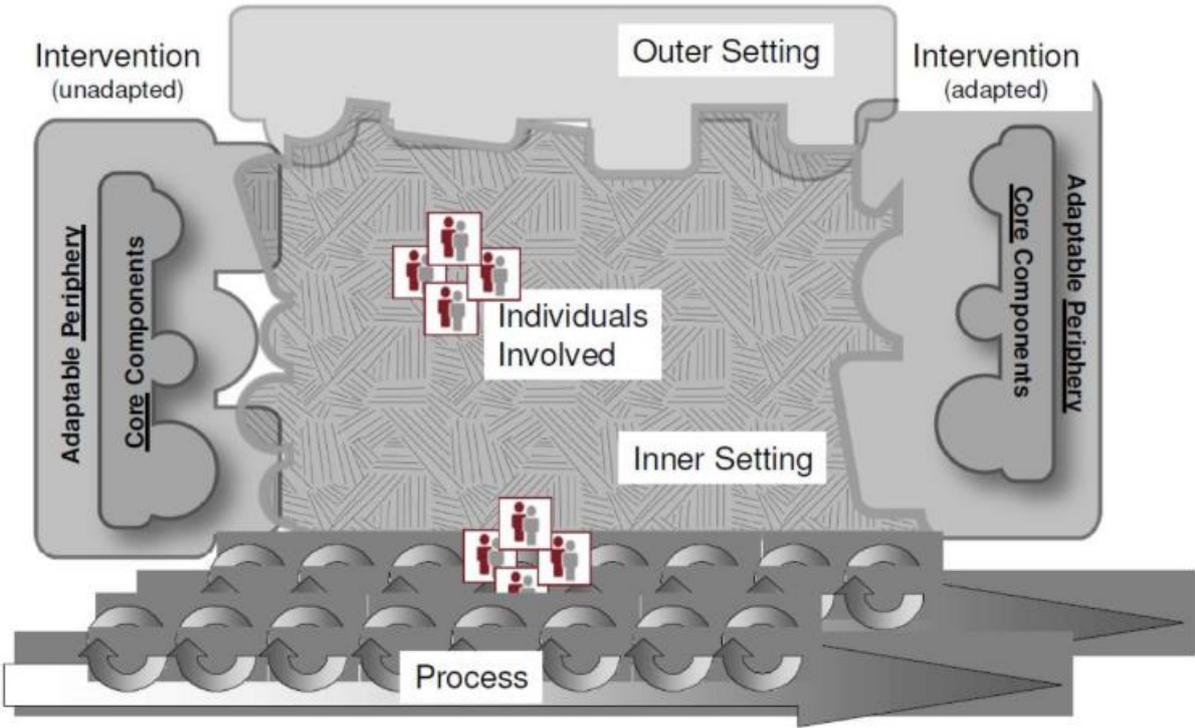


Figure 3: Consolidated Framework for Implementation Research (CFIR)

¹⁵ The development of this framework involved drawing on more than 500 published intervention and implementation studies. Since then, the framework has been applied repeatedly and more recently to understand system-level change.

¹⁶ Lukas CV, Holmes SK, Cohen AB, Restuccia J, Cramer IE, Schwartz M, et al. (2007) Transformational change in health care systems: an organizational model. *Health Care Management Review* 32:309-20.

The five major domains all interact with each other in complex ways to influence implementation effectiveness. The framework recognises that there are multi-level influences that shape implementation, including external influencers to the organisational and core implementation process components, which includes individuals and practitioners. Individuals play an important role in implementation as they can influence how the prototype is applied.

The domains

1. The intervention
2. Outer setting
3. Inner setting
4. The individuals involved
5. The process by which the implementation is accomplished.

1. The intervention: Mana Whaikaha is a system-level change prototype. This domain considers the characteristics of the intervention. It is a complex, multifaceted intervention designed to bring about system-level change for disabled people and the disability system. This domain considers the characteristics of the intervention, how the intervention has been designed, by whom and whether there is goodness of fit for the context it is implemented within. There are core components of the intervention that are integral (values and objectives) and essential in addition to an adaptable periphery. It is this adaptable periphery that allows the intervention to be modified to the setting without undermining the integrity of the intervention. In this instance, the Try, Learn and Adjust approach is the adaptable periphery while the values and objectives of the intervention (Mana Whaikaha) remain core.

2. The outer setting: This includes the economic, political, and social context within which an organisation (in this case, the prototype) resides.

3. The inner setting: This comprises the structural, political and cultural contexts within an organisation and through which the (prototype) implementation process will proceed.

Note that the interface between the outer and inner setting is dynamic. Whether factors are inner or outer depends very much on the context of the implementation effort.

4. The individuals involved: These are both with the design of the intervention and the implementation process. Individual behaviour can influence the implementation process in sometimes predictable and unpredictable ways. In this instance, employing a Try, Learn and Adjust approach involves adapting and making changes iteratively. It would be expected, from a behavioural science perspective, that individuals will have strong opinions, develop negative and positive feelings about the intervention, challenge it, modify particular tasks, complain about it, try to improve or redesign aspects and find or fail to find meaning in the innovation. For Mana Whaikaha, individuals in the inner setting include both the targeted users and affected individuals and the individuals who are part of the process of implementation. Advocating for or resisting implementation may involve individuals from the inner or outer setting.

5. The implementation process: For implementation to be successful, there needs to be both individual and organisational use of the prototype as it was intended. It involves several processes that do not necessarily occur sequentially. There can be multiple related processes happening simultaneously within the different levels of the organisation and outside of the organisation.

They may be formally planned, spontaneous, conscious or subconscious, linear or non-linear, aiming for successful implementation or undermining it.¹⁷

This framework has been applied to the large body of qualitative data collected and with a view to being able to identify what the barriers and enablers to success have been for Mana Whaikaha.

¹⁷ Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. (2009) Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implementation Science* 4, 50.