**Summary Report 2021**

**Repeat Study of the Disability Support System in the MidCentral Area**



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# Preface

“From the early 1970s New Zealand disability activists joined the growing international disability rights movement.”[[1]](#footnote-2)

Initial achievements of New Zealand’s disability rights movement included the inclusion of disability in the 1993 Human Rights Act, the 2001 *Disability Strategy*,and significant contributions to the development of the United Nations Convention on the Rights of Persons with Disabilities.

Momentum for change was building. In 2008, two significant events further increased awareness and opportunity:

* New Zealand ratified the United Nations Convention on the Rights of Persons with a disability.
* There was a Social Services Select Committee Inquiry into care and service provision for disabled people.

In 2011, the then Minister for Disability Issues commissioned an independent working group, comprised of leaders from the disability community, to develop a new approach to support for disabled people. The working group produced the landmark Enabling Good Lives Report (2011).

With the report now in place to guide change, the Enabling Good Lives (EGL) approach was developed further, through a series of community forums in the Waikato and Christchurch. In 2012, the then Ministerial Committee on Disability Issues agreed the EGL vision and principles would be the basis for change right across the disability support system. In 2013, the Minister for Disability Issues set up a National Leadership Group, to advise on aligning changes to the disability support system with the EGL vision and principles.

The next step was rolling out EGL demonstrations. In July 2013, Cabinet agreed to a three-year demonstration of aspects of EGL in Christchurch. This focused on school leavers, who experience considerable barriers in transition into education or employment. In December 2014, Cabinet agreed to the high-level design for a similar demonstration in the Waikato. The Waikato demonstration allowed a group of people (up to about 270) including all ages and different levels of complexity of needs, to opt in. It had a particular focus on beginning early,[[2]](#footnote-3) and on tāngata whaikaha-māori me ō rātou whānau  
Learnings from the Christchurch and to an extent from Waikato demonstration sites fed into the co-design of a prototype for a transformed system in the MidCentral area. Once co-designed, this prototype, now named Mana Whaikaha, was agreed to by Cabinet in 2017. It aimed to inform the nationwide transformation of the disability support system. Mana Whaikaha formally began on 1 October 2018.

The diagram that follows shows the five ways that the voices of disabled people and their families directly influenced the EGL approach grounded in EGL principles (see Appendix 3)

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In 2018, before the prototype started, SAMS Evaluate, Innovate, Educate (Standards and Monitoring Services[[3]](#footnote-4)) was commissioned by the Ministry of Health to undertake a Baseline Study in the MidCentral region.[[4]](#footnote-5) The Baseline Study was intended to provide a credible and robust foundation for future evaluations, to enable the assessment of system level change over time. It would help to measure what difference the transformed system is making, and its effects on the quality of experience, and life outcomes for disabled people and their whānau in MidCentral.[[5]](#footnote-6)

The 2021 Repeat Study was then commissioned by the Ministry as a follow up to the 2018 Baseline Study. Surveys and interviews for the Repeat Study took place in June 2021. The Repeat Study examined changes experienced by disabled people and their whānau in the MidCentral region over three years, including the introduction of Mana Whaikaha.

The purpose of the Repeat Study was to answer some key questions. These questions included:

* How do disabled people and their whānau experience Mana Whaikaha and what impact does it have on their lives?
* Do disabled people and their whānau experience Mana Whaikaha differently from the old system? If so, how, and why?
* What are the strongest critical shifts against the outcome domains showing statistical significance?

This document sets out the main findings of the Repeat Study. It will enable readers to:

* understand the key shifts brought about by the introduction of Mana Whaikaha;
* appreciate any changes, positive or negative, that have occurred in the wellbeing and experiences of people using the disability support system compared to the Baseline Study of 2018;
* explore areas requiring further evaluation and/or development.
* consider the findings in this report when planning the national rollout of EGL.

This research was conducted on behalf of the Ministry of Health by SAMS, an evaluation and education organisation governed and primarily staffed by disabled people and whānau. More information about SAMS is provided in appendix one.

# Executive summary

***Purpose and context of the Repeat Study***

This report provides an overview of the 2021 Repeat Study of the disability support system in the MidCentral region, conducted by SAMS.

The purpose of the Repeat Study in the MidCentral region, was to understand if the outcomes and experiences of disabled people and their whānau had changed since the Baseline Study conducted in 2018. Disabled people in MidCentral have historically had worse outcomes than disabled people in other parts of the country[[6]](#footnote-7). MidCentral disabled people also include ex-residents of the now-closed Kimberley Centre, an institution which provided residential support for people with learning disabilities.

During the period between the 2018 Baseline Study and the 2021 Repeat Study, Mana Whaikaha was established in MidCentral. Therefore, a key part of the Repeat Study was understanding the impact of Mana Whaikaha. This report briefly describes Mana Whaikaha, including the role of Connectors, and the use of personal budgets. It also describes other important features of the MidCentral disability support landscape. In particular, the main supports provided by contracted providers: Home and Community Support Services (HCSS), residential services, and Supported Living.

***Participants and methodology of the Repeat Study***

The Repeat Study, like the Baseline Study, involved two surveys: a disabled peoples survey, and a whānau survey. 154 disabled people took part in the disabled peoples survey, and 134 whānau members took part in the whānau survey.[[7]](#footnote-8) Most of these people had also been involved in the surveys conducted through the Baseline Study.

Participants in the disabled peoples study were made up of different subgroups, including people with different disability types, different levels of support need, and different services received. For the whānau survey, the most important subgroups were those; (1) who were supporting one or more disabled whānau members at home (the ‘at home’ group) and, (2) those who were supporting a disabled whānau member who lived somewhere else (the ‘not at home’ group). Both surveys included some people who had been in contact with Mana Whaikaha and/or a Connector, and some who had not.

Both surveys were designed in line with the principles of EGL. The surveys were carried out by interviewers who are skilled in working with disabled people, many of whom have lived experience of disability. The surveys comprised of a mix of demographic questions, open-ended questions, questions using Likert scales (asking people to rate their experiences and feelings), and questions using the Cantril ladder (a scale for measuring people’s self-reported wellbeing).

The disabled peoples survey was designed and carried out in such a way as to maximise the involvement of disabled people. Where participants did not wish to answer all the questions, interviewers focused on some key questions meaningful to the person. Some participants were not able to answer the questions directly so made use of a proxy respondent, notably a whānau member, partner or friend.

***Results of the Repeat Study***

For the disabled people’s survey, high level results are as follows:

* Over 65% (100 out of 154) had contact with Mana Whaikaha, and 54% (83 out of 153) had contact with a Connector. The Connector was reported to play an important role in improved results. Particularly around social connectedness, flexibility of funding and ability to exercise choice in services. Of the people who had contact with a Connector, three quarters had positive comments about the Connectors or the new system overall.
* The subgroup of children and young people experienced the clearest improvements since the Baseline Study, comparatively to other groups in the disabled person’s survey. Eight questions about the usability and flexibility of supports produced statistically significant results for children and young people.
* Mana Whaikaha has had high levels of engagement with children and young people and their whānau. 91% of children (30 out 33) had a Connector, compared to 44% of adults (53 out of 120).
* Across the whole group that took part in the disabled peoples, there were two statistically significant improvements[[8]](#footnote-9) between 2018 and 2021. These were in relation to the choice people had over their supports, and whether they had enough support to achieve their plan for a good life
* In addition to these statistically significant results, nearly half of the remaining questions showed a trend toward improvement. Although further review found these trends were significant in specific subgroups (rather than the whole group). This particularly applies to children and young people and individuals who had a Connector. Qualitative data also indicated positive trends in areas, such as, impressions about the current disability support system, and community participation.
* The questions which produced these results were as follows:

|  |  |  |  |
| --- | --- | --- | --- |
| **Eight questions about usability and flexibility of supports produced statistically significant results for disabled children and young people** (percentages based on two highest scores in five-point scale) | | 2018 | 2021 |
| 1.1 | Supports/services help me pursue my own interests | 38% | 75% |
| 2.1 | I can easily find out about the things I need for my support | 36 | 64 |
| 2.2 | I can make changes to my supports if I need to | 32 | 87 |
| 2.8 | I have choices about the kind of support I receive | 19 | 59 |
| 2.10 | I can make plans based on what I want and what I’m good at | 36 | 85 |
| 4.1 | My support happens at the times that work for me | 52 | 88 |
| 7.1 | I choose where my support money is used | 23 | 95 |
| 7.2 | I feel the amount of support I have is right for what I need | 42 | 88 |

* Within the 2021 disabled people’s survey, there was a statistically significant difference between people who had Connectors and people who did not. People with Connectors were more likely to report that they could choose where their support money was used.
* Within the 2021 disabled people’s survey, there was a statistically significant difference in wellbeing. This showed that people with physical disabilities reported poorer wellbeing than people with other disabilities.
* Within the 2021 survey disabled people were generally satisfied with their supports. However, disabled people supported by HCSS were less likely to be satisfied. Participant insights from disabled people identified a range of issues that suggested they did not feel empowered to influence the supports they were receiving.
* Within the 2021 survey disabled people were aware of the pressures placed on Mana Whaikaha as a result of high demand. This was impacting the amount of engagement disabled people were having with Connectors This was due to high workloads experienced by those in the Connector role.

For the whānau survey, high level results are as follows:

* 71% of whānau members (95 out of 134) indicated they had contact with Mana Whaikaha. Levels of contact were higher for whānau who supported at least one disabled person in the family home or the ‘at home’ group; 85% (or 71 out of 84), compared with the remaining “not at home” group 48% (24 out of 50).
* The ‘at home’ group were more likely to have had contact with a Connector, at 81% (68 out of 84) compared to 26% (13 out of 50) of the remaining group.
* 54% of the overall group (56 out of 103) indicated that the new system of support had made changes in their lives. 84% of these people indicated the changes had been positive.
* There were five statistically significant improvements[[9]](#footnote-10) when all respondents in the whānau survey were considered together. These related to the ease of use of the funding process, how well supports were working, and people’s connectedness to the community. The questions that produced these results were as follows:

|  |  |  |  |
| --- | --- | --- | --- |
| **Five questions across different areas produced statistically significant results for all whānau** **respondents** (percentages based on two highest scores in five-point scale) | | 2018 | 2021 |
| 5 | I think the funding allocation process is clear | 36% | 55% |
| 13 | Overall, our supports work flexibly (how we want them to) | 66 | 78 |
| 14 | Supports enable us to do the things that are important to us | 59 | 76 |
| 18 | Overall, supports for my family member work well | 63 | 81 |
| 22 | We are supported to be connected in the community | 39 | 62 |

* Whether whānau were in the ‘at home’ group or the ‘not at home’ group was found to be an important factor. 17 statistically significant improvements were seen for the ‘at home’ group, between 2018 and 2021. Five of these results relate to improvements to funding, and the remaining 12 to other areas. The questions that produced these results are as follows:

|  |  |  |  |
| --- | --- | --- | --- |
| **Seventeen questions produced statistically significant results for the ‘at home’ group of whānau** (percentages based on two highest scores in five-point scale) | | 2018 | 2021 |
| 3 | Supports are easy to access and use | 41% | 64% |
| 4 | Contact with the disability support system helps us achieve our goals. | 41 | 66 |
| 5 | I think the funding allocation process is clear | 26 | 64 |
| 6 | I believe the funding allocation is positive | 32 | 72 |
| 7 | I know how much money is allocated for support | 46 | 83 |
| 8 | I know what the funding is used for | 68 | 85 |
| 9 | The funding is sufficient to meet our needs | 37 | 74 |
| 10 | Supports anticipate what I/we need | 32 | 54 |
| 12 | Supports work when we want them | 44 | 76 |
| 13 | Overall, our supports work flexibly (how we want them to) | 58 | 79 |
| 14 | Supports enable us to do the things that are important to us | 46 | 73 |
| 17 | We can make the changes to our supports as we need to | 63 | 76 |
| 18 | Overall supports for my family member work well | 57 | 78 |
| 19 | I can access all of the information I need about support services | 44 | 54 |
| 20 | I think information from support services is easy to understand | 34 | 56 |
| 22 | We are supported to be connected in the community | 21 | 66 |
| 23 | We can use community options, connections, and services that are for everyone before we have to use specialised disability services | 42 | 77 |

* Within the 2021 whānau survey, two statistically significant differences could be seen between the ‘at home’ group and ‘not at home’ group. The ‘at home’ group felt more in control of their supports, but the ‘not at home’ group reported higher levels of wellbeing.
* Participant insights from whānau indicated that they valued the flexibility in their supports. They also felt positive about the role of Connectors, and were aware of the impacts of high demand on Connectors’ workloads.

***Implications of results and directions for further research***

The report concludes with the implications of the Repeat Study, and proposes directions for further research, drawn from the findings by the study authors. The results of the Repeat Study have implications for Mana Whaikaha, and for the provision of disability supports more broadly. People receiving contracted services (HCSS, residential services and Supported Living) need greater ability to influence these services. Focus is needed to improve the experiences of people with physical disabilities, including their experience of HCSS. Information for disabled people and their whānau could be improved. Support and appropriate resourcing are required in the future to reduce the size of Connectors’ current caseloads, which are unsustainable.

Potential directions for further research raised by this study relate to the experiences of disabled people. Especially for tāngata whaikaha Māori, who engaged with Mana Whaikaha after the 2018 Baseline Study, and who therefore were not included in the Repeat Study. Research into the experiences of Māori will ideally be framed by Maori within a Te Ao Māori approach. Based on the results, the experiences of people with physical disabilities, and people’s experiences of traditional services (residential and HCSS) point to a need for change. This includes exploration of service models and commissioning in an EGL environment. Specific issues to do with vocational options for disabled people were raised in the Repeat Study, and warrant exploration of how a variety of community options could be established based on individuals needs and preferences. Finally, the impacts caused by delays in access to diagnosis and assessment, as well as the impacts of delays in obtaining equipment need to be better understood.

The findings outlined in this report, as well as the directions for future research, are considered important inputs into the current redesign of the wider disability support system.

# Purpose of the Repeat Study

The main objective of the 2021 Repeat Study was to understand the experiences and life outcomes of disabled people and their whānau in the MidCentral region. The Repeat Study follows on from the Baseline Study conducted in 2018.

By updating the 2018 Baseline Study, the Repeat Study also aimed to show how the experiences of disabled people and their whānau have changed over three years. The Repeat Study also explored the experiences of MidCentral disabled people and their whānau since Mana Whaikaha was established shortly after the Baseline Study in 2018.

The Baseline Study had found that, while there were areas of strength in MidCentral’s disability supports, significant improvements were also needed. Revisiting these results in 2021 is an opportunity to see whether positive change is occurring.

The insights generated by the Repeat Study are intended to inform further improvements to the services and supports accessed by disabled people and their whānau.

# Context for Repeat Study

## Disabled people and their families/whānau in MidCentral

While it is difficult to know the total number of disabled people living in MidCentral, 2021 data indicated 2439 MidCentral disabled people were identified by Mana Whaikaha. These are people who prior to the establishment of Mana Whaikaha would have been eligible for Disability Support Services[[10]](#footnote-11). Note that not everyone eligible to access supports through Mana Whaikaha has accessed support through them and continue to receive the supports they already had. Within the previous system reviews of support were completed annually and at three-to-five-year intervals. Except for those who contacted Mana Whaikaha early on, young families and those reported to be in crisis, the aim has been to contact people as their reviews became due. More information on the population that Mana Whaikaha is responsible for is included in appendix four.

In 2018 Ernst & Young (EY) undertook research comparing MidCentral Disability Support Service (DSS) clients to the national average for DSS clients across the country. The research confirmed that MidCentral DSS clients were below the national average for access to education and academic achievement; employment and income; and ambulatory-sensitive hospitalisations[[11]](#footnote-12) in most age groups. In other areas, such as use of mental health services and family and relationships, MidCentral DSS clients scores trended closer to the national average.

While it is not known definitively why MidCentral DSS clients have experienced worse outcomes, researcher insights (Allen and Clarke, 2020)[[12]](#footnote-13) suggest that contributors are potentially demographic factors, socioeconomic status, and access to services.

Disabled people in the MidCentral region include ex-residents of Levin’s Kimberley Centre, an institutional facility for people with both physical and learning disabilities. Kimberley finally closed its doors in 2006, after “a lengthy period of uncertainty and false starts”, as part of a movement towards the deinstitutionalisation of disabled people.[[13]](#footnote-14) [[14]](#footnote-15) MidCentral disability support services have many clients with high and complex needs who have transitioned into the community post deinstitutionalisation.

## Mana Whaikaha: a MidCentral prototype for a transformed disability system

### How Mana Whaikaha began

Mana Whaikaha has its roots in the disability rights movement, as well as in the vision and principles of EGL. Drawing on learnings from EGL demonstration projects in Christchurch and Waikato, disabled people and their whānau in MidCentral embarked on a co-design process to transform the disability system. Cabinet agreed to the establishment of the prototype in 2017, and on 1 October 2018, Mana Whaikaha formally began.

The MidCentral region was chosen because of the size and characteristics of its disabled population, and because it did not already have a demonstration project or Local Area Coordination.[[15]](#footnote-16)

Mana Whaikaha replaced Enable, previously the MidCentral Needs Assessment and Service Coordination (NASC) service. However, as discussed below, Mana Whaikaha takes a different approach based on disabled people’s strengths and aspirations as opposed to a needs-based deficit focused approach.   
  
From the outset, disabled people and whānau have been involved in influencing the development of Mana Whaikaha through a regional leadership group. Day to day activities under the Mana Whaikaha ‘umbrella’ are supported by the Ministry of Health. They provide some of the back-office functions related to contracts with providers. Mana Whaikaha facilitates the allocation of the funding available, making sure disabled people get their personalised budgets and the services they choose.

### Who Mana Whaikaha supports

Mana Whaikaha is not a service provider but is a prototype of a transformed system that provides supports to disabled people in a new way. It is available to adults and children in the MidCentral region who meet the criteria for DSS.[[16]](#footnote-17)

Disabled people and whānau can contact Mana Whaikaha, be referred in from the community, or may be contacted for a review of support when due by Mana Whaikaha. They may choose to engage directly with a budget advisor directly to discuss budgets and what is possible. The level of contact with Connectors is driven by the disabled person and whānau. Reduced contact with connectors occurs usually when they feel they are clear about what they need, have confidence in their allocation and do not require detailed planning with a connector. Information and processes aim to be easy to use[[17]](#footnote-18).

. At the beginning of Mana Whaikaha there was a high influx of new people accessing the system, particularly children and young people. However, people who engaged early also included others who connected proactively to seek a review of their already established support. People living at home with their whānau are more highly represented among those who have Connectors. This group also showed higher representation of children and young people.

### Connectors and personal budgets are part of Mana Whaikaha

Mana Whaikaha represents a move away from more prescriptive support arrangements to an approach grounded in the eight principles of EGL[[18]](#footnote-19)

Disabled people and their whānau have the option of working with a Connector, who helps them identify what they want and how to get there. Connectors can support disabled people by working with government agencies and services, for example early childhood education or the Ministry of Social Development). They also support the disabled person to get what they need, build relationships, and stay connected. Connectors may also help people plan how they will use their personal budgets.

Personal budgets are also a feature of Mana Whaikaha.[[19]](#footnote-20) Personal budgets are intended to provide disabled people and their whānau with greater decision-making over their support, and more flexible options. The level of a personal budget is decided according to what the disabled person wants to achieve, and their strengths and aspirations, including their perspective on how day to day needs can be met.

To buy something with their personal budget, a disabled person must be able to show it helps them overcome a barrier which will decrease the impact of their impairment. This means disabled people can spend their personal budgets on ‘traditional’ supports if they wish, as well as diverse things like counselling or therapy, equipment, or involvement in a gym, improved community connections or learning a new skill.

Disabled people may choose to purchase their own services and supports, rather than engage with ‘traditional’ services, so survey responses that comment on ‘services’ should be read with this in mind.

Disabled people can choose to have their personal budget managed by a funding host, a provider of supports, or another person of their choice; or they can choose to manage it themselves[[20]](#footnote-21).

### The evolution of Mana Whaikaha

During the early days, 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.”[[21]](#footnote-22) Mana Whaikaha personnel quoted “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.

Researcher and participant insights (discussed further throughout) help explain some key trends Mana Whaikaha has seen in its first three years.   
  
From the point Mana Whaikaha began in October 2018, there has been unexpectedly high demand, including for Connectors. [[22]](#footnote-23) This high demand has placed pressure on Connectors. While disabled people in the Repeat Study were generally positive about the Connector role, Connectors have been ‘spread thin’. Their high caseloads have reduced the amount of time available to support individual disabled people. Some disabled people and their whānau in the Repeat Study had limited contact with their Connectors or were on a waiting list to be allocated a Connector.

A high proportion of people engaged with Mana Whaikaha are disabled children and young people. 91% of the children and young people in the Repeat Study had contact with Connector, compared to 44% of adults.

However, disabled adults’ contracts with existing providers (for HCSS, Supported Living contracts and residential services) have usually been rolled over, so the adults already receiving these services have continued as before. For those who had their existing arrangements rolled over, some did not know about Mana Whaikaha, what it offered, or had the option to work with a Connector. This was evident from interviews with disabled people and whānau.

Contract changes to include Flexible Disability Support (FDS) arrangements with these same providers are subject to analysis in an upcoming report on FDS in MidCentral and Christchurch.

As well as children and young people, Mana Whaikaha has been supporting people in crisis. This could be a disabled person experiencing crisis, or the whānau that support them. In these situations. Mana Whaikaha was likely to provide additional support and resources from crisis funding. The aim being to intervene early to prevent more significant, and/or long-term issues in the future.

Over the course of three years, there has been a marked increase in people who have come under the responsibility of Mana Whaikaha. Further work is required to look at a Te Ao Māori approach, with Māori for Māori, in terms of planning and delivery of culturally appropriate services. As discussed further on, there are a range of important issues for MidCentral tānagata whaikaha Māori disabled people and their whānau, with more research required.

## Other features of the Disability Support Services landscape in Midcentral

As part of the Baseline and Repeat Studies, both the disabled persons surveys and whānau surveys asked people about the supports they received. Disabled people, including those involved with Mana Whaikaha, receive funded supports of various types. These may be contracted formal DSS supports or may be supports a person chooses to buy with their personal budget.

The objective of this report is not to describe the full range of DSS supports available to disabled people.[[23]](#footnote-24) However, the three main DSS services (involving contracts with formal service providers, with funding allocated by Mana Whaikaha) are briefly described below. This is because the role of supports in people’s wellbeing and outcomes was a key line of inquiry for both the Baseline Study and Repeat Study, meaning that being familiar with these supports is important to understanding the results. Note that HCSS and residential services could be considered ‘traditional’ service models whereas Supported Living was established in 2003 and aimed in its design to enable greater flexibility and choice.

**Home and Community Support Services (HCSS)** help people live at home, and while they are mostly used by adults with physical disabilities, they are also used by whānau of children and younger people with a range of needs. HCSS can provide household management support, such as help with preparing meals and cleaning, as well as personal care, including help with eating, showering, and getting around the house. Despite their name, HCSS typically does not support people’s community involvement.

**Residential services** provide the disabled person with 24/7 live-in support (this is their key difference from other supports provided in the home), usually in a group home situation involving six or fewer residents. Sometimes, the disabled person lives in a larger facility, like an aged residential care facility. Residential services are open to adults with a disability, regardless of the type of disability, and provide full support based on personal plans. In MidCentral, there is a higher proportion of older people in residential services partly because people who had lived at Kimberley moved into residential care when Kimberley closed.

**Supported Living** is a service that enables disabled people to live independently, by providing support in the areas of life where it is most needed. People receiving Supported Living are generally those with learning disabilities or Autism Spectrum Disorder (ASD).[[24]](#footnote-25) Supported Living is open to people aged 17 or older, and people who receive it typically live in their own home or flat, although some will live with whānau. Support is based on a personal plan and can include assistance with activities like getting up and getting ready for work, attending a community activity, or learning to cook a meal.

It is important to note that people receiving the services above are eligible to be supported by Connectors through Mana Whaikaha, and a proportion of the study participants have already chosen this. However, because Connectors are a limited resource, and because children and young people make up a high proportion of disabled people involved with Mana Whaikaha, groups using the above services (usually adults) are less likely to have engaged yet with Connectors.

# Participants in the Repeat Study

Both the Baseline Study and Repeat Study made use of surveys and interviews to gather data. A disabled people’s survey was held, as well as a whānau survey. Survey participants were asked about different aspects of their identity and experience. This enabled the Repeat Study to analyse the experiences and outcomes of different groups.

## Participants in the disabled people’s survey

There were 154 participants in the 2021 disabled people’s survey, who belong to different and overlapping subgroups. 119 of these participants (77%) had carried over from the 2018 disabled people’s survey, and the remaining 35 (33%) were new participants (matched pairs, explained further below). Some of the key characteristics of these participants are described below. These are important for the interpretation of the results of the Repeat Study.

* 118 (77%) of survey participants were adults, and 36 (23%) were children or young people.
* 122 people identified as New Zealand European, 31 identified as Māori, and 10 identified as other ethnic groups (note that people could identify as having more than one ethnicity).
* 81 (53%) of participants identified as male, 70 (45%) identified as female, and 3 (2%) identified as gender diverse.
* 84 (55%) of participants have a learning disability, 39 (25%) have a physical disability, and 31 (20%) have ASD.
* Survey participants had different levels of need. 50 (32%) had very high needs, 45 (29%) had high needs, and 58 (38%) had moderate needs.
* 69 of the 154 participants (45%) used a proxy to answer the survey. People with very high needs most commonly used proxies.
* Some disabled people received DSS services involving formal contracts with providers: 39 (25%) lived in residential services; 24 (16%) used Supported Living contracts; and 23 (15%) used HCSS.
* People with physical disabilities were mostly likely to live in their own home. They made up 83% (19 out of 23) of the participants receiving HCSS.

## Participants in the family/whānau survey

There were 134 whānau participants in the 2021 whānau survey. 99 of these participants (73%) also took part in the 2018 whānau survey, and the remaining 36 (27%) were new participants. Some of the key characteristics of participants in the whānau survey are:

* 84 out of 134 (63%) of whānau members were supporting one or more disabled family member at home. They are referred to as the ‘at home’ group. The other 37% (50 out of 134) were supporting a disabled family member living in another setting outside their home. They are referred to as the ‘not at home’ group.
* 68% whānau members in the ‘not at home’ group (34 out of 50) were using residential services to support their disabled family member.
* Whānau members in the ‘at home’ group tended to be younger than those in the ‘not at home’ group. This reflected the fact that disabled children and younger people are more likely to live at home, and less likely to live in other settings, than disabled adults.
* 118 of the whānau members who participated identified as New Zealand European, 18 were Māori, and 11 identified as other ethnic groups (note that people could identify as having more than one ethnicity).

# Methodology

This section looks at the methodology used for the Repeat Study, starting by describing features that were common to both the disabled people’s survey and the whānau survey. Then follows a section about the specific methodology of the disabled people’s survey, and a shorter section about the specific methodology of the whānau survey. The disabled people’s survey receives greater focus because of how its methodology was designed to be suitable for disabled people.

## Ethical considerations across both the disabled people’s survey and whānau survey

Standard ethical considerations were applied through both surveys, in relation to consent (and the ability to stop taking part at any time without any consequence); cultural appropriateness; confidentiality; privacy and data storage; and how to respond to any disclosures made by survey participants. Consideration was also given to interviewer security in the event of a safety risk that might be caused by a participant in crisis.

Because disabled people were being interviewed, particular care was taken to ensure ethical considerations took their specific circumstances into account. This is discussed further below.

## Basis of survey questions in Enabling Good Lives principles and outcomes domains

The questions in both the disabled people’s survey and the whānau survey relate to outcomes domains that built on other existing outcome domains and approaches. These are:

* Self-determination
* Health and wellbeing
* Physical and financial security
* Relationships
* Social and community inclusion
* Self-fulfilment/life satisfaction

These outcomes domains relate closely to the principles underpinning EGL, as shown in the table below. Answers to the survey questions can therefore be seen as indications of whether the experiences of disabled people in MidCentral are helping them move towards experiencing the EGL principles practically in their lives.

|  |  |
| --- | --- |
| Vision |  |
| In the future, disabled children and adults and their families will have greater choice and control over their supports and lives and make more use of natural and universally available supports. | |
| Principles |  |
| Self-determination | Disabled people are in control of their lives. |
| Beginning early | Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available. |
| Person-centred | Disabled people have supports that are tailored to their individual needs and goals and take a whole of life approach rather than be split across programmes. |
| Ordinary life outcomes | Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, social participation – like others at similar stage of life. |
| Mainstream first | Disabled people are supported to access mainstream services before specialist disability services. |
| Easy to use | Disabled people have supports that are simple to use and flexible. |
| Relationship building | Supports build and strengthen relationships between disabled people, their whānau and community. |

## Types of questions used

Both the disabled person’s survey and the whānau survey used the following question types:

**Demographic questions:** for example, participants were asked questions about age, ethnicity and income.

**Open-ended questions:** answers to these questions were subject to analysis applied by an expert panel who coded people’s answers according to themes. The frequency with which those themes appeared was then calculated.

**Likert scale questions:** survey participants were given statements, such as ‘I believe the funding process is clear’, and were asked to rate their response on a five-point scale, ranging from ‘yes/totally’ to ‘no/not at all’. Participants could also respond ‘don’t know’ or ‘prefer not to answer’.

**The Cantril ladder:** this is a well-known wellbeing measurement used worldwide in Gallup polls. It asks people to “imagine a ladder, with steps numbered from 0 at the bottom to 10 at the top. The top of the ladder represents the best possible life for you and the bottom of the ladder represents the worst possible life for you.  On which step of the ladder would you say you personally feel you stand at this time?”.[[25]](#footnote-26)  The ladder was represented in the disabled people’s survey as a staircase, as this was visually and conceptually more relevant to people with disabilities.  It was intended to capture a single point in time (the day the person did the survey).

## Use of matched pairs

Some disabled people and members of whānau who took part in surveys for the 2018 Baseline Study did not opt to take part in surveys for the 2021 Repeat Study. As far as possible, the researchers replaced those people in the 2021 Repeat Study with ‘matched pairs’, or people with similar characteristics. For example, age, gender, ethnicity, geographical location, disability type and degree of assessed need. Using this approach meant the group for each survey stayed as similar as possible between the Baseline Study and the Repeat Study.

For the 2021 disabled people’s survey, 119 out 154 people (77%) had also taken part in the 2018 disabled people’s survey. For the 2021 whānau survey, 98 out of 134 people (73%) had also taken part in the 2018 whānau survey.

## Key features of the methodology for the disabled people’s survey

### How participants in the disabled people’s survey were selected

As described above, most of the participants in the 2021 disabled people’s survey carried over from 2018, with matched pairs as far as possible replacing those who did not carry over.

Participants were originally drawn in 2018 from a Ministry of Health list of MidCentral people using DSS services. It was not possible to include a fully representative sample of MidCentral people using DSS services, as this would have required more than 400 people. Instead, stratified random samples of participants were used, which categorised disabled people based on disability type, degree of support needed, geographical location, ethnicity, gender, and age. Participants were invited to take part by letter.

154 people took part in the 2021 disabled people’s survey (compared to 172 people in the 2018 disabled people’s survey).

Note that five people who took part in the 2018 Baseline Study as children and young people have moved into the adult age bracket for the 2021 disabled people’s survey (ie 18+ years of age).

### How interviews for the disabled people’s survey maximised disabled people’s involvement

Both the disabled people’s survey and the whānau survey used an interview-based approach, to ensure the greatest accessibility possible for a range of participants. Interviews were conducted by trained and experienced interviewers, including interviewers with lived experience of disability.

The format of the interviews was designed to maximise participants’ involvement and self-reporting. Efforts were made to match the skills of the interviewer with the requirements and preferences of the participants. Before interviews took place, there was a period for interviewer and participant to ‘get to know each other’. This enabled a connection to be built and allowed the interviewer to understand the participant’s preferred approach.

Interviewers provided assistance to the person, depending on their ability. During interviews, interviewers had the discretion to decide whether the participant was able to complete all or only part of the survey. This means that for some people, only key questions, or a limited range of questions, were answered.

**The use of proxies to answer on behalf of disabled people**

Participants in the disabled people’s survey could be seen as belonging to two groups:

* Disabled people who were able to respond to the survey themselves, with or without support
* Proxy respondents (proxies) who completed the survey on behalf of the disabled person

A proxy was a person who knew the disabled person well, such as a family/whānau member, spouse, or friend. Disabled people’s support workers, or managers of services, could not act as proxies because some of the questions in the survey were about them.

One challenge with the use of proxies was where the survey asked subjective questions about disabled people’s quality of life. This issue is discussed further below.

### Specific ethical considerations when interviewing disabled people

Some people who took part in the disabled people’s survey had learning disabilities. Special care was taken to gain consent from these participants, to make sure they clearly understood the implications of their involvement (for example, having consent forms written in plain language; using assistive technology where available; and involving people who know the disabled person well to assist with understanding).

Where potential participants were unable to give informed consent due to the significance of their learning disabilities, researchers sought agreement for participation from either the person’s main caregiver (if they were under 18 years of age) or their legal guardian. [[26]](#endnote-2)

Several of the questions in the disabled people’s survey asked about the person’s subjective state; for example, if they felt happy with life, or safe and secure. Only a person experiencing a subjective state can report on that subjective state, so proxies did not answer subjective questions.

Researchers who work with disabled people must consider particular factors in disabled people’s lives that may influence their answers. These factors include:

* acquiescence: people may wish to please the interviewer or others with their responses (this can be a particular challenge with people who have learning disabilities)[[27]](#footnote-27)
* lack of alternative viewpoints: for example, people with disabilities and their supporters may view the support system as working perfectly because they do not know of any other alternative
* low expectations and gratitude: having some help, when there was none previously, can result in relief and gratitude, without an understanding of what may be possible
* hegemony: people may be genuinely positive about the support system because they are heavily invested in the system in various ways.[[28]](#footnote-28)
* homeostasis: people can adapt to their situation in a manner that they reach an acceptable degree of subjective satisfaction either with services or their own life (wellbeing), even when others (outsiders) may judge the situation quite differently.[[29]](#footnote-29)

Interviewers were trained and had tools to use if they detected these factors such as acquiescence and comprehension issues; however, the situation did not arise.

### Non-responses, and ‘not applicable’ responses

Participants in both the disabled people’s survey and whānau survey did not have to answer any questions they did not wish to.

The disabled people’s survey was designed not to tire the people surveyed. Where a person did not wish to answer all questions or where the interviewer believe fatigue may be an issue, priority questions were highlighted, so interviewers could focus on these first.

## Key features of the methodology for the whānau survey

### How whānau survey participants were selected

The whānau survey involved whānau, spouses, legal guardians[[30]](#footnote-30) and other advocates for the disabled people who took part in the disabled people’s survey.

Permission was gained from disabled people to contact these people. Where the disabled person was legally represented by someone else, whānau or a guardian, then the representative was contacted directly. 134 people took part in the 2021 whānau survey (compared to 152 in 2018).

## Strengths and limitations of the methodology

Strengths of the Repeat Study methodology include its mix of qualitative and quantitative methods, which allows a more complete picture to be developed than if only one method was used.

The longitudinal nature of the Baseline Study and Repeat Study allows for changes over time to be explored among largely the same group of people. With matched pairs helping to ensure continuity where disabled people or whānau members did not opt to take part in the Repeat Study.

However, a limitation of the longitudinal nature of the study was that, because it followed broadly the same two groups of people across three years, newcomers to Mana Whaikaha were not included in the Repeat Study.

Practicality and resourcing limitations meant the Baseline Study and Repeat Study had relatively small sample sizes for both the disabled people’s survey and the whānau survey. Stratified random samples of respondents helped ensure that different subgroups were represented. However, in some cases numbers remained quite small for some subgroups and significance testing was not possible

This included relatively small numbers of Māori disabled people and Māori whānau. While statistically significant results were not generated for some subgroups, important directions for future research are suggested. These are discussed further on, in the section ‘Implications of results and directions for further research’.

## Impacts of COVID on the Repeat Study

Interviews for the Repeat Study took place in June 2021, during the COVID pandemic. While the surveys did not specifically ask about COVID, it is possible that people’s experiences of COVID influenced their survey responses – for example, their subjective wellbeing, or how recently they had engaged in activities outside the home.

# Results of the Repeat Study

## Interpreting the results of the Repeat Study

This report of the Repeat Study is based on different kinds of evidence. These are:

* **Statistically significant results**. Statistical significance occurs when there is confidence (95% or higher) that a difference is unlikely to occur by chance[[31]](#footnote-31).
* **Descriptive statistics.** These describe frequency, or how often a thing happens; for example, how many people had a Connector. Because questions about Mana Whaikaha and Connectors were asked for the first time in 2021, we do not yet have data to show shifts over time.
* **General trends**. These are quantitative findings that may not reach the threshold of statistical significance, and/or results from qualitative analysis.
* **Participant insights**. These are drawn from qualitative analysis. They may not fall into the categories of statistically significant results or general trends, but offer practical insights into issues, causes, and options for change.
* **Researcher insights.** These draw on the evidence above, plus a thematic analysis of qualitative data conducted by a panel involving the principal researcher, and representatives of both whānau and disabled people.

In the section that follows, quantitative results are split out from other kinds of results. This is to distinguish between results that are backed by evidence from data, and those backed by other types of evidence. Quotes included in italics are used to identify participant insights.

## Results from the disabled people’s survey

As well as ‘about me’ demographic questions, the disabled people’s survey asked questions grouped into the following topics:

* Wellbeing
* Identity
* Authority
* Connections
* ‘My time’
* Contribution
* Resources

The questions asked as part of the disabled people’s survey can be found in appendix five. A comparison of results from selected questions, between the 2018 and 2021 disabled people’s surveys, can be found at appendix six.

### Quantitative results from the disabled people’s survey

***Number of disabled people who had contact with Mana Whaikaha and Connectors, and the experiences they had, in 2021***

To interpret the descriptive statistics below, note that not everyone who has contact with Mana Whaikaha is allocated a Connector (or seeks one).

As discussed above, that Mana Whaikaha has not been able to prioritise contact with people already traditional services, like residential services and HCSS. However, where people have requested a Connector or a funding specialist, this has been provided. Overall, 65% of the disabled people surveyed (100 out of 154) indicated they had contact with Mana Whaikaha.

|  |
| --- |
| 54% of this overall group (83 out of 153) indicated they had contact with a Connector. |
| Out of this overall group, 98 people answered the question, ‘For you, do you experience Mana Whaikaha differently from the old system?’ (Q.A20). Two thirds of these people (65 out of 98) experienced Mana Whaikaha differently from the old system. One third (33 out of 98) experienced no change. |
| Of the people in Supported Living arrangements, only 54% had contact with Mana Whaikaha (13 out of 24). Only 42% had contact with a Connector (10 out of 24). |
| Out of the overall group, 123 people answered the question ‘Has the new system of support made any changes in your life?’ (Q.A22). 46% indicated that the new system of support had made changes in their lives (57 out of 123). |
| Of the people with very high support needs, 60% had contact with Mana Whaikaha (30 out of 50). However, only 36% had contact with a Connector (18 out of 50). This group includes children and young people with very high needs. |

The disabled people’s survey confirmed that children and young people have a high level of contact with Mana Whaikaha and Connectors, with 92% of children and young people having had contact with a Connector.

|  |  |  |  |
| --- | --- | --- | --- |
|  | Children and Young people (<18 years) | Adults (18+ years) | Total |
| Had contact with Mana Whaikaha | 92%  33/36 | 57%  67/118 | 65%  100/154 |
| Had contact with a Connector | 91%  30/33 | 44%  53/120 | 54%  83/153 |

Analysis of open-ended questions also showed that disabled people generally expressed that they have positive experiences with Mana Whaikaha.

Disabled people had mostly had positive experiences with their Connectors, and more specifically the personal contact they had with them:

* Of the 67 written responses from participants who had contact with a Connector, 75% (50 out of 67) had positive comments about Connectors or the new system overall
* A further 20% (13 out of 67) gave neutral or mixed responses.

Participant insights in the section below shed more light on why disabled people were having these positive experiences.

***Statistically significant improvements for all respondents in the disabled people’s survey, between 2018 and 2021***

There were 42 Likert scale questions in the 2021 disabled people’s survey that were asked of all participants. Two showed statistically significant[[32]](#footnote-32) improvements from 2018 to 2021 for all respondents. These questions related to people’s supports.

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | Percentage who agreed (“Yes/Totally” or “Mostly”)[[33]](#footnote-33) | |
| Q |  | 2018 | 2021 |
| 2.8 | I have choices about the kind of support I receive | 48%  54/112 | 61%  67/110 |
| 4.2 | I have enough support to achieve what I want | 67%  104/155 | 79%  108/136 |

***Statistically significant improvements for children and young people, between 2018 and 2021***

The early resources and capacity of Mana Whaikaha have been focussed particularly on children and young people. This may be why there were more statistically significant improvements from 2018 to 2021 for this group than for all respondents. It should be noted that 82% of the responses for children and young people in the 2021 survey were proxies.

Of the 47 quantitative questions, nine showed statistically significant improvements from 2018 to 2021 for children and young people.

Figure 1 - Significant Findings for Children and Young People

***A statistically significant difference for people with Connectors and without Connectors, in 2021, in their ability to choose where their support money is used***

A key part of a Connector’s role is supporting disabled people to plan what they want to achieve, and how they will use their allocation to achieve it. The disabled peoples survey found that disabled people with Connectors were more likely than than without Connectors to report they could choose where their support money was used.

Figure 2: Agreement with "I choose where my support money is used", Connector versus no Connector, 2021

***A statistically significant difference in wellbeing between people with physical disabilities and those with other disabilities, in 2021***

The survey explored disabled person’s perceptions of their wellbeing, by asking people to indicate on an eleven-step Cantril Ladder how they felt about their life. Because wellbeing is subjective, proxies cannot report on another person’s wellbeing. Most children and young people used proxies, as did most people with ASD, so this means most people in these groups were generally not included. In the two groups we can compare, participants with physical disabilities scored significantly lower than respondents with learning disabilities. People with learning disabilities scored almost identically as the general population in 2018.[[34]](#footnote-34)

|  |  |
| --- | --- |
|  | Average Cantril Ladder Score |
| Overall | 6.79 (n = 82) |
| People with Physical Disabilities | 6.25 (n = 37) |
| People with Other Disabilities | 7.26 (n = 39) |

***Disabled people’s satisfaction or dissatisfaction with support workers or providers, in 2021***

Disabled people were asked about the types of supports they receive, and follow-up questions to understand how satisfied they were with those supports. Their responses included both the support workers they engage with, and service providers.  
  
Coding of open-ended questions shows that disabled people generally made positive comments about support workers. When asked what they disliked about their supports, comments focused on service providers rather than support workers.

Disabled people who use formal services (such as people in residential homes and those supported by HCSS contracts) were the least satisfied with their supports:

* Over half (57% or 13 out of 23) of respondents who used residential services in 2021[[35]](#footnote-35) indicated some dissatisfaction with service providers.
* 87% (13 out of 15) of respondents using HCSS contracts indicated dissatisfaction with their provider, and 33% indicated dissatisfaction with their support staff.

Nearly half (49%) of people with physical disabilities use HCSS providers or 83% of all people who use HCSS. In contrast, the majority of people who use residential services have a learning disability (89%).

Disabled person’s participant insights, set out further below, shed light on why some people felt dissatisfied with supports.

### Participant insights from the disabled person’s survey

This section focuses on issues that disabled people identified through open-ended questions in the disabled people’s survey. Quotes used are taken directly from disabled people, in their own words.

***Disabled people’s insights about challenges with their supports***

As discussed above, most disabled people made positive comments about their support workers. However, people using traditional services expressed some dissatisfaction, with people using HCSS expressing the most dissatisfaction.

The main issues people identified with service providers tended to be lack of stimulation or activities, poor resourcing, poor communication, lack of partnership, and providers making changes without consultation. People who used formal service providers felt they had few opportunities to influence how services are delivered and few opportunities to personalise supports.

Responses also indicated that there appears to be a lack of certain specialists in MidCentral (especially occupational therapists) to conduct assessments and this, in turn is creating delays in obtaining needed equipment.

*She doesn't do anything! she bored, she's angry. She frustrated. They don't understand ... They don't try to understand.*

*It’s because he's bored. Only got his flatmates all day. He loves Kapa Haka and sometimes he misses out on his swimming with Special Olympics but again they say it is a staffing issue.*

*[They] don't supply what they’re contracted to – one service won't even give me my medication.*

*Whole organisation stinks [organisation named]. The personal touch is gone. We ring a Palmerston number and get transferred to Auckland. They don't know who we are.*

*Sometimes the communication with the agency [service named]. They can be quite short in telling you about changes… They don't tell you about changes until the last minute. We're quite flexible but it pays to be. Sometimes we stay home and then no one comes.*

***Disabled people’s insights into overall experiences with Mana Whaikaha and Connectors***

As discussed above, disabled people generally expressed that they have positive experiences when having contact with a connector.

*[The] Connector helped a lot – she is a lot of help... A work in progress, but much better. [It’s a] great experience, really like her.*

*Good positive experience – only a phone call or text away. [They’re] proactive.*

*I texted her when [he] had his surgery... The surgery didn’t go to plan [so I texted the Connector] and she was there Monday to put extra supports in place.*

***Disabled people’s insights into the pressure on Mana Whaikaha***

Some disabled people who had contact with Connectors felt that Mana Whaikaha was facing high demand, affecting Connectors’ ability to do their jobs well.

*My Mana Whaikaha lady... is gone. She’s left the job and [name] was put in by the boss. Who is a lot more busy, so I haven’t really had the contact with her. Certainly the lady I had was brilliant. Absolutely brilliant.*

*The waits are much longer – it is really hard to get a Connector now ... we were told there was almost a year’s wait for a Connector, [so] we sent an email to the Director and she was absolutely brilliant.*

***Disabled people’s insights into the flexibility of their supports***

Disabled people spoke positively about the flexibility in how they could use their support money. These insights reinforce the statistically significant results above, also related to flexibility of funding.

*Much better, because now you can get flexible funding. Before that you had to sign [the] form and wait for government to get back to you.*

*It’s flexible... a better use of funds and it has less impact on my personal life than using a provider.*

*There are less rules... it’s about my son having a good life.*

*It’s a lot better... easier to access [and] can use it to go to the movies and do social things.*

## Results from the whānau survey

The whānau survey asked demographic questions and other questions covering these topics:

* Wellbeing
* Funding
* Quality and flexibility of supports, and
* Information availability.

The questions asked as part of the whānau survey can be found in appendix seven, and a comparison of selected results between the 2018 and 2021 whānau surveys can be found at appendix eight.

### Quantitative results from the whānau survey

***Number of whānau members who had contact with Mana Whaikaha and Connectors, and the experiences they had, in 2021***

Overall, whānau who were supporting at least one disabled person in the family home had high levels of contact with Mana Whaikaha: the ‘at home’ group. People who had contact with a Connector were more likely to be in the ‘at home’ group.

* 67% of whānau members in the whānau survey (92 out of 134) indicated they had contact with Mana Whaikaha.
* Of this overall group, 63% (61 out of the 92 who answered this question) experienced Mana Whaikaha differently than the old system, while 16% (15 out of 92) experienced no change.
* 60% of the overall group (90 out of the 134) indicated that they had contact with a Connector.
* Of the group who had contact with a Connector, 81% (68 out of 84) were in the ‘at home’ group.
* 76% of those who had contact with connectors (64 out of 71) indicated they the contact had been positive.

***Statistically significant improvements for all respondents in the whānau survey, 2018 to 2021***

Whānau members were asked 28 Likert scale questions. Five showed statistically significant improvements from 2018 to 2021, for all respondents to the whānau survey. As with the disabled persons survey, most significant results for the whānau survey involved one main subgroup. Notably whānau who supported at least one disabled person in their own home or the ‘at home’ group. Those who supported a person elsewhere did not indicate any significant changes between 2018 and 2021.

Figure 3 – Statistically significant findings for whānau

***Statistically significant improvements for the ‘at home’ group (whānau members supporting at least one disabled person at home), between 2018 and 2021***

17 positive changes are seen for whānau members in the ‘at home’ group (supporting at least one disabled person in their own home), and who were respondents in both 2018 and 2021. Note that this aligns with the positive shifts seen for children and young people in the disabled people’s survey, as children and young people are more likely to be supported by whānau at home (so their whānau are in the ‘at home’ group).

There were two sets of statistically significant results for the ‘at home’ group. The first indicates positive improvements in how funding is allocated and used. The ‘at home’ group is highly likely to have a connector (86%) through Mana Whaikaha and had a change in how their funding (or funding for the disabled person in their home) is allocated.

Figure 4 - Statistically significant results regarding funding for whānau supporting at least one disabled person at home (the ‘at home’ group)

The second is statistically significant results for the ‘at home’ involved 12 indicators in areas such as the quality of the support people experience, how much they feel in control over the supports that are provided and improved participation in the community.

Figure 5 – Statistically significant results regarding all other areas for whānau supporting at least one disabled person at home (the ‘at home’ group)

***Statistically significant results for the ‘at home’ group compared to the ‘not at home’ group, in relation to feeling in control of their supports, in 2021***

The ‘at home’ group reported that they had greater ability to control and direct supports than the not at home group.

Figure 6 - Agreement with "we control and direct the supports that are needed" for whānau supporting people at home (‘at home’ group) versus not supporting people at home (‘not at home’ group), 2021

***Statistically significant results between the ‘at home’ group and the ‘not at home’ group in relation to wellbeing, in 2021***

The survey explored perceptions of wellbeing. Participants were asked to indicate on an eleven-point Cantril Ladder how they felt about their life. The ‘not at home’ group scored higher than the ‘at home’ group.

|  |  |
| --- | --- |
|  | Average Cantril Ladder Score |
| Overall | 6.55 (n = 135) |
| Whānau who do not support a disabled person at home (‘not at home’ group) | 7.03 (n = 51) |
| Whānau who support at least one disabled person at home (‘at home’ group) | 6.25 (n = 84) |

For the ‘at home’ group, those who were happy with their supports reported greater wellbeing overall than those who were not happy with their supports. This result was based on responses to one question that had resonance with all other satisfaction questions, ‘Overall supports for my family member work well’. ‘Happy with services’ was defined as people responding in the two highest categories (‘all of the time’ or ‘mostly’) while ‘less than happy’ encompassed the lower three categories.

## Participant insights from whānau survey

***Whānau insights into their contact with Mana Whaikaha and Connectors***

As reported above, 54% all whānau (59 out of 109), and 68% of whānau in the ‘at home’ group (49 out of 72), believed the new system had enabled changes in their lives. Most whānau who believed the new system had changed their lives also believed that these changes were positive.

When asked how they experienced differences in the new system, 39% of whānau indicated they valued the personal contact they had with Connectors, and/or the fact that they received personalised help and felt listened to (19 of 52 verbal responses).

*She came and assessed [name], talked to us both... she was fantastic... It was just liberating.*

*Really great Connector – constantly checking in.*

*Both kids have the same Connector – she comes to the kids’ IEP at school – she’s really quite good.*

However, Whānau who had contact with Connectors also believed that high demand and large caseloads were affecting perceptions of Mana Whaikaha.

*The waits are much longer – it is really hard to get a Connector now.*

*[We need] more clarity from our Connector... waiting, waiting, and still waiting.... This is putting some families off seeking personal budgets.*

While it was good news to hear whānau believed they were listened to in verbal responses, likert scale questions suggested that while there were significant improvements on 2018 figures (44%), only about half (54%) of whānau who supported a disabled person at home, believed they had access to all the information they needed about support services.

***Whānau members’ insights into flexibility of supports***

As with disabled people, an important change for whānau was more flexibility in how funding can be allocated and used. This was particularly true where personal budgets were involved; people believed their personal budgets allowed them to use their funding more freely than before. Note that where children and young people were involved, the whānau had control of their funding.

*[There is] more support and more options available. It has given [my son] the opportunity to have therapy that’s not provided for him otherwise. [This has] helped with his learning and development.*

# Implications of results and directions for further research

## Implications of results for services and supports

The Repeat Study identified several areas where improvement is possible. These are discussed briefly below, with recommendations provided by the study authors.

### People receiving traditional services (HCSS and residential services) should have more opportunity to influence their supports

People receiving traditional services were the least satisfied with their care[[36]](#footnote-36). They felt that they had few opportunities to influence how services are delivered and few opportunities to personalise supports. Further work or partnership in this area to improve people’s experiences and control over their supports is likely to have a meaningful effect on disabled people’s experiences.

**Recommendation:** Specific approaches are initiated to ensure people receiving traditional services experience increased choice and control.

**Recommendation**: Evaluation based on EGL outcomes should be extended beyond routine evaluation programme against contracts to build capability among providers. Additional disability-led monitoring of experiences will provide an independent voice highlighting areas that are working well and areas for improvement.

### Focus is needed to improve the experiences of people with physical disabilities, including their experiences with HCSS

People with physical disabilities had wellbeing scores that were lower than people with learning disabilities and the general population. They were more likely to be part of the group that uses HCSS and were dissatisfied with this service[[37]](#footnote-37). An exploration of how traditional service models can be replaced by more diverse options for all groups would be of value.

**Recommendation:** Consideration should be given to developing a future system that is responsive to life stage transition. This would include co-development of practical cross-agency responses to improve access to housing, health, and disability support.

### Information for disabled people and their whānau should be improved

Although disabled people and whānau felt more informed about supports than in 2018, over half of whānau who supported disabled people at home believed there was still room for improvement in this area[[38]](#footnote-38). Providing clear, easy to access, and timely information for disabled people and whānau about supports and services could improve their experience, including with Mana Whaikaha. Information should be tailored to the person. Additionally, assisting whānau to plan and implement supports would help them feel in control of their services.

**Recommendation:** Provide accessible and timely information via multiple media, to enable disabled people to understand what they can access and how they can increase clarity and control over their budgets. This would also assist Connectors to better provide options in the planning process.

### Connectors need support to manage their caseloads

Both disabled people and whānau noticed that Mana Whaikaha and Connectors were being impacted by high demand, flowing through to high caseloads. This is not sustainable and has negatively affected people’s experiences with Mana Whaikaha. Additional support for Connectors and adequate resourcing for managing caseloads will be important to ensure that Mana Whaikaha continues to enable good lives for disabled people in MidCentral.

**Recommendation**: Future scaling and development of Mana Whaikaha considers a range of supports available in the work force, the role of regional leadership and ways to manage diverse demographics more effectively. Planning should draw on results of this survey and on the qualitative study yet to be reported on Flexible Disability Supports.

## Directions for further research

In addition to the results described above, the Repeat Study also generated several areas where further research would be beneficial. Sometimes these were areas where a general trend was evident, but the result did not reach the threshold of statistical significance, perhaps because the sample size was small (especially for subgroups)[[39]](#footnote-39). . In other cases, the results told only part of a richer story, which researcher and participant insights can shed further light on. In this section, researchers recommend further areas for research, explaining why they are important.

### Experiences of disabled people and whānau who have engaged with Mana Whaikaha since the 2018 Baseline Study

As described above, the longitudinal nature of the 2018 Baseline Study and 2021 Repeat Study means that the Repeat Study worked with essentially the same group as the Baseline Study, with the addition of matched pairs. This meant that people who engaged with Mana Whaikaha after the Baseline Study were not included in the Repeat Study. This new group of people who have engaged over the last three years may have its own characteristics, reasons for engaging with, and experiences of Mana Whaikaha. Exploring this group’s experiences is important to getting a fuller understanding of the impact of Mana Whaikaha.

### A dedicated Te Ao Māori research approach is needed

Both the disabled people’s survey and the whānau survey involved relatively small numbers of Māori participants. The sample sizes were small, but it was impossible to know whether the changes would have been different with a larger cohort. For the most part, general trends for tāngata whaikaha-māori me ō rātou whānau did not indicate major differences from the wider groups in each survey.   
  
However, there were two important general trends observed, which require further research: that compared to non-Māori, Māori whānau tended to view services as less flexible, and were less positive in response to open-ended questions. In view of future system scaling and the under representation of Maori compared to the wider Maori population using Mana Whaikaha a Te Ao Maori approach and engagement with Mana Whenua would be critical. This applies locally and nationally where similar trends occur

### The experiences of people with physical disabilities

When participants in the disabled people’s survey were asked to rate their wellbeing on a Cantril ladder, participants with physical disabilities scored lower than respondents with other disabilities, and the general population This statistically significant result was supported by other general trends showing lower wellbeing for people with physical disabilities, including answers to the questions ‘I am happy with my life’ (Q.A42), and ‘I worry about things’ (Q.A44). [[40]](#footnote-40)

Researcher insights indicate there may be several complex reasons why people with physical disabilities experience lower wellbeing. Participants in the Repeat Study who had physical disabilities tended to be older on average than other participants. Their group included people with both lifelong and acquired disability, and who may have been experiencing progressive disability, pain, or other health concerns. There is some qualitative evidence from the Repeat Study that shows, even though equipment is particularly important to the quality of life of people with physical disabilities, some were waiting too long to access the equipment they needed[[41]](#footnote-41). This question requires specific research, with the aim of identifying where supports can assist with enhancing wellbeing and looking into service quality.

### Disabled people’s experiences of residential services need to take account of complex factors

Results of the disabled people’s survey, in relation to disabled people’s experiences of residential services, did not yield statistically significant results or clear general trends. However, care should be taken interpreting these results for residential services, since there appears to be a split in opinion over the quality of these services, and people’s satisfaction with them.

This split in views may be because people using residential services tend to be older and may have previously lived in institutional settings (such as Kimberley). They may have different expectations from those younger than them, and those who have not experienced institutional care. There are moral and ethical reasons why this group and their views should be treated with care and respect.

Further research should take a sensitive approach to understanding the views of older people using residential services, including the context and experiences that have shaped their views. It should also explore the experiences of the subgroup of other people in residential services who have not experienced long term or life-long support, or previous institutional support.

This further research should also follow up on several participant insights about residential services made through the Repeat Study. Specific issues include the impact of a lack of transport for group homes; the perception of poor staffing ratios, especially for vocational/day and one-to-one activities; and the lack of consultation with families/whānau.

### Specific issues to do with vocational options for disabled people, with a view to developing a new approach

Further independent research is needed to gauge the impact of reducing external (bricks and mortar) vocational options for people living in group home (residential) settings or semi-independently, and for families/whānau who are supporting an adult with disabilities in the family home.

Further research needs to recognise the limitations of the more traditional approaches to vocational support and focus instead on what is possible. A new service model, as part of a transformed disability system, should also transform how vocational services are provided. An international review of innovative vocational options for adults, particularly those with significant support needs, should underpin this research.

### Delays in support to young children, and the impacts of these delays

There was some evidence from comments by whānau with very young children that the system is too slow, and too costly, in providing the diagnosis necessary to access support. Delays can create issues with access to early intervention services and can impact how well children are supported at pre-school.

Research should focus on challenges faced by whānau seeking a diagnosis, including difficulties accessing the system; and how well support is provided while the whānau are waiting for a diagnosis.[[42]](#footnote-42) It will require multi-level government cooperation to conduct research of this type, including:

* the Ministry of Health (paediatrician and diagnostic systems, access to DSS)
* the Ministry of Education (assessment by an educational psychology or associated professionals, access to special educational supports before and after diagnosis, and a focus on early intervention strategies in mainstream environments) and
* the Ministry of Social Development (broad whānau supports, including income support).

### Lack of access to assessment for equipment, which in turn is delaying access to equipment

Participant insights indicate some disabled people are experiencing a lack of access to appropriate assessment, which in turn means delay (in some cases, significant delay) in approval for necessary equipment. Research should consider the impact of delays in assessment for people who require equipment or home modifications to live safely and with dignity. Research should also consider how these impacts flow through to disabled people’s quality of life, Conclusion

This report has provided an overview of the 2021 Repeat Study of the disability support system in the MidCentral Area, conducted by SAMS. In doing so, it has offered an insight into the outcomes and experiences of MidCentral disabled people and their whānau and whether there has been change since the 2018 Baseline Study. A core part of the Repeat Study was understanding the impacts of Mana Whaikaha, especially the Connector role and personal budgets.

Results of the Repeat Study suggest that Mana Whaikaha is beginning to create a fundamental change in MidCentral’s approach to disability supports, helping disabled people to achieve good lives. Positive change has been reported by children and young people, who have driven much of the high demand for Mana Whaikaha and Connectors. Whānau in the ‘at home’ group also report positive change. These changes appear to be linked the child and young person’s group in the disabled people’s survey. These whānau also report greater flexibility of Mana Whaikaha, compared to traditional disability supports.

The Repeat Study has also shown that for some disabled people change remains too slow. People with physical disabilities, and those in traditional contracted services, do not report the same gains as other groups. Although small sample sizes limit our ability to draw conclusions, there is some indication that there is scope to improve the experience of Mana Whaikaha for Māori.

A strength of the Repeat Study is its implications for better service delivery, and for future research into the lives of disabled people in New Zealand. At a time when the disability support system is being fundamentally reimagined, these lessons are more relevant and important than ever.

# Appendix one: About the researchers

The Lead SAMS Researcher, Christine Wilson, has a 1996 PhD from Monash University in community-based support for disabled people. She has worked in the disability sector for over 30 years. Christine has completed several monographs and papers for the sector and is a lead evaluator and principal researcher for SAMS.

SAMS is governed by disabled people and their whānau. Eighty percent of SAMS’ experienced evaluators and educators have direct lived experience of disability or are whānau members of a disabled person. Since 1991, SAMS has been an independent monitoring and evaluation organisation that has worked across New Zealand. SAMS has received international acknowledgement for pioneering approaches where disabled people and their whānau have key roles in all aspects of monitoring and evaluation.

# Appendix two: Glossary of key terms

**‘At home’ group:** this group comprises of participants in the whānau survey, who supported one or more disabled people in their home.

**Connectors** - these support roles are a key feature of Mana Whaikaha.  They plan with the disabled person to identify what they want and how to get there.  Connectors can work with government agencies and services, helping the disabled person to get what they need, build relationships, and stay connected.  Connectors may also help people plan how they will use their personal budget.

**Disability Support Services (DSS)** - these are nationally available services that are funded by the Ministry of Health, and either provided by the Ministry itself, or by contracted providers.  For the purposes of the Repeat Study, the most important DSS services are Home and Community Support Services (HCSS), residential services, and Supported Living.

**Home and Community Support Services (HCSS)** - providers are contracted to offer these services which help people live at home. HCSS can provide household management support, such as help with preparing meals and cleaning, as well as personal care, such as help with eating, showering, and getting around the house.

**‘Not at home’ group:** this group comprised of participants in the whānau survey who are not in the ‘at home’ group. Whānau in this group supported a disabled whānau member living in another setting, outside the home.

**Personal budgets** - these describe a range of flexible funding options and are a key feature of Mana Whaikaha. The level of apersonal budget is decided according to what the disabled person wants to achieve, their strengths and their aspirations, not on the basis of a needs assessment.  To buy something with their personal budget, a disabled person must be able to show it helps them overcome a barrier related to ult their disability.

**Residential services** - these are contracted services that provide the disabled person with 24/7 live-in support, usually in a group home situation involving six or fewer residents.  Sometimes, the disabled person lives in a larger facility, like an aged residential care facility.

**Supported Living** - these are contracted services that help disabled people live independently, by providing support in the areas of life where help is needed.  Support is based on a personal plan and can include help with activities like getting up and getting ready for work, attending a community activity, or cooking a meal.

# Appendix three: Enabling Good Lives (EGL) vision and principles

|  |  |
| --- | --- |
| **Vision** | In the future, disabled children and adults and their families will have greater choice and control over their supports and lives and make more use of natural and universally available supports. |
| **Principles** |  |
| Self-determination | Disabled people are in control of their lives. |
| Beginning Early | Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available. |
| Person-Centred | Disabled people have supports that are tailored to their individual needs and goals and take a whole of life approach rather than be split across programmes. |
| Ordinary Life Outcomes | Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, social participation – like others at similar stage of life. |
| Mainstream First | Disabled people are supported to access mainstream services before specialist disability services. |
| Easy to Use | Disabled people have supports that are simple to use and flexible. |
| Relationship Building | Supports build and strengthen relationships between disabled people, their whānau and community. |

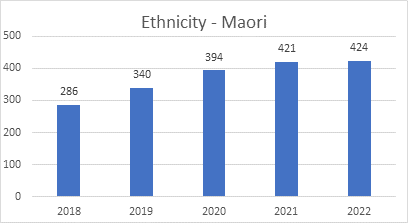
# Appendix four:  Information about the population for whom Mana Whaikaha is responsible

Between 2018 and 2021, the number of people for whom Mana Whaikaha was responsible rose from **(1637)** to **(2686)**.  **The current active number of people whom Mana Whaikaha are responsible for at the end of 2021 was 2443 as people have exited for various reasons (moved out of region, deceased etc).**

In 2018, the **(1637)** people for whom Mana Whaikaha was responsible was made up of **(286)** Māori **(17.5%)** and **(1351)** non-Māori **(82.5%).**

In 2021, the **(2443)** people for whom Mana Whaikaha was made up of **(424)** Māori~~,~~ and **(2019)** non-Māori (a large increase of over 600 people). However, 2022 figures demonstrate a 48% increase in Maori since establishment.

**Note:**  There are 579 people who do not have a recorded ethnicity which may increase the recorded statistics



This meant the proportions in 2021 have remained almost unchanged, with Māori **(17%)** and non-Māori higher **(83%).**

Note that, for the reasons set out in this report, Mana Whaikaha has experienced high demand and has not been able to engage with all the people for whom it is responsible.  The Ministry of Health is confident more people will come into active engagement with Mana Whaikaha over time, particularly those who are currently supported by contracted services, but will have future reviews.

# Appendix five: **Disabled person’s survey for the Repeat Study questions**

**About Me**

|  |  |  |
| --- | --- | --- |
| A1 | Age | 4-year categories |
| A2 | Over 18? | Yes / No |
| A3 | Gender | Male / Female / Gender Diverse |
| A4 | Ethnic group(s) | NZ European / Māori / Samoan / Cook Island Māori / Tongan/ Niuean / Chinese / Indian / Prefer not to say / Don’t know / Other |
| A5 | How many people do you live with? | Free answer |
| A6 | How many of these people are members of your family? | Spouse: Yes / No  Siblings  Children under 18  Children over 18  Other |
| A7 | I own my home | Yes / No |
| A8 | I lease (rent) where I live | Yes / No |
| A9 | I am in a boarding arrangement (including residential) | Yes / No |
| A10 | I live with family/whānau or similar | Yes / No |
| A11 | Are you in a supported living situation? | Yes / No |
| A12 | I am supported in a residential service (or similar) | Yes / No |
| A13 | Rest home/hospital level care | Yes / No |
| A14 | What type of support do you get from the disability support system? | Free answer |
| A15 | What do you like about your supports? | Free answer |
| A16 | What don’t you like about your supports? | Free answer |
| A17 | If you could change one thing about your supports, what would that be? | Free answer |
| A18 | How can the service best assist you in creating the life you want? | Free answer |

**Experience/impressions of contact with Mana Whaikaha**

|  |  |  |
| --- | --- | --- |
| A19 | Have you had contact with Mana Whaikaha | Yes / No |
| A19a | Discuss this | Free answer |
| A20 | If yes (A19) – For you, do you experience Mana Whaikaha differently from the old system? | Yes / No |
| A20a | If it is different, in what way is it different? | Free answer |
| A21 | Have you had contact with a Connector | Yes / No |
| A21a | If so, tell us how this contact went for you and did it meet your expectations | Free answer |
| A22 | Has the new system of support made any changes in your life | Yes / No |
| A22a | If so, what are some of the changes that have happened? | Free answer |
| A22b | How has this change helped you? | Free answer |
| A22c | If not, what was missing or what did not happen for you? | Free answer |

**Education**

|  |  |  |
| --- | --- | --- |
| A23 | Have you completed a course of study in the past three years, and if so, what did you complete? | Free answer |
| A23a | Are you currently in education or doing a course? | Yes / No |
| A23a | Please tell us what it is and where you are up to | Free answer |
| A24 | Do you want to do more training/courses? | Yes / No |
| A25 | Is there anything stopping/preventing you from doing more training/courses? | Free answer |
| 6.1 | I have opportunities for learning and development | Likert scale (5 options) |

*For school students only*

|  |  |  |
| --- | --- | --- |
| E1 | Where do you attend school? | Free answer |
| E2 | Is this a separate school or class for disabled young people? | Yes / No |
| E3 | Apart from your teacher, do you have supports at school to help you learn? | Yes / No |
| E4 | What supports do you have at school? | Free answer |
| E5 | My supports at school help me learn | Likert scale (5 options) |
| E6 | I can participate in everything I want to at school | Likert scale (5 options) |
| E7 | I have friends at school | Likert scale (5 options) |
| E8 | Other students at school treat me well | Likert scale (5 options) |

**Employment and Voluntary Work**

|  |  |  |
| --- | --- | --- |
| A26 | Paid employment in the last week | 5-hour categories |
| A27a | What do you do? | Free answer |
| A27b | Do you have enough hours? | Yes / No |
| A28 | Voluntary work in the last week | 5-hour categories |
| A28a | If you are currently working, what are you doing? | Free answer |
| A29 | If you are not in work right now, is working something you would like to do? | Yes / No/ Maybe |
| 6.2 | If you are interested in paid employment, do you think you can easily find help when looking for work? | Likert scale (5 options) |

**Relationships**

|  |  |  |
| --- | --- | --- |
| A30 | I had contact or visits with friends in the last | Week / Fortnight / Month / Longer than one month / In the last year / Longer than one year |
| A31 | I had contact with family/whānau in the last | As A30 |
| A32 | Relationship status | Live with a partner / In a relationship / I am currently single / I have never been in an intimate relationship |

**Health**

|  |  |  |
| --- | --- | --- |
| A33 | What health professionals do you access? | Free answer |
| A33a | Of these, who do you like the best and why? | Free answer |
| A33b | Who do you like the least and why? | Free answer |

**Community Connections**

|  |  |  |
| --- | --- | --- |
| A34 | What have you done and where have you gone in the community in the last two weeks? | Free answer |
| A35 | Usual form of transport | Free answer |
| A36 | I am a member of a local group, club, church, Marae, sports team, etc. | Yes / No + comments |

**Wellbeing**

|  |  |  |
| --- | --- | --- |
| A37 | Life satisfaction | Cantril ladder |
| A38 | Why have you made the choice you made [on the Cantril ladder] | Free answer |
| A39 | I know who to ask for help, advice, or support if I need it | Likert scale (5 options) |
| A40 | I am a happy person | Likert scale (5 options) |
| A41 | In most ways my life is close to the way I would want it to be | Likert scale (5 options) |
| A42 | I am happy with my life | Likert scale (5 options) |
| A43 | I am optimistic about my future | Likert scale (5 options) |
| A44 | I worry about things | Likert scale (5 options) |

**My Identity**

*Thinking about your support services…*

|  |  |  |
| --- | --- | --- |
| 1.1 | Supports/services help me pursue my own interests | Likert scale (5 options) |
| 1.2 | My culture is respected | Likert scale (5 options) |
| 1.3 | My spirituality/beliefs are respected | Likert scale (5 options) |
| 1.4 | I am understood when I communicate | Likert scale (5 options) |

**My Authority**

|  |  |  |
| --- | --- | --- |
| 2.1 | I can easily find out about the things I need for my support | Likert scale (5 options) |
| 2.2 | I can make changes to my supports if I need to | Likert scale (5 options) |
| 2.3 | I choose what happens in my life | Likert scale (5 options) |
| 2.4 | I have help to make choices if I need/want it | Likert scale (5 options) |
| 2.5 | I can choose who my support staff will be | Likert scale (5 options) |
| 2.6 | I know who will be supporting me each day/shift | Likert scale (5 options) |
| 2.7 | I choose who lives with me | Likert scale (5 options) |
| 2.8 | I have choices about the kind of support I receive | Likert scale (5 options) |
| 2.9 | I choose what happens in my day | Likert scale (5 options) |
| 2.10 | I can make plans based on what I want and what I’m good at | Likert scale (5 options) |
| 2.11 | I am achieving the things I want in my life | Likert scale (5 options) |

**My Connections**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |
| --- | --- | --- |
| 3.1 | My family is as involved in my life as I want them to be | Likert scale (5 options) |
| 3.2 | I am important to my family | Likert scale (5 options) |
| 3.4 | I have friends outside of where I live (not paid staff/flatmates etc) | Likert scale (5 options) |
| 3.5 | I have a network of people who support me (family, whānau, friends, community and, if needed, paid support workers) | Likert scale (5 options) |
| 3.7 | I can attend community events, hui, concerts, and celebrations if I like | Likert scale (5 options) |
| 3.9 | My supports assist me to strengthen my relationship with my community (incl. culture/community of choice) | Likert scale (5 options) |
| 3.10 | My supports help me connect to people and places that are important to me | Likert scale (5 options) |
| 3.11 | I feel I belong in my wider community | Likert scale (5 options) |

**My Time**

|  |  |  |
| --- | --- | --- |
| 4.1 | My support happens at the times that work for me | Likert scale (5 options) |
| 4.2 | I have enough support to achieve what I want | Likert scale (5 options) |
| 4.4 | My support hours can be flexible | Likert scale (5 options) |
| 4.5 | My support occurs when I need it in my life | Likert scale (5 options) |

**My Wellbeing**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |
| --- | --- | --- |
| 5.2 | My paid workers understand how to support me safely | Likert scale (5 options) |
| 5.4 | I am supported to maintain and improve my health | Likert scale (5 options) |
| 5.5 | I am encouraged to think about what I want in my life | Likert scale (5 options) |
| 5.6 | I feel safe and secure | Likert scale (5 options) |
| 5.7 | I have all the equipment I need | Likert scale (5 options) |
| 5.7a | If you have concerns about equipment, what would these be? | Free answer |

**My Contribution**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |
| --- | --- | --- |
| 6.3 | I am supported to be an active member of my community | Likert scale (5 options) |
| 6.5 | I feel supported to try new things | Likert scale (5 options) |
| 6.6 | I am supported to be actively involved in my homelife | Likert scale (5 options) |
| 6.7 | I am learning skills to do more things | Likert scale (5 options) |

**My Resources**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| 7.1 | | I choose where my support money is used | | Likert scale (5 options) | | |
| 7.2 | | I feel the amount of support I have is right for what I need | | Likert scale (5 options) | | |
| 7.3 | | I think the money I get for my support is well spent | | Likert scale (5 options) | | |
| 7.4 | | I know the amount of money available to me for my support | | Likert scale (5 options) | | |
| 7.5 | | I know where to get help to manage my own supports | | Likert scale (5 options) | | |
| 7.6 | | I can easily find skilled paid workers/staff for myself if I need to | | Likert scale (5 options) | | |
| 7.7 | | Do you receive a benefit or pension from the Government | | Yes / No, If yes, what type? | | |
| 7.8 | | Are you the sole income earner in your home? (excluding residential and rest home/hospital care/boarding). | | Yes / No | | |
| 7.9 | | What your total before tax income for the last 12 months? | | 5k categories | | |
| Appendix six: 5.4 | I am supported to maintain and improve my health | | 84% (131/156) | | 86% (126/147) | ➖ |
| 5.5 | I am encouraged to think about what I want in my life | | 63% (66/105) | | 73% (79/108) | 🟩 |
| 5.6 | I feel safe and secure | | 90% (147/163) | | 93% (137/148) | ➖ |
| 5.7 | I have all the equipment I need | | 76% (83/109) | | 82% (97/119) | 🟩 |

**My Contribution**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 6.3 | I am supported to be an active member of my community | 54% (73/135) | 68% (92/135) | 🟩 |
| 6.5 | I feel supported to try new things | 68% (102/149) | 66% (95/145) | ➖ |
| 6.6 | I am supported to be actively involved in my homelife | 75% (116/155) | 77% (106/138) | ➖ |
| 6.7 | I am learning skills to do more things | 58% (79/136) | 58% (73/125) | ➖ |

**My Resources**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 7.1 | I choose where my support money is used | 32% (41/129) | 67% (73/109) | 🟩 |
| 7.2 | I feel the amount of support I have is right for what I need | 63% (81/129) | 82% (97/118) | 🟩 |
| 7.3 | I think the money I get for my support is well spent | 73% (88/120) | 82% (87/106) | 🟩 |
| 7.4 | I know the amount of money available to me for my support | 24% (28/115) | 46% (46/99) | 🟩 |
| 7.5 | I know where to get help to manage my own supports | 53% (58/110) | 70% (71/102) | 🟩 |
| 7.6 | I can easily find skilled paid workers/staff for myself if I need to | 31% (27/88) | 46% (36/79) | 🟩 |

# Disabled people’s survey for quantitative comparison to baseline

🟥 – Deterioration between years (see note below)

➖ - no change between years (less than 5%)

🟩 – Improvement between years (see note below)

**☀**️ - Statistically significant improvement between years

**NB: Results that are not statistically significant should be treated with caution since the variance within each five-point scale when comparing two time periods (or other data sets) may not support a significant result, even though a trend indicated by the two highest points on the scale is greater than 10%. A significant result indicates there is 95% confidence (or higher) that a suggested difference is not due to chance.**

**Education**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who answered “yes” | |  |
|  |  | 2018 | 2021 |  |
| 6.1 | I have opportunities for learning and development | 61% (64/105) | 45% (23/51) | 🟥 |

*For school students only*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who answered “yes” | |  |
|  |  | 2018 | 2021 |  |
| E2 | Is this a separate school or class for disabled young people? | 40% (15/38) | 38% (14/37) | ➖ |
| E3 | Apart from your teacher, do you have supports at school to help you learn? | 85% (33/39) | 83% (29/35) | ➖ |

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| E5 | My supports at school help me learn | 81% (26/32) | 82% (28/34) | ➖ |
| E6 | I can participate in everything I want to at school | 77% (27/35) | 84% (32/38) | 🟩 |
| E7 | I have friends at school | 51% (18/35) | 73% (27/37) | 🟩 |
| E8 | Other students at school treat me well | 81% (30/37) | 76% (28/37) | 🟩 |

**Employment and Voluntary Work**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 6.2 | If you are interested in paid employment, do you think you can easily find help when looking for work? | 55% (27/49) | 28% (13/46) | 🟥 |

**My Identity**

*Thinking about your support services…*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 1.1 | Supports/services help me pursue my own interests | 63% (95/151) | 70% (96/137) | 🟩 |
| 1.2 | My culture is respected | 90% (108/120) | 85% (106/125) | 🟥 |
| 1.3 | My spirituality/beliefs are respected | 91% (84/92) | 89% (83/93) | ➖ |
| 1.4 | I am understood when I communicate | 66% (109/165) | 75% (110/146) | 🟩 |

**My Authority**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 2.1 | I can easily find out about the things I need for my support | 58% (69/118) | 72% (83/115) | 🟩 |
| 2.2 | I can make changes to my supports if I need to | 56% (60/108) | 76% (83/109) | 🟩 |
| 2.3 | I choose what happens in my life | 59% (83/140) | 66% (81/122) | 🟩 |
| 2.4 | I have help to make choices if I need/want it | 78% (109/139) | 81% (91/113) | ➖ |
| 2.5 | I can choose who my support staff will be | 46% (64/140) | 46% (59/129) | ➖ |
| 2.6 | I know who will be supporting me each day/shift | 78% (105/135) | 79% (88/112) | ➖ |
| 2.7 | I choose who lives with me | 54% (58/108) | 50% (56/112) | ➖ |
| 2.8 | I have choices about the kind of support I receive | 48% (54/112) | 61% (67/110) | **☀**️ |
| 2.9 | I choose what happens in my day | 63% (97/153) | 66% (91/138) | ➖ |
| 2.10 | I can make plans based on what I want and what I’m good at | 66% (74/112) | 66% (71/107) | ➖ |
| 2.11 | I am achieving the things I want in my life | 56% (85/152) | 63% (83/132) | 🟩 |

**My Connections**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 3.1 | My family is as involved in my life as I want them to be | 84% (124/148) | 79% (102/129) | 🟥 |
| 3.2 | I am important to my family | 89% (147/165) | 94% (136/145) | 🟩 |
| 3.4 | I have friends outside of where I live (not paid staff/flatmates etc) | 60% (88/147) | 64% (84/132) | ➖ |
| 3.5 | I have a network of people who support me (family, whānau, friends, community and, if needed, paid support workers) | 78% (124/158) | 86% (128/149) | 🟩 |
| 3.7 | I can attend community events, hui, concerts, and celebrations if I like | 67% (94/141) | 77% (102/133) | 🟩 |
| 3.9 | My supports assist me to strengthen my relationship with my community (incl. culture/community of choice) | 56% (57/101) | 73% (82/112) | 🟩 |
| 3.10 | My supports help me connect to people and places that are important to me | 65% (90/138) | 76% (99/130) | 🟩 |
| 3.11 | I feel I belong in my wider community | 53% (67/127) | 65% (74/113) | 🟩 |

**My Time**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 4.1 | My support happens at the times that work for me | 77% (121/158) | 86% (113/132) | 🟩 |
| 4.2 | I have enough support to achieve what I want | 67% (104/155) | 79% (108/136) | **☀**️ |
| 4.3 | My support hours can be flexible | 66% (83/126) | 67% (65/97) | ➖ |
| 4.4 | My support occurs when I need it in my life | 78% (102/130) | 78% (90/115) | ➖ |

**My Wellbeing**

*Question numbers are based on the 2018 survey; some questions from the 2018 survey were not asked in 2021.*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots” or “some”) | |  |
|  |  | 2018 | 2021 |  |
| 5.2 | My paid workers understand how to support me safely | 92% (134/145) | 91% (126/138) | ➖ |

# Appendix seven: Whānau survey questions

**Demographic information**

|  |  |  |
| --- | --- | --- |
| B1 | Age | 4-year categories |
| B2 | Gender | Male / Female / Gender Diverse |
| B3 | Relationship Status | Single/Divorced/Live-in-Relationship/Married or civil union |
| B4 | Ethnic group(s) | NZ European / Māori / Samoan / Cook Island Māori / Tongan/ Niuean / Chinese / Indian / Prefer not to say / Don’t know / Other |
| B5 | Iwi affiliation (if applicable) | Free answer |
| B6 | What is your current work situation? | (see B6 options) |
| B6a | Working in paid employment | Yes / No |
| B6ai | If yes, hours worked last week | Free answer |
| B6aii | Would you like to be working more or fewer hours? Why? | Free answer |
| B6bi | Not in paid work, and looking for a job | Yes / No |
| B6bii | Wanting to work, but cannot right now | Yes / No |
| B6c | Not in paid work, and not looking for a job | Yes / No |
| B6d | Other (specify) | Free answer |
| B7 | I own my home | Yes / No |
| B8 | Rent from a private landlord | Yes / No |
| B9 | Rented from social/community housing | Yes / No |
| B10 | Other living situation | Yes / No |
| B11 | Total income of the household | $10k increments / Prefer not to answer / Don’t Know |
| B12 | Number of closely involved people who receive support from disability services of Mana Whaikaha in MidCentral | Free answer |
| B13 | Details of these people | Disability type/Gender/Age/Relationship |
| B13a | Type of support for these people | Free answer |
| B14 | Which are involved in the disabled persons survey? | Free answer |
| B15 | Which of these people live with you? | Free answer |
| B16 | Level of support | All / most / some / none |
| B17 | Other people who help provide supports | Another family member / partner / spouse / support workers(s) / friend / other |
| B18 | Time spent actively providing supports per weekday | Most (18+) / A lot (8-17) / Some (5-7) / A little (1-4) / None |
| B19 | Time spent actively organising or managing support | Most (18+) / A lot (8-17) / Some (5-7) / A little (1-4) / None |
| B20 | How many people who rely on you for support live with you? What are their ages? | Free answer |
| B21 | Time spent doing thing for yourself | Most (12+) / A lot (8-11) / Some (5-7) / A little (1-4) / None |
| B22 | What type of supports do you currently use? | Free answer |
| B23 | (If supporting people at home) I have regular breaks from my caring responsibilities | Likert scale (5 options) |
| B24 | (If supporting people at home) I find it easy to find carers (for the funding provided) | Likert scale (5 options) |
| B25 | (If supporting people at home) I know what respite options are available in MidCentral | Likert scale (5 options) |
| B26 | (If supporting people at home) My supports help me continue with my caring role | Likert scale (5 options) |

**Support**

|  |  |  |
| --- | --- | --- |
| C1 | What do you like about the supports provided | Free answer |
| C1a | Further explanation | Free answer |
| C2 | What don’t you like about the supports provided? | Free answer |
| C2a | Further explanation | Free answer |
| C3 | If you could change one thing about the supports provided, what would that be? | Free answer |
| C4 | Thinking outside your supports, is there anything stopping you from achieving your goals? | Free answer |
| C5 | If you were to describe what your supports have been like for you in a couple of words what would they be? | Free answer |
| C6 | How can the service system best assist you in creating the life you want? | Free answer |

**Experience/impressions of contact with Mana Whaikaha**

|  |  |  |
| --- | --- | --- |
| A16 | Have you had contact with Mana Whaikaha | Yes / No |
| A16a | If no, explain why or why not | Free answer |
| A17 | If yes (A16) – For you, do you experience Mana Whaikaha differently from the old system? | Yes / No |
| A17a | If it is different, in what way is it different? | Free answer |
| A18 | Have you had contact with a Connector? | Yes / No |
| A18a | If so, how successful was your experience? | Free answer |
| A19 | Has the new system of support made any changes in your life? | Yes / No |
| A19a | Has this been positive or negative? | Free answer |
| A19b | How has this change helped you progress towards living the life you want? | Free answer |

**Likert Scale Questions**

|  |  |  |
| --- | --- | --- |
| 1 | I feel welcomed by the supports/services we use | Likert scale (5 options) |
| 2 | Supports respect our culture | Likert scale (5 options) |
| 3 | Supports are easy to access and use | Likert scale (5 options) |
| 4 | Contact with the disability support system helps us achieve our goals. | Likert scale (5 options) |
| 5 | I think the funding allocation process is clear | Likert scale (5 options) |
| 6 | I believe the funding allocation process is positive | Likert scale (5 options) |
| 7 | I know how much money is allocated for support | Likert scale (5 options) |
| 8 | I know what the funding is used for | Likert scale (5 options) |
| 9 | The funding is sufficient to meet our needs | Likert scale (5 options) |
| 10 | Supports anticipate what I/we need | Likert scale (5 options) |
| 11 | I am valued for the support I provide | Likert scale (5 options) |
| 12 | Supports work when we want them | Likert scale (5 options) |
| 13 | Overall, our supports work flexibly (how we want them to) | Likert scale (5 options) |
| 14 | Supports enable us to do the things that are important to us | Likert scale (5 options) |
| 15 | Paid support workers are reliable and consistent | Likert scale (5 options) |
| 16 | We control and direct the supports that are needed | Likert scale (5 options) |
| 17 | We can make the changes to our supports as we need to | Likert scale (5 options) |
| 18 | Overall supports for my family member work well | Likert scale (5 options) |
| 19 | I can access all of the information I need about support services | Likert scale (5 options) |
| 20 | I think information from support services is easy to understand | Likert scale (5 options) |
| 21 | In general, I believe my family member / friend / partner / spouse is safe | Likert scale (5 options) |
| 22 | We are supported to be connected in the community | Likert scale (5 options) |
| 23 | We can use community options, connections, and services that are for everyone before we have to use specialised disability services | Likert scale (5 options) |
| 24 | Our wellbeing benefits from contact with the disability support system | Likert scale (5 options) |
| 25 | Our supports help us connect to people and places that are important to us | Likert scale (5 options) |
| 26 | My/our rights are respected | Likert scale (5 options) |
| 27 | I support my whānau/family member / friend / partner / spouse to make their own decisions in life | Likert scale (5 options) |
| 28 | I / we know where we are heading and have the supports in place to build the life, we want | Likert scale (5 options) |

**Quality of Life**

|  |  |  |
| --- | --- | --- |
| D1 | Life satisfaction | Cantril ladder |
| D2 | Overall quality of life | Extremely Poor / Poor / Neither good nor poor / Good / Extremely Good |
| D3 | Why do you view your overall quality of life this way? | Free answer |
| D4 | Quality of life compared to 12 months ago | Decreased significantly / Decreased to some extent / Stayed about the same / Increased to some extent / Increased significantly |

# Appendix eight: Whānau survey quantitative comparison to baseline

*All Respondents*

🟥 – Deterioration between years (see note below)

➖ - no change between years (less than 5%)

🟩 – Improvement between years (see note below)

**☀**️ - Statistically significant improvement between years

NB: Results that are not statistically significant should be treated with caution since the variance within each five-point scale when comparing two time periods (or other data sets) may not support a significant result, even though a trend indicated by the two highest points on the scale is greater than 10%. A significant result indicates there is 95% confidence (or higher) that a suggested difference is not due to chance.

**Supporting people at home**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots”, or mostly”) | |  |
|  |  | 2018 | 2021 |  |
| B23 | (If supporting people at home) I have regular breaks from my caring responsibilities | 15%  14/96 | 18%  16/91 | ➖ |
| B24 | (If supporting people at home) I find it easy to find carers (for the funding provided) | 23%  21/90 | 37%  28/76 | 🟩 |
| B25 | (If supporting people at home) I know what respite options are available in MidCentral | 36%  25/70 | 26%  19/72 | 🟥 |
| B26 | (If supporting people at home) My supports help me continue with my caring role | 57%  49/86 | 58%  49/84 | ➖ |

**Likert Scale Questions**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | Percentage who agreed (“yes, lots”, or mostly”) | |  |
|  |  | 2018 | 2021 |  |
| 1 | I feel welcomed by the supports/services we use | 80%  112/140 | 80%  103/128 | ➖ |
| 2 | Supports respect our culture | 86%  106/123 | 86%  104/121 | ➖ |
| 3 | Supports are easy to access and use | 50%  70/141 | 66%  85/128 | 🟩 |
| 4 | Contact with the disability support system helps us achieve our goals | 53%  71/133 | 64%  76/119 | 🟩 |
| 5 | I think the funding allocation process is clear | 36%  47/132 | 54%  65/121 | ☀ |
| 6 | I believe the funding allocation process is positive | 46%  61/132 | 69%  77/112 | 🟩 |
| 7 | I know how much money is allocated for support | 54%  96/128 | 63%  75/119 | 🟩 |
| 8 | I know what the funding is used for | 69%  92/133 | 76%  96/126 | 🟩 |
| 9 | The funding is sufficient to meet our needs | 49%  68/138 | 74%  87/117 | 🟩 |
| 10 | Supports anticipate what I/we need | 41%  52/126 | 51%  60/116 | 🟩 |
| 11 | I am valued for the support I provide | 55%  73/133 | 64%  79/124 | 🟩 |
| 12 | Supports work when we want them | 58%  82/142 | 75%  92/123 | 🟩 |
| 13 | Overall, our supports work flexibly (how we want them to) | 66%  91/137 | 78%  97/124 | ☀ |
| 14 | Supports enable us to do the things that are important to us | 59%  82/140 | 76%  93/122 | ☀ |
| 15 | Paid support workers are reliable and consistent | 72%  94/130 | 72%  78/109 | ➖ |
| 16 | We control and direct the supports that are needed | 65%  82/126 | 69%  80/116 | ➖ |
| 17 | We can make the changes to our supports as we need to | 60%  73/122 | 72%  80/111 | 🟩 |
| 18 | Overall supports for my family member work well | 63%  90/144 | 81%  104/128 | ☀ |
| 19 | I can access all of the information I need about support services | 53%  73/138 | 58%  70/120 | 🟩 |
| 20 | I think information from support services is easy to understand | 53%  72/137 | 63%  77/122 | 🟩 |
| 21 | In general, I believe my family member / friend / partner / spouse is safe | 91%  136/150 | 91%  117/129 | ➖ |
| 22 | We are supported to be connected in the community | 39%  47/121 | 62%  73/117 | ☀ |
| 23 | We can use community options, connections, and services that are for everyone before we have to use specialised disability services | 42%  49/117 | 72%  78/109 | 🟩 |
| 24 | Our wellbeing benefits from contact with the disability support system | 62%  82/133 | 73%  88/121 | 🟩 |
| 25 | Our supports help us connect to people and places that are important to us | 60%  71/119 | 72%  78/109 | 🟩 |
| 26 | My/our rights are respected | 78%  111/142 | 89%  108/122 | 🟩 |
| 27 | I support my whānau/family member / friend / partner / spouse to make their own decisions in life | 83%  114/137 | 83%  101/122 | ➖ |
| 28 | I / we know where we are heading and have the supports in place to build the life we want | 60%  81/135 | 67%  76/113 | 🟩 |

1. [A short disability history of Aotearoa New Zealand • Access • Public Address](https://publicaddress.net/access/a-short-disability-history-of-aotearoa-new/) [↑](#footnote-ref-2)
2. In this context beginning early focused on reaching children and young people before more significant challenges were presented within school, community and other key services [↑](#footnote-ref-3)
3. SAMS is an acronym of this original name now out of use [↑](#footnote-ref-4)
4. Wilson, C.S. and Benjamin, M. (2019). Baseline Study of the Disability Support System in the MidCentral Area: Disabled People’s Report. Prepared on behalf of the Ministry of Health, New Zealand. SAMS Evaluate, Innovate, Educate   
   (1) (PDF) Document-in-Read-Only-Health-Reports-BASELINE-STUDY-REPORTS-OF-THE-DISABILITY-SUPPORT-SYS3. Available from: <https://www.researchgate.net/publication/337114113_Document-in-Read-Only-Health-Reports-BASELINE-STUDY-REPORTS-OF-THE-DISABILITY-SUPPORT-SYS3> [accessed Dec 16 2021]. [↑](#footnote-ref-5)
5. The MidCentral region includes Palmerston North, Horowhenua, Manawatū, Ōtaki and Tararua districts. [↑](#footnote-ref-6)
6. Ernst and Young (2018). MidCentral DSS population compared to the rest of New zealand. Report to the Ministry of Health [↑](#footnote-ref-7)
7. Throughout this report, the phrase whānau is used to be inclusive of different family types. It is intended to encompass a range of participants in the whanau survey, both Māori and non-Māori, and can include parents, siblings, grandparents, cousins, aunts and other relatives. [↑](#footnote-ref-8)
8. From the main group of 42 likert scale questions. Four more likert scale questions focused on people still at school, one for adults seeking further education, and one on people who were seeking employment. The Cantril ladder (an 11 point scale) was also used for statistical analysis across both year groups. [↑](#footnote-ref-9)
9. There were 35 likert scale questions in the whanau survey with five being directed toward with a specific subgroup and two being associated with quality of life. The main body of 28 likert scale questions showed the greatest improvement in trends between 2018 and 2021. The only other quantitative questions to show positive improvement within the ‘at home’ group was the cantril ladder. [↑](#footnote-ref-10)
10. Disability Support Services (DSS) is a range of services funded by the Ministry of Health, and delivered by providers under contract. Mana Whaikaha is open to the group of people that would otherwise be eligible for DSS. [↑](#footnote-ref-11)
11. Ambulatory-sensitive hospitalisations are defined by the Ministry of Health as hospitalisations of people less than 75 years old resulting from diseases sensitive to prophylactic or therapeutic interventions that are deliverable in a primary health care setting. [↑](#footnote-ref-12)
12. Allen and Clarke Policy and Regulatory Specialists Ltd (2020). Unpublished review for the Ministry of Health. [↑](#footnote-ref-13)
13. Milner, P., Gates, S., Mirfin-Beitch, B., & Stewart, C. (2008). An examination of the outcome of the resettlement of residents from the Kimberley Centre. Dunedin Donald Beasley Institute. [↑](#footnote-ref-14)
14. There was a strong community objection to deinstitutionalisation in MidCentral and while all people who left were older, younger families retain a preference for the perceived safety provided by residential care, as opposed to engagement with an Enabling Good Lives approach to a focus on a good life rather than services. [↑](#footnote-ref-15)
15. Local Area Coordination is a service offered in some parts of New Zealand. Coordinators support disabled people and their whānau and/or carers to strengthen connections with their communities and receive the support they need, while engaging with and supporting communities to become more welcoming and inclusive of disabled people. [↑](#footnote-ref-16)
16. DSS criteria can be found on the Ministry of Health website: [Am I eligible for Ministry-funded support services? | Ministry of Health NZ](https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services) [↑](#footnote-ref-17)
17. Connectors perform a critical role in facilitating Access to support, community networks, other government agencies and support people to write a good life plan. They act as allies who work under the direction of the persons and their whanau [↑](#footnote-ref-18)
18. See appendix four [↑](#footnote-ref-19)
19. ‘Personal budget’ is the term that disabled people and their families/whānau typically use. It can include different forms of individual and flexible funding streams, including Flexible Disability Supports (FDS). [↑](#footnote-ref-20)
20. Funding hosts can be providers holding a Flexible Disability support contract, hosts who manage individualised funding across the country or a person or whānau who are requested to manage the funds on behalf of a person. [↑](#footnote-ref-21)
21. https://manawhaikaha.co.nz/assets/Uploads/Mana-Whaikaha-Implementation-Evaluation-Final-Version-3-March-2020-002.pdf [↑](#footnote-ref-22)
22. Connectors faced system challenges due to lack of established payment systems, planning templates and IT systems to manage service allocation. Some of these issues were addressed in 2020 when the two teams merged improving ease of use for staff and outcomes for people as they engaged [↑](#footnote-ref-23)
23. Information on DSS can be found on the Ministry of Health website: [Disability services | Ministry of Health NZ](https://www.health.govt.nz/your-health/services-and-support/disability-services) [↑](#footnote-ref-24)
24. Note there are some complexities describing the group of people with ASD, because this group tends to involve people under the age of 35-40. For older people, records usually describe someone with ASD as having a learning disability. There is a system capability gap for the assessment of older people with ASD. [↑](#footnote-ref-25)
25. Gallup World Poll (Bjørnskov, C. 2010. How Comparable are the Gallup World Poll Life Satisfaction Data? *Journal of Happiness Studies*, *11* (1), 41-60. [↑](#footnote-ref-26)
26. [↑](#endnote-ref-2)
27. the desire to please may come from environmental factors such as being used to being told what to do, living in services, being too scared not to please people they see as in positions of power for fear of repercussions, not having been encouraged to speak out or take the lead. Questions are multi layered in this kind of research to try to mitigate these possibilities. [↑](#footnote-ref-27)
28. In particular, people can collude quite unconsciously in their own predicament (hegemony). [↑](#footnote-ref-28)
29. See in particular the theory of homeostasis. This suggests that people appear well adjusted on subjective indicators but can live in circumstances that do not help them maintain or improve aspects of their personal or physical lives. Cummins, R.A. (2005). Moving from the quality of life concept to theory. Journal of Intellectual Disability Research, 49(10), pp. 699-706; Cummins, R.A. (1995). On the trail of the Gold-Standard for Subjective Well-Being. Social Indicators Researchers, 35, 179-200. [↑](#footnote-ref-29)
30. For example, children and young people under the age of 18, and people with welfare guardians under the Protection of Personal and Property Rights Act 1988. [↑](#footnote-ref-30)
31. The type of statistical analysis used and other technical questions are available in the full report. [↑](#footnote-ref-31)
32. Significance tests are based on all five points of the likert scales. A 95% or higher confidence that a change was not due to chance is denoted (p<0.05). [↑](#footnote-ref-32)
33. Many figures are reported in terms of the two highest points on the likert scale to provide an easy comparison across time. As noted in the footnote above, significance tests used the entire five point scale to determine changes across time. [↑](#footnote-ref-33)
34. New Zealand mean in 2018 was 7.37 <https://worldhappiness.report/ed/2019>, means for learning disabled people in 2018 were 7.38 (SD 2.4) and in 2021 7.43 (SD 2.5) [↑](#footnote-ref-34)
35. For those providing verbal responses to the question: what did you dislike about the supports you receive. [↑](#footnote-ref-35)
36. See section ‎8.2.1 page 32 [↑](#footnote-ref-36)
37. ibid [↑](#footnote-ref-37)
38. See figure 1 (disabled people) and figures 4,5 (whānau) and page 40. [↑](#footnote-ref-38)
39. A representative study would have been more resource intensive. This was noted in the 2018 baseline. Refer to methodology and limitations of this methodology [↑](#footnote-ref-39)
40. This distinction is important. People with other types of disabilities were on par with the general population – this meant that their perceived happiness or wellbeing was the same as every one else. Theories in wellbeing and quality of life, indicate when people move off the average (ie lower) then there are significant stressors in their lives. Cummins, in particular, indicated that people who did not reach the “average” or equilibrium (or as he called it ‘homeostatus’) then they were unable to adapt and were in crisis. [↑](#footnote-ref-40)
41. Not all people provided comment on equipment needs as many did not need specific equipment. However, 31% of people who commented on equipment provided a list of what they needed. Another 27% stated they were waiting, sometimes for a long time, for equipment to arrive. Many of the reasons for these delays was a perceived lack of OT support in MidCentral region at the time. [↑](#footnote-ref-41)
42. Diagnosis is delayed due to high demand in the wider health system. Eligibility criteria for DSS can sometimes delay services funded by DSS due to diagnostic criteria. This is particularly true for children with global delay, who do not receive a firm diagnosis until 7 years of age. Diagnosis of ASD is more problematic due to skills gaps. [↑](#footnote-ref-42)