**Flexible Disability Support**

**MidCentral and Christchurch Evaluation Report**



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Standards and Monitoring Services

March 2022

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1. Executive Summary

Flexible Disability Support (FDS) is offered by the Ministry of Health as an option to provide a range of flexible funding options to disabled people and whānau. FDS is available in the MidCentral region and in Enabling Good Lives (EGL) Christchurch.

This evaluation was commissioned by the Ministry of Health (the Ministry) to explore the experiences of people using FDS as a contract mechanism for flexible funding. It aims to establish whether elements of the approach, like purchasing and provision of support, within an EGL context are working well (nor not). It is hoped this approach may contribute to an understanding of how purchasing and flexibility can be strengthened in the future.

SAMS[[1]](#footnote-1) undertook this evaluation in 2021. It involved a total of twelve case studies with disabled people and their whānau. Six participants came from the MidCentral region and six from EGL Christchurch. Interviews were also undertaken with Connectors from each region, an independent Connector and a financial adviser from Mid Central, and some FDS service providers from both regions.

Findings from these case studies have been analysed to inform this evaluation report. The report highlights the common themes from both regions and notes differences that may have occurred because of the varying systems, process and cohort groups across the two sites.

Results from this evaluation will contribute to consideration of improvements for FDS, future commissioning and purchasing decisions, and the wider system transformation work.

The structure of the evaluation report is outlined as follows:

Section 2: Introduction: This provides an overview of the findings and key themes arising from the evaluation.

Background information: describes FDS, including a description of how it is implemented in the two regions. The evaluation SAMS was contracted to undertake and key questions.

Section 3: Methodology: the case study approach used and selection of participants including information about their characteristics.

Section 4: Section 4 through to 7 present the collective findings from the evaluation which are grouped in the evaluation question areas.

Section 4: The partnership between disabled people and their whānau and their chosen provider(s): this section describes the features and effectiveness of this relationship.

Section 5: Opportunities offered by FDS in transforming systems and services: this highlights changes in thinking about services and providers working together. It includes some proactive initiatives and community engagement.

Section 6: What works well, challenges and areas of improvement: this section draws on experiences and perspectives of participants, Connectors and providers, and includes key positive findings for improvement.

Section 7: Flexible support and what can be learnt for the future: here we identify what was learned and what conclusions can be drawn from the work.

Section 8: Appendices: Appendix 1 includes information about Mana Whaikaha and in Appendix 2 the Evaluation Interview Questions are provided.

1. Introduction

2.1 Key Findings

A summary of the key positive findings of the evaluation show:

* An increase in self-determination was evident for most disabled people in both the Mana Whaikaha and Christchurch case studies of FDS. This was expressed by disabled people as examples of having more control and ‘say so’ in what they wanted to do in life, and people describing how their lives were more fulfilled.
* FDS was contributing, in the main, to disabled people’s lives being better now due to the way they were supported.
* Ordinary life outcomes were being experienced by people e.g. their living arrangements, participation in exercise, education courses, volunteer work/employment and activities/groups of interest.
* More autonomy was also noticeable for most people. They were accessing places by cycle(s), and some supported by their purchasing through FDS were using mobility scooters, learning to or catch buses, or using transport like taxis.
* The lives of some whānau were positively changing with their experience of FDS for their family member and themselves.

The service contract specifies the success of FDS is dependent on the EGL Principles being embedded into practice. Although primarily a funding model, feedback on FDS reflected strengths and issues with how supports are purchased and utilised and also how people perceive their supports. A focus on support was important to some people and whānau in this evaluation and several themes arising from findings were either directly or indirectly related to the translation of the EGL approach into practice. This also included person-specific issues such as advocacy and safeguards for vulnerable people. The main themes from the evaluation findings identify some of these areas.

**Thematic Evidence**

The themes that arose from the combined case studies included:

Disabled people and whānau roles and key feedback

* Partnership: relationships between disabled people, whānau, their Connector and/or provider were important in establishing trust and forming a partnership approach.
* Flexibility: the flexibility of FDS was contributing to changing conversations between disabled people and providers. Some disabled people were determining when and how their support was provided.
* Authority, confidence and information: having confidence, adequate information and a sense of authority to fully partner in the FDS process.
* Awareness and understanding of EGL: disabled people and whānau awareness, and understanding of an EGL approach, was variable as was how FDS worked for some people.
* Person-directed support: the support people received was important to people in achieving what they want. People were pleased with purchases they had made, and the support people wanted was working for most people. For some people parts of their support didn’t work as intended and needed improvement.

Connector’s roles and key feedback

* Potential of FDS: Connectors spoke positively about FDS and the potential it had to make a difference in people’s lives.
* Partnership: providers and Connectors worked together. While their roles differed, their relationship appeared strengthened when there was an understanding of each other’s role, processes were clear, and communication was open.
* Community engagement: relationships were developing with local communities and government agencies to increase awareness of an EGL vision, its key features, and to strengthen relationships.

Provider’s role and key feedback

* Flexibility and opportunities: FDS was described positively by providers with the flexibility and opportunities it provides.
* A shift to working differently: FDS has been a fundamental shift for some providers, in managing some or all of a person’s budget, providing support that people want and/or purchasing items. It has allowed them to work in different ways and think creatively when exploring options with disabled people and whānau.
* EGL approach: for providers, understanding FDS and having a consistent EGL approach has meant the development of an EGL approach into workforce practice, the need to develop and adapt systems, and the recognition of a broad skill set needed among support people.
* Partnership: a strengthening of relationships between providers in both regions was apparent as they worked collaboratively with each other and were more aware of the support each offered.

**Summary**

In each region the foundation for FDS to be further developed and successful is in place. However, it is still to be fully tested as both regions operate within different systems and not all disabled people in each area have had the opportunity to choose FDS as a support option.[[2]](#footnote-2)

Findings from the case studies undertaken in this review highlight consideration for improvement be given to:

* increased emphasis on the EGL Principles within FDS and in practice. A closer focus on the EGL approach generally to facilitate greater understanding by all stakeholders,
* the sharing of stories of people’s experience using FDS to support greater awareness,
* information and clarity about FDS and interpretations of how FDS works, including systems, roles and processes which is easily understood and easy to use by everyone,
* providing proactive strategies for some disabled people regarding decision-making and safety,
* strengthening relationships between disabled people and providers and between providers and local communities / government agencies.

Key areas for consideration: While the experiences of the people interviewed suggest there has been a shift to an EGL approach, prevention of a return to former ways of working may rely on having transparent processes that are easy to use by everyone.

* 1. Background

2.2.1. What is Flexible Disability Support?

Flexible Disability Support (FDS) is a contractual mechanism provided by the Ministry of Health to enable people to choose supports from providers.

FDS enables a disabled person to purchase the supports they require from a provider, and to work with their chosen provider in directing their support.

The service objectives for FDS are:

* A person receives FDS to support them in living the everyday life that they choose[[3]](#footnote-3).
* The EGL Principles are the foundation of FDS.
* Successful FDS occurs when the EGL Principles have been embedded in the provider’s practice.

In having a provider manage the supports a disabled person wants and supporting them to manage their personal budget, it was anticipated FDS would be a good option for some who did not want to be in charge of fully managing a personal budget.

2.2.2. Overview of EGL Christchurch and FDS

Enabling Good Lives (EGL) in Christchurch started in July 2013 as a three-year demonstration project of the EGL Principles as first outlined in the 2011 paper[[4]](#footnote-4). The aim was to test and apply the EGL approach as proposed in the 2012 Canterbury Plan[[5]](#footnote-5). The project was overseen by the Ministries of Health, Social Development (MSD) and Education (MOE), and National and Local EGL Leadership Groups were established.

At the completion of the demonstration project in June 2016, Cabinet made the decision for EGL to continue to be trialled, with the Ministry of Health, Disability Support Services (DSS), as the lead agency.

The service operates primarily in the wider Christchurch city area and extends into the Selwyn and Waimakariri districts. There is an ability to keep in contact with people having EGL budgets who have moved out of the Canterbury area.

EGL Christchurch continues to use and develop the initiatives introduced in the demonstration project within traditional NASC structures and processes. The EGL Connector works with the young person and their whānau to create a good life plan, the disability-related costs of which can be funded from the person’s EGL personal budget allocated by the NASC.

The group eligible to be involved in EGL Christchurch has remained the same. For example, students in receipt of High Needs (HN) or Very High Needs (VHN) Ministry of Education Ongoing Resource Funding (ORS) funding and in their last years of school. Changes in the last year have allowed Connectors to start earlier on transition planning with students from the age of 14 years and provide for more Connector time if needed with individuals and their families.

EGL Christchurch reported a cumulative total of 668 participants until the end of 2021. The number of new participants, in the years between 2018 and 2020, ranged from 83 to 93. In 2021 there were 143 new participants.

The average case load for a full-time Connector is 50 people.

DSS introduced FDS in March 2016 as a contract mechanism to offer a flexible range of supports to disabled people and whānau in the demonstration. DSS contracted 10 providers to provide FDS. Initial training sessions for these providers were given by EGL Christchurch and DSS. These sessions provided an overview of FDS aims, expected outcomes, with examples from Choice in Community living[[6]](#footnote-6) (a comparative model of support for disabled people moving out of their family home or a residential facility and into their own home).

Figures at the end of 2021, provided by EGL Christchurch, show 40% of those using a host for all or part of their budget use an FDS provider, with 60% using Manawanui[[7]](#footnote-7). Many of those who use a host divide their budget between providers. Seven FDS providers were listed as the main host for EGL personal budget allocations. More than 11 agencies were identified as secondary/other services. These represented a proportion of providers who contributed support but were not primary hosts.

2.2.3 Overview Mana Whaikaha

The MidCentral prototype, Mana Whaikaha, began in 2018. It brings together elements that had been trialled and researched in previous projects into a co-designed different way of working for a ‘whole of system’ change. The prototype of the transformed system together with its objectives and intended impacts are included in Appendix 1. The transformed system is available to disabled people of all ages in the MidCentral region who are eligible for DSS funding.

The Ministry of Health is the lead government agency. There is a Regional Leadership Group, with a subgroup being MidCentral Regional Governance Group (the Governance Group) which oversees implementation and operation.

Mana Whaikaha Connectors and independent Connectors assist people in creating their plans or people can create their plan themselves. Mana Whaikaha budget advisers approve the personal budget.

When Mana Whaikaha started, there was a significant, and for some an unanticipated[[8]](#footnote-8), interest in the new system shown by disabled people and whānau. Initially, due to some people being in a crisis situation, priority of response was given to these people. In addition, a priority was placed on starting early with young children and whānau. These priorities contributed to a delay in other disabled people and their whānau receiving support through Mana Whaikaha. At the time of this evaluation, the caseload for individual Connectors was indicated as being upwards of 100.

FDS was available from the start of Mana Whaikaha as an enabler for system transformation and to provide options to disabled people and whānau for both choice, partnership and continuity of support.

There were originally eight providers contracted to provide FDS by the Ministry of Health, of whom seven actually provide FDS support. Mana Whaikaha is also using approximately five other agencies to provide FDS who have secondary contract lines in their contract with the Ministry of Health. There have been several training sessions provided in MidCentral for providers and staff in the understanding of EGL and FDS.

Data was requested from the Ministry of Health to provide more context for the MidCentral evaluation and case study in terms of the overall number of people using FDS and their demographics. The complexity of the data systems currently operating in MidCentral and the different reporting lines from providers offering FDS in MidCentral has created no single reliable data set. At the time of writing this report this information has been unable to be obtained.

2.2.4. Comparisons between FDS Mana Whaikaha and EGL Christchurch

There are similarities in the way FDS is being offered by Mana Whaikaha and in EGL Christchurch.

In both areas:

* FDS contract mechanisms aimed for alignment to EGL Principles.
* There was integrated funding in a personal budget for individuals.
* There was a Connector involved in the development of a good life plan and options for management before the NASC or funding advisor made the allocation.
* FDS was offered as an option to all eligible participants.
* Both EGL entities are managed primarily by the Ministry of Health with involvement from MSD and the Ministry of Education.
* There were local leadership and/or governance groups.

There are several differences, in the context in which FDS operates, in EGL Christchurch and Mana Whaikaha. These relate to system structures and processes, the eligible cohort, and the length of time FDS has been available.

* At the time of this evaluation EGL Christchurch had been operating for eight years with FDS being offered for five years. Mana Whaikaha had been running for three years with FDS offered for the same time.
* EGL Christchurch Connectors are responsible for development of a good life plan with the person/whānau, discussion about possible options and the NASC subsequently arranges allocation based on current eligibility. Mana Whaikaha begins with the disabled person choosing whether to manage the process themselves or use a Connector or independent connector. If a Connector is chosen, they explore with an individual what they want to do in their lives, and how this may work in terms of support/purchases to assist. The plan developed forms the basis for developing a personal budget which is provided for approval to Mana Whaikaha financial advisers.
* Mana Whaikaha is available to all disabled people eligible for DSS funding in the region whereas the eligibility criteria for EGL Christchurch is limited to young people with VHN or HN and ORS funding.

## **2.2.5. Evaluation purpose and questions**

SAMS (Standards and Monitoring Services[[9]](#footnote-9)) was asked by the Ministry to undertake an evaluation of the implementation of FDS in MidCentral and Christchurch. The evaluation focuses on the experiences of people using FDS as a more flexible contracting option and not the FDS contracts per se.

This evaluation examines:

* the implementation of FDS through the experiences of disabled people, whānau and FDS service providers who have taken this option of FDS as a contract mechanism. This includes additional information gathered to provide perspectives from EGL Christchurch Connectors, Mana Whaikaha Connectors and a financial adviser, and an Independent Connector; and
* the success of this option in meeting its intended objectives of greater flexibility and working effectively with an EGL approach.

Key questions to be addressed:

* To what extent has partnership between chosen disability providers and disabled people been achieved?
* What changes to service styles etc have happened with FDS? For providers and people partners?
* What’s working well regarding achieving life outcomes?
* What’s not working well in achieving a good life?
* What needs to improve?

Across all question areas consideration is given to the translation of EGL Principles into practice. Attention is also paid to outcome domains including but not limited to self-determination, health and wellbeing, physical and financial security, relationships, inclusion and self-fulfilment/life satisfaction.

# **Methodology and Participants**

## **3.1. Methodology**

The evaluation used a qualitative methodology to explore the evaluation questions and analyse themes using a case study method.

A collective case study approach was used drawing from 12 case studies with disabled people and their families/whānau who used FDS. Case studies generate an in-depth multi-faceted understanding of complex issues in a real-life context. This type of research design is well suited to addressing the questions asked in this evaluation and has been used in similar research. For example, the qualitative review(s) of EGL Waikato[[10]](#footnote-10) and qualitative aspects of the baseline and repeat studies[[11]](#footnote-11) in MidCentral region.

Semi-structured interviews were the primary method for gathering information about the experiences of disabled people and their whānau in using FDS. These were drawn from and combined across the two sites to form the collective case study.

Semi-structured interviews were also undertaken with Connectors, an independent connector and a financial adviser.

Two group meetings – one in Palmerston North for MidCentral and one in Christchurch – were held with FDS providers. There were also some individual interviews with some FDS providers in relation to their experiences with case study situations and/or to further explore issues raised at the group meetings.

The interview guides for disabled people and for whānau comprised mostly of open-ended questions with a small number of questions asking participants to indicate whether they thought something happened ‘all of the time/yes’, ‘mostly’, ‘sometimes’, ‘not really’, ‘no/never’. Interview guides for Connectors and providers contained open-ended questions only.

The Ministry’s FDS service specifications including Mana Whaikaha and EGL Christchurch information sheets about personal budgets was available to all stakeholders.

Using these different sources allowed for triangulation of information and an overview of what was working well, what were the challenges and what could be improved.

## **3.2. Selection of case study participants**

**Mana Whaikaha**

The FDS evaluation took place concurrently with a larger survey (The Repeat Study)[[12]](#footnote-12) being undertaken of Mana Whaikaha. Each person using FDS in the region was provided with a code number[[13]](#footnote-13).

Each person was then checked against the Repeat Study concurrently in order to avoid double ups. The list was also checked against active EGL Core Group members in the region to eliminate any conflicts of interest. This process was applied until there were six randomly selected people who met the sought profile[[14]](#footnote-14) and had provided initial verbal consent.

The final selection of disabled people interviewed met nearly all[[15]](#footnote-15) of the features of the profile of the participants that the Ministry had requested. Interviews took place from the middle of May till the end of the first week of June 2021.

**Christchurch**

For EGL Christchurch adjustments were made to the sought profile and initial selection processes to meet the age range of disabled people in EGL Christchurch.

Each person using FDS was provided with a code number by EGL Christchurch, and a list was supplied to the evaluator from which 18 were selected. These people were contacted by their Connectors who gave information about the study and asked for their permission to pass their contact details to the SAMS evaluator if they were interested in participating. This resulted in a much smaller number of potential participants.

Contact[[16]](#footnote-16) was about to start to arrange interviews with people on this smaller list when COVID restrictions were reintroduced that precluded face-to-face interviews being able to take place.

Contact to arrange interviews was then resumed some four months later when conditions to undertake face-to-face interviews were approved by the Ministry. At this stage some potential participants were no longer able to take part in interviews. Attempts were made with assistance from EGL Christchurch to increase the pool of potential interviewees and to better match the originally sought profile characteristics. However, this did not prove to be possible within the available timeframes[[17]](#footnote-17). This resulted in the number of Māori participants and the balance of female/male originally sought being unable to be achieved.

## **3.3. Limitations**

* The study draws insights from a limited number of people’s experiences, and findings will be only indicative.
* The inter-relatedness of many factors created complexities and no single conclusion could explain all scenarios.

## **3.4. Case study participants characteristics**

**Mana Whaikaha**

* There were six participants interviewed (50% female and 50% male) and their ages ranged from 20 years to 58 years.
* Three participants were under the age of 30.
* The whānau of five participants were also interviewed, with agreement from their family member to take part. Some supported their family member at the interview.
* Two participants were selected from each of the following impairment categories: learning/intellectual, physical, sensory and ASD.
* Two participants had impairments acquired from a medical event, such as a stroke.
* Two participants identified as Māori and four of the participants spoke of their iwi.
* Two participants had the same provider and each of the other participants had different providers/service. Two people each received support from two different providers.
* Two participants had an independent Connector associated with an agency, and each of the other participants had Connectors from Mana Whaikaha.
* Three participants were currently living independently (on their own) in a flat which they rented, and three were living with other people in flats they rented or their family/own home.
* Some people required support in the home and/or support to learn life skills, such as building connections, support with shopping, meal planning and participating in community activities.

**EGL Christchurch**

* Seven[[18]](#footnote-18) young people from six families participated in the case studies.
* The ages of the young people ranged from six to 26. Five of the group were between 19 and 23 years of age. One of the participants was female.
* Three participants were identified as having autism spectrum disorder (ASD) and three as having learning disability. One person lived with learning disability and ASD.
* Three young people identified as NZ European (NZE), one as Māori, two as NZE/Asian and one as Asian.
* Of the seven parents who participated in interviews four were NZE, one Māori and two Asian. There were three mothers, two fathers and for one disabled person both parents who contributed. One parent identified as having an intellectual disability.
* Five of the participants were living in their family home, one was flatting, and one was temporarily living elsewhere. Two of the three participants who were still at school were in their last year, two were one year out of school, one was in their third-year post school, and one was in their fifth year since having left school.
* At the time of the interviews four of the families were actively involved with three different FDS host providers (defined as the provider hosting most of the EGL budget)[[19]](#footnote-19). Two of the four were with the same FDS provider.
* Supports and services used by participants ranged from FDS providers paying invoices for equipment, finding,and paying support workers for community activities to hosting a personal budget for community living arrangements including employing support staff.

## **3.5. Connectors and FDS Providers**

Interviews were undertaken with nine Connectors and a budget adviser.

* Four were Connectors from Mana Whaikaha and one from an independent agency. An interview was also held with a Mana Whaikaha financial advisor.
* Of the four participating Connectors in Christchurch, one was the Connector for two of the participating family groups. Another interviewee had been involved with the same provider for five years and had not needed contact with a Connector for some time.

The hui in MidCentral was attended by representatives from five FDS providers with 10 attendees. Seven FDS providers were represented at the Christchurch hui with 17 attendees. Written information was also sent to the SAMS evaluation team from an FDS provider unable to attend the hui. Individual interviews were also undertaken with five FDS providers – three from MidCentral and two from Christchurch.

1. Evaluation Results

The following sections present findings from the collective experiences of disabled people and their whānau using FDS. These are grouped in the evaluation question areas:

* The partnership between disabled people and their whānau and their chosen provider(s).
* Working with FDS host providers to achieve sought outcomes and consistency with EGL Principles.
* Identifying what worked well, what are the barriers and what needs improving.
* What can be learnt from FDS.

Included are the perspectives of Mana Whaikaha (Connectors and a financial adviser), an independent Connector, EGL Christchurch staff (mostly Connectors) and FDS service providers.

There were many common themes across the two evaluation sites. Where there were contextual differences in how the two areas operated that may have contributed to particular results, these are discussed.

## **4.1. The partnership between people and their chosen provider(s)**

Partnership is at the core of the Ministry of Health/DSS FDS contract. For most participants, establishing connections with FDS providers came against a background of relatively new involvement with Mana Whaikaha and EGL Christchurch Connectors. Even for the small number, who continued with a previously known provider, this was under a different arrangement with FDS.

Partnerships with providers were inter-related and varied in different situations and points in time. This was especially pronounced in Christchurch with the focus on transition from school to post-school life. Schools were significant initial partners. EGL Christchurch liaised with schools and provided information evenings for students and their families.

In Christchurch, having an FDS service provider, to manage all or part of a personal budget, introduced a different way of working not only for disabled people and their whānau, but also for other services.

In Mana Whaikaha, with its whole of system change, the local NASC no longer existed and Connectors and/or a funding advisor formed the key point of contact. The whole relationship was through the Connector. For EGL Christchurch participants, plans were created with the support of Connectors, but the budget allocation was still undertaken by the local NASC. While much less than previously, many of the families still had some contact with the Needs Assessor for their family member.

The following subsections consider the features and effectiveness of partnerships experienced by disabled people and their whānau, specifically, those with FDS service providers.

### 4.1.1. Developing trust with disabled people and whānau

*“They (provider) were just brilliant, they were so professional.”* *(Disabled person)*

*“I don’t look at it as a partnership, it’s a relationship.” (Parent)*

It was evident that trusted, respectful and reliable relationships were the basis of valued and effective partnerships.

Connectors were highly regarded in their roles providing support and information. Their work was spoken about positively by almost all people and their whānau in the evaluation. Connectors, including an independent Connector[[20]](#footnote-20), were usually the initial contact and connection for disabled people in understanding of EGL and the system, including the option of having FDS.

The most concentrated Connector engagement came at the earlier stages in helping develop plans and putting in place initial steps to progress an individual’s goals. For some people this involved a considerable amount of support to help identify what was important to them in having a good life.

* **Connectors supported the development of relationships between people and their chosen provider(s)**

The Connector supported building a relationship between disabled people and their chosen provider, which then enabled the Connector to start to step back. Fostering this relationship was important, particularly for disabled people. Features of this included having support coming into their home, getting help to manage a crisis or a tense situation, and trusting people to manage transactions for them. Connectors were aware of needing to give time to ensure disabled people were well supported.

Most Connectors continued to maintain ongoing contact by telephone/text/email with people or their whānau to check on how things were going after initial support was faded. There were times, for some participants, where changed circumstances meant plans had to be altered and different connections made. At these points, the Connectors stepped up their involvement. People and their whānau knew they could contact their Connector if they needed information or had concerns, and Connectors usually responded promptly to their calls. Some people had changed their Connectors, but this seemed primarily related to Connectors leaving the position.

Case loads impacted on the capacity of Connectors to follow up with and respond to people. As discussed earlier, Mana Whaikaha Connectors had high caseloads including having to work intensely with many people in crisis situations. From 2016 to 2019 there were limited hours available for Connectors to work with whānau in Christchurch. One parent mentioned this as possibly limiting the times they contacted the Connector as they didn’t want to use up all the hours too soon.

The role of Connectors was perceived as vital to successfully navigate each person’s FDS contract. Previous limitations relating to hours available have been addressed in recent years in Christchurch. This has enabled Connectors to have more time with young people and whānau where needed. However, in Mana Whaikaha there was a perception expressed about barriers created by large Connector case loads.

* **Developing and maintaining partnerships with FDS providers**

*“Of course, when you start off you don’t know how it’s going to work” (Parent)*

Participants in the MidCentral region expressed that support was very important to them as it assisted them to live their life and achieve what they wanted.

The types of support people in MidCentral received from their FDS provider(s) varied. Some people had support in their home, were supported to learn life skills to live independently, and/or had support with shopping and meal planning. The assistance provided for some people included support in the home, personal support, therapy sessions and community activities.

For EGL Christchurch participants, FDS providers administered personal budgets to pay for equipment purchases and services such as community activities (both individual and group), learning, work and holiday programmes, and finding and employing support workers. In one of the case studies the FDS provider employed and managed 24-hour staff support in a home shared with others using the same FDS provider. Changes in personal circumstances and/or individual plans had led to two participants not actively using or discontinuing use of FDS at the time interviews were undertaken rather than dissatisfaction with the chosen provider. One of them was in the process of choosing a new FDS provider better suited to their changed circumstances and revised plans. For the other person an opportunity that arose after the initial planning meant that the chosen FDS provider was no longer required.

* **Relationships were strengthening over time between disabled people, whānau and providers**

The development of a partnership approach, that was a trusted relationship between people and FDS providers, appeared to be influenced by how supports were provided and had evolved. Where people and whānau were more comfortable, and had a longer relationship with a provider, they seemed to approach the provider first for some information rather than their Connector.

The role of Connectors in assisting people to make the most of their funding was crucial. Especially as they were a conduit between the person/whānau and providers. Without the clear direction from the person and whānau, the Connector would find it difficult to help them search for the best options available.

The Connector also must take the plan to both the providers and either the NASC in Christchurch or the Mana Whaikaha financial advisers. Connectors also offer ongoing support until the individual is comfortable with the direction of their chosen options and goals. They are also available if changes need to occur. The connection they make is independent of service provision.

However, the boundaries between what the Connector offers in setting things up and the role the provider takes on can become blurred or become a point of conflict. For example, some provider comments in the hui held suggested they knew the person better than the Connectors, and the Connectors were at times stepping into service facilitation roles. Conversely, some providers in MidCentral believe some Connectors were not passing on crucial information about an individual as a lead up to them providing services. In these cases, providers were interested in being involved in early interviews with the person and whānau alongside the Connectors.

In the MidCentral study, approximately half the people indicated they had a supportive relationship with their chosen providers, and this had developed over time. Almost all the people and whānau in Christchurch reported having helpful and supportive providers. Although, there were some examples given where relationships could be improved.

The nature of the partnership with FDS providers varied for Christchurch participants. For two whānau this had largely been transactional i.e. making purchases and paying invoices rather than a relationship with staff. Communication was mainly by phone or email, and participants[[21]](#footnote-21) would deal with different people depending on who answered the phone or responded to the email. For others, using an FDS service provider was a more personal relationship with staff they got to know.

### 4.1.2. Person-directed support

#### The natural authority of disabled people and whānau

There was an overall sense the people and whānau felt valued and respected by many of the providers and they had developed trust over time with them. They were generally positive about being listened to and felt more in control. Not only did people believe some service providers were more person-directed but they believed services respected their natural authority.

All participants in the case studies, who were able to participate in discussions with their Connectors, felt heard and understood – with their preferences and choices reflected in their plans. A sense of direction for people appeared to be established by the Connectors. Agreed supports and services were either in place or being put in place.

For some people it can be difficult for them to communicate their preferences, and this is when Connectors are reliant on people who know them well. For example, one parent of one young person noted:

*“When they’re not vocal you don’t know what they want, and I felt I don’t want to overlay my desires and designs when it’s not what he wants… so we started with the things he’s enjoyed in the past and find out how he reacts.”*

The Connector role was described as supportive in working with providers to ensure the voice of the person was heard. For example, Connectors in working with people focused on what the person wanted. At times, this could differ to what their whānau thought their family member wanted. The Connector could support a provider by having the Connector step in and out as needed in supporting the person.

*Shifting to a person directed support approach*

For many their providers were not just their fund holders. They also actively managed support. Any breakdown in this support structure reflected on the people’s perception of the success of FDS.

Providers, particularly those in Christchurch, spoke of FDS as being a fundamental shift in the way in which individuals are supported. It was stressed that change took time and processes needed to be developed or adjusted. Some indicated it could take as long as five years, or more to make the needed changes.

It was reported some providers were stepping up to support people in the way they wanted. However, there were also examples given of situations where inappropriate attitudes and core practices were shown by support workers/staff towards the people in some services.

In MidCentral a Connector noted:

*“…there was a lot of work coming out to bring providers on board with Enabling Good Lives” (Connector).*

People expressed feelings in these situations of:

*“not being listened to”*, and being

*“powerless to change anything”*.

Whānau also identified that some providers were more aware of individuals and the support they wanted. Other providers were described as not actively looking to enhance a person’s life or understanding how to support the person to express their will and preference.

Approximately half of the people in the MidCentral study had experienced some discontent with their support or reported that that their supports weren’t working. Some whānau had made complaints, on behalf of their family member, which resulted in some complaints being resolved. However, in some instances, issues reappeared some months later. Where support was not working the way people had anticipated, or was considered insufficient, it was whānau who were unexpectedly picking up this support.

For some people it was not always easy to change providers and start new relationships when they weren’t entirely happy with their supports. In some situations, there were aspects people liked that they didn’t want to lose or there may be no other options available. Talking with their Connector, or service provider, was often the first step to resolving these situations.

Providers acknowledged they were continuing to support staff in learning about working using an EGL approach to enhance the ability of the person and whānau to direct their lives. Findings identified the critical importance of investing in the ‘understanding or getting to know people’ that is required to enhance lives and to respect natural authority. Moving to a different way of working appeared to take time and effort for some providers to ‘deinstitutionalise staff’ and begin focusing on the person and their journey.

#### Self-determination – People are in control of their lives

Overall people were generally clear about what they wanted to do in their lives, what they wanted to purchase and how their support could make it happen. FDS was described as:

*“Better than it used to be – [You] can tell people what you want.” (Disabled person)*

Some people were taking the lead in the way they wanted their support provided. For some, person-directed support was enhancing their confidence and sense of control in their lives. An increase in confidence was also reported by some whānau about their family member. Seeing their family member taking on more responsibility, and being happy with his life gave one family, with the support he had from the provider, greater confidence that his life was on track.

The increase in self-determination was contributing to most participants having fuller lives. Most people were making choices about how they wanted to live their life and what they wanted to be involved in, such as volunteer work/employment, education, exercise and groups of interest.

There were still areas of some people’s lives where they indicated improvements in support would assist their autonomy and independence.

#### Ordinary Life Outcomes

* **Person-directed support was enhancing some people’s lives**

Positive examples were evident of support people getting to know individuals and supporting them to learn new skills and achieve what they wanted in life. Working at the person’s pace and listening to them appeared to have a positive influence on people’s confidence and sense of control.

Christchurch case study participants were at different stages in their EGL plans. Some were in the early stages of putting supports in place or thinking about steps towards longer term goals while others were making changes to plans or were building on initial outcomes that had been achieved. For all young people interviewed this involved doing things just like everyone else their age. For example, getting more independence, doing further study, having a job and going flatting. As described by one participant, “*I want a job so I can pay my bills”*. Some whānau commented on their family member’s greater independence and were happy to see the new skills they had learnt.

* **Consistency in having the same support people was important to people**

Several people in the MidCentral study spoke of wanting the same support person/people to support them. There were good examples given of providers rearranging people’s support schedules to ensure this could happen. Most people were receiving support from a consistent support person(s). This gave disabled people assurance of continuity of their support by the same person/people, rather than having a different person each time.

As noted previously, it is difficult to separate how people perceive the FDS funding from their actual support. The driver for most is the promise that having the flexibility will allow them to choose, not only their goals, but who and how their support is provided. If the end outcome is successful or unsuccessful, the focus goes back to the ‘promise’ of FDS.

It can be argued that the introduction of any new approach or positive improvements in how support is provided could drive positive change and a greater sense of autonomy. FDS is informed by the EGL Principles. Within the contract specifications there is an explicit expectation that providers are responsive to how people want their supports provided. While it is impossible to say if FDS caused the positive improvements people experienced, a move from a top-down approach to a situation that puts the person in the driver’s seat has been perceived by some to indicate that it resulted from these positive changes.

#### Person-centred

The change to a more person-directed approach was enabling support to be more personalised and focus on what people wanted to do. Over half the participants in MidCentral were clear with their providers/support people about the support they wanted. There were examples of this being ‘person-directed’, with some people having worked out prearranged times for their support and/or a process to be followed.

The goals of individuals in plans developed with the Connector were described as having a whole of life approach which included their preferences, interests and social/wellbeing. For some people they spoke about what they did during the week, including voluntary work and/or what they were working towards, and for some they were still at school and yet to start what they had decided on.

Current situations for some people were evolving, as they gained confidence and tried out new things. For one person, this resulted into a few hours of unpaid work in return for access to an exercise programme at little/no cost. For another person, it was being able to now walk independently to buy something at a nearby shop. Changes in circumstances, for some individuals, had meant they were looking at changing some parts of their plan.

Where some people had more than one provider, the second provider they had chosen supported them with different areas of their life, e.g. accessing the community or shopping. Some people spoke of their lives being enriched and expanded by having the support of a second provider during the day/week.

Having more than one provider often required providers to work together. In some situations, they attended meetings arranged by an individual, or worked together to ensure arrangements during the week were clear for the individual and easier to understand.

#### Mana Enhancing

The mana of the participants was being enhanced in various ways. At times this was through the connections disabled people made with people at the places they went to or were involved with in the community. This was in turn precipitated by the direction they indicated in their plans.

People in the case studies indicated they were generally happy with their lives. One person’s response about being ‘happy with their life’ was received positively by whānau and a change from a few years ago when they were in a tense situation. The plans and purchasing together with support were contributors to making a difference for them.

In both regions, whānau were involved in all the people’s lives. There were examples of some support workers acknowledging and giving recognition to the knowledge and support whānau had provided. When whānau gained trust in support workers, this contributed to whānau starting to think about what they may want to do themselves, and/or as one family member described it:

*“{I} can have a life”.*

### 4.1.3. Easy to use information and processes

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

In MidCentral, supports were flexible but information (written and verbal) about elements of the new system and FDS were not transparent, accessible or easy to use by disabled people and others. There were several areas identified where people and whānau were unclear about FDS such as expectations, budgets, updates on budgets and purchasing items. One whānau described the need for information as:

*“It’s not a partnership if we don’t have all the information.”*

The information, processes and system in Christchurch were described by whānau as understandable *“only with the connector’s help”*. Even then for some whānau there was still confusion and uncertainty not just in relation to FDS but about how the system as a whole worked. The Connector has been the person to assist an understanding of how both EGL and FDS work (this was evident in both locations).

Providers in MidCentral similarly voiced the need for everyone knowing how the system works, ease of use and transparent processes. They related to the fact they were working with the system which differed to the experience of people and whānau who had received variable information about FDS. As one provider commented:

*“They [disabled people and whānau] haven’t been bought along on the same journey the same way, it’s all foreign to them and that’s just the reality of it at the moment but a bit more work or more effort promoting some of the ideas….”*

#### Budget information

The support for young people to understand funding and processes was also raised by whānau as being important. This enabled young people to be more fully informed and to take on more responsibility for decisions and directing how their budget is used.

#### Purchasing guidelines

The purchasing guidelines were described by disabled people, Connectors and providers as being hard to work with and unclear.

What was considered disability support funding was also still confusing. This could cause delays and extra work before needed and agreed supports in a person’s plan were in place. This is illustrated in one example given where the purchase of glasses was included in the person’s plan, since computer use (which was an important part of their learning and communication) was causing migraines. It was believed blue light glasses would assist the situation. However, when the purchase request was made to the FDS provider by a family member, it was refused on the basis that glasses didn’t qualify as disability support. The family then went back to their Connector who made the case again for the glasses as a disability support. After some time and the Connector’s intervention the glasses were finally approved for funding by the FDS provider.

Where whānau worked with providers to arrange situations their family member wanted, such as have their own home, to flat with people of their choice, receive support to meet their needs/shared needs, this required a considerable amount of planning and understanding of information and processes. In one example given, there was still a lot of effort required by some whānau, working with an FDS provider, to support a group of young disabled people to be successful in flatting together. This supports earlier discussion about the flexibility of contracting not being successful on its own and it being reliant on factors like the supports people receive. In this situation it points to the need for ongoing support and skills to bring about the experience of a good life for people.

#### Clear communication

Several people and whānau in MidCentral needed clearer information about the roles and responsibilities of each party in relation to FDS. As well as providing clarity and understanding, this would support a more transparent process.

* **Clarity of roles related to Connectors and providers was important for disabled people and whānau**

Providers of FDS are expected to work with Connectors to achieve the vision and principles of EGL but their roles differ. At times, a blurring of boundaries was described in the roles of the Connector and providers as previously discussed. While the role of the Connector was valued, and the change in EGL Christchurch to increase Connector support appreciated, some expressed that greater clarity around boundaries was needed. Increased clarity of the Connector and provider roles was important for people and whānau too.

* **Open communication and the sharing of information was essential in maintaining a trusted relationship between Connectors and providers**

Relationships between Connectors and providers were mostly described as supportive. However, there were indications of this relationship needing to be strengthened. Across both evaluation sites, more open communication and sharing of ideas and information could assist in consistency of information and processes including the understanding of different roles and responsibilities. People and whānau could then know who to approach for what.

### 4.1.4 Trust and equity

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

#### Trust

* **People’s trust in their supports appeared greater than their trust in the wider system**

The trust people, in the MidCentral study, had with supports they received was positive for half of the people. This differed to comments from people or whānau, where support was not working as intended, such as:

*“not really as far as providers [were concerned]”,*

*“[I] ask for some things ….[but] and won’t happen unless somebody else asks”, and*

*“they turn up”.*

The evaluators asked the question “whether people trusted the system?” In MidCentral, approximately half of the people and whānau responded and their comments reflected that most didn’t fully trust the wider system. This could relate to the length of time in using the new system, or previous experiences by people of the system.

One comment from whānau in Christchurch reflects:

*‘You get to the stage [with so many people and services involved] where you feel very tired and so you're starting to get to the stage where if there's someone new coming along I want them to start making it simpler for me [to get the supports needed for disabled son]*’.

For this parent, that is what the EGL Connector did, and they had trust in and chose the FDS provider because they ‘*liked their [provider’s] philosophy’.*

#### Equity and power shifting

* **An example of inequity was indicated within the current systems**

There was evidence from interviews of some people not being as well informed as others about FDS and EGL. Whānau were actively involved in the lives of all case study participants. Some whānau and providers from both regions raised a concern about people who did not have whānau involved in their lives to assist or no longer around to provide support. There were also some comments made by a few providers in both regions about people who had strong advocates seeming to attract greater funding.

* **A difference in opportunities through personal budgets were becoming noticeable for people using FDS and people living in residential services**

Christchurch providers highlighted the disparities between what was possible for people using FDS. This disparity is particularly evident where people using FDS are compared with those who used alternative, more traditional funding systems.

In one example, flatmates in the one household who were all using FDS had more opportunities available than their peers without FDS in residential services with the same provider. This was particularly the case for those with higher levels of support needs. Having a personal/EGL budget managed by an FDS provider and the flexibility it offered enabled greater choice and control in individual’s lives.

Although the situation described was beneficial to individuals concerned, there were issues of fairness and a two-tiered system at the wider level.

Some providers raised that people with FDS funding can purchase someone to support them during the day to go to places unlike people in a residential setting who have to wait for a day service/support or individually may not get out to places of interest to them.

A concern was expressed by some providers about the ability for inequality to widen for people without whānau or other support networks.

* **Charges for administration by the providers varied, with no set rate among providers for specific support provided**

An increase in administration work was evident with FDS and some providers indicated the costs of this administration work was not covered in the individual’s packages of support they received. For some they needed to create a charge for the administration or ask for more money to cover this charge. A difference in provider rates/charges was also expressed in both regions, with no set rate for charges of similar support such as invoicing. Some Connectors raised a concern, as did some whānau, that the charges resulted in much less money being available to be spent directly on personal supports. This could often affect those with the least resources the most.

People and whānau had chosen their provider and were aware of their personal budget, but more transparency around costs would be beneficial.

### 4.1.5. FDS and Māori

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

The feedback provided by Māori and non-Māori reflected similar themes. However, the importance of the need for Māori and Pacific peoples and access to the wider system was strongly emphasised by FDS service providers.

Māori who were involved in the case studies had whānau support and some had regular connections with their wider whānau. FDS through its flexibility gave them the ability to be creative around aspects of how support could work. In one situation arrangements were in place whereby whānau supported them in areas such as making a meal each day or helping them with information or appointments when needed. Some Tāngata Whaikaha Māori (disabled Māori) expressed contentment with their living situation, were achieving their goals and some were managing their supports. The knowledge that whānau were around for support was indicated as important to them and having supports that worked for them.

### 4.1.6. Achieving and sustaining sought outcomes

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

#### Planning process

The planning process was enabling disabled people in MidCentral to think ‘big’ about their lives, what they wanted to do and taking a whole of life approach. Plans developed with the Connector were individualised, supporting people to decide what was important to them.

‘Life taster sessions” by Connectors or providers in MidCentral were just beginning and this gave some people the chance to try out activities like their peers such as basketball games, concerts, or movies. This was assisting people to experience new things and in thinking about what might be important to them.

In the MidCentral case study, half of the people involved had contacted Mana Whaikaha when in a tense or crisis situation. Responses by Connectors had concentrated on stabilising the immediate situation. At the same time the person’s long-term goal was upmost in the Connector’s focus as they began to explore and work with the person, and at times whānau and other agencies, to achieve what the individual wanted and purchase any items that would support them. This process was supporting most people to achieve their outcomes, and some were progressing with new goals.

As part of life, and unexpected situations such as COVID, adjustments had occurred in people’s education/activities. A few participants were thinking about or had made changes to their plans. These changes included a change of living situation, being accepted into a programme or developing new activities of interest. This seemed to reflect situations in the general population where some people during COVID were rethinking areas of their life, such as hours of work, changing jobs or further education. For example, one participant discontinued their tertiary course as the shift to online did not work for them. In some of these situations, providers were helpful in supporting the person.

* **Administration work had increased for providers**

FDS brought with it an increase in paperwork and administration requirements. Providers spoke of developing invoice systems and maintaining systems to ensure information and the tracking of budgets was up to date for each person.

In MidCentral, some providers were working with both the new and the old system depending on the contract for some individuals. There were some challenges with the language being used by providers (units) or Mana Whaikaha (days) to quantify cost.

#### Changing conversations

* **FDS was contributing to changing conversations between providers and people with opportunities to support people differently**

FDS created a space for different thinking and doing things in a different way as people and providers explored what was possible. The flexibility and freedom assisted people to have more opportunities with the environment it created. The liberation from the residential support subsidy[[22]](#footnote-22) in Mana Whaikaha enabled providers to be able to support people into a home of their own or to live with flatmates of their choice.

If FDS had not been available for four young disabled people to flat together, one young person explained further, they would most likely still be living at home with their parents. Their whānau had not wanted a traditionally funded residential option.

The involvement by providers, early on in discussions between a person and the Connector, supported the chosen provider in their understanding of what the person wanted and gave them the ability to explore with the person what they may want in terms of support from them.

* **FDS funding and its ability to purchase specialist support**

Access to DHB specialist appointments/assessment was made easier through flexible budgets in Mana Whaikaha. Through the purchasing resources, people were able to get equipment, specialist appointments or assessment earlier which supported them to get on with their lives. In MidCentral it was often the Connector arranging the appointment because the specialist appointment was identified during the planning process.

People were no longer spending time on a waiting list for an appointment which was estimated as being approximately twelve to eighteen months. There was an indication that some DHBs were understaffed which could also impact on waiting lists.

The purchase of appointments at the DHB and the use of disability funding did raise comments from a Connector about:

*“ ..we are taking responsibility away from people [DHB] who should be responsible for provision within their budget. So how does that affect the overall budget [disability budget] for disabled people moving forward?”*

* **Changes in people’s health were being supported by some providers**

In some circumstances, a change in a person’s health or wellbeing was noticed by a provider/support person. In MidCentral, it was reported some providers offered to contact Connectors or people on behalf of the disabled person. This was reported to take stress off the person and their whānau. Where extra support was required, it was understood the Connectors were responsive.

* **The flexibility of FDS was giving some people the ability to control how they wanted their support delivered**

Participants reported they were able to use their support flexibly to purchase the things they wanted. The flexibility of the FDS approach was changing lives. This included the ability to change the times of their support which was adapted to meet individual’s requests, as one provider commented:

*“…look I need to change this, or they’d cancel today, or can I shift it – so it really gives them the power back to do what they need for themselves”.*

For one parent of two young disabled people being able to use the same FDS service provider to manage both personal budgets made it better and easier financially for them.

* **Flexibility of support workers to support people with their support in other settings**

The flexibility of support workers was also enabling some people to have their support person(s) continue providing their personal care support should they move to another temporary setting like a hospital or rest home or to accompany them on work commitments/travel out of town.

#### Checks or reviews of how people’s plans are going

Some providers were ‘checking in’ to make sure support was going as planned with people. However, some people reported this had not occurred nor were they aware they could talk with their provider about changes to their plan, or be supported to lead a review of their plan. The leading of a review by people can require confidence and clear direction. The confidence of some people varied, particularly in relation to raising things with their providers.

The evaluators asked people the question “Do you feel confident about raising whatever you want with people?” In MidCentral the responses were a third indicated ‘yes’, a third indicated they would with support, and the others indicated ‘no’.

Although the question did not directly relate to a review of their plan, it could indicate the need for some people to have support in leading a review of their plan or at least initial support. It also relates to the trust and relationship a person has with their provider.

The person’s chosen provider/s and Connector each have a role in making sure everything is working as planned. It was unclear in MidCentral who has overall responsibility for checking progress with an individual or whether it is a discussion with all parties together.

One Connector commented:

*“...you can put any support into an FDS, but somebody has to keep an eye on it….”*

The period of review may differ for some individuals, but more consideration needs to be given to regular checking in to see how everything is working for people and supporting people in gaining confidence and leading reviews of their plan.

#### Non-Contracted FDS providers

Approximately five providers, without a specific FDS contract, were being used by Mana Whaikaha, e.g. Home and Community Support Services (HCSS)[[23]](#footnote-23) and Supported Living services[[24]](#footnote-24). They were able to provide FDS under the contract they had with the Ministry.

There was evidence of unfamiliarity with the EGL approach by some of these providers. Some examples were given where support continued to be provided in the usual way in which the provider had always operated. The inflexibility of this support and different staff turning up made some people change providers or find other people to support them.

It was also indicated that some providers were not interested in having a flexible line in their contract or found working in this way challenging. One Connector added:

*“…they’ve [providers] really struggled already with the change to Mana Whaikaha and [it’s] not just like service authorisations and that's it.”*

4.1.7. Two themes emerged from interviews related to wider support for people

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

The following themes were not directly related to FDS as a contract mechanism or caused by FDS, but they are important to the wider support for people in having the life they want. Both require further discussion particularly in regard to system transformation.

#### Safeguarding

Concerns for the wellbeing and security of people were expressed by some whānau, Connectors and providers in MidCentral. There were a couple of examples in the studies, particularly where some participants living in the community had been taken advantage of by other people at home or in the community. Whānau were the safety net. Some talked of the strategies they had put in place should their family member feel unsure/unsafe. Some Connectors were also checking in on a few people regularly.

There was an expectation with EGL that people’s networks, such as friends/community/ providers or individuals who people trusted, could assist those who are considered at higher risk. This could include learning ways to keep safe in their home, in the community, accessing social media and online.

Without the right support, or strategies in place for people to use, there is a possibility some disabled people could be set up to fail. For example, in moving to flatting situations or engaging with people they don’t know such as salespeople. Further consideration in this area is needed so it’s clear for people and whānau about the support available.

#### Advocacy

Advocacy seeks to ensure that people can have their voice heard and make decisions in their lives with support if needed. Reference was made by some providers in both regions and Connectors to the necessity of having independent advocates to ensure the voice of the person was heard particularly when there were no whānau /close friends/networks in a person’s life.

There was an indication in MidCentral by providers that there was:

*“no advocacy in place currently or mediation,” and with,*

*“Long waiting lists for advocacy … people with an intellectual disability miss out a lot.“*

Access to advocacy provides individuals with independent support in the role of decision making and this was expressed by providers in both regions as important for some individuals to ensure there was no bias affecting a person’s decisions. Further discussion in this area needs consideration.

1. Opportunities offered by FDS in transforming systems and services

## **5.1. Summary of changes and initiatives happening**

*The following themes reflect the perspectives of providers and Connectors*

### 5.1.1. A strengthening of relationships among providers and others was evident

FDS had bought a strengthening in relationships between providers with a *‘more partnership type approach happening and more working collaboratively’*. This was further explained as ‘all parties looking for the same outcomes in order to improve the quality of people’s lives’. The sharing of ideas and learnings from each other were described as helpful[[25]](#footnote-25) as were the lunch box meetings that began at the start of FDS in Christchurch and still continue monthly.

An improvement in relationships was occurring for some providers with agencies such as Oranga Tamariki in the MidCentral region. Increased engagement with local communities was also occurring which provided a greater understanding of the resources available that may offer options for disabled people and others.

### 5.1.2. Realising the potential of FDS

For some Connectors in MidCentral, having the knowledge of the intent of FDS and recognition of its potential could build confidence, and as one Connector commented:

*“I think that's probably one of our challenges at the moment is getting people and providers to a place where they can go actually, we've got the confidence to just go…” (Connector comment)*

It was understood some providers had the opportunity to experience an FDS approach in situations when working to support people in crisis/complex situations or support people into flats/houses of their own. Realising what is possible with FDS and interpretations of how FDS works, including knowledge of the community, was described as important for Connectors and providers in supporting people as they explore what a person wants in their life and creating opportunities.

### 5.1.3. Reconsidering how support is provided

From the providers perspective the flexibility and freedom through FDS assisted people to have more opportunities. The ability to think differently and create different ways to support people and/or purchase items was changing the way in which providers worked.

Over time FDS was also beginning to make some organisations think about how they supported people:

*“We’ve become specialised more in what we do rather than try and do everything, hosting partially really helps...” (Provider comment)*

* **Developing different types of accommodation for individuals**

There were different types of accommodation starting to be explored in MidCentral through the ability to think differently that FDS enabled. For example, people wanting to live in their own flat, to flat with students in the community, or try boarding arrangements with other people. Similar situations were in place in Christchurch, where whānau using FDS and having support from the provider had created a successful flatting arrangement for their family member.

The ‘try, learn, adjust approach’[[26]](#footnote-26) being used in the prototype in MidCentral was an important process in understanding how well initiatives were working for individuals and what could be learned in terms of outcomes. This type of review has the ability to identify early on what’s working well and where possible improvements are necessary for an individual or for the initiative itself.

### 5.1.4. Proactive initiatives supported decisions for people and whānau to make both now and in the future

The ‘Life Taster Sessions’, mentioned earlier, enabled people in MidCentral to understand and try out different experiences. It assisted them to broaden their knowledge, and to have the ability to make a wider range of choices.

Similarly, there were proactive initiatives in place in MidCentral where Connectors worked with some parents and their adult disabled family member living at home to support their understanding of the new system and the options available.

### 5.1.5. Relationship building with local communities and other agencies

Connectors, community development advisers[[27]](#footnote-27) and providers were all working with local communities and/or councils and local businesses to raise awareness of EGL and FDS and strengthen relationships. This supported an increased understanding of the EGL approach, particularly in the whole community, and linking it in with the work of some local councils and businesses. Connecting with and educating the community assisted the increased engagement by people, and their involvement in community activities, roles and services.

# **6. What works well**

## **6.1. Overview**

In achieving the intent of the FDS contract, people have more flexibility in the support provided and more choice in options available to them.

* A ‘whole of life approach’ has enabled participants to work towards what they wanted in their life and for a few make changes to plans along the way.
* Confidence appeared to be increasing for most individuals.
* For a few people, this increased their ability to take more control of their supports.
* More personalised support was now occurring.
* For most people, they were making choices in their lives about how they wanted to live their life and what they wanted to be involved in.

For one family, where the older sibling was already connected with EGL Christchurch and using FDS, being able to start early and include a younger sibling (who also had ORS funding) brought benefits to the younger child and the whānau.

### 6.1.1 Opportunity for learning, employment and social participation like others at similar stages of life

People were accessing the community in ways similar to other people who live in the community. For example, to go shopping, take part in exercise/rehabilitation programmes, meet friends, undertake volunteer roles/work, or attend groups of interest in the community.

Education courses were being pursued by some people to support employment opportunities. Learning the Road Code and learning to drive were also providing opportunities for cycling and driving in the future.

An increase in autonomy meant some were now experiencing the ability to get around their community independently or learning to catch buses. For some people, they were independent prior to FDS being introduced but they continued to have strong community connections and the opportunity to pursue new things if they chose. In these cases, flexible funding was a different way to help them direct their lives.

### 6.1.2. Living arrangements reflected those of other people living in the community

Over half the people in the MidCentral case studies were living on their own in a flat they rented or in their own accommodation. In both locations, some people were flatting with other disabled people or living in the family home. Some individuals were getting to know their neighbours and mixing socially with them.

Where four young disabled people were flatting together and using FDS, whānau had a say in staff selection that assisted in creating a balance of genders and cultures. The housemates were meeting together with their staff to discuss how things were run, like rosters for cooking/helping and meal preparation. Joint meetings with the young people, their families and house staff had initially been held monthly but moved to once every two months as the running of the house became more established.

### 6.1.3. Health and wellbeing were supported

Health and wellbeing were of particular importance for some disabled people with higher health needs, and the assistance they needed to live their lives. Support that some people received in the community enabled them to keep on track in terms of exercising and feeling motivated. These people spoke of their health and wellbeing having improved considerably with exercise and in terms of self-sufficiency.

* **Independence and wellbeing were increasing for some people with the purchase of equipment/aids**

For some people, independence in the home and community had increased due to easier access for equipment to support them. For example, equipment that assisted computer work, their ability to get around their home like ramps or handrails and/or to independently access the community.

### 6.1.4. Friendships and connections were important and part of people’s lives

Friendships and connections with people that disabled people knew were important to them. Some people spoke about regularly catching up with friends and a few had got to know new people. There were relationships beginning with people they knew or saw regularly in the community at places they worked/volunteered at, or at courses or groups.

### 6.1.5. Life was changing for some whānau

Some whānau spoke of their lives being different now and being able to do more. For a few whānau, they spoke of now being able to undertake some part-time work. They expressed their relationship with their family member had strengthened. For some they were now able to meet up with their family member, or spend time at their flat with them, like other families in the community where adult children/students live away from home.

## **6.2. The challenges and what could be improved?**

### 6.2.1. A greater understanding of EGL and it’s approach

*This section describes the perspectives expressed by people and whānau and in some areas by providers and Connectors.*

EGL Principles form the foundation of FDS and the transformed disability system. Some people and whānau in the studies indicated they wanted more information about the EGL approach. While there is awareness of EGL within the disability sector, there is a need for information to be clearer so everyone understands what they can expect from providers/supports using an EGL approach.

Demystifying the principles and operationalising them into practice could support more understanding and consistency in the approach. A few Connectors in the MidCentral case study explained it can at times be too easy to revert to former ways of working especially when it’s busy, or when people are not familiar working with an EGL approach. As one Connector described:

*“…it was just oh [name], yep, you're happy with your package, that's fine, roll over, another twelve months, gone. That's not the EGL approach.” “So our own system wasn’t working to an EGL approach”. (Connector comment)*

The implementation of the organisational self-review process gives services the opportunity to measure how well they are doing in terms of alignment with the EGL Principles. The voice of people and/or whānau using FDS and their experience is important to know how things are working or not for them. The building in of feedback mechanisms to provider and funding systems may be worth consideration to enable regular feedback from people and/or their whānau.

The possible drawbacks to not being informed about EGL could include reverting to former ways of working, unawareness of expectations of support by people/whānau, and a hesitancy for disabled people to try something different or have trust in the system.

### 6.2.2. Increased information about FDS and sharing stories of people’s experience

In the MidCentral case studies and the gathered interpretations of how FDS works, FDS did not appear to be well understood by most disabled people and their whānau including some providers. One Connector described this further:

*“FDS enhances the opportunity in flexibility, but you’ve got to think of those first otherwise you’re just gonna invest in personal care and community support”. (Connector comment)*

Sharing information about people’s experience of FDS and it’s potential could support more awareness and understanding for people, whānau and their networks. Information or stories may support more emphasis being given to FDS being seen as a different option to other types of support currently available, which may prevent any misconceptions.

* **Having easy to use and clear information about FDS and associated processes**

People and their whānau similarly spoke of information about FDS and the purchasing guidelines needing to be easy to use and clear. This would make ‘the system’ more transparent. Likewise, knowing about the options available to them in FDS and/or choice if they wish to manage some or all supports at some stage.

Providers similarly added the importance in having clear expectations and clear pathways/ information for how to use FDS.

* **Updates about budget spend are important and should be easily accessible and able to be understood by an individual**

Receiving an update on individuals’ budgets and how they were tracking appeared varied. In Christchurch, most participants (mainly whānau on the disabled person’s behalf) received regular information on their EGL budget spend and knew they could ask at any time. This differed to some disabled people in MidCentral who were not aware of receiving any updates on their budget.

People may want variable amounts of information. Whatever the level of detail required by the person, it should be in a form that is easy to use and accessible for everyone.

### 6.2.3. Person-directed support

Providers have made changes in services with the introduction of EGL and were learning as they go. Training and education workshops about FDS and person-directed support were occurring in MidCentral but it was expressed some changes still needed to happen.

*“ ….. you can change the funding under Enabling Good Lives but if you don’t change how you provide, you're just providing it under a different contract.” (Connector comment)*

There was a sense of frustration being voiced by some people and whānau in the MidCentral case studies about some support workers not providing the support people wanted and/or them not feeling like they were heard. These concerns mainly centered on:

* respect and understanding of the disabled person,
* listening to them,
* following their plan, and
* providing the support they wanted, such as support with life skills and household tasks, and supporting them in keeping safe.

Some providers acknowledged there was more work required in shifting the thinking to a person-directed approach and, as described by one provider, support people *“believing in the capabilities of disabled people and themselves”.*

### 6.2.4. Costing and pricing

Some providers talked of it being difficult at times to check the accuracy of individual’s budgets with the Mana Whaikaha system. In managing individual’s budgets, some providers spoke of the importance of providing accuracy of each person’s budget spend and enabling individuals to have easy access to updates on their budget.

A difference between costing and pricing was expressed by some providers. In some situations, this resulted in a gap in actual costs that occurred that may need to be met in other ways. It also raises a query about sustainability and understanding the true cost of supporting individuals. Although, it could change in time as more people use personal budgets and/or as greater disability system transformation occurs with FDS/EGL expansion more widespread.  While this area was beyond the scope of this evaluation, it was indicated that as FDS is rolled out the true costs of supporting individuals and any gaps in funding may become more apparent.

### 6.2.5. A broader skillset identified for support people

There were some challenges and complexities expressed by some providers in the shift to a more flexible way of supporting people. This included accommodating the varying types of support each person wanted, training of staff and staff who worked flexible hours, transport arrangements for people to go to places, and pricing/invoicing.

The different types of support people may want was identified as necessitating a broader set of skills and knowledge by support workers. It was expressed that the value in investing in capability and capacity building, including technology systems for providers and support people, was beneficial as part of the change FDS brings.

### 6.2.6. Inclusion and accessibility in the community

FDS contributed to a small extent to address barriers in the community to full participation by disabled people, such as access to buildings, public transport and employment. This, however, is an overall goal of an EGL approach not of FDS as a funding mechanism.

### 6.2.7. Strengthening of networks

There were a few comments from providers in MidCentral where people had been admitted to hospital and communication from the DHB with providers and Connectors was varied. For example, in letting them know about a person’s admission, updates on progress and planned discharge.

### 6.2.8. Rules and Potential Barriers

The guidance around how to balance duty of care and the dignity of risk was indicated as being unclear for some providers, regarding people using FDS. This area was identified as needing to be explored further in a broader discussion around responsibilities and liabilities, so everyone is clear.

Other potential barriers like Occupational Health and Safety (OSH) requirements may arise from time to time in regard to support provided. Sharing of information with other providers could support solutions to be found, or the obtaining of specialist advice.

# **7. Flexible Support and what can be learnt for the future**

## **7.1. FDS case studies and MidCentral Repeat Study results**

The findings from the Repeat Study (2021)[[28]](#footnote-28) in MidCentral also form part of the information to learn about flexible support with its reflection by people and whānau of their experiences.

The Repeat Study and its purpose may differ to that of the case studies of people using FDS, but both focus on the quality of life of people and whānau and their experience with having a personal budget and/or the support they receive.

There were several areas where the findings in the case studies reflected those in the Repeat Study Report. The following table illustrates similar findings in both studies:

*Table One: Similar findings of Case Study with the MidCentral Repeat Study*

|  |  |
| --- | --- |
| FDS Case Study Findings – MidCentral and Christchurch | Repeat Study Findings – MidCentral |
| * People were positive about having choices and more say so or control in their lives. | * An increase in people who believe they have real choice about the kind of support they receive. |
| * People liked the flexibility they had under FDS and for some the ability to control how they wanted their support delivered. | * People believe they have more control over their support. * Young people and people using supported living contracts have indicated improvements in the flexibility of their support options. |
| * Supports were assisting most people to connect with people/places important to them and pursue their interests in the community. * A few people were independently involved in their community before the transformed system. | * There are significant improvements in how much young people believed supports assisted them to pursue their own interests. * Children, young people and adults appear to have been more active in the community. |
| * Two thirds of people in response to the categories of happiness with their life[[29]](#footnote-29) (personal wellbeing) indicated being “mostly” happy and one third indicated “sometimes”. | * In a simple statement about how happy people are with their life, most people with learning disabilities were very positive in both year groups but people with physical disabilities gave more varied and less positive responses. |
| * Connectors were spoken of positively by nearly all disabled people and whānau in both case studies and the Repeat Study findings. | * Three quarters of people who had contact with a Connector gave positive comments about either the Connector or the system overall. |

Several people in the case studies received support such as personal care, household management and support in the community. Some of the findings of the MidCentral Repeat Study focused on disabled people who were using formal services, such as personal care and household management (HCSS), and community residential services. These findings were like the experiences of case study participants using FDS.

* Overall, the term ‘FDS’ did not appear to be well known in relation to the type of support people were receiving. It was only directly referred to by a few in the Repeat Study and in both case studies.

Instead, people in the Repeat Study referred to their ‘EGL budget’ which was the same as participants in the Christchurch case study. People in the MidCentral case study talked about their ‘funding’ or their ‘personal budget’. This could relate to some people in the case study MidCentral referring to the provider receiving funding to support them but could also indicate some people not being aware of how their personal budget worked or was tracking.

* The dissatisfaction of people with providers of HCSS and community residential services indicated in the Repeat Study Report was similar to the experiences expressed by almost half of the people in the MidCentral case study.

The main issues they raised (in this case study) linked with those reported by participants in the Repeat Study, such as a lack of partnership and poor communication. Similarly, a few people expressed comments akin to the findings of the Repeat Study such as limited opportunities to personalise support and a sense of powerlessness.

The findings for this small group of people using FDS (in the case study) point to the importance of support to people in what they wanted to achieve. As noted previously, it is difficult to separate how people perceive the FDS funding from their actual support.

## **7.2. Learnings from the case studies of FDS**

The themes arising from the cases studies of FDS as a funding mechanism and the comparative variable impacts on people provide learnings for any future work.

### 7.2.1. Experience of FDS providers in MidCentral and Christchurch

The experiences from disabled people, providers and Connectors in MidCentral and Christchurch and their learnings would provide good insights into any further work relating to FDS and flexible supports. For example, sharing of their knowledge and information about successes, ways of working they have developed, and any pitfalls in working with FDS.

EGL Waikato also operates flexible support options that are very different from the FDS contracts used in Midcentral and Christchurch with the majority[[30]](#footnote-30) of disabled people self-managing their budgets and some people having EGL hosts to support them. The Waikato demonstration site has been in place since July 2015. The Waikato evaluations phase 1 to 4 have demonstrated some good outcomes without using FDS as a funding mechanism.

## **7.3. Key implications of FDS as a funding mechanism**

This section highlights a summary of the main learnings from the case study findings from the experiences of participants and the perspectives of Connectors, the financial adviser and providers.

The main learnings from the case studies:

* It takes time to embed new ways of operating such as FDS. Disabled people and providers need time to trust the new system and understand how it can work for them.
* There were positive examples of people purchasing items that made a big difference in their lives. Only a few people or whānau were self-directing support and an increase in confidence and autonomy was evident in some people.
* FDS is one of several interrelated factors in case study participants’ lives that contributed to achieving good life outcomes. The support people received from a provider was important to them. Flexible approaches and flexible funding were making a small contribution to enable most participants to have lives closer in quality to their non-disabled peers.
* Good life planning and personal planning were found to be integral to FDS processes.[[31]](#footnote-31) The focus was ’whole of life’, and people reported they were involved in identifying what was important to them. For a few people and some whānau, it created a sense of direction for them or their family. This was not the case for all, particularly in relation to implementation of the plan, where a few people and whānau in MidCentral expressed confusion or dissatisfaction about how FDS worked and/or their relationship with the provider.
* The Connector role was vital to the successful navigation of each person’s FDS contract. They assisted the introduction to FDS and relationships with providers. The Connector role was always more than just FDS and undertaking their other work commitments was also occurring. Their ongoing contact with people maintained the relationship despite some having a heavy workload.
* FDS facilitated and created space for providers to work differently and to be more person-centred as there was no one set way of working. Providers working in a flexible way required them to be continually assessing and developing their way of working. There was the need to adapt to changes made by people or whānau, or to explore further options with them as progress was made with their goals.
* Relationships between and among people/whānau, Connectors and providers and how these relationships worked appeared essential in FDS. They established trust and support for people and whānau, the ability to share information, and to check with people or whānau that things were working as planned or needed to change.
* Information about FDS was important to people but they were unclear about how parts of FDS worked including EGL. Easy to use systems and processes would provide greater clarity about roles and coordination and would be necessary to reduce confusion and complexity. Clarifying Connector and provider boundaries seems important.
* Management of personal budgets was less onerous for people and whānau, and some wanted to know more about their personal budgets and how they were tracking. The personal budgets of some participants were not all with one provider.
* Support workers needed to work flexibly to meet the support that people wanted and accommodate any changes people may make. FDS aims to work with disabled people on achieving a good life which is not always measured in hours delivered. With the different types of support or assistance people may want, there was a need for a broader set of skills for support workers. This includes an understanding of EGL vision and principles, the ability to collaborate and enable people to direct their own support, and to demonstrate how they implement the vision of EGL consistently in their practice.
* There was variable understanding of the EGL approach in practice, and it was also not well understood by people, whānau and some providers. The EGL approach underlies not only the FDS contract but service provision and the way Connectors and providers work.

## **7.4. Conclusion**

The EGL Principles are the foundation of FDS and guide the associated service provision. Essentially FDS is a contract mechanism to enable people to benefit from flexible funding, but EGL vision and principles are the driver. This evaluation has attempted to understand how far FDS has made a contribution to the enactment of a positive Enabling Good Lives approach. In this context this includes clarity of purchase options for disabled people, the quality of planning and how these then contribute to people’s perceived achievement of good life outcomes.

The understanding of EGL in practice among providers varied and indicated different interpretations of how FDS works. This was also true for how providers and Connectors viewed their role. Blurred boundaries did create tension and confusion on occasion.

The relationship between the person with their Connector or provider, and the relationship between the Connector and provider varied. They are all inter-related and the strength of these individual relationships become important for developing trust, sharing information, understanding roles, and supporting outcomes. High caseloads for Connectors and/or constant changes of Connectors have been seen to delay or even negatively impact on outcomes for individuals.

As people in the case study tended to focus on outcomes, often in terms of their actual support, when talking about FDS, the importance of what providers and Connectors were doing became important. The findings did not reflect simple and easy to use approaches to benefit any party. For example, where providers were not just managing funds, but providing actual support, the boundaries in roles and management interests could confound the aims of FDS. Where services are sought elsewhere, the outcomes of that support also reflected on how successfully managed the flexible options were or how the options butted against the reality of what is currently available for people.

Despite the inherent issues experienced in any new system, the promise of FDS is the enhanced emphasis of the EGL approach in people’s lives. This has been evident in how people describe their experiences of greater satisfaction in services, improved autonomy, ease of use, positive relationships, person-focused and mana enhancing.

### 7.4.1. Improvements to be considered

* Review of the scope and implementation of any flexible contract going forward including the learning from the experience of disabled people, whānau, providers, community agencies who are using/involved with FDS. Sharing of stories about people’s experiences of FDS and how they have used resources so more disabled people and whānau are informed.
* Consideration be given to having a similar case study undertaken of EGL Waikato. The use of flexible supports in Waikato[[32]](#footnote-32) by disabled people and whānau would also provide learning and experiences from a range of young people and adults over time, to draw on and support improvement in overall availability of future flexible approaches.
* Increasing people’s awareness of what person-directed means within an EGL approach may improve understanding and consistency of responses. Operationalising the EGL Principles into practice would assist organisational self-reviews[[33]](#footnote-33) by providers. Feedback mechanisms would give disabled people and whānau the opportunity to regularly provide comment on what’s working or not.
* Develop and circulate accessible, easy to understand and use information about FDS and interpretations of how FDS works. This may include clarifying budget processes as some disabled people and whānau were unaware how FDS and the system(s) worked.
* Develop clear expectation for providers and pathways for how to use FDS, including clarifying purchasing guidelines and making them easy to use.
* Ensure support is available for disabled people to understand how their budget works. This is of particular importance during transition when people move from home to living independently in the community so they can self-direct. The budgets of individuals and updates could also be useful in a more accessible format to aid understanding. Providing easier access for individuals to view or receive a copy of the spend/balance of their budget could be beneficial.
* Increased importance needs to be placed on actual relationship building between disabled people and providers to understand the kind of relationship and input disabled people and whānau require of their provider. Hosting and/or direct funding can mean there is limited interface with disabled people and/or whānau, and relationships instead become a contractual transaction. This is acceptable and easy for some but should be a choice. Where a trusted relationship and a closer partnership approach is required, the skills to build that non-intrusively are required.
* Ensure the Connector case loads are at a level that allows for the varied support needed by disabled people. This involves attention to the ecosystem around Connectors to ensure a range of skills and experience is considered rather than an over-dependence on the Connector role. This would allow Connectors resources for follow-up options with individuals and to manage urgent situations in a timely way.
* FDS requires a flexible workforce and support people who have a set of skills that appropriately respond to all the disabled people and whānau involved. Investment in capability and capacity building of support workers, for example, building relationships between people and their community where required, how to support people to learn new skills themselves, and knowing when to step back as people gain confidence/skills in undertaking tasks/roles themselves. Some issues were also raised about technology and payment systems which require improvement and attention in future.
* Advocacy and safeguarding individuals who have no one to assist them (i.e. family) is an important consideration. Increased emphasis is needed on ensuring disabled people who require or request it have support to keep safe. Consideration is also suggested to support formal advocacy, especially if there are long waiting lists.
* Continue to build and provide supportive relationships at a local level with, for example, DHBs, local businesses and community networks.
* Develop clarity around how to balance the ‘dignity of risk’ and ‘duty of care’ for providers supporting disabled people using FDS. Discussion needs to occur so disabled people, whānau and providers are clear about their responsibilities and liabilities.
* Ensure there is a sustainable, transparent and equitable system within which FDS operates including:
  + Develop safeguards such as feedback mechanisms to give people and whānau an opportunity to provide information on what’s working or not.
  + Provide some reassurance to disabled people and whānau that they can trust the system and the intent of FDS continuing into the future.
  + Make sure the system is equitable, and no one is disadvantaged.

# **8. Appendices**

## **Appendix 1**

**Prototype of the transformed system in MidCentral**

A nationwide transformation of the cross-government disability support system was co-designed with the disability sector during 2017. The design of the transformed system is based on the Enabling Good Lives (EGL) vision and principles and takes into account what has been learnt from the EGL demonstrations in Christchurch and the Waikato, the baseline survey of MidCentral 2018 and the mid-point implementation evaluation of Mana Whaikaha 2019.

The objectives for the transformed system are to:

* give disabled people and their whānau more options and decision-making authority about their supports and lives,
* to improve their life outcomes,
* and to create a more cost-effective disability support system.

Table 1: 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 that take a whole life approach rather than being split across programmes. |
| Ordinary life outcomes | Disabled people are supported to live an everyday life in everyday places, and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life. |
| Mainstream first | Disabled people are supported to access mainstream services before specialist disability services. |
| Mana enhancing | The abilities and contributions of disabled people and their families are recognised and respected. |
| Easy to use | Disabled people have supports that are simple to use and flexible. |
| Relationship building | Supports build and strengthen relationships between disabled people, their whānau and community. |

**Components of the transformed system**

The key features of the new system that will directly contribute to a different experience for disabled people and whānau include:

* People are welcomed into the system in multiple ways, and can then be provided with information, linked with a Connector, peer network, government agency or disability organisation.
* Access to Connectors who can walk alongside disabled people and whānau if they choose, to help them identify what they want in their lives, how to build that life, and the range of supports available to live that life.
* Easy to use information and processes that meet the diverse needs of disabled people and their whānau.
* Seamless support across government, with Government Liaisons supporting people in the background to access other government services (e.g. benefit applications), and to build positive relationships with other parts of government (e.g. learning support in school).
* A straightforward process for accessing funding, with flexibility about what can be purchased and how it can be administered, and easy reporting on how funding has been used.
* Capability funding for disabled people and whānau to develop their skills.
* Greater system accountability to disabled people and their whānau so that disabled people and whānau are involved in monitoring and evaluating the system and making recommendations to Ministers about changes to the system.

**Intended impacts of the transformed system**

The key intended impacts of the transformed system include:

* Disabled people and their whānau have greater options about the supports they use to live the lives they want and greater autonomy over their lives.
* Disabled people and their whānau have a better experience of and interface with the disability support system.
* Disabled people and their whānau experience better outcomes in all aspects of their lives – health and wellbeing, physical and financial security, relationships, social inclusion, self-determination, and self-fulfilment and natural authority.
* Disabled people and their whānau experience greater partnership e.g.:
* Trust
* Transparency
* Natural authority
* Equity
* Clear communication
* Shared goals.

## **Appendix 2**

**Study questions**[[34]](#footnote-34)

To understand the contribution to transform people’s lives made by implementation of FDS contracts implemented in the MidCentral and Christchurch areas. This includes:

1. To what extent has partnership between chosen disability providers and disabled people been achieved?
2. What changes to service style etc have happened with FDS?
3. What is working well regarding achieving life outcomes?
4. What is not working well in achieving a good life?
5. What needs to improve?

**Questions to guide conversations with disabled people / tangata whaikaha[[35]](#footnote-35)**

|  |  |  |
| --- | --- | --- |
|  |  | Study Question / Reference[[36]](#footnote-36) |
|  | Tell me about yourself and your life? | 1, 3, 4 and 5 |
|  | Tell me/us about the contact you have with your Connector? | 2 |
|  | A) Do you choose what happens in your life? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B)Tell me more about why you think this? | Partnership |
|  | Do you think your supports “get you” (understand/respect)? | Partnership |
|  | How much trust do you have in your supports and/or “the system”? | Partnership |
|  | How has the planning process been for you? What works and/or what would you change? | 2–5 |
|  | What do you think is different because of FDS (the way things have been done over the last year or so/ changes to how things happen)? | 2 |
|  | Having used FDS for more than 6 months, overall how happy are you with your life now?  DON’T KNOW – ALL THE TIME/YES–- MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER | 3 |
|  | What difference, if any, do the people providing support have in your life? | 2–5 |
|  | How well understood (respected/valued) do you feel (by supports)? | Partnership |
|  | A) Can you easily find out about the things you need/want for your support? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B)Tell me more about why you think this? | Partnership |
|  | What are some of the changes you have made in the last two years? | 2 |
|  | A) Can you choose where your support money is used? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B)Tell me more about this? | Partnership |
|  | A) Do your supports enable you to connect with the people and places that are important to you? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B) Give me some examples of what this looks like for you? | 3 and 4 |
|  | How would you describe the partnership you have with your supports (and others)? | Partnership |
|  | What would make things easier for you? and/or If you could change anything about your supports/or life, what would that be? How might this change happen? | 5 |
|  | Do you think you have more say so/control/authority in your live? Tell me more. | Partnership |
|  | Do you feel confident about raising whatever you want with people? | Partnership |
|  | If I am going to understand your experience of supports and services, what else do I need to know? | All |

**Questions to guide discussions with families and whānau**

|  |  |  |
| --- | --- | --- |
|  |  | Study Question / Reference |
|  | Tell me about yourself and your life? | 1, 3, 4 and 5 |
|  | Tell me/us about the contact you have with your Connector? | 2 |
|  | 1. Do you find supports are easy to access and use? (choose one statement below)   DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES –- NOT REALLY – NO/ NEVER    B) Tell me more about why you think this? | Partnership |
|  | What impact do supports have in your life? | 2 |
|  | How much trust do you have in your supports and/or “the system”? | Partnership |
|  | How has the planning process been for you? What works and/or what would you change? | 2–5 |
|  | What do you think is different because of FDS (the way things have been done over the last year or so/ changes to how things happen)? | 2 |
|  | Having used FDS for more than 6 months, overall how happy are you with your life now?  DON’T KNOW – ALL THE TIME/YES – MOSTLY –- SOMETIMES – NOT REALLY – NO/ NEVER | 3 |
|  | What difference, if any, do the people providing support have in your life? | 2–5 |
|  | How well understood (respected/valued) do you feel (by supports)? | Partnership |
|  | A) Does contact with the disability support system help you to achieve your goals? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B) Tell me more about this? | 3 |
|  | What are some of the changes you have made in the last two years? | 2 |
|  | A) Can you choose where your support money is used? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B)Tell me more about this? | Partnership |
|  | A) Would you describe your supports as flexible (changing in response to your preferences, circumstances and goals)? (choose one statement below)  DON’T KNOW – ALL THE TIME/YES – MOSTLY – SOMETIMES – NOT REALLY – NO/ NEVER    B) Give us some examples so we can better understand this? | Partnership |
|  | How would you describe the partnership you have with your supports (and others)? | Partnership |
|  | What would make things easier for you? and/or If you could change anything about your supports/or life, what would that be? How might this change happen? | 5 |
|  | Do you think you have more say so/control/authority in your life? Tell me more. | Partnership |
|  | Do you feel confident about raising whatever you want with people? | Partnership |
|  | If I am going to understand your experience of supports and services, what else do I need to know? | All |

**Questions to guide discussion with Connectors**

|  |  |  |
| --- | --- | --- |
|  |  | Study questions/ reference |
|  | Describe for us what types of arrangements/tasks this FDS situation has meant for you? | 2 |
|  | How has the process been working for you in this instance?   * positive opportunities / challenges | 3 |
|  | What might you change about the current situation?   * Are there ways your role could more effectively be a catalyst for/support for a partnership approach? | 4, 5 |
|  | What do we really need to understand in order to appreciate the extent to which FDS as one form of flexible funding is operating to achieve a person-directed/EGL approach? | 3, 4 |
|  | To what degree do you believe the disabled person and their family are able to determine their own lives and how supports can best assist them?  Are there ways the system could make this journey easier for them? | 1 |
|  | How would you describe the partnerships you have been able to build? Areas for further development? | 1 |
|  | How well has the planning process been working? | 2 |
|  | With what you have seen generally, what do you see as the advantages and challenges associated with using FDS to achieve a person-directed approach? | 3, 4 |
|  | How could an EGL approach be better achieved so:   * It is easier for disabled people and families to have more control. * Your role is most effective. * Service providers can make the best use of this opportunity. | 5 |

**Questions to guide discussions with Providers**

|  |  |  |
| --- | --- | --- |
|  |  | Study questions/ reference |
|  | Tell us how the process (FDS) has been working for you?   * Significant positive opportunities/experiences? * Challenges to realising the objectives of flexibility, partnership and self-determination? | 2, 3, 4 |
|  | How would you describe where you are up to with regard to developing partnerships with disabled people and their families?   * Tell me/us about some of the strategies/approaches/ measures you are using so that disabled people and families are having more control in their lives. | 1 |
|  | What do you think is different because of FDS (the way things have been done over the last year or so/ changes to how things happen)? | 2 |
|  | How well do you think the EGL approach (including FDS) is doing in making it easier for people to create good lives for themselves? Ideas for development. | 3,4,5 |
|  | What do you think would make it easier for disabled people and families to have a better/great experience of FDS/system change? | 5 |
|  | What else do I/we need to understand if we are going to get a good picture of how well FDS is going? | 1-5 |
|  | What would be the key things you would develop further/emphasise if FDS was to be widely available? | 5 |

Note: Questions to guide the discussion with people in Mana Whaikaha associated with funding will mirror those asked of Connectors.

1. SAMS was commissioned by the Ministry of Health to undertake this evaluation. [↑](#footnote-ref-1)
2. The NASC still operates in Christchurch. [↑](#footnote-ref-2)
3. # Note – FDS is not intended as an option to continue to support people to live in residential services – Ministry of Health Disability Support Services, Tier Two Service Specification, Flexible Disability Supports – Enabling Good Lives.

   [↑](#footnote-ref-3)
4. Enabling Good Lives, a report to the Minister for Disability Issues by the Independent Working Group on ‘Day Options’ July 2011. [↑](#footnote-ref-4)
5. 5. The Enabling Good Lives in Canterbury Report, June 2012 became known as the Canterbury Plan (Boxall and Benjamin). [↑](#footnote-ref-5)
6. Choice in Community Living offers disabled people more choice and control over where they live, who they live with and how they are supported. [↑](#footnote-ref-6)
7. Manawanui is a national provider hosting individualised funding that began in 2004. They now also host personal budgets in areas where this is available. [↑](#footnote-ref-7)
8. More detail is explained in: Wilson, C.S. and Benjamin, M. (2021). Repeat Study MidCentral Region 2018 – 2021. Project commissioned by the Ministry of Health, NZ, part two after the 2018 baseline, available on request to SAMS [www.sams.org.nz](http://www.sams.org.nz) . [↑](#footnote-ref-8)
9. The meaning of the original SAMS acronym is outdated and rarely used. [↑](#footnote-ref-9)
10. Were, L. and Crocket, A. (2019). Enabling Good Lives Waikato Demonstration: Phase Three Evaluation Report. [↑](#footnote-ref-10)
11. Refer: Wilson, C.S. and Benjamin, M. (2018). Wilson, C.S. and Benjamin, M (2021). [↑](#footnote-ref-11)
12. Refer: Wilson, C.S. and Benjamin, M. (2021). [↑](#footnote-ref-12)
13. A random number generator was used to initially select names – <https://www.calculator.net/random-number-generator.html> . [↑](#footnote-ref-13)
14. The profile sought by the Ministry in MidCentral included two participants from each of three specific age ranges provided, with two participants from each of the following disability type: learning, physical, sensory or ASD. Two of the six participants needed to identify as Māori. The six participants needed to have a balance of male/female and supported by different providers. [↑](#footnote-ref-14)
15. The area unable to be met in MidCentral was the selected people each having a different provider. This was due to ensuring the profile of participants was met rather than people’s choice of provider. [↑](#footnote-ref-15)
16. All initial contact details were for a parent. Information about the study was given to the disabled person and their consent was taken at the interview. For one person unable to take part in an interview they gave consent for their father to be interviewed. In a family group situation where both a six-year-old and their older sibling used FDS for their personal budgets, their mother gave consent for the younger person’s information to be used. [↑](#footnote-ref-16)
17. While the numbers of participants with different impairments was different than being looked for prior to the study, impairment groups of participants in the study were reflective of the majority of those using FDS. [↑](#footnote-ref-17)
18. There were two siblings using FDS in the same family and one interview was with a parent only as the young person was not able to participate in an interview. [↑](#footnote-ref-18)
19. The situations for the two young people and their families not actively involved with an FDS provider are discussed in the next section on evaluation results. [↑](#footnote-ref-19)
20. Independent Connectors were involved in MidCentral and these worked in the same way as Mana Whaikaha Connectors. A few were connected to provider organisations. [↑](#footnote-ref-20)
21. Given the age and support needs of these young people, it was the parents who were in contact with the FDS provider. [↑](#footnote-ref-21)
22. The Residential Support Subsidy is paid to the residential service provider by the Ministry of Health to help with the cost of residential care. [↑](#footnote-ref-22)
23. Home and Community Support Services (HCSS) – The name of contract for providers who are supporting people in their own home. It is based on personal and household support. [↑](#footnote-ref-23)
24. Supported Living Services – The name of the contracted service for providers to support disabled people to live independently by providing support in those areas of their life where help is needed. [↑](#footnote-ref-24)
25. Lunchbox sessions are whānau led and provide a regular opportunity for all involved to share experiences and knowledge as well as to ask outsiders/providers for more information. [↑](#footnote-ref-25)
26. A 'try, learn, adjust' approach is being used to assist in continuing to improve Mana Whaikaha. Learning cycles in this approach include developmental evaluations to provide regular feedback on how its working for people, and any areas to improve; and outcome evaluations that look at differences Mana Whaikaha has made to the quality of experience and life outcomes for disabled people and whānau over time. [↑](#footnote-ref-26)
27. Mana Whaikaha has community development advisers who work with community groups, local councils and businesses in the region to raise awareness and support disabled people’s access, inclusion and participation in the community. [↑](#footnote-ref-27)
28. Refer to: Wilson, C.S. and Benjamin, M. (2021). [↑](#footnote-ref-28)
29. Categories included: Don’t know, All the time/Yes, Mostly, Sometimes, Not Really, No/Never. [↑](#footnote-ref-29)
30. The EGL Waikato Evaluation Report-Phase Three, April 2019. [↑](#footnote-ref-30)
31. In Christchurch there is a process of good life planning while in Midcentral the process is more often referred to as personal planning. [↑](#footnote-ref-31)
32. EGL Waikato does not use FDS as a funding mechanism like Christchurch and MidCentral but does enable flexible options to managing personal budgets. A comparison is recommended. [↑](#footnote-ref-32)
33. The organisational self-review process can provide a measure of where services are at in terms of, for example, the alignment of the service with the EGL Principles and areas of improvement. The self-review process can assess change over time. [↑](#footnote-ref-33)
34. Based on the research questions extracted from the MoH contract for this work and the Evaluation Plan. [↑](#footnote-ref-34)
35. Items in blue have been based on questions extracted from the Repeat Study Survey Tools. [↑](#footnote-ref-35)
36. Study Question/Reference: the numbering reflects the Study Question Numbers. [↑](#footnote-ref-36)