133 Molesworth Street
PO Box 5013
Wellington 6140
New Zealand
T+64 4 496 2000

27 May 2022

s 9(2)(a) [redacted]

By email: s 9(2)(a) [redacted]
Ref: H202205203

Tēnā koe s 9(2)(a) [redacted]

Response to your request for official information

Thank you for your request under the Official Information Act 1982 (the Act) to the Ministry of Health (the Ministry) on 4 April 2022 for:

> *"During, before or after the pilot project, research and evaluation of the Enabling Good Lives approach, has your organisation engaged the ethnic communities such as immigrants and refugees who identify as disabled persons? If yes, would you please share the relevant publications?"*

The Ministry has not been able to identify any information in scope of your specific request. This is because immigrants and refugees were not specifically targeted in the consultation process for Enabling Good Lives. Instead, we have endeavoured to engage with minority communities that identify as disabled and/or whānau who support disabled children and adults.

We have identified 10 documents that we believe provide further context about both the Christchurch site and the MidCentral prototype by way of evaluations that have been undertaken. We hope you find these useful in terms of the Enabling Good Lives experience for disabled people.

MidCentral prototype (7 documents)
The district health board (DHB) region survey was commissioned by the regional leadership group in MidCentral (available in Documents 1 - 2). The baseline study of 2018 is attached as Documents 3 - 7.

Christchurch EGL (3 documents)
Documents 8 - 10 include: the lessons learned from the demonstration; the phase two evaluation report; and a complex case review is attached to evaluate how EGL responds to people who face the most barriers in their system interactions.

Under section 28(3) of the Act, you have the right to ask the Ombudsman to review any decisions made under this request. The Ombudsman may be contacted by email at: info@ombudsman.parliament.nz or by calling 0800 802 602.

Please note that this response, with your personal details removed, may be published on the Ministry website at: www.health.govt.nz/about-ministry/information-releases/responses-official-information-act-requests.

Nāku noa, nā

Deborah Kent
Deputy Director-General
Disability

Appendix 1: Documents for release

#	Date	Title	Decision on release
1	N/A	MidCentral DHB region Provider Survey	Released in full
2	September 2018	MidCentral DHB region Provider Survey Letter	
3	N/A	Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools	
4	N/A	Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report	
5	N/A	Baseline Study of the Disability Support System in the MidCentral Area: Summary Report	
6	N/A	Baseline Study of the Disability Support System in the MidCentral Area: Easy read information	
7	N/A	Baseline Study of the Disability Support System in the MidCentral Area: Disabled People's Report	
8	N/A	Enabling Good Lives Christchurch: Lessons, Experiences, Opportunities	
9	June 2016	Evaluation of Feedback From Participants with Complex Situations: Report by Rebekah McCullough	
10	9 March 2017	EGL Christchurch Demonstration: Phase two evaluation report	

Document 1

MidCentral DHB region Provider Survey

Confidentiality and Privacy

Please read the consent information carefully

The information you provide for this survey will be confidential and is protected by the Privacy Act 1993. No person or organisation will be able to be identified. The answers you give in the survey will be added to other people's answers to create grouped results, so your information cannot be traced back to you. It will only be reported as part of grouped results in a report about the survey results. **Your information will always remain confidential.**

I/we understand my answers will be treated anonymously and agree that the information I provide can be used in a report about the disability support services and the new system in the MidCentral region.

I/we understand I have the right to withdraw my contribution (survey) including quotations and comments at any point before it is added to other organisation's answers for the report.

I/we know that my participation in this survey is confidential and no information that could identify the organisation or any personnel will ever be used in any reports. The information gathered will NOT reveal participant names or organisational identifiers. All my answers are protected by the Privacy Act 1993.

I/we understand the aims of this survey and consent to my/our participation in the provider survey.

Date: ..../................/ 2018

Name of Organisation: --

Name & role of consenting party: --

I consent to the organisation providing this information (please tick box)

☐

FOR TRACKING PURPOSES ONLY: Name of Organisation: --

The individual completing this feedback form:

- understands all material will be anonymous and be used in the development of a baseline report associated with system transformation in the MidCentral region
- has knowledge of the views and practices associated with the service/organisation
- has the authority to complete this on behalf of the service/organisation
- has involved other members of the management team and/or board of governance, and where required consulted with the workforce to assist with answering the questions in this survey
- agree to potentially participate in a review process of answers provided in Section C.

Role of the individual completing this form: --

Section A

Organisation Information

Please tell us about your organisation

A1.1 What is the legal structure of your organisation (please tick)?

☐ Charitable Trust
☐ Incorporated Society
☐ Limited Liability Company
☐ Co-operative Company
☐ Unlimited Company
☐ Sole trader (self-employed or contractor)

Other (please state): ....

A1.2 Who do you currently have contracts with to provide disability support services in the MidCentral DHB region and all of New Zealand *(tick as many options as you need)?*

	MidCentral DHB region	**All New Zealand**
Disability Support Services (DSS), Ministry of Health	☐	☐
Ministry of Social Development	☐	☐
ACC	☐	☐
District Health Board	☐	☐
Funding directly from disabled people	☐	☐

Others? Please list: ....

A2 In your organisation, how many service users were there in the MidCentral DHB region and nationally in 2017/18?

Type of Service	**MidCentral DHB region** Number of service users in 2017/18	**Total New Zealand** Number of service users in 2017/18
Aged care (YPD)		
Residential support		
Vocational/day support		
Home support (Home help/Personal care)		
Hosted services		
Respite care		
Supported employment		
Supported Living		
Individual Wrap Around Support		
Residential Rehabilitation		
Child development services		
Carer relief		
Other (please state service type below):		
Other (please state service type below):		
Other (please state service type below):		

A3 Disability Support Workforce information for your organisation

A3.1 How many (number and full time equivalent) staff are employed by your organisation in the MidCentral DHB region and all of New Zealand?

	MidCentral DHB region	New Zealand
Total number of staff		
Full-time equivalent (FTE) number of staff		
Percentage of full-time staff	%	%
Percentage of part-time staff	%	%

A3.2 In MidCentral DHB region, what is the gender profile of your staff?

Gender	Number
Female	
Male	
Gender diverse staff	

A3.3 In MidCentral DHB region, what is the age profile of your staff – as a percentage of total MidCentral DHB region staff?

15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70+ years
%	%	%	%	%	%	%	%	%	%	%	%

A3.4 In MidCentral DHB region, which ethnic group do your staff belong to?

Ethnicity	Number
NZ European	
Māori	
Samoan	
Cook Island Māori	
Tongan	
Niuean	
Chinese	
Indian	
Other	
Don’t Know	

A3.5 In MidCentral DHB region, what is your organisation’s staff turnover per year? _______%

A3.6 In MidCentral DHB region, how many disabled staff are employed by your organisation?

_______ Number _______ Full Time Equivalent

Section 1

The Current System

Definition - the disability support "**system"** refers to the cross-government disability support system

Please tick the most appropriate box for each statement.

In terms of our organisation, the **current system**:	**ALL THE TIME/YES**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/ NEVER**
1.1 enables us to respond to disabled people in creative and flexible ways	☐	☐	☐	☐	☐
1.2. encourages and values our input	☐	☐	☐	☐	☐
1.3 enables us to be proactive in our assistance of disabled people	☐	☐	☐	☐	☐
1.4 enables us to tailor our support according to people's aspirations and goals	☐	☐	☐	☐	☐
1.5 enables us to make it easier for people to experience an everyday life	☐	☐	☐	☐	☐
1.6 enables us to work collaboratively with mainstream (i.e. universal) services	☐	☐	☐	☐	☐
1.7 enables us to easily understand its requirements	☐	☐	☐	☐	☐

1.8 enables us to build trusting relationships with disabled people and their families/whānau	☐	☐	☐	☐	☐
1.8 enables us to raise issues and improve systems	☐	☐	☐	☐	☐
1.9 enables us to provide services that are responsive to Māori	☐	☐	☐	☐	☐
1.10 enables us to provide services that are responsive to Pacific peoples and other cultures	☐	☐	☐	☐	☐

Section B

B1 For your organisation, what are the main challenges with the current system?

I.	
II.	
III.	
IV.	

B2 How does your organisation currently apply the Enabling Good lives (EGL) principles in your work with disabled people and families/whānau ?

Section 2

Your Organisation

Thinking about your **organisation** and how you work with disabled people

Please tick the most appropriate box for each statement.

As an organisation we **actively**:	ALL THE TIME/YES	MOSTLY	SOMETIMES	NOT REALLY	NO/ NEVER
2.1 respond to disabled people's preferences	☐	☐	☐	☐	☐
2.2 value the involvement of disabled people and their families/whānau in decision-making	☐	☐	☐	☐	☐
2.3 actively involve disabled people and families/whānau in staff interviews	☐	☐	☐	☐	☐
2.4 have disabled people and families/whānau on our Board of Governance	☐	☐	☐	☐	☐
2.5 anticipate disabled people's support requirements	☐	☐	☐	☐	☐
2.6 work with disabled people to plan ahead and set goals and outcomes	☐	☐	☐	☐	☐
2.7 are responsive to disabled people's changes in support requirements	☐	☐	☐	☐	☐

2.8	create opportunities for disabled people to experience everyday lives in everyday places	☐	☐	☐	☐	☐
2.9	assist disabled people to have multiple valued roles	☐	☐	☐	☐	☐
2.10	connect disabled people with community (non-disability specific) resources and services	☐	☐	☐	☐	☐
2.11	ensure people understand what services we do and do not provide and make this information available, eg on a website	☐	☐	☐	☐	☐
2.12	ensure materials are in a format suited to people who use our service eg, easy read, braille, large font, words with visual descriptions, pictorial, etc	☐	☐	☐	☐	☐
2.13	work collaboratively together with disabled people and families/whānau	☐	☐	☐	☐	☐
2.14	provide services that are responsive to Māori	☐	☐	☐	☐	☐
2.15	provide services that are responsive to Pacific peoples and other cultures	☐	☐	☐	☐	☐

Section 3

System Transformation

Thinking about your organisation and how prepared you are for system transformation

Please tick the most appropriate box for each statement.

3. Please tick the following scale where you think your organisation's understanding of system transformation is currently?

Very little 1	2	3	4	Quite a bit 5	6	7	8	9	A lot 10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

In the MidCentral region our organisation has…				This was completed in the last…		
	no	**partially**	**yes**	**week**	**Month**	**Year or more**
3.1 a strategic plan, that responds to system transformation, that is signed off by the Board/senior management.	☐	☐	☐	☐	☐	☐
3.2 completed the Enabling Good Lives Organisational Self Review process.	☐	☐	☐	☐	☐	☐

3.3 developed an action plan from the Review process.	☐	☐	☐	☐	☐	☐
3.4 implemented staff development on the basis of completing the Enabling Good Lives Organisational Self Review process.	☐	☐	☐	☐	☐	☐
3.5 ensured our own Governance Group participated in meetings/training specific to the Enabling Good Lives approach and system transformation.	☐	☐	☐	☐	☐	☐
3.6 is satisfied that our whole workforce understands the core elements of the Enabling Good Lives approach.	☐	☐	☐	☐	☐	☐
3.7 circulated resources or documents related to the objectives of System Transformation to disabled people using the service.	☐	☐	☐	☐	☐	☐
3.8 confidence that we are able to equip our workforce to be effective in the transformed system.	☐	☐	☐	☐	☐	☐
3.9 specific communication/materials that will communicate what services the organisation will provide once system transformation begins.	☐	☐	☐	☐	☐	☐

Section C

C.1 What expectations do you have of the transformed disability support system?

C.2 What impact (positive or negative) do you think system transformation will have for your organisation?

C.3 Do you have any concerns about system transformation, if yes please state?

C.4 In terms of your organisation, what do you think are the challenges to achieving the objectives of system transformation i.e. disabled people and families/whānau having increased choice and decision making authority over their supports and lives?

I.	
II.	
III.	
IV.	

C.5 What ideas do you have that would make it easier for disabled people and their families/whānau to have increased choice and decision making authority?

I.	
II.	
III.	
IV.	

C.6 What information and support would assist you to prepare for the system change?

C.7 Do you have any other comments?

Thank you **for taking the time to complete this survey**

SAMS
EVALUATE • INNOVATE • EDUCATE

MidCentral DHB region Provider Survey

(September 2018)

Information for Providers

Disabled people, families, whānau and disability service providers have been working with government to design a better way for disabled people and their families/whānau to be supported.

The new disability support system is being launched in the MidCentral DHB region (Mana Whaikaha) on 1 October 2018.

Before that starts, the Ministry of Health has asked Standards and Monitoring Services (SAMS) to survey organisations and support workers to get a better understanding of the current system, awareness and expectations of the new system and what information and support would help everyone to prepare for change.

We appreciate that completing these surveys will involve your time and focus. This is an important opportunity to contribute your views to the development and evaluation of the system transformation.

This survey was developed in consultation with the New Zealand Disability Support Network (NZDSN) and Inclusive NZ.

The Provider Survey will take approximately 10 - 15 minutes to complete.

We require the survey to be completed and sent back by 20th September 2018.

Who is asked to participate?

The Ministry of Health has asked SAMS to survey all 35 providers and their support workers in the MidCentral region. SAMS is a charitable trust run and staffed by disabled people and family/whānau.

How is my privacy protected?

The Provider Survey contains information about privacy and confidentiality and asks for your consent to use the information provided in a report about disability support services and the new system in the MidCentral region.

You can choose not to participate and can withdraw your information any time prior to your survey results being added to other organisation's answers for the report.

What information will be collected from Providers?

The type of information collected includes:

- information about your organisation and your workforce

- views about the current system and how your organisation operates
- your understanding and expectations of system transformation
- what information and support could assist you to prepare for the system change.

Completing the Survey
You can fill out the MidCentral DHB region Provider Survey and email it back. Use your mouse or your tab key to move between checked boxes and text boxes, when clicking on a box you want to highlight an automatic X will appear, by clicking again the box will disappear.

Alternatively you can print it off, write on it, scan it and email it back, however you will need to ensure the scan is of good quality and the writing is legible.

Where will I find the survey results?
Disabled people and whānau are also being surveyed. The baseline information from all the surveys will be used to tell us how things are currently.

The grouped and summarised results from all the surveys will be written into a report available to everyone. The reports will be published on the System Transformation website: *www.enablinggoodlives.co.nz/system-transformation.* Easy read versions will also be produced.

Need more information?
If you have any questions about the survey you can contact Rebecca Walton, Development Manager, SAMS on 0274 260 150 or email samsrw@outlook.com

If you have questions about why these surveys are being undertaken please contact Marianne Linton, Disability Support Services, Ministry of Health, by emailing Marianne_Linton@moh.govt.nz

If you wish to raise a concern then please contact Mark Benjamin (CEO of SAMS) on 027 434 5001 or email samsmb@xtra.co.nz

If you want to talk to someone who is not involved with the survey, you can contact an independent health and disability advocate on 0800 555 050 or (03) 3537236 (Palmerston North Advocacy) or email advocacy@advocacy.org.nz

.

Document 3

Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools

SAMS

EVALUATE • INNOVATE • EDUCATE

Contents

Acknowledgements

SAMS would like to thank the many people who took the time to respond to our surveys and provide feedback on New Zealand's existing and proposed disability support system.

We thank the following key people for their contribution in developing the framing and guidance for the baseline study. These people also played a critical role in analysing the responses to the various surveys.

- Christine Wilson, PhD
- Carey-Ann Morrison, PhD
- Esther Woodbury PhD
- Aloma Parker, PhD
- Andrew Coleman, PhD
- Gary Williams
- Tina Lincoln
- Rebecca Walton
- Richard Lucy

Thank you also to our interviewers

- Audrey Buel
- Richard Buchanan
- Tina Lincoln
- Maureen Steed
- Hamish Taverner
- Cassandra Pickett
- Julie Senescall
- Lianne Clarke
- Dr Christine Wilson

Key people involved in preparing this report were:

- Dr Christine Wilson
- Mark Benjamin

Document 3

1. What is happening in the MidCentral Area

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018.[1]

The transformed system is based on the Enabling Good Lives (EGL) vision and principles. Mana Whaikaha aims to give disabled people and their whānau:

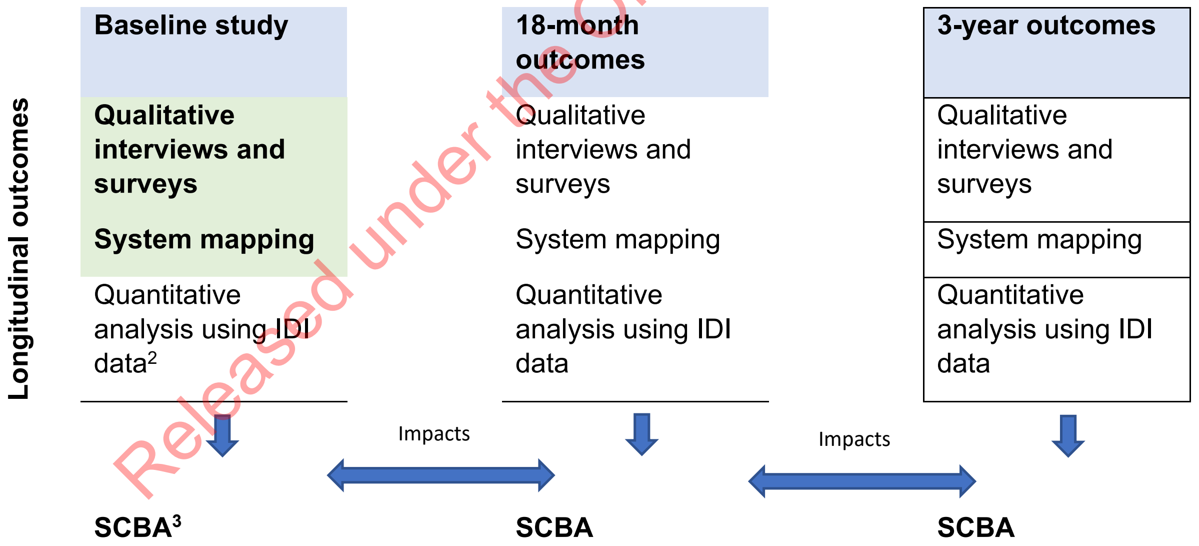
- more options and decision-making authority about their supports and lives
- to improve their wellbeing outcomes, and
- to create a more cost-effective disability support system.

Evaluation context

Mana Whaikaha will require ongoing evaluation to help everyone understand if its objectives are being achieved, where improvements are needed and how the approach should be adapted or expanded.

A high-level evaluation approach was developed, with advice from the Monitoring and Evaluation Working Group, as part of the overall work programme for designing the MidCentral area prototype.

Overview of the evaluation framework



---

[1] For more information about Mana Whaikaha see www.manawhaikaha.co.nz/about-us/mana-whaikaha/

[2] The IDI stands for the Integrated Data Infrastructure. The IDI is a linked longitudinal dataset that combines unit-record administrative information from a range of agencies and organisations. The IDI is maintained by Statistics New Zealand under strict privacy and confidentiality protocols.

[3] Social Cost Benefit Analysis

As shown in the previous diagram, the evaluation has two key inter-related components:

- Longitudinal outcomes evaluation
    - to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau
    - to determine how the system is changing over time and to what effect
- Social cost benefit analysis (SCBA) to value the impact of Mana Whaikaha.

In addition, a developmental evaluation will be used to support the 'Try, Learn and Adjust' approach being adopted for Mana Whaikaha, and to help drive meaningful change throughout the prototype period.

Baseline Study reports include information from the qualitative interviews, surveys and system mapping parts of the evaluation (the components in the diagram are highlighted on the previous page in green).

2. Why we did a Baseline Study

With change about to happen, we wanted a clear picture of how things were before the change (i.e. the MidCentral prototype/ Mana Whaikaha) started.

The Baseline describes and measures what was happening before Mana Whaikaha started on the 1st October 2018. Having this information means we can repeat the study and find out what has changed as a result of doing things differently.

3. What the Baseline Study looked at

The overall Baseline Study had three main objectives:

Objective 1: to develop a detailed 'map' of the current disability support system in the MidCentral area

Objective 2: to understand and measure the current experiences and life outcomes of disabled people and whānau in the MidCentral area

Objective 3: to identify what support is needed to help disabled people, whānau, service providers and community-based organisations in the MidCentral area prepare for system change.

This report focuses on responses to the following questions:

- How disabled people experience the current disability support system and what impact does it have on their lives?
- How well does the current disability support system support disabled people to live the lives they want?
- Do disabled people experience the current disability support system differently? If so, how and why?

- What life outcomes are disabled people achieving under the current disability support system?
- What is most important to disabled people in creating a life they want?

4. How we did the Baseline Study

The Baseline Study was made up of six types of work:

1. Talking with disabled people
2. Talking with whānau
3. Surveying service providers
4. Surveying people who worked for service providers (workforce survey)
5. Talking with people who worked for a range of government agencies and other stakeholders, eg Disabled Persons Organisations (DPOs).
6. Reviewing documents that described the disability support system

People were picked by chance (stratified random sample). It was important that there was a range of disabled people who represented all different types of people who were connected with disability support services.

Categories of disabled people were developed based on impairment/disability type, level of assessed need and age. Approximately ten percent of people from each of the three main types of disability were randomly sampled. We also assigned proportionally similar numbers of people to each group relative to their assessed needs. These groups represented people with learning and physical disabilities and people with Autism Spectrum Disorder (ASD). A sample of children and young people were also drawn at random within each category dependent on the proportion of children/young people to adults in each group.

Involved disabled people were asked for permission for their family member to also take part in the survey.

The survey involved a number of sections that attempted to review important things relating to personal experiences of disability and of the service system. These criteria were based on other survey tools in the sector and on documents such as Enabling Good Lives (EGL)[4]. EGL has the guiding principles behind the development of the new system.

Gathering information for the Baseline Study took place between early August and late September 2018.

During interviews disabled people worked their way through the survey with an experienced interviewer.

The survey included open ended (long answer questions) and some where people gave scores on a five-point scale (Likert Scale). People were encouraged to say whatever they wanted in addition to the survey questions. Approximately half the group gave permission to have their interview audio recorded.

All participants received an information sheet and consent form.

Interviews were confidential. All the information was put together to make a picture of what life was like before change happened.

---

[4] See www.enablinggoodlives.co.nz

Document 3

5. Who contributed to the survey

Stakeholder group	**Disabled people[5]**	**Whānau**	**DSS funded organisations**	**Members of the workforce**	**Government and other stakeholders**
Number of survey participants	**172**	**152**	**9**	**108**	**21**
Method of selection	Stratified random sample selected	Stratified random sample selected	Self-selected in response to email sent to all 32 provider organisations	Self-selected in response to notification from provider organisations	National and local DPO nominated representatives
Form of interview	Individual face-to-face interviews	Individual face-to-face or telephone interviews	Emailed survey for voluntary completion	Emailed link to an opt-in web-based survey	Individual face-to-face or telephone interviews
Stakeholder group details	56% male; 43% female 1% gender diverse 76% NZ European; 17% Māori; 6% other, including Asian, Fijian & Pasifika 53% learning disability; 28% physical disability; 19% ASD	82% female 67% married; 9% divorced; 24% single or widow / widower 78% NZ European; 18% Māori; 7% other (Pasifika, Asian, etc)	Representing: Residential Vocational Supported living Respite Home support Assistance for self-managed supports	67% female 67% NZ European; 19% Māori; 13% Other 51% residential services; 37% vocational services; 37% supported living; 12% home support; 88% direct support workers	Ministry of Health, particularly DSS (Disability Support Services) Ministry of Social Development Oranga Tamariki Ministry of Education MidCentral DHB CDS (Child Development Service)

---

[5] The survey involved disabled people who were clients of the Enable New Zealand Needs Assessment and Service Coordination Agency (NASC).

6. Background to the Survey Tools

The survey tools were developed to ensure questions were clear and definite. It was important to minimise the length of survey tools while having a sufficient number of questions to obtain the information needed.

Further considerations in designing the survey tool included:

- the specific objectives and research questions associated with the Baseline Study
- alignment with the EGL principles and vision
- validity.

Survey tools were fit-for-purpose and developed specifically for the purposes of this study. They included items drawn from or linked to:

- Enabling Good Lives vision and principles
- Whāia te Ao Mārama: Māori Disability Action Plan
- the Treasury's Wellbeing Framework
- Quality of Life Survey (2016), Colmar Brunton
- Quality of Life Questionnaire, Schalock, R.L and Keith, K.D. (1993)
- Evaluation frames of reference used by Standards and Monitoring Services (SAMS) in previous projects that were aimed toward determining life outcomes and quality of support[6].

Demographic questions in the survey are, where possible, aligned with the format used by Statistics New Zealand and address outcomes such as education, income, employment, and health status.

The disabled peoples survey draws on material co-developed with disabled people. Whānau were actively involved in the development and testing of the Whānau survey tool.

The disabled peoples survey was trialled with their representative groups and refined prior to use with the main sample. During testing with disabled people, particular attention was given to comprehension and survey length.

The whānau survey had many similar questions to the disabled persons survey. However, these were adjusted to ensure it was the whānau perspective and experience gathered.

The support worker (workforce) survey tool was loaded onto Survey Monkey. Access to the survey was provided via a link that was widely distributed through service providers and at workforce forums.

The organisational (provider) survey tool was emailed, as an attachment, to 32 providers in the MidCentral area.

Disabled people and whānau were provided with Information Sheets and Consent Forms. These included Easy Read translations. A copy of the Information Sheets and Consent Forms can be obtained by contacting SAMS at samsno@actrix.gen.nz. In addition to this, SAMS can supply a table describing how each question relates to other previously mentioned sector documents if requested.

---

[6] SAMS has developed evaluation and research tools since 1979. All SAMS materials are co-developed with disabled people and their whānau.

7. Disabled Persons Survey

About me

A1 **-** Your age:

0-4	5-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80+

A2 Are you 18 or older: YES/NO

A3 I am: male / female / gender diverse

A4 The ethnic group, or groups, I belong to (circle all that apply)

NZ European / Māori / Samoan / Cook Island Māori / Tongan/ Niuean / Chinese / Indian

Prefer not to say / Don't Know (circle if this applies) or other: (please state) …

A5 How many people do you live with? …

A6 Do you live with members of your family (include partner/spouse)? …

	Living situation (tick all that apply)	Yes	No
A7	I own my own home		
A8	I lease (rent) where I live		
	If yes, is the lease in your name?		
A9	Are you in a supported living situation?		
A10	I am supported in a residential service (or similar)		
A11	I have chosen to live where I do		

A12 What type of support do you get from the disability support system?: …

A13 What do you like about your supports? …

Can you explain that further? …

A14 What don't you like about the support you receive? …

Can you explain that further? …

A15 If you could change one thing about your supports, what would that be? …

A16 Thinking about your life, what is most important to you? …

A17 If anything were possible, what are some things you would like to achieve, start doing, or do more of? (These can be day-to-day things or big things about your life) …

A18 Why are these things important to you? …

Education

A19	What is your highest educational qualification? (this can include the year/age you left school or the class you are in now) Tell us about your education experiences	
A20	If you are currently in education or doing a course Please tell us what it is and where you are up to (ie for school or university – ie 1st, 2nd 3rd year etc)	
A21	Do you want to do more training / courses etc? What would you want to do?	
A21a	Is there anything stopping/preventing you from doing more training/courses?	

Document 3

FOR SCHOOL STUDENTS ONLY

	FOR SCHOOL STUDENTS (Early childhood/Primary/Secondary)		
E1	Where do you attend school …………………………………………………………………..	E2	Is this a separate school or class for disabled young people? **YES / NO**
E3	Apart from your teacher, do you have supports at school to help you learn (such as a teacher aid, technology, other teachers) **YES / NO**	E4	What supports do you have at school?

						
	N/A	**YES/TOTALLY**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/NOT AT ALL**
E5 My supports at school help me learn						
E6 I can participate in everything I want to at school						
E7 I have friends at school						
E8 Other students at school treat me well						

Employment and Voluntary work

		None	1-10 hours	10-15 hours	15-20 hours	20-25 hours	25-30 hours	30-35 hours	35-40 hours
A22	Paid employment in the last week								

A23 If you are currently working, tell us about your paid employment

A23a What do you do? …………………………………………………………………………………………

A23b Do you enjoy your job? ……………………………………………………………………………………..

A23c Do you have enough hours? ………………………………………………………………………………

A23d Do you think you are paid sufficiently for your work? ………………………………………………………

		None	1-10 hours	10-15 hours	15-20 hours	20-25 hours	25-30 hours	30-35 hours	35-40 hours
A24	Voluntary work in the last week								

A24a If you are currently doing voluntary work, what are you doing? ……………………………………………………………

A25 What type of work have you had before now (if any)? ……………………………………………………

……

A26 If you are not in work right now, is working something you would like to do? **YES / NO / maybe**

Relationships

		Week	Fortnight	Month	Longer than one month	In the last year	Longer than one year
A27	I had contact or visits with friends in the last… (not including support workers)						
A28	I had contact with a family member in the last						

A29

Live with partner (ie married, defacto, civil union etc)	Long-term relationship (Don't live with partner)	I am in a relationship (Don't live with partner)	I am currently single	Never been in an intimate relationship

A30 Do you have any children yourself (If so can you tell us about them, ages, gender etc)

……..

	FOR ADULTS	**n/a**	Yes	no	comments
A31	I am enrolled as a voter				
A32	I voted in the last general election				(i.e age at the time etc)

Community connections

		Week	Fortnight	Month	Longer than one month	In the last year	Longer than one year	Never
A33	I went out for a meal in the last							
A34	I visited a café or hotel (pub/bar) in the last							
A35	What community facility/s did I use in the last week/fortnight (e.g. swimming pool, parks, sports grounds/halls, library, shopping centres, malls, businesses etc)							
A36	My usual form/s of transport is….							
A37	I used public transport in the last							

		n/a	Yes	no	comments
A38	I am a member of a local group, club, church, Marae, sports team etc				(I.e. which ones)

	Health and Wellbeing	At least monthly	More than once a year	Once a year	Less than yearly	Almost never	Never	Clarifying comments e.g dentures etc
A39	I see a doctor							
A40	I visit a dentist							
A41	I visit a health professional (optometrist, counsellor, nutritionist, podiatrist etc)							

Health and Wellbeing						
A42	**Prefer not to respond**	**Excellent**	**Very good**	**Good**	**Fair**	**Poor**
My general health is….						

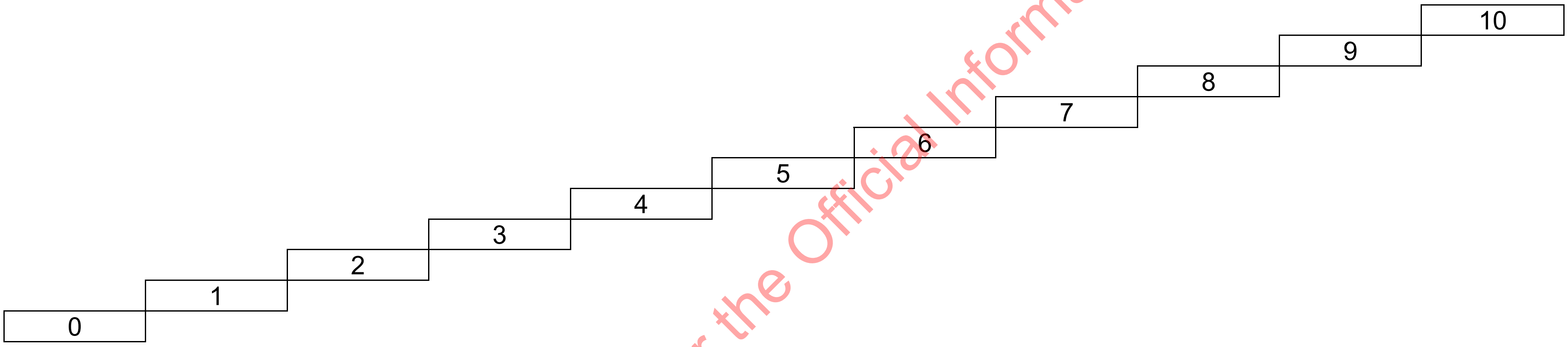
A43	What would make you start puffing **first**	**Prefer not to respond**	**Getting to your kitchen**	**Getting to the driveway/car (if near the house)**	**Walking 50 metres (e.g to your neighbours)**	**Walking 100m (e.g to next block in typical street)**	**Walking up a small slightly steep hill 100 metre**	**Walking up a large slightly steep hill 200+ metres**

A44 Please imagine the steps in the diagram below as a progression.

Suppose we say that the top step (10) represents the **best possible life you can have in terms of everything you need and want from life** and,

the bottom step (0) represents the **worst possible life for you**. Remember, the steps in between could also be where you feel you are right now.

On which step do you feel you personally stand at the present time?



A45 Why have you made the choice you made? …

Emotional Wellbeing						
	N/A	**YES/ TOTALLY**	**MOSTLY**	**OKAY/SO SO**	**NOT REALLY**	**NO/NEVER**
A46 I trust people who are important to me						
A47 I am a happy person						
A48 I know who to ask for help, advice, or support if I need it						
A49 I love life						
A50 I worry about things						
A51 I believe more good things than bad things will happen to me						
A52 I am optimistic about my future						
A53 In most ways my life is close to the way I would want it to be						
A54 I am happy with my life						

Document 3

1 My Identity						
Thinking about your support services….	**N/A**	**YES/ TOTALLY**	**MOSTLY**	**OKAY/SO SO**	**NOT REALLY**	**NO/NEVER**
1.1 Supports/services help me pursue my own interests						
1.2 My culture is respected						
1.3 My spirituality/beliefs are respected (e.g go to church, talk to elders, pray at home etc)						
1.4 I am understood when I communicate						

A55 Is English your first language: **Yes / No**

A55a Is your **main** form of communication (circle which applies)

Verbal **Limited verbal** **NZ sign language** **Makaton Sign Language** **Other signs language**

Picture board systems **Computer based systems** **Body language** **Other ……………………………**

2 My Authority	**N/A**	**ALL THE TIME/YES**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/ NEVER**
2.1 I can easily find out about the things I need for my support						
2.2 I can make changes to my supports if I need to						
2.3 I choose what happens in my life						
2.4 I have help to make choices if I need/want it						
2.5 I can choose who my support staff will be						
2.6 I know who will be supporting me each day/shift						
2.7 I choose who lives with me						
2.8 I have choices about the kind of support I receive						
2.9 I choose what happens in my day						
2.10 I can make plans based on what I want and what I'm good at						

		😄👍	😃👍	😕	🙁👎	😠👎
	N/A	**ALL THE TIME/YES**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/ NEVER**
2.11 I am achieving the things I want in my life						
2.12 I decide when to share my personal information						
2.13 I am involved in developing support services						
2.13a How are you involved in developing support services? (e.g. system co-design, making things happen and seeing how well things are going, being on a board of trustees, being a disabled person representative somewhere, being involved in strategic planning, evaluation, being on a committee, being involved in meetings etc)						

3 My Connections		😃	🙂	😕	☹️	😠
	N/A	**YES/LOTS**	**SOME**	**SORT OF**	**NOT REALLY**	**NO/NEVER**
3.1 My family is as involved in my life as I want them to be						
3.2 I am important to my family						
3.3 Any (intimate) relationships I have are supported (e.g boyfriend/girlfriend)						
3.4 I have friends outside of where I live (not paid staff/flatmates etc)						
3.5 I have a network of people who support me (family, whānau, friends, community and, if needed, paid support workers)						
3.6 I use typical/universal community services (e.g hair dressers, dentists, cafes, bars, doctors, shops etc)						
3.7 I can attend community events, hui, concerts, and celebrations if I like						
3.8 People from the community do things for me						
3.9 My supports assist me to strengthen my relationship with my community (incl. culture/community of choice)						
3.10 My supports help me connect to people and places that are important to me						
3.11 I feel I belong in my wider community						

4 My Time						
	N/A	**YES/TOTALLY**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/NOT AT ALL**
4.1 My Support happens at the times that work for me						
4.2 I have enough support to achieve what I want						
4.3 My support hours can be flexible						
4.4 My support occurs when I need it in my life						

My Wellbeing: My supports are safe, they understand my health and safety needs. My supports are well trained. I am safe where I live and outside of my home.

5 My Wellbeing		😁	🙂	😕	🙁	😠
	N/A	**YES/TOTALLY**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/NOT AT ALL**
5.1 I feel safe in my home						
5.2 My paid workers understand how to support me safely						
5.3 My paid workers receive the training they need						
5.4 I am supported to maintain and improve my health						
5.5 I am encouraged to think about what I want in my life						
5.6 I feel safe and secure						
5.7 I have all the equipment I need						

Document 3

6 My Contribution		😃	🙂	😕	🙁	😠
	N/A	**YES/TOTALLY**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/NOT AT ALL**
6.1 I have opportunities for learning and development (e.g skills and education, personal competence, workforce training, leadership)						
6.2 I can easily find help when looking for work						
6.3 I am supported to be an active member of my community						
6.4 The people in my life value what I can do						
6.5 I feel supported to try new things						
6.6 I am supported to be actively involved in my homelife						
6.7 I am learning skills to do more things						
6.8 I help others when they need my assistance						
6.9 I can work with others so they understand more about disability e.g community leaders, facilitate/lead training						
6.10 How are you involved in helping others understand more about disability? (e.g teaching others, being on committees etc)						

7 My Resources						
	N/A	**YES/TOTALLY**	**MOSTLY**	**SOMETIMES**	**NOT REALLY**	**NO/NOT AT ALL**
7.1 I choose where my support money is used						
7.2 I feel the amount of support I have is right for what I need						
7.3 I think the money I get for my support is well spent						
7.4 I know the amount of money available to me for my support						
7.5 I know where to get help to manage my own supports						
7.6 I can easily find skilled paid workers/staff for myself if I need to						
7.7 I can manage my own money						
7.8 I get enough spending money						
7.9 I can get help with my finances if I need it						

7.10 What is the total income that <u>you yourself</u> got from <u>all sources</u>, before tax or anything was taken out of it, in the last 12 months?) – (for children without investment income – list as no income)

No income	Less than 10K	$10001 to $20K	$20001 to 30K	$30001 to $40K	$40001 to 50K	$50001 To 60K	$60001 to $70K	$70001 to 80K	$80001 to 90K	$90001 to 100K	$100001 to 150K	$150001 to 200K	More than to 200K

8. Whānau Survey

Demographic Information for Statistical Purpose Only

B1 Select your age group?

15-19	☐	20-24	☐
25-29	☐	30-35	☐
35-39	☐	40-44	☐
45-49	☐	50-54	☐
55-59	☐	60-64	☐
65-69	☐	70-74	☐
75-79	☐	80+	☐

	Male	Female	Gender diverse
B2 What is your gender?	☐	☐	☐

B3 Are you?

Single	☐	Divorced	☐
Live in relationship	☐	Married or civil union	☐

B4 Which ethnic group, or groups, do you belong to

NZ European	☐	Niuean	☐
Māori	☐	Chinese	☐
Samoan	☐	Indian	☐
Cook Island Māori	☐	Prefer not to say/Don't know	☐
Tongan	☐	Or Other	☐

B5 Iwi affiliation (if applicable)

B6 What is your current work situation?

		Yes	No
(a) working in paid employment (includes self-employment)		☐	☐

i. If Yes, hours worked last week

ii. Would you like to be working: **More / Fewer Hours** Why?

		Yes	No
or ii. Wanting to work (but cannot right now)		☐	☐

Why?

		Yes	No
(c) Not in paid work, and not looking for a job (for any reason, such as being retired, a homemaker, caregiver or full-time student).		☐	☐

(d) Other (specify)

What is your living situation (tick all that apply)

	Yes	No
B7 I own my own home (owner occupied or occupy a home owned by our family trust)	☐	☐
B8 Rented from Private Landlord	☐	☐
B9 Rented from Social/Community Housing ie rented from Government/City Council/Community organisation	☐	☐

B10 Other

B11 What was the total income that your household got from all sources, before tax or anything was taken out of it, in the last 12 months?

No income	☐	Less than 10K	☐
$10001 to 20K	☐	$2001 to 30K	☐
3001 to 40K	☐	$4001 to 50K	☐
$5001 to 60K	☐	$6001 to 70K	☐
$7001 to 80K	☐	$8001 to 90K	☐
$9001 to 100K	☐	$100001 to 150K	☐
$150001 to 200K	☐	More than 200K	☐
Prefer not to answer or don't know	☐		

B12 How many people, who are close to you, receive support from disability services in MidCentral area?

Document 3

B13 In the table below please tell us about each of these people (but not necessarily living with)

e.g parent, sibling, child of, partner, friend, spouse, foster family etc. State if this includes a legal relationship i.e welfare guardian/power of attorney, personal property manager etc

Person	Disability type	Gender	Age	Your relationship to each person
1				
2				
3				

B13a From the table above, can you say what type of support does each person receive through the disability support services?

Person 1

Person 2

Person 3

B14 Which of these people is/are also involved in the disabled persons survey? ie none, or person/s 1, 2, and/or 3

B15 Which of these people **live with you**? (i.e none, or person/s 1, 2 and/or 3)

	All	Most	Some	None
B16 Do you provide some, most or all of their support?	☐	☐	☐	☐

	Another family member	Partner	Spouse	Support worker(s)	Friend	Other
B17 Do you have other people who help provide support(s) Tick as many as applicable	☐	☐	☐	☐	☐	☐

B18 On average (per week day), how much time do you spend actively providing supports for the people listed above? If less than an hour list as 1-4hrs.

i.e: active supervision, supervising carers, running errands, transport, personal care, meals, health care, night time waking.

Most 18+ hrs	☐	A lot 8-17 hrs	☐
Some 5-7 hrs	☐	A little 1-4 hrs	☐
None	☐		

B19 On average (per week day), how much time do you spend actively organising or managing support for the people listed above? Ff less than an hour list as 1-4hrs.

i.e: attending needs assessment meetings, talking with services, hiring staff, arranging rosters, budget management, paying invoices etc

Most 18+ hrs	☐	A lot 8-17 hrs	☐
Some 5-7 hrs	☐	A little 1-4 hrs	☐
None	☐		

B20 How many people who rely on you for support live with you in total? And what are their ages?

(this can mean other children in the family, older people, disabled and non-disabled people etc)

B21 How much of your **average week day** (24 hours) is spent doing things **for yourself - for leisure.** If less than an hour list as 1-4hrs.

i.e walking/hiking/sports/socialising with friends & family/hobbies/TV/computers/movies/theatre/music/reading/naps, resting

Most 18+ hrs	☐	A lot 8-17 hrs	☐
Some 5-7 hrs	☐	A little 1-4 hrs	☐
None	☐		

B22 Do you receive through Disability Support Services any of the following? (sometimes the term *alternative support* is used for carer support hours)

	Yes	No
Respite funding (including Individualised funding)	☐	☐
Carer Support Hours	☐	☐
Family/whanau or home support	☐	☐
Support to assist with Personal cares	☐	☐

IF yes to any of the above, please complete the next question. **Otherwise go to Question C1.**

Complete B23-B26 if your family has received facility-based respite, Individualised Funding (IF) respite, carer support and family/whanau home support, home support/personal care support. Otherwise go to the next question (C1).

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
B23 I have regular breaks from my caring responsibilities	☐	☐	☐	☐	☐	☐
B24 I find it easy to find carers (for the funding provided)	☐	☐	☐	☐	☐	☐
B25 I know what respite options are available in MidCentral	☐	☐	☐	☐	☐	☐
B26 My supports help me to continue with my caring role	☐	☐	☐	☐	☐	☐

C1 What do you like about the supports that are provided?

(Interviewer: consider all the supports that are provided, for the person doing the survey and the person with the disability)

C1a Can you explain that further?

C2 What don’t you like about the supports that are provided?

(Interviewer: consider all the supports that are provided, for the person doing the survey and the person with the disability)

2a Can you explain that further?

C3 If you could change one thing about the supports that are provided, what would that be?

(Interviewer: consider all the supports that are provided, for the person doing the survey and the person with the disability)

C4 Thinking outside your supports, is there anything stopping you from achieving your goals?

C5 If you were to describe what your supports have been like for you in a couple of words, what would they be?

C6 Thinking about your life, what is most important to you? (Interviewer: seek further explanation as needed)

C7 If anything were possible, what are some things you would like to achieve, start doing, or do more of?

(These can be day-to-day things or big things about your life)

C8 Why are these things important to you?

When we use the term “supports” or “services” we are talking about anything funded by the Ministry of Health through the disability needs assessment. We are asking with reference to your contact with support services.

WE REFER TO ‘WE’, ‘US’ OR ‘OUR’ AS YOUR RELATIONSHIP WITH THE DISABLED PERSON/S. THIS *MAY* INCLUDE THE PERSON WITHIN THE BROADER RELATIONSHIP OF YOUR WHANAU OR FAMILY.

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
I feel welcomed by the supports/services we use. **Example / explanation (if needed): they know who we are, they are friendly and they are interested in what we have to say.**	☐	☐	☐	☐	☐	☐
2 I believe my views are valued by supports/services. **Example / explanation (if needed): they listen well, accurately record information and act on what we say/agree.**	☐	☐	☐	☐	☐	☐
3 Supports respect our culture. **Example / explanation (if needed): our way of doing things (including beliefs) is respected, services are responsive to Te Ao Maori.**	☐	☐	☐	☐	☐	☐

Document 3

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
4 Supports value our preferences. **Example / explanation (if needed): what they do is linked to what you have said and what you think is important.**	☐	☐	☐	☐	☐	☐
5. Supports are easy to access and use. **Example / explanation (if needed): there is clear information about what is happening and you don't need to repeat yourself or follow-up on what is decided.**	☐	☐	☐	☐	☐	☐
6 Contact with the disability support system helps us achieve our goals. **Example / explanation (if needed): you are able to make progress with what you are wanting because of the involvement of supports/services**	☐	☐	☐	☐	☐	☐
7 I think the funding allocation process is clear. **Example / explanation (if needed): We understand how to obtain funding and get decisions reviewed**	☐	☐	☐	☐	☐	☐
8 I believe the funding allocation process is positive. **Example / explanation (if needed): We think getting funding values who we are and is constructive.**	☐	☐	☐	☐	☐	☐

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
9 I know how much money is allocated for support. **Example / explanation (if needed): I know how much money is provided and what this is for**	☐	☐	☐	☐	☐	☐
10 I know what the funding is used for. **Example / explanation (if needed): I know where the money goes / how it is used.**	☐	☐	☐	☐	☐	☐
11 The funding is sufficient to meet our needs.	☐	☐	☐	☐	☐	☐
12 Supports anticipate what I/we need. **Example / explanation (if needed): we experience supports/services that are proactive / looking ahead**	☐	☐	☐	☐	☐	☐
13 I am valued for the support I provide. **Example / explanation (if needed): both at home and generally, I am recognised for the contribution I make**	☐	☐	☐	☐	☐	☐
14 Supports work when we want them. **Example / explanation (if needed): When things happen to suit us (time of the day/week).**	☐	☐	☐	☐	☐	☐
15 Supports work how we want them. **Example / explanation (if needed): What happens is consistent with what suits us and what we have agreed with**	☐	☐	☐	☐	☐	☐

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
16 Overall our supports work flexibly (how we want them to).	☐	☐	☐	☐	☐	☐
17 Supports enable us to do the things that are important to us	☐	☐	☐	☐	☐	☐
18 Paid support workers are reliable and consistent.	☐	☐	☐	☐	☐	☐
19 We control and direct the supports that are needed	☐	☐	☐	☐	☐	☐
20 We can make changes to our supports as we need to	☐	☐	☐	☐	☐	☐
21 We choose who provides assistance for ongoing support.	☐	☐	☐	☐	☐	☐
22 Overall supports for my family member work well. **Example / explanation (if needed): things are happening the way we though they would (doing the right things at the right time and place).**	☐	☐	☐	☐	☐	☐
23 I can access all of the information I need, about support services. **Example / explanation (if needed): Information is easy to get hold of.**	☐	☐	☐	☐	☐	☐
24 I think information, from support services is easy to understand. **Example / explanation (if needed): Information provided is using language and a format which means it is easy for me to understand it.**	☐	☐	☐	☐	☐	☐

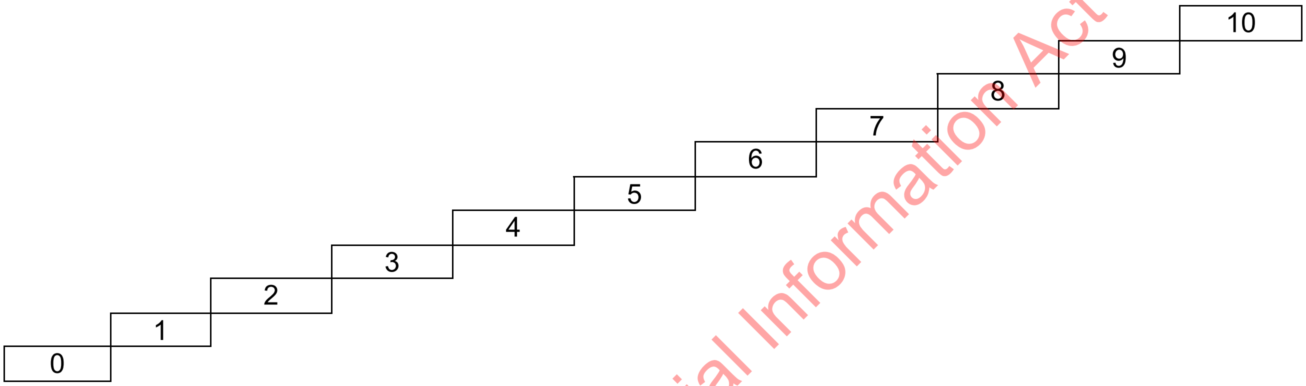
	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
25 In general, I believe my family member / friend / partner/ spouse is safe. **Example / explanation (if needed): I am not concerned my family member / friend / partner/ spouse is a risk**	☐	☐	☐	☐	☐	☐
26 We are supported to be connected in the community. **Example / explanation (if needed): We are given information that enables us to make contact with other community based networks/services if we choose to do this, supported to be connected with Te Ao Maori.**	☐	☐	☐	☐	☐	☐
27 We can use community options, connections and services that are for everyone before we have to use specialised disability services. **Example / explanation (if needed): We are not always directed straight into disability services.**	☐	☐	☐	☐	☐	☐
28 Our wellbeing benefits from contact with the disability support system. **Example / explanation (if needed): As a family we believe we are better off because of contact with the supports and services**	☐	☐	☐	☐	☐	☐

	N/A not sure	No/ Never	Occasionally	Sometimes	Most of the time	Yes/ Always
29 Our supports help us connect to people and places that are important to us.	☐	☐	☐	☐	☐	☐
30 My/our rights are respected. **Example / explanation (if needed): as a whanau/family, as a legal decision maker on behalf of the person.**	☐	☐	☐	☐	☐	☐
31 I support my whanau/family member / friend / partner / spouse to make their own decisions in life.	☐	☐	☐	☐	☐	☐
32 I have the skills and confidence to support them to live the life they want.	☐	☐	☐	☐	☐	☐
33 I/we know where we are heading and have the supports in place to build the life we want.	☐	☐	☐	☐	☐	☐
34 We can be involved in developing support services. **Example / explanation (if needed): co-design, making things happen and seeing how well things are going.**	☐	☐	☐	☐	☐	☐
35 I can work with others so they understand more about disability . **Example / explanation (if needed): share our story, lead training.**	☐	☐	☐	☐	☐	☐

Document 3

D1 Please imagine the steps in the diagram below as a progression. (If reading this question out to person talk about it as a ladder rather than steps: imagine a ladder with the top step (10) and the bottom step (0) etc)

> Suppose we say that the top step (10) represents the **best possible life you can have in terms of everything you need and want from life** and,
>
> the bottom step (0) represents the **worst possible life for you**. Remember, the steps in between could also be where you feel you are right now.
>
> On which step do you feel you personally stand at the present time?



	Extremely Poor	Poor	Neither good nor poor	Good	Extremely Good
D2 What would you say that your overall quality of life is	☐	☐	☐	☐	☐

D3 Why do you view your overall quality of life in this way?

	Decreased significantly	Decreased to some extent	Stayed about the same	Increased to some extent	Increased significantly
D4 Compared to 12 months ago, would you say your quality of life has	☐	☐	☐	☐	☐

	Yes	No
36 Are you connected to a family/carer support network?	☐	☐

	Yes	No	Not sure yet
36** IF NO, **Do you want to be connected to a family/carer support network	☐	☐	☐

	Yes	No
37a. **IF YES**, can we pass on your contact details for this purpose only	☐	☐

What is you preferred method of contact?

Thank you for taking the time to complete this survey

9. MidCentral Area Support Worker Survey

Disabled people, families, whānau and disability service providers have been working with government to design a better way for disabled people and their families/whānau to be supported.

The new disability support system is being launched in the MidCentral area on 1 October 2018.

Before that starts, the Ministry of Health has asked Standards and Monitoring Services (SAMS) to survey organisations and support workers to get a better understanding of the current system, awareness and expectations of the new system and what information and support would help everyone to prepare for change.

Disabled people and their families/whānau are also being surveyed. The grouped and summarised results from all the surveys will be written into reports available to everyone. The reports will be published on the System Transformation website: *www.enablinggoodlives.co.nz/system-transformation.* Easy read versions will also be produced.

This survey will take you approximately 15 minutes to complete. Completing this survey is an important way for you to provide your views to the development of the new system.

The information you provide for this survey will be confidential and is protected by the Privacy Act 1993. No person or organisation will be able to be identified. The answers you give in the survey will be added to other people's answers to create grouped results, so your information cannot be traced back to you. It will only be reported as part of grouped results in a report about the survey results. **Your information will always remain confidential.**

I understand my answers will be treated anonymously and agree that the information I provide can be used in a report about disability support services and the new system in the MidCentral area.

I agree ☐

Please tick if you agree

Document 3

Profile Section A

Please tell us about yourself

	Male	Female	Gender diverse
A.1 What is your gender?	☐	☐	☐

A.2 Which ethnic group do you belong to

NZ European	☐	Niuean	☐
Māori	☐	Chinese	☐
Samoan	☐	Indian	☐
Cook Island Māori	☐	Prefer not to say/Don’t know	☐
Tongan	☐	Or Other	☐

A.3 What is your age group

15-19	☐	20-24	☐
25-29	☐	30-35	☐
35-39	☐	40-44	☐
45-49	☐	50-54	☐
55-59	☐	60-64	☐
65-69	☐	70+	☐

A.4 What type of disability support service do you work in (please tick all that apply)?

Aged care (YPD)	☐	Vocational/day support	☐
Home support	☐	Respite care	☐
Supported employment	☐	Supported Living	☐
Child development services	☐	Direct employment	☐
Carer relief	☐	Other (please state below)	

A.5 What is your main disability support services role/job (please tick)?

Working directly with disabled people	☐	Administration	☐
Finance, accounts, contract management	☐	Human resources	☐
Management	☐	Other (please state below)	

A.6 In that job, which one of these applies to you (please tick)?

A paid employee	☐	Self-employed and not employing others	☐
An employer of other person(s) in my own business	☐	Other (please sate below)	

A.7 In disability support services, how many hours to the nearest hour do you usually work each week?

		More hours	Less hours
A.8 Would you like to be working		☐	☐

Document 3

Why?

A.9 In a usual day how many hours (to the nearest hour) do you spend working directly with disabled people?

1 hour	☐	2 hours	☐
3 hours	☐	4 hours	☐
5 hours	☐	6 hours	☐
7 hours	☐	8 hours	☐
9+ hours	☐		

A.10 In a usual day how many hours (to the nearest hour) do you spend doing other work (eg, administration) but not directly working with disabled people?

1 hour	☐	2 hours	☐
3 hours	☐	4 hours	☐
5 hours	☐	6 hours	☐
7 hours	☐	8 hours	☐
9+ hours	☐		

A.11 How long have you worked in disability support services?

Less than1 year	☐	1-2 years	☐
3-4 years	☐	5-6 years	☐
7-8 years	☐	9-10 years	☐
11-12 years	☐	13-14 years	☐
15+ years	☐		

		Yes	No
A.12 Are you currently enrolled in the New Zealand Certificate in Health & Wellbeing or equivalent		☐	☐

	Level 1	Level 2	Level 3	Level 4	Don't know

Document 3

A.12.1 What level do you expect to attain	☐	☐	☐	☐	☐

		Yes	No
A.13 Do you plan to enrol in the New Zealand Certificate in Health & Wellbeing or equivalent		☐	☐

	Level 1	Level 2	Level 3	Level 4	Don’t know
A.13.1 What level do you expect to attain	☐	☐	☐	☐	☐

Your opinion about the Current System

Please tick the most appropriate box for you, for each statement

Definition The disability support “**system”** refers to the cross-government disability support system

1. In terms of our organisation the current system

	All the time/Yes	Mostly	Sometimes	Not really	No/Never
1.1 enables us to respond to disabled people in creative and flexible ways	☐	☐	☐	☐	☐
1.2. encourages and values our input	☐	☐	☐	☐	☐
1.3 enables us to be proactive in our assistance of disabled people	☐	☐	☐	☐	☐
1.4 enables us to tailor our support according to people’s aspirations and goals	☐	☐	☐	☐	☐
1.5 enables us to make it easier for people to experience an everyday life	☐	☐	☐	☐	☐
1.6 enables us to work collaboratively with mainstream (i.e. universal) services	☐	☐	☐	☐	☐
1.7 enables us to easily understand its requirements	☐	☐	☐	☐	☐

1.8 enables us to build trusting relationships with disabled people and their families/whānau	☐	☐	☐	☐	☐
1.9 enables us to raise issues and improve systems	☐	☐	☐	☐	☐
1.10 enables us to provide services that are responsive to Māori	☐	☐	☐	☐	☐
1.11 enables us to provide se that are responsive to Pacific pe and other cu	☐	☐	☐	☐	☐

B.1 For you, what do you think are the main challenges with the current system?

B.2 How do you currently apply the Enabling Good Lives (EGL) principles in your work with disabled people and families/whānau?

2. Thinking about your organisation and how you work with disabled people, please tick the most appropriate box, for you, for each statement.

In our organisation we actively:

	All the time/Yes	Mostly	Sometimes	Not really	No/Never
2.1 respond to disabled people's preferences	☐	☐	☐	☐	☐
2.2 value the involvement of disabled people and their whānau in decision-making	☐	☐	☐	☐	☐
2.3 anticipate disabled people's support requirements	☐	☐	☐	☐	☐
2.4 work with disabled people to plan ahead and set goals and outcomes	☐	☐	☐	☐	☐

2.5 are responsive to disabled people's changes in support requirements	☐	☐	☐	☐	☐
2.6 create opportunities for disabled people to experience everyday lives in everyday places	☐	☐	☐	☐	☐
2.7 assist disabled people to have multiple valued roles	☐	☐	☐	☐	☐
2.8 connect disabled people with community (non-disability specific) resources and services	☐	☐	☐	☐	☐
	All the time/Yes	Mostly	Sometimes	Not really	No/Never
2.9 ensure people understand what services we do and do not provide and we make this information available, eg on a website	☐	☐	☐	☐	☐
2.10 ensure materials are in a format suited to people who use our service eg, easy read, braille, large font, words with visual descriptions, pictorial, etc	☐	☐	☐	☐	☐
2.11 work well together with disabled people and their families/whānau	☐	☐	☐	☐	☐
2.12 provide services that are responsive to Māori	☐	☐	☐	☐	☐
2.13 provide services that are responsive to Pacific peoples and other cultures	☐	☐	☐	☐	☐

System Transformation

C.1 Please circle on the following scale where you think your understanding of system transformation is currently?

Very little				Quite a bit					A lot
1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

C.2 What expectations do you have of the transformed disability support system?

C.3 What impact (positive or negative) do you think system transformation will have for your role/job?

C.4 Do you have any concerns about system transformation, if yes please state?

C.5 What ideas do you have that would make it easier to support disabled people to have a good life?

C.6 What information and support would assist you to prepare for system change?

C.7 Do you have any other comments?

Thank you for taking the time to complete this survey

10. MidCentral Area Provider Survey

Please return this survey to ________________ by _____/_____/_____

Confidentiality and Privacy

Please read the consent information carefully

The information you provide for this survey will be confidential and is protected by the Privacy Act 1993. No person or organisation will be able to be identified. The answers you give in the survey will be added to other people's answers to create grouped results, so your information cannot be traced back to you. It will only be reported as part of grouped results in a report about the survey results. **Your information will always remain confidential.**

I/we understand my answers will be treated anonymously and agree that the information I provide can be used in a report about the disability support services and the new system in the MidCentral area.

I/we understand I have the right to withdraw my contribution (survey) including quotations and comments at any point before it is added to other organisation's answers for the report.

I/we know that my participation in this survey is confidential and no information that could identify the organisation or any personnel will ever be used in any reports. The information gathered will NOT reveal participant names or organisational identifiers. All my answers are protected by the Privacy Act 1993.

I/we understand the aims of this survey and consent to my/our participation in the provider survey.

Date ______/ ______/ _______

I/we have the authority and will consult with others to complete on behalf of my service/organisation.

Name of organisation ____

Name & role of consenting party ____

I consent to the organisation providing this information (please tick box) ☐

Section A

Organisation Information

Please tell us about your organisation

A1.1 What is the legal structure of your organisation

Charitable Trust	☐	Incorporated Society	☐
Limited Liability Company	☐	Co-operative Company	☐
Unlimited Company	☐	Sole trader (self-employed or contractor)	☐

Other (Please state)

A1.2 Who do you currently have contracts with to provide disability support services in the MidCentral area and all of New Zealand (tick as many options as you need)?

	MidCentral area	All New Zealand
Disability Support Services (DSS), Ministry of Health	☐	☐
Ministry of Social Development	☐	☐
ACC	☐	☐
District Health Board	☐	☐
Funding directly from disabled people	☐	☐

Others? Please list

A2 In your organisation, how many disability support service users were there in the MidCentral area and nationally in 2017/18?

Type of Service	MidCentral area **Number of** service users **in 2017/18**	Total New Zealand **Number of** service users **in 2017/18**
Aged care (YPD)	☐	☐
Residential support	☐	☐
Vocational/day support	☐	☐
Home support (Home help/Personal care)	☐	☐
Hosted services	☐	☐
Respite care	☐	☐
Supported employment	☐	☐
Supported Living	☐	☐
Individual Wrap Around Support	☐	☐
Residential Rehabilitation	☐	☐
Child development services	☐	☐
Carer relief	☐	☐

Other (please state service type below)

Disability Support Workforce information for your organisation

A3.1 How many (number and full time equivalent) staff are employed by your organisation in the MidCentral area and all of New Zealand?

	MidCentral area	All New Zealand
Total number of staff		
Full-time equivalent (FTE) number of staff		
Percentage of full-time staff	%	%
Percentage of part-time staff	%	%

A3.2 In MidCentral area, what is the gender profile of your staff?

Female	Male	Gender diverse staff
No.	No.	No.

A3.3 In MidCentral area, what is the age profile of your staff – as a percentage of your total MidCentral area staff?

15-19	%	20-24	%
25-29	%	30-35	%
35-39	%	40-44	%
45-49	%	50-54	%
55-59	%	60-64	%
65-69	%	70+	%

A3.4 In MidCentral area, which ethnic group do your staff belong to?

Ethnic Group	Number	Ethnic group	Number
NZ European		Māori	
Samoan		Cook Island Māori	
Tongan		Niuean	
Chinese		Indian	
Other			

A3.5 In MidCentral area, what is your organisation's staff turnover per year? **%**

	Number	Full time equivalent
A3.6 In MidCentral area, how many disabled staff are employed by your organisation?		

Section 1

The Current System

Definition – the disability support “**System**” refers to the cross-government disability support system.

Please tick the most appropriate box for each statement.

The current **disability support system**

	All the time/Yes	Mostly	Sometimes	Not really	No/Never
1.1 enables us to respond to disabled people in creative and flexible ways	☐	☐	☐	☐	☐
1.2 encourages and values our input	☐	☐	☐	☐	☐
1.3 enables us to be proactive in our assistance of disabled people	☐	☐	☐	☐	☐
1.4 enables us to tailor our support according to people’s aspirations and goals	☐	☐	☐	☐	☐
1.5 enables us to make it easier for disabled people to experience an everyday life	☐	☐	☐	☐	☐
1.6 enables us to work collaboratively with mainstream services ie universal	☐	☐	☐	☐	☐
1.7 enables us to easily understand its requirements	☐	☐	☐	☐	☐
1.8 enables us to build trusting relationships with disabled people and their families/ whānau	☐	☐	☐	☐	☐
1.9 enables us to raise issues and improve systems	☐	☐	☐	☐	☐
1.10 enables us to provide services that are responsive to Māori	☐	☐	☐	☐	☐
1.11 enables us to provide services that are responsive to Pacific peoples and other cultures	☐	☐	☐	☐	☐

Section B

B1 For your organisation, what are the main challenges with the current system?

1
2
3
4
5
6

B2 How does your organisation currently apply the Enabling Good lives (EGL) principles in your work with disabled people and families/whānau?

Section 2

Your Organisation

Thinking about your organisation and how you work with disabled people.

Please tick the most appropriate box for each statement

As an organisation we **actively**

	All the time/Yes	Mostly	Sometimes	Not really	No/Never
2.1 respond to disabled people's preferences	☐	☐	☐	☐	☐
2.2 value the involvement of disabled people and their families/whanau in decision-making	☐	☐	☐	☐	☐
2.3 involve disabled people and families/ whānau in staff interviews	☐	☐	☐	☐	☐
2.4 have disabled people and families/ whānau on our Board of Governance	☐	☐	☐	☐	☐
2.5 anticipate disabled people's support requirements	☐	☐	☐	☐	☐
2.6 work with disabled people to plan ahead and set goals and outcomes	☐	☐	☐	☐	☐
2.7 are responsive to disabled people's changes in support requirements	☐	☐	☐	☐	☐
2.8 create opportunities for disabled people to experience everyday lives in everyday places	☐	☐	☐	☐	☐
2.9 assist disabled people to have multiple valued roles	☐	☐	☐	☐	☐
2.10 connect disabled people with community (non-disability specific) resources and services	☐	☐	☐	☐	☐
2.11 ensure people understand what services we do and do not provide and make this information available eg on a website	☐	☐	☐	☐	☐

	All the time/Yes	Mostly	Sometimes	Not really	No/Never
2.12 ensure materials are in a format suited to people who use our services eg easy read, braille, large font, words with visual descriptions, pictorial, etc	☐	☐	☐	☐	☐
2.13 work collaboratively together with disabled people and families/ whānau	☐	☐	☐	☐	☐
2.14 provide services that are responsive to Māori					
2.15 provide services that are responsive to Pacific peoples and other cultures	☐	☐	☐	☐	☐

Section 3

System Transformation

Thinking about your organisation and how prepared you are for system transformation.

Please tick the most appropriate box for each statement

3. Please tick the following scale where you think your organisation's understanding of system transformation is currently?

Very little				Quite a bit					A lot
1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

In the MidCentral area our organisation has | This was completed in the last

	No	Partially	Yes		Week	Month	Year or more
3.1 a strategic plan, that responds to systems	☐	☐	☐		☐	☐	☐
3.2 completed the Enabling Good Lives Organisational Self Review process	☐	☐	☐		☐	☐	☐
3.3 developed an action plan from the Review process	☐	☐	☐		☐	☐	☐
3.4 implemented staff development on the basis of completing the Enabling Good Lives Organisational Self Review process	☐	☐	☐		☐	☐	☐
3.5 ensured our own Governance Group participated in meetings/training specific to the Enabling Good Lives approach and system transformation	☐	☐	☐		☐	☐	☐

3.6 is satisfied that our whole workforce understands the core elements of the Enabling Good Lives approach	☐	☐	☐		☐	☐	☐
	No	Partially	Yes		Week	Month	Year or more
3.7 circulated resources or documents related to the objectives of System Transformation to disabled people using the service	☐	☐	☐		☐	☐	☐
3.8 confidence that we are able to equip our workforce to be effective in the transformed system	☐	☐	☐		☐	☐	☐
3.9 specific communication/materials that will communicate what services the organisation will provide once system transformation begins	☐	☐	☐		☐	☐	☐

Section C

C.1 What expectations do you have of the transformed disability support system?

C.2 What impact (positive or negative) do you think system transformation will have for your organisation?

C.3 Do you have any concerns about system transformation, if yes please state?

C.4 In terms of your organisation, what do you think are the challenges to achieving the objectives of system transformation i.e. disabled people and families/whānau having increased choice and decision-making authority over their supports and lives?

1

2

3

4

5

6

C.5 What ideas do you have that would make it easier for disabled people and their families/whānau to have increased choice and decision making authority?

1

2
3

4

5

6

C.6 What information and support would assist you to prepare for the system change?

C.7 Do you have any other comments?

Thank you for taking the time to complete this survey

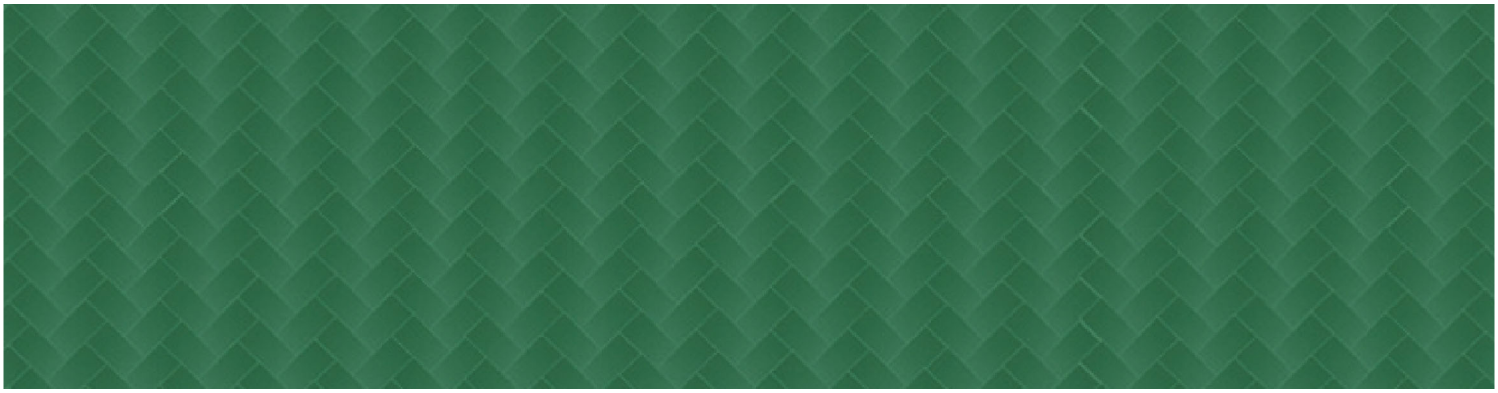
11. What now

Other things to read

- Baseline Study of the Disability Support System in the MidCentral Area: Summary Report
- Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report
- Baseline Study of the Disability Support System in the MidCentral Area: Disabled Peoples Report

Document 4

Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report



Contents

Table of figures

Tables of tables

Acknowledgements

SAMS would like to thank the many people who took the time to respond to our surveys and provide feedback on New Zealand's existing and proposed disability support systems.

We would also like to thank the following key people for their important contribution in developing the framing and guidance for the Baseline Study discussed in this report. These people also played a critical role in analysing the responses to the various surveys that were conducted:

- Christine Wilson, PhD
- Carey-Ann Morrison, PhD
- Esther Woodbury PhD
- Aloma Parker, PhD
- Andrew Coleman, PhD
- Gary Williams
- Tina Lincoln
- Rebecca Walton
- Richard Lucy

Thank you also to our interviewers:

- Audrey Buel
- Richard Buchanan
- Tina Lincoln
- Maureen Steed
- Hamish Taverner
- Cassandra Pickett
- Julie Senescall
- Lianne Clarke
- Dr Christine Wilson

Key people involved in preparing this report are:

- Dr Christine Wilson
- Mark Benjamin

To reference this document:
Wilson, C.S. and Benjamin, M. (2019). *Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report.* Prepared on behalf of the Ministry of Health, New Zealand. SAMS Evaluate, Innovate, Educate.

1. What is happening in the MidCentral Area

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018.[1]

The transformed system is based on the Enabling Good Lives (EGL) vision and principles, and aims to give disabled people and their whānau:

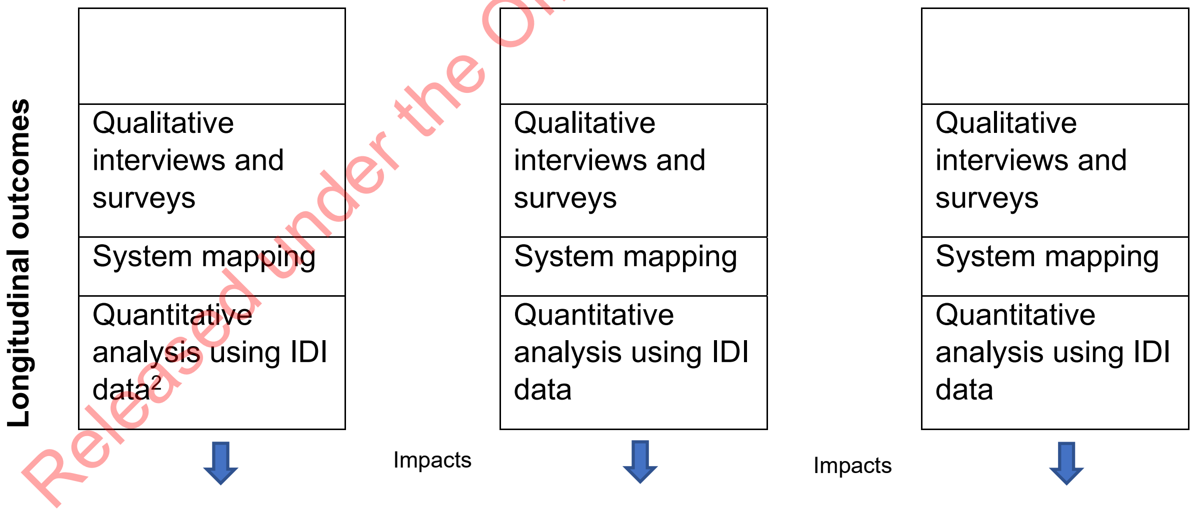
- more options and decision-making authority about their supports and lives
- to improve their wellbeing outcomes
- and to create a more cost-effective disability support system.

Evaluation context

Mana Whaikaha will require ongoing evaluation to help everyone understand if its objectives are being achieved, where improvements are needed and if and how the approach should be adapted or expanded.

A high-level evaluation approach was developed, with advice from the Monitoring and Evaluation Working Group, as part of the overall work programme for designing the MidCentral area prototype.

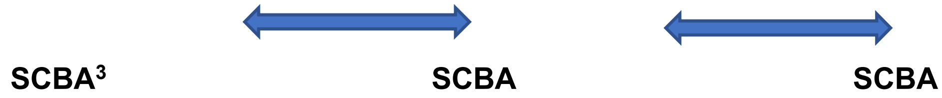
Overview of the evaluation framework



---

[1] For information about Mana Whaikaha and the MidCentral area trial, see www.manawhaikaha.co.nz/about-us/mana-whaikaha/.

[2] The IDI stands for the Integrated Data Infrastructure. The IDI is a linked longitudinal dataset that combines unit-record administrative information from a range of agencies and organisations. The IDI is maintained by Statistics New Zealand under strict privacy and confidentiality protocols.



As shown in the diagram on the previous page, the evaluation has two key inter-related components:

- Longitudinal outcomes evaluation
    - to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau
    - to determine how the system is changing over time and to what effect
- Social cost benefit analysis (SCBA) to value the impact of Mana Whaikaha.

In addition, a developmental evaluation will be used to support the 'Try, Learn and Adjust' approach being adopted for Mana Whaikaha, and to help drive meaningful change throughout the prototype period.

The Baseline Study reports include information from the qualitative interviews, surveys and system mapping parts of the evaluation (the components in the diagram on the previous page, highlighted in green).

2. Why we did a Baseline Study

With change about to happen, we wanted a clear picture of how things were before the change started.

The Baseline Study describes and measures what was happening before Mana Whaikaha started on the 1st October 2018. Having this information means we can repeat the study and find out what has changed as a result of doing things differently.

---

[3] Social Cost Benefit Analysis.

3. What the Baseline Study looked at

The overall Baseline Study had three main objectives:

Objective 1: to develop a detailed ‘map’ of the current disability support system in the MidCentral area

Objective 2: to understand and measure the current experiences and life outcomes of disabled people and whānau in the MidCentral area

Objective 3: to identify what support is needed to help disabled people, whānau, service providers and community-based organisations in the MidCentral region prepare for system change.

This report focuses on responses to the following questions:

- How whānau experience the current disability support system and what impact does it have on their lives?
- How well does the current disability support system support whānau to live the lives they want?
- Do whānau experience the current disability support system differently? If so, how and why?
- What life outcomes are whānau achieving under the current disability support system?
- What is most important to whānau in creating a life they want?

4. How we did the Baseline Study

The Baseline Study was made up of six types of work:

1. Talking with disabled people
2. Talking with whānau
3. Surveying service providers
4. Surveying people who worked for service providers (workforce survey)
5. Talking with people who worked for a range of government agencies and other stakeholders, eg Disabled Persons Organisations (DPOs).
6. Reviewing documents that described the disability support system.

The whānau survey gathered the views, experiences and opinions of family, whānau, spouse/partner, welfare guardian, and advocates in the MidCentral area prior to the introduction of the new system (Mana Whaikaha).

The disabled persons survey is reported on separately, but involved 172 individuals with learning and physical impairments, and people with Autism Spectrum Disorder (ASD).

Disabled people were asked for permission for their whānau member to also take part in the survey. Where permission was not obtained or no whānau were available, the remaining sample were drawn at random from legal guardians (welfare guardians or whānau of people under 18 years of age) who were not part of the disabled persons survey.

The survey involved a number of sections that attempted to review important things relating to personal experiences of the service system. These criteria were based on other survey tools in the sector and on documents such as Enabling Good Lives (EGL). EGL has the guiding principles behind the development of the new system.

The Baseline Study information gathering took place between early August and late September 2018.

During the interviews whānau worked their way through the survey with an experienced interviewer.

The survey included open ended (long answer questions) and some where people gave scores on a five-point Likert scale. Whānau were encouraged to say whatever they wanted in addition to the survey questions.

The interviews were confidential. All the information was put together to create a picture of what life was like before the changes happened.

5. Defining some key words or terms used in this report[4]

Term or word		In this report, the word means:
Whānau		family, whānau, spouse/partner, welfare guardian and advocates
Disabled people		people with a physical, intellectual or sensory disability who were clients of the Enable New Zealand Needs Assessment and Service Coordination service (NASC)
Residential services/homes		a community residential support service funded by Disability Support Services, Ministry of Health (unless specifically stated otherwise)
Disability Support Services		Ministry of Health funded Disability Support Services
MidCentral Area		The MidCentral area has the same geographic boundaries as the MidCentral District Health Board (DHB) which is a North Island DHB area that covers from Otaki / Te Horo in the south, to Apiti north of Sanson in the north and Dannevirke and south-west to the west coast.
Very High Needs (VHN)		Very High Needs refers to a level of support, where people are identified as having multiple and significant challenges with daily living activities. The support required is likely to be intensive. The level is identified through the NASC process and based on a facilitated needs assessment. The level was developed as a consistent way to describe a person's total disability support level for their service package allocation.
Subjective Wellbeing (SWB)		A measure of a person’s own perceived life satisfaction or happiness.

---

[4] Also see Glossary of abbreviations and terms, page 76

6. Method of analysis

The main method of analysis of survey items was the use of frequencies (percentages) for each question. Where comparisons are made between groups for specific questions, a simple significance test was used to tell us if the difference between each group was actually a clear or statistically significant difference. We used the Wilcoxon Mann-Whitney (WMW) test for non-parametric statistics for this purpose. Further information about this methodology is available on request.

On some occasions we grouped some questions together and used averages. This was particularly the case if we were looking for general trends in similar questions, such as 'satisfaction' with support services. *These grouped questions are only a guide or a taster* as to show an overall trend. However, because individual questions are asking different constructs, it is important to consider each question individually before forming conclusions. Construct validity stresses the need to consider what a question is measuring or what construct it is measuring. When grouping similar questions together within a loose heading, such as 'satisfaction with support services overall', the construct 'satisfaction with support services', is much more loosely defined and thus is only a guide or a suggestion of overall satisfaction.

On other occasions we reported averages for questions that provided a range of responses (continuous or non-discrete responses).

Satisfaction and wellbeing – cautions when interpreting some subjective results

Satisfaction is a difficult concept to define. It can be relatively objective in terms of having something tangible, such as equipment, or it can be more subjective, in terms of satisfaction with staffing. Satisfaction can include thoughts such as how 'happy' a person is or how 'pleased' they are with something.

When we talk about satisfaction in this report, we are only referring to how people view the supports that are provided through/after their needs assessments with Enable (the local needs assessment and service coordination service or NASC) and prior to Mana Whaikaha starting on October 1st, 2018.

Measures relating to satisfaction with services may be reported as a grouped or overall suggestion of satisfaction. However, individual questions each ask a unique construct of their own which added together may not provide a sufficiently definable construct of satisfaction, especially in a survey (as contrasted with a normative tool). For this reason, grouped responses to satisfaction are balanced against individual responses to specific questions, and in relation to who is making the response.

Wellbeing is a subjective indicator that asks people about their personal life satisfaction or happiness.

7. Who contributed to the survey

Disabled people and their whānau, who were clients of the Enable New Zealand Needs Assessment and Service Coordination Agency (NASC), contributed to this survey.

Enable New Zealand was the NASC for the MidCentral area until the launch of Mana Whaikaha on October 1st, 2018. Enable is governed by the MidCentral DHB and is overseen by the Enable New Zealand Governance Group.

According to the Ministry of Health's website[5], to be eligible to receive funding from Disability Support Services, and become a client of the NASC, people need to "have a physical, intellectual or sensory disability (or a combination of these) which:

- is likely to continue for at least 6 months
- limits their ability to function independently, to the extent that ongoing support is required.

These are mainly younger people under the age of 65 years.

The Ministry will also fund DSS for people with:

- some neurological conditions that result in permanent disabilities
- some developmental disabilities in children and young people, such as autism
- physical, intellectual or sensory disability that co-exists with a health condition and/or injury".

This survey involved a total of 152 face-to-face or telephone interviews with whānau who had whānau members using disability support services in the MidCentral Area.

---

[5] https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services.

8. Interesting things we discovered

☑ **Overall it appeared that the whole group of whānau were relatively satisfied for their family member (63%).**

☑ **In particular, whānau who were NOT supporting a disabled person in their own home were generally most satisfied with services overall (81%) and were most satisfied with their personal wellbeing.**

↓

☒ **However, this group were also less convinced they had control over the supports that were provided and indicated that the disabled people they represented had poor choice and control in their life and with regard to their supports.**

This group also indicated contentment with services or gratitude for services being available.

☑ **55 percent of whānau who were supporting at least one disabled person in their own home indicated they were generally satisfied with services overall and were 'somewhat' satisfied with their personal wellbeing.**

BUT

☒ **Forty-five percent of whānau supporting at least one disabled person in their home were less than satisfied with services overall.**

↓

☒ **These results were mirrored in all questions relating to service satisfaction.**

☒ **This group of whānau indicated poor satisfaction with their own lives (wellbeing) or their quality of life.**

☒ **This group of whānau provided indicators of more stress factors in their lives, such as having time for themselves and other family members.**

☒ **This group of whānau were less convinced they had sufficient support and believed services were rigid, siloed or inflexible. They also indicated they had difficulty securing paid carers.**

9. Where we found whānau survey participants

Just over half the sample (57 percent) involved whānau, welfare guardians or partners/spouses of people who had been involved in the disabled persons survey.

The remaining sample was drawn from all 77 welfare guardians in the MidCentral DSS data as at July 2018 (16 percent of this group) and sampled from all 405 whānau of children and young people under the age of 18 years (11 percent of this group).

Whānau were close supporters of 87 people with learning disability (57 percent), 12 with physical disabilities (8 percent) and 44 people with ASD (30 percent)[6].

Whānau also were close supporters of 69 children and young people (45 percent of all disabled people being represented by whānau).

Sample bias

Because of the selection process, the sample has a bias toward the whānau of children and young people (under the age of 18). Forty-five percent of the whānau survey group represent children and young people compared with twenty-four percent of the whole MidCentral DSS population (data supplied by DSS, July 2018)[7].

Who were the whānau respondents?

Eighty-two percent of the whole group indicated they were female and 16 percent indicated male. The remaining three identified as gender diverse.

Table 1 indicates that the majority of respondents were parents, followed by siblings and a person's spouse or partner.

Table 1: How respondents were related to disabled people[8]

Parents (including foster parents)	74.5%
Grandparents	2.9%
Siblings	10.3%
Other Whānau (aunt/uncle etc)	2.9%
Spouse/partner	6.6%
Advocates/friends	0.7%

Because most respondents were whānau members or spouses/partners, we refer to the survey generally as the whānau survey.

---

[6] The remainder (6 percent) were unclear or had multiple people with disabilities in the same home.
[7] The proportion of children and young people in the disabled person survey was 22 percent.
[8] Only 136 people offered clear responses with regard to their relationship with the person.

Sixty-seven percent of all respondents in this survey were married or lived with a partner. The remainder were single (14 percent), divorced (9 percent) or were a widow/er (10 percent).

Three main groups

During this analysis we divided whānau responses into three different groups:

- the whole group, 152 people
- whānau who did not support disabled people in their own home, 42 people
- whānau who did support disabled people in their own home, 106 people[9].

The average age for all participants was between 50 and 54 years, but there were variations in age dependent on whether the respondents supported a disabled person in their own home or if they did not. In particular, the average age of participants who were not supporting at least one disabled person in their own home was older, 65 to 69 years (range 50 to 80 years). For those supporting at least one disabled person the average age was younger, 45 to 49 years (range 15 to 79 years).

---

[9] Four people did not give enough information to slot them into either of these groups.

10. Whānau who supported at least one disabled person in their own home

The group was further divided into whānau who were supporting at least one disabled person in their own home, and who indicated overall satisfaction with support services based on one question (often referred to as Question 22), and those who were less satisfied.

Table 2: Overall supports work well for my family member – Always and Mostly responses (responses to Question 22)

	All whānau, guardians, etc	**Do not** have disabled people living in their home	Supporting a disabled person(s) in their home
Overall supports for my family member work well	63.4%	80.5%	55.1%

Table 2 suggests whānau who were supporting at least one disabled person in their own home were less satisfied with services overall. Dividing this group into people who were ‘mostly’ and ‘always’ satisfied with services (called the satisfied group) and those who were ‘somewhat’, ‘not really’ and ‘never’ satisfied with supports overall (the less satisfied group), we were able to make a number of distinctions.

☑ **Eight-one percent of whānau, who do not have a disabled person living at home with them, indicated they were satisfied with supports for their family member.**

☒ **Only 55 percent of whānau, who did support at least one disabled person in their own home, were satisfied overall with supports for their family member.**

Table 3: ‘Overall supports for my family member work well’; whānau who were supporting at least one disabled person in their own home (responses to Question 22)

	Satisfied with Services overall **Mostly / always**	Less satisfied with Services overall **Somewhat/ not really/ no/never**
Overall supports for my family member work well	55%	45%

n=53	n=44
average 45-49 years	average 45-49 years
19% Maori	18% Maori
30% unemployed	49% unemployed
68% married or with partner	68% married or with partner
83% female	82% female

There are few differences in terms general characteristics (age, gender, ethnicity, marital status) between the two groups. However, there were differences in terms how many people were unemployed, with higher numbers for people who were less satisfied with services overall (based on question 22). Other differences between the two groups are noted in Table 4 below.

Table 4 indicates the 'less satisfied' group were characterised by respondents who predominantly supported children and young people (82 percent) and often multiple people with disabilities in the same household (21 percent). In addition, the group that were satisfied with services overall were more likely to be supporting at least one adult with disabilities, (47 percent[10]) in contrast to whānau who were less satisfied with services (30 percent[11]). There were few differences in the numbers supporting more than one child or young person in the same home, whether or not at least one of the children/young people was disabled.

Table 4: Composition of homes for whānau who are supporting at least one disabled person in their own home

	Satisfied with services overall n=53	Less satisfied with services overall n=44
More than one disabled person supported in the same home	7[12] 13.2%	9[13] 20.5%
Supporting at least one child and young person with and/or without disabilities	33 62.3%	36 81.8%
Supporting at least one disabled adult in the home (18+ years)	25 47.2	13 29.5
Supporting at least one disabled child/young person	30 56.6	33 75.0
Supporting more than one child/young person in the home	24 45.3%	21 47.7%
Supporting more than one child/young person in home including at least one disabled child/young person	22 41.5	17 38.6

There were more people with very high needs (VHN) and high assessed needs in the less satisfied group (74 percent), in comparison with whānau who were

---

[10] Three of these had a mix of disabled young people (under 18 years of age) and adults who were supported through DSS funding and two included more than one disabled adult.

[11] Two included a mix of disabled young people and adults, and one included more than one disabled adult.

[12] Including 3 children and young people only, two with adults only and two with adult(s) and children and young people.

[13] Including 6 children and young people only, one with adults only and two with adults(s) and children or young people.

supporting disabled people in their own home and who were satisfied with services overall (54 percent)[14].
This comparison is important as it effectively provides five different groups to consider when reviewing the survey findings. These include:

1. All 152 participants in the whānau survey
2. Participants who were **not** supporting at least one disabled person in their own home
3. Participants who **were** supporting at least one disabled person in their own home – and of these:
   4. Participants who were supporting at least one disabled person in their own home but who **were satisfied with services overall**
   5. Participants who were supporting at least one disabled person in their own home but who **were less satisfied with services overall.**

---

[14] These figures are based on each person associated with a whānau or guardian who were chosen at random from the Enable client data base. Information about people in the household (with or without disabilities) and presented in Table 4 was gathered from the survey itself.

11. What whānau think about their lives

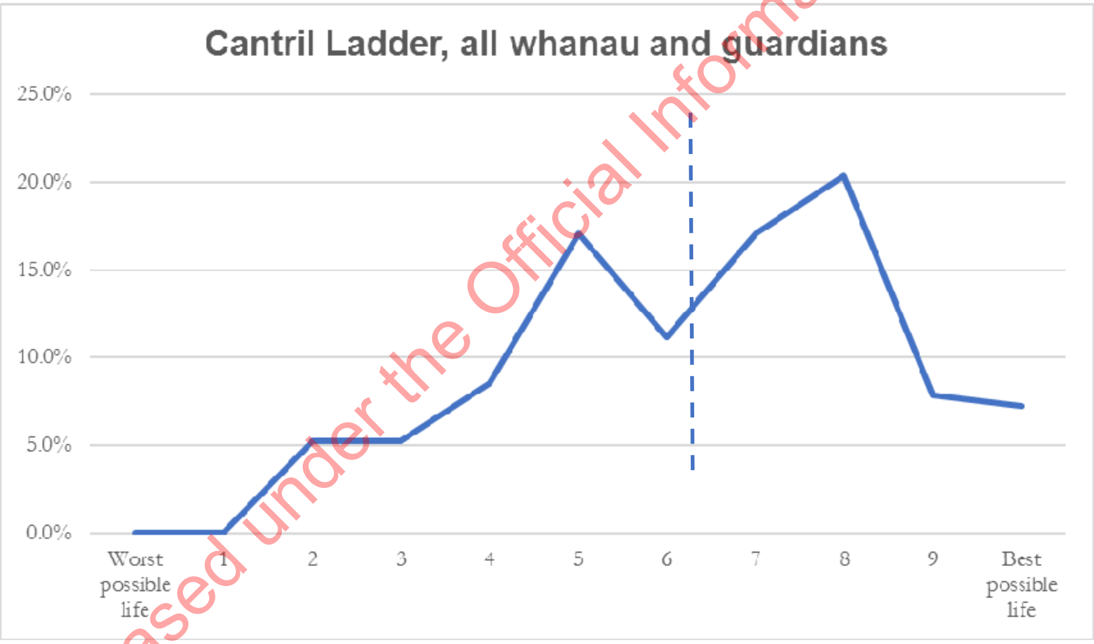
Subjective wellbeing measures how satisfied or happy a person is with their own life.

The whānau survey had three questions relating to subjective wellbeing (SWB).

The first was the Cantril Ladder[15]. This ladder asks people to rate where they would place themselves on an eleven-point scale where zero is the worst possible life they could imagine, and 10 the best.

The overall results for all whānau responses to the Cantril Ladder are presented in Figure 1. It indicates a slight bimodal distribution (twin peaks or clues of two distinct groups) with an average rating of 6.3 (SD 2.1).

Figure 1: Cantril Ladder for all whānau



(VERTICAL DOTTED LINE=MEAN/AVERAGE)

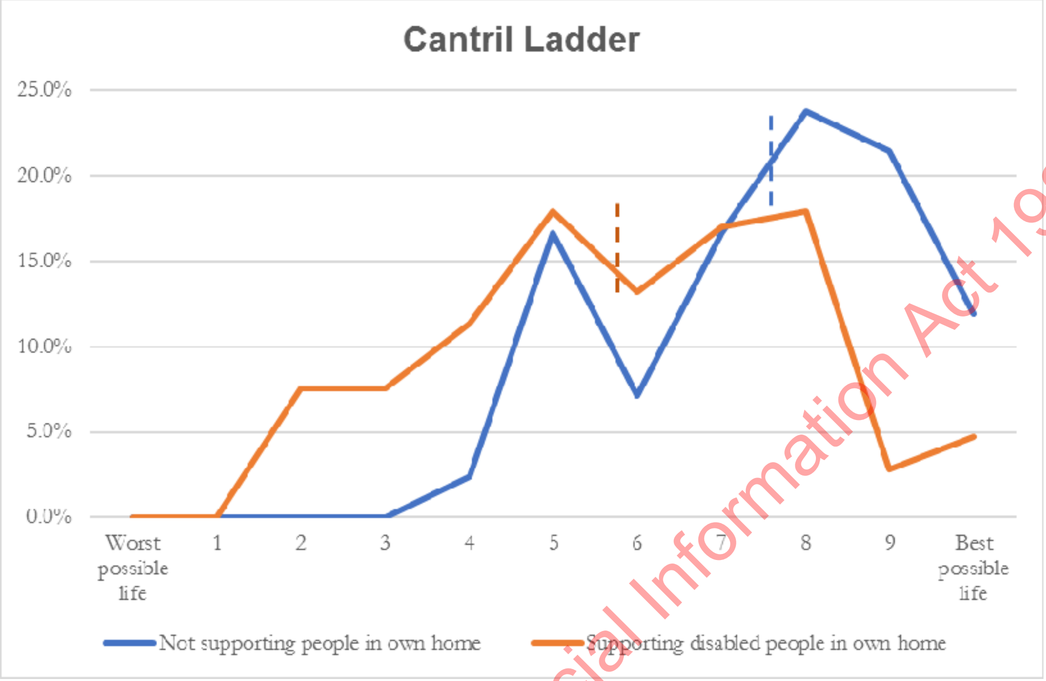
Differences between whānau who were supporting people in their own home and those who were not supporting people in their own home is the source of the twin peaks. Figure 2 indicates whānau who were not supporting disabled people at home scored themselves higher on the Cantril Ladder (average 7.5, SD 1.7) when

---

[15] The Cantril Ladder is a simple SWB indicator that is used internationally. Gallup World Poll (Bjørnskov, C. 2010. How Comparable are the Gallup World Poll Life Satisfaction Data? *Journal of Happiness Studies*, *11* (1), 41-60.

contrasted with whānau who were supporting at least one disabled person in their own home (average 5.8, SD 2.1)[16].

Figure 2: Cantril Ladder, whānau with and without disabled people in their own home



(VERTICAL DOTTED LINES=MEANS/AVERAGES)

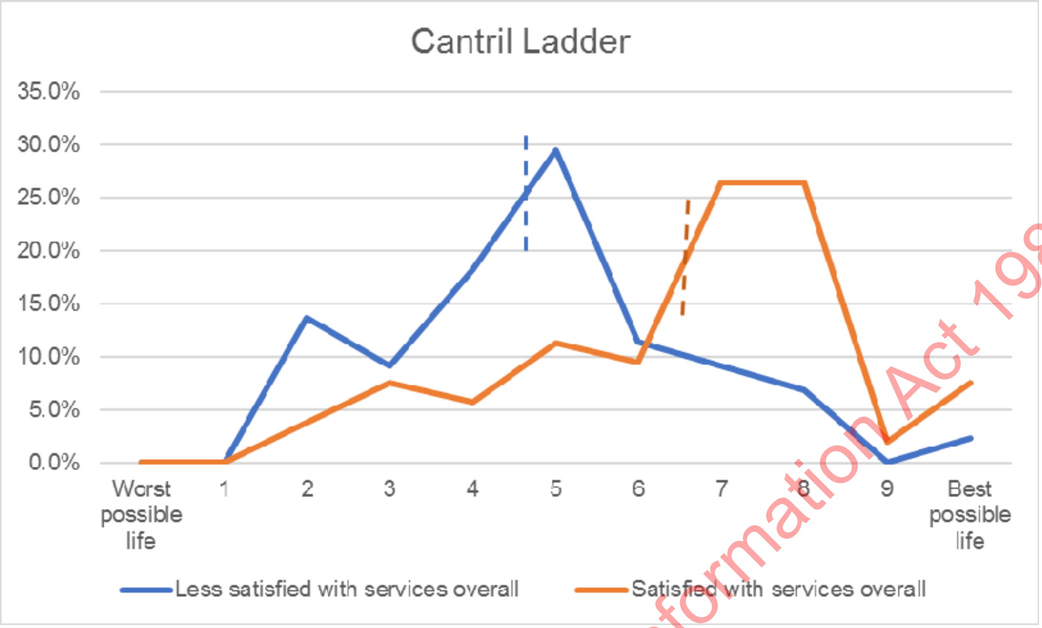
☒ **Whānau supporting disabled people in their own home had poorer perceived subjective wellbeing (SWB) than whānau who were not supporting a disabled person in their own home.**

If we divide the group who were supporting people in their own home, according to their satisfaction with services overall, we can see the source of a second bimodal distribution (twin peaks). Figure 3 indicates that whānau, who were supporting people in their own home and who were less satisfied with services overall, were scoring lower on the Cantril Ladder (average 4.8, SD 1.8). This is in contrast to whānau who were satisfied with services (average 6.5, SD 2.0)[17]. This suggests that satisfaction with services overall may be a factor when considering subjective wellbeing using the Cantril Ladder.

---

[16] WMW=4.5, *p*<0.001, df=95, diff in mean=1.7, *t*=5.2, *p*<0.001.
[17] WMW=4.1, *p*<0.001, df=94, diff in mean=1.7, *t*=4.0, *p*<0.001.

Figure 3: Cantril Ladder: whānau supporting people in their own home



(VERTICAL LINES=MEANS)

☒ **Perceived subjective wellbeing (SWB) for whānau supporting disabled people in their own home may be linked to their reported satisfaction with services overall (Question 22); those indicating less satisfaction scoring poorest overall on SWB.**

Two more questions focused on SWB in the whānau survey. Figure 4 indicates self-reported *quality of life* on a five-point Likert Scale. There were significant differences in the overall trend between those supporting at least one disabled person in their own home and those who did not[18]. However, the trend indicates a one third split between the two lower, two higher and central scores (33, 32 and 34 percent) for people who did support at least one disabled person in their own home, but a large central result for those who did not support at least one disabled person in their own home (ie neither good nor bad). This may be a function of the age of this group (see page 18).

Those supporting at least one disabled person in their own home, who were less satisfied with services overall, were generally less satisfied with their quality of life (68 percent). This is compared with people who were satisfied with services overall (44 percent)[19]. When both of the latter groups were asked if their quality of life had changed, compared with 12 months previously, there was very little difference between the groups. **This means that those who have indicated a poor quality of life in Figure 4 have considered their quality of life to be poor for some time.**

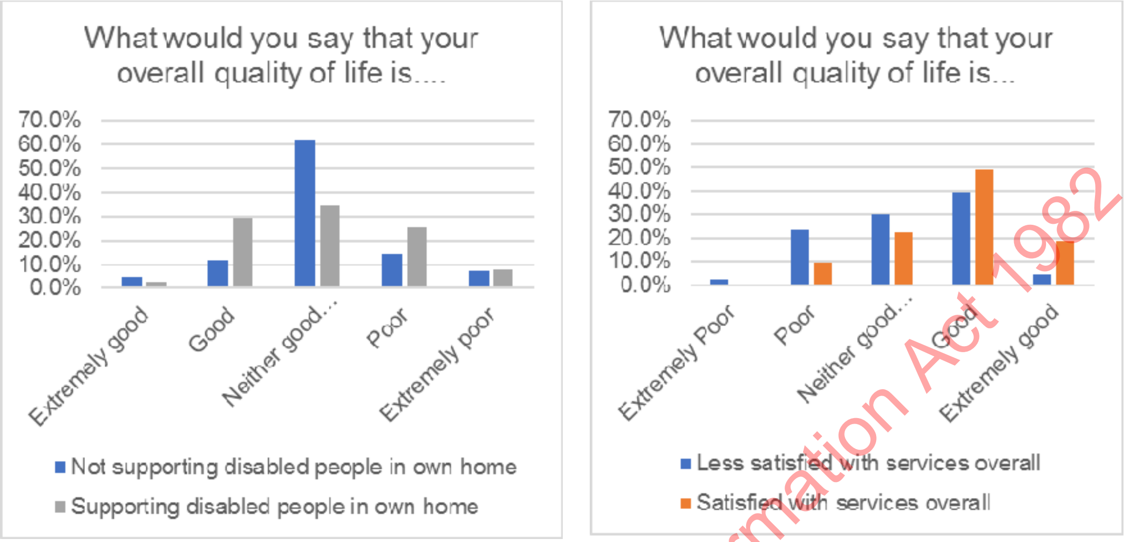
---

[18] WMW=4.0, $p<0.001$, df=103, diff in mean=0.7, $t=4.8$, $p<0.001$.

[19] WMW=2.8, $p<0.01$, df=76, diff in mean=0.6, $t=3.1$, $p<0.001$.

Open-ended questions or verbal descriptions provided valuable insight into the lives of these whānau.

Figure 4: Rated quality of life by whānau



12. What is important to whānau

Whānau described what was important in their own lives. Of the three most prevalent responses, listed in Table 5, the most common was family. References to family were more frequent for whānau who were supporting disabled people in their own home.

The average age of whānau who were not supporting people in their own home was between 65 and 69 years old whereas the average age of whānau who were supporting at least one disabled person in their own home was 45 to 49 years old[20]. It is possible that as whānau age they are more focused on the future support of the disabled person, especially as they are living away from home. Aging may also account for whānau considering their own health as an important consideration in their life.

Table 5: 'Thinking about your life, what is most important to you?', by whether or not whānau supported disabled people in their own home

		Supporting a disabled person(s) in own home	
	Not supporting a disabled person(s) in own home	Less satisfied with services overall	Satisfied with services overall
No response	4 9.5%	3 6.8%	2 3.8%
Family	19 45.2%	26 59.1%	35 66.0%
Health	7 16.3%	4 9.1%	6 11.3%
Future support & wellbeing of disabled person(s)	13 31.0%	7 15.9%	8 15.1%

---

[20] It was interesting to note that the majority of whānau and guardians, regardless of where the disabled person lived, were parents (72 percent of each group).

13. What whānau would like

Whānau were asked 'if anything were possible, what are some things you would like to achieve, start doing or do more of?'

Travel and holidays were the most frequent response by whānau regardless of whether they were supporting disabled people in their own home (Table 6).

Sometimes the range of dreams and aspirations of whānau took in a lot of detail as the next example indicates:

> *Do art classes, socialise, be able to visit people, have regular time out, breaks – go on holiday, have time relaxing – spend time with my grand-children – have fun times with my [disabled] son.*

However, Table 6 also indicates that having time to self and family, seeing friends and having time to socialise were raised more often by whānau who were less satisfied with services overall and supported at least one disabled person in their own home.

A theme running through many statements was time:

> *Just more TIME for myself (to be more social with friends, have some hobbies). HEALTH, both physical and mental has deteriorated due to having NO time to relax. Cannot leave my two family members [to be] responsible for themselves. Would improve with better support and I could have some "ME" time.*

Table 6: What are some things you would like to achieve, start doing or do more of, by whether or not whānau are supporting disabled people in their own home

		Supporting a disabled person(s) in own home	
	Not supporting a disabled person(s) in their home	Less satisfied with services overall	Satisfied with services overall
No response	20 47.6%	4 9.1%	10 18.9%
Vacation/holiday	10 23.8%	11 25.0%	11 20.8%
Time for self, time to relax, time	3 7.1%	14 31.8%	9 17.0%
Time for family, other children, husband	2 4.8%	12 27.3%	7 13.2%
Seeing friends	1 2.3%	5 11.4%	3 5.7%
Socialising, having social life	3 7.1%	7 15.9%	3 5.7%
Work, employment	0 0%	8 18.2%	11 20.8%
Study, classes, courses	0 0%	4 9.1%	4 7.5%
Future support & wellbeing of disabled person(s)	4 9.5%	3 6.8%	6 11.3%
Hobbies, activities (varied)	4 9.5%	10 22.7%	5 9.4%

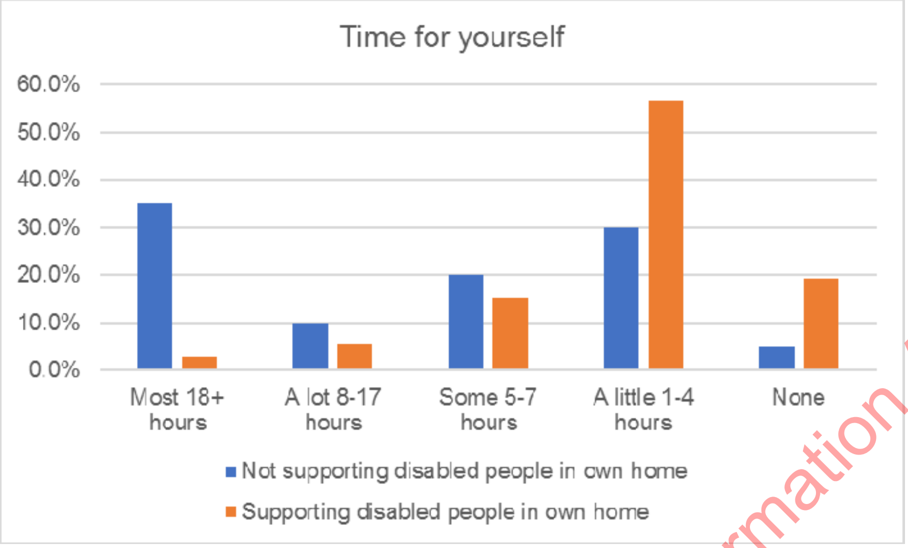
Time for self

Whānau supporting disabled people in their own home indicated far fewer hours spent for themselves (Figure 5). Notably,19 percent of this group indicated no time for themselves[21]. Having time for oneself and having time for other members of the family were important goals for many whānau who were supporting disabled people in their own home. This was more so for whānau who were less satisfied with supports overall.

---

[21] WMW=5.0, *p*<0.001, df=54, diff in mean=1.2, *t*=5.2.

Figure 5: How much of your average week day is spent doing things for yourself, whānau with and without disabled people in their own home



An important aspiration raised by whānau, who were supporting disabled people in their own home and who were less satisfied with services overall, concerned 'having a normal life'. There was a desire to be less stressed or to have an improved sense of wellbeing. One whānau indicated a need for:

> *More 'time out' and having a reliable support network… for mental wellbeing.*

Another whānau member provided a very similar response in stating a desire to:

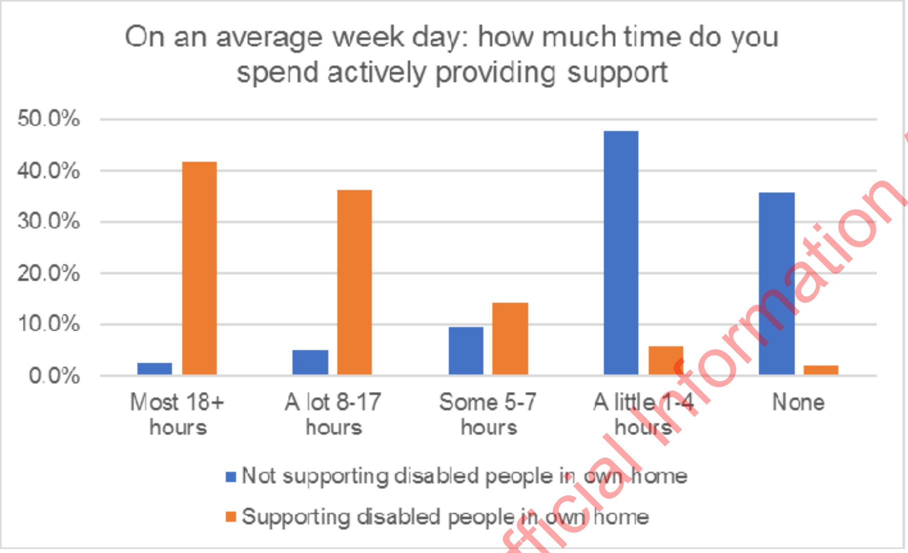
> *Spend more time outdoors. Have access to good overnight care… [because we] miss things, a normal life. Things that other parents of a ten-year-old could expect.*

Stress factors were cited regularly by those who were less satisfied with services. Over half the whānau, who were less satisfied with services and supported at least one disabled person in their own home, indicated they had little time for themselves or their family in general in verbal responses (55 percent). Many indicated stress was a constant feature, with tiredness and ongoing responsibility being a particular concern. For example, when asked what was most important in their own life, one whānau member stated:

> *To have some time off and [I need to] recover from tiredness and be able to make plans for my daughter's future. [It's] so hard to plan or see a future when I'm tired. [I] haven't seen my elderly family for years; also, my grandchildren. I have grandchildren I have never met.*

Figure 6 illustrates whānau who were supporting at least one disabled person in their own home were far more involved with their daily support than whānau who do not support a disabled person in their own home[22]. There were, however, no notable differences for whānau who did have disabled people in their own home as the hours of support are nearly identical.

Figure 6: On an average weekday, how much time do you spend actively providing support (ie, active supervision and caring responsibilities), by whether whānau supporting people in their own home



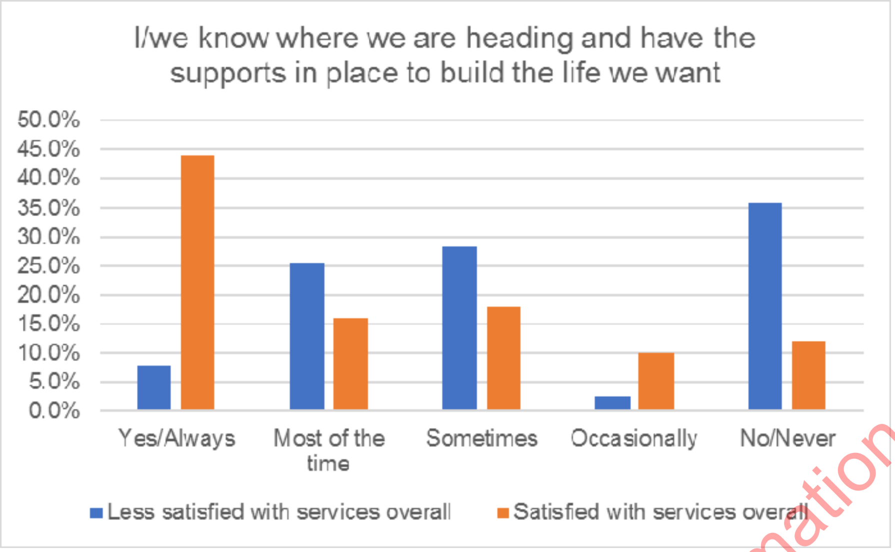
One question asked how supports assist whānau to build the kind of life they wanted. Whānau who were less satisfied with services were more likely to respond negatively to this survey item (Figure 7)[23]. A difficulty with this question was the two parts to the statement. One part focuses on whether whānau believe they 'know where they are heading' and the second, that they 'have the supports in place to build the life they want'. In either event, Figure 7 shows the two groups are significantly different in their pattern of responding.

---

[22] WMW=8.1, p<0.001.

[23] WMW=3.4, p<0.001, df=165, diff in mean=1.0, t=3.4, p<0.001.

Figure 7: We know where we are heading and have the supports in place to build the life we want, for whānau who are supporting disabled people in their own home



A theme for whānau, supporting at least one disabled person in their own home, concerned the degree to which they experienced stress in their own lives and how much this was influenced by their caring responsibilities and how supported they felt.

14. Goals, dreams and aspirations

Three questions in the survey asked whānau to describe the following:

1. Thinking outside your supports, is there anything stopping you from achieving your goals?
2. Thinking about your life, what is most important to you?
3. If anything were possible, what are some of the things you would like to achieve, start doing, or do more of?

Barriers to achieving goals

Whānau, supporting at least one disabled person in their own home, were more likely to mention their caring responsibilities as a barrier to them achieving their goals (Table 7).

Non-responses to 'is there anything stopping you from achieving your goals?' are noted in Table 7. Whānau, who were supporting at least one disabled person in their own home and who were less satisfied with services overall, were most likely to respond to this question. Non-responses can indicate that either whānau did not perceive any barriers to them achieving their goals, or they did not have any goals.

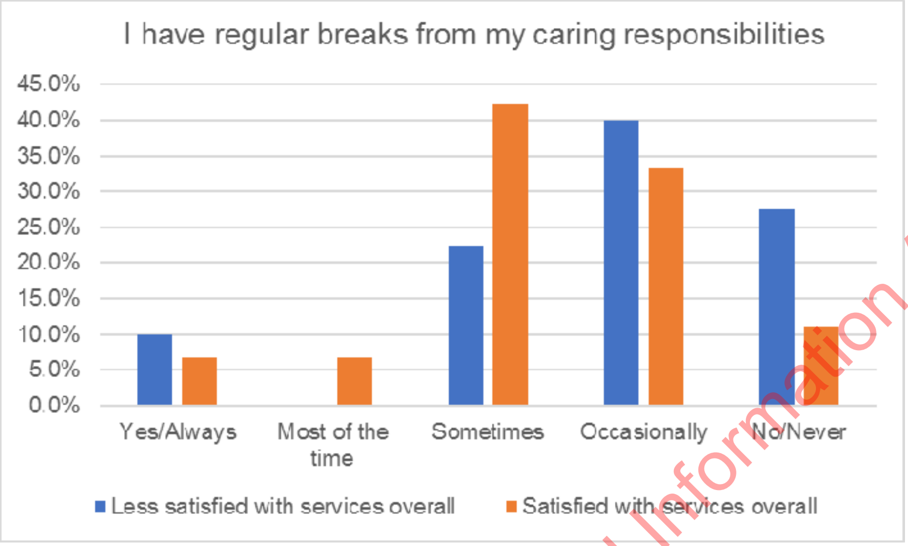
Table 7: Is there anything stopping you from achieving your goals? Whānau both supporting and not supporting a disabled person in their own home

		Supporting a disabled person(s) in own home	
	Not supporting a disabled person(s) in their home	Less satisfied with services overall	Satisfied with services overall
No response	26 61.9%	8 18.2%	22 41.5%
Responsibility of supporting a disabled person(s)	4 9.5%	24 55.0%	16 30.2%

Notable in Figure 8 is the number of whānau who did not believe they got regular breaks from their caring responsibilities. Closer scrutiny indicates that 42 percent of whānau, who were generally satisfied with services (Question 22), believed that they "sometimes" got a break from their caring responsibilities. This compares to 23 percent of those who were less satisfied with services.

Sixty-eight percent of those who were less satisfied with services did not believe they got regular breaks from their caring responsibilities (at all or occasionally). This compares with 44 percent of those who were satisfied with services overall[24].

Figure 8: I have regular breaks from my caring responsibilities, whānau who are supporting disabled people in their own home[25]



A previous comment from whānau highlighted getting a break can include having time to catch up on sleep. Sleep is a big issue for many whānau[26], one person noted with reference to the carer support subsidy:

> *Twelve days a year – not much money – $9.00/hr[27]. People [are] not willing to work for that amount. [I] wanted to employ someone to look after him and have a break… [I work] nightshift. Not much sleep… No family in NZ[28].*

Another parent said in reference to her child:

> *[She] can't cope with sounds. [She's] awake all night sometimes. [She] sleeps with headphones.*

A review of Figure 8 indicated whānau, who were supporting at least one disabled person in their own home, did not generally believe that they had a break from their caring responsibilities (only 11 percent)[29]. This reflects the stress felt by whānau

---

[24] WMW=2.1, $p<0.02$, df=77, diff in mean=0.38.

[25] This question was not asked of whānau who were not supporting at least one disabled person in their own home so no comparison between those who were and those who were not supporting a person at home was possible.

[26] As will be discussed again in the following sections.

[27] Appears to be based on the $76 per day subsidy payment (for 8 hours).

[28] The open-ended questions were either answered by the whānau directly (by writing on the form themselves) or responses were written down by the interviewer who then checked the response with the person. In both cases, responses can appear abbreviated as a result.

[29] WMW=2.1, $p<0.02$, df=77, diff in mean=0.38.

supporting disabled people in their own home. It may also explain why caring responsibilities were cited as the main barrier for whānau, who were supporting disabled people in their own home, from achieving their goals (in Table 7).

One question asked whānau whether contact with the disability support system helped them achieve their goals.

Figure 9: Contact with the disability support system helps us achieve our goals, by whether whānau are supporting disabled people in their own home

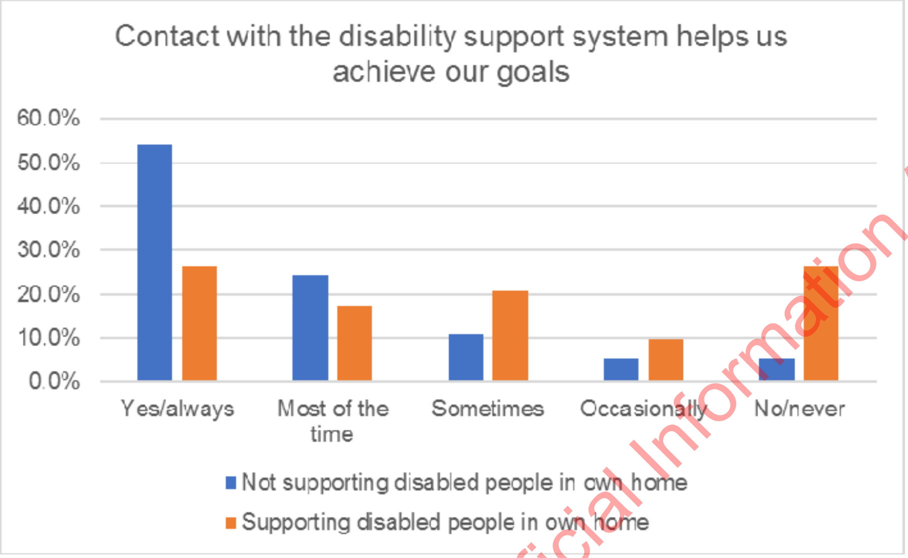


Figure 9 indicates:

☑ **Over 50% of whānau who are not supporting a disabled person in their own home believed contact with the disability support system definitely helped them achieve their goals (54 percent, 'yes/always').**

☒ **Responses from whānau who did support at least one disabled person in their own home was mixed, with a quarter indicating that contact with the disability support system <u>definitely did not</u> help them achieve their goals (26 percent, 'no/never')[30].**

---

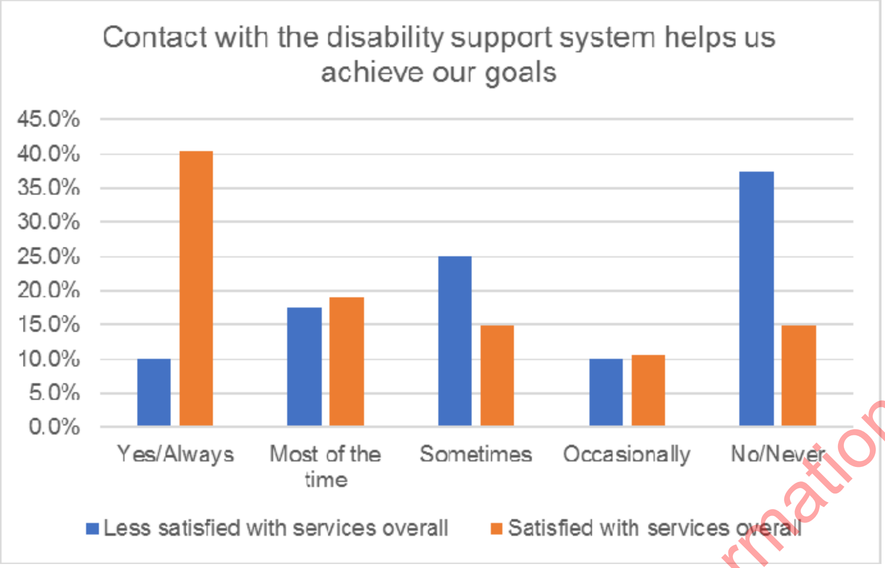
[30] WMW=3.9, *p*<0.001, df=91, diff in mean=1.1, *t*=4.6, *p*<0.001.

Figure **10** reveals those least likely to agree with the statement, ‘contact with the disability support system helps us achieve our goals’, were whānau who were less satisfied with their supports overall[31].

---

[31] WMW=3.3, $p<0.001$, df=175, diff in mean=1.1, $t=3.4$, $p<0.001$.

Figure 10: Contact with the disability support system helps us achieve our goals, whānau who were supporting disabled people in their own home



☒ **Thirty eight percent of whānau who were supporting at least one disabled person in their own home and who were less satisfied with services overall did not believe supports helped them achieve their goals (at all).**

15. Employment and income

☒ **Forty-four percent of the whole whānau group had a combined household income of $40,000 or less. This rate did not vary between the different groups.**

- 13 percent had a household income of over $100,000[32].
- The median for all whānau was between $40,000 and $50,000[33].

In many situations, whānau who were supporting a disabled person at home talked about needing to have someone at home. This was particularly the case for whānau with school age children as there needed to be someone home before and after school, during school holidays (in particular) and when the disabled child/young person was sent home from school due to sickness or behaviour issues.

Employment versus carer responsibilities

An economic issue for whānau can occur if a carer gives up work in order to support a disabled person.

Giving up work to become a carer has significant issues for whānau. Particularly where there is only one carer and in situations where one partner in a relationship has had to give up a career and/or income to support a disabled person.

In one of the families taking part in this survey, both parents had to give up professional work due to the needs of the children in the home. In another situation, where one parent reported needing to give up their employment, the household income was effectively halved (down to $45,000).

---

[32] Note: 67 percent of all people completing the whānau survey lived with a partner/spouse who may or may not be employed.

[33] The average for the respondents taking part in these surveys was slightly higher at $50,000 to $60,000. The national median household income (regular and recurring) for 2018 as calculated by Statistics New Zealand was $83,001 and the average was $105,109 nationwide (see https://figure.nz/chart/yiJz6VUr64vQ68Du and https://www.stats.govt.nz/information-releases/household-income-and-housing-cost-statistics-year-ended-june-2018). The median annual income (regular recurring) for the North Island (excluding Auckland and Wellington) was $68,600 as of June 2017 (average $84,115) https://www.stats.govt.nz/information-releases/household-income-and-housing-cost-statistics-year-ended-june-2017. Statistics New Zealand listed the gross national disposal income average in 2016 as $48,504 (per person) http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-progress-indicators/Home/Economic/disposable-income.aspx with poverty indicators set at below 50 and 60 percent of the median disposable income per person. This equates to 10 and 18 percent of New Zealanders respectively falling below that line. http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-progress-indicators/Home/Social/population-with-low-incomes.aspx.

In some situations, whānau reported that the disabled child/young person was only sleeping a few hours at night. This can significantly reduce the ability of one caregiver (or both) to work. Sometimes, this was due to whānau needing to catch up on sleep while the child/young person was at school. School holidays for these individuals were particularly difficult.

Many whānau reported concerns regarding the lack of before and after school support and holiday support. One person noted her son had missed a term of school because no one was available to support him for one hour prior to the time the school opened.

For some whānau the work-caring role was fraught with issues and concerns. Comments from whānau[34]:

> *When I am at work, I have a break. Carer support can't be used when you are working. Not flexible.*
>
> *No [I can't work]. Looking after my son, I couldn't work full-time – [he] can't stay on his own. [I] need someone to keep an eye on my son.*
>
> *My qualification is a counsellor but I have never been able to put it into practice!! [I want the] flexibility to have my own small business. [And] no pressure working for someone else. [I] wish MoH could support people with disabilities with transport – you can't have a good quality of life if you can't move safely around. Very frustrating.*
>
> *Would like to work more – not enough support to work full time – can't find support worker.*
>
> *I had to give up working to look after my children for 7-8 years because of their disabilities, which has impacted hugely on our financial situation. I now work part-time and find it difficult to find work.*
>
> *I would like a job that is part-time and I could work around my kids. More money would be good.*
>
> *Not enough hours for me to work and support my son. School holidays a problem with my new job. Worried about this. I can't take time off work.*
>
> *I would love to go back to work but can't because of my daughter's needs. I was on $120k before I had my daughter. She had so many hospital visits and appointments. I have to pick her up from school, health issues. I can't work because I need to be available for her.*
>
> *If he doesn't go to school, I take time off work.*

---

[34] Note – some comments were written by the respondents themselves and can appear abbreviated.

Thirty-two percent of all working age respondents were not employed at the time of the survey[35].

When isolated to whānau respondents, who were supporting people in their own home and who were less satisfied with their disability support services, the number indicating they were **unemployed rose to 49 percent**, compared with those who were satisfied with services overall (30 percent).

16. Māori whānau

Māori represented 15 percent of the whānau survey[36].

Three-quarters of this group believed their culture was respected all or most of the time. Of the four people who did not believe supports respected their culture, they also stated they did not believe the support system provided sufficient support for their whānau. In general, there were few differences between Māori and NZ European whānau in terms of their views of the supports they receive. For example, 63 percent of NZ European whānau believe supports worked well (all or most of the time) compared with 57 percent of Māori.

Unemployment rates for the respondents in this survey were higher for Māori (55 percent) compared with NZ Europeans (38 percent).

Four of the eleven Māori who were not in paid employment were single carers and all but one of those not employed were supporting children and young people at home. Three people had more than one child with a disability, and seven supported from two to seven children or young people in their home.

---

[35] The employment rate in New Zealand in the third quarter of 2018 was 68.3 percent with an official unemployment rate of 3.9 percent https://tradingeconomics.com/new-zealand/employment-rate.

[36] N=22 Maori whanau, and n=118 NZ European. Eleven people identified as neither Māori or NZ European (7 percent) and one person did not respond to this question.

17. Satisfaction with disability support services

To date we have been referring to satisfaction with support services in relation to one question, “overall supports for my family member work well” (or Question 22). In total, there were 22 questions that related to satisfaction with support services. The next three tables reveal that people who were not supporting disabled people in their own home were generally more satisfied with services across most of the 22 satisfaction questions (average 73 percent, SD 13 percent), when compared with whānau who were supporting at least one disabled person in their own home (57 percent, SD 16 percent).

There were a set of positive responses from all three groups to five of the satisfaction questions. Table 8 indicates that whānau seemed to believe that support services were respectful of them and their views. They also seemed reasonably positive about support workers if they were utilised.

Table 8: Positive responses to questions concerning satisfaction with support services, yes/always and mostly responses

✓	All whānau, guardians, etc	Do not have disabled people living in their home	Supporting a disabled person(s) in their home
I feel welcomed by the supports/services we use[37]	80.0%	85.7%	78.1%
I believe my views are valued by supports/services	75.2%	70.7%	77.8%
Supports respect our culture	86.2%	81.1%	88.2%
Supports value our preferences	70.5%	75.6%	68.0%
Paid support workers are reliable and consistent	73.4%	80.6%	71.6%
	n=152	n=42	n=106[38]

---

[37] Whānau who do and do not support disabled people in their own home, WMW=2.8, $p<0.001$, diff in mean=0.4, student t statistic $p<0.01$.

[38] Four people gave unclear responses and were not included in either for the subgroups.

Three of the satisfaction questions indicated whānau who did not support a disabled person in their own home were less likely to believe that they had control over aspects of support (see Table 9 below).

Table 9: Autonomy and whānau supporting and not supporting disabled people in their own home, yes/always and mostly responses

	All whānau, guardians, etc	Do not have disabled people living in their home	Supporting a disabled person(s) in their home
We control and direct the supports that are needed[39]	64.8%	36.4%	74.4%
We can make changes to our supports as we need	60.3%	48.3%	64.0%
We choose who provides assistance for ongoing support[40]	63.9%	43.8%	71.3%

The majority of those who were not supporting a disabled person in their own home (68 percent) were whānau of people living in community residential homes (42 percent of whom were ex-Kimberley residents). In the disabled persons survey, people living in community residential homes were reporting (typically through proxy respondents) reduced autonomy in areas such as:

- control over their life
- their services
- who their staff would be
- with whom they lived.

The converse was true, however, for 14 of the remaining satisfaction questions. Table 10 indicates significantly reduced satisfaction for whānau who were supporting at least one disabled person in their own home as opposed to those who were not (significant across 13 of the 14 questions in Table 10).

---

[39] Whānau who do and do not support disabled people in their own home, WMW=4.0, $p<0.001$, diff in mean=1.3.

[40] Whānau who do and do not support disabled people in their own home, WMW=2.2, $p<0.025$, diff in mean=0.6.

Table 10: Questions relating to varied satisfaction with support services, yes/always and mostly responses

☒	All whānau, guardians, etc	Do not have disabled people living in their home	Supporting a disabled person(s) in their home	WMW Sign test Col. 3 & 4	Diff in mean
Easy to access and use	50.0%	73.0%	42.0%	3.7***	1.0^{+++}
Contact with the disability support system helps us achieve our goals	53.8%	78.4%	43.5%	3.9***	1.1^{+++}
Supports anticipate what I/we need	41.6%	69.7%	31.5%	3.1***	1.0^{+++}
Supports work when we want	58.2%	78.9%	49.5%	3.6***	1.0^{+++}
Supports enable us to do the things that are important to us	58.3%	76.9%	50.5%	3.5***	0.9^{+++}
I can access all of the information I need about support services	53.3%	69.2%	46.9%	2.9**	0.9^{+++}
I think information from support services is easy to understand	52.6%	78.9%	42.6%	3.7***	1.1^{+++}
We are supported to be connected to the community	39.2%	73.1%	29.3%	3.0**	0.9^{++}
Supports work when we want	61.2%	76.9%	54.1%	2.6***	0.7^{++}
Overall supports work flexibly	66.9%	78.4%	61.9%	2.6***	0.6^{++}
	63.4%	80.5%	55.1%	3.4***	0.9^{+++}
Our supports help us connect to people and places that are important to us	60.2%	83.3%	51.7%	2.5**	0.8^{++}
I/we know where we are heading and have the supports in place to build the life we want	60.0%	89.2%	49.0%	4.3***	1.2^{+++}
Our wellbeing benefits from contact with DSS	62.1%	76.3%	57.0%	1.9	0.5

$^{**}p<0.01$, $^{***}p<0.001$. Diff in mean student *t* statistics $^{+}p<0.01$, $^{+++}p<0.001$

Satisfaction with services for those who have a disabled person in their own home

Respondents who were supporting at least one disabled person in their own home were divided into two groups (based on Question 22[41]):

- those who were satisfied with services overall (yes/always and mostly) (55 percent of all those supporting people in their own home), and
- those who were less satisfied with services overall (somewhat to no/never)[42].

Table 11 shows the group who scored ‘yes/always’ and ‘mostly’ to the question highlighted blue, also provided higher satisfaction results across all remaining satisfaction survey items (average 75 percent, SD 16 percent) when contrasted to those who were less certain in their responses (average 36 percent, SD 18 percent). For all of these survey items the difference between the two groups was significant.

☒ **Whānau who were supporting at least one disabled person in their own home and who were less satisfied with service overall (Question 22) were consistently and significantly less satisfied with services across all other service satisfaction questions.**

---

[41] Question 22: “Overall supports for my family member work well”.

[42] WMW=8.7, $p<0.001$.

Table 11: Satisfaction with services (yes/always to mostly) for people supporting at least one disabled person in their own home, satisfied versus less satisfied groups

	Satisfied with services overall	Less satisfied with services overall[1]	WMW Sign test Col. 3 & 4	Diff in mean
I feel welcomed by the supports/services we use	94.0%	57.5%	4.3***	1.0^{+++}
I believe my views are valued by supports/services	88.2%	64.3%	3.7***	1.0^{+++}
Supports respect our culture	97.9%	73.5%	2.9**	0.9^{+++}
Supports value our preferences	83.0%	47.5%	3.7***	1.0^{+++}
Easy to access and use	64.7%	18.2%	4.1***	1.3^{+++}
Contact with the disability support system helps us achieve our goals	59.6%	27.5%	3.3***	1.1^{+++}
Supports anticipate what I/we need	44.9%	12.5%	3.8***	1.2^{+++}
Supports work when we want	77.4%	18.2%	5.7***	1.7^{+++}
Supports work how we want	82.7%	20.9%	5.8***	1.7^{+++}
Overall supports work flexibly	86.8%	31.0%	5.3***	1.6^{+++}
Supports enable us to do the things that are important to us	79.2%	14.3%	6.0***	1.8^{+++}
Paid support workers are reliable and consistent	90.9%	51.2%	3.7***	1.1^{+++}
We control and direct the supports that are needed	88.9%	59.5%	3.1***	1.0^{+++}
We can make changes to our supports as we need	82.2%	42.5%	4.0***	1.3^{+++}
We choose who provides assistance for ongoing support	87.0%	51.3%	3.9***	1.5^{+++}
	100.0%	0.0%		
I can access all of the information I need about support services	60.4%	30.0%	3.1***	1.1^{++}
I think information from support services is easy to understand	54.0%	29.3%	3.9***	1.3^{+++}
We are supported to be connected to the community	40.4%	12.8%	3.1***	1.0^{++}
Our wellbeing benefits from contact with the disability support system	74.5%	35.1%	3.5***	1.0^{+++}
Our supports help us connect to people and places that are important to us	73.9%	21.6%	4.0***	1.3^{+++}
I/we know where we are heading and have the supports in place to build the life we want	60.0%	33.3%	3.4***	1.0^{+++}
	n=53	n=44		

[1] Rated Question 22 as somewhat to not at all satisfied.

**$p<0.01$, ***$p<0.001$ Diff in mean student *t* statistics $^{+}p<0.01$, $^{+++}p<0.001$

Descriptions of service satisfaction

A question asked whānau to describe what supports had been like in a couple of words.

Table 12 lists the majority of the adjectives in a type of order, from fantastic/excellent to terrible/abysmal. Whānau, who did not support a disabled person in their own home and those who did and have indicated they were satisfied with services overall, provide a wider range of positive adjectives relating to supports than whānau who were supporting a disabled person(s) in their own home and who were less satisfied with services (the middle column).

Document 4

Table 12: If you were to describe what your supports have been like for you in a couple of words, what would they be? Word usage per group

Not at home	Disabled people at home and less satisfied with services	Disabled people at home and satisfied with services
Appreciative/Grateful 1	Appreciative/Grateful 1	Appreciative/Grateful 2
Fantastic Excellent Great Gold standard 8	Great 1	Fantastic Excellent Great Best A God-send Pretty awesome 81
Peace of mind 2		
Happy 2		
Excellent communication		
Very good 5		Very good 1
Pretty Good 1	Supportive 1	Great support & Supportive 2
		Pretty Good & Very adequate 2
Good 5		Good 4
Alright 2	Adequate/Average/Ok 4	Adequate/Fine/Ok Satisfactory 6
		Consistent 2
	Helpful 2	Helpful 4
Provides relief for family/self 3	Provides relief for family/self 2	Provides relief for family/self 4
Same old/same old Variable 3	Haphazard/Variable Inconsistent 4	Spotty/Inconsistent Up and down 4
	Inadequate/Lacking/ No continuity/Limited Very limited 11	Could be improved 1
	Insufficient/Not enough 4	Insufficient/Not enough 5
Difficult 1	Hard to get/Very hard 5	Hard to get/Difficult 4
Lazy, lazy staff / Bullying service/staff / Worrying 3	A struggle/Tiring Frustrating/Inflexible Isolating 11	
	Non-existent 4 / Terrible 1	Abysmal 1

18. What whānau liked about supports

☑ **Supports gave the whānau a break[43] from their caring responsibility.**

Forty-seven percent of people, who were supporting at least one disabled person in their own home (regardless of their general satisfaction with services), stated support services gave them a break from their caring responsibilities. These responses were more frequent for whānau who were supporting people in their own home and who were satisfied with services overall (42 percent). This is in contrast to those who were supporting disabled people in their own home and who were less satisfied with services overall (14 percent).

In reviewing these responses some whānau would indicate the importance of getting a break to "keep me sane" or "re-energise". One parent noted that support was used to help get her son ready for school:

> *It gives me a break and helps me to get him up in morning. Sometimes he sleeps badly. With support for him I can get up later [and] get things arranged during school hours.*

Other people noted getting a break from their caring responsibility allowed them also to spend time with other members of their family, especially a spouse or other children.

As noted in Section 14 (Figure 8), more whānau who were less than satisfied with services did not believe they got regular breaks from their caring responsibilities (68 percent) compared with whānau who were satisfied with services (44 percent).

When considering whānau who were not supporting a disabled person in their own home, the most prevalent response related to how happy[44] the person was with the supports that were provided for them (24 percent):

> *[The] service goes out of way to make sure he is happy.*
>
> *[They] made him happy & more content…Doesn't run away anymore.*
>
> *I'm happy, & the main thing is he is happy.*
>
> *She is very happy – not anxious.*

---

[43] Defined as statements that directly referred to getting break, relief, respite or time away from supporting a disabled person. Can be referred to as 'giving me time to…' do a certain activity or similar or providing time to spend with others (ie, a spouse or other children in the family).

[44] Defined specifically with reference to the word "happy" in the context of the disabled person being supported.

It is notable that whānau, who were not supporting disabled people in their own home, also voiced their own contentment with services (17 percent). For example, whānau would talk about themselves in the following terms:

> *Happy.*
>
> *Over the moon.*
>
> *Peace of mind.*
>
> *Full of confidence, and having the stress off.*

Good and caring staff[45] were listed as one thing whānau who did not support disabled people in their own home liked about services, 26 percent compared with five percent of people who were supporting disabled people in their own home.

---

[45] Defined in direct reference to staff or support workers (paid employees) being “good”, “caring”, “nice”, “trustworthy”, “excellent”, “great”.

19. What whānau did not like about the supports & what they wanted to change

A method of exploring open-ended questions is to consider how many people did not respond to various questions. In particular, Table 13 considers the non-responses[46] to two questions that examined:

- what people did not like about the supports that were provided, and
- what they would change (if they could change one thing).

Table 13 shows the non-responses for each of these questions is much lower for whānau who were supporting disabled people in their own home and who were less satisfied with services (according to Question 22). This suggests whānau, who had disabled people in their own home and who were less satisfied with services, had much more to say about what they did not like about services or wanted to change, in contrast to the other two groups. Conversely, it may be suggested the other two groups were less concerned with services overall or had fewer issues with services.

Table 13: Non-responses to opened ended questions concerning what whānau/guardians did not like about supports and what they would change

	Not at home	Disabled people at home and less satisfied with services	Disabled people at home and satisfied with services
What don't you like about the supports that are provided?	25 59.5%	5 11.4%	23 43.4%
If you could change one thing about the supports that are provided…?	17 40.5%	1 2.3%	19 35.8%

Responses to the two questions about what whānau did not like about the services they received and what they would like to change have similarities in the pattern of responses, especially with regard to the most prevalent response. Table 14 indicates nearly a quarter of whānau who were supporting a disabled person in their own home believed their support was insufficient.

---

[46] Non-responses include (1) no written comment for both questions, or (2) a statement suggesting everything is fine/good and therefore no dislikes or suggested changes.

Table 14: Comparison of responses between 'what you don't like about the supports provided' and 'if you can change one thing', whānau supporting disabled person in their own home

	What I did not like about supports provided	One thing to change
Not enough support/want more hours/days	25 23.6%	29 27.4%
Not flexible/rigid/rule driven	14 13.2%	9 8.5%
Finding carers	17 16.3%	7 6.6%
Information too complex, lacking, not offered	9 8.5%	6 5.6%
Paperwork issues	6 9.1%	0 0%

What whānau who were supporting disabled people in their own home disliked about the supports that were provided is considered in Table 15. This table provides a breakdown of whānau who were satisfied with services against those who were less satisfied. There were similar numbers in each group who did not believe they had sufficient support. However, whānau who were supporting at least one disabled person in their own home and were less satisfied with services overall were much more likely to report difficulties in finding paid carers.

Table 15: Responses to the question, 'what don't you like about the supports that are provided?' Whānau who are supporting disabled people in their own home

	Disabled people in own home and less satisfied with services	Disabled people in own home and satisfied with services
Not enough support/want more hours/days	13 25.9%	16 30.2%
Not flexible/rigid/rule driven	8 18.2%	7 13.2%
Finding carers	13 29.5%	3 5.6%
Information too complex, lacking, not offered	5 11.4%	4 7.5%
Paperwork issues	6 13.6%	0 0%

Perceptions about funding

When whānau, who were supporting disabled people in their own home, expressed what they did not like about supports, many simply said “not enough”[47]. The few that offered more explanation referred to running out of funding:

> *I am trying to get his aunty to have him every second weekend but hours don't cover them. All the days have been used up in the school holidays.*
>
> *[I] Struggle when I run out of days – we always run out – NASC has never offered more.*

Others simply lamented the lack of hours:

> *Not enough hours… Rate needs to change - Not even $10/hr for respite person.*

Or even to get some support at all:

> *More support – carer support… there is no support or help until diagnosis.*
>
> *Change one thing? To have some. You know having the choice to know where the money is best directed for him. I mean at the end of the day… it’s a real hard one for me because I find it frustrating when I find out what other people are getting… Why are they different? And I know the squeaky wheel gets oiled and that’s pretty sad but that’s the way it is.*

Many issues raised by whānau, who were supporting disabled people in their own home, were also raised in the Likert Scale items in the survey. For example, Figure 11 indicates:

☒ **Whānau who were less satisfied with services were less likely to believe the funding was sufficient (61 percent ‘occasionally and never’). This is in contrast to those who were satisfied with services (29 percent ‘occasionally and never’)[48].**

---

[47] Also, statements such as we “need more”, or simply “more”, or “insufficient”.

[48] WMW=4.1, $p<0.001$, df=187, diff in mean=1.4, $t=4.0$, $p<0.001$.

Figure 11: The funding is sufficient to meet our needs, whānau who were supporting disabled people in their own home

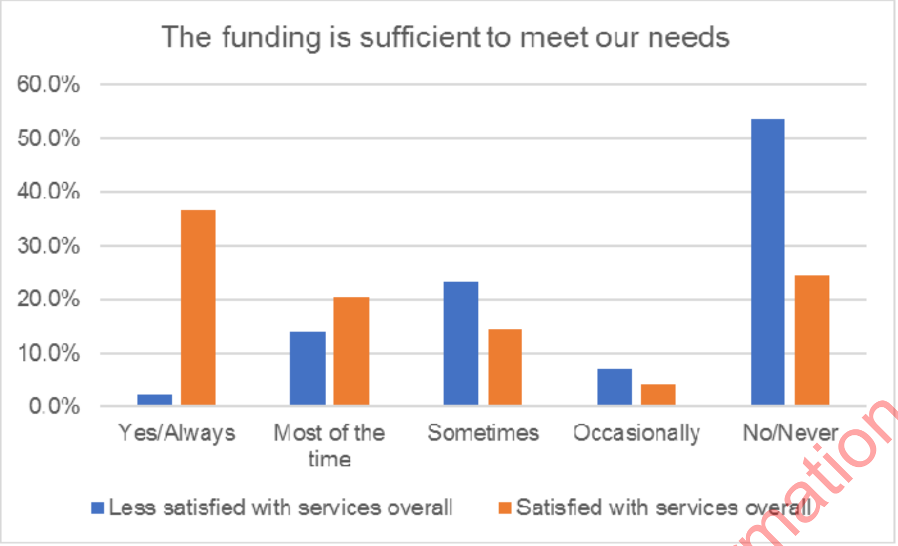


Table 16 indicates moderate satisfaction with funding for people who were not supporting disabled people in their own home as well as those who were, and who were satisfied with services. These two groups were also more convinced they understood what the funding was used for. Very low rates of satisfaction (highlighted) was noted for whānau who support people in their own home and who were less satisfied with services overall.

Table 16: Satisfaction with funding (yes/always or mostly), whānau supporting people in their own home or not, and satisfaction based on Question 22

	Not supporting a disabled person(s) in their home	Supporting a disabled person in own home	Supporting a disabled person in own home	
			Satisfied with services overall	Less satisfied with services overall[1]
I think the funding allocation process is clear	51.4%	30.5%	50.0%	**9.3%***
I believe the funding allocation process is positive	61.8%	40.6%	60.0%	**19.0%****
I know what the funding is used for	71.4%	68.4%	84.0%	**51.2%*****

[1] Rated Question 22 as somewhat to not at all satisfied.
Supporting disabled people at home, satisfied to less satisfied *(WMW 4.4, p<0.001, df=153, diff in mean=1.5, *t*=4.6, *p*<0.001), **(WMW=5.5, p<0.001, df=146, diff in mean=1.9, *t*=6.9, *p<0.001*), ***(WMW=3.8, p<0.001, df=153, diff in mean=1.2, *t*=5.2, *p*<0.001)

Some whānau referred directly to the carer support subsidy of $76 per day (rates in quotes can vary). One person stated:

> *A full day being 8 hours – $76. A lot of people don't have the money to top up. Need to reassess the figure – not fair – under minimum wage.*

It is not clear whether many people understood the carer support subsidy was not enough to pay a minimum wage, and a top-up was expected by the recipient.

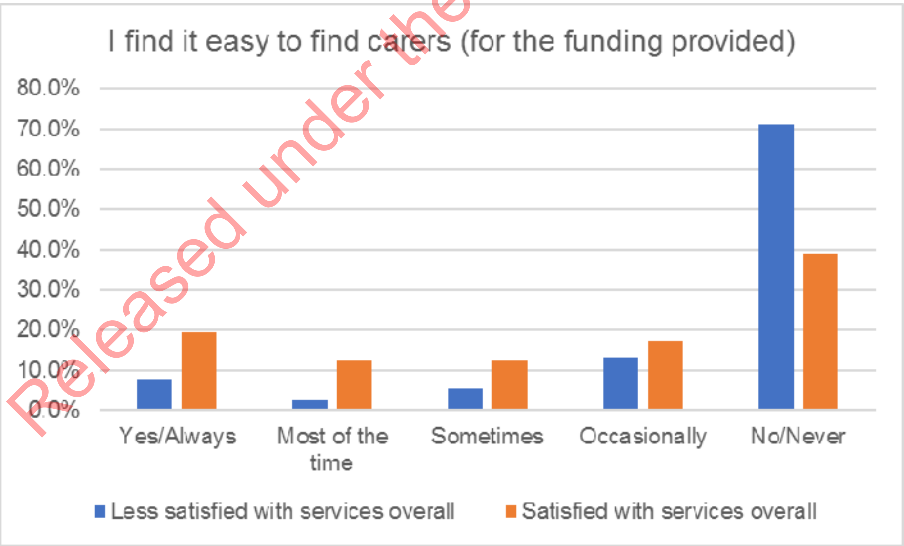
Employment and income can be an important consideration in determining whether whānau can manage a top-up of the carer support subsidy.

Finding carers

Finding carers was highlighted as an issue for whānau. This was particularly the case for whānau who were supporting at least one disabled person in their own home, and who were less satisfied with services overall.

There was one Likert Scale item that considered the ease (or otherwise) of finding support workers or carers. Figure 12 indicates that the majority of whānau, who were supporting disabled people in their own home, did not find it easy to secure carers. This difference was largest for whānau who were less satisfied with services (84 percent compared with 56 percent ‘occasionally’ and ‘no/never’).

Figure 12: I find it easy to find carers (for the funding provided), whānau who were supporting at least one disabled person in their own home



In reviewing responses to the question posed in Figure 12, many simply stated that finding carers was difficult, others offered some explanation as to why finding carers was difficult, such as:

> *Not enough carers to use hours…4hr/wk for community access – not happening.*

Or the disabled person brings their own challenges that may reduce the possibility of finding suitable support workers:

> *You've got a limited pool to start with, you know also your child has these sleeping issues and stuff like that, you don't want to ask your friends to do it. You know she can be awake from half past one in the morning.*

Or simply, finding the right support worker(s) is a problem:

> *Finding additional support workers – funding okay, but can't find decent ones – only one great SW.*
>
> *Very hard to find someone… [need to] have a 'pool' of people that are consistent and have knowledge & confidence.*

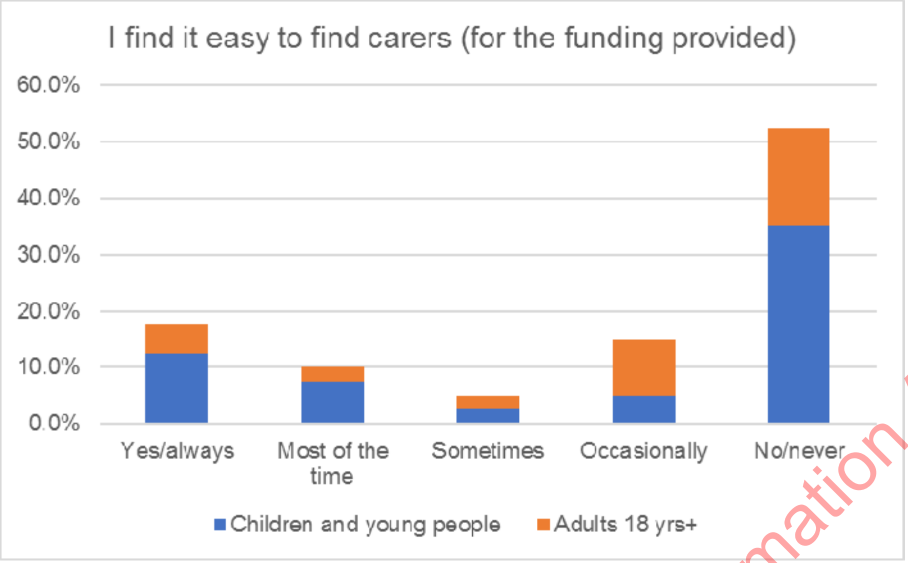
Carer Support and Respite

Carer support subsidy is available to the disabled person and their main carer, usually whānau, to provide time when the disabled person can be supported by someone else. Prior to the system's change in October 2018, carer support was allocated at a daily rate of $76 a day. For a 24-hour period this equates to $3.17 per hour. On average, 30 carer support days were allocated per person, with a range of three to 95 days (SD 22 days). Thirty-three people in the disabled persons survey received carer support. Just under half of this group *only* received the carer support subsidy (49 percent).

In the whānau survey 45 people received the carer support subsidy, of whom 27 only received this subsidy (60 percent). Of those receiving the subsidy 62 percent were children and young people (or 70 percent of those only receiving carer support). Fifty-nine percent of children and young people (n=16) receiving the carer support subsidy had high assessed needs (plus one more person who had VHN). Of those children and young people with high assessed needs 13 had learning disabilities (of 14 children and young people with learning disabilities in total within this group). Of the 12 children and young people with ASD, eight had moderate assessed needs and three had high assessed needs (one did not provide this information).

Figure 13 indicates that people receiving carer support days do not generally agree they can easily find carers for the funding provided.

Figure 13: I find it easy to find carers (for the funding provided). People receiving carer support days



For people who are looking for support workers there can be rules governing who may be employed. Many people using the carer support subsidy will hire other whānau or friends[49] who are willing to take over support of the person for the entire allocated period (ie, 24 hours) or part thereof. However, whānau living at the same address could not be hired under the existing rules. Whānau who could find paid support easily were people often hiring other whānau or friends who do not live at the same address. Not completely understanding the rules can cause difficulties for some people. For example, one whānau member noted:

> *It's hard to find someone to do the support – I bought a house with a granny flat for my mother to move into so she could support my son, but I have been told she can't do the support as she resides at the same address but lives under a different roof. She can't get a job as I need her to support my son.*

In general, people who are allocated carer support days cite the following issues in accessing support workers:

- the poor funding for the carer support if the 24-hour period is considered
- an insufficient number of days allocated in the year to make it attractive to support workers
- the location where some disabled people live (small towns, rural locations, etc)
- turnover
- lack of back-up carer options if the main paid carer was away or sick.

---

[49] Nine people (27 percent) referred to using whānau or friends for carer support days during interviews.

Another issue raised is trust, especially for the whānau of children and young people. Unlike provider organisations, it is not a requirement for people employed by whānau to undergo police checks. On occasion people may have heard of others who had bad experiences, or they may have had a bad experience themselves[50].

One issue is the challenge of using the allocations within the specified period. For example:

> *We got respite [ie, carer support] days allocated to us but we didn't know how to find a carer... So, we then got told since we weren't using our days, they took them off us and said we could reapply again. But I asked them quite a number of times how to do it, and they said you just advertise, and they didn't give me any help. Like what am I supposed to do? Put an ad on Facebook [and say] hey, do you want to look after my seven-year-old? Yeah, a bit dodgy, so yeah there was no help there.*

Respite

Respite options generally refer to providing out-of-home arrangements for a disabled person for a set amount of time. There are several types referred to in the DSS material. For example, respite that uses individualised funding where the choice of options is open to the person/carer, respite in nursing homes for adults, and respite for children and young people – typically, in a small home (up to six people) specifically allocated for respite purposes.

The word 'respite' is often used by carers to describe the options listed in the paragraph above but is also used to describe carer support days. To confuse matters, some people referred to 'alternative' support days or care. For example, one whānau member said:

> *But with the other [SW] the alternative care is great. She's basically, she's better than me. She is great. She tells me about the gluten free stuff to buy, and I don't because it's too dear, but she is great.*

In these instances, the interviewers attempted to determine what type of support they were referring to. However, in total, only three to four clear instances of people using respite were found in the disabled persons survey and only three were noted in the whānau survey. In most other cases it appears people were referring to carer support days.

Lack of assistance was cited by another person when she was allocated 12 days respite. The person asked how to use the allocation and was told:

> *'She goes to stay in a foster home'… and I was like, no… It's not what [I] asked for, for her.*

---

[50] For more discussion on the issue of trust, refer to section 22 of the whānau and guardian survey sections.

One parent lamented the rules around respite (carer support) stating:

> *I had said to them, 'look you know that respite isn't enough, I work two mornings a week and so that respite is only when I work', and I was told, 'well we don't give you respite so you can work'. [I] just gave up.*

The balance between maintaining employment and providing support for a person at home can be a challenging one. The dialogue highlights the issues people have with the rules concerning both respite and carer support days. Another issue is how the funding is compartmentalised. One parent stated:

> *I don't like that money isn't available for other things, it's only available for one thing which is respite. So, you don't have a choice how it's used. And for us that funding could be used a different way… private swimming lessons, more one-on-one time... to do activities a normal four-year-old would do, but he can't.*

Another person who has respite allocated to a nursing home stated:

> *I can't use respite in a way I want…but I don't feel I have any choice. I don't want to go to an old people's home.*

Respite options for adults are limited and are often only used when a main carer is away for some reason or unwell. However, the few experiences of this type of respite cited during interviews were not positive:

> *I was showered on the Friday having arrived on the Thursday and by the time I got to the Tuesday I hadn't had another shower, and I asked for a couple of flannels … but when it gets down to it, if the overnight… responses to the bell aren't going to happen within half an hour then it wasn't going to happen. It wasn't dignified and it wasn't respectful.*

Out-of-home respite for children and young people was viewed more favourably although it was believed few vacancies are available. There were two examples of a child/young person enjoying the experience, one stating her son loves going and "could not go enough". However, the same parent noted they were limited by the allocation provided and felt they were being pressured to use the facility occasionally during the week as an alternative to the popular weekend:

> *Well, basically, our needs as a family are not being met. I have to send [person's name] to respite when [provider name] can fit him into their scheduled roster. Also, weekends are when I need respite which [provider name] cannot always provide so I've been asked to use my days during the week to which I refuse as we are supported during school week.*

Another parent noted her son liked the "company of other kids" but doesn't like being away from home.

Type of support provided where whānau support people at home

There were a variety of types of support provided where whānau provided support to at least one disabled person in their own home (see Table 17).

Table 17: Type of support provided where whānau support at least one disabled person in their own home

Carer support subsidy	45	43.7%
Only carer support subsidy	27	26.2%
Respite support (including Individualised Funding IF)	3	2.9%
Personal care (including IF)	17	16.5%
Household management (including IF)	14	13.6%
Household management and/or personal care support	21	20.4%
MidCentral DHB Child Development	17	16.5%
Explore behaviour support	11	10.7%
No information provided	14	13.6%

Table 18 indicates whānau, who were less satisfied with services overall and were supporting at least one disabled person in their own home, were less satisfied with the support that was offered to the whānau (highlighted) with regard to being able to continue their caring role and finding support workers or carers to assist. Both groups suggested that the support offered did little to give them a break from their caring responsibilities, and only a third suggested they understood what respite options were available in MidCentral area.

Table 18: Whānau views of respite, carer support, household management and personal care support

	Supporting a disabled person in own home			
	Satisfied with services overall	Less satisfied with services overall	WMW	Diff in mean
I have regular breaks from my caring responsibilities	13.3%	10.0%	2.1*	0.4
I find it easy to find carers (for the subsidy provided)	31.7%	**10.5%**	2.9**	0.9
I know what respite options are available in Midcentral	36.4%	35.5%	0.2	0.05
My supports help me continue with my caring role	75.0%	**42.1%**	2.8**	1.0

Some whānau did refer to out-of-home respite when completing the survey with interviewers. One person, for instance, referred to the “age barrier” for respite services (typically up to 21 years of age). Respite services are not always seen as providing the best solutions.

Perception of flexibility in service provision

What some whānau did not like about the supports they received (ie, what they wanted to change), was simply stated as being:

- not flexible
- too rigid
- too rule-governed.

One man indicated his appreciation of supports when responding to the question about what he disliked about the supports provided, and then stated:

> *Without them I’d be lying on the ground.*

However, he then went on to consider the question a little more:

> *They cut the home support hours – don’t really know why – too many rules about what support can be used for. For example, getting my wife’s nails cut.*

Other examples from a range of whānau included the rules associated with the funding:

> *I don’t like the inflexibility and not being able to use it while I am working.*
>
> *It has to be used by certain date – have lost 4 days. Should not be time limited – should be able to carry over. For example, [I] could have used the four days this school holiday, but gone now.*
>
> *[I] can't use it on holiday programme… very restrictive. It needs to be flexible as to how we use the resource travel funds.*
>
> *Respite too far away to be used flexibility – and can only use it when available – no guarantee – no spontaneity – not organised around need.*
>
> *You can only use respite funding one way! Mum would like to use it in the day. Possibly 1:1 in day care or at home.*
>
> *Lack of flexibility. Apart from carer relief hours, all other support is quite rigid in the hours they work.*

Other respondents provided more general responses regarding the perceived lack of flexibility and alluded to the need to take a more holist approach:

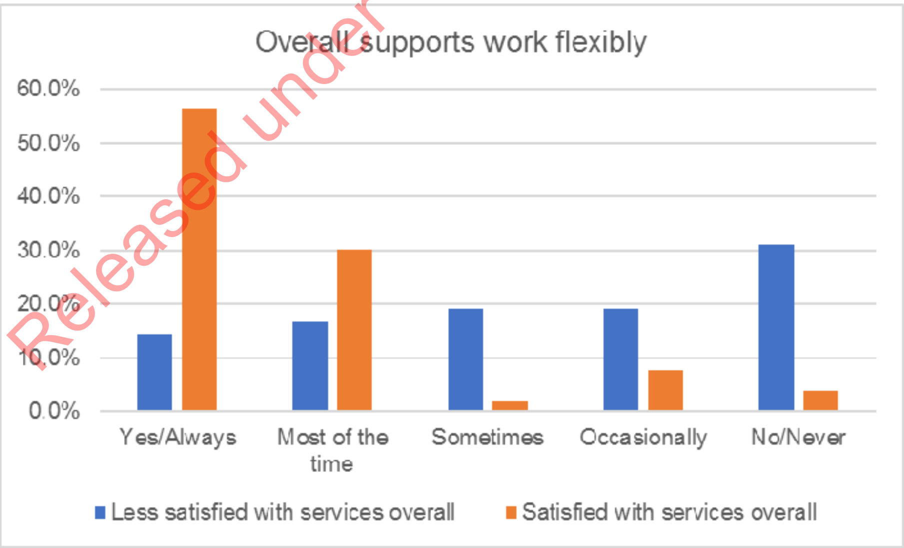
> *At times it is very inflexible. No knowing what I can do or not. [Need to] look at the person as a whole and also the needs of the family.*
>
> *Not flexible enough. Individual needs need to be more flexible. Criteria from MoH is not culturally inclusive. Very colonial – mono-cultural.*

One whānau considered the flexibility issue from a range of perspectives concerning how supports also impact on their lives:

> *That the criteria don't fit the person's life… Support workers work in our home. This is not a workplace but our home. Often supporting support workers. [Need to] Put all $$ together and use flexibly, including holidays, to give wellbeing for whole family.*

Figure 14 indicates a split in views between those whānau who are satisfied and those who are less satisfied with services (and who supported at least one disabled person in their own home) when flexibility in service provision is considered. In particular, 87 percent of those who were satisfied with services believed their supports worked flexibly compared with 31 percent of those who were less satisfied with services overall. Conversely, 11 percent of whānau who were satisfied with services did not believe supports worked flexibly ('occasionally' or 'no/never') compared with 50 percent of those who were less satisfied with services overall[51].

Figure 14: Overall supports work flexibly, whānau who are supporting disabled people in their own home



---

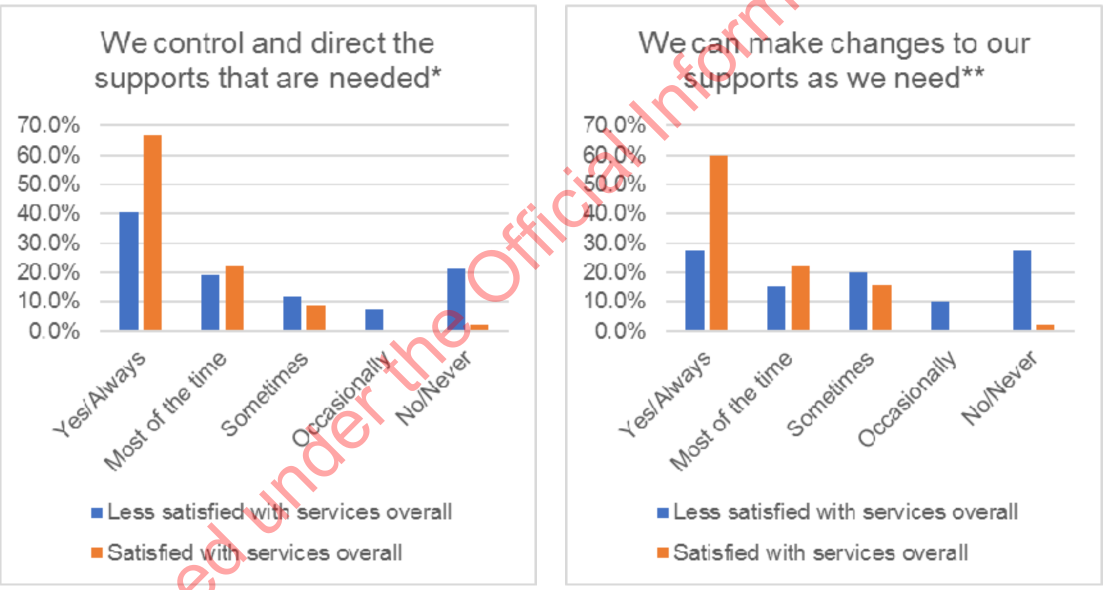
[51] WMW=6.3, p<0.001, df=140, diff in mean=1.6, *t*=7.3, *p*<0.001.

Two more Likert Scale items considered flexibility in relation to how much control whānau believed they had over the supports that were provided (Figure **15**).

☑ **Only two percent of whānau, who were supporting disabled people in their own home and who were <u>satisfied with services</u>, did not believe they had control over their supports (‘occasionally’ and ‘no/never’).**

☒ **Twenty-nine percent of whānau, who were supporting disabled people at home and who <u>were less satisfied</u> with services overall, indicated they had few to no opportunities to control and direct supports and 38 percent suggested they had few to no opportunities to make changes to their supports (‘occasionally’ or ‘no/never’).**

Figure 15: Control over supports, whānau who were supporting disabled people in their own home



*(WMW=3.1, p<0.001 df=135, diff in mean=1.0, *t*=5.6, *p*<0.001) **(WMW=4.0, p<0.001 df=133, diff in mean=1.3, *t*=6.7, *p*<0.001)

Clarity of Information

An issue raised by whānau concerned access to information. Whānau referred to ease of access:

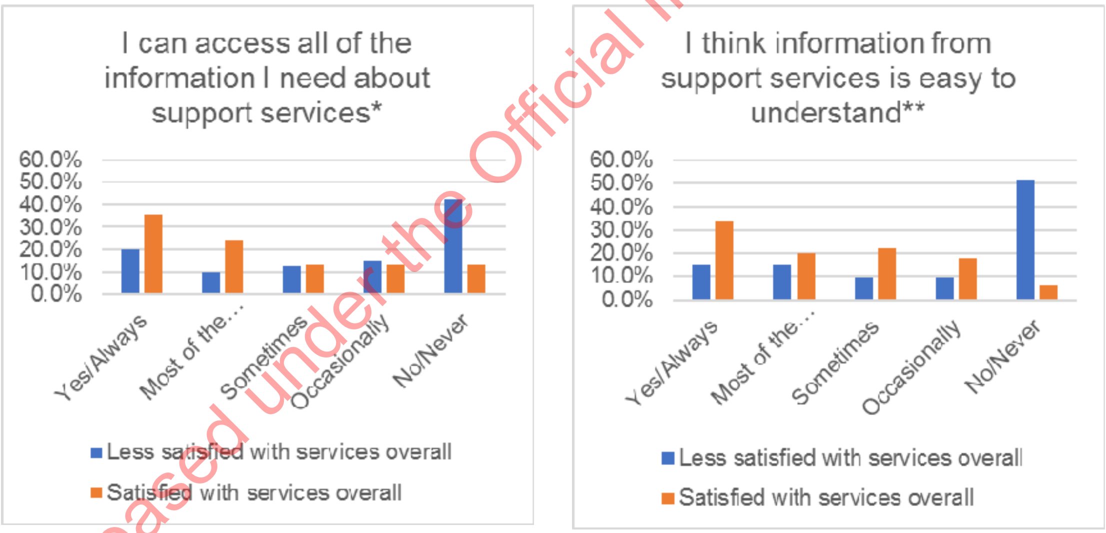
> *We don't know what is available and nothing seems easy to access.*

And others referred to having to find out things for themselves rather than have it freely offered to them:

> *I found out about lots of things but too late for my son as he is now too old.*
>
> *I find I didn't know enough about my rights – it took a long time to find out [disabled persons name] was entitled to the hours.*
>
> *[I] find everything confusing – what/who does what… everything should be under the umbrella.*
>
> *Half of time don't hear about support services… Didn't know about travel grant and many other things.*

Figure 16 shows at least a quarter of whānau who supported at least one disabled person in their own home did not believe that information was easy to access or easy to understand. This figure rose to over 50 percent for those whānau who were less satisfied with services overall.

Figure 16: Information provided by disability support services, whānau who were supporting disabled people in their own home



*(WMW=3.1, p<0.001, df=194, diff in mean=1.1, *t*=4.6, *p*<0.001) **(WMW=3.9, *p*<0.001 df=175, diff in mean=1.3, *t*=4.6, *p*<0.001)

In considering the Likert Scale items themselves whānau offered the following observations:

> *[I] don't understand what can/can't do.*
>
> *If I wanted to find out I could, but not told it. It's not handed to you.*
>
> *Mum had to find out about the support for her son.*

Some [information] can be quite hard to read and work through.

No, I don't get information, unless I ask, but it's not offered.

Always given confusing/conflicting info.

[It] needs lots of processing.

There needs to be more information on what other things you are entitled to.

Some is [easy to understand] others not helpful or understandable or accessible. Depends on agency.

Information is very hard to get – I don't know everything that is available – no-one asks us what we need or want changed so we don't know what to ask for.

It's very poor, the information that is given out.

20. Community participation

Community participation can be an important consideration for whānau as it can open up a range of experiences and opportunities for the disabled people they advocate for or support.

The disabled persons survey indicated for some groups the success of community participation was dependent on disability type and the type of support package the individual received. Community participation also varied according to age, with children and young people appearing to be a lot more active in the community than adults. Whānau were often focused on community participation for the disabled people they supported, especially as it related to the support they received. One person noted:

> *I don't like that my daughter doesn't get to access the community. I want her to have same opportunities as her sister. She needs to be with younger people. She doesn't want me to take her to these things/activities… [I want her] to go to activities with support and independently, and not requiring Mum and sister to have to be there.*

A whānau member highlighted the flexibility around their individualised funding (IF):

> *We pick and choose our carers. IF allow us to use it for expenses, so my daughter goes out in community.*

For other whānau there is an understanding that supporting some people to venture into the community can be difficult:

> *I would like to get more support to get my son out of bed more to engage in community. [He needs] two to one support.*

When asked, 'if anything were possible, what are some things you would like to achieve, start doing, or do more of?', one whānau simply said:

> *Take [person's name] out in public.*

When asked why this was important, this whānau then followed with:

> *To integrate [person's name] into the community and not be shunned or have little old ladies tell me off as a parent.*

Barriers to community participation are not always about lack of support.

Three Likert Scale items in the whānau survey concerned community participation or engagement. The majority of whānau, who do not support a disabled person in their own home, were advocating for them in community residential homes (68 percent). The remainder were living independently and were being supported through supported living. Figure 17 indicates 73 percent of whānau, who were not supporting people in their own home, believed they were supported to be connected to the community. This is in contrast to whānau who were supporting people in their own home (29 percent). Figure 17 suggests close to 20 percent of both groups did not believe there was support to be connected to the community at all (19 and 25 percent respectively[52]).

Figure 17: We are supported to be connected to the community, whānau with and without a disabled person in their own home

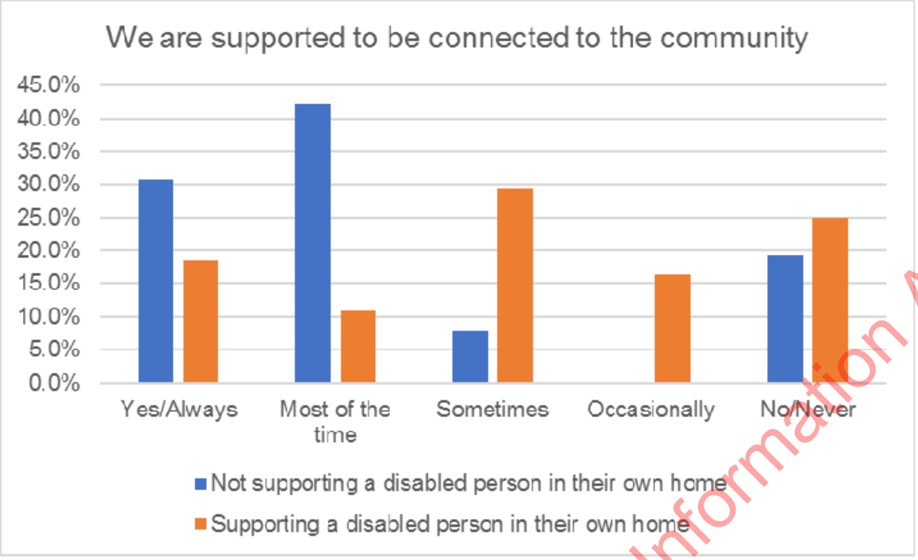


Figure 18 demonstrates the range of responses from whānau who were supporting at least one disabled person in their own home. This figure indicates over a half of whānau, who are less satisfied with services overall were least likely to believe they were supported to be connected with the community (59 percent).

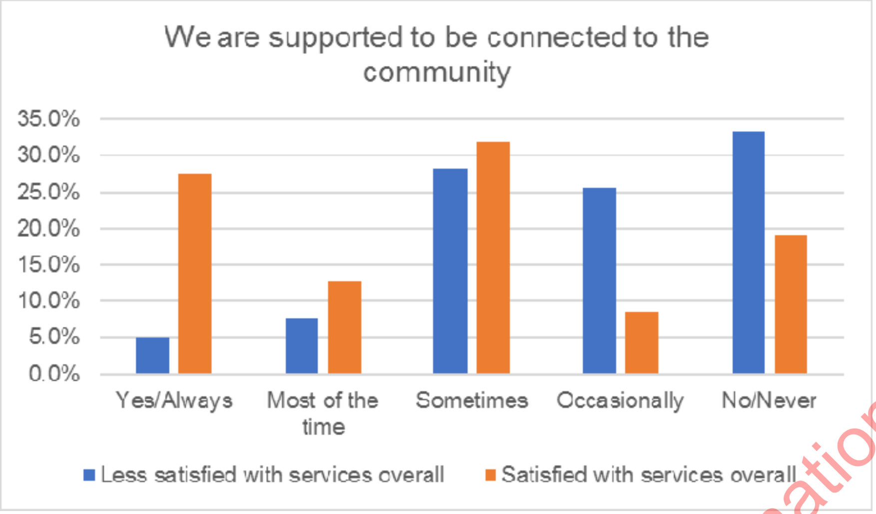
A third of those less satisfied with services overall (33 percent) did not believe *at all* they were supported to be connected with the community, in contrast to 19 percent of those who were satisfied with services[53].

---

[52] WMW=3.0, $p<0.01$, df=41, diff in mean=0.9, $t=2.9$, $p<0.01$.

[53] WMW=3.1, $p<0.001$, df=143, diff in mean=0.9, $t=3.0$, $p<0.01$.

Figure 18: We are supported to be connected to the community, whānau who are supporting disabled people in their own home



The second Likert Scale item that considered community participation examined the use of community-based (universal or generic) options and services. This item was met with a varying response from some whānau. One stated:

> *Often it is specialised services. For some things she can go to community options but others need to be specialised to meet her needs – extra staff etc.*

Another whānau member noted about his son, the community:

> *Couldn't meet his needs always. Others don't understand or support.*

For others, it is was simply the acknowledgement that getting into the community at all was often an issue:

> *It's too hard to go with four children that have anxieties and don't like new situations.*
>
> *Would love to get him into swimming lessons but can't afford it and it is hard to get him out of the house.*

Figure 19 indicates whānau, who were supporting at least one disabled person in their own home, were not confident they could use community-based options and services (universal/generic) before they used specialist disability services. This is in contrast to whānau who did not support a disabled person in their own home[54].

---

[54] WMW=2.5, p<0.01, df=42, diff in mean=0.9, t=2.6, p<0.01.

Figure 19: Use of universal/generic services before specialised services, whānau who were and were not supporting disabled people in their own home

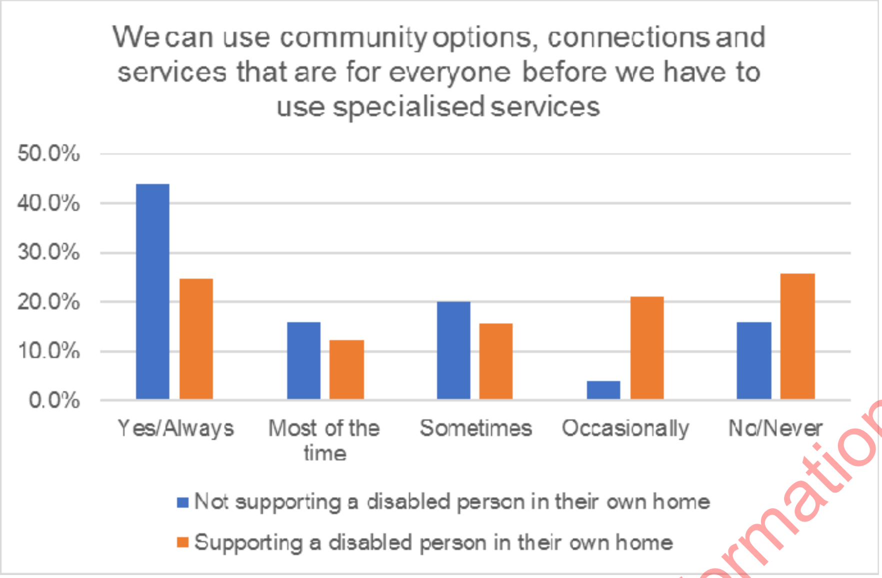
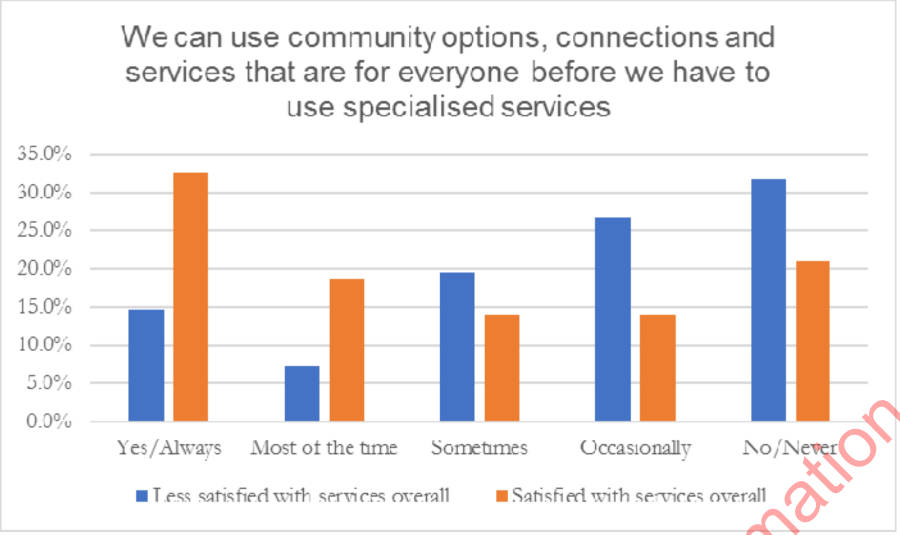


Figure 20 indicates how whānau, who were supporting at least one disabled people in their own home, responded to the same question. Fifty-nine percent of those who were less satisfied with their supports overall and were supporting at least one disabled person in their own home suggested they were not generally able to use community options before they had to use specialised services. This is in contrast to 35 percent of those who were satisfied with services[55]. It may be important that 74 percent of whānau, who were less satisfied with services, were supporting an individual with very high or high assessed needs. This compares with 54 percent of those who were satisfied with services overall. Degree of assessed need may account for some of the differences noted in Figure 20.

---

[55] WMW=2.4, $p<0.01$, df=180, diff in mean=0.8, $t=2.4$, $p<0.01$.

Figure 20: Use of universal/generic services before specialist services, whānau who are supporting disabled people in their own home



Another Likert Scale item considered community and social connectedness, in the sense of connecting with people and places.

Figure 21 indicates whānau, who were not supporting a disabled person in their own home, were more likely to believe supports were assisting them to connect with people and places that were important to them. This is in contrast to whānau who were supporting at least one disabled person in their own home[56].

Figure 21: Our supports help us connect to people and places that are important to us, whānau who were and were not supporting disabled people in their own home

---

[56] WMW=2.5, p<0.01, df=65, diff in mean=0.8, t=2.9, p<0.01.

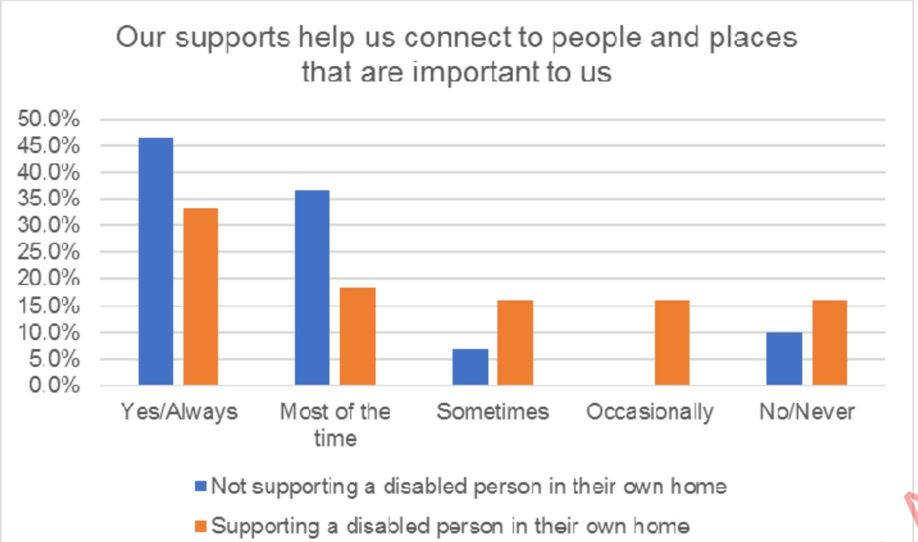
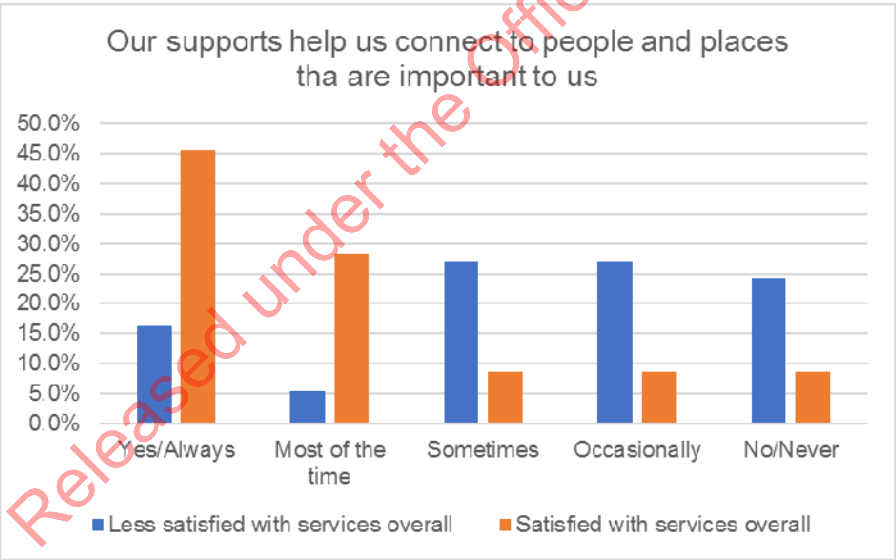


Figure 22 indicates 51 percent of whānau, who were supporting at least one disabled person in their own home and were less satisfied with services overall, did not believe that supports could connect them with people and places that were important to them (occasionally or at all). This is in contrast to 17 percent of whānau who were satisfied with services[57].

Figure 22: Our supports help us connect to people and places that are important to us, whānau supporting disabled people in their own home



Community participation and engagement is a consideration in both the New Zealand Disability Strategy and the Enabling Good Lives approach. Whānau, who were less satisfied with services overall and were supporting at least one disabled person in their own home, appear least likely to believe supports were encouraging

---

[57] WMW=4.0, $p<0.001$, df=65, diff in mean=1.3, $t=4.6$, $p<0.001$.

or maintaining sufficient community participation for their disabled person(s). This dissatisfaction can be compounded by variables such as:

- trust in paid support workers
- an ability to secure paid support workers
- degree of assessed need
- any issues the disabled person(s) may have themselves (such as social anxiety or behavioural issues).

There is also a consideration that the rules around funding packages (what funding can be used for) can limit opportunities for community participation. Some may believe funding is simply insufficient. For whānau on lower incomes an expectation that they could top-up funding and subsidies, such as carer support, may be an additional factor.

21. Unpaid carers

Unpaid carers, who were most stressed, were those who indicated less satisfaction with support services according to almost all the survey items. Those who indicated less satisfaction with services were also more likely to be unemployed and often supporting children and young people, and in some cases, multiple people with disabilities in their home.

It is difficult to know whether stress and quality of life issues impact on perceptions of satisfaction with support services or whether poor satisfaction with services added to stress factors. Whichever way the cause and effect work for these whānau, the evidence clearly suggests a need to increase focus on unpaid carers.

☒ **The less satisfied group accounted for over a quarter of all the whānau who responded to the survey (27 percent), and close to a half (45 percent) of all whānau supporting people in their own home.**

These numbers are significant in terms of reviewing the support that is being provided.

22.

22. Trust

A persistent theme running through the whānau surveys was trust.

Whānau talked about having ‘peace of mind’, or of the service being ‘gold standard’ or ‘a God send’. For many whānau, knowing that the disabled person is safe and well cared for is a primary consideration.

☑ **Ninety-eight percent of whānau, who were not supporting a disabled person in their own home (and the person(s) lived elsewhere), believed they were safe all or most of the time (76 percent all the time).**

☑ **Eighty-eight percent of whānau, who did support at least one disabled person in their own home, believed the disabled person they supported was safe (all or most of the time)[58].**

It is important to note the exact wording of this Likert Scale item:

> In general, I believe my family member/friend/partner/spouse is safe.

The explanation for this item, which is provided if the respondent is unclear of the question’s intent, states:

> I am not concerned my family member/friend/partner/spouse is at risk.

This is not a support service specific item but takes a holistic view of risk and safety.

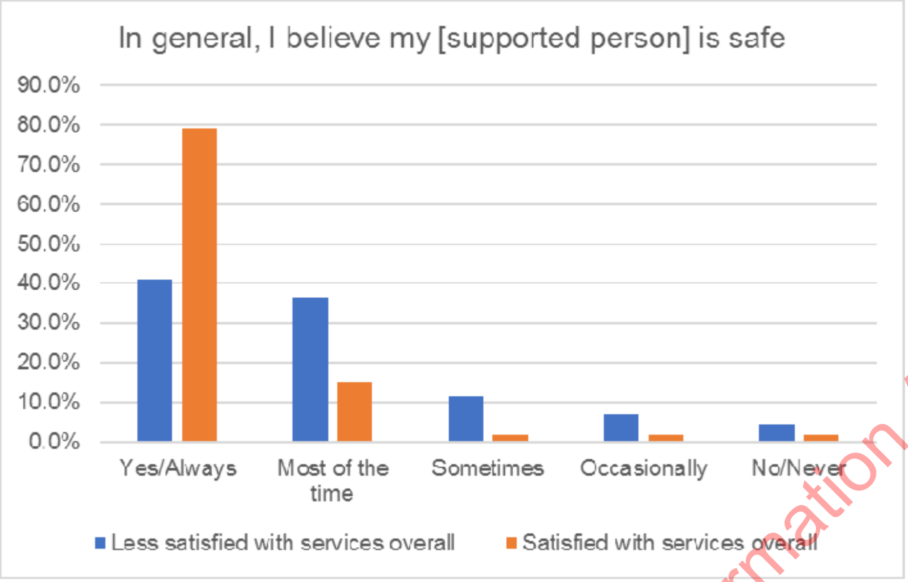
Figure 23 considers whānau, who support a disabled person in their own home, relative to their satisfaction with support services overall. Whānau who were less satisfied with supports were less likely to believe the disabled person(s) living in their home were completely safe (yes/always). In fact, 22 percent of this group believed the disabled person living in their home was ‘sometimes’ to ‘never’ safe, in contrast to six percent of those whānau who supported disabled people in their own home and who were satisfied with services overall[59].

---

[58] WMW=1.8, $p<0.038$, df=107 i.e. not significant, diff in mean=0.3, $t=2.0$, $p<0.024$.

[59] WMW=3.9, $p<0.001$, df=82, diff in mean=0.7, $t=4.1$, $p<0.001$.

Figure 23: In general, I believe my family member / friend / partner / spouse is safe, whānau and guardian supporting disabled people in their own home



The source of where people were unsafe varied. One person noted:

> *At home he is safe, when he is upset he storms off and he [is] not safe in the street.*

Another whānau simply wrote:

> *Runs away.*

And on other occasions a variety of concerns are expressed:

> *[It] depends. He climbs up on things… he has serious seizures, [and] haven't had the resources to house-proof.*

Whānau, who are supporting at least one disabled person in their own home and who are less satisfied with services, were also more often supporting individuals with VHN and high assessed support needs. Safety for this group of people may not be in reference to support services per se – but in relation to the person being supported. However, there were occasions where safety had some links to the support system. For example, in one situation the interviewer noted the whānau had been denied a bathroom modification for 18 months and the parents had been doing the lifting manually, as:

> *Staff cannot do this due to health and safety.*

Safety was also raised as a concern with regard to support workers during general discussion with whānau while they completed the survey:

> *[The] ORS person is most supportive [but] other respite [funding is] not used because people need to know the boys. And boys' behaviour is an issue.*

Another set of parents noted:

> *[Mum]: It's identifying good carers.*
>
> *[Dad]: That's also people you trust…And she's big and strong.*

Later in the interview the same whānau noted:

> *[Dad]: Even if someone said, 'hey, there's the centre who does caring', I'm not going to send her there, hell no. She's a young girl, they all get abused.*
>
> *[Mum]: You can't be sure, yep. She's got no voice.*

In reference to similar fears, word of mouth or rumours also create trust issues with some whānau. One recalled a story of abuse occurring in a respite service in another district as a reason for not using respite in MidCentral. Another whānau noted, when asked if there was anything they wanted to change about supports:

> *Respite that is safe for your child to go to.*

In another situation a person suggested (paraphrased by interviewer):

> *Can't access carers respite – don't trust agencies after previous poor experiences.*

Most whānau were more concerned that if they had to use another person to provide support, even for a short time, then that person would have to be someone they knew and trusted, such as another whānau member or friend:

> *Trust is a big issue with him – doesn't enjoy being with older sisters, [however, it] has to be with known people.*
>
> *I am able to use someone I trust … being able to pay someone who the boys know – very important due to anxieties.*
>
> *[I] use family, not strangers… relates best to family.*
>
> *If my sister didn't do it, I wouldn't know where to look or who to trust.*
>
> *Before I couldn't use it [funding] for his sister. It is important he goes to sister and family – he would prefer to go to family members. Hardly used it before because we couldn't use it like that.*
>
> *I can use mum and brother – they know my son on a personal level – we trust each other.*

When asked, 'if anything were possible, what are some things you would like to achieve, start doing, or do more of', one whānau said:

> *Get a nanny. Someone to take my daughter out. I have younger kids. Someone we could trust and not have to worry about her going out.*

In responding to the same question another whānau member stated she would like to find employment, however:

> *If I was working full-time, I would need to know my son is looked after. At the moment I can't do this, as I don't have people I can trust to do this.*

When asked if there were barriers to finding employment, another whānau member noted (paraphrased by interviewer):

> *Don't trust people with [my] child – [work] has to be around school hours.*

Trust was raised in discussions with whānau, who supported at least one disabled person in their own home, in at least 17 percent of surveys. Trust does appear to be an impediment to finding support workers who are not already known to the whānau. Issues with turnover of paid supports is also an important consideration as establishing rapport and trust with new carers is not necessarily an easy process. The more paid support workers are involved with a disabled person the more likely an issue with a support worker will arise at some point. Hearing first or second hand of issues with support workers in other places can also create scenarios where whānau are less likely to use external supports. This can result in a reluctance to search for, or consider, paid supports who are not already known to the person or whānau.

23. Visual representation and conclusions

There were five groups who were the focus of this analysis. The overall sample of 152 whānau provided a reasonable response to service satisfaction across most questions. The main point of difference was an indication that whānau, who were not supporting a disabled person in their own home, had a reduced sense of control of the services that were provided. This result is consistent with the disabled persons survey that suggested people with very high needs and people who lived in community residential homes were more likely to have a proxy respondent (such as whānau) who believed they have poor choice and control of their lives and their services.

Whānau who did not support people in their own home were generally more satisfied with services overall and were more satisfied with their own sense of wellbeing than whānau who did support at least one disabled person in their own home.

For those whānau who were supporting at least one disabled person in their own home, two conflicting sets of results occurred dependent on whether or not they were satisfied with services overall.

45 Percent of whānau who were supporting at least one disabled person in their own home were less than satisfied overall with the support provided for their family member. This result was mirrored in **all other** questions concerning service satisfaction for this group of people.

Whānau who were supporting at least one disabled person in their own home and who were less than satisfied with services overall

Not only were this group less satisfied with support services overall, but they also indicated greater stress in their lives. This was indicated through:

- their own perceptions of subjective wellbeing
- their view that they had very little time in their lives for themselves or other family members (or friends)
- the view that they had insufficient funding and support
- the reality that they could not often find paid carers who were not other whānau or friends
- the perception that services were siloed and rule driven
- the view that services did little to assist them (and the disabled person) to be connected with their community.

This baseline survey suggests a complex set of variables (or factors) that influenced perceptions of wellbeing and of service satisfaction. Most important were consideration for whānau, who were unpaid carers, many of whom provided indications they were having difficulties coping with their caring responsibilities.

24. What now

Other things to read

- Baseline Study of the Disability Support System in the MidCentral Area: Summary Report
- Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report
- Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools

25. Glossary of abbreviations and terms

ASD	Autism spectrum disorder
DSS	Disability Support Services
Enable NASC	Enable was the NASC in MidCentral area (the only area it is the NASC) before the implementation of Mana Whaikaha.
EGL	Enabling Good Lives
IF	Individualised funding
Learning disability	This is the term preferred by People First rather than 'intellectual disability'.
MidCentral area	The MidCentral area has the same geographic boundaries as the MidCentral District Health Board (DHB) which is a North Island DHB area that covers from Otaki / Te Horo in the south, to Apiti north of Sanson in the north and Dannevirke and south-west to the west coast.
MOE	Ministry of Education
MOH	Ministry of Health
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Coordination service. The NASC within the MidCentral DHB area is Enable NZ.
ORS	Ongoing Resource Scheme (MOE)
People First	Self-advocate organisation for people with learning disabilities
PPPR Act	Protection of Personal and Property Rights Act 1988
Survey Items	Questions or statements in the survey documents requiring a response
Stakeholders	Includes Government Ministries, NGO and governmental organisations associated with disability, providers, DPOs and national family organisations
SWB	Subjective wellbeing: people making their own assessment of their happiness or wellbeing
Universal services	The health, education and other community services available to all New Zealanders
VHN	Very high assessed need based; based on the needs assessments done through Enable
WMW	Wilcoxon Mann-Whitney test for non-parametric statistics

Document 5

Baseline Study of the Disability Support System in the MidCentral Area: Summary Report

SAMS

EVALUATE • INNOVATE • EDUCATE

Contents

Tables and figures

Acknowledgements

SAMS would like to thank the many people who took the time to respond to our surveys and provide feedback on New Zealand's existing and proposed disability support systems.

We would also like to thank the following key SAMS people for their important contribution in developing the framing and guidance for the Baseline Study discussed in this summary report process. These people also played a critical role in analysing the responses to the various surveys that were conducted:

- Christine Wilson, PhD
- Carey-Ann Morrison, PhD
- Esther Woodbury, PhD
- Aloma Parker, PhD
- Andrew Coleman, PhD
- Gary Williams
- Tina Lincoln
- Rebecca Walton
- Richard Lucy

Key people involved in preparing this report were:

- Carey-Ann Morrison, PhD
- Christine Wilson, PhD
- Aloma Parker, PhD

To reference this document:

Morrison, C.A. and Wilson, C.S. (2019). *Baseline Study of the Disability Support System in the MidCentral Area: Summary Report*. Prepared on behalf of the Ministry of Health, New Zealand. SAMS Evaluate, Innovate, Educate.

1 Executive Summary

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018.[1] The transformed system is based on the Enabling Good Lives (EGL) vision and principles and aims to give disabled people and their whānau more options and decision-making authority about their supports and lives, to improve their wellbeing outcomes, and to create a more cost-effective disability support system.

Mana Whaikaha will require ongoing monitoring and evaluating to help stakeholders understand if its objectives are being achieved, and to what extent; where improvements are needed; and if and how the approach should be adapted or expanded. A baseline study was undertaken prior to the implementation of Mana Whaikaha to provide a basis for assessing system level change over time, and for determining what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and whānau.

This summary report provides an overview of the findings from the baseline study components undertaken by Standards and Monitoring Services (SAMS).

The study utilised interviews and surveys with key stakeholders and a review of key documentation. The components of the Baseline Study undertaken by SAMS include:

- a system map of the current disability support system, outlining who was involved, how they worked together and the order of interactions throughout the system
- surveys with disabled people (and/or their proxies) and whānau, partners, welfare guardians and advocates of the disabled people
- surveys with support workers and providers.

The findings highlight important considerations for both the development of Mana Whaikaha and for service providers operating within the existing national system. The existing system will continue to be used in other areas until a decision is made on whether to expand system transformation beyond the MidCentral prototype (Mana Whaikaha).

Limitations were identified in the current system. There appears to be a disconnect at the national and local levels, particularly with reference to bureaucratic systems and service delivery. Lack of coordination between and within agencies is highlighted as impeding effective service delivery. The development of key policies appeared to many stakeholders as following a top-down approach, resulting in few opportunities for the perspectives of disabled people and whānau to be heard.

---

[1] For more information about Mana Whaikaha see www.manawhaikaha.co.nz/about-us/mana-whaikaha/

Stakeholders contributing to the system map indicated that fostering cross-agency and cross-ministry relationships was crucial to providing a seamless approach to supporting individuals and whānau.

The system map also highlighted gaps between services specific to disabled people and those services universally available. A person's health needs being seen as a 'disability support issue' rather than a health issue, for example, is viewed as a serious barrier to access to universal health services, limiting the best possible life for an individual or whānau. Gaps have also been highlighted in the quality of workforce development, transition from school to adult life, and lack of available local services. The need for individual advocacy was identified as especially important to help people navigate complex disability support services.

Overall findings regarding the current system suggest the following:

- The service system prior to the implementation of Mana Whaikaha in the MidCentral area was rigid and rule governed. This is reported to have reduced the ability of:
  - providers to deliver flexible, individualised options that may occur outside their contract specifications
  - whānau to effectively utilise a variety of respite options including being able to hire other whānau for carer support days
  - disabled people to have the type of support they desire.
- There was a belief among providers and consumer groups that the system was hierarchical with very few opportunities for disabled people and whānau, support workers, providers and consumer groups at the local level to influence policy.

Seventy-four percent[2] of disabled people and 62 percent[3] of whānau, welfare guardians, partners or advocates were satisfied with the disability support services that had been provided in the MidCentral area. However, the degree of general satisfaction needs to read against other satisfaction measures such as autonomy, social isolation, community participation and subjective wellbeing. There are a number of variables that affected satisfaction levels, such as the type of disability and degree of assessed need; the type of support package they received; their age; whether whānau were supporting the disabled person in their own home and how many people the whānau were supporting at any one time.

The indicated level of satisfaction should also be tempered by noting that nearly one quarter of disabled people and nearly one third of whānau, welfare guardians, partners or advocates said they were not satisfied with the services received:

Forty-five percent of whānau supporting at least one disabled person in their own home were less than satisfied with services.

---

[2] N = 172.

[3] N = 152.

Whānau supporting people in their own home were least satisfied, citing perceived poor connections with community, little or no time to themselves and poor subjective wellbeing.

- These whānau were typically characterised as younger families supporting children and young people in their own home.
- Whānau receiving carer support days often found it difficult or impossible to secure support workers, and when possible, relied instead on other whānau and friends.
- Support options were not well understood by whānau respondents.

Respondents for disabled children and young people in the disabled persons survey (typically whānau) indicated less satisfaction (64 percent) with services overall in contrast to disabled adults (76 percent).

Disability type, age, level of assessed need and the type of support packages provided influence how people experienced services.

Fifty-six percent of all disabled people or their proxies reported they were achieving what they wanted in their own lives all or most of the time. These figures, however, vary when age, level of assessed need and disability type are considered.

For example:

- People with very high assessed needs (VHN) were judged by their proxy representative to be less likely to achieve the things they wanted in their life, in contrast to people with lower assessed needs (43 versus 62 percent respectively)[4].
- People in residential accommodation indicated they were less likely to achieve the things they wanted in their own life in contrast to adults with supported living funding (43 percent versus 89 percent).
- People living in community residential group homes were primarily adults with learning disabilities (86 percent), most of whom had very high assessed need (92 percent)[5]. For 80 percent of these people proxy respondents such as close whānau or welfare guardians reported high levels of satisfaction with their support services, but also indicated that these people had very little control over what happened in their lives, including:
    - the kind of support they receive
    - the selection of support workers
    - with whom they live.
- Adults with physical disabilities were less likely to achieve the things they want in their life (47 percent) compared to adults with learning disabilities (66 percent)[6].

---

[4] Regardless of age.

[5] As a primary diagnosis, although many people had complex or global impairments, including significant physical and sensory impairments, behavioural and psychiatric issues and autism (almost all individuals (98 percent) over 40 years of age did not have a separate diagnosis of autism).

[6] WMW=2.6, p<0.01, df=91.

Social connectedness and an ability to access community was noted in interviews as very important in the lives of both whānau and disabled people.

A key principle of EGL is the degree to which people have access to social networks both at home and in the community. Of disabled people surveyed:

- Eighty-nine percent believe they are important to their family.
- Seventy-seven percent of all adults surveyed indicated they were single and were not now or had never been in a relationship.
- Only 15 percent[7] of adults lived with a partner or spouse. In all but two cases the disabled person had a physical disability.
- Sixty-two percent of all disabled adults surveyed indicated they had friends outside of where they lived. Nine percent said they did not.
- Seventy-two percent had visited friends in the last two weeks, but 24 percent had not visited with friends in more than a month.
- Thirteen percent of all disabled people had not ventured out into the community in the two weeks prior to the survey and seven percent of those people who had been in the community only visited shops.

Eighty-three percent of all disabled adults in the Baseline Study had not worked in the week prior to the survey.

The rate of unemployment and lower personal and household incomes for both disabled people and their whānau was cause for concern.

- The majority of people in residential accommodation pay the bulk of their benefit to the service with a set amount of spending money left aside each week.
- Of the 17 percent who had paid employment in the previous week, 64 percent of them worked less than ten hours. Only two people (of 22) worked 25 or more hours that week. Nobody said they had worked more than 35 hours.
- More Māori than NZ Europeans were unemployed (94 versus 79 percent).
- Ninety-five percent of disabled people earned less than $30,000 per year.
- All survey respondents living in community residential homes indicated they either received a benefit or earned under $30,000 per year.
- Some whānau respondents who were supporting disabled people in their own home indicated they had given up employment to provide support. The median household income levels for these whānau was between $40,000 and $50,000.

---

[7] Nineteen people.

A snapshot of key findings: Disabled Persons Survey

Disabled People or their Proxies:	Percent agreeing[8]
EXERCISE CHOICE AND CONTROL:	
Believe their spirituality/beliefs are respected	91%
Believe their culture is respected	90%
Believe support happens at times that work for them	77%
Can choose where they live	73%
Feel understood when they communicate (all adults)	73%
Feel understood when they communicate (learning disability – adults)	68%
Feel understood when they communicate (all ages)	66%
Believe support hours can be flexible	66%
Can choose what happens in their own life (all adults)	64%
Can choose where they live (learning disability – adults)	63%
Can choose who they live with (all adults)	57%
Can choose who they live with (learning disability – adults)	40%
Believe they have real choice about the kind of support they receive	48%
HAVE WHAT THEY NEED:	
Can get help with finances if they need it	87%
Are satisfied overall with services provided (combined 14 questions)	74%
Have enough support to achieve what they want	67%
HAVE POSITIVE RELATIONSHIPS	
Believe they are important to their family	89%
Have visited friends in the last two weeks	72%
Have friends outside of where they live	60%
Are in a relationship (all adults)	23%
Are in a relationship (learning disability – adults)	11%
BELONG, CONTRIBUTE AND ARE VALUED	
Are a member of a local group, club or church (all adults)	54%
Believe people in their lives value what they can do	84%
Feel they belong in their community	53%
ARE DEVELOPING AND ACHIEVING	
Feel supported to try new things (children & young people)	85%
Feel supported to try new things (all adults)	64%
Have employment (all adults)	17%
Work more than 20 hours per week (all adults – three people only)	2%
EMOTIONAL/SUBJECTIVE WELLBEING[9]	
Trust people who are important to them (learning disability)	89%
Are happy with their lives (learning disability)	89%
Are happy with their lives (physical disability)	59%
PHYSICAL WELLBEING	
Feel safe in their home	95%
Feel safe and secure	90%
Rate their general health as excellent, very good or good	75%

---

[8] Agreement with these statements is defined as answering with: ‘mostly’ or ‘always’; ‘yes/totally’ or ‘mostly’; ‘all the time/yes’ or ‘mostly’; ‘yes/lots’ or ‘some’.

[9] Self-reports only – Subjective Wellbeing questions cannot be summarised for proxy respondents.

A snapshot of key findings: Whānau Survey

Whānau, Welfare Guardians, Partners or Advocates:	Percent agreeing[10]
Are satisfied overall with services provided	63%
Believe supports work how they want	61%
Believe they can make changes to their supports if they need to	60%
Agree supports enable the person to do things that are important to them	58%
Know how much money is allocated for support	46%
Believe they are valued for the support they provide	55%
Believe support has helped them achieve their goals	54%
Can access all the information they need about support services	53%
Find supports are easy to access and use	50%
Believe support has assisted the person to connect with the community	39%
Believe the funding allocation process is clear	36%

The perceptions of whānau and welfare guardians of people supported in community residential homes are important as they are typically the only people outside of the service who play an active advocacy role:

- Many of these whānau and welfare guardians indicated during interviews they are grateful for the services provided and are generally content with the quality of care.
- Many also drew a distinction between care on the one hand and enabling individuals to live the best possible life on the other.

There was a very low response to both the provider and the support worker surveys, so results are indicative only and must be interpreted with caution. Other ways are being investigated to get further data. Of those who did respond:

- Eight of the nine providers and 60 percent of the 108 support workers who responded felt they were not easily able to raise issues or improve services.
- One-quarter of support workers were concerned about job security in the new system, although 12 percent said they didn't know much about EGL.
- Some support workers and providers believed the new system would not change anything substantially for most people as no increases in the funding were believed to accompany the change.
- Some providers were concerned about the lack of progress in completing current contract negotiations.

Many support workers and providers, however, believed that the new system would give people more control of their resources, and make the whole system less rigid and rule driven.

---

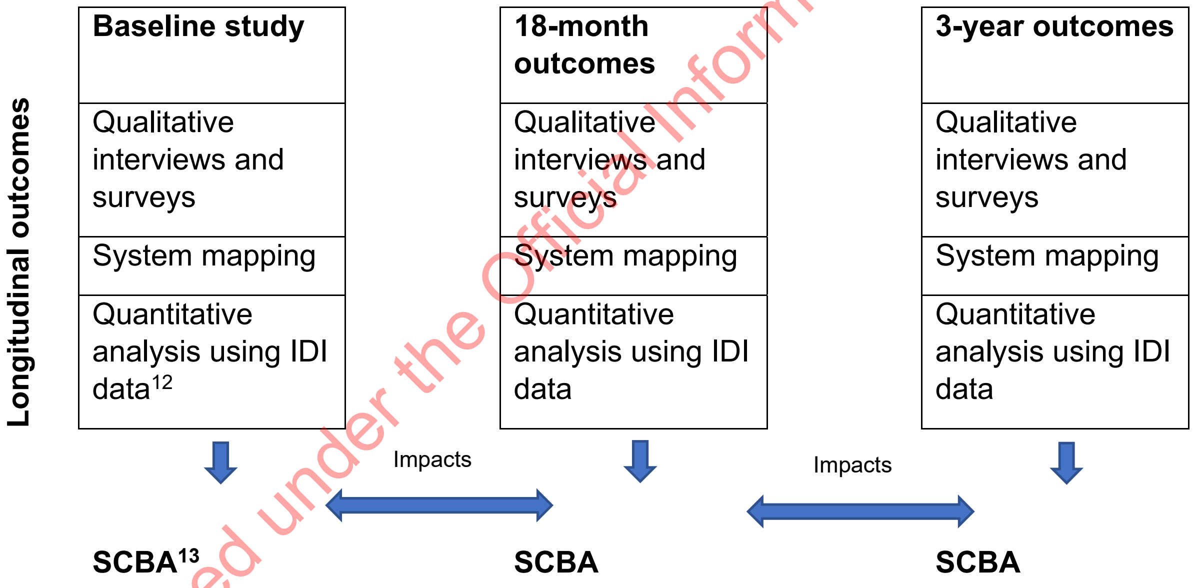
[10] Agreement with these statements is defined as answering with: 'mostly' or 'always'; 'yes/totally' or 'mostly'; 'all the time/yes' or 'mostly'; 'yes/lots' or 'some'.

2 Introduction and Background

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018[11]. The transformed system is based on the Enabling Good Lives (EGL) vision and principles and aims to give disabled people and their whānau more options and decision-making authority about their supports and lives, to improve their wellbeing outcomes, and to create a more cost-effective disability support system.

Mana Whaikaha will require ongoing monitoring and evaluation to help stakeholders understand if its objectives are being achieved, and to what extent; where improvements are needed; and if and how the approach should be adapted or expanded. A high-level evaluation approach was developed with advice from the Monitoring and Evaluation Working Group, as part of the overall work programme for designing the MidCentral area prototype.

Overview of the evaluation framework



---

[11] For more information about Mana Whaikaha see www.manawhaikaha.co.nz/about-us/mana-whaikaha/

[12] The IDI stands for the Integrated Data Infrastructure. The IDI is a linked longitudinal dataset that combines unit-record administrative information from a range of agencies and organisations. The IDI is maintained by Statistics New Zealand under strict privacy and confidentiality protocols.

[13] Social Cost Benefit Analysis.

As shown in the diagram on the previous page, the evaluation has two key inter-related components:

- Longitudinal outcomes evaluation
    - to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau
    - to determine how the system is changing over time and to what effect
- Social cost benefit analysis (SCBA) to value the impact of Mana Whaikaha.

In addition, a developmental evaluation will be used to support the 'Try, Learn and Adjust' approach being adopted for Mana Whaikaha, and to help drive meaningful change throughout the prototype period.

This report addresses the findings from qualitative interviews, surveys and system mapping parts of the Baseline Study (the components in the diagram on the previous page highlighted in green).

Aims of the Baseline Study

A baseline study is the first stage in the longitudinal outcomes evaluation, with the aim of providing a basis for assessing system level change over time. In this case, it is designed to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau. The framework for the Baseline Study is based on the theory of change and outcomes to which Mana Whaikaha will be monitored and evaluated.

The Ministry of Health commissioned Standard and Monitoring Services (SAMS)[14] to undertake the qualitative interviews, survey and system mapping components of the Baseline Study. These components were time-sensitive, reliant on people's views and experiences prior to the implementation of Mana Whaikaha on 1 October 2018, so were prioritised. This study involved collecting data through four sets of surveys and interviews including:

1. a detailed system map involving review of key documents, data analysis and interviews with representatives of both national and local government ministries, consumer organisations and providers groups
2. face-to-face interviews and surveys of 172 disabled people, or a proxy representative such as a close family member[15]

---

[14] SAMS is a national evaluation organisation governed by disabled people and whānau. It has operated in New Zealand since 1979. Interviewers were trained SAMS evaluators, comprising disabled people, family or whānau and others. For more information, see www.sams.org.nz

[15] The 172 disabled people were selected at random from the DSS data base of July 2018 using a stratified sampling process (this system chooses a certain number of people randomly from a set of groups based around disability type, level of assessed need and age).

3. face-to-face and telephone interviews with 152 whānau, welfare guardians, spouses/partners or advocates of disabled people[16]
4. surveys with 108 support workers[17] and nine provider organisations in the MidCentral area[18].

The previously established system will continue to be used in all the other areas of New Zealand until Mana Whaikaha has been fully developed and approved. Thus, the previous system is referred to as the current system throughout this summary report.

Almost all of this work was completed in September 2018 prior to the implementation of the new system through Mana Whaikaha on October 1st, 2018. Data gathering for the baseline began on 8th August 2018 and was completed in the first week of October. For more detail on the methodology of this work and the composition of the various streams of interviews and surveys, please refer to Appendix 1.

Purpose of this Summary Report

The purpose of this summary report (the report) is to describe the key findings of SAMS's study of the disability support services system in MidCentral area prior to the implementation of the Mana Whaikaha prototype in October 2018, and to provide a baseline for measurement of outcomes over time.

The report provides:

- an overview of the disability support services system prior to October 1st, 2018
- a brief overview of how disabled people and whānau responded to some survey items within key themes (service satisfaction, community engagement, income and employment, dreams and aspirations, and subjective wellbeing)
- comments from organisations and the workforce related to the implementation of the Mana Whaikaha prototype.

---

[16] These people were chosen either as a result of a disabled persons survey (where a legal guardian agreed to continue on with the whānau and guardian survey) or permission was obtained from the disabled person, or they were chosen at random from legal guardians listed in the DSS data base.
[17] Self-selected participation using an emailed Survey Monkey questionnaire.
[18] For a detailed review of the surveys and the results for each survey item within various sub-groupings, please refer to the Survey Tools Report.

3 The Current Disability Support System

The system map involved reviewing key documents and interviews with representatives of key government agencies, consumer groups and providers[19]. The New Zealand disability support system operates at two levels:

> **The national disability system** is primarily made up of government agencies responsible for creating and managing disability-related policy and legislation. Disabled persons organisations (DPOs), national provider bodies and family network organisations also work at this level. The national disability system sets the conditions for disability funding, defining eligibility criteria and service specification.
>
> **The local disability system** is made up of people using and providing disability supports and services in the MidCentral area. This includes disabled people and their whānau, people working with and for disabled people, disability-specific services and universal services that provide support, goods and services to and for disabled people.

The national and local disability systems

There appears to be a close relationship between the national and local disability systems. The national disability system has a strong influence over the local disability system. Decisions and policy made at the national level impact on the lives of disabled people, families and whānau engaged in the local disability system. It appears the local disability system does not have the same influence over the national disability system.

Findings indicate that:

- interactions between and within the two systems tend to be hierarchical
- some stakeholders have a greater ability to act directly upon the system
- other stakeholders appear to have less ability to interact directly with or modify the system
- within the national disability system, government agencies work together in different ways and to varying degrees to create policy, although several key policies support cross-government collaboration.

Each Ministry also holds its own policy around supporting disabled people, families and whānau and sets their own criteria for eligibility and funding[20]. They also appear to have their own priorities and areas of focus, as summarised in Table 1.

---

[19] For more details on those involved and the method refer to Appendix 1 and for discussion on key national programmes, strategies and commitments see Appendix 5. Diagrams for the system map are available in Appendix 3.

[20] See Appendix 5: Key national programmes, strategies and commitments.

Table 1: Summary of government agency priorities

Government agency	Agency priority and focus
Ministry of Health, through Disability Support Services (DSS)	DSS is responsible for planning and funding disabled people with disability-related support needs, primarily by purchasing disability support services and/or equipment. DSS does not provide for any income-related needs. Access to DSS services is through local Needs Assessments and Service Coordination services.
Ministry of Social Development	MSD defines its core role as income support and supporting people into employment. Access to income support and employment support is through Work and Income.
Ministry of Education	MOE works to support early childhood educators and schools to embed inclusive education into everyday practice. Access to learning support for children identified as having additional learning needs is through schools and local Special Education offices.
Oranga Tamariki	Oranga Tamariki supports the well-being of children and young people who are at significant risk of harm in their home environment. It also works with young people involved in the criminal justice system. Access to Oranga Tamariki is usually by referral or through the Oranga Tamariki website.

Access to the disability system can be through any of these agencies, and people and their whānau often struggle to access the various components and identify all the resources available to them. Conversations with stakeholders indicate that:

- Disability-related priorities held by the different Ministries do not always align.
- Many stakeholders believe differences between agency's priorities make it difficult for them to work together in a coordinated way, for example, some ministries provide funding and support directly to disabled people, family and whānau, while others direct funding and support to upskilling professionals working with disabled people, families and whānau. This impacts upon the delivery of supports to disabled people, families and whānau.

We note that there seem to be limited opportunities for the local disability system to influence the national disability system:

- Many stakeholders across both national and local systems claimed that the perspectives of government and service providers have traditionally been prioritised over the perspectives of disabled people and whānau.
- They claimed there was little opportunity for the voice of disabled people and whānau to be heard at the national disability level.
- They felt that key policies have been developed in a top-down approach.
- At the local disability system level, relationships between disabled people and whānau, support workers, service providers and agency staff were seen as crucial to the system's success and enabling people to navigate the system[21].

Stakeholders reflected upon the importance of relationships and collaborations. In particular, they spoke about:

- cross-system relationships (between the national and local disability system)
- cross-organisation relationships (between and amongst disability-specific service providers and providers of universal services)
- cross-government relationships (between government agencies).

However, respondents identified resource and budgetary constraints relating to Ministry priorities as limiting the degree to which collaboration could happen consistently. Stakeholders believed the current system infrastructure does not foster collaboration and that it is relationships between people that facilitate cross-system/organisation/government collaborations. It was suggested that this makes the system relatively unstable and susceptible to changes, for example, related to staffing and personnel.

National disability system boundaries

Findings indicate that:

- The current national disability system's boundaries create a local disability system that is difficult to use.
- Relationships between the national and local disability systems have resulted in local supports and services that are prescribed and tightly regulated.
- Stakeholders believe relationships between the national and local-level systems have created a local system that is, at times, rigid, complex and fractured.
- They spoke about a local disability system that often does not meet the needs and changing circumstances of disabled people and whānau.
- It was suggested that government agencies are inaccessible and, sometimes, 'discriminatory'[22]. A number of people highlighted poor inclusion attitudes and practices within the wider community.
- Stakeholders reflected upon complex and lengthy application procedures.

---

[21] For more information about the local disability support system, refer to Appendix 6.
[22] This term and other descriptive words in this paragraph were used by participants.

- They talked about the system as ‘deficit-based’, with disabled people and families/whānau required to focus on the ‘problems’ related to their impairments and undergo numerous assessment procedures to justify their disability-related need.
- Stakeholders talked about the strain providers and support workers feel working within a system that doesn’t allow them to provide individualised supports.

Gaps in service provision

All stakeholders talked about gaps in policy and service provision at both the national and local levels.

The national level

Interviews with stakeholders indicated government agencies hold limited statistics about the disabled people and their whānau using their services. Many people use multiple services and it seems that any cross-agency sharing of disability data that does exist is minimal.

The relationship between disability-specific services and universal services

Stakeholders reported the current system makes it difficult for disability-specific services and the universal services to work together. The implication of this is that many universal services lack the knowledge to interact confidently and appropriately with disabled people and their whānau. For example:

- Stakeholders talked about universal services as having:
    - limited community-development opportunities to learn about disability rights
    - limited knowledge of accessibility needs and reasonable accommodation
    - limited understanding of the value of including disabled people’s perspectives during consultation, planning and design.
- Stakeholders spoke in-depth about disabled people who have multiple health issues, particularly mental ill-health, dual disability diagnoses and/or multiple support needs and their experiences of universal services. Stakeholders believe that for this group of disabled people the system leads to inequitable access to, and experience of, universal health services.

Workforce development

Stakeholders remarked that there is no cross-agency policy for a nationally consistent, fit-for-purpose training scheme and qualification for support workers and teacher aides:

- We note a combination of low pay, lack of training and challenging working conditions can make it difficult for the disability services sector to attract and retain staff.
- Inadequate workforce development negatively impacts on the lives of disabled people and their whānau.

Independent individual-level advocacy

A number of stakeholders highlighted the need for independent one-on-one advocacy that could support people to understand and navigate the disability services system:

- Stakeholders talked in particular about the importance of advocacy for people with learning and communication impairment or for people who have limited support networks.
- This seems particularly important within the context of ideas around personalisation, choice and control, which are beginning to inform the national disability services system.
- As people begin to action more choice and control over their disability supports, they will need to be able to convey their own circumstances, needs and aspirations to the system.

Transitioning from school into employment or further education/training

Stakeholders stated that there is limited support to prepare people for the transition from school into employment or further education/training:

- They drew attention to the lack of a co-ordinated, cross-organisation approach between schools and adult disability services.
- Stakeholders also talked about limited meaningful post-school options, including pathways to further study/training or work and community activities.

The local level

Traditional disability support system, lack of availability of local services and stretched resources

The MidCentral area is dominated by large providers who offer traditional support options, such as residential services. A traditional provider market offers little flexibility and few community options:

- Stakeholders were concerned there is limited availability of local services and stretched resourcing of those that are available.
- In particular, there are limited respite options and long waiting times for services.

People living in rural/isolated areas

Disabled people living beyond the urban setting face additional barriers to accessing supports:

- Stakeholders commented on the limited availability of supports in rural/ isolated areas.
- They noted that the disability services system often requires people to travel to attend face-to-face meetings with agency workers. Stakeholders referred to a lack of accessible transport and the high costs associated with traveling long distances.

Perceived barriers to service access based on ethnicity

Stakeholders made the point that there are disabled Māori and their whānau who are eligible for disability support services but are currently not engaged with the system. They stressed that the current disability services system is not facilitating access for and engagement with these people[23].

The area also lacks culturally appropriate supports for the refugee community:

- Stakeholders believe that this group's needs and voices are often unaccounted for in the local disability services system.
- Several stakeholders felt that a lack of translation services is a particular barrier to access for the refugee community in the MidCentral area.

---

[23] Note: the results in Section 3: Disabled People and their Whānau relate to people already receiving services and do not address access issues.

4 Disabled people and their Whānau

When making assessments for service provision, a holistic approach is required that takes into account multiple factors that may influence outcomes for people. In particular, the context of a whānau is an important consideration, especially where the primarily unpaid carers may themselves require support. Likewise, the impact of disabling conditions, the degree of assessed need, age and specific health issues may contribute to how people experience the disability support system.

With these variables in mind, this section focuses on people's experiences of the disability support system and considers whether some groups experience the system differently and what outcomes they experience as a result, especially in terms of their hopes and dreams, work and income, community and social isolation, and subjective wellbeing (SWB).

Disabled people's satisfaction with & experience of the disability support system

Adults **with** disability

Disabled people's general level of satisfaction with supports and services offered to them appeared, at first glance, to be reasonable, with approximately three-quarters of the people who completed the disabled persons survey indicating they were mostly or always (74 percent)[24] satisfied with their supports across a number of indicators:

- The remaining quarter did not provide overwhelmingly positive responses to Likert Scale items of satisfaction, instead they opted for moderate (somewhat satisfied) to completely dissatisfied responses.
- The variation in responses appeared to be influenced by multiple factors, including who the disabled people were (their impairment, level of assessed need[25] and age), where they lived and the support packages they received.

---

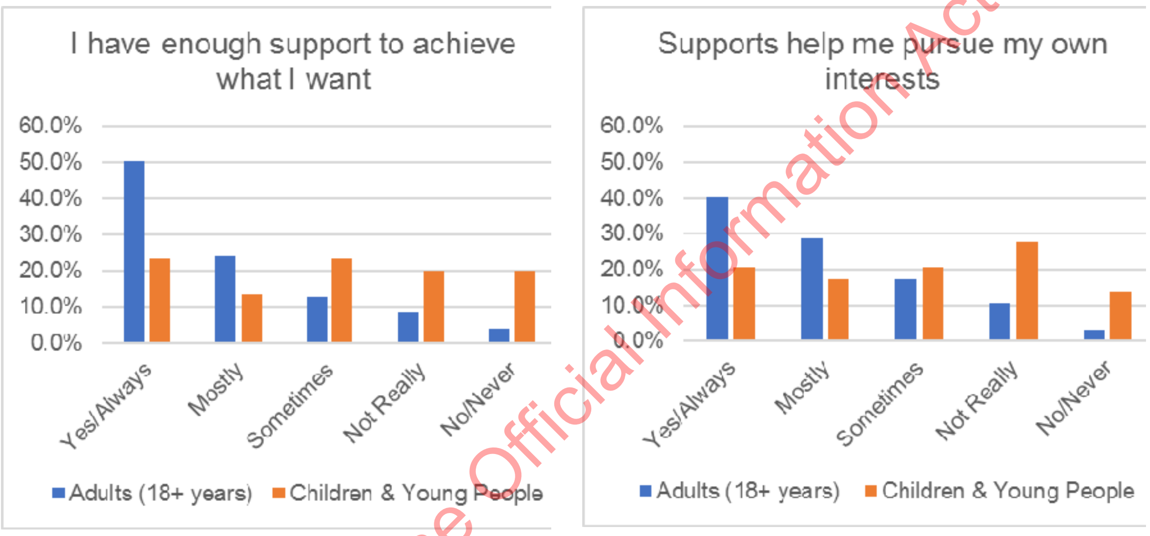
[24] This percentage was calculated from 14 Likert Scale survey items (questions) that focused on service satisfaction. As an 'overall' percentage it should be treated with caution since each Likert Scale item tested an independent construct. However, it provides the flavour of responses concerning service satisfaction.

[25] According to the needs assessments conducted by Enable New Zealand and provided in the DSS data base (two ratings in the data base were provided – the SPA rating and the total disability support level). The level of assessed need used in this report is the higher of the two levels of assessed need. For 98 percent of the disabled people who responded to this survey level of assessed need was the same for both variables in the DSS data as at July 2018.

Whānau responding for children and young people with disabilities[26]

In contrast to adults with disability, proxy respondents for children or young people in the disabled persons survey were generally less satisfied with services over a number of indicators in the survey. As shown in Figure 1, respondents for children or young people expressed less satisfaction overall, in areas such as getting enough support[27] and supports helping them pursue their own interests[28] when compared to adult disabled people.

Figure 1: Children and young people compared with adults on satisfaction with disability support services



Whānau provided similar responses when completing their own survey:

- Whānau who were not supporting disabled people in their own home were generally satisfied with services overall[29] (81 percent all or most of the time).
- Whānau who were supporting disabled people in their own home were less satisfied with services overall, at 45 percent[30].
- Those not supporting people in their own home were less dissatisfied with services (10 percent not really/never) compared with those who were supporting disabled people in their own home (32 percent).

---

[26] In 87 percent of cases, a proxy respondent (typically an immediate whānau member) responded for children and young people under the age of 18 years.

[27] WMW=3.8, *p*<0.001, df=38.

[28] WMW=3.2, *p*<0.001, df=37.

[29] Based on survey item, ‘overall services for my family member work well’.

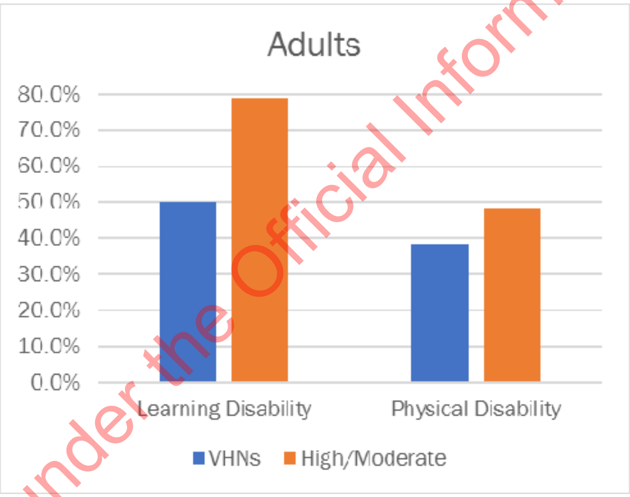
[30] WMW=8.7, *p*<0.001, df=70.

Satisfaction by type of disability

Variations between people with different types of disabilities were also noted in the survey results:

- Fifty-six percent of all disabled people or their proxies suggested they were achieving what they wanted in their own lives all or most of the time.
- These figures vary when age, level of assessed need and disability type are considered separately.
- People with very high assessed needs (VHNs) were less likely to agree that they were achieving the things they wanted in their lives all or most of the time, compared with people with lower levels of assessed need[31].
- Fewer adults with physical disabilities agreed that they were achieving the things they wanted in their lives all or most of the time, compared with adults with learning disabilities[32].

Figure 2: Responses to the item: 'I am achieving the things I want in my life (all or most of the time)', by disability type and degree of assessed need



- Respondents for children and young people with moderate assessed needs were more likely to indicate they were achieving the things they wanted in their life all or most of the time, when compared with those with very high needs (VHN)[33] and high assessed needs.

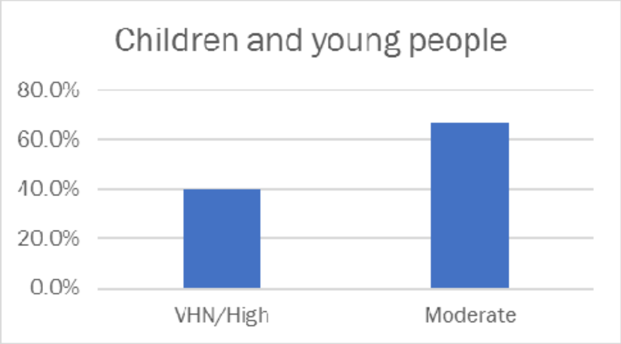
---

[31] For learning disability only, VHN versus high/moderate assessed needs, WMW=3.3, p<0.001, df=23.

[32] WMW=2.6, p<0.01, df=91.

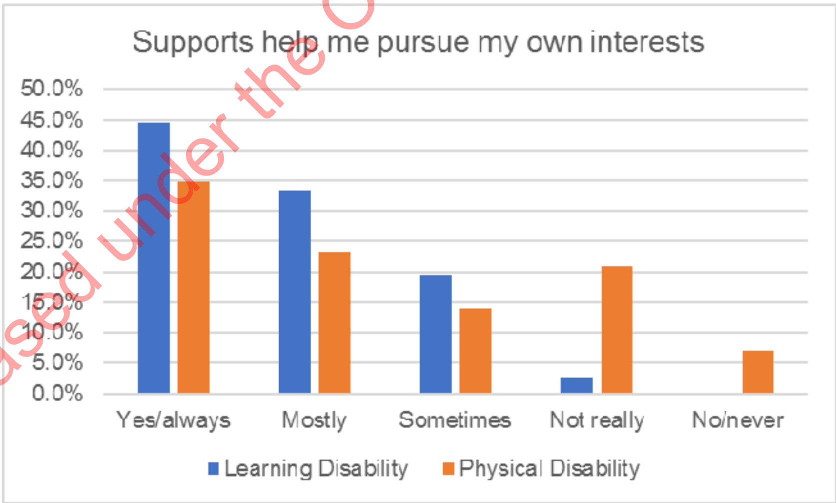
[33] Only two children and young people in this sample had VHNs. Nineteen were assessed with high needs and 17 moderate needs (sample size was too small for significance testing).

Figure 3: Responses to the item: 'I am achieving the things I want in my life (all or most of the time)', children and young people by degree of assessed need



- Considering disability type by satisfaction with supports, people with physical disabilities are less likely to believe that supports assist them to pursue their own interests[34] when compared with adults with learning disabilities. However, people with physical disabilities were more likely to be receiving household management and/or personal care support, which does not provide for community integration. Only 15 percent of this group are in supported living or community residential services.

Figure 4: Response to the survey item; 'Supports help me to pursue my own interests', by disability type (adults)[35]



- There were no differences of note for degree of assessed need between these groups for this particular survey item.

---

[34] Fifty-eight percent (all or most of the time) and 28 percent (not really or never), compared with 78 percent and 3 percent respectively for people with learning disabilities.

[35] There were insufficient numbers of adults with a primary diagnosis of ASD (n=7) to include in this figure.

Satisfaction by type of support

Level of satisfaction and the experience individuals had of the support system varied according to the type of support packages they received.

Household management and personal care support

In total, 20 percent of the adult disabled people surveyed[36] received only household management and/or personal care support. The majority of this group were people with physical disabilities (89 percent):

- This group was generally very satisfied with support worker(s) services.
- There was a great deal of satisfaction with the quality of the support provided and qualitatively the friendliness and dedication of staff.
- Physically disabled people receiving household management and personal care support only are less likely to agree that their supports can assist them to connect with community or friends in comparison with all other adults receiving services. Household management and personal care support do not include support with community engagement.
- Positive perceptions for this group may be due to a belief that the support they do get enables them to make their own connections with community and friends.

Residential services and people with very high needs

One of the more traditional supports available was residential services. Residential services offer 24/7 support and are expected to be responsive to each person as an individual and provide for their personal aspirations and interests[37]. Of disabled people surveyed:

- Twenty-seven of the adults surveyed in the disabled persons survey who now live in residential services had previously lived in the Kimberley Centre, the last institution for people with learning disabilities in New Zealand, which closed in 2006.
- The majority of the people with a principal diagnosis of learning disability who are living in community residential homes are assessed with very high support needs (90 percent)[38].
- Sixty-seven percent of all those surveyed who lived in residential services had proxy respondents (30 people), typically being legal guardians (welfare guardians)[39] who were also whānau.
- All but two of these people were assessed with VHNs (93 percent). All but one person living in residential services who had a proxy respondent was an adult (29 people).

---

[36] At the time data was extracted from material within the DSS data base, July 2018.

[37] Unless otherwise stated, residential services refer to all disabled people in residential accommodation, not just community residential homes for people with learning disabilities.

[38] Only 8 percent of learning disabled adults who have high and moderate assessed needs (in total) live in community residential homes.

[39] Protection of Personal and Property Rights Act 1988.

- Eighty percent of whānau and welfare guardians of people living in residential services who also acted as proxy respondents indicated in their own survey that ‘overall supports for [their] family member worked well’ (all or most of the time).
- Proxy respondents for people in residential services also indicated in more specific questions that they were satisfied with the quality of services provided (both in their own and in the disabled persons survey where they acted as proxies).

However, despite these indications of satisfaction proxy respondents for adults in residential services did not believe the disabled person they supported experienced a great deal of control over their own life or the services they received[40]. They said:

- They had little control of their own life. Only 17 percent believed they had this control all or most of the time.
- They experienced few choices in the kind of support they received. Only 25 percent believed they had this choice all or most of the time.
- They had few opportunities to choose support staff. Only 11 percent felt they had this choice all or most of the time.
- They had little choice about housemates. Only 9 percent believed they had this choice all or most of the time.
- Fifty percent believed they were achieving the things they want in their life all or most of the time.

The perceptions of whānau and welfare guardians for people supported in community residential homes are important as they are typically the only people outside of the service who play an active advocacy role:

- Many of these whānau and welfare guardians indicated during interviews they are grateful for the services provided and are generally content with the quality of care.
- Many also drew a distinction between care on the one hand and enabling individuals to live the best possible life on the other.

Having a sense of control over what happens in life (autonomy) and being able to plan and actively pursue interests and aspirations is central to Enabling Good Lives principles.

Similar to responses for people in residential settings, perceptions for people with very high assessed needs were positive with regard to support services but lacking with regard to how much control people had in their own life and what they were achieving. For instance, people with very high assessed needs (VHN) indicated (either themselves or through proxy respondents) they were less likely to achieve the things they wanted in their life, in contrast to people with lower assessed needs (43 versus 62 percent respectively)[41].

---

[40] Responses from proxy respondents only for adults in residential services: all disability types.

[41] Regardless of age. For people with learning disabilities only, the same comparison is 34 to 78 percent. WMW=4.8, $p<0.001$, df=48.

Carer support and respite

Typically, carer support subsidy days are allocated to whānau and other carers to give them time for themselves or other tasks. Thirty-five people in the disabled persons survey received carer support and 45 whānau who were supporting people in their own home received carer support[42]. Whānau, in particular, were generally grateful to get carer support days and/or respite, however, they also expressed many concerns. They reported difficulty in securing support workers because of:

- Inadequate funding for the carer support and respite role. Sixty-two percent of whānau who supported at least one disabled person in their own home could only occasionally or could not easily find carers for the funding provided. At the time of the survey, carer support was funded at $76 a day.
- Insufficient hours, when paying people at the hourly rate, to make it attractive to support workers.
- Insufficient days allocated in the year to make it attractive to support workers[43].
- Location where some disabled people live – small towns, rural, etc.
- Trust issues: 17 percent of respondents in the whānau and guardians survey who were supporting at least one disabled person in their own home talked about trust, especially in relation to paid support workers or respite services.
- Turnover: the effort required to secure support workers and the time required to get to know them, and vice versa, made potential turnover issues a real concern.
- Lack of back-up carer options if the main paid carer was away or sick.

Because of the funding for carer support days, many people utilised other whānau and friends who were willing to provide relief for the entire allocated period. A few respondents, however, lamented the rules concerning utilising whānau members who lived at the same address. As one respondent explained:

> *It's hard to find someone to do the support – I bought a house with a granny flat for my mother to move into so she could support my son, but I have been told she can't do the support as she resides at the same address but lives under a different roof. She can't get a job as I need her to support my son.*

Thirteen percent of whānau and guardians who were supporting at least one disabled person in their own home raised issues concerning rigid and inflexible services or rules. Rules about how funding can be used and who can be hired (eg, no one living at the same address) have created situations where funds are not being used or not being used in a manner preferred by the disabled person and/or their carer. For example, one person noted:

> *They cut the home support hours – don't really know why – too many rules about what support can be used for. For example, getting my wife's nails cut.*

---

[42] Fifty-one whānau/disabled people were represented in both surveys.

[43] On average 24 days were allocated per year per disabled child/young person with a range of 3–83 days (n = 28) and for adults an average of 40 days with a range of 11–95 days (n = 17).

A parent also noted:

> *It has to be used by certain date. Have lost 4 days. Should not be time limited – should be able to carry over. For example, [I] could have used the four days this school holiday, but gone now.*

Carer support days were intended as one type of respite for whānau among others. Yet, respite options were not well understood by whānau (whānau survey):

- Only 36 percent of people getting respite or carer support days[44] understood what respite options were available to them in MidCentral (all or most of the time).
- Most respondents were only aware of the type of respite offered to them, the most common of which were carer support days.

Respite options included individualised funded (IF) respite packages and facility based (out-of-home) respite. Other support also included buddy support and specifically ear-marked carer support subsidies for such things as community participation or for someone to attend Special Olympics.

Facility-based respite options (or out-of-home respite) for adults usually involved allocated time (days) at a rest home. This type of support was not favoured by most people who referred to it in conversations with interviewers.

Out-of-home respite for children and young people is generally only available to a small number of people, and many whānau (in both surveys) were concerned about not knowing the staff on duty at the time of a visit or the other children and young people staying at the time.

Trust was an important issue for whānau with regard to hiring support workers and placing children and young people in out-of-home care.

Supported living

Supported living is provided to individuals who are able to live reasonably independently in their own home. While supported living packages do involve a degree of personal and household support, the emphasis is toward increasing the person's independence in these activities and providing active supervision where needed. It may also involve assistance with appointments, filling out forms, budgets, diet, exercise, and attending activities in the community. For most people, a person-centred, aspiration-based plan is developed and support workers assist people to pursue particular goals or aspirations. Among those surveyed:

- Supported living was used most often by people with learning disabilities (88 percent) who had moderate to high support needs (96 percent).
- For the most part, people with supported living funding were very satisfied with the services they received[45] and believed those services helped them stay connected with friends and the community[46].

---

[44] There also appeared to be some confusion with regards to terminology, with 'respite' being used to describe the carer support subsidy.

- Unlike those individuals in community residential homes, people who have supported living funding indicated they had a great deal of control over their daily lives.
- None of those in supported living believed they did not have control of their own lives to some extent.
- This contrasts with respondents for people who live in residential services[47], where 31 percent indicated the person had no or little control of their own life[48].

Resources, modifications and equipment

Nineteen people (or 17 percent of all disabled people) indicated they did not believe they had all the equipment they required ('not really' or 'not at all'). There were five cases where people indicated delays in receiving modifications and equipment[49]. They also noted the rules that govern provision of equipment sometimes created these delays or limited what they could receive.

For example, one person who lived rurally indicated he had been waiting on a ramp to assist with exiting his home and had in the meantime built a ramp to his back door. Because he had already built a ramp, he was told he could not have one installed to his front door, even though this was the most logical and efficient exit point.

---

[45] For example, for the Likert Scale item, 'My support occurs when I need it in my life', 86 percent indicated this was the case all or most of the time (n=22). Further, 76 percent believed support helped them pursue their own interests all or most of the time (for all people receiving supported living funding, n=25).

[46] Seventy-five percent indicated that their supports helped them connect to people and places that are important to them (n=20) and 73 percent believed they were supported to be an active member of their community (n=22) all or most of the time.

[47] Both self and proxy respondents.

[48] All people in residential services versus all people with supported living funding, n=45 and n=25 respectively, WMW=4.6, $p<0.001$, df=55.

[49] Or 14 percent of the 35 people who provided an additional verbal or written response to the question regarding equipment.

Māori Respondents

Māori disabled people

The survey sample for disabled people included 17 percent Māori[50], 76 percent NZ European and the remainder included a mix of other Europeans[51], Asian, Fijian Indian and Pasifika.

- Eighty-six percent of Māori surveyed believed their culture was respected by their supports all or most of the time (compared with 91 percent of NZ Europeans)[52].
- Ninety-five percent of Māori surveyed believed their spirituality or beliefs were respected by their supports all or most of the time, compared with 92 percent of NZ Europeans surveyed.

The main point of difference for Māori taking part in this survey was in regard to work:

- Ninety-four percent of working-age[53] disabled Māori had not worked in the previous week compared with 79[53] percent NZ Europeans.

Māori whānau

Māori represented 15 percent of the whānau and guardian survey:

- Three-quarters of this group believed their culture was respected all or most of the time.
- Of the four people who did not believe supports respected their culture, all also stated they did not believe the support system provided sufficient support for their whānau.
- In general, there were few differences between Māori and NZ European whānau in terms of their views of the supports they receive. For example, 63 percent of NZ European whānau believe supports worked well (all or most of the time) compared with 57 percent of Māori.
- Unemployment rates for the whānau survey respondents was higher for Māori (55 percent) compared with NZ Europeans (38 percent).

---

[50] Some people identified only as Māori, others included other ethnicities as well as Māori.
[51] German, British, North American, and Australian.
[52] There were insufficient numbers of people in the Pasifika and Asian (n=3 in total) categories to provide a viable comparison.
[53] Ie, 17 to 65 years and not in school.

Community engagement

Enabling Good Lives (EGL) is an approach to supporting disabled people and their whānau that was developed by disabled people and whānau. It is the guiding principle for Mana Whaikaha and questions reflecting the principles were embedded in the survey documents. The principles can be found on the EGL website[54].

The EGL and Mana Whaikaha approach offers individuals greater choice and control over the disability supports they receive. This enables people to plan for the lives they want to live. At the heart of EGL is the expectation that disabled people will be enabled to live ordinary lives in ordinary places. For most, this expectation relates to living their lives in the general community.

Belonging, contributing and being valued

One Likert Scale item in the disabled persons survey asked people to respond to the statement, 'My supports help me to strengthen my relationship with my community':

- Overall, 30 percent of the 101 people who responded to this question stated supports did little to strengthen their relationship with the community (never or not really).
- Some support packages are more likely to contribute to community involvement directly, such as residential, supported living and day programme support, as components of this support should be built into what people receive.
- For example, only 23 percent of people in residential settings did not believe their supports helped them strengthen their relationship with the community.
- Conversely, of those receiving only household management or personal care support, a support package that does not contribute to community involvement as such, 63 percent[55] did not believe supports assisted them to strengthen relationships with their community, as community involvement does not form part of these packages.
- A few packages were designed specifically to assist with community involvement. In particular, two people identified funding that had been made available to help them attend Special Olympics, two whānau used funding to engage a 'buddy' for their disabled children[56] and three people listed community activities or outings as part of their funding arrangements.

In the two weeks before the survey, 13 percent of disabled survey respondents had not ventured out into the community[57], and of those who had, seven percent had *only* gone to a shopping centre or grocery store.

---

[54] www.enablinggoodlives.co.nz

[55] N = 19.

[56] A paid support worker for a disabled child or young person with the specific role of being a buddy to the disabled person, ie, helping the disabled person engage in community activities and hobbies that the disabled person enjoys.

[57] It is possible that access to the community was also affected by the season (late winter/early spring).

The most common place respondents noted they visited in the previous two weeks were:

- cafes and restaurants (62 percent)
- shops, often grocery stores but also other retail outlets and malls (55 percent)
- swimming pool, such as the Lido in Palmerston North (28 percent)
- local library (25 percent)
  parks, including play parks, beaches, walking tracks, etc (20 percent).

The survey also asked people to list community groups or clubs they may attend and/or have membership, such as religious groups, marae, sports teams, etc.

- Forty-six percent of survey respondents did not belong to any group or club.
- Close to one-quarter (26 percent) stated they belonged to or attended a religious group such as a church.
- Eleven percent belonged to Special Olympics.
- Eight percent belonged to a support group such as Multiple Sclerosis New Zealand, Cerebral Palsy Society, Parent to Parent or People First New Zealand.

Having positive relationships

Another key principle of EGL is the degree to which people have access to social networks, both at home and in the community. Social isolation is an important consideration for people with disabilities, particularly with regard to their friendship networks and relationships.

- Eighty-nine percent believe they are important to their family.
- Seventy-seven percent of all adults surveyed indicated they were not now or had never been in a relationship.
- Only 15 percent[58] lived with a partner or spouse. In all but two cases the disabled person had a physical disability.
- Sixty-three percent of the adults surveyed indicated they had friends outside of where they lived[59]. Nine percent said they did not.
- Seventy-one percent said they had visited friends in the last two weeks. Thirty-six percent had not had contact with friends in the previous week and 24 percent had not had contact with friends in more than a month.

For people in residential settings, there is a realistic understanding among welfare guardians and whānau that the social networks of these individuals generally consist of family/whānau and people from other residential homes and vocational settings. These networks are important and for some include life-long friendships. The ability of people in these settings to develop relationships with other people in the community is limited due to a lack of opportunity.

---

[58] Nineteen people.

[59] And 60 percent of all disabled people surveyed (including children/young people)

Transportation

A few respondents to both the disabled persons and whānau surveys[60] talked about the issue of transportation:

- The most prominent issue concerned costs, particularly with regard to use of taxis (five people), but also simple issues such as the cost of parking.
- Some people talked about not knowing what they were entitled to with regard to transport costs (two people).
- Others referred to not being able to use funding for transport (three).
- Two people referred to support workers not being permitted to provide any sort of transportation in their own cars. For individuals who are being supported to go shopping, this may be particularly limiting.
- Other services do provide transport. For one man who lives alone in a rural location, the once-a-week trip into town for groceries and a fish-and-chip lunch was the only time he got out in the week.

Being able to get out and about may have direct implications for social isolation or simply enjoying life outside the home. The transport issues identified included:

- Cost: even with taxi vouchers, a return fare can be too high for many disabled people to afford.
- Loss of ability to drive: many people, especially those who have acquired disabilities, are no longer able to use their own vehicles.
- Location: some people live in small towns or rural locations where public transport options are limited.
- Access: some respondents noted that even where buses were available, they were not yet fully accessible.
- Time: two whānau commented on the time spent transporting people to places such as school or work. One parent noted early starts and up to two hours a day spent in transport.

---

[60] Eleven disabled people and five whānau raised issues about transport without prompting (word searches for car, cars, transport, taxi, scooter).

Income and employment

Whānau and guardians

Forty-three percent of all people who supported at least one disabled person in their own home had a combined household income of $40,000 or less, and only 12 percent had a household income of over $100,000. The median for this group was between $40,000 and $50,000[61]. An economic issue for some of these whānau occurs when a carer gives up work or simply cannot work due to the support needs of a disabled person. This has significant issues for families where there is only one carer and in situations where one partner in a relationship has had to give up a career and/or income to support a disabled person:

- In one of the families taking part in this survey, both parents had to give up professional work due to the needs of the children in the home.
- In another situation, where one parent reported needing to give up their employment, the household income was effectively halved (down to $45,000).
- In many of these cases, whānau reported needing to have someone home before and after school, during school holidays in particular, and when the disabled child or young person was sent home from school due to sickness or behaviour problems.
- In a few cases, whānau reported that the disabled child/young person was only sleeping a few hours at night, significantly reducing the ability of one care giver (or both) in the whānau to work.
- Thirty-two percent of all working age whānau were not employed at the time of the survey[62].
- When we considered whānau respondents who were supporting people in their own home and who were less than happy with their disability support services[63], the number indicating they were unemployed rose to 49 percent, compared with those who were happier with services (30 percent).

---

[61] The average for the respondents taking part in these surveys was slightly higher at $50,000 to $60,000. The national median household income (regular and recurring) for 2018 as calculated by Statistics New Zealand was $83,001 and the average was $105,109 nationwide (see https://figure.nz/chart/yiJz6VUr64vQ68Du and https://www.stats.govt.nz/information-releases/household-income-and-housing-cost-statistics-year-ended-june-2018). Statistics New Zealand listed the gross national disposal income average in 2016 as $48,504 (per person) http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-progress-indicators/Home/Economic/disposable-income.aspx with poverty indicators set at below 50 and 60 percent of the median disposable income per person. This equates to 10 and 18 percent of New Zealanders respectively falling below that line. http://archive.stats.govt.nz/browse_for_stats/snapshots-of-nz/nz-progress-indicators/Home/Social/population-with-low-incomes.aspx

[62] The employment rate in New Zealand in the third quarter of 2018 was 68.3 percent with an official unemployment rate of 3.9 percent https://tradingeconomics.com/new-zealand/employment-rate

[63] Based on people who responded (somewhat, not really or no/never) to the item: Overall supports for my family member work well. See section 2.6.1.

Developing and achieving

The rate of unemployment and lower personal and household incomes for both disabled people and whānau is cause for concern:

- Over one-third of all disabled adults taking part in the survey indicated they were on a benefit or superannuation (40 percent)[64].
- Survey respondents living in community residential homes all indicated they either received a benefit or earned under $30,000 per year.
- The majority of people in residential accommodation pay the bulk of their benefit to the service with a set amount of spending money left aside each week.
- Of the remaining forty-two disabled adults who provided useable figures, the average and median reported incomes were between $10,000 and $20,000, with two people indicating earnings over $40,000.
- Eighty-three percent of the disabled adults surveyed had not engaged in paid employment in the week before the survey.
- Of the 22 people who had paid employment, 14 people (64 percent) had worked less than 10 hours in the previous week. Five worked between 10 and 20 hours and three between 20 and 35 hours in that week.

Currently more adults with learning disabilities reside in residential accommodation or with whānau (78 percent in total), and more adults with physical disabilities live with a spouse/partner or alone[65] (75 percent in total). For respondents who were living with a spouse or partner who was earning, there may be a boost in the amount of disposable income that could be shared. Others may have the support of other whānau to supplement their available income.

A concern that continually recurred in the survey related to the disabled person's financial situation and not being able to afford to pay for things. This ranged from visiting dentists or other health professionals to transport[66].

One man who really focused on his financial situation during interviews stated he couldn't go out into the community:

> *It's not happening due to finances and health. I can't go out. Can't remember the last time I had a good dinner…. I would like to join the Cossie Club. I would like to join the 'four stroke club'*[67]*. I don't have the money to get there every Tuesday. Gas money and stuff.*

---

[64] In 2018, the median annual household income from Government benefits, excluding superannuation and war pensions, was $11,262 with a mean of $14,651. The median for people on superannuation and war pensions was $17,801 with a mean of $18,839. https://figure.nz/chart/OToNBIID6B7ZkZlp-Scm6oim0HTjX7LB2

[65] All children and young people and five (of nine) adults with ASD live with family/whānau.

[66] For example, eight people with physical disabilities stated they could not afford dentists, seven people stated the cost of transport was an issue, six people believed they could not access the community in various ways due to cost, and nine people thought they could not pursue further education due to cost.

[67] A Waikato project for stroke victims that sees them dismantling cars as a form of rehabilitation.

Eighteen percent of people with physical disabilities referred to financial concerns. The man from the example above went on to state:

> *I didn’t realise you had to be rich to be ill or injured.*

Dreams and aspirations of disabled people and their whānau

Several important principles in EGL concern self-determination, person-centred and ordinary life outcomes[68]. With these principles in mind, both the disabled persons survey and the whānau survey asked respondents to describe what was most important in their lives, and what they would like to achieve, do more of or start doing:

- Carers of disabled people are often not just parents (72 percent) but also extended whānau, such as grandparents, uncles, aunties and siblings.
- A concern expressed by many of these whānau was the future of the disabled person(s) they supported, whether or not they lived in the same setting (see next section).
- Some packages, such as personal care and household management and carer support, only provide support for the present and do not involve next steps or provide contingency plans.
- Some are able to consider some dreams and aspirations (such as residential or supported living packages) but few are sufficiently equipped to deliver.

What is important in your life?

When asked what was most important in their lives:

- Seventy-three percent of responses by disabled people revolved around family and 22 percent around friends.
- For whānau, the predominant response also related to family (58 percent) followed by concerns for the future support and wellbeing of their disabled person(s) (13 percent).
- Having a sense of security was important both for the disabled person's immediate physical wellbeing and also in terms of feeling positive about the future. For example, one whānau member stated she would like:
    - *to do things without worrying about my son. [I] have only just retired – good to go on holiday without worrying about what is going to happen.*
- Whānau were also concerned for their own health (12 percent)[69]. This sentiment was expressed best by one couple when asked what was most important to them:
    - *[Mum] Sleep! It's like you've had to give up your whole life.*
    - *[Dad] We have already, I look at what my friends do in their lives ... all these cool things – we have none of that.*
    - *[Mum] Take the kids camping, do this, do that, and we're just like we'd love to, but we can't do it. ... Just find at least one or two carers that help, and then we would actually start a bit of a*

---

[68] www.enablinggoodlives.co.nz
[69] Including happiness and reducing stress and tiredness, having time to self and time for others.

> *life together. The last time we went out to dinner was three years ago.*

What do you want to be doing more of in your life?

Both disabled people and their whānau were asked what they would like to achieve, start doing or do more of in their lives:

- For whānau, the most prevalent response was to travel more or take a holiday (23 percent), especially with other family members.
- Also important was having time to self (19 percent) and spending time with family/partner and others (15 percent, including friends). The emphasis was around the importance of being able to do normal things and have time to relax and socialise.

Responses from disabled people were more diverse, but core aspects were getting out more[70] (10 percent), having a holiday (9 percent), getting a job (6 percent) and seeing family and friends (10 percent).

Subjective Wellbeing (SWB)

Whānau

One statement[71] in the whānau and guardians survey asks respondents the extent to which they agree that, 'Overall, supports for my family member work well'. Using this question to separate the satisfied from less satisfied respondents proved reflective of all other satisfaction questions. All other satisfaction questions showed those responding as satisfied to Question 22 were significantly more satisfied (all or most of the time) for all 21 other satisfaction questions[72]:

- Sixty-three percent of whānau and guardians generally were satisfied with the disability support services available in the MidCentral area[73].
- Of those people who were less satisfied about how well supports were working, 85 percent were whānau who were supporting at least one disabled person in their own home.
- Of those who were supporting at least one disabled person in their own home, 55 percent were satisfied with services all or most of the time. The remainder were less satisfied (sometimes to not at all satisfied) with services.
- This suggests that 45 percent of whānau and guardians who are supporting at least one disabled person in their own home are less satisfied with services in general, not just in relation to the key question above.

---

[70] As a general statement, such as "getting out more", "getting into the community", "getting out of the house", "join a club".

[71] Question 22.

[72] $p<0.01$ (for one question), $p<0.001$ (for 20 questions).

[73] These figures were derived from Question 22 that asked respondents to rate the following statement on a five-point Likert Scale: 'Overall, supports for my family member work well'.

Figure 5: Cantril Ladder: SWB of whānau and guardians who were supporting disabled people in their own home

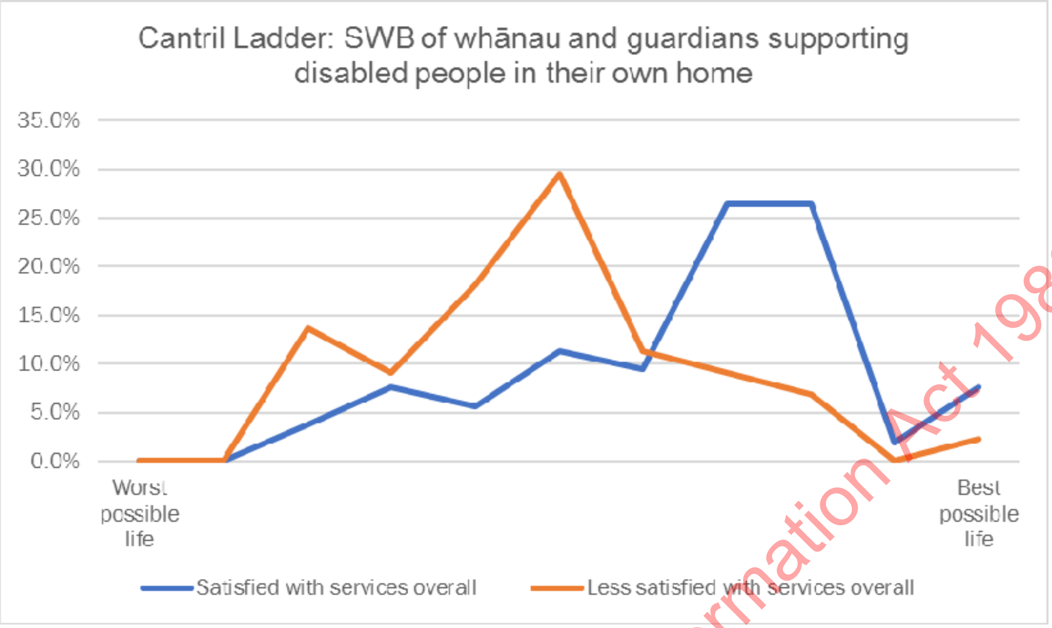


Figure 5 above shows the less satisfied group also scored lowest on the main SWB score, which in this case was the Cantril Ladder[74] (the average for this group was 4.8 compared with 6.5 for the upper group), (WMW=4.1*, p*<0.001):

- The less satisfied group was characterised by respondents who predominantly supported children and young people with or without disabilities in their own home (84 percent, compared with 62 percent for the more satisfied group), and often more than one disabled people in the same household (23 percent, compared with 13 percent for the more satisfied group).
- The more satisfied group were people who more often supported at least one adult with a disability in their own home (42 percent) in contrast to those who were less satisfied with services (27 percent).
- Stress factors were cited regularly for whānau who were less satisfied with services overall, with over half indicating they had little time for themselves or their family in general (55 percent of interview comments)[75]. This contrasts with 32 percent whānau who were satisfied with services.
- When asked directly how much time they had for themselves, 76 percent of the people who support a disabled person in their own home stated zero to four hours on an average weekday compared with 35 percent of those who did not support a disabled person in their own home.

---

[74] The Cantril Ladder is widely used in social science research, most notably the Gallup World Poll. It asks respondents about their satisfaction with their lives. It asks them to imagine a ladder representing life satisfaction with steps up from 0 to 10. It then asks them which rung of the ladder they see themselves standing on, with 0 representing the worst life they could imagine for themselves and 10 the best.

[75] Based on the question, “If anything were possible, what are some of the things you would like to achieve, start doing, or do more of?’.

Many people indicated that stress was a constant feature, with tiredness and ongoing responsibility being a particular concern. For example, when asked what was most important in their own life, one family member stated:

> To have some time off and [I need to] recover from tiredness and be able to make plans for my daughter's future. [It's] so hard to plan or see a future when I'm tired. [I] haven't seen my elderly family for years; also, my grandchildren. I have grandchildren I have never met.

Whānau and guardians who support at least one disabled person in their own home and who were less satisfied with services overall indicated poorer responses to many survey items and questions. For example, this group indicates:

- Higher unemployment rates (see employment section).
- A reduced perception that supports assist them to be connected with the community (59 percent, occasionally or never, compared with 28 percent of the more satisfied group)[76].
- A reduced perception that funding was sufficient (61 percent, occasionally or never sufficient, compared with 28 percent of the satisfied group)[77].
- Well over half did not believe the information provided by the sector was easy to understand (61 percent) and did not believe they had all the access to information they needed (58 percent), compared with those who were satisfied with services (24 and 26 percent respectively)[78].
- Half did not believe they were valued for the support they provided (50 percent compared with 18 percent of those who were satisfied with services)[79].
- The majority indicated they could not easily find paid carers (84 percent compared with 56 percent of the satisfied group).
- Close to half did not believe contact with the disability support system helped them achieve their goals (48 percent compared with 26 percent of the satisfied group)[80].

Overall, close to half of all whānau and guardians (45 percent) who are supporting at least one disabled person in their own home are not only less satisfied with services but are also indicating several factors that taken together can indicate these families are in crisis or at the very least under severe stress.

Disabled people

The reported SWB for disabled people varied according to disability type:

- People with learning disabilities[81] provided higher average scores on the Cantril Ladder (7.4, SD 2.4) than people with physical disabilities (5.4, SD 2.4), (WMW=3.2, $p<0.001$).

---

[76] MWM=3.1, $p<0.001$, df=83.
[77] MWM=4.1, $p<0.001$, df=88.
[78] MWM=3.9, $p<0.001$, df=77 and MWM3.1, $p<0.001$, df=79 respectively.
[79] MWM=3.0, $p<0.001$, df=85.
[80] MWM=3.3, $p<0.001$, df=83.
[81] All self-reports (ie, no proxies).

- There were particular stresses noted for people with physical disabilities when SWB was considered. People with lower self-reported SWB were predominantly individuals with progressive conditions (40 percent) compared with people scoring five or higher on the ladder (23 percent).
- These people, as well as people with learning disabilities who scored lower SWB scores, were also more socially isolated compared with people providing higher scores[82].
- Social isolation for these individuals may be related to how often they were able to get out and about in the community, how often they were able to see or visit friends or even how many friends they had.

From a support point of view, this may relate to transportation issues and how much support (from a support worker) these individuals need in order to access the community.

Limitations posed by disabilities

The capacity of some people with disabilities to access the community or extend/ strengthen their social networks can be limited by personal factors. In the section above, it was noted that progressive conditions and chronic health issues may compound factors that lead to social isolation for people with physical disabilities. Challenging issues such as social anxiety and behaviour can also increase social isolation, not just for the disabled person but also for their whānau, partners and other carers:

- It was noted in open responses by whānau that behavioural issues were pivotal in how successfully disabled people interacted with other members of the community.
- The impact of these issues on whānau, as well as the individual, is demonstrated in an observation from one whānau respondent:
    - [I'd like] more time as family – more things with my son in the community – he is big strong boy and can take off – I can't chase him. ... [I] would love to go to Auckland to spend time with my daughter.
- Survey respondents welcomed and supported behaviour support for people with challenging needs in social environments or at home. Behaviour support is provided in the MidCentral area through Explore Specialist Advice (Explore) and through school-based options.
- Thirty-three percent of all whānau, partners and other carer respondents indicated they were either currently using or had used Explore services in the past.

---

[82] For example, 53 percent of those scoring less than five on the Cantril Ladder live alone (compared with 38 percent of those scoring five or more). Likewise, only 36 percent had contact with friends in the previous week and only 27 percent lived with family or friends (compared with 75 and 52 percent of those scoring five or more on the Cantril Ladder respectively).

5 Providers and Support Workers[83]

In contrast to the disabled persons and whānau surveys, which involved stratified random sampling, the support workers and providers surveys were opt-in surveys. As a result, the samples are not representative and the results from both these surveys should be treated with caution. There was a very poor response to both the provider and particularly the support worker survey, so the results are indicative only.

People working in services for people with learning disabilities are more highly represented in the support workers survey, and people providing home support and personal care, either through companies or through individualised funding (IF), are less well represented.

Likewise, the response rate from providers was 28 percent, and numbers were too low to provide descriptive statistics.

Experience of the current system

Despite not being representative of all support workers or all providers, both groups provided some valuable insights that support other findings in the Baseline Study:

- Fifty-six percent of support workers and four out of nine providers surveyed believed the disability support system enabled them to be proactive in terms of their support of disabled people.
- Fifty-three percent of support workers and four out of nine providers suggested the disability support system enabled them to tailor supports according to each individual's aspirations and goals[84].
- However, 60 percent of support workers and eight of nine providers felt the system did not enable them to raise issues or improve the system[85].
- In terms of their own internal practices, both were more positive. Seventy percent of support workers and seven out of nine providers believed in their ability to build trusting relationships with the people they supported and their whānau.
- Further, over two-thirds of the support workers gave a positive rating for their own practices in relation to disabled people and whānau for eight of 13 indicators/questions[86].

---

[83] For a breakdown of local disability providers in MidCentral and types of services they provide. refer to Appendix 6.
[84] All or most of the time, item 1.3, 'The current disability support system enables us to be proactive in our assistance of disabled people' and item 1.4, 'The current disability support system enables us to tailor our support according to people's aspirations and goals'.
[85] Sometimes, No/never or Not really, item 1.9, 'The current disability support system enables us to raise issues and improve systems'.
[86] The average over all 13 items was 66 percent (SD 7.7 percent). Range 49 to 74 percent.

Some areas for improvement within organisations according to the support workers' self-assessment included:

- Being responsive to Māori. Only 59 percent of support workers believed this occurred 'all' or 'most' of the time.
- Being responsive to Pasifika peoples and other cultures. Only 49 percent of support workers believed this occurred 'all' or 'most' of the time.
- Connecting people with community resources and services. Only 59 percent of support workers believed this occurred 'all' or 'most' of the time.
- Providing accessible information. Only 59 percent of support workers believed this occurred 'all' or 'most' of the time.
- Supporting people to experience multiple valued roles. Only 62 percent of support workers believed this occurred 'all' or 'most' of the time.

Challenges with the current system

Both providers and support workers were asked for their views on the main challenges with the current system.

In written responses, a quarter of support workers and the majority of service providers indicated there was insufficient funding in the system to provide for the sort of life expected of disabled people and their whānau.

- This seemed particularly the case in relation to residential services. For example, one provider noted:

> *Providing sustainable and viable services to those requiring individualised services [such as] one-on-one support. More often than not, the funding does not meet the needs or levels of support required and to remain viable usually requires some form of cross-subsidising by other services within the organisation. As a result, providers are reluctant to take on new one-on-one services, which then adversely affects families looking for support.*

- Likewise, a support worker stated:

> *If you want to drop a banding*[87] *in funding, it will happen straight away. If the banding needs to increase because of needs – no way is that going to happen.*

The other main concern noted by both groups was too much rigidity and inflexibility in the system, noted by 18 percent of support workers:

- Support workers referred to this in terms of too many rules and restrictions that limited what they could do with individuals.
- Providers looked at this in the same way but also explained that the rigidity was founded on contractual rules about what they could offer to individuals.

---

[87] People in residential homes are sometimes funded according to bands (1–5, with 5 being the highest). Banding is typically determined by degree of assessed need at a given point in time (VHNs, High and Moderate/Low).

Applying the EGL Principles

The system transformation in the MidCentral area[88] is tied to the EGL principles[89]. Both support workers and providers were asked key questions concerning their understanding of EGL:

- In the main, providers gave detailed notes on how their organisation responded to each of the principles.
- However, responses from support workers tended to focus on choice-making and self-determination (22 percent) and person-centred practice (25 percent).

Preparing for the new system

On a sliding scale of zero to 100, support workers were asked to rate how much they understood the system transformation. The midway point was declaring they understood 'quite a bit'[90].

- Fifty percent of respondent rated themselves below the 43 percent mark.
- A quarter rated themselves below the 24 percent mark.
- Twelve percent stated they did not know anything about EGL.

This suggested that at the time of the survey, understanding of the system transformation was poor to moderate.

While providers indicated they mostly or completely understood the system transformation:

- Only half (4) stated they had completed the organisational self-review of EGL.
- Seven then said they had developed (or were in the process of doing so) a plan based on their organisational self-review.
- Six also stated they had implemented or partially implemented staff development based on the same review.
- Only one provider indicated they were satisfied that their support workers understood the core elements of EGL.
- Four more thought they partially understood the elements.
- Five of eight providers had not circulated resources or documents relating to EGL or the system transformation to disabled people and their whānau.

---

[88] See Appendix 6: Support Packages.

[89] www.enablinggoodlives.co.nz

[90] The average was 45 percent (SD 30 percent), however, the midway marker may have been misleading.

Main concerns regarding the systems change

Support workers' concerns

The main concerns listed by support workers who provided a lower assessment of their understanding of the new system related to anxiety about issues, such as changing roles and job security:

- When asked what impact the new system would have on their role, 15 percent of support workers believed it would destabilise job security.
- Five people believed it would throw the whole system into chaos and create unsafe working conditions.
- When specifically asked to list their concerns about the new system, a quarter of the support workers again raised the issue of job security and changing roles.
- Twelve percent of support workers reported they didn't know much about EGL.
- However, it is also noted that one-quarter of all support workers did not believe their own role would change and were much more positive about the change (see Opinions about Mana Whaikaha section below).

Providers concerns

A concern raised by at least one provider regarding the new system was a perceived lack of certainty about their contracts and as such how the new system would impact on their current practice. One provider stated:

> *There is still a distinct lack of detail about how providers will operate within the system. For example, we are told we will receive a flexible disability support contract to better match the ST [system transformation], but to date this has neither been provided to us nor confirmed that we will get it. In this context, it is very hard to plan for our response as we don't know the environment within which we will operate … we are working on supposition and best guess.*

Fund management and resources

Providers were also concerned about how the new system was going to assist people to manage their funds. This was also a view shared by many support workers, some of whom believed there was a potential for abuse of the system. More importantly, however, was the belief raised by both providers and support workers that without changing the resource allocation per person, there would be insufficient funds to offer any real difference. One provider referred to this as:

> *Sustainability – given the cost of human resources involved, we have a concern that the approach will not be sustainable. We think … supports and options should be more proactively considered to address this. We think there is also a danger that the change in government may lead to a lack of commitment to the initiative, and*

> *this leads to a situation of over promising and under delivering, which is unethical in this kind of context.*

Opinions about Mana Whaikaha

Despite the concerns noted above:

- Support workers were generally positive about the new Mana Whaikaha system. In additional written comments, 23 percent[91] believed disabled people would have more choice and control in their lives.
- One-third of support workers also gave other generally positive additional comments about the new arrangements.
- All of the providers were positive about the impact of the new system for disabled people and their whānau. For example, one stated the system would provide:

> *... more flexibility for our clients and the ability for more people to be authentically self-directed. We are hopeful that people can proactively plan for a good life (not just an ordinary one – but an extraordinary one!) and a whole of life approach that sees the person as a valued community participant and citizen.*

Keeping support workers and providers informed

Feedback from support workers and providers related to being kept informed and understanding how the new system and EGL would affect their practice:

- Provider respondents felt there was uncertainty regarding contract negotiations.
- Support worker respondents felt their lack of knowledge of EGL and system transformation potentially heightened their anxiety over work roles and job security.

Over two-thirds of the support workers agreed they needed more information, and many provided examples of how this could occur. This included:

- receiving frequent updates through written and electronic media
- having training to learn about EGL and what system transformation is all about, and how it will affect both the workers and the people they support
- including support workers in the new system's development
- establishing discussion groups, both internally and across the area
- meeting the connectors and finding out about how they work.

---

[91] This does not mean that three-quarters of support workers did not believe disabled people would have more choice and control, only that one-quarter offered this as a highlight of what can potentially happen with the change.

6 Other things to read

- Baseline Study of the Disability Support System in the MidCentral Area: Summary Report
- Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report
- Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools

7 Glossary of abbreviations and terms

ASD	Autism Spectrum Disorder
CDS	Child Development Service (supported through the MidCentral DHB)
DPA	Disabled Persons Assembly NZ
DPO	Disabled persons organisation
DSS	Disability Support Services
EGL	Enabling Good Lives
IF	Individualised funding
Learning disability	We use this term instead of 'intellectual disability' as it is the preferred term used by *People First*
MidCentral area	The MidCentral area has the same geographic boundaries as the MidCentral District Health Board (DHB) which is a North Island DHB area that covers from Otaki / Te Horo in the south, to Apiti north of Sanson in the north and Dannevirke and south-west to the west coast.
MOE	Ministry of Education
MOH	Ministry of Health
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Coordination service – the NASC within the MidCentral area is Enable New Zealand
NZDSN	New Zealand Disability Support Network
People First	Self-advocate organisation for people with learning disabilities
PPPR Act	Protection of Personal and Property Rights Act 1988
Survey Items	Questions or statements in the survey documents requiring a response

SWB	Subjective wellbeing: people making their own assessment of their happiness or wellbeing
Universal services	The health, education and other community services that are available to all New Zealanders
VHN	Very high assessed need; based on the needs assessment done through Enable
WMW	The Wilcoxon Mann-Whitney test for non-parametric statistics

Appendix 1: Method and components of the Baseline Study

The Baseline Study involved collecting data through a system map and four surveys. Table 2 on the following page, provides details for the five stakeholder groups involved in providing data for the study.

Baseline surveys

SAMS conducted the baseline surveys to understand key stakeholder experiences of the current system. The surveys involved disabled people, their whānau and advocates, support workers and disability support service providers.

The surveys involved detailed face-to-face interviews with 172 disabled people and/or their proxies (typically whānau[92] and other supporters[93]), telephone and face-to-face interviews with 152 whānau, partners and welfare guardians, an online survey with 108 support workers and an emailed survey completed by nine providers.

All surveys included sections for open-ended responses, Likert Scale items and some closed questions[94]. Analysis included qualitative, thematic methods and quantitative statistical review.

Besides demographic data gathering in the disabled persons survey, there were six main open-ended questions and 67 Likert Scale items.

Respondents could choose to answer as many questions as they desired. Interviewers did attempt to have all respondents focus on the six open-ended questions and 21 key Likert Scale questions. The majority of questions were, however, completed. All verbal responses were either audio-recorded or written down and read back to respondents wherever possible.

The whānau and guardians survey had seven main open-ended questions and 44 Likert Scale questions (in addition to a range of demographic questions).

Fifty-seven percent of disabled persons surveys completed had a corresponding whānau and guardian survey also completed.

The surveys (including the provider and support worker surveys) will be provided in the Baseline Study Survey Tools report.

---

[92] Whānau refers to both immediate family members, extended family, partners and spouses.
[93] Other supporters refer to friends, welfare guardians and advocates.
[94] For example, 'yes/no' or category questions such as gender, ethnicity (typically for demographic data).

Table 2: The five stakeholder groups providing data for the Baseline Study

Stakeholder group	**Disabled people**	**Whānau, advocates or welfare guardians**	**DSS funded organisations**	**Members of the workforce**	**Government and other stakeholders**
Number of survey participants	**172**	**152**	**9**	**108**	**21**
Method of selection	Stratified random sample selected	Stratified random sample selected	Self-selected in response to email sent to all 32 provider organisations	Self-selected in response to notification from provider organisations	National and local DPO nominated representatives
Form of interview	Individual face-to-face interviews	Individual face-to-face or telephone interviews	Emailed survey for voluntary completion	Emailed link to an opt-in web-based survey	Individual face-to-face or telephone interviews
Stakeholder group details	56% male; 43% female 1% gender diverse 76% NZ European; 17% Māori; 6% other, including Asian, Fijian & Pasifika 53% learning disability; 28% physical disability; 19% ASD	82% female 67% married; 9% divorced; 24% single or widow / widower 78% NZ European; 18% Māori; 7% other (Pasifika, Asian, etc)	Representing: Residential Vocational Supported living Respite Home support Assistance for self-managed supports	67% female 67% NZ European; 19% Māori; 13% Other 51% residential services; 37% vocational services; 37% supported living; 12% home support; 88% direct support workers	Ministry of Health, particularly DSS (Disability Support Services) Ministry of Social Development Oranga Tamaraki Ministry of Education MidCentral DHB CDS (Child Development Service)

Disabled persons survey

The first surveys involved face-to-face interviews with disabled people and/or proxy respondents if the disabled person was not able to respond to the survey questions themselves. Stratified random samples of respondents were drawn from specific categories of all people funded by Disability Support Services (DSS) in the MidCentral area. Categories of disabled people were developed based on disability type, level of assessed need and age. Approximately 10 percent of each group was randomly sampled. These groups represented people with learning and physical disabilities and people with autism spectrum disorder (ASD)[95]. A sample of children and young people were also drawn at random within each category, dependent on the proportion of children to adults in each group.

Cautions when interpreting some subjective results

Satisfaction is a difficult concept to define. Satisfaction can include thoughts such as how ‘happy’ a person is or how ‘pleased’ they are with something. It can be objective in terms of having something tangible, such as equipment. Satisfaction can also be subjective, in terms of satisfaction with staffing.

When we talk about satisfaction in this report, we are only referring to how people view the supports that are provided through/after their needs assessments with Enable (the local needs assessment and service coordination service or NASC) and prior to Mana Whaikaha on October 1st, 2018.

About half the disabled people answered on their own behalf. The remainder were responses from someone who knew the person very well (*not* including support staff) who we refer to as their proxy. For many satisfaction questions, proxy respondents did not or were not comfortable in providing responses and these were either left blank or ‘not applicable’ was indicated.

Measures relating to satisfaction with services are initially reported as a grouped or overall suggestion of satisfaction. However, individual questions each answer a unique construct of their own which added together may not provide a sufficiently definable construct of satisfaction, especially in a survey (as contrasted with a normative tool). For this reason, grouped responses to satisfaction are balanced against individual responses to specific questions and in relation to who is making the response.

Example

A finding that surprised some is that almost three-quarters of disabled adults, who completed the survey, were generally satisfied with the disability support services they received. However, as an overall percentage this should be treated with caution since each question in the group represents an independent construct. It also needs to be read against other Likert scale measures in the survey, such as autonomy, social isolation, community participation and subjective wellbeing, which paint a far less positive picture.

Wellbeing is a subjective indicator that asks people about their personal life satisfaction or happiness.

---

[95] The total population for people with sensory impairments (38 people) recorded in the DSS data as too small to sample.

These questions are intrinsic to a person and only that person will be able to provide a valid response. Proxy respondents are not used in any analysis of subjective wellbeing.

Ideally, many variables need to be considered when reviewing the findings in this report. Such as what the question is asking and who is responding. We also consider issues such as:

- Acquiescence: people may wish to please the interviewer or others with their responses (this can be a particular challenge with people who have learning disabilities).
- Lack of alternative viewpoints: for example, people with disabilities and their supporters may view the support system as working perfectly because they do not know of any other alternative.
- Low expectations and gratitude: having some help, when there was none previously, can result in relief and gratitude, without an understanding of what may be possible.
- Hegemony: people may be genuinely positive about the support system because they are heavily invested in the system in various ways[96].
- Homeostasis: we are aware that people can adapt to their situation in a manner that they reach an acceptable degree of subjective satisfaction either with services or their own life (wellbeing), even when others (outsiders) may judge the situation quite differently[97].

Non-responses or ‘not applicable’ responses

For some questions proxy respondents could not or would not answer a question as some questions are very subjective. This was reassuring, as proxy respondents were asked to answer questions as if they were the person concerned. For these questions the proxy would either not respond to the question or indicate ‘not applicable’.

There were some questions not answered by some disabled people. We designed the survey so that it did not overly tire individuals. Priority questions where highlighted so interviewers could focus on these first, particularly if they were concerned the person may find it difficult completing the whole survey. Twenty people (12 percent) used this method exclusively for the seven final sections of the survey (what is often referred to as the Likert scale questions). Four more people (2 percent) completed the survey up until the last seven sections.

---

[96] In particular, people can collude quite unconsciously in their own predicament (hegemony).

[97] See in particular the theory of homeostasis. This suggests that people appear well adjusted on subjective indicators but can live in circumstances that do not help them maintain or improve aspects of their personal or physical lives. Cummins, R.A. (2005). Moving from the quality of life concept to theory. *Journal of Intellectual Disability Research, 49*(10), pp. 699-706; Cummins, R.A. (1995). On the trail of the Gold-Standard for Subjective Well-Being. *Social Indicators Researchers, 35*, 179-200.

Some disabled people did not answer some questions (ie, ‘not applicable’ responses) because they did not know how to answer the question, did not think it was applicable to their situation, or did not understand the question.

Because of the number of non-responses (question left blank) or ‘not applicable’ responses (ticked this option), all frequencies for each individual question were calculated without non-responses (including ‘not applicable’). This was because it was not always possible to determine the motivation for either a blank or a ‘not applicable’ response.

Non-responses, as distinct from ‘not applicable’ responses, were analysed separately for the 21 priority questions (Table 3). They indicate that the average non-response was up to 6 percent for various groups. The exception to this is for those in residential services, where the rate of non-response was higher. This is discussed in the sections concerning residential homes in later sections.

Table 3: Average rate of non-responses for 21 priority questions

	Average	Standard Deviation
Whole sample n=172	5.7%	2.9%
Adults only n=134	5.5	3.1
Children & young people n=38	6.0	4.5
Learning disability adults only n=77	6.1	3.8
Physical disability adults n=48	3.0	2.6
Proxy respondents only n=83	4.9	4.4
Self reports only n=89	6.4	2.1
Residential learning disabled adults n=37	9.0	5.9

The total number of non-responses *and* ‘not applicable’ responses combined, for the 21 priority questions was 16 percent on average for the whole group (172 people), and 14 percent for people providing self-reports only (not including proxies). It is higher for adults with learning disabilities (15 percent) than adults with physical disabilities only (10 percent).

Whānau, friend, partner, legal guardian and advocate survey

The second survey involved whānau, spouses, legal guardians and other advocates. Permission was obtained from disabled people to contact these people, or the interviewers directly approached whānau or guardians who legally represented an individual (for example, children and young people under the age of 18 years and people with welfare guardians under the PPPR Act[98]). Just over half the sample (57 percent) involved whānau, welfare guardians, partners or spouses of people who had been involved in the disabled persons survey. The remaining sample was drawn from welfare guardians (15.6 percent of this group) and whānau of children and young people under the age of 18 years (10.9 percent of this group). People with learning disability (58.8 percent) and ASD (29.7 percent) and children and young people (44.7 percent) are over-represented in this group[99].

Provider and support workers surveys

The provider and support worker surveys involved self-selected groups responding to an emailed survey document that was completed and returned via email (providers) or an online survey (support workers) forwarded to them by their employer. The survey respondents in both cases are not representative due to the sample size and, in the case of support workers, are over-represented by support workers who support adults with learning disabilities in a variety of settings.

Statistics used in this report

The main statistics used in this report were simple percentages based on the number of people making a response to each question.

The significance testing used the Wilcoxon Mann-Whitney test for non-parametric statistics. The test is notated WMW in the report.

---

[98] Protection of Personal and Property Rights Act 1988.

[99] Because 43 percent of whānau or guardian respondents were randomly selected for interviews and were legal guardians of a disabled person (who was not involved in the disabled persons survey), the sample selected was biased in favour of younger families and people who live in community residential homes (who typically had learning disabilities).

Development of the System Map

SAMS conducted a series of interviews with key stakeholders and reviewed key documentation to create a system map. This is a visual description of the MidCentral area's experience of the current system, showing who was involved, how they worked together and the order of interactions throughout the system (see Appendix 3: System Map).

Information for the system map was gathered at both national and local levels. Key participants included representatives of the following organisations and ministries[100]:

At the national level:

- Ministry of Health (MOH)
- Ministry of Social Development (MSD)
- Ministry of Education (MOE)
- Oranga Tamaraki
- Disabled Persons Assembly NZ (DPA)
- People First New Zealand
- New Zealand Disability Support Network (NZDSN)
- Inclusive NZ
- IHC New Zealand.

At the local level:

- MSD
- MOE
- Oranga Tamariki
- MidCentral DHB Child Development Service (CDS)
- Enable New Zealand Needs Assessment and Service Coordination service (NASC)
- Parent to Parent
- New Zealand Down Syndrome Association.

The stakeholders were sent a summary of their interview and were asked to confirm it as an accurate record of the conversation.

A 'systems thinking' approach was used to analyse the interconnected components of the disability system and the patterns of interaction that emerge between stakeholders.

The review of key documentation involved gathering information from policy documents and online material from each of the relevant government agencies. This study provided information about the roles and responsibilities of each government agency and details on specific disability-related policy.

---

[100] The scope of the project and time constraints limited the focus to four key ministries.

Appendix 2: MidCentral area NASC

Enable New Zealand

Needs Assessment and Service Coordination (NASC) services are important gateways to disability services funded by the Ministry of Health. NASCs are NGOs or DHB services contracted by the Ministry of Health to provide Needs Assessment and Service Coordination services for eligible disabled people[101]. Enable New Zealand was the NASC for the MidCentral area until the launch of Mana Whaikaha on 1 October 2018. Enable is governed by the MidCentral DHB and is overseen by the Enable New Zealand Governance Group.

NASCs can be accessed by referral from an individual, their whānau, GP, service provider or other community groups. Their role is to provide:

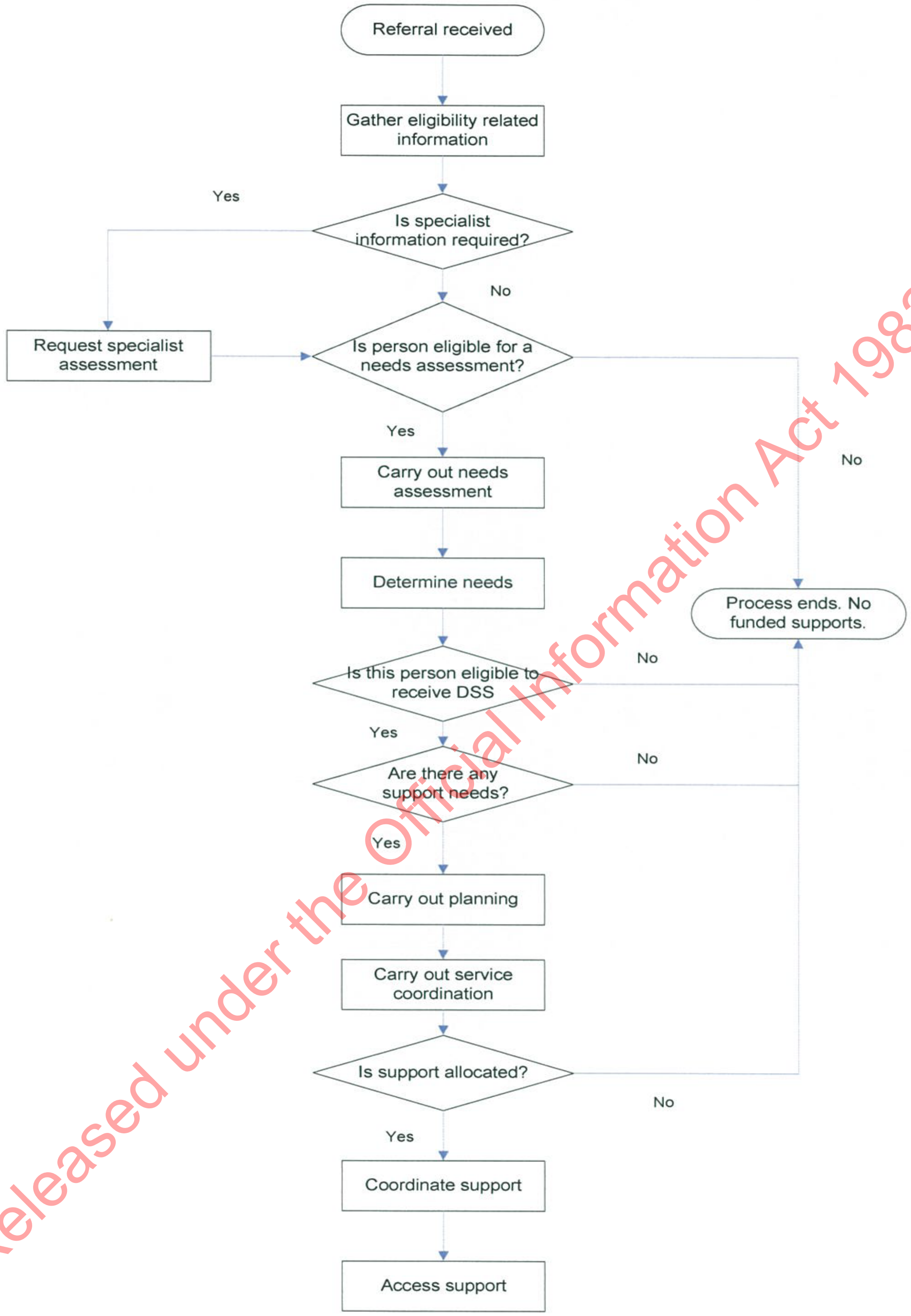
- Facilitated Needs Assessment: NASC Assessors meet with the person, their whānau and support staff to identify the abilities, resources, goals and needs of a person and establish which of those needs are most important. Needs will include, where appropriate: recreational, social and personal development needs; training and education needs; and vocational and employment needs.
- Service Co-ordination: Assessors identify and plan the package of services required to meet the prioritised assessed needs and goals of the person and, where appropriate, their family/whānau and carers. There is a process for a second review if the whānau is not happy with the level of support offered. The NASC also provides a crisis service so that respite beds can be accessed during emergencies. The Assessor will review the package at least annually, but sometimes this will be conducted by phone.
- Budget Management: Funding is expected to be according to the Support Package Allocation tool, and within Benchmark Indicators determined by the Ministry for the identified population for a NASC area[102]. Assessors are required to ensure that people with the highest priority needs receive priority access to services.

The process by which support needs are assessed and coordinated by NASCs is shown in the following flowchart:

---

[101] The Ministry of Health funds people who are under 65 years old and have a physical, intellectual or sensory disability or a combination of these, that is likely to: remain even after provision of equipment, treatment and rehabilitation, continue for at least six months and result in a need for on-going support. The Ministry will also fund DSS for people with: some neurological conditions that result in permanent disabilities; some developmental disabilities in children and young people (such as autism, physical, intellectual or sensory disabilities that co-exist with a health condition and/or injury).

[102] https://www.health.govt.nz/our-work/disability-services/contracting-and-working-disability-support-services/contracts-and-service-specifications#NASC



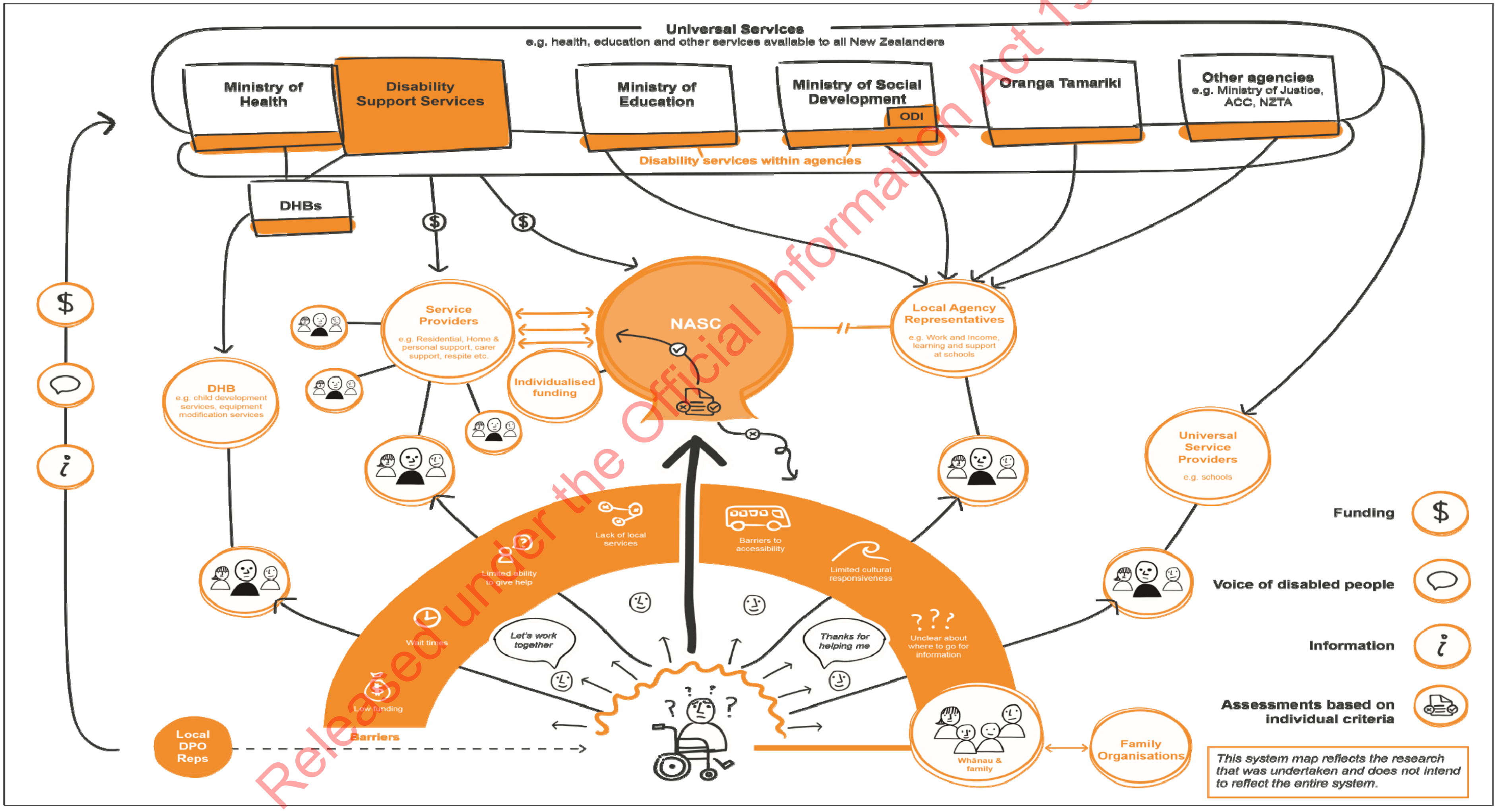
Following the launch of Mana Whaikaha, access to assessment and coordination services in MidCentral is now through the Mana Whaikaha freephone or website[103].

---

[103] https://manawhaikaha.co.nz/getting-started/am-i-eligible/

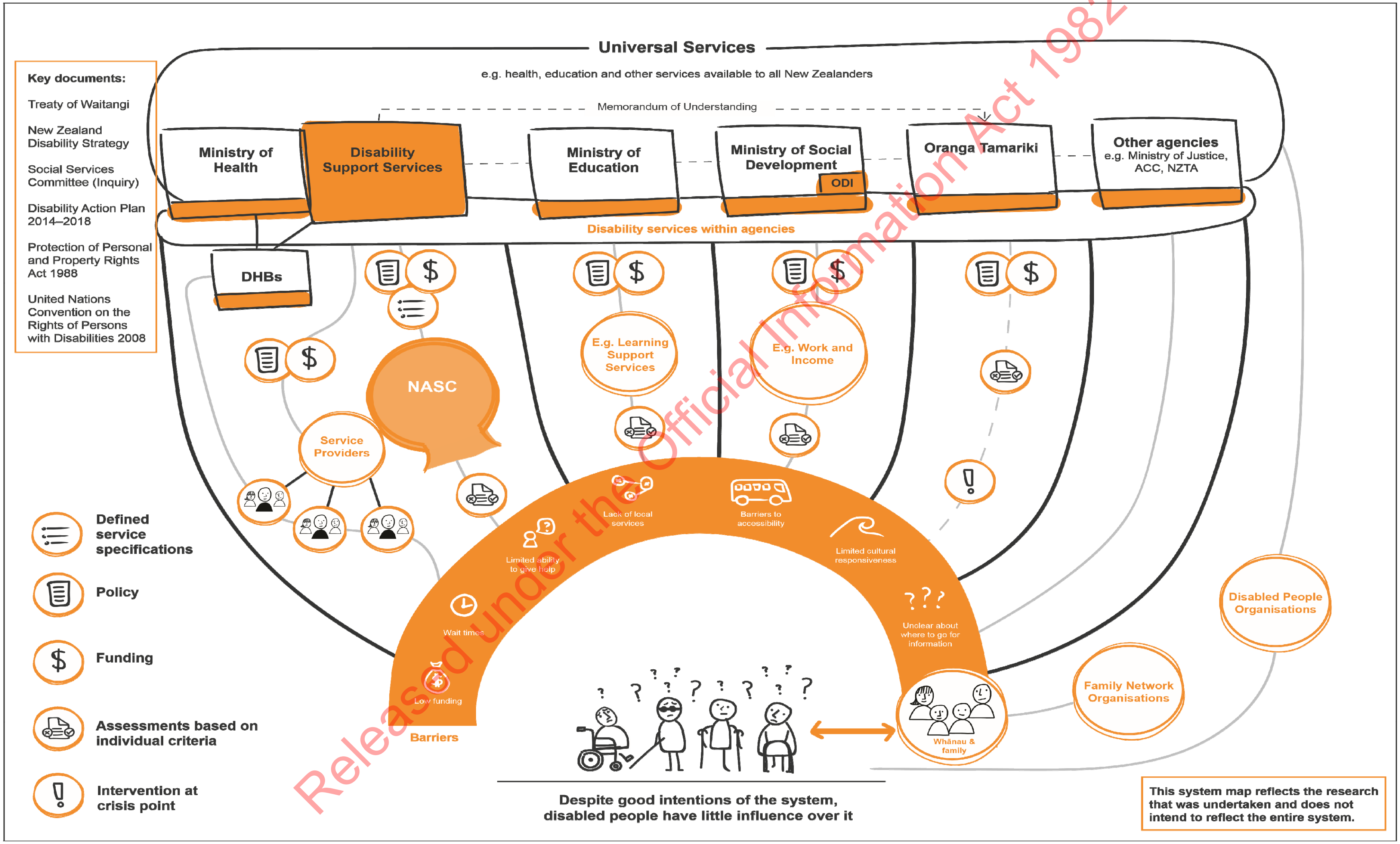
Appendix 3: System maps from the stakeholder perspective

Local System Map
What happens on the ground (reflected in the research)



This system map reflects the research that was undertaken and does not intend to reflect the entire system.

National System Map



Characteristics of the local system were seen as:

- requiring advocacy to help people navigate the system
- people doing their best within the constraints of the system
- influenced directly by the national system
- little ability to influence the national system
- prescribed and tightly regulated
- deficit-based
- rigid, complex and fractured
- traditional provider market
- providers being constrained by contract specifications.

Gaps in the local system are seen as:

- lack of availability of local services
- stretched resources and long wait times
- people living in rural or isolated areas face access barriers
- Māori, Pasifika and other cultural groups have low engagement.

Disabled people and whānau experience:

- the system can be confusing and inaccessible
- little support to understand and use the system
- their voice and perspective not heard or prioritised.

Characteristics of the national system were seen as:

- focusing on policy and funding
- having a strong influence over the local system
- setting the conditions for funding
- defining eligibility criteria and service specifications
- little cross-government collaboration
- all agencies having their own priorities, eligibility and assessments
- prioritising the perspectives of government and service providers.

Gaps in the national system are seen as:

- the current infrastructure doesn't foster collaboration
- limited relationship between universal services and disability-specific services
- lack of independent advocacy
- limited transition opportunities from school into training, education or work
- quality of workforce development
- lack of data about people using services.

Appendix 4: The socio-demographic profile of disability support services users in the MidCentral area

The MidCentral area is diverse, both in terms of physical geography and socio-demographic make-up. It varies from people living in urbanised cities, suburbs and towns to coastal zones and remote and isolated rural areas.

The June 2018 population projection for the MidCentral area is 178,240. Twenty percent of people in MidCentral area are Māori and three percent are Pasifika. Māori and Pasifika people are proportionally over-represented in the under-20-year-old age group and proportionally under-represented in the over 65-year-old group in MidCentral area.

There were 1690 disabled people funded for MOH disability support services in the MidCentral area (DSS data as at July 2018). Three hundred and ninety-eight (24%) were children and 1,292 (76%) were adults. The largest group of 835 people (49%) had a primary diagnosis of learning disability and 367 (22%) were physically disabled. Three hundred and seven people (18%), mostly children, were on the Autism Spectrum. Only 38 (2%) had a primary diagnosis of sensory disability and 143 people, mostly adults, were classified as having unclear or global diagnoses of disability.

The composition of this group is shown in Table 4 on the following page.

Table 4: People funded for Ministry of Health disability support services in MidCentral area by disability type, support level and age, as at July 2018

Primary diagnosis	Disability support level	Adult – 18 and over	Youth/ child	TOTAL	Percentage of total sample
Learning or intellectual /developmental disabilities (ID)	Very high	308	14	322	19.1%
	High	225	61	286	16.9%
	Moderate[104]	158	69	227	13.4%
	TOTAL	691	144	835	
	Percentage of total sample	40.9%	8.5%	49.4%	
Physical disabilities (not including sensory) (PD)	Very high	68	2	70	4.1%
	High	113	4	117	6.9%
	Moderate[105]	178	2	180	10.7%
	TOTAL	359	8	367	
	Percentage of total sample	21.2%	0.5%	21.7%	
Autism spectrum disorder	Very high	29	6	35	2.1%
	High	38	62	100	5.9%
	Moderate[106]	26	146	172	10.2%
	TOTAL	93	214	307	
	Percentage of total sample	5.5%	12.7%	18.1%	
Disability type unclear/global	Very high	49	11	60	3.6%
	High	43	11	54	3.2%
	Moderate[107]	20	9	29	1.7%
	TOTAL	112	31	143	
	Percentage of total sample	6.6%	1.8%	8.5%	
Sensory-sight/hearing	TOTAL	37	1	38	0.02%
	Percentage of total sample	2.2%	0.06%	2.2%	
TOTAL		**1292**	**398**	**1690**	
Percent		**76.4%**	**23.6%**	**100%**	

---

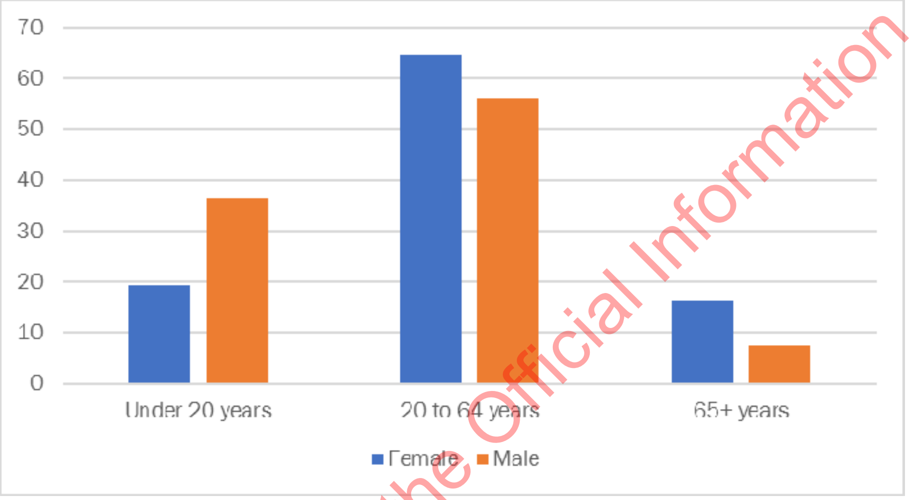
[104] Includes 5 people at low support level.
[105] Includes 13 at low support level, all adult.
[106] Includes 4 at low support level, all youth.
[107] Includes 2 people at low support level, 1 adult & 1 youth.

Gender

Fifty-five percent of people funded for disability support services (DSS) in the MidCentral area were male.

Figure 6 below indicates that there were proportionally more males in the under-20-years age group[108] and proportionally more females in the 65-years-and-older age group[109].

Figure 6: Percentage of DSS population in the MidCentral area by age group and gender



---

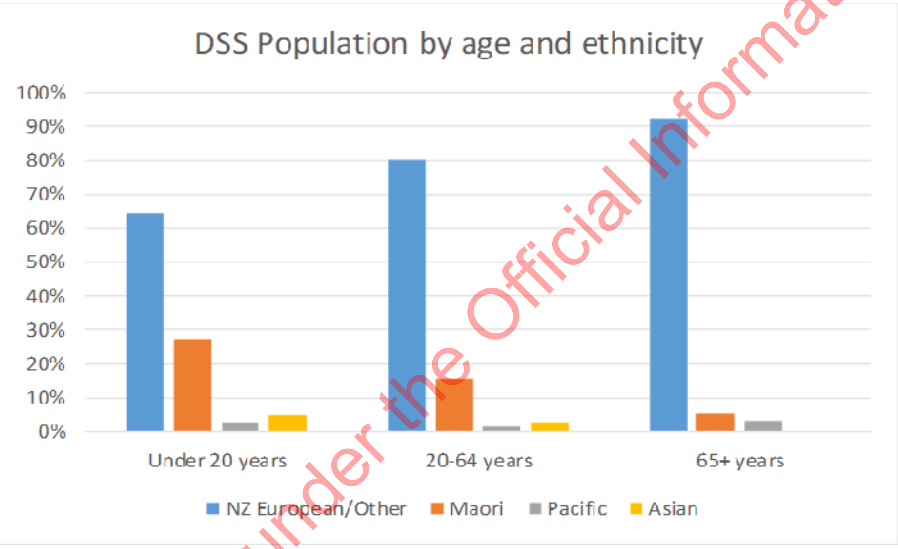
[108] This is largely due to the higher prevalence of ASD in males compared to females. For children and young people (under 20 years of age) in the MidCentral DSS population, 57 percent had ASD of whom 80 percent were male, and 41 percent had learning disabilities of whom 62 percent were male. In total, 71 percent of all children and young people in the DSS population under 20 years of age were male.

[109] For people aged 65 years and older, there were no differences in gender ratios for people with learning disabilities and only one person with ASD was in this age range. For people with physical disabilities, 73 percent were female in the same age range. The largest difference in this age range for people with physical disabilities was for those with moderate to low assessed need where 80 percent were female. The total for the entire MidCentral DSS population over 65 years and over were 35 percent male. See Te Pou o te Whakaaro Nui. (2018). *DHB population profiles, 2018-2028: Statistics New Zealand projections 2017 update*.

Ethnicity

The majority of people allocated Disability Support Services (DSS) in the MidCentral area identified as either New Zealand European/Other (76 percent) or Māori (17 percent)[110]. Māori are a younger population compared to New Zealand European, and Figure 7 demonstrates this with proportionally more Māori represented in the younger age groups. This contrasts with New Zealand Europeans/Other where the proportion of New Zealand Europeans/Other is highest in the over 65-year age group. Figures for all age groups are consistent with the total MidCentral population. Asian and Pasifika groups are underrepresented in the DSS population, at three percent for Asians and two percent for Pasifika, when compared with the MidCentral population of eight and three percent respectively.

Figure 7: Percentage of each ethnic group by age group for DSS population in MidCentral area



---

[110] Figures provided by DSS, July 2018.

Appendix 5: Key national programmes, strategies and commitments

- United Nations Convention on the Rights of Persons with Disabilities 2008[111]
- New Zealand Disability Strategy[112]
- Treaty of Waitangi
- Social Services Committee: Inquiry into the Quality of Care and Service Provision for People with Disabilities[113]
- Disability Action Plan 2014–2018: Cross-Government priorities to improve disabled people's ability to participate and contribute to New Zealand (Update 2015)[114]
- Protection of Personal and Property Rights Act 1988[115]

Ministry of Health, Disability Support Services

- Whāia Te Ao Mārama: The Māori Disability Action Plan for Disability Support Services 2018 to 2022[116]
- Putting People First[117]
- New Model for Supporting Disabled People[118]
- Enabling Good Lives[119]
- New Zealand Public Health and Disability Act 2000[120]
- Health and Disability Services (Safety) Act 2001 and the associated Health and Disability Standards NZS 8134:2008[121]
- Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, referred to as the ID(CC&R) Act[122]
- New Zealand Health Strategy: Future direction, Wellington
- Respite Strategy: 2017 to 2022[123]

---

[111] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
[112] https://www.odi.govt.nz/nz-disability-strategy
[113] https://www.parliament.nz/en/pb/sc/reports/document/48DBSCH_SCR4194_1/inquiry-into-the-quality-of-care-and-service-provision
[114] https://www.odi.govt.nz/nz-disagility-strategy/disability-action-plan/
[115] http://www.legislation.govt.nz/act/public/1988/0004/latest/whole.html
[116] https://www.health.govt.nz/publication/whaia-te-ao-marama-2018-2022-maori-disability-action-plan
[117] https://www.health.govt.nz/our-work/disability-services/disability-projects/putting-people-first-quality-review
[118] https://www.health.govt.nz/our-work/disability-services/disability-projects/new-model-supporting-disabled-people
[119] http://www.enablinggoodlives.co.nz/
[120] http://www.legislation.govt.nz/act/public/2000/0091/latest/DLM80051.html
[121] http://www.legislation.govt.nz/act/public/2001/0093/latest/DLM119975.html and https://www.standards.govt.nz/sponsored-standards/health-care-services-standards/ respectively
[122] https://www.health.govt.nz/our-work/disability-services/about-disability-support-services/intellectual-disability-compulsory-care-and-rehabilitation-act-2003
[123] https://www.health.govt.nz/our-work/disability-services/disability-projects/respite-strategy-2017-2022

Ministry of Education

- Education Act 1989[124]
- United Nations Convention on the Rights of the Child[125]
- Ka Hikitia – Accelerating success 2013–2017[126]
- Pasifika Education Plan 2013–2017[127]

Ministry of Social Development

- The New Zealand Carers' Strategy Action Plan for 2014–2018[128]
- Disabled Persons Community Welfare Act 1975 (except Part 2A)[129]
- Enabling Good Lives

Oranga Tamariki

- Oranga Tamariki Act 1989 Children's and Young People's Well-being Act 1989[130]
- Children's Commissioner Act 2003[131]

There are also five key government agencies that protect the rights of disabled people or monitor progress to improve their lives:

- Office of the Health and Disability Commissioner[132]
- Office for Disability Issues[133]
- Human Rights Commission[134]
- Office of the Ombudsman[135]
- New Zealand Police[136].

---

[124] http://www.legislation.govt.nz/act/public/1989/0080/latest/DLM175959.html
[125] https://www.ohchr.org/en/professionalinterest/pages/crc.aspx
[126] https://www.education.govt.nz/Ministry-of-education/overall-strategies-and-policies/the-maori-education-strategy-ka-hikitia-accelerating-success-20132017/
[127] https://www.education.govt.nz/Ministry-of-education/overall-strategies-and-policies/pasifika-education-plan-2013-2017/
[128] https://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/carers-strategy-2014-18.pdf
[129] http://www.legislation.govt.nz/act/public/1975/0122/latest/whole.html?search=ts_act%40bill%40regulation%40deemedreg_%e2%80%a2Disabled+Persons+Community+Welfare+Act+1975+_resel_25_a&p=1#DLM436794
[130] http://www.legislation.govt.nz/act/public/1989/0024/127.0/DLM147088.html
[131] http://www.legislation.govt.nz/act/public/2003/0121/latest/DLM230429.html
[132] https://www.hdc.org.nz/
[133] https://www.odi.govt.nz/
[134] https://www.hrc.co.nz/
[135] http://www.ombudsman.parliament.nz/
[136] http://www.police.govt.nz/

Appendix 6: Support Packages

Service categories

The table below shows total numbers funded in the MidCentral area for services accessed through the Enable New Zealand NASC:

Table 5: MidCentral DSS client numbers by service type and age group, at July 2018

Service Category	<18 years	18 years or over	Total
Behaviour Support	94	28	122
Carer Support	347	313	660
Day Services		153	153
Home Support – Individualised Funding (IF)	28	105	133
Home Support – non-IF	24	375	399
Home Support – Funded Family Care		32	32
Community Residential	4	422	426
Respite Care	59	117	176
Supported Living		213	213
Equipment & Modifications[137]	93	327	420

Note: Clients are counted more than once if they are allocated to more than one service type.

Some services specialise in particular areas while others, usually the larger agencies, provide multiple types of services. Some services such as Behaviour Support, Child Development Services and Equipment Services are contracted to a single provider.

Community residential support services

DSS purchases community residential services[138] for disabled people who need 24-hour support so they can enjoy a good quality of life and live in a place that feels like home. Access to residential support services is by referral from the NASC following an individual needs assessment process to assist disabled people to live in a supported community environment.

Community Residential Services aim to be home-like settings in the community, where people can receive support for up to 24 hours a day.

---

[137] Data is available for 0 to 6-year-olds and 17- to 64-year-old age groups.

[138] See the MOH webpage, Community Residential Support Services, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/community-residential-support-services

This might include help with things like:

- shopping
- preparing and cooking meals
- household chores
- personal care
- getting out and doing things in the neighbourhood.

Services are provided in a range of community settings such as small or large homes, groups of small homes or flats. The Community Residential Category also includes people who live in Aged Care Facilities.

Home and community support services

DSS purchases household management and personal care services[139] to assist people to live at home.

Household management may include help with:

- meal preparation
- washing, drying or folding clothes
- essential house cleaning, vacuuming and tidying up.

Personal care may include help with:

- eating and drinking
- getting dressed and undressed
- getting up in the morning and getting ready for bed
- showering and going to the toilet
- getting around the home.

People access home and community support services (HCSS) either through a provider contracted to the Ministry of Health or via Individualised Funding.

Individualised Funding is a mechanism where disabled people engage their own disability supports and use a budget allocated by their NASC to pay for these supports. People using Individualised Funding are supported by a host provider. Host providers are contracted to provide people with advice on how to use Individualised Funding and carry out their responsibilities. Host providers may also assist people with other aspects of managing and purchasing supports, such as providing payroll or assisting with other human resource matters.

---

[139] See the MOH webpage, Home and Community Support Services, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/home-and-community-support-services

Respite and Carer Support

DSS purchases respite supports[140] to assist people caring for the disabled person to take a break. Respite can take many forms such as:

- Facility-based respite – where the disabled person goes to a respite facility, usually overnight
- Family Whānau Home Support – where a support worker from a contracted provider focuses on respite, supervision, buddy support, afterschool care, and community-based activities
- Individualised Funding Respite – where the full-time carer purchases their own respite support
- Carer Support – which is a subsidy that helps a full-time carer take some time out.

Funded Family Care

Funded Family Care[141] is health funding for some eligible disabled people to employ their parents or family members over 18 who they live with to provide them with their personal care and/or household management supports. It allows payment of people to care for resident family members assessed as having high or very high needs relating to disability, long-term chronic health conditions, mental health, and addiction and aged care needs. Funded Family Care policies are administered by the Ministry of Health (Disability Support Services) and District Health Boards.

Supported Living

DSS purchases Supported Living[142] to help disabled people live independently by providing support in those areas of their life where help is needed.

Supported Living is provided by a support worker to assist eligible people who need assistance in their own homes with:

- using community facilities
- shopping, budgeting or cooking
- dealing with agencies such as Work and Income New Zealand or the bank.

These services cover:

- household management: services that assist a person with activities such as meal preparation, washing and drying clothes, household-cleaning, vacuuming and tidying up
- personal care: services may include help with activities of daily living such as:

---

[140] See MoH webpage, Respite, https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite

[141] See the MOH webpage, Funded Family Care, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care

[142] See MoH webpage, Supported Living, https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/supported-living

  - eating and drinking, getting dressed, getting up in the morning and getting ready for bed, showering and going to the toilet, that enables a disabled person to maintain their functional ability at an optimal level
  - night support: a service where the support worker or other staff member is required to sleep at the home of the person in order to provide intermittent care throughout the night.

This category also includes supported living, which is a service that supports an eligible person to build skills to live independently in their own home and participate in their community. Support might include:

- using community facilities
- shopping, budgeting or cooking
- help when dealing with agencies, such as Work and Income.

Equipment and modifications

DSS can fund equipment and modifications[143] to a person's home or vehicle. This support is accessed through District Health Board Occupational Therapy Departments, and includes:

- providing advice on the best equipment or modifications to the person's house and/or vehicle to suit their needs
- providing equipment on long-term loan
- helping pay all or part of the costs of modifying the person's house or vehicle.

Community day services[144]

Day services and vocational programmes are also funded by MSD. DSS also funds a number of people who have historically been unable to attend MSD-funded day services. These people currently have grand-parented funding arrangements.

DSS has responsibility and funding for day services for eligible people including:

- disabled people who were deinstitutionalised as part of an agreed deinstitutionalisation plan
- people who are subject to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

Day services are funded by DSS for disabled people and are traditionally run as group activities. Each person has an individual day programme service plan that describes the range of activities they require and the outcomes they hope to achieve through those activities.

---

[143] See the MOH webpage, Equipment and modifications for disabled people, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/equipment-and-modifications-disabled-people

[144] See the MOH webpage, Community Day Services, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/community-day-services

DSS also funds additional support (Discrete 1:1) to enable some people to attend an MSD or MOH funded Day Service. This support assists with additional personal care or challenging behaviour.

Child development services (accessed through MidCentral DHB)

Child development services (CDS)[145] are non-medical, multidisciplinary, allied health and community-based services that work with whānau to determine how best to support children's development.

The CDS is a therapy-based service of the MidCentral DHB. It provides assessment and therapy services to babies, children and adolescents (from birth to 16 years of age) who have developmental or ongoing disability needs. It also works with babies at risk of disability, such as babies born prematurely. The service focuses on early intervention.

Behaviour support services

Behaviour support services[146] is contracted by DSS to NZCare Disability through Explore Specialist Advice for people with an intellectual disability and autism whose behaviour makes it difficult for them to engage in everyday routines, settings, activities and relationships. Behaviour support services:

- work with the disabled person and support network (family and whānau, welfare guardian, staff/carers), including from vocational and residential services, advocates and friends
- develop and implement a plan to reduce the impact of the person's challenging behaviour. This plan is monitored and reviewed by the service provider alongside the disabled person to make sure it works well, making it easier for the disabled person to be independent and involved in the community.

Disability support services expenditure

The annual cost of various types of services are highlighted in Table 6 on the following page. They indicate that the largest costs include traditional services, such as residential support (including rest homes and hospitals) and day services. Home support, personal care support and supported living options are also high-expenditure services.

---

[145] See the MOH webpage, Child Development Services, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/child-development-services and the MidCentral DHB webpage, Child Development, at: http://www.midcentraldhb.govt.nz/HealthServices/ChildHealth/Pages/Child-Development.aspx#

[146] See the MOH webpage, Behaviour Support Services, at: https://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/behaviour-support-services

Table 6: Ministry of Health DSS MidCentral expenditure by service, 2017/18[147]

Service Category		Expenditure ($millions)
Enable NASC Management Fee		1.43
Carer Support Subsidy		1.37
Respite Care		0.85
Funded Family Carer		0.59
Supported Living		4.05
Home Support (26% Individualised Funding (IF))		2.62
Personal Care (IF 50%)		4.83
Community Residential		36.38
Rest Homes & Hospitals		1.67
Assessment, Treatment & Rehabilitation/Habilitation[148]		2.10
DHB Child Development		0.99
Behaviour Support		1.04
Day Programmes		3.29
Information & Advisory		0.73
Equipment & Modifications - NASC clients		0.93
Equipment & Modifications - non-NASC clients		1.28
Equipment repairs, refurbishment, freight etc		1.12
Environmental (Sensory)[149]		2.49
High and Complex		2.32
Other		1.30
Total	**$**	**71.36**

---

[147] These figures are actual expenditure for the year ending 30 June 2018 (actual based) and include all expenditure which can be attributed to the MidCentral area.

[148] Includes DHB Assessment, Treatment & Rehabilitation, Head Injury Rehabilitation and other Rehabilitation/Habilitation

[149] Environmental (Sensory) includes, for example the Blind Foundation and Deaf Aotearoa.

Document 6

SAMS
EVALUATE • INNOVATE • EDUCATE

Here is some Easy Read information about research done by SAMS.

The research was about the way people get disability support.

Document 6

What is in this booklet?

Page Number

Page Number

Before you start

This is a long document.

While it is written in Easy Read it can be hard for some people to read a document this long.

Some things you can do to make it easier are:

- read it a few pages at a time
- have someone assist you to understand it.

Document 6

About the research

A new **disability support system** is being tried at the moment.

A **disability support system** is the way that disabled people in a region or country get the support they need.

The new disability support system that is being tried is called **Mana Whaikaha**.

People started trying **Mana Whaikaha** on the 1st of October 2018.

Only people who live in the MidCentral area can try **Mana Whaikaha**.

The MidCentral region includes:

- Palmerston North
- Horowhenua
- Manawatu
- Ōtaki
- Tararua.

Mana Whaikaha aims to give people:

- more choice about their disability support

- more power to make choices about their lives.

Mana Whaikaha also wants to make sure the disability support system uses money in a good way.

The Ministry of Health wanted to do some **research**.

Research is:

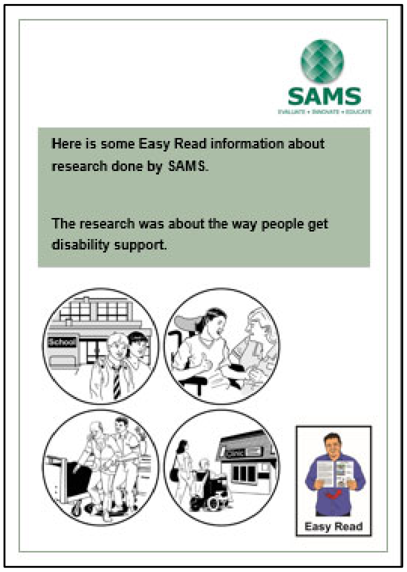
- looking to find an answer to a question you have
- trying to find out how to do things better.

The Ministry of Health did some research on what the disability support system was like before Mana Whaikaha started.

This kind of research is called a **baseline study**.

SAMS
EVALUATE • INNOVATE • EDUCATE

The research was done by an organisation called **Standards and Monitoring Services.**



SAMS

Here is some Easy Read information about research done by SAMS.

The research was about the way people get disability support.

School

Clinic

Easy Read

Standards and Monitoring Services are also known as **SAMS**.

This booklet will tell you what the baseline study found out.

How was the research done?

SAMS did the research by:

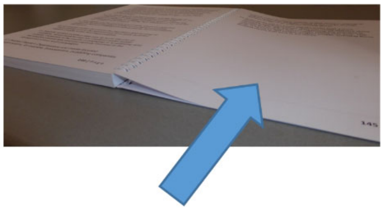
- making a map of the disability support system
- asking people living in the MidCentral area to do surveys.

A **survey** is a way to get information from people.

A survey asks questions about something an organisation wants to know about.

SAMS did 1 survey with disabled people.

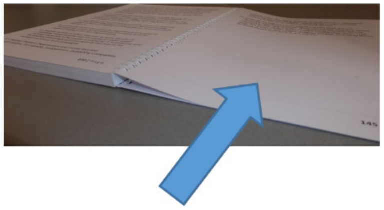
This survey was done by 1 hundred and 72 disabled people or their **proxies**.



You can see what proxies are on the next page.

SAMS also did a survey for family members of people with disabilities.

This survey was done by 1 hundred and 52 family members or **representatives** for disabled people.



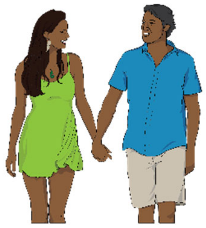
You can see what representatives are on the next page.

Proxies or **representatives** are people who **advocate** for disabled people.

Advocate means speaking up for someone else.

An **advocate** can be:

- whānau / family members
- guardians



- partners
- friends

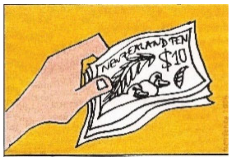
- other people.

SAMS also did surveys with:

- 9 disability support services
- 1 hundred and 8 support workers.

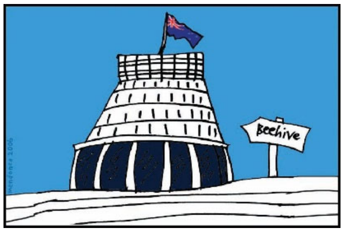
Disability support services are organisations that:

- give disability support to people
- get money from the disability support system to support disabled people.



Support workers are paid to assist disabled people.

SAMS also did a survey with 21 **government stakeholders and others.**



Government stakeholders are people who:

- work for the government

- want the disability support system to work in a good way

- helped to make the map of the disability support system.

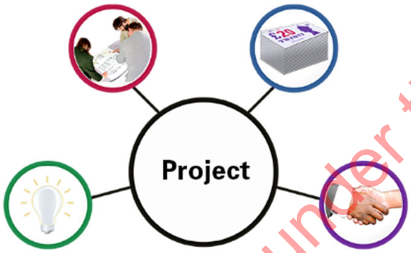
The other groups include groups like Disabled People’s Organisations like:

- People First New Zealand
- Disabled Persons Assembly.

What did the map show?

SAMS made a map of the old disability support system.

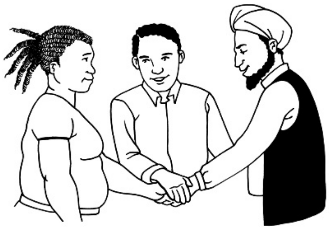
The map of the disability support system showed:



- the people and organisations who are part of the old disability support system

- how these people and organisations work together.

The map also showed that there needs to be more:



- working together between the local and national disability support systems

- communication between different disability services
- support for disabled people wanting health care

- support for disabled people wanting to find work
- support for disabled people leaving school

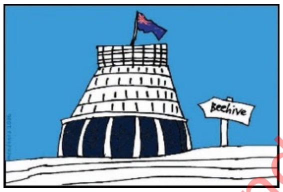
- support to teach people about being advocates in the disability support system.

How is the old disability support system working?

Our research showed that the old disability support system is very **bureaucratic**.

This means that:

- the old disability support system has lots of rules



- the rules have been made by the government

- everyone has to follow the rules

- disabled people and other people do not help to make the rules.

The rules in the old disability support system also mean that:

- disabled people do not always get the disability support they want or need

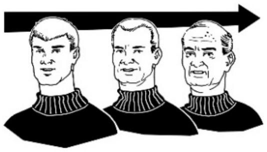
- many disabled people are not able to pay other whānau / family members to support them

- disability support services can only give people some kinds of disability support.

What did disabled people and representatives say?

Not all people feel the same way about the old disability support system.

The way people feel about a disability support system can change because of:



- their age

- their disability

- the kind of disability support they get
- how much disability support they get

Being happy

Most disabled people who did the survey were happy with the support they were getting from the old disability support system.

Some people felt both:

- happy with the support they were getting from the old disability support system
- unable to do everything they want to do in their lives.

Most family members of people with disabilities who did the survey were happy with the old disability support system.

Some disabled people and family members were unhappy with the old disability support system.

Family members of disabled people were more unhappy with disability support services than disabled people.

The **most unhappy** people were **family members** who:

- have young families
- support a disabled child or young person at home

- do not know about different disability support.

These people said they:

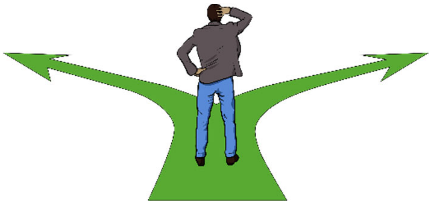
☒

- cannot find anyone to support their disabled child or young person when they need a break.

☒

- have little time to do what they want to do

- do not feel like part of the community.



Choice and control

Many disabled people or their proxies said they were doing what they wanted in their life:

- most of the time
- all of the time.

Many disabled people are living in group homes in the community.

This means that they are living:

- in houses in the community
- with other disabled people.

Many of these people:

- have learning disability
- need a lot of disability support.

Many **family members** told us that disabled people in group homes are not given the support they need to think about what they want to do in their lives.

Many of the **people with disabilities** also told us they did not have control over some things in their lives.

Some disabled people do not have control over:

- what disability support they get
- who supports them
- who they live with.

People with disabilities and **family members** said:

- disabled people who can do more things for themselves have more choice and control over their lives

- many adults with learning disability can do the things they want to do

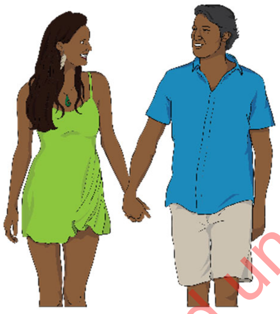
- many adults with physical disability cannot do the things they want to do.

Relationships

Most disabled people felt they were important to their family.

Most disabled adults said they:

- were single
- have never been in a relationship.



A few disabled people said that they lived with a:

- husband
- wife
- boyfriend
- girlfriend.

Most of these people had a physical disability.

Most disabled people said they have friends who do not live with them.

Some disabled people said they had not visited any friends in the 4 weeks before the survey.

Some disabled people said that in the past 2 weeks they had:

- only been to the shops

- not been anywhere in the community.

A lot of disabled people said they do not feel like they fit in with the rest of the community.

Work and money

Most disabled people said that they had not done any paid work in the week before they took the survey.

Many disabled people said they have an **income** of 30 thousand dollars or less.

Income is money people get from:

- working
- benefits.

Some **family members** who support a disabled person in their home:

- have given up other work to do this work

- live in a house where everyone together has an income of between 40 thousand dollars and 50 thousand dollars.

Many people with disabilities who live in group homes:

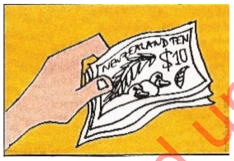
- get less than 30 thousand dollars per year to live on.

- use most of their money to pay for the disability support they get in their house.

What did the disability support services and support workers say?

Surveys were also done by:

- disability support services
- support workers.



Disability support services are organisations that:

- give disability support to people
- get money from the disability support system to support people.

Support workers are paid to assist disabled people.

This is what the survey found out.

Document 6

Some support workers are worried that a new disability support system will take away or change their jobs.

Many disability support services and support workers feel they cannot:

- talk about bad things that are happening in the disability support system

- make things better in the disability support system.

Many services and support workers feel a new disability support system will:

- give people more choice over their disability support

- mean government money will be used better.

Many services and support workers feel a new disability support system will not change things if there is not more money to pay for disability support.

What happens next?

More research will be done to find out:

- how well Mana Whaikaha is working
- what changes could make Mana Whaikaha better
- if more people in New Zealand should have a disability support system like Mana Whaikaha.

This information has been translated into Easy Read by the
Make It Easy service of
People First New Zealand Inc. Ngā Tāngata Tuatahi.

The ideas in this document are not the ideas of
People First New Zealand Ngā Tāngata Tuatahi.

Document 7

Baseline Study of the Disability Support System in the MidCentral Area: Disabled People's Report

SAMS

EVALUATE • INNOVATE • EDUCATE

Contents

Table of figures

Table of tables

Acknowledgements

SAMS would like to thank the many people who took the time to respond to our surveys and provide feedback on New Zealand’s existing and proposed disability support system.

We would also like to thank the following key people for their contribution in developing the framing and guidance for the baseline study. These people also played a critical role in analysing the responses to the various surveys:

- Christine Wilson, PhD
- Carey-Ann Morrison, PhD
- Esther Woodbury PhD
- Aloma Parker, PhD
- Andrew Coleman, PhD
- Gary Williams
- Tina Lincoln
- Rebecca Walton
- Richard Lucy

Thank you also to our interviewers:

- Audrey Buel
- Richard Buchanan
- Tina Lincoln
- Maureen Steed
- Hamish Taverner
- Cassandra Pickett
- Julie Senescall
- Lianne Clarke
- Dr Christine Wilson

Key people involved in preparing this report were:

- Dr Christine Wilson
- Mark Benjamin

To reference this document:
Wilson, C.S. and Benjamin, M. (2019). *Baseline Study of the Disability Support System in the MidCentral Area: Disabled People’s Report*. Prepared on behalf of the Ministry of Health, New Zealand. SAMS Evaluate, Innovate, Educate.

1. What is happening in the MidCentral Area

A prototype of a transformed disability support system, Mana Whaikaha, was introduced in the MidCentral area on 1 October 2018.[1]

The transformed system is based on the Enabling Good Lives (EGL) vision and principles. Mana Whaikaha aims to give disabled people and their whānau:

- more options and decision-making authority about their supports and lives
- to improve their wellbeing outcomes, and
- to create a more cost-effective disability support system.

Evaluation context

Mana Whaikaha will require ongoing evaluation to help everyone understand if its objectives are being achieved, where improvements are needed and how the approach should be adapted or expanded.

A high-level evaluation approach was developed, with advice from the Monitoring and Evaluation Working Group, as part of the overall work programme for designing the MidCentral area prototype.

Overview of the evaluation framework

Longitudinal outcomes

Baseline study	**18-month outcomes**	**3-year outcomes**
Qualitative interviews and surveys	Qualitative interviews and surveys	Qualitative interviews and surveys
System mapping	System mapping	System mapping
Quantitative analysis using IDI data[2]	Quantitative analysis using IDI data	Quantitative analysis using IDI data

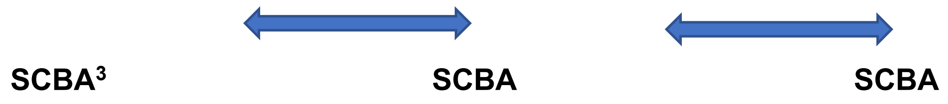
Impacts

Impacts

---

[1] For more information about Mana Whaikaha and the MidCentral area trial, see www.manawhaikaha.co.nz/about-us/mana-whaikaha/.

[2] The IDI stands for the Integrated Data Infrastructure. The IDI is a linked longitudinal dataset that combines unit-record administrative information from a range of agencies and organisations. The IDI is maintained by Statistics New Zealand under strict privacy and confidentiality protocols.



As shown in the diagram above, the evaluation has two key inter-related components:

- Longitudinal outcomes evaluation:
    - to determine what difference Mana Whaikaha is making in terms of quality of experience and wellbeing outcomes for disabled people and their whānau
    - to determine how the system is changing over time and to what effect
- Social cost benefit analysis (SCBA) to value the impact of Mana Whaikaha.

In addition, a developmental evaluation will be used to support the ‘Try, Learn and Adjust’ approach being adopted for Mana Whaikaha, and to help drive meaningful change throughout the prototype period.

The Baseline Study reports include information from the qualitative interviews, surveys and system mapping parts of the evaluation (the components in the diagram above highlighted on the previous page in green).

2. Why we did a Baseline Study

With change about to happen, we wanted a clear picture of how things were before the change (ie, the MidCentral prototype/ Mana Whaikaha) started.

The Baseline Study describes and measures what was happening before Mana Whaikaha started on the 1st October 2018. Having this information means we can repeat the study and find out what has changed as a result of doing things differently.

3. What the Baseline Study looked at

The overall Baseline Study had three main objectives:

Objective 1: to develop a detailed ‘map’ of the current disability support system in the MidCentral area

Objective 2: to understand and measure the current experiences and life outcomes of disabled people and whānau in the MidCentral area

---

[3] Social Cost Benefit Analysis.

Objective 3: to identify what support is needed to help disabled people, whānau, service providers and community-based organisations in the MidCentral region prepare for system change.

This report focuses on responses to the following questions:

- How disabled people experience the current disability support system and what impact does it have on their lives?
- How well does the current disability support system support disabled people to live the lives they want?
- Do disabled people experience the current disability support system differently? If so, how and why?
- What life outcomes are disabled people achieving under the current disability support system?
- What is most important to disabled people in creating a life they want?

4. How we did the Baseline Study

The Baseline Study was made up of six types of work:

1. Talking with disabled people
2. Talking with whānau
3. Surveying service providers
4. Surveying people who worked for service providers (workforce survey)
5. Talking with people who worked for a range of government agencies and other stakeholders, eg Disabled Persons Organisations (DPOs).
6. Reviewing documents that described the disability support system.

People were picked by chance (stratified random sample). It was important that there was a range of disabled people who represented all different types of people who were connected with disability support services.

Categories of disabled people were developed based on impairment/disability type, level of assessed need and age. Approximately ten percent of people from each of the three main types of disability were randomly sampled. We also assigned proportionally similar numbers of people to each group relative to their assessed needs. These groups represented people with learning and physical disabilities and people with Autism Spectrum Disorder (ASD). A sample of children and young people were also drawn at random within each category dependent on the proportion of children/young people to adults in each group.

Involved disabled people were asked for permission for their family member to also take part in the survey.

The survey involved a number of sections that attempted to review important things relating to personal experiences of disability and of the service system. These criteria were based on other survey tools in the sector and on documents such as Enabling Good Lives (EGL)[4]. EGL has the guiding principles behind the development of the new system.

Gathering information for the Baseline Study took place between early August and late September 2018.

During the interviews disabled people worked their way through the survey with an experienced interviewer.

The survey included open ended (long answer questions) and some where people gave scores on a five-point scale (Likert Scale). People were encouraged to say whatever they wanted in addition to the survey questions. Approximately half the group gave permission to have their interview audio taped.

All participants received an information sheet and consent form.

Interviews were confidential. All the information was put together to create a picture of what life was like before change happened.

Method of analysis

The main method of analysis of survey items was the use of frequencies (percentages) for each question. Where comparisons are made between groups a simple significance test was used to tell us if the difference between each group was actually a clear or statistically significant difference. We used the Wilcoxon Mann-Whitney (WMW) test for non-parametric statistics for this purpose.

On some occasions we grouped questions together and used averages. This was the case if we were looking for general trends in similar questions, such as satisfaction with support services. *These grouped questions are only a guide or a taster.* However, they lead into further more intensive review of what is actually being said within individual questions.

On other occasions we reported averages for questions that provided a range of responses (continuous or non-discrete responses).

Satisfaction and wellbeing – cautions when interpreting some subjective results

Satisfaction is a difficult concept to define. Satisfaction can include thoughts such as how ‘happy’ a person is or how ‘pleased’ they are with something. It can be objective in terms of having something tangible, such as equipment. Satisfaction can also be subjective, in terms of satisfaction with staffing.

---

[4] See www.enablinggoodlives.co.nz

When we talk about satisfaction in this report, we are only referring to how people view the supports that are provided through/after their needs assessments with Enable (the local needs assessment and service coordination service or NASC) and prior to Mana Whaikaha on October 1st, 2018.

About half the disabled people answered on their own behalf. The remainder were responses from someone who knew the person very well (*not* including support staff) who we refer to as their proxy. For many satisfaction questions, proxy respondents did not or were not comfortable in providing responses and these were either left blank or 'not applicable' was indicated.

Measures relating to satisfaction with services are initially reported as a grouped or overall suggestion of satisfaction. However, individual questions each answer a unique construct of their own which added together may not provide a sufficiently definable construct of satisfaction, especially in a survey (as contrasted with a normative tool). For this reason, grouped responses to satisfaction are balanced against individual responses to specific questions and in relation to who is making the response.

Example

A finding that surprised some is that almost three-quarters of disabled adults, who completed the survey, were generally satisfied with the disability support services they received. However, as an overall percentage this should be treated with caution since each question in the group represents an independent construct. It also needs to be read against other Likert scale measures in the survey, such as autonomy, social isolation, community participation and subjective wellbeing, which paint a far less positive picture.

Wellbeing is a subjective indicator that asks people about their personal life satisfaction or happiness.

These questions are intrinsic to a person and only that person will be able to provide a valid response. Proxy respondents are not used in any analysis of subjective wellbeing.

Ideally, many variables need to be considered when reviewing the findings in this report. Such as what the question is asking and who is responding. We also consider issues such as:

- Acquiescence: people may wish to please the interviewer or others with their responses (this can be a particular challenge with people who have learning disabilities).
- Lack of alternative viewpoints: for example, people with disabilities and their supporters may view the support system as working perfectly because they do not know of any other alternative.

- Low expectations and gratitude: having some help, when there was none previously, can result in relief and gratitude, without an understanding of what may be possible.
- Hegemony: people may be genuinely positive about the support system because they are heavily invested in the system in various ways[5].
- Homeostasis: we are aware that people can adapt to their situation in a manner that they reach an acceptable degree of subjective satisfaction either with services or their own life (wellbeing), even when others (outsiders) may judge the situation quite differently[6].

Non-responses or ‘not applicable’ responses

For some questions proxy respondents could not or would not answer a question as some questions are very subjective. This was reassuring, as proxy respondents were asked to answer questions as if they were the person concerned. For these questions the proxy would either not respond to the question or indicate ‘not applicable’.

There were some questions not answered by some disabled people. We designed the survey so that it did not overly tire individuals. Priority questions where highlighted so interviewers could focus on these first, particularly if they were concerned the person may find it difficult completing the whole survey. Twenty people (12 percent) used this method exclusively for the seven final sections of the survey (what is often referred to as the Likert scale questions). Four more people (2 percent) completed the survey up until the last seven sections.

Some disabled people did not answer some questions (ie, ‘not applicable’ responses) because they did not know how to answer the question, did not think it was applicable to their situation, or did not understand the question.

Because of the number of non-responses (question left blank) or ‘not applicable’ responses (ticked this option), all frequencies for each individual question were calculated without non-responses (including ‘not applicable’). This was because it was not always possible to determine the motivation for either a blank or a ‘not applicable’ response.

Non-responses, as distinct from ‘not applicable’ responses, were analysed separately for the 21 priority questions (Table 1). They indicate that the average non-response was up to 6 percent for various groups. The exception to this is for those in residential services, where the rate of non-response was higher. This is discussed in the sections concerning residential homes in later sections.

---

[5] In particular, people can collude quite unconsciously in their own predicament (hegemony).

[6] See in particular the theory of homeostasis. This suggests that people appear well adjusted on subjective indicators but can live in circumstances that do not help them maintain or improve aspects of their personal or physical lives. Cummins, R.A. (2005). Moving from the quality of life concept to theory. *Journal of Intellectual Disability Research, 49*(10), pp. 699-706; Cummins, R.A. (1995). On the trail of the Gold-Standard for Subjective Well-Being. *Social Indicators Researchers, 35*, 179-200.

Table 1: Average rate of non-responses for 21 priority questions

	Average	Standard Deviation
Whole sample n=172	5.7%	2.9%
Adults only n=134	5.5	3.1
Children and young people n=38	6.0	4.5
Learning disability adults only n=77	6.1	3.8
Physical disability adults n=48	3.0	2.6
Proxy respondents only n=83	4.9	4.4
Self reports only n=89	6.4	2.1
Residential learning disabled adults n=37	9.0	5.9

The total number of non-responses *and* ‘not applicable’ responses combined, for the 21 priority questions was 16 percent on average for the whole group (172 people), and 14 percent for people providing self-reports only (not including proxies). It is higher for adults with learning disabilities (15 percent) than adults with physical disabilities only (10 percent).

5. Who contributed to the survey

The survey involved disabled people who were clients of Enable New Zealand.

Enable New Zealand was the Needs Assessment and Service Coordination Agency (NASC) for the MidCentral area until the launch of Mana Whaikaha on 1 October 2018. Enable is governed by the MidCentral DHB and is overseen by the Enable New Zealand Governance Group.

According to the Ministry of Health website[7], to be eligible to receive funding from Disability Support Services (DSS), and become a client of the NASC, people need to “have a physical, intellectual or sensory disability (or a combination of these) which:

- is likely to continue for at least 6 months
- limits their ability to function independently, to the extent that ongoing support is required.

These are mainly younger people under the age of 65 years.

---

[7] https://www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/am-i-eligible-ministry-funded-support-services.

The Ministry will also fund DSS for people with:

- some neurological conditions that result in permanent disabilities
- some developmental disabilities in children and young people, such as autism
- physical, intellectual or sensory disability that co-exists with a health condition and/or injury".

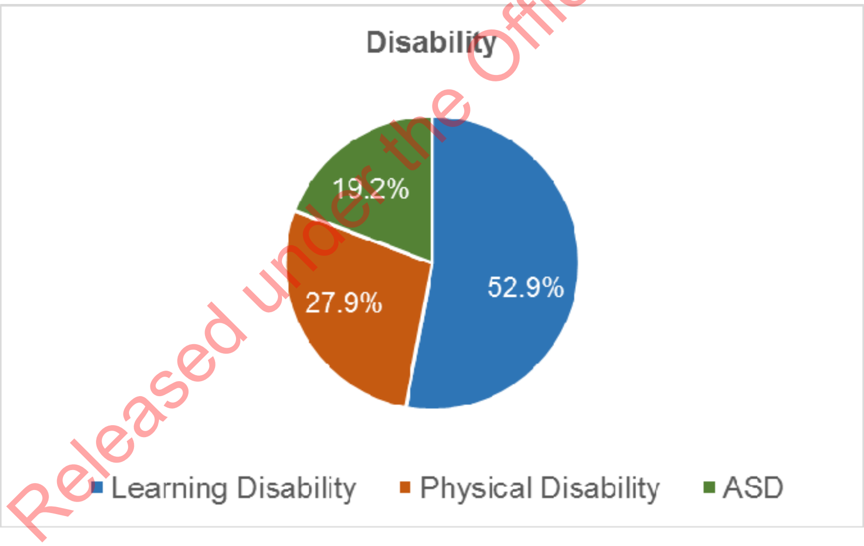
This survey involved a total of 172 face-to-face interviews with disabled people.

6. Who participated in the survey

Type of impairment/disability

There were three distinct groups of disabled people involved in this survey. Those with a primary diagnosis of learning disability, those with a primary diagnosis of Autism Spectrum Disorder (ASD), and those with physical disabilities without other impairments (ie, they did not include people with learning disabilities or ASD). The physically disabled group did not include people with *only* sensory disabilities[8].

Figure 1: Disability type



Type of disability by level of assessed need

---

[8] There were insufficient numbers of people only with sensory impairments (and no other disabilities) to include in this survey. People with Sensory Impairments are likely to access support services through agencies other than the NASC, such as Blind Foundation and Deaf Aotearoa.

The level of assessed needs is based on the ratings provided through the needs assessment by Enable NZ. They include people with very high assessed needs (VHN), high and moderate needs[9].

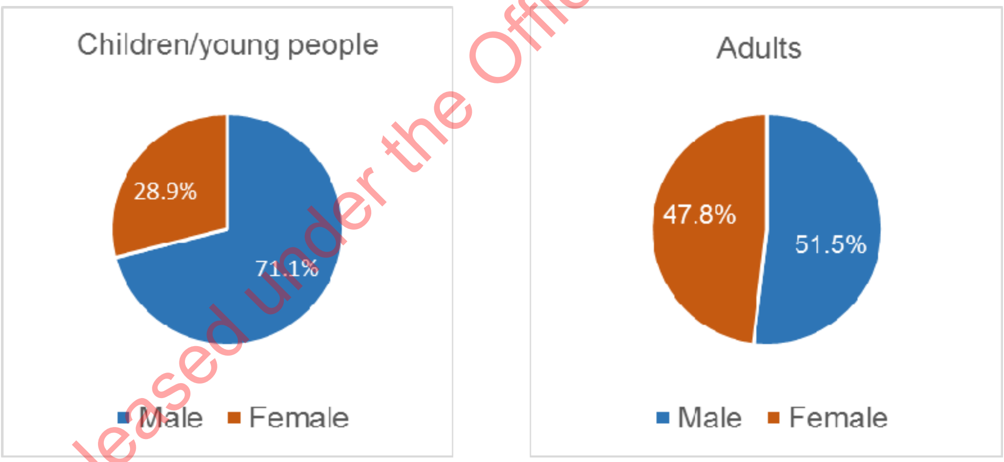
Table 2: Type of disability by level of assessed need

	VHNs	High	Moderate
Learning Disability	38 41.8%	36 39.6%	17 18.7%
Physical Disability	14 29.2	12 25.0	22 45.8
ASD	6 18.2	8 24.2	19 57.6

Gender

Slightly more males (56 percent)[10] are represented in the Baseline Study than females, with greater numbers of males present in the sample of children and young people when contrasted with adults (see Figure 2).

Figure 2: Gender differences between children and young people versus adults



Ethnicity

The majority of the sample identified as:

- NZ European (76 percent) and
- 17 percent as Māori.

---

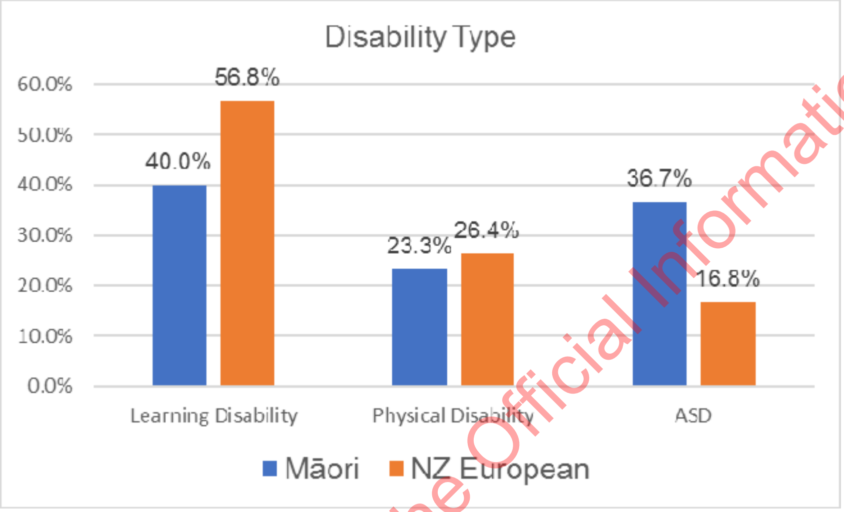
[9] For a small number of people (n=27) in the July 2018 DSS data the level of assessed need is rated as 'low'.

[10] A further 0.6 percent identified as gender diverse.

The remaining six percent represented a range of other ethnic groups and were insufficient in number to provide further analysis[11]. There were fewer Asian representatives in this sample (1.2 percent) than the total DSS population[12] in the MidCentral area (3 percent) and only one person identified as Pasifika (or 0.6 percent, compared with the DSS MidCentral population of 2 percent).

There were few differences related to gender between the two main ethnic groups. However, differences were noted with regard to the type of disability (Figure 3) and the number of adults to children/young people who have ASD. In the latter case, Māori supported more children and young people with ASD (83 percent) than NZ Europeans (52 percent).

Figure 3: Proportion of Māori to NZ Europeans by disability type



Age

Seventy-eight percent of the disabled people surveyed were adults (18 years of age and older).

The average age for people with autism spectrum disorder (ASD) was only 25 years with a range up to 35 years. Older individuals with ASD did not previously have a separate diagnosis and were represented as learning disabled. Many people with physical disabilities acquire their disability later in life (not accident related) and are, therefore, older on average than the other two groups.

Table 3: Age by disability type

	Mean	SD	Range	CI	Total
Learning Disability	43.0	14.5	18-81	3.3	77
Physical Disability	58.8	10.3	21-74	3.0	48

---

[11] Eleven people in total including other Europeans (6 people), two people who identified as Asian, two Fijian Indian and one person who identified as Pasifika.

[12] DSS MidCentral population figures derived from the Enable client database for MidCentral 2018.

ASD	25.4	6.4	18-35	5.0	9

Proxy respondents

Definition: a proxy is someone who represents someone else's interests and views.

Approximately half of those completing the disabled persons survey (48 percent) were proxy respondents. These people were external to support services and knew the disabled person very well (usually whānau). Of this group 46 percent represented children and young people. Of the children and young people, all but one lived with whānau (one lived in a residential school).

Of those proxy respondents representing adults, 80 percent were people with learning disabilities and twelve percent were people with ASD. The majority of adults represented by proxies had very high assessed needs (VHN). Eighty-three percent of all adults represented by proxy respondents, who have VHNs, live in fully supported residential accommodation (including group homes[13] and rest homes).

Type of supports

Community residential homes and people with Very High Needs (VHNs)

The majority of people living in fully staffed accommodation were adults with learning disabilities (86 percent)[14] who live in community residential homes. These homes are run by a variety of service providers and tend to house up to six people. The average number of flatmates (not including the person) for learning disabled people, who live in community residential homes, is three (SD 1.6). There is a range of no flatmates to five people. Sixty-five percent live in homes of four or more people in total[15] and only three of 44 people lived alone (8 percent).

Approximately 90 percent of all adults with learning disabilities, who have very high needs (VHNs), live in community residential homes.

VHNs can include people with complex or global disabilities and related health needs, including significant cognitive impairments, physical impairments and/or sight and hearing impairments. The VHN group may also include people with less complex disabilities but significant behavioural, anxiety or psychiatric issues that require intensive support.

---

[13] Typically supporting up to six people.

[14] The remainder include two people with physical disabilities who reside in rest homes, and three who live in residential homes.

[15] Including themselves.

All twelve individuals of the people surveyed, who used to live at Kimberley Centre before it closed in 2006[16], are represented in the VHNs group living in community residential homes (35 percent[17] of adults with learning disabilities with VHNs living in residential homes).

Proxy respondents (welfare guardians and/or whānau) were used for many of the people with learning disabilities who were living in community residential homes (71 percent)[18].

Supported living and high/moderate support needs

Supported living is provided to individuals who are able to live reasonably independently in their home. While supported living does involve a degree of personal and household support, the emphasis is towards increasing the person's independence in these activities and providing active supervision where needed. It may also involve assistance with appointments, filling out forms, budgets, diets, exercise and attending activities in the community. For most people, a person-centred, aspiration-based plan is developed and support workers assist people to pursue particular goals or aspirations.

Among those surveyed, supported living was used most often by people with learning disabilities (88 percent) who had moderate to high support needs (96 percent).

Household management and personal care (HM&PC)

Twenty percent of the adult disabled people surveyed received only household management and/or personal care support (HM&PC)[19]. Household management involves a support worker assisting with household routines and chores according to a pre-planned schedule of activities for each person. Personal care support also provides a pre-planned schedule that is individualised for the person. Typically, support workers are provided by agencies. On occasion a person may have individualised funding and hire their own staff. Thirty-five people only received this type of support – of whom 31 were adults with physical disabilities only (89 percent).

Whānau support and support for children/young people

---

[16] Kimberley Centre was the last total institution for people with learning disabilities. It was located in Levin (MidCentral area) and many of those who left were relocated in the same region.

[17] DSS records only refer to ex-Kimberley residents with reference to day service packages. These records were confirmed (with one addition) from conversations with respondents during interviews.

[18] Regardless of level of assessed need. There were 38 adults with learning disabilities living in community residential homes, 27 used proxy respondents or a mix of a proxy respondent for some information and information gathering from the service by the interviewer for non-subjective information (two cases).

[19] N=35 people in total receiving only HM&PC support including n=31 adults with physical disabilities, n=2 children and young people (one each with learning disability and ASD) and two more adults (one each with learning disability and ASD).

There are several types of support offered to whānau or carers and children and young people. These may include HM&PC support options noted above. One of the most common is the carer support subsidy. The carer support subsidy is made available to the disabled person and their main carer, usually whānau, partner or spouse. This is to provide a time when the disabled person can be supported by someone else. Prior to the system's change in October 2018, carer support was allocated at a daily rate of $76 a day. For a 24-hour period this equates to $3.17 per hour. On average, 34 carer support days were allocated per person. Thirty-three people in the disabled persons' survey received the carer support subsidy. Just under half of this group *only* received the carer support subsidy (49 percent). When combined with the whānau survey, a total of 51 people received the carer support subsidy.

Another support involves out-of-home respite. This respite is provided for children and young people, usually in designated services designed for this purpose. For example, a house for around six young people. Whānau with this funding would be able to book the disabled child/young person into this service for a set number of days per year. Respite is also offered to adults. Typically, this is people with physical impairments and is often associated with designated nursing homes. Only one person, in the disabled persons survey, indicated they received respite funding (in this case individualised funding for respite where they can choose their own type of respite).

Whānau may also be offered access to the DHB Child Development Service (CDS). This is a personalised therapy-based service that provides assessment and therapy services to babies, children and adolescents (birth – 16 years) who have developmental or ongoing disability needs. They also work with babies at risk of disability, such as babies born prematurely. The service focuses on early intervention. Eight children/young people in our survey were making use of this service at the time of the survey.

Behaviour support is also offered through a behaviour support agency.

Individualised funding, hospital and nursing home care, equipment and day services

Three other types of funding are represented in this survey. Ten people received individualised funding (IF). This was primarily in household management (seven people) and/or personal care support (seven people). One person received IF funding for respite. IF funding allows individuals or whānau to choose the style of support they desire, within particular parameters, and allows them to either hire their own staff or acquire staff through an agency.

Hospital or nursing home care was provided for two people in this survey on a full-time basis. These people may be referred to in this report with reference to residential supports but for the most part residential services refer to people in fully staffed residential homes unless otherwise stated.

Enable NZ also provides funding for equipment for most people with physical impairments who have reduced mobility or similar needs. A small number of people in this survey (seven) also received Ministry of Health funded day services.

7. Defining some key words and terms used in this report[20]

Term or word		In this report, the word means:
Whānau		family, whānau, spouse/partner, welfare-guardian and advocates
Disabled people		people with a physical, learning or sensory disability, or ASD, who were clients of the MidCentral Needs Assessment and Service Coordination Service (NASC).
Residential Services		A community residential home funded by Disability Support Services, Ministry of Health (unless specifically stated otherwise). 'Residential supports' in this report refer to people who are also supported in nursing homes.
Disability Support Services (DSS)		Ministry of Health funded Disability Support Services
MidCentral Area		The MidCentral area includes Palmerston North, Horowhenua, Manawatu, Ōtaki and Tararua.
Very High Needs (VHN)		Very High Needs refers to a level of support, where people are identified as having multiple and significant challenges with daily living activities. The support required is likely to be intensive. The level is identified through the NASC process and based on a facilitated needs assessment. The level was developed as a consistent way to describe a person's total disability support level for their service package allocation.

---

[20] Also see the Glossary of abbreviations and terms, page 94.

8. Interesting things we discovered

Summary

There were significant variations in how people were experiencing their lives and between different groups of disabled people.

Some of the highlights and areas requiring major development are listed below:

Highlights

☑ (all disabled people unless otherwise stated)

Believe paid workers understand how to support them safely

Believe their culture is respected

Believe people value what they can do

Love life (self-reports only)

Have the equipment they need

Believe they are supported to maintain and improve their health.

Areas requiring development

☒ (all disabled people unless otherwise stated)

83%	Had not worked in the week prior to the survey (adults only)
77%	Were single at the time of the survey (adults only)
57%	Chose who they lived with (adults only)
56%	Were achieving the things they wanted
48%	Had real choice about the support they received.

The Disability Support System (DSS) in the MidCentral area prior to the Mana Whaikaha was generally meeting a variety of needs.

Many people were pleased with aspects of their support and some received all the support they felt they needed.

However, services did not appear to be assisting some people to overcome the barriers they face to live a happy and fulfilled life.

The system often provided for basic needs but did not seem responsive to the New Zealand Disability Strategy or Enabling Good Lives (EGL) principles[21].

A major issue, identified in this report, was the structured use of funding that effectively siloed support into different packages that were tied up with inflexible rules.

9. Māori

There were very few differences between Māori disabled people participating in the survey and NZ Europeans.

- Eighty-six percent of Māori surveyed believed their culture was respected by their supports all or most of the time (compared with 91 percent of NZ Europeans)[22].
- Ninety-five percent of Māori surveyed believed their spirituality or beliefs were respected by their supports all or most of the time (compared with 92 percent of NZ Europeans surveyed).

The main points of difference were in regard to work and income and home ownership:

- Ninety-four percent of working-age[23] disabled Māori had not worked in the previous week compared with 79[23] percent NZ Europeans.
- Initial review of home ownership for disabled Māori suggest four people own their own home (22 percent) in contrast to 42 percent of NZ Europeans.

---

[21] http://www.enablinggoodlives.co.nz/ and https://www.odi.govt.nz/assets/New-Zealand-Disability-Strategy-files/pdf-nz-disability-strategy-2016.pdf

[22] There were insufficient numbers of people in the Pasifika and Asian (n=3 in total) categories to provide a viable comparison.

[23] Defined as 17 to 65 years of age and not in school

10. What disabled people think about their lives

When thinking about the life experiences of disabled people many complex things need to be considered.

These complex things we refer to as variables. They created different sets of results for different groups. These variables included:

- Age – specifically adults versus children and young people
- Disability type
- Degree of assessed need
- Where people live and with whom
- The support package they receive.

These variables had an effect on results relating to:

- Wellbeing
- Autonomy: choice and control
- Social connectedness and relationships
- Community participation
- Development, achieving and planning
- Education, employment, living situation and income
- Satisfaction with support services.

11. Wellbeing

Subjective wellbeing (SWB) measures involve a number of different questions related to general happiness and other impressions.

They are not questions another person (proxy respondent) can easily answer on behalf of a disabled person, so only self-report responses were used for this section.

Things that stood out for disabled people were:

☑

Table 4: Positive Wellbeing Indicators – self-reports only

	Yes/totally Mostly	Okay/ So-so	No/never not really
I trust people who are important to me	89.4%	8.2%	2.4%
I am a happy person	79.3%	14.9%	5.7%
I know who to ask for help, advice, or support if I need it	81.7%	9.8%	8.5%
I love life	82.1%	9.5%	8.3%
I am happy with my life	74.1%	8.2%	17.6%

☒

Table 5: Wellbeing indicators – self-reports only

	Yes/totally Mostly	Okay/ So-so	No/never not really
I worry about things	48.2%	37.6%	14.1%
I believe more good things than bad things will happen to me	58.3%	23.6%	18.1%
I am optimistic about my future	55.3%	26.3%	18.4%
In most ways my life is close to the way I would want it to be	56.0%	12.0%	32.0%

Comparing adults with learning disabilities and adults with physical disabilities in Table 6, some variation is noted.

People with physical disabilities are:

- not as happy as people with learning disabilities
- less optimistic regarding their future
- less convinced their life is the way they want it to be.

Table 6: People with learning and physical disabilities who self-reported on subjective wellbeing questions, (‘yes/always’ and ‘mostly’)

	Learning Disability	Physical Disability	WMW
I am a happy person	86.5	72.7	2.4**
I know who to ask for help, advice, or support if I need it	88.2	76.2	1.8
I am optimistic about my future	66.7	46.5	2.2*
In most ways my life is close to the way I would want it to be	82.1	35.7	4.7***
I am happy with my life	88.6	59.1	3.7***

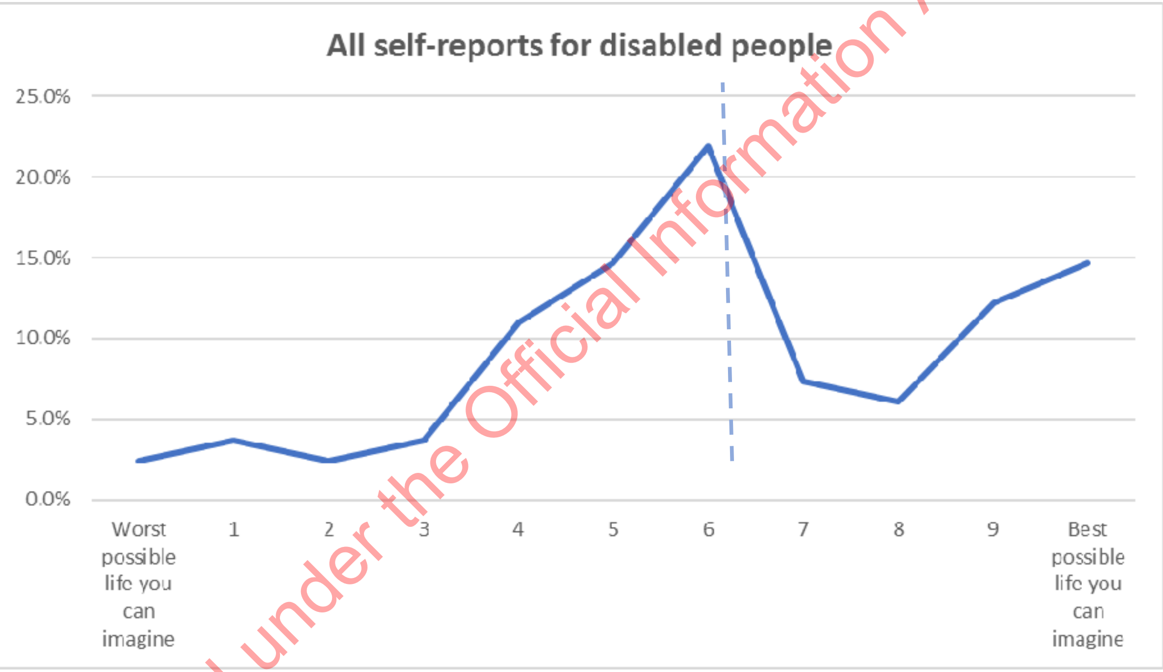
$^{*}p<0.025$, $^{**}p<0.01$, $^{***}p<0.001$

The Cantril Ladder: A measure of Personal Wellbeing

One measure of wellbeing is the Cantril Ladder[24]. The Cantril Ladder is an international scale used in many countries and is being considered for use by the Treasury in New Zealand. It asks people to rate where they would stand on a ladder[25], if zero represented the worst life for them and ten represented the best.

Figure 4 below indicates the range of responses on the Cantril Ladder for all disabled people who provided their own responses (self-reports). The average (or mean) for this group was 6.2 (SD 2.6) and suggests most people (77 percent) were scoring themselves at five or better.

Figure 4: Cantril Ladder for all disabled person sample – self reports



(vertical line=mean)

The following section concerns how Cantril Ladder measures are influenced by disability type.

People with Physical Disability

There are variations in responses to the Cantril Ladder depending on the type of disability. For example, the range of responses for people with physical disabilities is presented in Figure 5. The average score on the Cantril Ladder for adults with

---

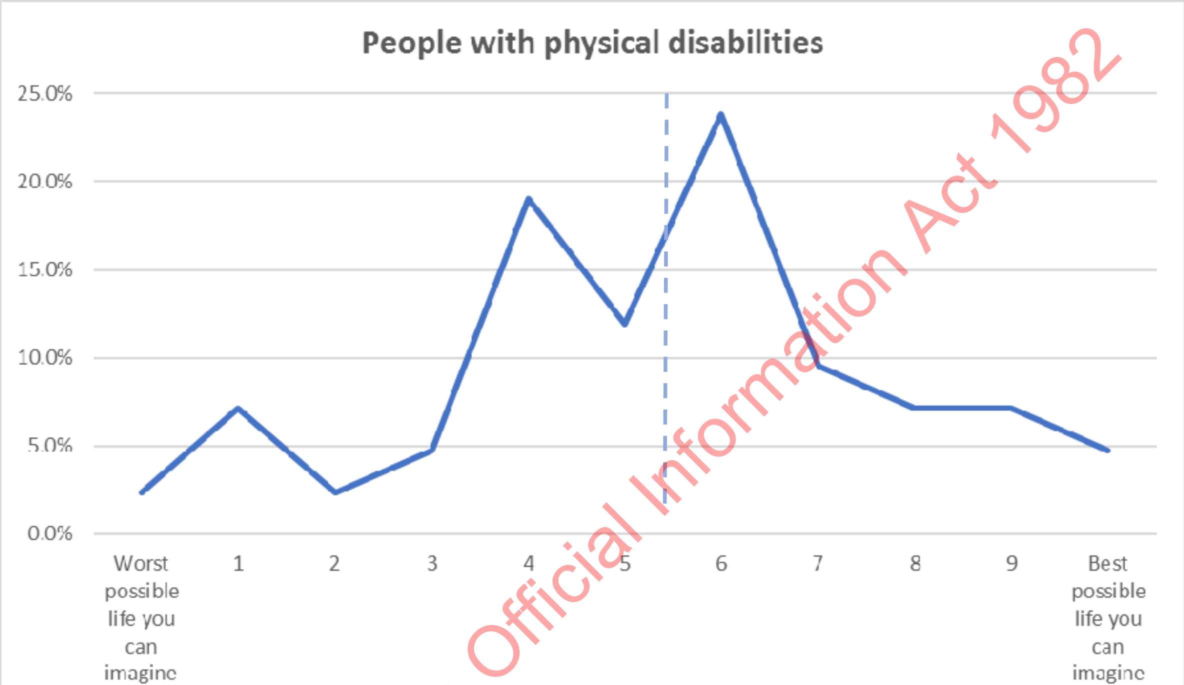
[24] Gallup World Poll. Bjørnskov, C. 2010. How Comparable are the Gallup World Poll Life Satisfaction Data? *Journal of Happiness Studies*, *11* (1), 41-60.

[25] In the case of disabled persons survey, a staircase.

physical disabilities is 5.4 (SD 2.4) compared with 7.4 (SD 2.4) for adults with intellectual disabilities[26].

Sixty-four percent of people with physical disabilities scored themselves at five or more on the ladder compared with 91 percent of people with learning disabilities.

Figure 5: Cantril Ladder for people with physical disabilities – self report only



(vertical line=mean)

---

[26] WMW=3.2, p<0.001, df=66. Diff in mean=2.0, $t=3.5$, $p<0.001$. There were only three adults with ASD who provided self-reports for SWB material. Adding them in with self-reporting adults with learning disabilities decreases the mean to 7.1 (2.3). WMW=2.8, p<0.01, df=69. Diff in mean=1.7, $t=2.9$, $p<0.01$.

An examination of the results for people with physical disabilities indicates those scoring four or less on the Cantril Ladder[27] were often people with:

- progressive conditions[28] (40 percent) and/or
- poor health (33 percent).

When compared with people scoring five or more on the ladder, progressive conditions were indicated in 24 percent of cases and poor health in three percent.

This suggests that health plays a significant part in individual perceptions of wellbeing.

A theme for people with physical impairments

A theme running through all of the results for people with physical impairments was social isolation.

This could be about:

- being stuck at home and being dependent on others (eg, loss of mobility and transport)
- the need to involve others to utilise the community
- losing contact with other people.

One person stated when giving a low score on the Cantril Ladder:

> *I can’t get out to socialise. People who were friends have moved on.*

Another stated:

> *[I] would like to see my son in [town name stated] and take my own support with me to help. [I] would like to see my grandchildren.*

Another person both grieved the loss of her independence and her changing role. When she was asked to respond to the statement, “I know who to ask for help, advice, or support if I need it”, she said:

> *[I] don’t do it because I don’t want others to get involved and put in their time.*

Later she added:

> *I see my family as family and to be supported. I am the Mum and [I] support them.*

When asked about her sense of belonging in the community, she stated, “I feel isolated”.

---

[27] Fifteen people with physical disabilities were scoring lower on the ladder compared with 28 people scoring 5 or more.

[28] From self-descriptions and information obtained from the DSS database, July 2018.

The answers to many of the questions in the survey are often linked together and complex.

For some, being visited by support workers is the only point of contact people have with others in their day. When asked what was most important to him in his life, one man said:

> *Oh, to improve my life. I would love to work you know, only a few hours a day and just to have human contact. Unfortunately, my family's not the greatest, so yeah, having human contact is a biggie to me.*
>
> *[Interviewer]: So, you don't see lots of people…?*
>
> *No. If I don't go out at all, all I see is my lady in the morning to put the sock on and the lady at night to take it off. And an hour of home help a week. That's all I have. So, if it wasn't for the sock…*

What can make a difference

Table 7 indicates the differences in perceived isolation between those scoring higher on the Cantril Ladder and those scoring lower. It is clear that living alone or living with others makes a difference. People lower on the scale have fewer opportunities to connect with others (who were not support workers). Although, the rate of contact with family is similar for both groups, the rate of contact with friends is much lower for people who are scoring lower on the scale.

These results are an indication only, as the size of one group was only 15 people.

Table 7: Social contacts and isolation questions – people with physical disabilities reporting high or low on Cantril Ladder

	Scoring low on Cantril Ladder (4 or less)	**Scoring higher on the ladder (5 or more)**
Live with family or friends	26.7%	51.7%
Live alone	53.3	37.9
Contact with friends in the last week	35.7	75.0
Contact with family in the last week	78.6	71.4
	n=15	n=28

Contrasting the two groups on other dimensions it appears that while the rate of unemployment appears similar, at 93 percent[29], the number of people engaged in other activities is higher in the group who were scoring higher on the Cantril

---

[29] Self-reports only for people with physical disabilities.

Ladder (13 as opposed to 26 percent for voluntary work). When people talked about voluntary activities these ranged from “knitting for the babies at the hospital” to running their own charitable trust for people with mental health issues.

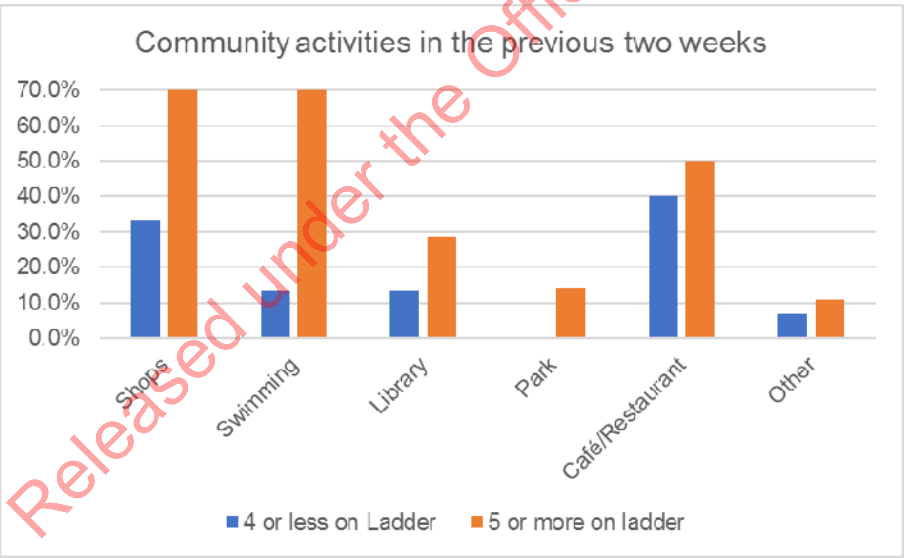
Fifty percent of the people with physical disabilities, who scored higher on the scale, were engaged in further education at the time of the survey compared with 28 percent of those scoring lower on the scale.

Social isolation

For those scoring lower on the Cantril Ladder, it is noted that 79 percent *did not* feel they had a sense of belonging in the wider community (not really or at all). This figure is almost a complete reversal of those who scored higher on the ladder with 74 percent believing they *did* have a sense of belonging all or most of the time. Again, we need to remember that one of these groups had only 15 people.

Figure 6 indicates people with physical disabilities who were scoring low on the Cantril Ladder were much less active in their communities in the two weeks prior to the survey than people scoring themselves higher on the ladder. People higher on the ladder were involved in 22 different clubs, groups and organisations[30], compared with the four[31] listed for people who were scoring themselves lower on the ladder[32].

Figure 6: Community activities in the previous two weeks, people with physical disabilities low and high on Cantril Ladder



---

[30] From 28 different people (some people belonged to multiple clubs, groups or organisations).
[31] From 15 different people.
[32] 79 and 27 percent respectively.

Personal resources

Personal resources amongst disabled people was listed as one of the determinants in higher Social Wellbeing (SWB) scores on the Cantril Ladder scores in Europe[33]. The two features of personal resources that were most apparent were:

- social supportiveness (having people involved in your life), and
- vitality (being energised and well rested).

In our survey, one of the most common comments made by physically impaired people, scoring higher on the Cantril Ladder, was that simply being alive was sufficient to be more positive in their assessment of their life. People variously stated:

> *[I'm] lucky to be alive.*
>
> *I am, therefore I am.*
>
> *I'm still alive.*
>
> *[I'm] thankful I'm alive.*
>
> *Yes. Well I'm so grateful to be still alive but it doesn't worry which way I go because I've already been to heaven and back.*

The statement of "being alive" was almost used as a description of internal resourcefulness. A source of energy that kept people positive. However, for people where progressive conditions and health issues pose particular stresses that sense of inner resourcefulness can be lacking. One spouse simply commented:

> *Life as she knew it is over and all she is doing is waiting to die.*

People with physical disabilities, who scored lower on the Cantril Ladder, indicate issues that need to be considered when making assessments for support:

- where and with whom people are living (alone, with family, rest home),
- their mobility or factors that affect their ability to move outside the home (such as transportation and the availability of people to provide support), and
- their ability to connect with groups, places and people (this could be based on factors noted previously or their own motivational/ personal or health issues).

---

[33] van Campen, C. and van Santwoort, M. (2013). Explaining low subjective wellbeing in persons with disabilities in Europe: The impact of disability, personal resources, participation and socio-economic status. *Social Indicators Research*, 111, 839-854.

People with Learning Disability and ASD

People with learning disability and ASD had a higher average score (7.1) on the Cantril Ladder than people with physical disabilities. The graph for people with learning disabilities in Figure 7 indicates a bimodal distribution (0 to 6 and 7 to 10) ie, two contrasting results. While there are some similarities with those people with physical disabilities scoring higher or lower on the ladder, there were also some unique observations. As noted previously, nearly 90 percent (89 percent[34]) of adults with learning disabilities and ASD scored themselves 5 or higher on the Cantril Ladder. Fifty-four percent scored themselves 7 or higher.

Figure 7: Cantril Ladder for adults with learning disabilities and ASD – self reports only

(vertical line=mean)

People with learning disabilities and ASD who scored themselves less than seven on Cantril Ladder:

- lived alone (44 percent) compared to the upper group (25 percent[35]). This may suggest that living with someone, even if it is in a residential service, may provide higher scores on the Cantril Ladder.
- indicated they had *few or no* friends outside of where they lived (26 percent) compared to the people rating themselves higher on the ladder (9 percent).

Sixty-two percent of the lower group had contact with friends in the previous two weeks compared with 91 percent of the upper group.

---

[34] NB, learning disability *and* ASD in this case (as some previous comparisons only used ID adults). Three adults with ASD provided self-reports.

[35] Thirty-three percent lived with family.

People with learning disabilities and ASD can have an impoverished circle of friends when compared with people without disabilities. It is also noted that if we did not consider other people with learning disabilities, in those friendship circles, the differences between the groups would be even larger[36].

Seventy-seven percent of adults with learning disability and ASD, who scored themselves seven or higher on the Cantril Ladder, indicated they felt they belonged in the wider community (all or most of the time). This is in contrast to 42 percent of those who scored themselves less than seven on the ladder.

---

[36] E.g. Kersh, J., Corona, L, and Siperstein, G (2013). Social well-being and friendships of people with intellectual disabilities, In Wehmeyer, M.L. (ed.). *The Oxford Handbook of Positive Psychology and Disability*. Oxford University Press; Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities*, 17, 191–197; Cummins, R. A., & Lau, A. L. D. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16, 145–157.

12. Exercising choice and control - Autonomy

Choice with where I live and who I live with

☒

- **Having a choice of flatmates was rated poorly, with 37 percent of all disabled adults indicating little or no choice, and**
- **72 percent of adults with learning disabilities living in residential homes indicating little or no choice.**

Adults with learning disabilities who were living in residential homes appeared to have far less choice about who they lived with. Verbal responses to this question indicated this choice was often made by others, usually services, but on occasion whānau. For example, one person stated:

> *I'm in a flatting situation…It's a facility. My actual family chose the place where I wanted to live. So, I didn't have any say in living here.*

Some whānau put their faith in service providers to make the right decisions, especially those who left Kimberley Centre for residential homes:

> *That was decided when they left Kimberley. [They] put him in with someone he knows.*

Another person noted with to regard having a choice of flatmates:

> *I'm not sure about that but the people that live with her, they've all been chosen so that they can get on. I mean the first thing was that they all get on together, that they will all gel. And they do, they all get on together.*

In contrast, other comments suggest the balance of personalities in community residential homes are not always positive. One person noted that choice was an evolving process but one that was dictated by the person's behaviour or anxiety with having to live with others:

> *[It] Evolved through his need... [It] took a lot of work but it's evolved into what we see now. He's got a life.*

Those not assertive in expressing that they are not always happy about their flatmates, have developed coping mechanisms which may have evolved into normalised behaviour. For example, 18 percent of the group talked about raised anxiety in busy or noisy environments and 11 percent referred to issues with specific flatmates. However, coping with the problem tended to be the typical response:

> *One or two there are a lot worse than [name of person]. He doesn't seem to mind. If he gets brassed-off he just goes into his room.*

Table 8 indicates only about a third of all adults with learning disabilities believed they had control of choosing who they lived with (all or most of the time)[37]. The difference for people with learning disabilities is in part service-based, as close to half (48 percent) live in community residential homes.

Table 8: Responses to autonomy question: adults with learning and physical disabilities, (‘yes/always’ and ‘mostly’)

	All Adults	Physical Disability	Learning Disability
I choose who lives with me	56.7%	85.7%	39.6%

WNW=3.8, p<0.001, df=80, Diff in mean 1.5

Communication

Choice can be challenging if someone has limited speech. For example, in responding to the survey item, ‘I am understood when I communicate”, 63 percent of people with learning disabilities in residential homes believed they were understood (all or most of the time)[38].

☒ **Over one-third of people with learning disabilities in residential homes are not confident they are understood.**

Often communication is thought of in terms of speech. However, people with VHNs and with limited speech are able to express their needs and desires in other ways. One proxy respondent said:

> I guess if she were having a bad day and was throwing her toys out of the cot, they wouldn’t take her out.

Another proxy respondent speaking for the person (in first person) stated:

> Sometimes through body language I can show what I want.

Choice about the kind of support I get

For people with a learning disability living in a residential home

---

[37] WMW=3.8, p<0.001, df=80 learning disability versus physical disability. Diff in mean=1.5.

[38] Similarly, only 58 percent of adults with learning disability or ASD and who have VHNs believed they were understood when they communicate (all of most of the time). This contrasts with 75 percent of adults with learning disability and ASD with high and moderate assessed needs.

☒ **77 percent did not believe they had a choice of support workers (all or most of the time)[39],** although they did believe they knew who would be supporting them each shift.

Also, nearly a half did not believe they:

- had much choice in the kind of support they received (56 percent)
- could make changes to their support (54 percent)
- could easily find out about the things they needed for their support (47 percent)[40].

Timing of support

☑ **For fully staffed residential homes respondents believed they had support when they needed it and at times that worked for them.**

Table 9: Satisfaction and adults with learning disabilities living in community residential homes (n=33 & 25)

	Yes always/Mostly	Sometimes	Not really/No
My support happens at the times that work for me	81.8%	18.2%	0.0%
My support occurs when I need it in my life	80.0	16.0	4.0

☒ **Respondents for children and young people (who typically live with whānau):**

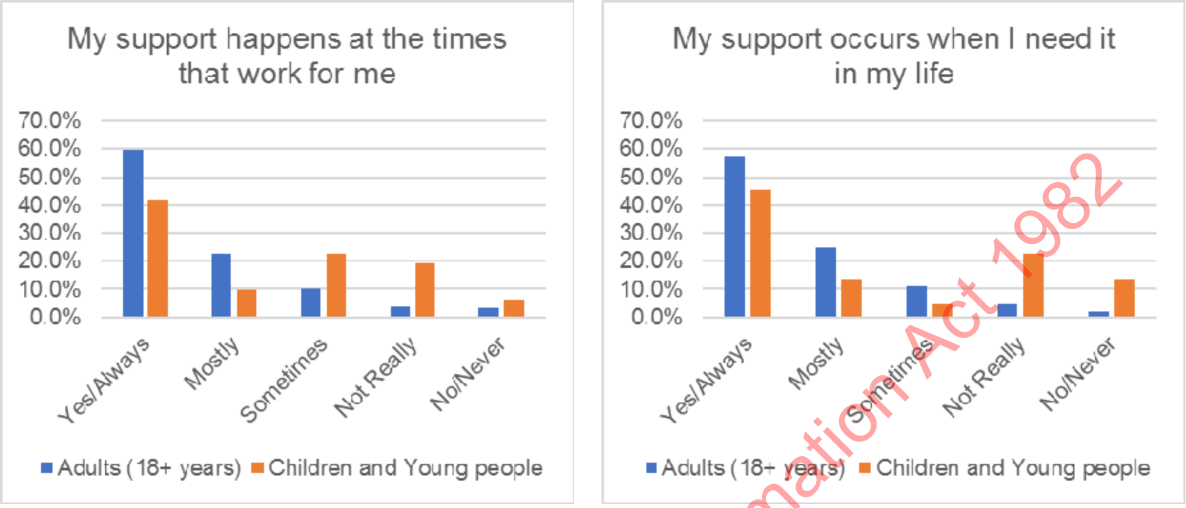
- **did not believe supports happened at times that worked for them (26 percent: ‘not really’ or ‘not at all’), or**
- **when they needed it in their life (36 percent).**

---

[39] From n=33 of people who did respond to this question.

[40] The total number of people in the residential homes sample for adults with learning disabilities was n=37. However, non-responses for these questions was high (51, 65 and 60 percent respectively) creating a sample size of n=18, 13 and 15 respectively). The lack of responses indicates respondents (mostly proxies) simply chose not to answer, did not feel they could answer for the person or did not believe the question was relevant.

Figure 8: Children and young people versus adults on whether support happens at times that work for the person or that it occurs when they need it in life



It was indicated that 38 percent respondents for children and young people were less convinced (‘sometimes’ to ‘no/never’) that paid support workers received the training they needed in contrast to all adults (14 percent).

Variations in these items may be due to differences in the type of support expected and received by various groups. In particular, adults are more likely to receive supports through agencies and service providers than children and young people. In the latter case, 34 percent of all children and young people have at least some support through the carer support subsidy[41], in contrast to 15 percent of adults.

Having what they need

☒ **Over one-third of disabled people are not certain they are receiving the support they need.**

Table 10: Having the support I need

	Yes always/Mostly	Sometimes	Not really/No
I feel the amount of support I have is right for what I need	62.8%	14.0%	23.3%

---

[41] Families or young people may also receive such things as only DHB support (21 percent), behaviour support (two people or five percent) or HM&PC support (18 percent).

Having positive relationships

Friends and family: Social Interaction

☒ **Seventy-seven percent of all adult respondents were single at the time of the survey and only 15 percent lived with a partner or spouse.**

Statistics in the USA indicate that 48 percent of individuals 18-29 years old are single, compared with 22 and 25 percent for two older age groups (30-49 years, 50+ years)[42]. In comparing these figures with those participating in the Baseline Study in Table 11, we found that far more people with disabilities were single in all age groups.

When considering statistics for people who were married in the US study, 58 percent of the over 50-year-olds reported being married. Only 39 percent of people with physical disabilities were married (or living with a partner) in the same age group[43]. In total[44], only two (of 77) adults with learning disabilities reported being married[45]. Sixty-three percent of people with physical disabilities had children of their own (28 people) compared with one person with a learning disability.

Table 11: Age by relationship status, 'single', all adults

	All adults	Physical Disability	Learning Disability
18 to 29 years	88.0%	-	100.0%
30 to 49 years	73.2	-	80.0%
50+ years	64.7	56.1%	95.5%

Missing data for people with physical disabilities is due to the small size of these subgroups.

Sixty percent of all those responding to the disabled persons survey stated they had friends outside of where they lived (yes/totally or mostly)[46]. Conversely, 31 percent said they did not have friends outside of their place of residence ('not really' or 'not at all'). Figure 9 indicates adults are much more likely to suggest

---

[42] (2017) https://www.statista.com/statistics/669122/americans-current-relationship-status-by-age/.

[43] Equivalent statistics for New Zealand are not available since only married/civil union rates seemed to be available. Not being married or in a civil union does not necessarily mean single. In New Zealand statistics 74% of men and 64% of women aged 25-29 years of age had never been married, also 16% and 13% of 45-49 year olds and 5% and 4% of 65+ year olds had never been married (2006 census) archive.stats.govt.nz/~/media/Statistics/browse.../3-mcud.xls also see 1999 statistics http://archive.stats.govt.nz/browse_for_stats/people_and_communities/marriages-civil-unions-and-divorces/marriage-and-divorce-in-nz.aspx

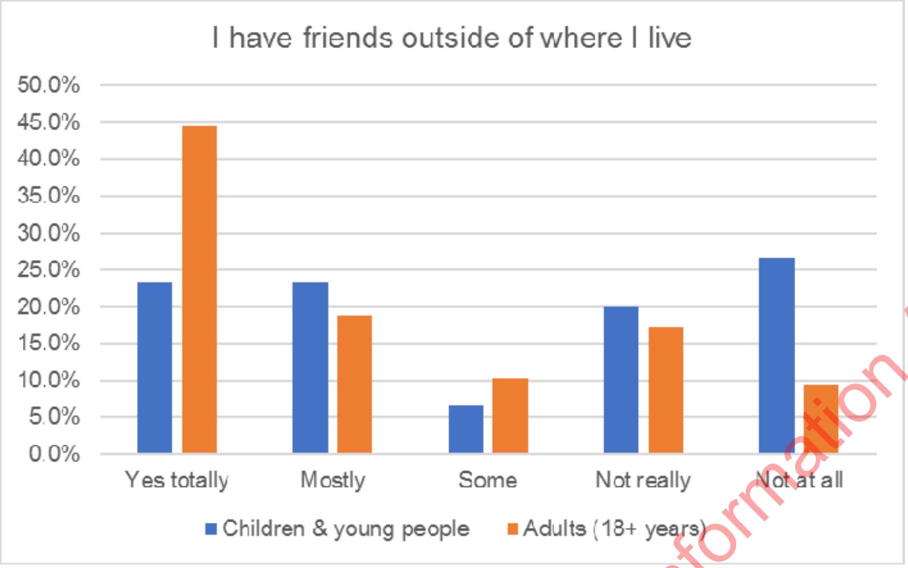
[44] Across all age groups.

[45] Nine percent of learning-disabled adults reported being in a short- or long-term relationship with another person who does not live with them. These relationships may or may not be intimate.

[46] For just adults, 63 percent indicated they had friends outside of where they lived.

they have friends (63 percent) than children and young people (47 percent), mostly or totally[47].

Figure 9: I have friends outside of where I live (not paid staff or flatmates, etc), adults versus children and young people



- Slightly more adults with physical disabilities (69 percent) said they had friends outside of their home (totally and mostly) than adults with learning disabilities (63 percent)[48].
- A third of all people with learning disabilities (33 percent) indicated they did not have friends (at all or not really) in contrast to people with physical disabilities (20 percent).
- When considering people with ASD, only 50 percent believed they had friends (totally or mostly) and over a third (39 percent) believed they had few or none.

This latter finding may be a combination of the average age of the ASD group (14.3 years, SD 8.4) compared with people with learning disabilities (39.7 years, SD 19.0). Similarly, people with physical disabilities are older (average 58.8 years, SD 10.3) and many have acquired their disability later in life and therefore may have had more opportunities to develop social networks.

People with learning disabilities in community residential homes are less likely to indicate friendships outside their home in contrast to all other adults.

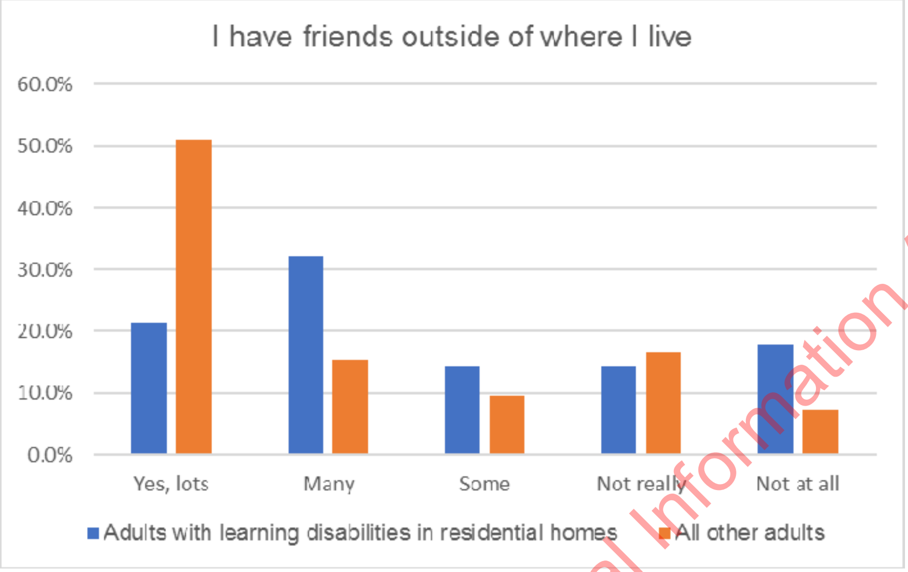
Adults with learning disabilities, living in community residential homes, predominantly have very high assessed needs. The level of assessed need and the character of group homes (with an average size of three people, SD 1.7) means that opportunities to meet and befriend people outside the home may be

---

[47] WMW=2.5, $p<0.01$, df=41. Diff in mean=0.8.
[48] Not statistically significant.

reduced as people are less likely to move around by themselves without staff support. Staffing levels may also limit opportunities for people to access the community on an individualised basis.

Figure 10: I have friends outside of where I live (not paid staff or flatmates, etc) adults with learning disabilities in community residential homes versus all other adults



In verbal comments, 29 percent of respondents for people in residential homes stated they had friends, but only at home or in day services. For some people in community residential groups homes, the main source of outings and social events are with people from the home or when they go to day services. When asked how often people see friends, one guardian stated:

> *Honestly, I don't know, I do know they take her out a lot, like she goes to the vocational place.*

Another guardian indicated that there were no friends outside of the home, but also stated in relation to what is important in her life:

> *Oh, I think she likes going out to dinner, shows, the van rides, the train rides and to have friends.*

For some people the narrow social group of home and day services (vocational services) is valued, especially due to the long-term associations people have had with one another. As one guardian stated:

> *There are four houses on the section and he goes visiting. Visiting friends in other houses.*

Yet, despite these obvious friendship links, guardians are also aware these networks may be limiting what is possible:

> *I really wish [person's name] could have a one-to-one friend… a friend he could relate to. The only thing I can think of that's missing in his life.*

Some people stated friendships were occurring for people in community residential homes through associations with other groups or people. For example, at least two people talked about friendships that had developed through attendance at church and one stated the person "got quite friendly with the chemist lady".

13. Belonging, contributing and being valued

Community participation

The degree of community participation was surveyed using open-ended questions in the disabled persons survey. People were asked to list what community facilities they used in the previous two weeks (ie, swimming pools, parks, sports facilities, library, shopping centres etc). They were also asked whether they were members of a local group, club, marae, sports team etc. Two more questions asked were: when was the last time they went out for a meal or visited a café or pub.

Table 12: Wording of the three community participation questions

I went out for a meal in the last… (options = week, two weeks, month, more than a month, in the last year, longer than a year, never)
I visited a cafe or hotel (pub/bar) in the last… (options = week, two weeks, month, more than a month, in the last year, longer than a year, never)
What community facility(s) did I use in the last week/fortnight?

Taking into account the combined results of the three questions in Table 12, especially with regard to people responding for the previous week to fortnight, a picture can be formed of community activity.

Results suggest that:

- Thirteen percent of all respondents indicated they did not visit community facilities or places in the previous two weeks, and
- seven percent suggested they *only* visited shopping centres[49].

There was very little variation in these figures between adults and children or young people.

Community involvement by disability type

Figure 11 below indicates more people with physical disability or ASD did not venture into the community when compared with people with learning disabilities. More people with physical disabilities only ventured out to the shops compared with the other two groups.

---

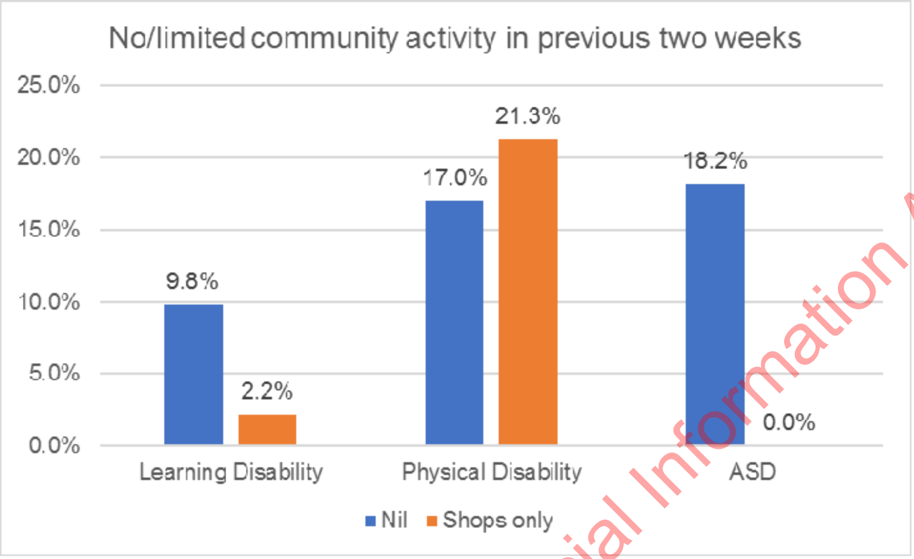
[49] Including grocery stores, shops in general, mall or plaza.

Document 7

☒ **38 percent of all physically disabled people had limited to no community engagement in the previous two weeks.**

This suggests that people with physical disabilities are more isolated than learning-disabled people and people with ASD.

Figure 11: Limited or no community participation by disability type



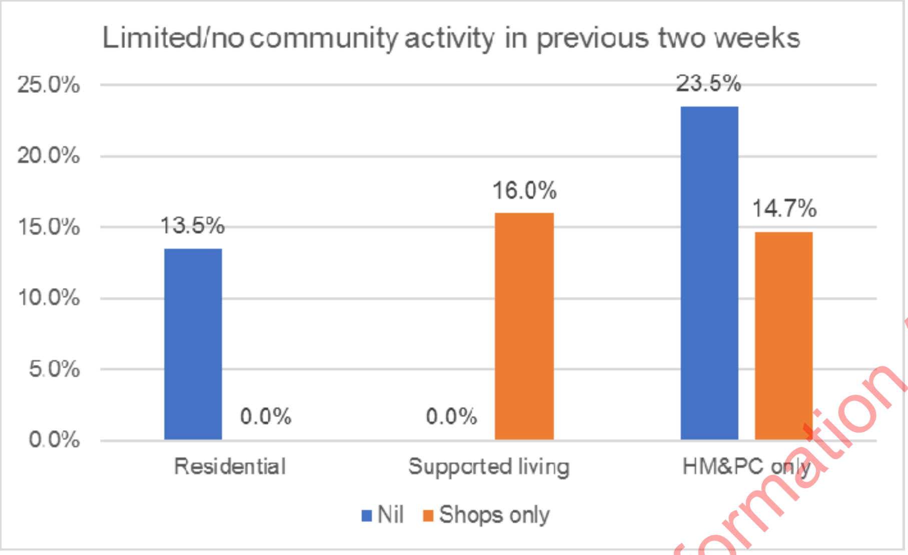
Community Involvement by support package

When considering the level of community engagement relative to the type of support provided for disabled adults in Figure 12, it is noted that people with household management and personal care support as their only form of support (HM&PC-only) were least likely to venture into the community. Given the majority of these individuals have physical disabilities, this finding is consistent with Figure 11.

☑ **All people associated with supported living accessed the community in the previous two weeks, although 16 percent only managed to visit shops in that time.**

It is suggested in Figure 12 that people receiving HM&PC-only support are less likely to have community involvement than other groups.

Figure 12: Limited to no community activities for disabled adults by type of support provided



Range of community activities

The range of community activities people have engaged in are presented in Figure 13. The overall results indicate visiting cafes (including pubs/bars) and restaurants in the previous two weeks was the most frequent activity, followed by shopping. Children and young people were more involved in swimming and visiting play areas and parks[50] than adults, while adults tended to favour the library and the gym.

---

[50] Including any area where people can go for walks or picnic such as gardens, city and forest parks, and beaches (sports ground were considered separately).

Figure 13: Range of community activities in the previous two weeks, adults versus children/young people

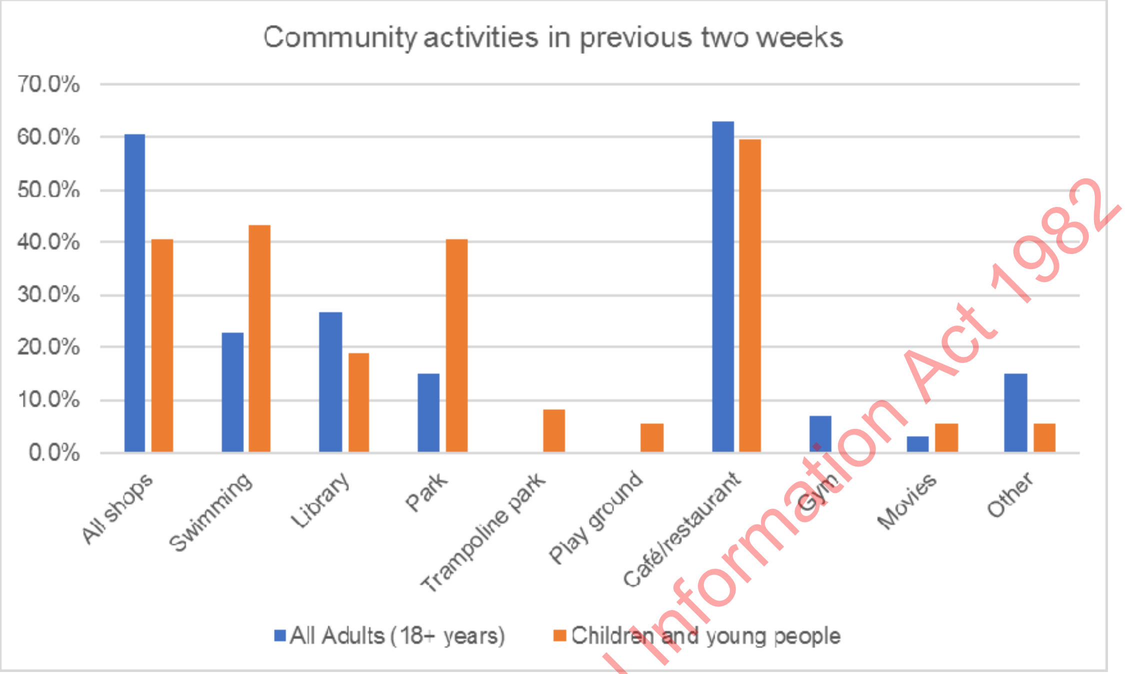
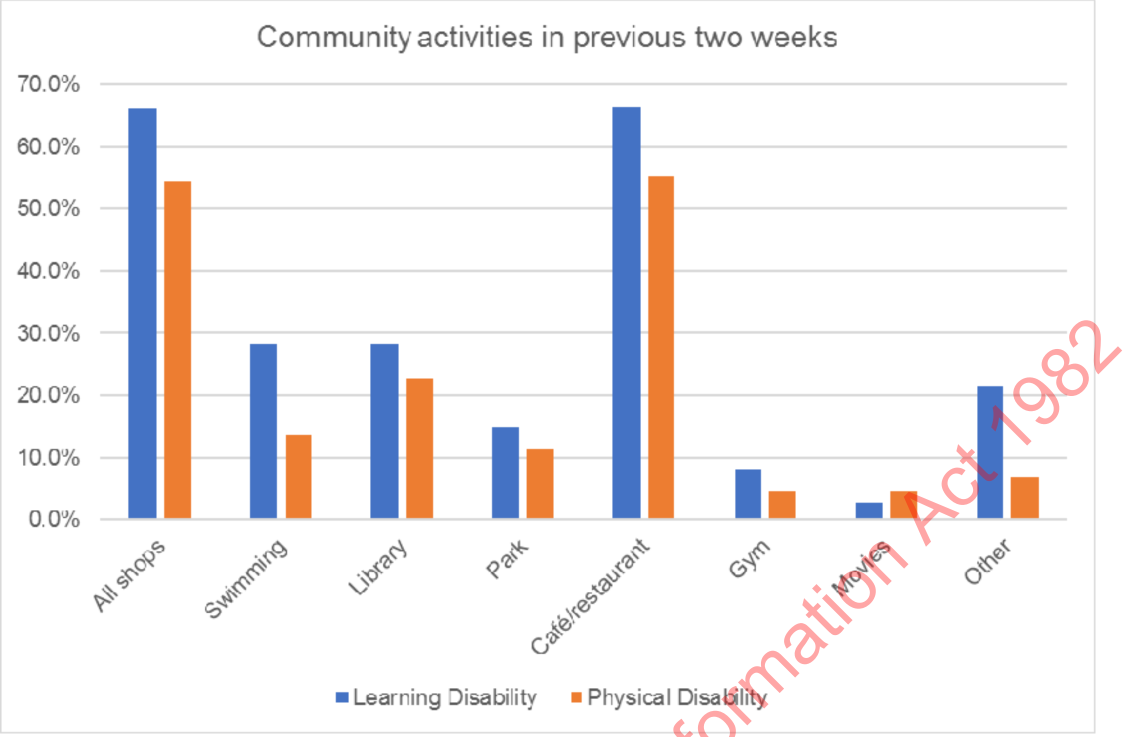


Figure 14 indicates the range of activities for adults with either learning or physical disabilities. The results suggest that people with learning disabilities are generally more active in the community than people with physical disabilities.

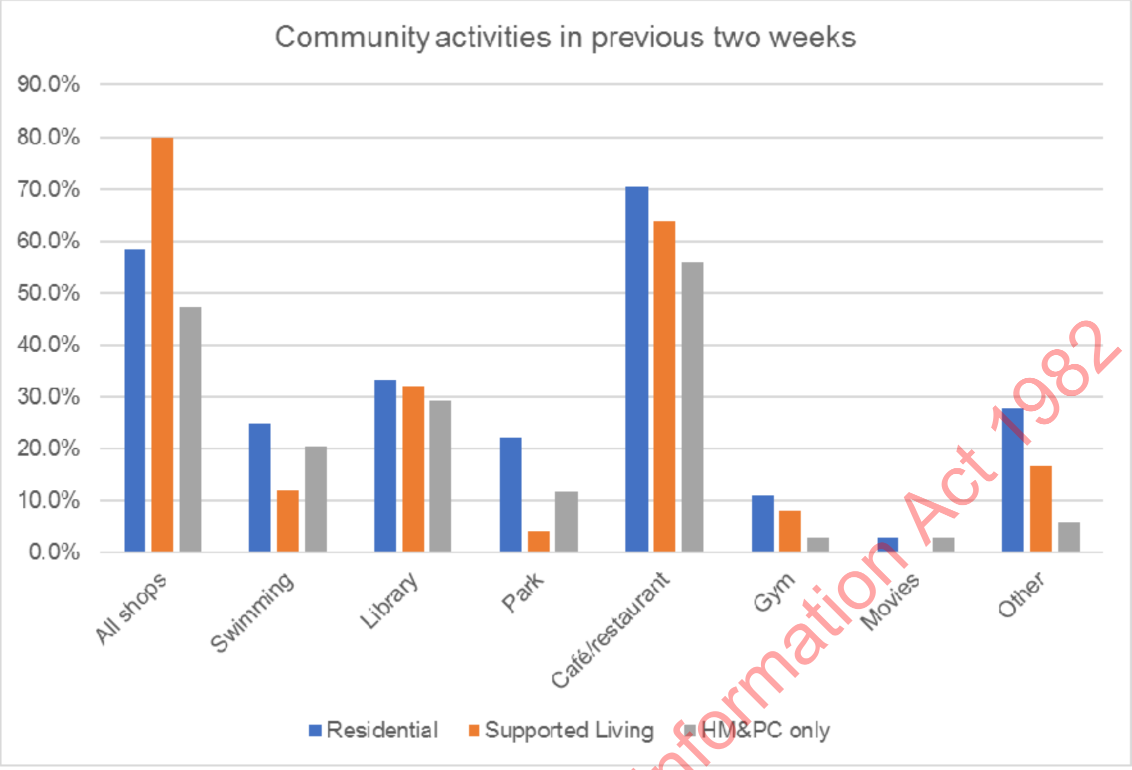
Figure 14: Range of community activities in the previous two weeks, adults with learning or physical disabilities



Many people in community residential homes will also attend day services for at least some of the working week. The higher level of activities in areas such as visiting parks (typically going for walks), cafes and swimming may reflect both group home and day service activities. People with supported living are typically assisted to go shopping by their support workers and the elevated result for this group may reflect that activity.

It should also be noted that the survey occurred in August and September. For some people with more fragile health, community participation may be reduced compared with activities in warmer months. Follow-up reviews of this work would need to take the time of year into account.

Figure 15: Range of community activities in the previous two weeks by type of support


Community activities in previous two weeks
90.0%
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
All shops
Swimming
Library
Park
Café/restaurant
Gym
Movies
Other
Residential
Supported Living
HM&PC only

Membership in clubs, groups – belonging

People were asked to indicate whether they were a member of a local group, club, church, marae, sports team etc. Fewer children and young people registered membership with groups (44 percent) than adults (57 percent). Figure 16 indicates children and young people are more likely to belong to sports[51], play and music groups[52]. Adults were more likely to belong to a church, Special Olympics[53], sports clubs/gym[54] and support groups[55]. 'Other', for adults included 29 different groups[56] and 'other' for children and young people included six different groups.

Figure 16: Membership of club or group, adults versus children and young people

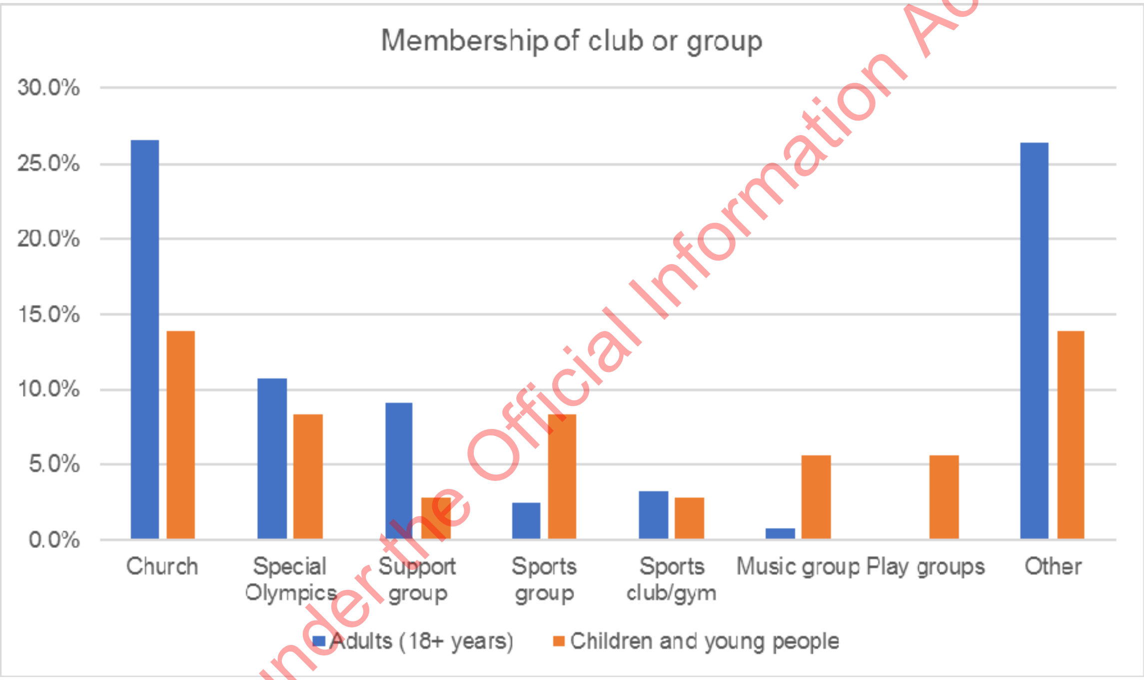


Figure 17 shows the range of groups or clubs people belong to relative to their type of support. Notably people with HM&PC-only packages are more involved in support groups and a range of smaller different groups ('other'). This group are most likely to be people with physical impairments. Groups such as Kumbayah

---

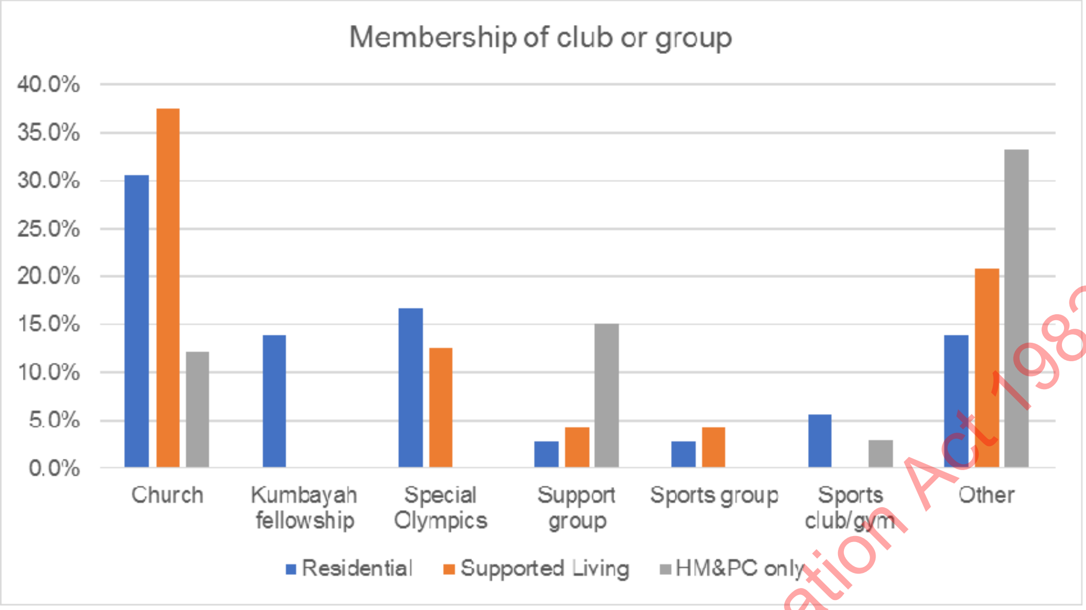
[51] Including Netball, Softball, Cricket, Rugby, Judo, Indoor Bowls.
[52] Two people were in a brass band.
[53] Often includes swimming, Ten Pin bowling, Bocce, weight lifting, track.
[54] Gym and Bocce Club.
[55] These included membership of *People First, Multiple Sclerosis Society, Stroke Foundation, Hearing Association, Cerebral Palsy Association, Parent to Parent, CCS Disability Action, Network group (Community Connections), Circle of Friends (Options)* and the *Stewart Centre.*
[56] Including three belonging to a marae, five belonging to the Kumbaya (ex-Kimberley) fellowship group, two with youth groups (Teenzone, church youth group), two with Cosmopolitan Club and two in Kapa Haka groups.

fellowship[57] and Special Olympics are specifically for people with learning disabilities.

---

[57] A Christian fellowship group set up for people who left Kimberley Centre where they can reconnect.

Figure 17: Membership of club or group by support type



14. Developing and achieving

Personal development and planning

One of the principles of Enabling Good Lives is to consider the whole person when planning and delivering services. The ‘person-centred’ principle states:

> 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.

For some, the type of service provided appears to influence the outcomes they could hope for from disability support services. A more holistic approach may be possible for people in community residential homes and for people receiving supported living. However, services are limited in what they can achieve for people on HM&PC-only packages or for people with carer support, respite, behaviour or child development services (DHB).

In this section, personal development is considered generically, especially in terms of life or social skills. Linked to personal development is autonomy. This is people having the right to make choices with regard to their life and personal development. This is particularly important in being able to plan for and develop personal goals and aspirations.

Table 13 indicates few differences between adults and children/young people with regard to being valued for what they can already do. However, the adult group does appear less convinced they have opportunities for learning and development, their current learning or feeling supported to try new things.

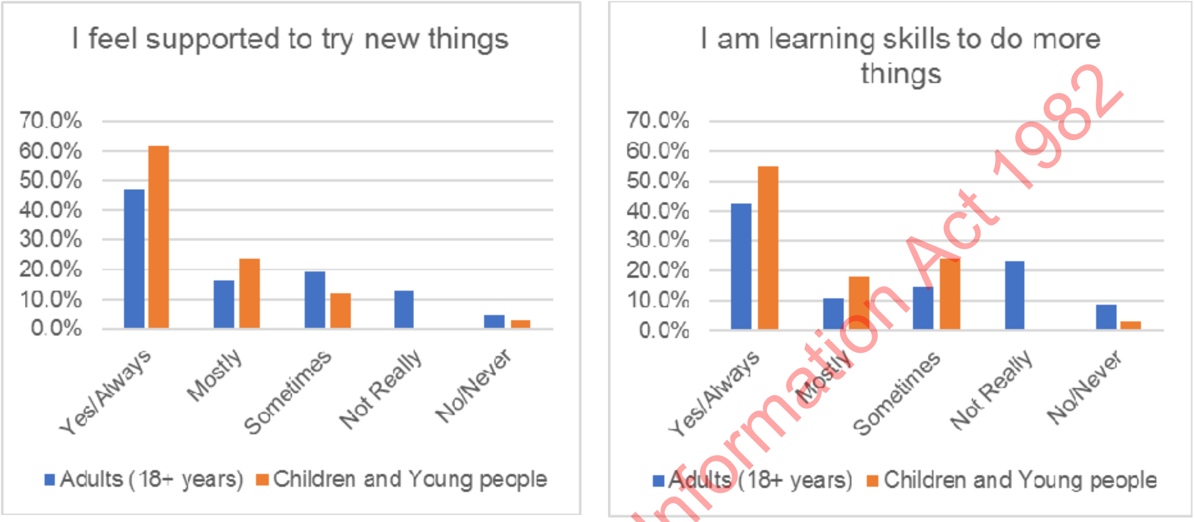
Table 13: Personal development, adults versus children, (‘yes/always’ and ‘mostly’)

	All adults	Children and young people	Diff in mean	WMW
I have opportunities for learning and development	57.7%	70.4%	0.4	1.7
The people in my life value what I can do	83.6%	86.7%	0.2	1.3
I feel supported to try new things	63.5%	85.3%	0.007	2.1*
I am learning skills to do more things	53.4%	72.7%	0.7^{++}	2.2*

*p<0.025, $^{++}$ Diff in mean t=2.9, p<0.01, df=76

Figure 18 shows that adults with disabilities were less convinced they were supported to try new things (see ‘sometimes’ to ‘no/never’)[58] and many believed they were not learning skills to do more things (‘no/never’ or ‘not really’)[59] when contrasted with children and young people.

Figure 18: I feel supported to try new things, and learning skills to do more things, adults versus children and young people



There were few variations between people with physical and learning disabilities except with regard to having opportunities for learning and development. In this situation, more adults with learning disabilities believed there were opportunities for learning and development (65 percent) when compared with adults with physical disabilities (55 percent).

When considering the type of support adults with disability receive, it is also important to recall that people with learning disabilities in community residential homes tend to have very high assessed needs. While, people on supported living have only high to moderate support needs (the majority also have learning disabilities). The majority of people only receiving HM&PC-only support have physical disabilities). Figure 19 indicates that those adults most likely to believe they have opportunities for learning and development are people who have supported living[60]. There is a hint in Figure 19 that level of assessed need may play a part in whether disabled people believe they have an opportunity for learning and development, based on the residential versus supported living comparison.

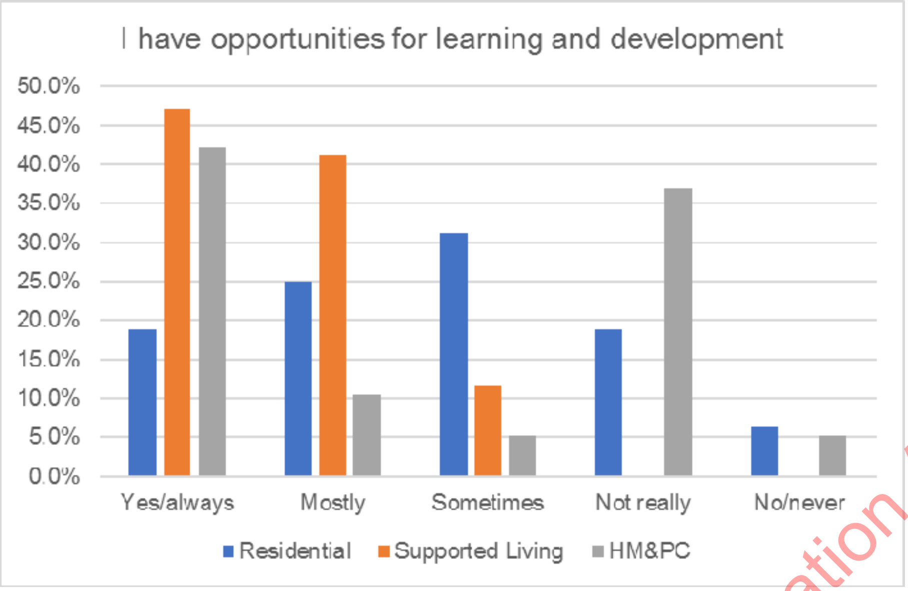
---

[58] Forty-three percent compared with 30 percent for children and young people, WMW=2.1, $p<0.02$, df=76. Diff in mean=0.5, $t=2.6$, $p<0.01$.

[59] Thirty-two percent compared with three percent for children and young people, WMW=2.2, $p<0.02$, df=76. Diff in mean=0.7, $t=2.9$, $p<0.01$.

[60] WMW=2.6, $p<0.01$, df=32, (diff in mean=1.1) regarding the difference between residential and supported living. Comparisons with HM&PC only are not significant.

Figure 19: Opportunities for learning and development by support type



Eighty-two percent of learning disabled adults with high and moderate assessed need believed they had some opportunity for learning and development (all or most of the time).

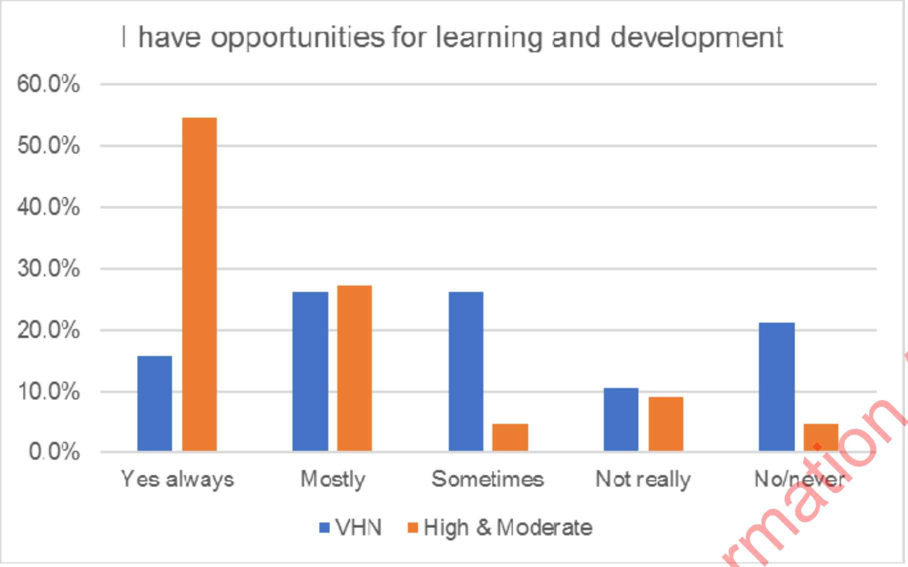
This result compares with 42 percent of people with very high assessed needs (VHNs)[61].

Figure 20 considers all adults with learning disabilities relative to their assessed need. What is not represented in these figures is the number of people from both groups who declined to answer this question. Fifty percent of respondents for learning disabled adults with VHNs failed to respond to this survey item (n=19 responded) and 45 percent of people with high to moderate assessed needs (n=22 responded). It is unclear why the non-response rate was this high, but perhaps for some, opportunities for personal development were not considered important, possible or relevant.

---

[61] WMW=2.8, $p<0.01$, df=35, diff in mean=1.1, $t=2.8$, $p<0.01$.

Figure 20: Opportunities for learning and development by level of assessed need, adults with learning disabilities or their proxies



Having opportunity to have aspirations, goals or plans in life are important to many people. One open-ended question in the disabled persons survey asked people:

> If anything were possible, what are some things you would like to achieve, start doing or do more of?

The most common responses of the 115 who responded were:

- To get out more[62] (17 people)
- Travel or have a holiday (15 people)
- Get a job, find work or open a business (adults) (11 people)
- Visit family (11 people)
- Have further education or training (8 people)
- Improve health (7 people)[63]
- Visiting (2) or finding friends (5 people)
- Be independent or more independent, not lose independence (7 people)
- Be cured[64] (5 people)
- Find own home, house or flat (3 people).

Then there was a long list of things that are personal goals or dreams that were not necessarily shared by many others, but which signalled where support could be invested[65].

---

[62] Defined as ‘get out more’, ‘get out of the house’, join a club or group in order to broaden community experiences.

[63] Defined as improve health, get well, lose weight, progress (physically).

[64] Defined not having a condition, to be cured, not to be sick/ill, to get better (with reference to a progressive condition).

[65] For example, living in a different home (4 people), cooking/baking (3 people), getting a driver’s licence or being able to drive (3 people), being able to work in the garden (2 people), being able to

Table 14 indicates that children and young people are less likely to make plans based on what they are good at (all or most of the time) when compared with adults, but do appear on par with adults with regards to achieving what they want in their life albeit only around 50 percent (all or most of the time) for both groups.

Table 14: Making plans and achieving goals, adults versus children and young people (all or most of the time)

	Adults (18+ years)	Children and young people
I can make plans based on what I want and what I'm good at	73.6%[66]	33.3%
I am achieving the things I want in my life	56.6%	53.3%
I am encouraged to think about what I want in my life	61.0%	69.6%

The difference in whether people are encouraged to think about what they want in life is highlighted in Table 14. It indicates that nearly two thirds of both groups are encouraged to think about what they want in their own life. However, more adults do not believe they are encouraged to think about what they want (23 percent) *at all or rarely*, when contrasted to children and young people (13 percent)[67]. This variation may be due to who might be encouraging people to think about their life. Most respondents for children and young people were whānau who lived with the person. Conversely, adults with disabilities live in a wider variety of settings with varying opportunities to have others encourage these questions.

---

contribute through voluntary work (3 people), going to shows or concerts (2 people), learning to swim, doing more walking, becoming a singer, writing a book, getting a mobility scooter, doing crafts, going on train rides, joining a Menz shed, joining the Cosmopolitan Club, flying a plane, making YouTube videos, writing a computer programme, bee keeping, various types of sport (4 people) and getting some needed equipment in place (2 people).

[66] WMW=3.5, $p<0.001$, df=31, diff in mean=1.0.

[67] Although this result is not statistically significant due to the number of people in both groups who did believe they were encouraged to think about what they wanted in their own life, all or most of the time (61 and 70 percent respectively).

Figure 21: I am encouraged to think about what I want in my life, adults versus children and young people

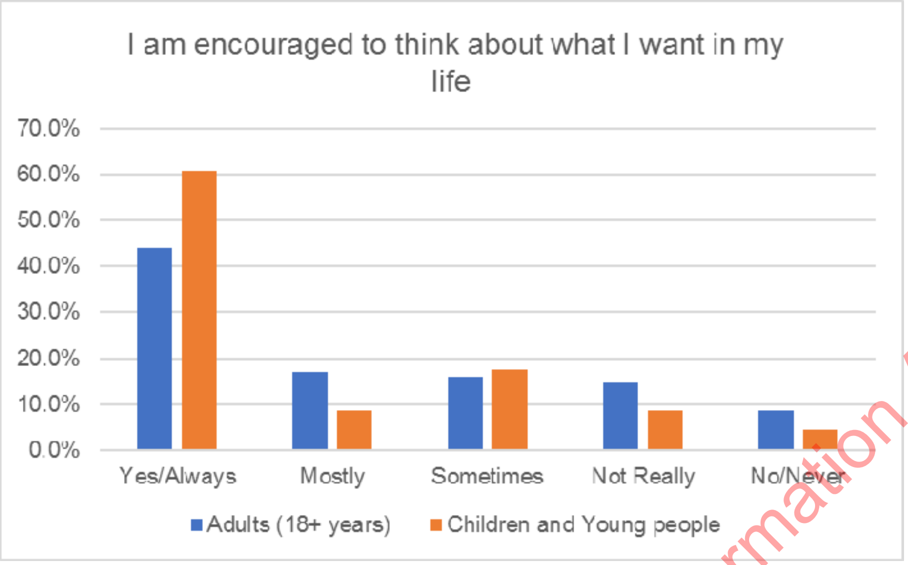


Table 15 indicates people with physical disabilities are less likely to believe they are achieving what they want in their life[68], or feel they are encouraged to think about what they want in their life[69]. This is in comparison with adults with learning disabilities.

Table 15: Making plans and achieving goals, adults with learning and physical disabilities, ('yes/always' and 'mostly')

	All Adults	Learning Disability	Physical Disability
I can make plans based on what I want and what I'm good at	73.6%	74.5%	76.9%
I am achieving the things I want in my life	56.6%	65.7%	46.8%
I am encouraged to think about what I want in my life	61.0%	69.0%	54.5%

When examining, 'I can make plans based on what I want and what I'm good at', some variation in responses start to occur when level of assessed need is considered.

---

[68] WMW=2.6, p<0.01, df=91, diff in mean=0.6, t=2.7, p<0.01.
[69] Not statistically significant, diff in mean=0.6, t=1.94, p<0.029 (not significant).

Figure 22 indicates respondents for learning disabled adults with VHNs are less likely to believe they are able to make plans based on what they want or what they are good at, when contrasted with learning disabled adults with high and moderate levels of assessed need[70]. The number of respondents who did not provide a response to this item was higher for adults with very high assessed needs (55 percent) compared with adults with high and moderate needs (23 percent). This suggests nearly half of all possible respondents for learning disabled adults with VHNs did not consider the question was relevant, overlooked the question, didn't understand the question or chose not to respond. Further analysis indicated all of these people resided in community residential homes.

Figure 22: I can make plans based on what I want and what I'm good at, learning disabled adults by level of assessed need

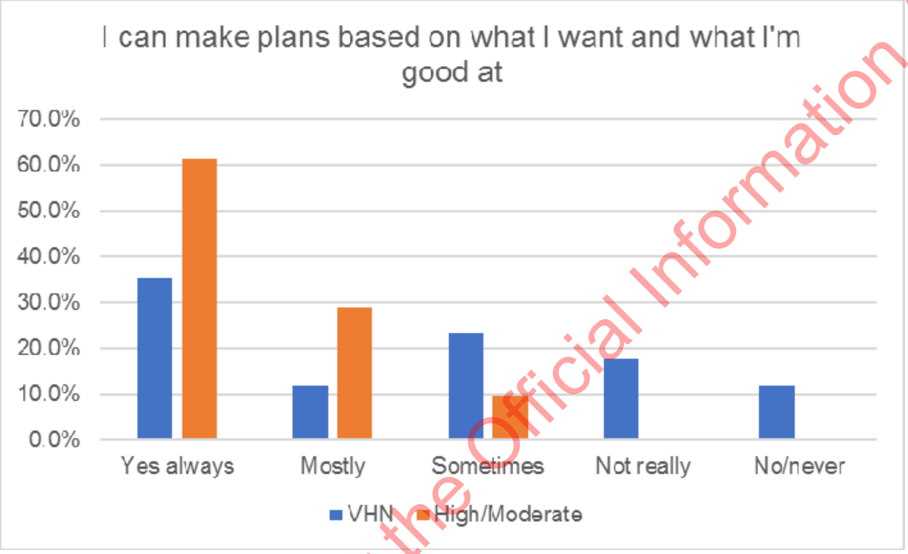


Figure 23 indicates that people with supported living were more likely to believe they could make plans based on what they were good at (68 percent indicating 'yes/always') compared with either people in community residential homes (27 percent)[71] or people with HM&PC-only support (52 percent).

---

[70] WMW=2.7, *p*<0.01, df=19, diff in mean=1.1, *t*=2.9, *p*<0.01.

[71] WMW=3.4, *p*<0.001, df=26 (diff in mean=1.3) residential versus supported living. Also, residential versus HM&PC only indicated a significant difference between them of WMW=2.3, *p*<0.01, df=32 (diff in mean=0.9).

Figure 23: I can make plans based on what I want and what I’m good at, by type of support

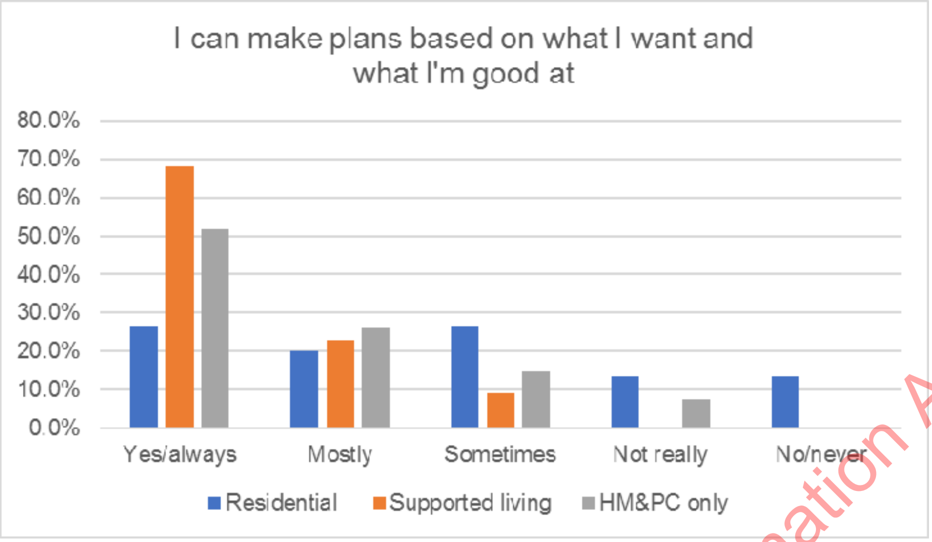
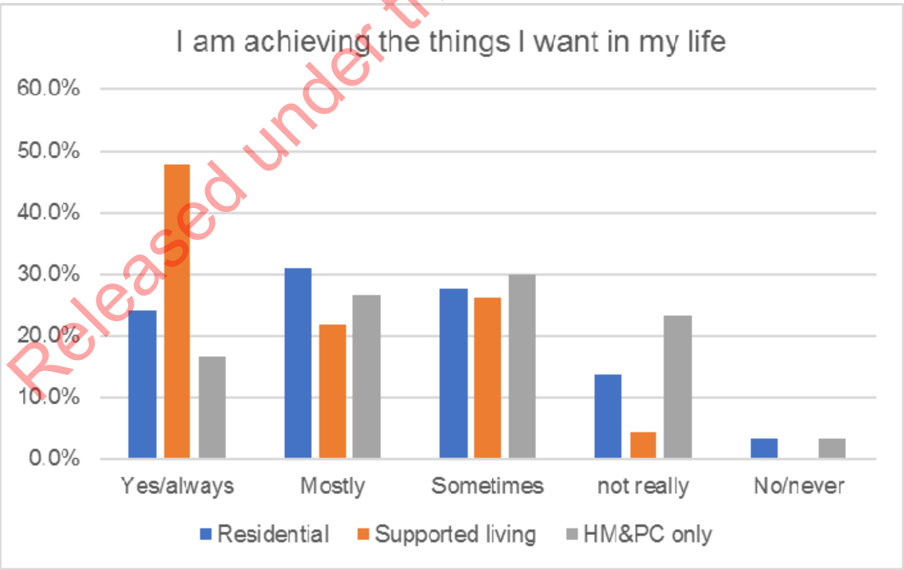


Figure 24 indicates people on supported living are more likely to believe they are achieving what they want in their life. In particular, 27 percent of people with physical disabilities on HM&PC-only did not believe they were achieving the things they wanted in their own life (at all or not really), in contrast to people on supported living[72]. Similarly, 55 percent of adults with learning disabilities in residential homes did not believe they were achieving the things they wanted in their own life (all or most of the time)[73].

Figure 24: I am achieving the things I want in my life, by type of support



---

[72] WMW=2.6, $p<0.01$, df=50, diff in mean=0.8, $t=2.8$, $p<0.01$.

[73] Compared with supported living WMW=1.9, $p<0.027$, df=53, ie, not significant. Diff in mean=0.6.

Learning, dreaming and having ambitions or aspirations can be important ingredients to having a good life. There appears to be reduced opportunities for learning and development for adults when contrasted with children and young people. This difference may be considered a natural difference between these two groups since adults are at different stages of personal development. There appears to be differences in the opportunities for learning and development made available to adults, based primarily on level of assessed need, especially for people with learning disabilities. These differences are reflected in direct comparisons (learning disabled VHN versus all other learning-disabled adults) and the support packages they receive, which are also divided between VHNs primarily in residential services and high/moderate assessed needs in supported living.

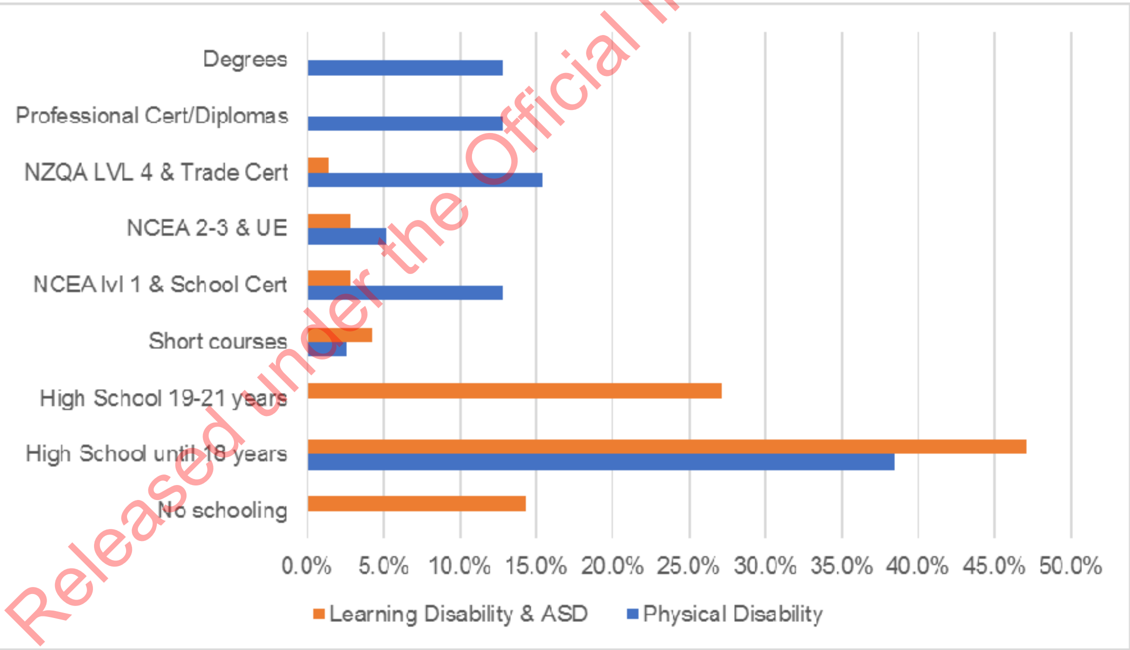
Adults appear to have more opportunity to make plans based on what they are good at. Although, both adults and young people indicated fairly low levels of achieving what they wanted (between 57 and 53 percent respectively). All adults listed a myriad of dreams and ambitions but people with physical disabilities and those supported only by HM&PC funding did not believe they were achieving what they wanted in their own life.

15. Education

Fourteen percent of adults with learning disabilities and ASD had no formal schooling in their lifetime. The majority of these people were individuals who had lived at Kimberley Centre from early childhood until the Centre closed in 2006. Figure 25 shows that the highest qualification for adults with either learning disability or ASD was one person out of 86 completing the Level 4 Certificate in Human Services (through *Careerforce*)[74]. Nearly three quarters (74 percent) of all adults in the Baseline Study with learning disabilities and ASD had some high school experience but no qualifications. Twenty-seven percent stayed in school until 21 years old.

People with physical disabilities had a wider range of qualifications and educational experience. Thirteen percent held university degrees and another 13 percent attained professional qualifications (certificates and diplomas). Thirty-nine percent of people with physical disabilities had some high school education but left without a qualification.

Figure 25: Qualifications and school experience by type of disability



Eight percent of all adults (11 of 134) and one young person (of 5 not in school) indicated they were continuing their education. Ten of these people suggested

---

[74] Only five individuals (7 percent) had at least one NCEA level 1, or school certificate level qualification or higher.

their training was formal in the sense that a certificate or diploma would be the result[75].
Six percent of all disabled people surveyed indicated an ambition of further training or education. When asked directly if people wanted further education, 42 percent of those who responded stated they would[76].

☒ **Of the people who wanted further education, 69 percent cited barriers to pursing this.**

One of these people had started a course but had to stop due to safety and access issues:

> *I was studying Māori at the Wānanga and it was a social work first year, but what I discovered is that although they had lifts it was really hard for me to get from there down to the bus stop, and I had a fall. They had uneven concrete and when I went down, I concussed myself so I ended up in A & E and staying a few nights. But at the end of a couple of months it was clear that I didn't, I'd missed too much, and even though my tutor had come here twice and I had all the reading material I just couldn't quite fill in the gaps.*

---

[75] These included land-based training, an online language course, computers at polytechnic, a health course (6 weeks), personal trainer qualification, "modified" course at polytechnic in woodwork, design course, UCol World of Work I & II (plus a first aid certificate), Māori at Wānanga in Palmerston North, Maths (by correspondence) NCEA level 2. Two more people indicated courses related to computing (at a day service) and kapa haka.
[76] Or 29 percent of all adults (31 percent of all adults did not provide a response to this survey item).

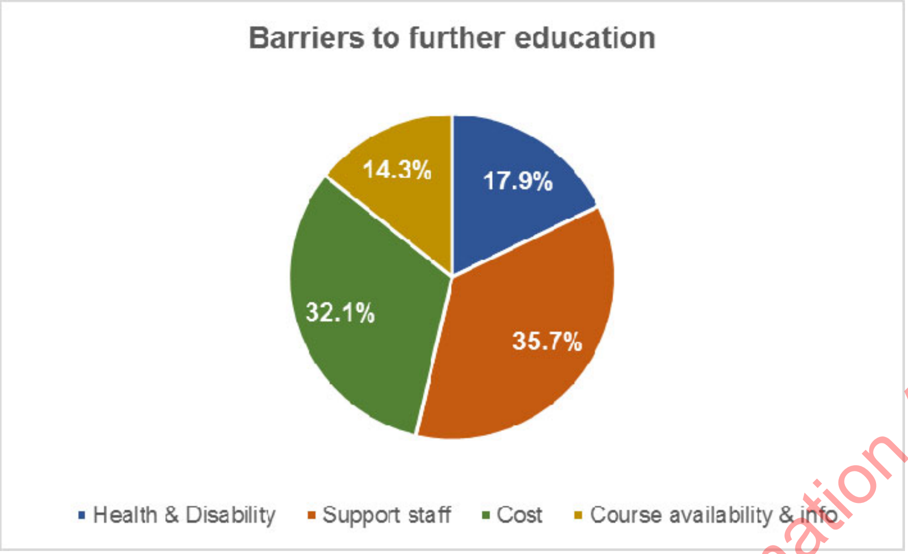
Figure 26 shows finding assistance or support workers was cited as the largest barrier to pursuing further education followed closely by cost. For adults with learning disabilities and ASD the larger barrier was finding support workers to assist with access and classroom support (50 percent), while for people with physical disabilities the larger issue appeared to be the cost of courses and/or the cost of transport to the courses (4/10 people)[77]. The following dialogue outlined at least one barrier to further study:

> *[Disabled person]: last week I looked at media design at Auckland. The website… [So, I'm] just like, like waiting to see if it's the right time for it. Yeah.*
>
> *[His mother]: There's nothing to support [person's name] if he went to Auckland, that's the thing. We all know the story with the cost of living. If he could find something in the Manawatu…*

---

[77] Only one person with physical disabilities cited a need for support workers. Twenty-eight percent of people with learning disabilities or ASD cited cost as a barrier.

Figure 26: Barriers to further education, all adults



Another whānau member noted with regard to barriers:

> *[Son] did want to try to do traffic control but then it was trying to find someone to sit with him and help with the book work etc. Not that many people around to sit with him 9-3. Services or people.*

People still in school

There were four questions concerning schooling[78]. Sixty-nine percent of school students (pre-school to 21 years old) indicated they had additional supports at school besides the classroom teacher. Although most were happy with the degree of classroom support, some clearly were not. In response to this question one parent stated:

> *This is a sore point at school, they're not good at supporting these kids. He's in the process of getting another RTLB[79], resource teacher learning behaviour, to support the teacher around special needs kids. But he's not getting access to a teacher's aide at all really.*

---

[78] People at school included individuals up to the age of 21. This included 86 percent of all children and young people (under the age of 18) or 81 percent of all people up to and including 21 years of age.

[79] Resource Teacher: Learning and Behaviour (RTLB)

There also appears to be concerns with how ORS[80] funding is used in the classrooms according to some whānau, as the following dialogue suggests:

> *[Mum]: So, she has obviously aides, she gets so many aid hours per week.*
>
> *[Dad]: But I don't think the aides necessarily go specifically to her.*
>
> *[Mum]: Well exactly because everything is pooled.*
>
> *[Dad]: Because they pool it so basically how it works, they throw all the ORS funding in the room basically and it gets split up. That's how it works.*
>
> *[Mum]: Exactly so [child's name] funding is actually helping fund kids that don't have ORS funding.*

How ORS money is used in schools can appear a little confusing to some people, while others seem to have their own grasp on how it should be working:

> *I feel under the new system the education department has really been put into a position where they are becoming more accountable, or they have to be more accountable, because if it goes over a certain value then every cent has to be accounted for… Say if this kid is entitled to ten grand [then] you have to justify that ten grand. If this kid over here is fifty grand, because he's really special needs, then that all has to be accounted for. Where my impression of what's happening, they've got this money, and it just went into a big bowl and the schools spent it how they wanted to spend it, not on individual people.*

Nineteen percent of respondents indicated they had ORS funding (although this question was not asked directly) and one stated they had an intensive wraparound service (which includes ORS).

Thirty-one percent of students at school indicated they were mainly in segregated classrooms or schools; however, as one whānau suggested this does not mean completely segregated for most people:

> *It's a special unit in the mainstream school but they're still part of mainstream they just go off certain times of the day to go do their thing. Yes, she's still part of mainstream and she does normal class work, well if they're doing class, she just does her work alongside, but then in the afternoon they all, the other special needs kids, come*

---

[80] The Ongoing Resourcing Scheme (ORS). ORS is provided to a student with severe to extreme difficulty in any of five areas of need (learning, vision, hearing, physical needs, or language/social communication) or where a student has moderate to high difficulty with learning and very high needs in any two of the five areas of need. According to the Ministry of Education websites, "ORS is managed by the Ministry of Education, Special Education at local district level and by a number of delegated schools known as Specialist Service Providers (SSPs)". http://education.govt.nz/school/student-support/special-education/ors/overview-of-ors#HowIsORSManaged

> *together and they do, you know, cooking or music or something like that. So, she's mainly mainstream I would say, yep.*

Table 16 shows that most respondents were satisfied with school experiences, with less than 20 percent responding in the 'no/not really' range across all items.

Table 16: School experiences of school age students (all pre-school and school students up to and including 21-year-olds)

	Yes/always	Sometimes	No/not really
My supports at school help me to learn	81.3%	6.3%	12.5%
I can participate in everything I want at school	77.1%	11.4%	11.4%
I have friends at school	51.4%	31.4%	17.1%
Other students at school treat me well	81.1%	8.1%	10.8%

Students currently at school have reasonably positive experiences with other young people at their school, even though they themselves may find social interaction difficult. Historically this may not have always been the case, at least seven of the adults who had completed school reported bullying (5 percent)[81] and another six indicated they had been expelled from school.

---

[81] The Youth 2000 survey conducted by the University of Auckland in 2012 indicated bullying was reported in 6 percent of students at school, with rates not changing dramatically since the survey began in 2000. Rather rates of cyberbullying were on the increase over the time period. Clark, T. C., Fleming, T., Bullen, P., Denny, S., Crengle, S., Dyson, B., Fortune, S., Lucassen, M., Peiris-John, R., Robinson, E., Rossen, F., Sheridan, J., Teevale, T., Utter, J. (2013). Youth'12 Overview: The health and wellbeing of New Zealand secondary school students in 2012. Auckland, New Zealand: The University of Auckland https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/ahrg/docs/2012-overview.pdf

16. Employment and voluntary work

☒ **Eighty-three percent of all disabled adults in the Baseline Study had not worked in the week prior to the survey.**

Of the people who worked (n=22), 64 percent had worked less than 10 hours. Only two people had worked in excess of 25 hours in the previous week. Only 14 percent of those who were working were people with physical disabilities, or 2 percent of all adults in the Baseline Study. People who acquired a disability later in life may be more likely to have retired and/or ceased work due to their disability. In particular, 74 percent of people with physical disabilities gave details of a prior history of paid employment, compared with 41 percent of adults with learning disability or ASD[82].

Slightly more women (88 percent) than men (79 percent) were not employed in the previous week, but similar numbers of those who had worked, had only worked ten hours or less (64 and 63 percent respectively).

All but one (of 18) adult Māori[83] (94 percent) had not worked in the week prior to the survey, compared with 80 percent of NZ Europeans.

When considering dreams, aspirations and goals, nine percent of adult disabled people indicated they wanted to work. When asked directly if working was something they wanted to do (if they were not working already), 29 percent said ‘yes’ and a further 17 percent said ‘maybe’.

When asked if they could easily find help when looking for work, 38 percent of those adults who responded to this question stated they could not (at all or not really)[84].

When all adults were asked if they were engaged in voluntary work, 22 percent indicated they were. Of this group, 86 percent worked for ten hours or fewer. Sixty-two percent of all volunteers were adults with learning disabilities or ASD, the remaining 38 percent were adults with physical disabilities.

---

[82] Where employment was defined as receiving payment. For people with physical disabilities employment included a high frequency of full-time and professional employment (for example, journalism, teaching, nursing, horticulture, science) whereas, many adults with learning disability and ASD were more often employed part-time and sometimes with reduced hourly rates (for example, paper runs, business enterprises).

[83] Working age (17 to 65) and not in school.

[84] Only 45 people responded to this survey item (or 66 percent of all adults).

Finances and income

☒ **95 percent of disabled people were earning under $30,000 a year.**

Given the low employment rate, the level of personal income for disabled people would be expected to be low. Unfortunately, many adults were not willing or able to provide information with regard to personal income in the survey (25 percent). Of those who did provide some information (n=86), 40 percent simply stated they were on a benefit or had the superannuation.[85] Of those that remained, 92 percent of the stated incomes were under $30,000 per year. Combined with those who simply stated they were on a benefit or pension; 95 percent were earning under $30,000 a year.

Survey respondents living in community residential homes all indicated they either received a benefit or earned under $30,000 per year. The majority of people in residential accommodation pay the bulk of their benefit to the service with a set amount of spending money left aside each week (typically less than $80).

Excluding residential services, of the remaining disabled adults who provided useable figures (n = 42) the average and median reported income was between $10,000 and $20,000 with 3.5 percent (two people) indicating earnings over $40,000.

For people living with a spouse or partner who was earning, there could be a boost in the amount of disposable household income that could be shared. Others may have the support of other whānau to supplement their available income.

Transportation

A few people, in both the disabled persons and whānau surveys[86], talked about the issue of transportation. The most prominent issue concerned costs, particularly with regard to use of taxis (five people), but also simple issues such as the cost of parking. Two people talked about not knowing what they were entitled to with regard to transport costs and three others referred to not being able to use funding for transport. Two people referred to support workers not being permitted to provide any sort of transportation in their own cars. For individuals who are being supported to go shopping, this may be particularly limiting.

---

[85] In 2018, the median annual household income from Government benefits, excluding superannuation and war pensions, was $11,262 with a mean of $14,651. The median for people on superannuation and war pensions was $17,801 with a mean of $18,839: https://figure.nz/chart/OToNBIID6B7ZkZlp-Scm6oim0HTjX7LB2.

[86] Eleven disabled people and five whānau in total freely raised issues about transport without prompting (word searches, car, cars, transport, taxi, scooter).

Other services do provide transport, and for one man who lives alone in a rural location, the once-a-week trip into town for groceries and a fish-and-chip lunch was the only time he got out in the week.

Being able to get out and about may have direct implications for social isolation or simply enjoying life outside the home. Transport issues included:

- cost: even with taxi vouchers, a return fare can be too high for many disabled people to afford
- loss of ability to drive: many people, especially those who have acquired disabilities, are no longer able to use their own vehicles
- location: some people live in small towns or rural locations where public transport options are limited
- access: some respondents noted that even where buses were available, they were not yet fully accessible
- time: two whānau indicated the time spent transporting people to places such as school or work. One parent noted early starts and up to two hours a day spent in transport.

Equipment and modifications

Table 17 indicates a small group of people were not satisfied they were receiving all the equipment (or modifications) they needed. When asked directly, many people provided details of what equipment they wanted and for some, what equipment they needed. Educational and communication equipment often carry large price tags and need to be robust especially for younger people. Replacing or upgrading items often becomes a financial burden when they cannot be provided by Enable NZ or the MidCentral DHB. Then some people talked about delays, for example, one man was waiting for his prosthetic leg, and another had been waiting three months for an assessment for a ramp and handrail. Another person said:

> *I need equipment to get in and out of bed (just had rails). Enable sent a letter to hospital – hospital replied they were short of staff and would get there at some point. This was 3-4 months ago.*

Rules governing what can be funded may also complicate some situations. One man noted he needed a ramp to get in and out of his house and had applied to have one installed. However, while he was waiting, he had made his own ramp to the back door and was then told he could not be funded for a new ramp because the one he made was sufficient. What he had been really needing was a ramp to his front door.

Table 17: I have all the equipment I need

	Yes/totally Mostly	Somewhat	No/Not really
Learning Disabled (adults)	89.5%	2.6%	7.9%
Physically Disabled	70.5%	6.8%	22.7%
All Adults	78.4%	4.5%	17.0%
Children and young people	66.7%	14.3%	19.0%

Living situation and financial situation

Currently, more adults with learning disabilities reside in residential accommodation or with whānau (78 percent in total), and more adults with physical disabilities live with a spouse/partner or alone[87] (75 percent in total).

Table 18 shows that adults with learning disability or ASD had lower rates of home ownership than people with physical disabilities. Excluding people who live with family/whānau or those in residential homes the number of adults with learning disabilities or ASD who own their own home reduced to two people.

Initial review of home ownership for disabled Māori suggest four people own their own home (22 percent) in contrast to 42 percent of NZ Europeans. The sample size was too small to break these figures down further (ie, by disability type).

Table 18: Home ownership by disability type and ethnicity (adults only)

	Learning disability/ASD	Physical disability	Māori	NZ European	All adults
I own my own home	12.9%	58.3%	22.2%	42.0%	29.3%

A recurring concern related to the disabled person's financial situation and not being able to afford to pay for things. This ranged from visiting dentists or other health professionals to transport[88]. For example, one man stated he could not go out into the community:

> *It's not happening due to finances and health. I can't go out. Can't remember the last time I had a good dinner… I would like to join the Cossie Club. I would like to join the 'four stroke club'. I don't have the money to get there every Tuesday. Gas money and stuff.*

Eighteen percent of people with physical disabilities referred to costs or financial concerns.

The man from the example above went on to state:

> *I didn't realise you had to be rich to be ill or injured.*

---

[87] All children and young people and five (of nine) adults with ASD live with family/whānau.

[88] For example, eight people with physical disabilities stated they could not afford dentists, seven people stated cost of transport was an issue, six people believed they could not access the community in various ways due to cost, and nine people thought they could not pursue further education due to cost.

17. What disabled people think about disability support services

There were 26 Likert Scale items specifically related to how people experience disability support. Satisfaction was considered as agreement with the two highest ratings on the five-point Likert Scale (‘yes/always’ and ‘mostly’). Taken together these items have an average satisfaction rating of 66 percent across all 26 questions (SD 17 percent). However, as noted in earlier sections, caution is needed when clumping together questions with potentially different constructs. A review of individual items is important.

For initial comparison purposes, 14 survey items that focused on how disability supports assist individuals are presented in Table 19.

Table 19: Fourteen survey items that focus on how disability supports services assist individuals, as an overall view of satisfaction

	Yes always/Mostly	Sometimes	not really/no
Supports help me pursue my own interests	62.9%	17.9%	19.2%
I know who will be supporting me each day/shift	77.8%	9.6%	12.6%
My supports help me connect to people and places that are important to me	65.2%	14.5%	20.3%
My support happens at the times that work for me	76.6%	12.7%	10.8%
I have enough support to achieve what I want	67.1%	14.8%	18.1%
My support hours can be flexible	65.9%	14.3%	19.8%
My support occurs when I need it in my life	78.5%	10.0%	11.5%
My paid workers understand how to support me safely	92.4%	5.5%	2.1%
My paid workers receive the training they need	82.6%	9.6%	7.8%
I am supported to maintain and improve my health	84.0%	6.4%	9.6%
I feel supported to try new things	68.5%	17.4%	14.1%
I am supported to be actively involved in my homelife	74.8%	16.1%	9.0%
I feel the amount of support I have is right for what I need	62.8%	14.0%	23.3%

I think the money I get for my support is well spent	73.3%	9.2%	17.5%

The satisfaction rating for these 14 questions raised the average satisfaction to 74 percent (SD 9 percent, CI 0.05[89]). A similar trend in responses were noted when people with learning disabilities (adults, children and young people) were considered separately. For this group the average satisfaction over the 14 survey items was 77 percent (SD 9 percent). Average satisfaction across all 14 survey items for people with physical disabilities was 72 percent (SD 11 percent). Three survey items scored lower for adults with physical disability when contrasted with adults with learning disabilities.

Figure 27 indicates people with physical disabilities are less likely to believe that supports assist them to pursue their own interests when compared with adults with learning disabilities[90]. While not significant overall, this item does indicate 28 percent of people with physical disabilities did not believe (at all or not really) that supports helped them pursue their own interests in contrast to 2 percent of adults with learning disabilities. However, as noted previously, most of the people with physical disability receive only HM&PC-only, which are not contracted to provide support for community integration.

Figure 27: 'Supports help me to pursue my own interests', by adults with learning or physical disabilities[91]

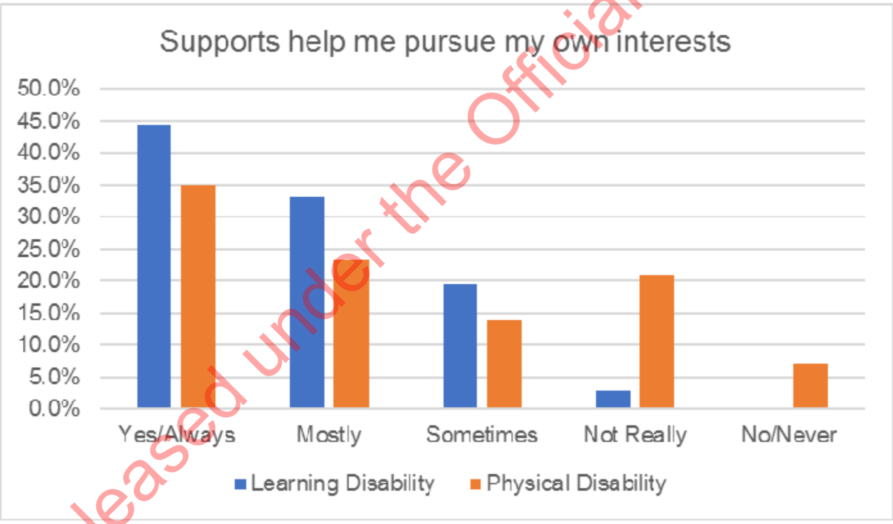


Figure 28 shows fewer physically disabled people believed supports connected them with people and places that were important to them than adults with learning disabilities. The overall trend in this item was not statistically significant between the two groups, but 38 percent of people with physical disabilities did not believe (not really or at all) that supports helped them connect with people and places that

---

[89] For a 95% confidence interval.

[90] Adults only are used for people with learning disabilities as all those with physical disabilities were adults.

[91] There were insufficient numbers of adults with a primary diagnosis of ASD (n=7) to separately include in this figure.

were important to them, in contrast to eight percent of adults with learning disabilities.

Figure 28: 'Supports help me connect to people and places that are important to me', by adults with learning or physical disabilities

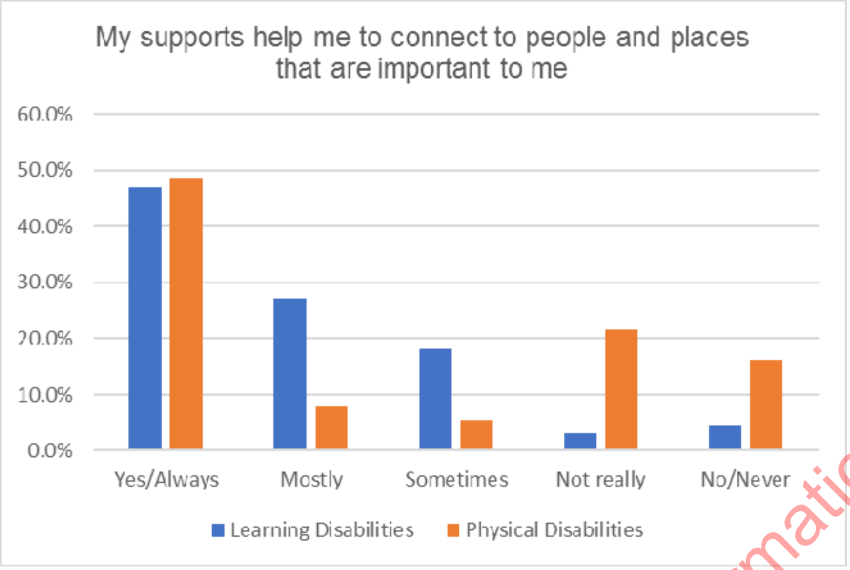
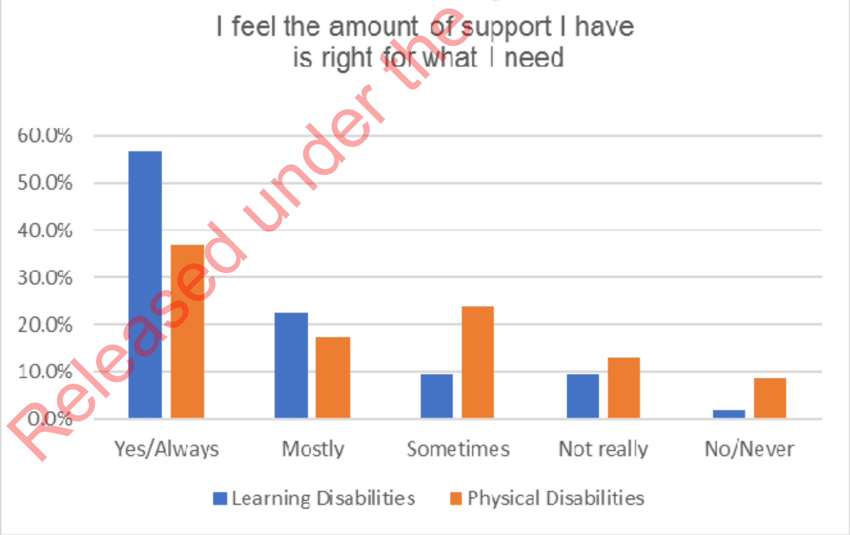


Figure 29 indicates 46 percent of people with physical disabilities were less certain ('sometimes' to 'no/never') that the amount of support provided was right for what they needed, compared with 21 percent of adults with learning disabilities[92].

Figure 29: 'I feel the amount of support I have is right for what I need', by adults with learning or physical disabilities



While these initial differences in satisfaction between adults with learning and physical disabilities were not strong, they add the clues of a more complex picture

---

[92] WMW=2.2, $p<0.01$, df=83. Diff in mean=0.6, $t=2.3$, p<0.01.

for both of these groups. It also raises questions regarding satisfaction among other subgroups within the overall sample.

Satisfaction for people with Autism Spectrum Disorder (ASD), Children and Young Adults

Overall, for people with Autism Spectrum Disorder (ASD), people were less satisfied with their support services across six of the 14 survey items in contrast to overall results, although sample size in for some of these items was quite small and should be read with caution (mean 65 percent, SD 15 percent). The difference between this group and those with learning and physical disabilities appears to be related to the different age distribution of the groups.

Table 20: Fourteen survey items indicating satisfaction with disability support services for all ASD respondents

	Yes always/Mostly	Sometimes	not really/no	n
Supports help me pursue my own interests	48.0%	12.0%	40.0%	25
I know who will be supporting me each day/shift	77.3%	4.5%	18.2%	22
My supports help me connect to people and places that are important to me	59.1%	18.2%	22.7%	22
My support happens at the times that work for me	52.0%	28.0%	20.0%	25
I have enough support to achieve what I want	42.3%	19.2%	38.5%	26
My support hours can be flexible	61.9%	14.3%	23.8%	21
My support occurs when I need it in my life	65.0%	10.0%	25.0%	21
My paid workers understand how to support me safely	88.9%	0.0%	11.1%	18
My paid workers receive the training they need	60.0%	20.0%	20.0%	15
I am supported to maintain and improve my health	86.7%	3.3%	10.0%	30
I feel supported to try new things	86.2%	10.3%	3.4%	29
I am supported to be actively involved in my homelife	67.9%	28.6%	3.6%	28
I feel the amount of support I have is right for what I need	50.0%	5.0%	45.0%	20
I think the money I get for my support is well spent	73.7%	0.0%	26.3%	19

Table 21 indicates respondents for all children and young people[93] (including both learning disabled and ASD) were generally less satisfied with services than adult respondents.

---

[93] The majority of whom are proxies (typically close whānau such as a parent).

Table 21: Fourteen survey items indicating satisfaction with disability support services, all children and young people and adults, ('yes/always' and 'mostly')

	All Children and young people	All adult	Difference in mean	WMW
Supports help me pursue my own interests	**37.9%**	68.9	0.9	3.2***
I know who will be supporting me each day/shift	83.3%	76.6%	0.09	0.4
My supports help me connect to people and places that are important to me	55.6%	67.6%	1.0	1.0
My support happens at the times that work for me	**51.6%**	82.7%	0.7	2.7**
I have enough support to achieve what I want	**36.7%**	74.4%	1.1	3.8***
My support hours can be flexible	60.9%	67.0%	0.4	0.9
My support occurs when I need it in my life	**59.1%**	82.4%	0.8	2.0*
My paid workers understand how to support me safely	95.7%	91.8%	0.05	0.4
My paid workers receive the training they need	**62.5%**	85.9%	0.7	2.5**
I am supported to maintain and improve my health	86.1%	83.3%	0.03	0.4
I feel supported to try new things	85.3%	63.8%	0.5	2.1*
I am supported to be actively involved in my homelife	69.7%	76.2%	0.04	0.2
I feel the amount of support I have is right for what I need	**41.7%**	67.6%	1.1	2.7**
I think the money I get for my support is well spent	65.4%	75.5%	0.5	1.2

**p*<0.025, ***p*<0.01, ****p*<0.001

The highlighted (and statistically significant) survey items in Table 21 suggest that only around one-third of respondents for children and young people believed they had enough support either to achieve what they wanted or found supports being right for what they needed. Only a third believed supports enabled them to pursue their own interests. Overall, the average satisfaction level for all of these items is lower (64 percent, SD 19 percent) in contrast to all adults surveyed (mean 76 percent, SD 8 percent).

Figure 30 indicates the range of differences between adults and children/young people on whether they believed they had sufficient services to achieve what they wanted or enough support for what they needed. In both cases respondents for children and young people tended to respond negatively to these questions. In particular:

☒ **Forty-two percent of respondents for children and young people did not believe, at all, that the amount of support provided was right for what they needed.**

Figure 30: Children and young people versus adults on satisfaction on whether they have sufficient services

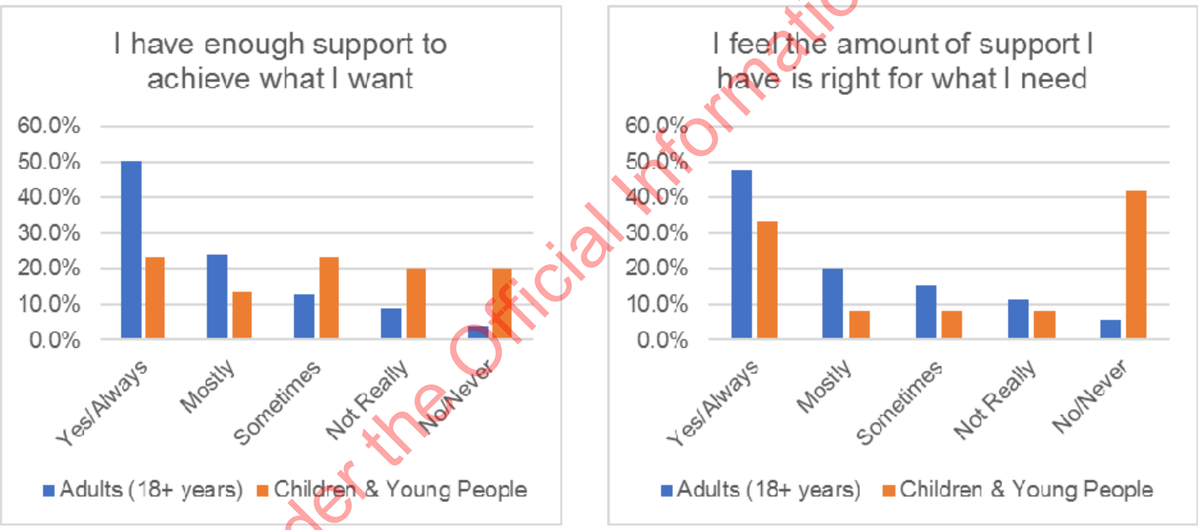
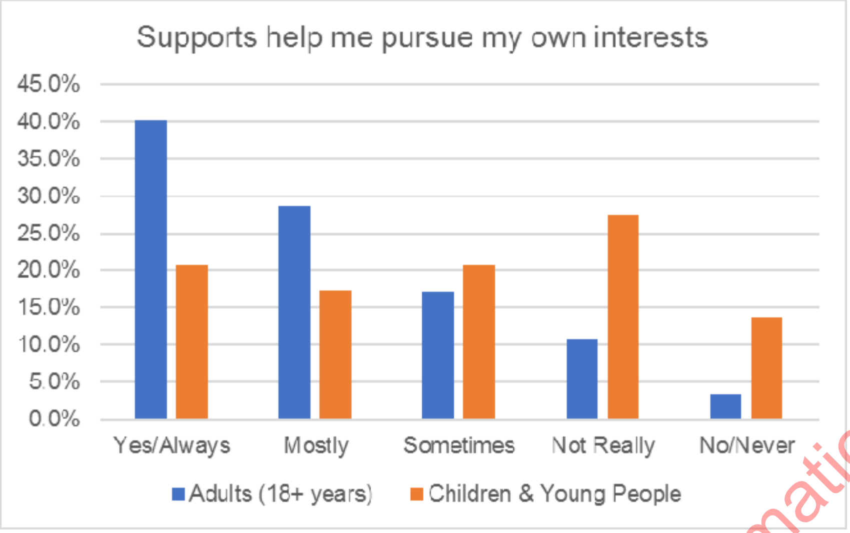


Figure 31 shows that only 38 percent of respondents for children and young people believed supports enabled them to pursue their own interests (1.1), all or most of the time, in contrast to 69 percent of all adults.

Document 7

Figure 31: Adults versus children and young people on whether they believe supports assist them to pursue their own interests



The variation in satisfaction noted in this section and the variation noted between different people based on disability type, suggest that blanket statements concerning satisfaction for whole populations may be misleading.

Satisfaction with supports and autonomy

Autonomy concerns how much choice or control a person experiences in their own life. The section, in the disabled persons survey, that examined autonomy had several questions related to the individuals' experience of the disability support system. For example, 'whether a person has a choice of who lives with them'.

Previously we considered autonomy in terms of life choices such as where and with whom people lived. However, taking into account all of the autonomy questions in Table 22 many are directly relevant to services or supports.

Table 22 indicates differences in perceived autonomy across a number of questions for adults who have learning versus physical disabilities. This raises questions about how satisfaction and autonomy may vary between other groups.

Table 22: Responses to autonomy questions: adults with learning and physical disabilities, (‘yes/always’ and ‘mostly’)

	All Adults	Physical Disability	Learning Disability
I can easily find out about the things I need for my support	62.5%	72.7%	54.3%
I can make changes to my supports if I need to	60.7%	65.9%	59.1%
I choose what happens in my life	63.8%	69.6%	61.9%
I have help to make choices if I need/want it	78.9%	74.4%	82.5%
I can choose who my support staff will be	44.9%	58.7%	36.4%
I know who will be supporting me each day/shift	76.6%	76.7%	75.8%
I choose who lives with me	56.7%	85.7%	39.6%
I have choices about the kind of support I receive	53.1%	59.5%	53.2%
I choose what happens in my day	67.7%	79.2%	63.9%
I can make plans based on what I want and what I'm good at	73.6%	76.9%	74.5%
I am achieving the things I want in my life	56.6%	46.8%[94]	65.7%
I decide when to share my personal information	78.9%	90.2%	70.5%[95]

---

[94] WMW=2.6, *p*<0.01, df=91 learning disability versus physical disability. Diff in mean=0.6, *t*=2.7, *p*<0.01. For further discussion of the results for this item see section 5, Personal Development and Planning.

[95] WMW=2.5, *p*<0.01, df=91. Diff in mean=0.8.

Document 7

Satisfaction, autonomy and type of support

Satisfaction, autonomy and community residential homes

Table 23 indicates, that for the most part, respondents for adults with learning disabilities living in community residential homes were satisfied with services across a number of indicators (n=38).

Table 23: Satisfaction and adults with learning disabilities living in community residential homes

	Yes always/Mostly	Sometimes	not really/no
Supports help me pursue my own interests	78.1%	15.6%	6.3%
I know who will be supporting me each day/shift	60.7%	14.3%	25.0%
My supports help me connect to people and places that are important to me	78.1%	12.5%	9.4%
My support happens at the times that work for me	81.8%	18.2%	0.0%
I have enough support to achieve what I want	81.3%	18.8%	0.0%
My support hours can be flexible	46.7%	26.7%	26.7%
My support occurs when I need it in my life	80.0%	16.0%	4.0%
My paid workers understand how to support me safely	97.1%	2.9%	0.0%
My paid workers receive the training they need	90.3%	9.7%	0.0%
I am supported to maintain and improve my health	91.2%	5.9%	2.9%
I feel supported to try new things	55.2%	27.6%	17.2%
I am supported to be actively involved in my homelife	70.6%	20.6%	8.8%
I feel the amount of support I have is right for what I need	85.0%	5.0%	10.0%
I think the money I get for my support is well spent	81.3%	12.5%	6.3%

When asked in open-ended questions what they liked about the supports that were provided:

- nearly a third referred to satisfaction with support workers[96] (34 percent),
- how well they were kept busy or active (37 percent)[97].

Other respondents suggested they were happy with ‘everything’ or the individual was simply ‘happy’ or ‘content’ (29 percent).

When asked what people did not like about their supports or what they wanted to change (or start doing or do more of in their life)[98], 24 percent stated they wanted to get out more, be less bored or be more active.

Table 24 indicates the majority of items had low levels of autonomy for people with learning disabilities living in community residential homes.

☒ **Only about a third of people with learning disabilities living in community residential homes believed they could make decisions in their life, or about what happens with their day[99].**

Similarly Table 25 indicates only about a third of respondents for adults with VHNs believed they could make decisions about what happened in their life (34 percent) and 42 percent indicated they could make decisions about what happened in their day.

Routine is often seen as positive, even necessary, especially for people who become anxious around change. However, many people in residential homes were expected to conform to a routine that is more about what others want, rather than the person. For example, after some struggles with day services one person is now looking for a routine that is personalised to herself and her choices:

> *If [she] doesn't want to go to day base they won't force her. They will either take her back home or find alternative option for the day.*

However, for many, fitting-in with the routine of others is the norm. As these respondents noted:

> *[Choice was] limited because of where he lives and the day base activities.*

And

---

[96] That is, support workers were described as being ‘good, nice, consistent, dedicated’ etc.

[97] As a general statement (kept busy, occupied, getting out and about) or with regard to specific things such as being involved in sport, gym, swimming, going to cafes, shopping and bars etc.

[98] This covered three questions, two directly related to supports (‘what do don’t you like about the supports you receive?’, and ‘if you could change one thing about your support, what would it be?’) while the third related to the person themselves, ie, their own goals or aspirations (‘if anything were possible, what are some things you would like to achieve, start doing, or do more of?’).

[99] N=30 and n=34 responses were made for each of these questions respectively.

She’s part of the routine of the house.

Table 24: Responses to autonomy questions: Adults with learning disabilities in community residential services

	Yes always/Mostly	Sometimes	No/Not really
I can easily find out about the things I need for my support	46.7%	6.7%	46.7%
I can make changes to my supports if I need to	30.8%	15.4%	53.8%
I choose what happens in my life	36.7%	33.3%	30.0%
I have help to make choices if I need/want it	75.9%	10.3%	13.8%
I can choose who my support staff will be	12.9%	9.7%	77.4%
I know who will be supporting me each day/shift	60.7%	14.3%	25.0%
I choose who lives with me	13.8%	13.8%	72.4%
I have choices about the kind of support I receive	33.3%	11.1%	55.6%
I choose what happens in my day	38.2%	35.3%	26.5%
I can make plans based on what I want and what I'm good at	46.7%	26.7%	26.7%
I am achieving the things I want in my life	55.2%	27.6%	17.2%
I decide when to share my personal information	50.0%	7.1%	42.9%

How satisfied people living in community residential homes were with the disability support system is complex. Adults with learning disabilities in residential homes were older on average (46 years, SD 14) and had a higher assessed level of need (90 percent VHN) than other adults with learning disabilities in this Baseline Study (who have an average age 40, SD 14, with 10 percent assessed as VHN). They were also more likely to have a proxy respondent (74 percent[100] compared with 33 percent for all other adults in the Baseline Study).

Assuming proxy respondents are making an effort to answer the survey items from the perspective of the person (rather than themselves), then the picture painted is one of apparent satisfaction with services, **except where personal autonomy is concerned.**

If we assume proxy respondents believe adults with VHNs have limited ability to make choices, the view they are not often able to have a choice in flatmates or staff is concerning. Likewise, the view that only a third have a choice of what

---

[100] This figure includes only people with VHNs with learning disabilities living in community residential homes. Regardless of assessed need the figure is 71 percent.

happens in their life, or even on a daily basis, paints a picture of a group of people who are controlled by others.

Table 25: Responses to autonomy questions, VHNs versus high and moderate needs, all people with VHNs ('yes/always' and 'mostly').

	VHNs	High/Moderate needs	Diff in mean	WMW
I can easily find out about the things I need for my support	47.1	70.3	0.9^{+}	2.0**
I can make changes to my supports if I need to	34.5	72.1	0.5^{+}	2.3***
I choose what happens in my life	34.0	85.3	1.4^{+++}	4.8*
I have help to make choices if I need/want it	72.0	84.8	0.7^{++}	2.4**
I can choose who my support staff will be	30.8	55.9	1.5^{+++}	4.0***
I know who will be supporting me each day/shift	62.5	87.7	1.0^{+++}	3.5***
I choose who lives with me	25.0	85.4	2.5^{+++}	4.6***
I have choices about the kind of support I receive	32.4	65.1	1.2^{++}	2.8*
I choose what happens in my day	41.8	86.5	1.4^{+++}	5.3***
I can make plans based on what I want and what I'm good at	48.4	85.5	1.1^{++}	2.7*
I am achieving the things I want in my life	42.9	64.0	0.8^{+++}	3.1***
I decide when to share my personal information	60.0	88.5	1.4^{++}	3.3***

*$p<0.025$, **$p<0.01$, ***$p<0.001$. Differences in mean for student *t*, $^{+}p<0.025$, $^{++}p<0.01$, $^{+++}p<0.001$.

Satisfaction, autonomy and supported living

✓ **People receiving supported living appear very satisfied with services over most of the survey items in Table 26 (average 81 percent, SD 9 percent).**

When asked what people liked about their support two thirds (66 percent) mentioned their relationship with their support workers. One person stated:

> *What I like is … if they have any problems they ring and let me know, if they can't make it, and they're always good to talk to, good to get on with. Yes. My carer's a lovely lady who is very friendly and very nice, very nice and friendly.*

When asked what they did not like about their support or what they wanted to change the same number stated that there was nothing they did not like or wanted to change.

Positive comments regarding the flexibility of support hours focused on a willingness of support workers to fit in around the individual as much as possible, but with an understanding that the support worker also had other people they visited. There were few long answer statements about flexibility, but those that were available were generally positive. One person stated:

> *They are flexible they can work around what days you want to do and they're there to do what you want to do, it's not about them. It's about me.*

In one service people had noted they can bank their support hours if they will be absent on a particular day and they provide enough notice.

One father talked about his general satisfaction with the supported living service for his son:

> *Every time [wife's name] and I've gone to meetings the information that we go hunting for on behalf [of our son] has all been free flowing and it comes across. They go out of their way to try and say, 'okay this is one option, that's another option, this is another option. But with the funding we suggest this option', if you know what I mean. The people that we talk to [at the service] are brilliant.*

Table 26: Satisfaction, supported living (n=25)

	Yes always/Mostly	Sometimes	not really/no
Supports help me pursue my own interests	76.0%	24.0%	0.0%
I know who will be supporting me each day/shift	87.5%	8.3%	4.2%
My supports help me connect to people and places that are important to me	75.0%	15.0%	10.0%
My support happens at the times that work for me	76.0%	8.0%	16.0%
I have enough support to achieve what I want	91.3%	4.3%	4.3%
My support hours can be flexible	70.8%	25.0%	4.2%
My support occurs when I need it in my life	86.4%	9.1%	4.5%
My paid workers understand how to support me safely	87.0%	8.7%	4.3%
My paid workers receive the training they need	94.7%	0.0%	5.3%
I am supported to maintain and improve my health	86.4%	13.6%	0.0%
I feel supported to try new things	72.0%	16.0%	12.0%
I am supported to be actively involved in my homelife	91.3%	8.7%	0.0%
I feel the amount of support I have is right for what I need	73.9%	13.0%	13.0%
I think the money I get for my support is well spent	69.6%	13.0%	17.4%

The more striking difference between people who use supported living as opposed to community residential homes (see Table 27) is with reference to autonomy.

Table 27 indicates positive responses on all indicators with the exception of, ‘choice of support worker’. Most people on supported living may be introduced to a support worker who had already been assigned to work with them. However, if the match between the person and the support worker does not appear to work well, then the individual is generally able to suggest they want a change.

Table 27: Autonomy, supported living, (all or most of the time) compared to residential (learning disabled)

	Supported living	Residential (learning disability)	Diff in mean	WMW
I can easily find out about the things I need for my support	80.0%	46.7%	1.5	3.0***
I can make changes to my supports if I need to	95.2%	30.8%	2.0	3.8***
I choose what happens in my life	90.9%	36.7%	1.5	4.6***
I have help to make choices if I need/want it	95.8%	75.9%	0.8	2.6**
I can choose who my support staff will be	60.9%	12.9%	1.8	4.4***
I know who will be supporting me each day/shift	87.5%	60.7%	1.1	3.2***
I choose who lives with me	83.3%	13.8%	2.6	4.4***
I have choices about the kind of support I receive	75.0%	33.3%	1.6	3.5***
I choose what happens in my day	100.0%	38.2%	1.7	5.5***
I can make plans based on what I want and what I'm good at	90.9%	46.7%	1.3	3.4***
I am achieving the things I want in my life	69.6%	55.2%	0.6	1.9
I decide when to share my personal information	90.9%	50.0%	1.5	3.7***
	n=25	n=38		

*p<0.025, **p<0.01, ***p<0.001.

For the most part, people with supported living were very satisfied with the services they received[101] and believed those services helped them stay connected with friends and the community[102]. Unlike those individuals in community residential homes, people who have supported living indicated they had a great

---

[101] For example, for the Likert Scale item 'my support occurs when I need it in my life' (4.4), 80 percent indicated this was the case all or most of the time. Further, 78 percent believed supported living helped them pursue their own interests all or most of the time (for all people receiving supported living).

[102] Seventy-eight percent indicated that their supports helped them connect to people and places that are important to them and 73 percent believed they were supported to be an active member of their community all or most of the time.

deal of control over their daily lives. None of those in supported living[103] believed they did not have control of their own lives to some extent. This contrasts with 84 percent of people in residential services indicating (via proxy respondents) they had no or little control of their own life.

Household management & personal care (HM&PC) only, satisfaction and autonomy

Table 28 indicates that for the most part, people with physical disabilities receiving HM&PC support only were satisfied with the services they received across most of the 14 satisfaction indicators. The two notable exceptions involve whether supports helped the person to pursue their own interests and whether supports assist the person to connect with people and places that are important to them.

Table 28: Satisfaction, people with physical disabilities receiving HM&PC support only, (n=31).

	Yes always/Mostly	Sometimes	not really/no
Supports help me pursue my own interests	50.0%	15.4%	34.6%
I know who will be supporting me each day/shift	78.6%	17.9%	3.6%
My supports help me connect to people and places that are important to me	39.1%	4.3%	56.5%
My support happens at the times that work for me	86.7%	10.0%	3.3%
I have enough support to achieve what I want	71.0%	12.9%	16.1%
My support hours can be flexible	73.3%	6.7%	20.0%
My support occurs when I need it in my life	85.7%	10.7%	3.6%
My paid workers understand how to support me safely	100.0%	0.0%	0.0%
My paid workers receive the training they need	91.7%	4.2%	4.2%
I am supported to maintain and improve my health	72.4%	3.4%	24.1%
I feel supported to try new things	72.0%	12.0%	16.0%
I am supported to be actively involved in my homelife	78.6%	14.3%	7.1%
I feel the amount of support I have is right for what I need	60.0%	16.7%	23.3%
I think the money I get for my support is well spent	70.8%	4.2%	25.0%

---

[103] Those providing self-reports only (n=21).

We compared the response differences between adults with learning and physical disabilities for both of these survey items. We note people with physical disabilities were less likely to believe they were enabled to pursue their own interests or connect with people and places that are important to them. Figure 32 suggests that differences may be associated with the type of support provided. People only receiving HM&PC support appeared less likely to experience support that enabled them to pursue their own interests[104] or connect them with people and places that were important to them[105] when compared to people with supported living[106].

Figure 32: People with physical disabilities receiving HM&PC support only and people on supported living

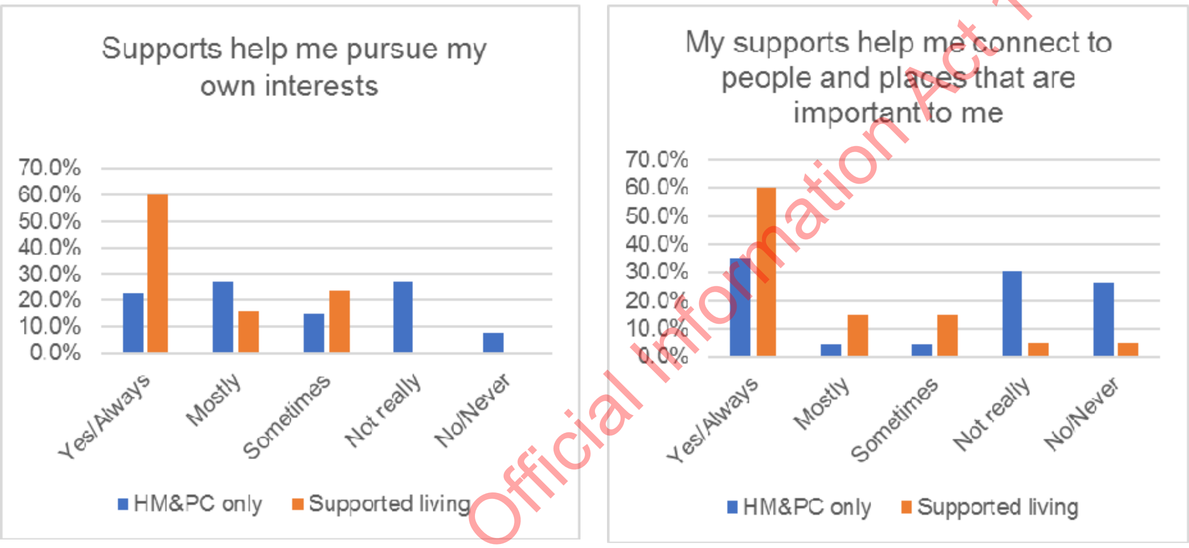


Table 29 outlines perceptions of autonomy for people with physical disabilities on HM&PC funding only, in contrast to adults on supported living. In general, people on supported living tend to be more positive about the degree of autonomy they believe they experienced, although less than a third of both groups believed they have complete control over decisions regarding support staff. People on HM&PC funding were also less certain they had control over what kind of support they received and whether they felt they could make changes to their supports.

---

[104] 'Supports help me pursue my own interests' WMW=3.0, $p<0.001$, df=43. Diff in mean=1.1, $t=3.4$, $p<0.001$.

[105] 'My supports help me connect to people and places that are important to me', WMW=2.4, $p<0.01$, df=43. Diff in mean=1.3, $t=2.9$, $p<0.01$.

[106] This group was chosen because they are not a residential sample and are not primarily supported through the carer support subsidy (also 88 percent of the people on supported living are people with learning disabilities).

Table 29: Autonomy, people with physical disabilities receiving HM&PC support only and people on supported living, all or most of the time

	HM&PC only (physical disability)	Supported living	Diff in mean	WMW
I can easily find out about the things I need for my support	75.0%	80.0%	0.3	1.3
I can make changes to my supports if I need to	65.4%	95.2%	0.7^{++}	2.1^{*}
I choose what happens in my life	70.0%	90.9%	0.6^{+}	1.5
I have help to make choices if I need/want it	71.4%	95.8%	0.7^{++}	1.8
I can choose who my support staff will be	60.0%	60.9%	0.3	0.5
I know who will be supporting me each day/shift	78.6%	87.5%	0.3	1.3
I choose who lives with me	95.5%	83.3%	0.2	0.7
I have choices about the kind of support I receive	59.3%	75.0%	0.5	1.4
I choose what happens in my day	80.6%	100.0%	0.6^{++}	2.5^{**}
I can make plans based on what I want and what I'm good at	76.9%	90.9%	0.3	1.2
I am achieving the things I want in my life	43.3%	69.6%	0.8^{++}	2.6^{**}
I decide when to share my personal information	92.6%	90.9%	0.09	0.1

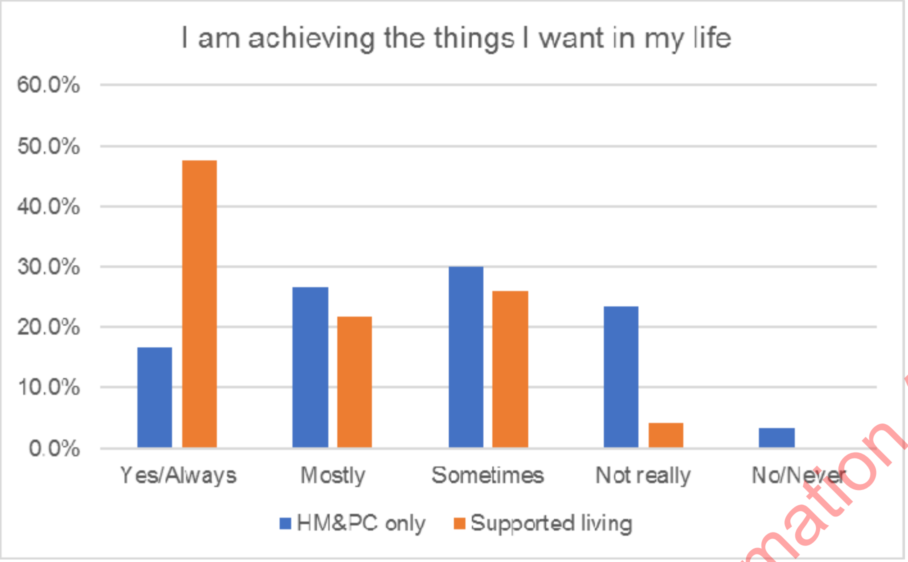
$^{*}p<0.025$, $^{**}p<0.01$, $^{***}p<0.001$. Differences in mean for student *t*, $^{+}p<0.025$, $^{++}p<0.01$, $^{+++}p<0.001$.

Figure 33 indicates 27 percent of physically disabled people who only receive HM&PC support did not believe (at all or not really) they are achieving the things they want in their own life, in contrast to 4 percent of people on supported living.

While this survey item does not focus on disability supports per se, it may suggest supports are not focused on anything other than household management and personal care support. On the other hand, having these supports may provide people with more time to focus on things that are important to them. For example, in response to the question ‘supports help me pursue my own interests’ (item 1.1) one person stated:

> *Well I think I would say that the Aqua Rehab has freed me up. But then I have only put that down as a club not as a service or a support. Yes [my support worker] does free me up because I can do things while she’s doing things. I just don’t, I can’t, vacuum any more.*

Figure 33: Achieving the things they want in their life: people with physical disabilities receiving HM&PC support and people with supported living



People receiving HM&PC-only support typically use agencies who provide support workers. In most cases, the agencies will introduce new support workers and people do indicate they can change support workers if they wish. However, it is not always easy for people to speak up about support workers that do not suit them and in some cases, people appear ambivalent. For example, the spouse of one disabled person stated with regard to their support worker:

> *She's good – we get on well. She's somewhat demanding but she does achieve a purpose.*

Another person noted:

> *Sometimes [my] caregiver gets a little personal. Like they are trying to control your life… or they think they are trying to make it easier for you. [You] feel like you're losing your independence…[I] just feel uncomfortable sometimes. But at the end of each day I say 'thank you very much for your help'.*

For other people the delay in asking for a change in support workers can leave a lasting impression, or even the last relieving support worker who was not known to the person:

> *It sort of made me degraded. And she was forcing me, I said if I don't want a shower tonight, I'm not having it… she was bossy and I didn't even know her.*

Over a third of physically disabled people on HM&PC-only support indicated they had very little or no choice in choosing support workers (37 percent)[107]. This response may be related to not being involved in choosing who was initially

---

[107] And 35 percent of all physically disabled people.

introduced as their support worker, rather than having a right to refuse the person. If having the right to refuse is seen as a ‘choice in support workers’ then the range of options in support worker is only related to the one person being introduced. As one person said with regard to having a choice in support workers:

> *I don’t know if that’s applicable really. I’m not sure because we live in [a small town]. I’m not actually sure if we can do that because… I don't think there are many.*

While we did not ask people to indicate whether they liked their support workers directly in the disabled persons survey, 40 percent[108] volunteered this information when asked in open ended questions what they liked about their support. One person said with regard her support worker:

> *She’s quite switched on. And she’s always careful so that’s really good and at times, between three and five, she assists in meal preparation too. So that’s great.*

Another stated:

> *I have amazing home help – great to have someone to aid when things are bad.*

Another thing people with physical disabilities on HM&PC-only liked about their support was the fact that they got the jobs that needed doing completed (40 percent).

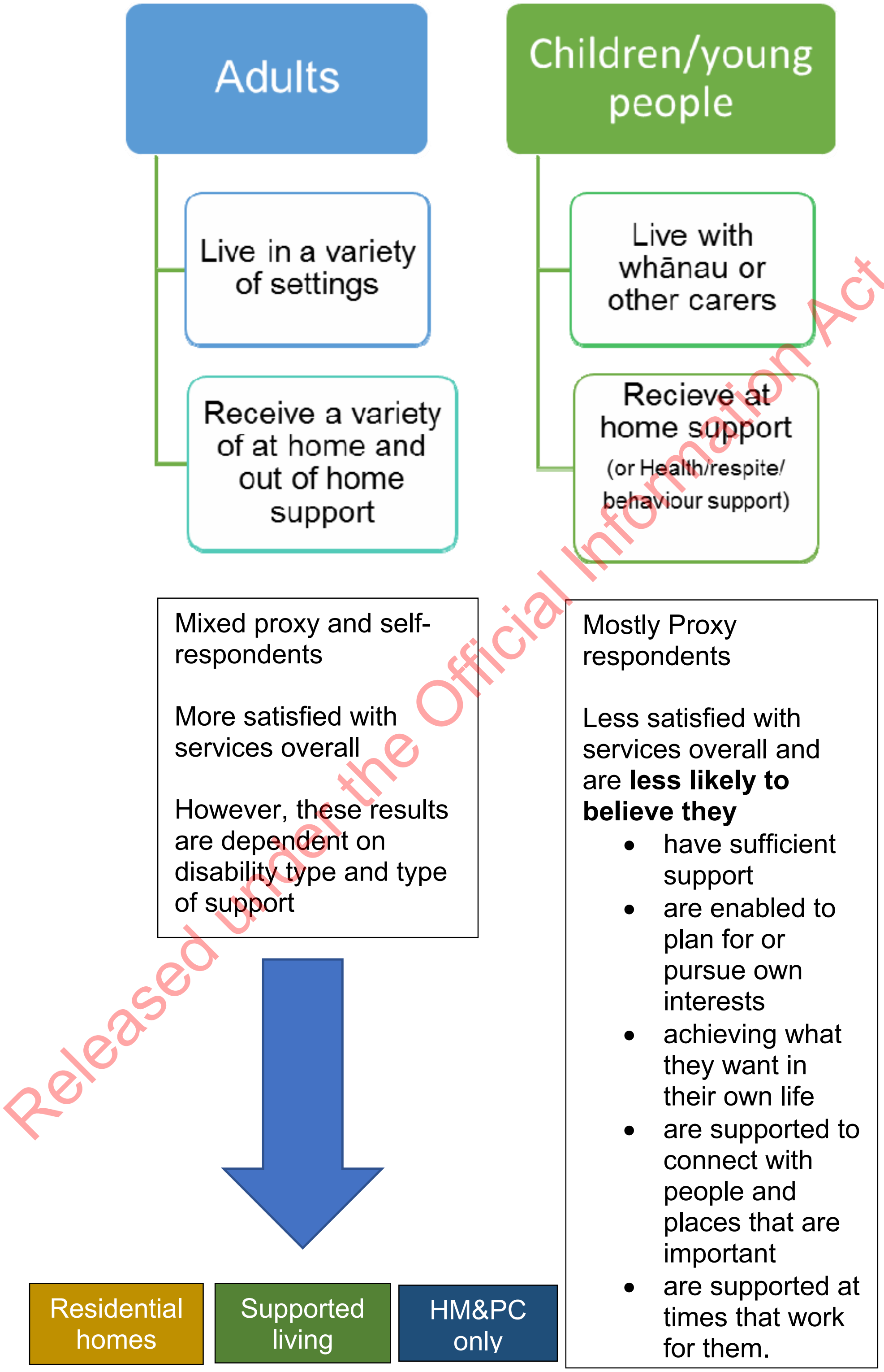
When asked what physically disabled people on HM&PC funding did not like or would like to change about their support:

- twenty-three percent indicated that they would either like more hours (10 percent) or they had lost support hours or had them re-assigned to other tasks (13 percent),
- nineteen percent indicated some issues with support workers, and
- twenty-three percent talked about a lack of flexibility (either in what support workers can or cannot do, the time of day they were assigned or issues about how funding could be used).

---

[108] People with physical disabilities with only HM&PC support.

18. Visual summary and conclusions



Adults

Live in a variety of settings

Receive a variety of at home and out of home support

Mixed proxy and self-respondents

More satisfied with services overall

However, these results are dependent on disability type and type of support

Residential homes

Supported living

HM&PC only

See next page

Children/young people

Live with whānau or other carers

Recieve at home support (or Health/respite/ behaviour support)

Mostly Proxy respondents

Less satisfied with services overall and are **less likely to believe they**

- have sufficient support
- are enabled to plan for or pursue own interests
- achieving what they want in their own life
- are supported to connect with people and places that are important
- are supported at times that work for them.

Residential homes	Supported living	HM&PC only
• People with learning disability • Typically Very High and complex support needs • Usually proxy respondents	• People with learning disability • Typically High and Moderate support needs • Usually self-reports	• Physical disability • Range of support needs • Usually self-reports
Higher satisfaction with services overall **BUT**	High satisfaction with services overall	Less satisfaction with services overall • Less likely to achieve what they want • Less planning towards what they want • Less choice in kind of support
Poor autonomy	Perceived reasonable autonomy	
Higher community participation but smaller friendship network • Usually access community in groups	Good community participation and wider friendship network	More socially isolated, can be associated with • Disabling conditions and health • Transport or mobility and support
		Poorer perceived sense of wellbeing

The results of the disabled persons survey were complex. They needed to consider a range of variables (factors) within and between various groups.

Differences between adults and children/young people may be influenced by the type of support received. Children and young people tend to receive at home support and for this reason involved whānau and other carers. The whānau survey highlights the complexity of support for younger people in much more detail and should be referred to at the same time as this survey. Overall, there is less satisfaction with services for children and young people. This is emphasised, in particular, when whānau caring for people in their own home is considered in the whānau survey.

For adults, the complexity involves consideration of the degree of assessed need and the type of services received. It is clear that people with very high support needs, who live in residential homes, have less control over their life than any other group. This is regardless of perceived satisfaction with services. Also, people with physical impairments may receive a narrower range of support options that may not include assistance with community participation, social connectedness, or personalised planning. People with physical disabilities may also be affected by their type of disability (for example, progressive conditions) and perceived personal health.

Disabled people in general were also **limited** in terms of their:

- employment
- education prospects
- income
- relationships and
- with regard to their sense of what they wanted to achieve in their lives.

Supports, prior to the implementation of Mana Whaikaha, did not appear to assist people to overcome many of the barriers faced by disabled people. For this reason, “the system” did not seem responsive to the main tenants of the New Zealand Disability Strategy or Enabling Good Lives.

19. What now

Other things to read

- Baseline Study of the Disability Support System in the MidCentral Area: Summary Report
- Baseline Study of the Disability Support System in the MidCentral Area: Whānau Report
- Baseline Study of the Disability Support System in the MidCentral Area: Survey Tools

20. Glossary of abbreviations and terms

ASD	Autism spectrum disorder
CDS	Child Development Service (provided through the MidCentral DHB)
DPO	Disabled persons organisation
DSS	Disability Support Services
Enable New Zealand	Enable was the NASC in MidCentral area before the implementation of Mana Whaikaha
EGL	Enabling Good Lives
IDI	Integrated Data Infrastructure
IF	Individualised funding
Learning disability	This is the term preferred by People First rather than ‘intellectual disability’.
Kimberley Centre	The last residential institution for people with learning disabilities that closed in 2006.
MidCentral area	The MidCentral area has the same geographic boundaries as the MidCentral District Health Board (DHB) which is a North Island DHB area that covers from Otaki / Te Horo in the south, to Apiti north of Sanson in the north and Dannevirke and south-west to the west coast.
MOE	Ministry of Education
MOH	Ministry of Health
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Coordination service. The NASC within the MidCentral DHB area is Enable NZ.
ORS	Ongoing Resource Scheme (MOE)
People First	Self-advocate organisation for people with learning disabilities
PPPR Act	Protection of Personal and Property Rights Act 1988
SCBA	Social Cost Benefit Analysis
SD	Standard Deviation
Survey Items	Questions or statements in the survey documents requiring a response
Stakeholders	Includes Government Ministries, NGO and governmental organisations associated with disability, providers, DPOs and national family organisations
SWB	Subjective wellbeing: people making their own assessment of their happiness or wellbeing
Universal services	The health, education and other community services available to all New Zealanders
VHN	Very high assessed need; based on the needs assessment done through Enable
WMW	Wilcoxon Mann-Whitney test for non-parametric statistics

To: National Enabling Good Lives Joint Agency Group & National Leadership Group

From: Gordon Boxall, Director, EGL Christchurch
Georgina Muir, Manager, Health and Disability Policy, Ministry of Social Development
Sally Jackson, Manager, Strategy, Special Education, Ministry of Education
Kate Challis, Manager, Disability Policy, Ministry of Health

Enabling Good Lives Christchurch: Lessons, Experiences, Opportunities

Purpose

This note summarises a series of discussions between the Ministries of Social Development, Education and Health, and the Christchurch EGL Team, on what the EGL Christchurch experience has taught us. It has been collated to inform the government's consideration of next steps to transforming the disability system.

The lessons from Christchurch EGL can generally be categorised under three key themes:

- the different levels of complexity in participants' lives, and what this means for the EGL approach
- the importance of cultural change, and that this takes time
- the need to recognise that the disability system is part of the broader social system, and because of these interdependencies, for the EGL approach to function, all parts of the social system need to be aligned to the EGL approach.

Background to the Christchurch demonstration

The Christchurch demonstration was funded through Vote Social Development at a cost of $1m per annum. Over the two and a half years of operation it has supported 246 participants. Christchurch made use of elements of the existing disability structures, including the Needs Assessment Service Coordination (NASC) organisation to act as the Funding Manager and to undertake assessments, a Host Provider (Manawanui-in-Charge) to assist people to manage their supports and budgets, and services contracts the Ministries of Health and Social Development had with providers in the region. The demonstration more recently has worked with the Ministry of health to develop Flexible Disability Support contracts (more information below).

The demonstration primarily targeted a full population cohort covering all school leavers with an ORS (On-going Resource Scheme) status in Christchurch. This approach differs from an opt-in approach, with people being referred or self-referring if they thought EGL might be right for them. In designing the demonstration, it was considered that a full cohort approach had the benefit of trialling a system that would need to respond to the complex range of individual situations, whereas an opt-in approach may be more likely to attract 'early adopters', for example people who already use individualised approaches[1].

The demonstration had limited lead in time, and was rolled out rapidly. Therefore, development of an implementation plan, and background work to ensure services, schools,

---

[1] However this is not always the case, as experience in Waikato is that vulnerable, and 'hard to reach' groups are showing that they are willing to opt in and try new approaches.

disabled people, whānau and community could engage meaningfully with the demonstration, was undertaken at the same time as the demonstration was 'live' and underway.

The demonstration was deliberately designed to test a different approach to disability support within the current system, rather than outside the system. As a result of the rapid rollout, and the need to trial new approaches over the top, and within the constraints of, the existing disability support system, the programme office had to find 'work-arounds' to respond to the range of situations. This triggered the development of innovative responses that can now be applied system-wide (such as the development of Flexible Disability Support contracts, discussed further below).

However, it has provided valuable lessons as a result of the difficulties encountered, particularly where a new system is transposed upon an existing system. Possibly one of the biggest lessons learnt from Christchurch is the need to allow sufficient time for the necessary system changes to be designed and adequately tested. System transformation requires significant changes to existing structures, processes and organisational cultures. Given the substantive nature of such change, adoption of an EGL type approach will take time.

It is worth noting that the design of the components within the EGL approach in Christchurch were co-developed with Wellington officials, the local EGL Team and local representatives of disabled people, families and providers. Whilst this was time consuming and resource intensive at the time, it has led to a consensus being reached on important areas such as independent facilitation, planning framework, purchasing options detailed below:

Independent Facilitation/Navigation

The independent facilitation/navigator function is a critical part of the transformed system so it is important to consider how this function is understood and features within a new system. Navigators have worked with families in a flexible, responsive manner according to families' individual situations. Some families had the "lightest touch" approach where they needed only a small amount of navigation in order to shape a good life. Others needed more of an investment approach due to the impact of their more complex life situations.

What remains essential is the two aspects to independent facilitation (or navigation)

a) Independence – the navigator/facilitator does not benefit from any choices the individual makes
b) Facilitator – the job is not to 'do for' but to make it easier for the individual and their family to do for themselves

The experience of the Christchurch demonstration highlighted some important issues around the scope of this role which warrant further thought if the approach is expanded more widely. These include:

- How to define the role?
- What is a reasonable level of time a navigator/independent facilitator might invest in supporting an individual? Should this be defined or remain discretionary?
- How will the role of navigators/independent facilitators interface with the support provided through Flexible Disability Support contracts?
- How should navigators/facilitators be employed/deployed? For example, who employs them and who are they accountable to?

Flexible Purchasing Options (including Flexible Disability Support contracts)

The Christchurch demonstration found that a single approach to the provision of support and budget management assistance did not work for everyone. People want choices in how they will be assisted to manage their personal budgets and purchase the supports they may require. Many participants in the demonstration benefited enormously from being able to manage their supports and budget with the assistance of Manawanui-in-Charge, a Funding Host. Others found this approach difficult and preferred to be assisted by a provider who was able to assist them with this while some chose a combination of the two.

EGL Christchurch responded to this need for flexibility by working with the Ministry of Health to introduce Flexible Disability Support contracts. These contracts enable a disabled person to work with a provider who will provide flexible support and budget management assistance that assists them to achieve the outcomes they have identified for themselves.

A provider with a Flexible Disability Support contract can offer a combination of:

- direct fundholding (for some or all of the support that people buy directly)
- facilitated buying – where a provider purchases support on behalf of the person
- delivering flexible support – where the provider delivers support as directed by the person.

Flexible Disability Supports suit people who do not want to have all of the responsibility of standard hosted services (for example being an employer) but wish to be able to have the flexibility to work with the provider of their choice, and to be supported in the way they choose.

The approach attracted a high level of interest from providers, resulting in a broad range of individual supports now being provided, and a growing level of interest from users and families in taking up this type of support.

EGL provides participants the opportunity to buy ‘things’ as well as services, as long as they aligned with approved purchasing guidelines and were within their overall allocation and plan. Situations where items do not clearly fit within the guidelines were considered by a multi-perspective local panel. This process led to consensus decisions and an acceptance of the importance of context i.e. the decisions made by the panel may differ for a similar item depending on a person’s unique circumstances. The Christchurch EGL Team strongly considers that this approach should continue to be tested in this way.

The overall utilisation of funds has remained remarkably constant for many months now at around 78% of funds allocated. This suggests that there shouldn’t be unreasonable concern that giving people more choice, control and flexibility will result in them spending all that they can.

While the development of Flexible Disability Support contracts has taken time, they can very easily be scaled up and rolled out to others within the existing disability support structure.

Inclusive NZ is working with providers who have Flexible Disability Support contracts and supporting them to undertake organisational self-reviews and develop action plans on how to align their supports and services with the principles of EGL. This approach has the potential to continue to support the provider sector in adjusting to transformational change and explore the opportunities for broader application of Flexible Support contracts. Such an approach has the potential to free up time for navigators/independent facilitators

Building Capacity and Fostering Culture Change

The Christchurch experience has shown the importance of increasing the capacity of individuals, agencies, families and services to respond to a system which is aligned to EGL principles. Peer support and actively demonstrating the EGL approach has shown to change how people work and their approaches, leading to exponential rather incremental change.

The demonstration has highlighted that successful implementation of the EGL approach and its associated principles is contingent on a belief in the approach, trust and relationships at all levels. All stakeholders need to believe in the principles of EGL and be willing to align their work, practice and approaches to these principles (i.e. if a school actively practices the principles of ELG, school leavers will have options and their transitions to the next step of their life will not, for example, be limited to the school's preferred provider).

Building community and family capacity

Putting an EGL approach into practice means seeing the disability system as broader than just the disability support structures. The system also includes families, schools, other government agencies, community groups and so on. Relationships between the different parts of the system are critical to fostering cultural and systems change.

The Christchurch demonstration has focused on building community one person at a time. This work with disabled people and their families/whānau has helped them to form their own networks, independently of the EGL Team or individual providers.

The demonstration also fostered links with community groups such as Volunteering Canterbury, church groups, vegetable co-ops and animal welfare organisations. These relationships helped foster ideas around how a community as a whole can operate differently.

Continual strengthening of networks amongst families and community providers has the potential to spark locally led innovations and initiatives, outside of the government funding disability support system. Examples of such innovations in Christchurch include:

- Sharing Carers – a Facebook page to recruit and share great support workers
- Keeping Safe, Feeling Safe – a 5-day workshop run by People First and hosted by the Police, with input from relevant mainstream agencies including Tenants Protection Association, Women's Refuge, and Male Survivors of Sexual Abuse
- Family Capacity Building workshops – focusing on a variety of things from housing to employing support staff, as well as strengthening family alliances and networks.

Supporting clients with complex needs

The experience in the Christchurch demonstration is that conservatively approximately 20% of participants were 'vulnerable' in some form. That is, they may have tenuous or no relationships beyond their immediate support person, or the family of support around them may be struggling and vulnerable to break-down. This is particularly the case for disabled young people exiting from Child, Youth and Family statutory care who return home to their family.

Other factors contributing to levels of vulnerability and complexity include people with a dual diagnosis, mental health and/or complex health issues within the family, having more than one child with a disability at home, being new to New Zealand, and poverty.

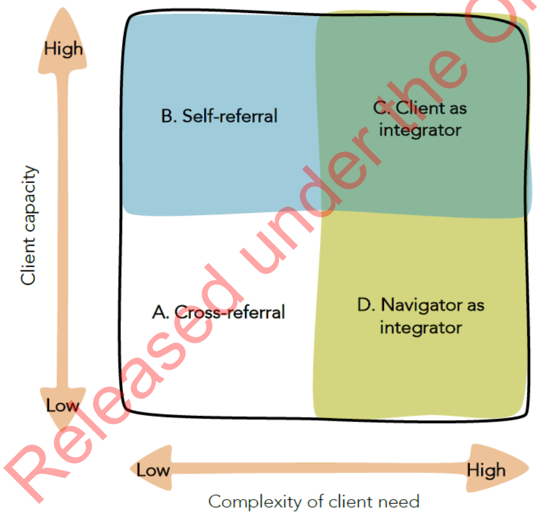
In particular, safeguarding is a big concern for this group, and the demonstration is learning a lot about it. The level of disconnect of vulnerable young people was highlighted in the demonstration as many of these young people's experiences through the demonstration was unable to be captured through the main evaluation. A separate evaluation of vulnerable young people in this group has just been completed with the outcomes to be shared at a final stakeholder event on 28th June.

Flexible funding approaches and, in particular, the introduction of Flexible Disability Support contracts for providers has meant that participants and their families/whānau have increased the range of supports available to them. Training initiatives like 'Keeping Safe Feeling Safe' are intended to support young people to manage risk in their lives and to be able to call on agencies like the Police to help them when necessary.

The Christchurch experience suggests that a one-size-fits-all model of navigation is unlikely to work for people with high complexity and low capacity (quadrant D in the Productivity Commission report, see figure below[2]). This group presents challenges for the original model of navigation designed for the demonstration. The time needed to build trust and then support people to make changes is more extensive that the navigator model originally envisaged. In addition, working with these people and families requires special skills which not all navigators have. The six hours of navigation in the next phase may be insufficient time for this group, and there is a risk that paying for extra navigation out of personal allocations could create inequities as it reduces the budget available for support.

Building up strong community support around disabled people and families with complex needs is a means of ensuring that they have additional layer of protections and supports where alternative family, friends or whānau support may be lacking.

Characteristics of clients of the social services system



Source: New Zealand Productivity Commission (2015); More Effective Social Services p3

---

[2] The Productivity Commission developed a framework to segment four typical client types, with Quadrant D clients described as those people who have high complexity of need and low capacity to coordinate services alone

Supporting the provider sector

The provider sector has a critical role to play in supporting roll out of a transformed system based on EGL principles. Ongoing work with providers, confirming and consolidating their role as equal partners in change, will be important to support broader application of the EGL approach and to ensure that they are equal partners as the system continues to transform.

The Christchurch demonstration identified early the importance of developing providers and their ability to respond to system changes, and established a Provider Development working group, which include Inclusive NZ, NZDSN, local providers and ministry officials. The demonstration also hosted "Provider Lunch Box" sessions, monthly informal sessions with providers and schools to share experiences and learn from each other.

Many providers themselves are undertaking innovations such as assisting people to establish micro enterprises and redesigning their financial systems to be able to account directly to people as to how their funding is being used. Although some providers are demonstrating the application of EGL principles in their services, a comprehensive application of 'choice and control' over supports across an entire sector will take significant changes to providers' culture, processes and business models.

One of the cornerstones of the demonstration has been to ensure the independence of the facilitation function, and that navigators do not benefit from any of the choices the participant might make. This creates some tensions for providers who may offer a 'navigation' type approach or who consider that independent facilitation may steer people away from provider options.

The EGL approach requires providers to turn their attention away from their bulk contract funder and towards individuals and navigators and, as part of this, being encouraged to be 'of service' rather than offer a menu from their 'suite of services'. This requires a considerable investment of provider time and resources, and, given that the demonstration is time limited, providers may be considering the trade-off of this investment against the risk that EGL does not continue.

With Flexible Disability Support contracts still in their infancy it is too soon to see if this, as planned, helps to build a new personalised market with personalised supports but there are already some interesting examples of EGL families who were early adopters of employing staff themselves now engaging one of the Flexible Support providers to take on the employment responsibilities. Interestingly the Flexible Support provider who has gained the most has a background in delivering personalised supports but not within the disability sector.

Early engagement and good communication with providers is essential, as the Christchurch demonstration illustrated. The rapid rollout of the demonstration, and the limited time available to ensure providers fully understood what was being proposed, and how they could work with the EGL Team, led to some early miscommunication, for example, the interpretation of the principle 'mainstream first' and payment difficulties. These experiences undermined the credibility of EGL as a workable model and, although were ultimately overcome and now easily avoided in any scaling up exercise, nevertheless were costly in terms of the time taken to resolve them and build back confidence from the sector.

There will continue to be a role for facility-based models of support for people who choose them. As change is rolled out and the expectations of disabled people and their families/whānau increase, there are opportunities for facility-based providers to offer services/supports that assist people within the community. The EGL approach can help incentivise these changing models. For example, several providers in Christchurch have recruited staff who focus on assisting people to connect with opportunities in their communities in authentic ways. These staff are being creative in their approach to potential barriers and work with the person to ensure full access and participation in things like employment, leisure and meaningful lives.

More recently, the responsibility for the provider development programme has been transferred from an EGL initiative to the two main peak bodies as supported by EGL in order to attempt a more sustainable outcome.

Role of Needs Assessment Service Coordination (NASC)

As noted above, Christchurch made use of the existing NASC structure to act as the Funding Manager and undertake needs assessments. This decision was made given the EGL Christchurch demonstration was designed to test a different approach to disability support within the system rather than outside the system as well as the very short timeframe in which the demonstration was initiated.

If change and system transformation is going to happen quickly, there is a role for NASC, however as with all other parts of the system, ongoing change is required in order that systems, structures and organisational approaches align with an EGL approach. Culture change requires ongoing commitment of people on the ground, and clear expectations set at a central government level, around the behaviours and practices at an operational level.

It is worth noting that the NASC have recently nominated a person to be their EGL Coordinator who has made a real difference to progressing the EGL approach across the NASC. While there is concern that they are the third person in this role within 18 months, it shows how important it is to have people in such key roles that are committed to the EGL principles. It is encouraging to hear that NASC colleagues have expressed interest in adopting the supported self-assessment tools and flexible disability support arrangements for some of their clients for whom the current system is not working well.

Working with young people transitioning from school

The period between ages 16 and 21, and what happens after a young person leaves school, is a crucial transition point for a young person. Schools play an important role in helping to ensure a young person is aware of all the opportunities available to them. For this to occur, schools, providers, whānau and communities need to have strong and trusting relationships. The school transition service and the 'navigator' function play an important role in fostering these relationships.

Transition experiences for students vary from school to school, including between fund-holder schools and mainstream schools and units, with little uniformity between schools about what is included, expected and funded.

It became apparent in the demonstration that it was necessary to start working with the young person before their final school year. By the last year of school a transition plan has generally already established and not necessarily aligned to the principles of EGL. Ideally in a transformed system, independent facilitation would commence with a young person as early as possible in their life, so that hopes, dreams and aspirations are nurtured and plans on how they achieve their goals, including access to education, can be fully in place throughout a young person's life. This includes working with tertiary providers early about training opportunities and reasonable accommodations available to the disabled young person.

The ability to keep ORS funding until 21 even if not attending school, provides young disabled people with more options and choices. Future system transformation could consider looking at planning and curriculum options within schools that help with transitions, such as tertiary studies or pre-vocational courses, leading to further learning or paid work and developing real expectations of further study or work at the end of school. The demonstration, to foster development of a greater range of options for young people, worked with the local polytechnic, Workbridge, schools, providers and employers about how we prepare young people for employment. It is likely this work will continue beyond the demonstration by the interested parties. Examples of employment innovations include:

- an enterprise established by a participant of the demonstration and their family/whānau (Pru's Green Laundry)
- a young Deaf woman who returned to school to gain English NCEA credits. She used her EGL funding to pay for an interpreter in English class, passed with Merit, and is now employed as an NZSL teacher in a number of local (mainstream) primary schools.

Assessment, Funding Allocation and Pooled Funding Arrangements

Tools and processes need to be aligned to the EGL approach and principles. Developing these has been, and continues to be, an iterative process. This includes the development and use of a strengths based assessment tool (Supported Self-Assessment), and the trial of a Funding Allocation Tool, which enables support funding from participating funders to be converted into a single dollar amount.

Disabled people, their families and the NASC, need to be trained and supported in how these new tools work which can take time, and requires a change in approach from traditional methods of entitlement and allocation. Once people feel comfortable and confident with the new systems, and understand how to use them, participants have more control over the process.

While funding in the Christchurch demonstration is 'pooled', in practice the pooled funding from Vote Education and Social Development continued to be provided at a set level for those who met the eligibility criteria for community participation services and/or ORS, irrespective of whether they needed this funding or not. There is potential to further develop the pooled funding model so that the total pool is available to all clients, irrespective of individual's eligibility for certain programmes.

The Joint Agency Group has now approved a new approach to pooling the funding for the next phase of EGL beyond the demonstration from 1 July. Relevant budgets will transfer from the Ministries of Education and Social Development to the Ministry of Health to manage and allocate to eligible school leavers and existing EGL participants. The Ministry of Health will manage any risks and the fact that there will no longer be a need to have a year-end 'wash-up' takes away the requirement to have to ask permission for apparently eligible people to be admitted to Enabling Good Lives which has been an issue during the demonstration. This greater flexibility would allow budget allocations to be more responsive to individual goals and aspirations, and further emphasise the move away from 'allocation of service based on need/deficits'.

This approach would need to be supported by a Funding Allocation Tool which responded to the developing Supported Self-Assessment process, worked effectively as a budget management tool, and could support fair allocation of limited resources. The demonstration showed an under-utilisation of pooled funds allocated (consistently below 80%) showing there is scope to do this. A considerable amount of work has been completed to co-design (with local stakeholders including disabled people and families) such a tool, shadow test it and enable it to fully integrate it into current DSS management information systems. There is an opportunity to trial it as part of the next phase of Enabling Good Lives in Christchurch (and it would be a great shame to lose the value of the work undertaken) but it is recognised this will require further investment by DSS.

Practical Considerations: Data Collection, Evaluation, Information Sharing and Payment Issues

Finally, there are a number of other practical issues that EGL Christchurch encountered. While "work-arounds" within the demonstrations were found for all of these issues, they will need to be addressed in a more systemic manner if the approach is expanded more broadly. These issues include:

Data collection & evaluation

The Government has emphasised the value it places on systematically measuring the effectiveness of social services, so we know what works well and for whom, and then feeding these learnings back into decision-making. Continuing to assess and measure the effectiveness of elements of system transformation in disability supports will be an ongoing process.

The Christchurch experience illustrated the importance of establishing upfront what is going to be measured, why, the data that needs to be collected and how we establish success. For example, the demonstration encountered challenges with attributing successful outcomes to the demonstration, due to the need to consider the frequency of requests for information from participants, difficulties in obtaining information from vulnerable participants and lack of information on outcomes achieved after the young person had exited active participation in EGL.

The initial evaluation undertaken at an early stage of the demonstration was able to inform the later phase of work and ongoing externally evaluated 'feedback loops' along with internally collected participant surveys were also more timely methods of checking where things were going well or not. To date there is considerable evidence that EGL has had a positive impact upon people's lives.

Information sharing

Protocols around how information is shared between agencies, organisations and services will need to be established, particularly if the EGL approach is established more widely.

Information sharing will avoid a person having to repeatedly provide information to multiple agencies. At the same time it is important personal information provided to an agency is 'owned' by the person and only shared as authorised by that person.

Payment issues associated with person-directed purchasing and funding

A number of payment and billing issues were uncovered through the demonstration. These issues include:

- Use of Manawanui-in-Charge not working for all participants as previously mentioned with it taking a long time to fill the gap (in the form of Flexible Disability Support contracts
- Issues with GST

Governance

The experience of the demonstration indicates that there are opportunities for further strengthening the governance arrangements as they apply to an EGL approach. For example:

- Local Leadership need to be clear about their role and the representative role of members (i.e. whether they are there as an individual or as a representative of particular group/s).
- Government officials need to work in tandem with Local Leadership, including being part of the Local Leadership, and that this occurs from the outset. This way, government officials have increased ownership and buy-in to the EGL approach.
- Aligning allied policy and operational decisions to the EGL principles and approach

Conclusion

This is a snapshot of lessons learned which will be augmented by the external evaluation when it is available.

Changing a total system even for a small cohort of people is disruptive and challenging.

Designing new components needed to meet such a principles based approach as Enabling Good Lives takes time and produces unintended consequences if not carefully planned in advance.

Trusting relationships are key to generating 'work-arounds' to problems and inform longer term, workable solutions

The workable solutions (being within an existing system) can then be more easily scaled up and/or rolled out

Staying true to the EGL principles and engaging disabled people and families in the design of a new way of working is time consuming but rewarding.

Joint working also builds trusting relationships.

It is important to be clear about what to measure from the outset.

It is also valuable to test progress in a number of ways in order to be able to know what is working and what isn't (so the former can be developed and the latter can be changed)

A demonstration cannot operate in isolation and it is important to consider how best to align other workstreams across agencies to ensure the approach is reinforced rather than undermined

An EGL approach does not need to cost more in order for people to get better lives

The EGL approach can be seen as an important investment in the lives of people in complex situations

Evaluation of Feedback
from
Participants with Complex Situations

June 2016

Report compiled by Rebekah McCullough

Table of Contents

Executive Summary

This evaluation, of the impact of Enabling Good Lives (EGL), was based on interviews with a small number of participants who fall into the criteria of 'Category D' from the Productivity Commission Report into Social Services. Category D is defined as including individuals with complex needs who have difficulties navigating systems to coordinate services and supports. This particular group of participants have not had their views and experiences captured in the current MSD evaluation due to their complex situations.

The two key aims of this evaluation were:

1. To determine what impact, if any, Enabling Good Lives has had on those participants
2. To determine if there were any changes or improvements to the current EGL processes that would make it easier to use for these participants.

A list of 15 individuals from Category D were identified as potential interviewees. Of these, 6 were interviewed, 3 declined to be interviewed, and 6 were unable to be contacted and/or did not show up at the interviews as agreed. Of the 6 people interviewed, 3 were men and 3 were women.
A set of questions provided the framework for the interviews. (Appendix A)

General findings indicate that these participants are making positive changes within the EGL framework albeit very slowly and with significant input from Navigators and other support networks.

- All reported developing trusting and positive relationships with their EGL Navigators and this was seen as crucial by the participants, family members, other agencies and navigators.
- All commented on EGL as assisting them to "do what they wanted to do."
- All had been or were involved in activities that they enjoyed and were looking forward to extending these and/or trying new things.
- Having an individualized budget was reported as very positive although there continues to be a need for further support to learn to access and manage this effectively.

Recommendations for consideration include:

- Development of an Investment Model to extend timeframes for development of relationships, activities and supports
- Re-thinking of planning process
- Development of strategies to support management of individual budgets
- Development of 'support' for supporters (e.g. Navigators, other agency staff, other key stakeholders)

The principles of EGL demonstrate the need for alignment of practices and resources to ensure good practices. While this group of people presents many challenges to support them to engage and begin developing "a good life" they also provide opportunities to review and refine the EGL process. With appropriate time and resources, these individuals will be able to become contributing members of their families and communities.

Aims

This evaluation of the impact of Enabling Good Lives (EGL) engaged with a small number of participants who fall into the criteria of 'Category D' from the Productivity Commission Report into Social Services. Category D is defined as including individuals with complex needs who have difficulties navigating systems to coordinate services and supports. This particular group of participants have not had their views and experiences captured in the current MSD evaluation due to their complex situations. The EGL team has identified the following factors of which one or more may be occurring in these participants' lives:

- Limited people in participant's life
- Living in residential care
- Health - mental health, other health issues
- Dual/multiple diagnosis
- Family complexity issues (e.g. other disabled children, carer fatigue, limited awareness of disability, reduced family networks)
- Difficulty managing "system" (disability, EGL, government or combination)
- Family capacity to manage change
- Poverty
- New to NZ
- Multiple issues happening for families
- Earthquake stresses

The two key aims of this evaluation were:

1. **To determine what impact, if any, Enabling Good Lives (EGL) has had on those participants**

2. **To determine if there were any changes or improvements to the current EGL processes that would make it easier to use for these participants.**

Methodology

Participants

A list of 15 individuals from Category D was identified as potential interviewees. Of these, 6 were interviewed, 3 declined to be interviewed, and 6 were unable to be contacted and/or did not show up at the interviews as agreed. Of the 6 people interviewed, 3 were men and 3 were women.

The evaluator also met with 4 family members, 2 support staff, one agency staff and 7 EGL Navigators.

Interview Process

Participants were initially contacted by either the EGL Navigator or current support provider to ask if they would agree to be interviewed. The Evaluator was sent contact information and then proceeded to make arrangements with each individual. Four of the interviews took place at the individuals' homes and 2 at a mutually agreed venue. While there was a set of questions that the evaluator used as a framework for discussion (Appendix 1), the interviews were intentionally informal and relaxed (e.g. no note taking during discussions) to promote the most comfortable setting for discussions.

General Findings

The following information is based on a summary of key questions answered during the interviews.

Tell me about your life? What are you doing/involved in now? What do you like doing?

Four of the participants discussed the activities they were currently involved in and what a ‘typical’ week might look like. These individuals appeared to have a level of support that was based on their current activities and requirements. Most of the activities identified were still within the “disability sector” and included attendance at various disability day service providers, recreational activities specifically for disabled people (e.g. Star Jam, etc.) and CPIT courses such as Work Skills. Two people were involved in work experience activities that they hoped would lead to some form of employment.

Participants and family members stated that they liked that EGL enabled you “to do what you wanted to do.”

One person’s parent was very pleased that they had been able to hire a support person that they felt they could trust. As a result the participant had begun to make some new friends and was starting to have social time with them (going to lunch on the weekend).

One person was just beginning to participate in activities outside the home and although the family had many concerns and worries, they stated that they were very positive about this first step. They had a much respected and long-standing support person who was, along with the EGL Navigator, encouraging them to further develop this activity or even try something new. The idea of a ‘buddy’ to assist the young person to participate in the community gardens was initiated by a family member as a possibility even though they remain cautious due to past experiences of failure and concerns regarding both health and financial issues.

One person, while very articulate, was having extreme difficulty in sustaining any plans or arrangements made regarding activities and work experiences due to extremely difficult family and personal situations. She reported that it was very hard to ‘stick to things’ but felt able to keep the discussion open with the Navigator and other supporters.

Most of the participants reported that they were pleased with having their say about what they wanted to do and having a budget to do these things.

What's next? Do you have a plan? Are there things you are keen to try?

Three of the participants "thought" they had a plan but were unable to say what it stated or was supposed to do for them. The other three were unsure if they had a plan. When asked how having a plan might be helpful, some thought it might help them get a job or do some new things.

The development of a "Plan" and how that might be useful is not something that was very well understood by the participants and their families. Most were unable to any give information about their thoughts or dreams for their futures.

Further discussion, elicited some information about activities that participants like to do and/or felt they were good at. This led to some discussions about the possibilities of developing these interests as a way of trying new things or meeting new people. For example, one participant really liked sport and thought the idea of being a 'helper' for a local rugby or soccer club could be a possibility.

Who was your Navigator? What did your Navigator do?

The first part of this question was not to identify the Navigator but rather to understand if the participant knew who was their Navigator. All of the participants were able to identify very clearly their Navigator.

Five of them stated that Navigators were good at linking up with other people or getting them into activities. One said the Navigator helped her with problems.

They also stated that they found the Navigators to be easy to talk to, non-judgemental and had good attitudes.

The only negative comment made was about when Navigators left and there was uncertainty about who would take over from there.

In general, Navigators were viewed as a very positive and helpful resource in the EGL process.

What has worked well for you in the EGL process?

There was general agreement that having a Navigator to link and negotiate was very important. The participants reported that they liked their Navigators and felt they could trust them.

One person stated that they had made new friends and one person said they were hopeful of getting a job because of the links made through EGL.

Most people liked having an individual budget and while often unsure of how to use it and understood that this could assist them to make choices about what they wanted to do.

What could be better? How could EGL work better for you?

One person wanted to know when Navigators were changing or leaving. They felt this had not been communicated clearly to them and they were not sure where to go next.

Three people requested more support to manage their budget.

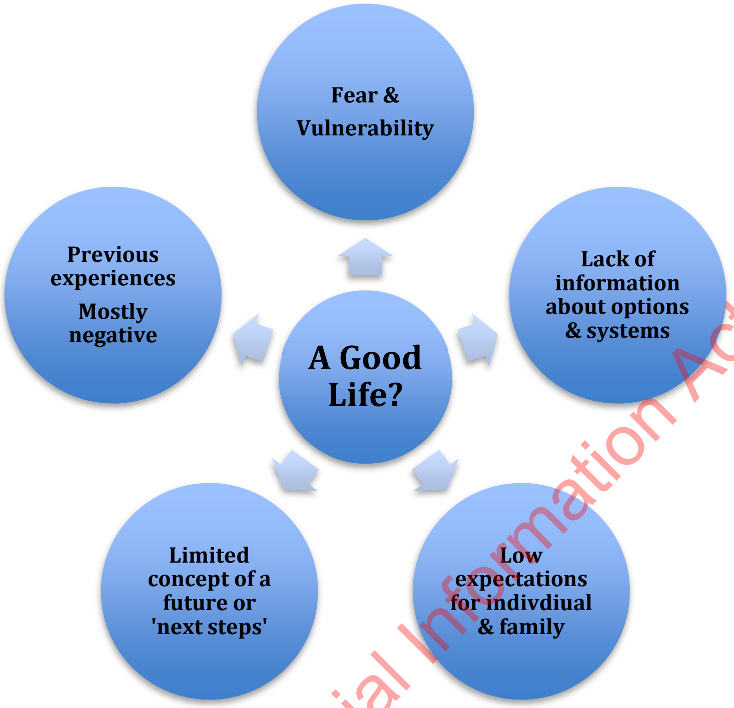
Where do you think you would have been without EGL?

Three of the participants stated clearly that they would just be at home not doing much. The other three people were not sure but didn't think they would be doing what they wanted to do.

All of the participants stated that their schools had initiated the contact with EGL.

Document 9

Issues Related to Understanding the Concept of a “Good Life”



The above graph is an indicator of the most common issues shared by this group of participants. The EGL team earlier identified these and other issues as challenges in supporting this group of participants in the EGL process. (It should be noted, that Navigators also pointed out that these challenges are not solely the domain of those in this evaluation and that many other participants and their families are grappling with one or more of these issues as well.)

The participants were mostly focused on the present, what was happening in their lives now and how they got by each day. For some, the idea of “future” or “next steps” was difficult to imagine and even more difficult to respond with any kind of options for something other than what they currently knew.

Even when participants spoke about things that were important to them and/or things they were good at, they still did not necessarily see those as leading them on to anything better or more than what they currently knew.

Most participants were unable to link what they enjoyed and/or felt they were good at, with something they could either continue to explore and develop.

The participants and their families' knowledge of opportunities, services and supports appears to be very limited. Family members were concerned with keeping their son/daughters safe and this sometimes limited choices and planning.

It was reported from all of the participants, as well as their families, that in spite of many previous negative experiences, they were developing positive relationships with their Navigators. They stated that Navigators were helpful in linking them up to other supports and activities and had non-judgemental attitudes.

The challenge for those supporting these participants is to develop trusting relationships that enable a foundation of learning and development to support meaningful decision-making towards a "good life."

Impact of Enabling Good Lives

What impact has EGL had on the lives of these participants?

While this particular group has many complex issues they all reported that EGL was a positive factor in their lives because they were actually doing things and not just sitting at home. While most of them were involved with disability support services, one had hired a staff person and two were involved in work experience. The ability to ‘do what I want to do” was a positive aspect although it also presented challenges as people still were developing trust, understanding about options and learning to manage their budgets.

It was clear that much more time was required to engage, build trusting relationships and to inform and educate participants and their support networks about options and possibilities. In taking things at the pace of the participant and their support networks, options and opportunities were beginning to emerge for them.

As discussed earlier in this report, previous negative experiences, low expectations, lack of understanding of options and opportunities and a lack of understanding of how to manage systems, budgets and finances have been the norm for these participants and their families. However, with time and support, these participants are beginning to engage with others and try new things. They are beginning to think about “what might be” due to considerable investment of time by many of the navigators and other supporters.

What changes or improvements would make EGL easier for participants?

Participants stated the following as ways that EGL could be improved:

- More time with Navigators to learn and understand about their options
- More communication with Navigators when any changes were being made, particularly if a Navigator was being replaced.
- Assistance with budgets

Support Practices and EGL Principles

Practices that have been utilised to date, to support these participants, also clearly demonstrate alignment with EGL principles.

Key Support Practice	**Actions/Strategies**	**EGL Principles**
Relationship based	• Building trusting relationships • Development of foundations for decision making • Building up of personal networks	• Person-centred • Mana enhancing • Relationship building
Educational and Information based	• Learning at individual's pace • Building up resources & networks	• Ordinary life outcomes • Mainstream first • Easy to use
Individualised	• Enabling participants to learn to make choices & decisions for themselves • Funding that supports decisions	• Self-determination • Person-centred
Flexible	• Responsive support • Adaptive and creative solutions to support choices and decisions	• Self-determination • Person-centred

Recommendations for Consideration

- **Investment Model**

  This group requires a significant amount of time to build trusting relationships with Navigators, support staff and their communities. Many of them stated that they needed "lots more time with their navigator." Investment in developing trusting relationships will be a key factor in breaking the cycle of limited expectations to one of hope and imaging a better future. The current model of time allocation needs to be reviewed and reworked to enable a regular, consistent and often very frequent amount of time to spend with individuals with complex challenges. This investment will enable a solid foundation for the participants and their support networks to take in new ideas and information at a pace that they understand and can process. As one Navigator stated "the starting point is getting people thinking."

- **Re-thinking "My Plan" and the planning process**

  As stated earlier, participants were unable to identify any relevant information about their plan. The idea of planning for the future appears to be very challenging, when many of these participants are focused on day-to-day survival. In discussion with the Navigators, it is clear that some of the planning is for the benefit of accountability, which it is agreed is an important aspect of planning. It was discussed that any plan should be a "living document" and there needs to be further discussion and clarification about who is responsible for keeping it alive.

  The participants taking "next steps" were those for whom, only one idea/activity had been developed at a time. For some, there were urgent issues that needed to be addressed (e.g. housing and safety). However, there was general consensus within the Navigator discussion that this approach enabled participants and supporters to 'come on-board' with one step at a time as they became more confident and clear about the EGL process.

- **Increased and Immediate supports for Budget management**

  These participants do not have an "agent" to assist them with MIC although a couple are beginning to be supported by staff from other providers. The need to attend to often-urgent issues was discussed. Ensuring that there was a flexible and fast way to use transition funds or other available funds might enable some positive groundwork to be laid to ensure a smoother and more helpful process. For example, ensuring that medication is provided in a blister pack may be pivotal in ensuring that the individual can maintain good health therefore alleviating worry and concern associated with their condition.

- **Supporting the Support Networks**

  In some situations it may be useful to ensure an on-going collaboration between all of the key stakeholders, especially those who may be seen as the primary supporters. This would promote keeping communications accurate and clear, broader networks for sourcing ideas and solutions and minimising undermining of plans, activities and relationships.

Concluding Remarks

This process of supporting those who appear to be the most disaffected shows clearly how, with good practices and appropriate resources, the principles of Enabling Good Lives has profound effects on both participants and the wider community.

> *"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around."*
>
> *Leo Buscaglia*

Appendix A

Document 9

EGL Framework Questions

Key information to inform:

- What impact has EGL had or not had?
- Has Navigation changed the direction for you?
- Has ‘flexible pooled budget’ changed your life path in anyway?

Tell me about your life
What are you doing/involved in now?
What do you like doing? How did you get involved in that?
What’s next? Do you have a plan?
Who was your Navigator? What did they do?
What worked well for you?
What could be better?
Where do you think you would have been now without EGL?
Who did you go to get EGL? Health, Education, MSD, DSS?
What issues did you seek help with?
What was the response to your request for help?
How effective was their response in helping you?
Other

MINISTRY OF EDUCATION
Te Tāhuhu o te Mātauranga

MINISTRY OF HEALTH
MANATŪ HAUORA

MINISTRY OF SOCIAL DEVELOPMENT
TE MANATŪ WHAKAHIATO ORA

EGL Christchurch Demonstration

Phase two evaluation report

Authors

Diane Anderson (Ministry of Social Development), Rowanne Janes (Ministry of Health) and Paula Pope (Ministry of Education)

Acknowledgements

We wish to thank all those involved in the Enabling Good Lives Demonstration who gave us their time to be interviewed for assisting with the data collection. We also thank everyone who provided feedback on the design of the evaluation and on this report.

Disclaimer

The views and interpretations expressed in this report are those of the researchers and are not an official position of the Ministry of Social Development, the Ministry of Education or the Ministry of Health.

Published

[Publishing details]

ISBN

[ISBN numbers go here]

Contents

1. Executive summary

This report details the findings from a second evaluation[1] of the Enabling Good Lives (EGL) Demonstration in Christchurch. The Demonstration finished in June 2016. EGL is a principles-based approach to supporting disabled people to live their vision of a good life. The Demonstration, developed to test this approach, is a partnership between representatives of disabled people, families, providers, and government agencies. The Demonstration primarily focused on school leavers (aged 18 to 21 years old) with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education's Ongoing Resourcing Scheme (ORS).

The theory of change is that enabling disabled people to have more choice and control over their supports and services to live the life they want will improve their quality of life. It is anticipated that disabled people will make more use of natural[2] and universally available supports in their communities. The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design, planning and navigation[3], individualised flexible funding[4], provider and school development, and community development.

The evaluation took place in late 2015 and will inform advice on the future direction of disability supports. The Ministries of Education (MoE), Ministry of Health (MoH) and Ministry of Social Development (MSD), along with the Demonstration Director and the Local Advisory Group (LAG), wanted to understand how the Demonstration was being implemented and how it was working towards supporting disabled people to live the life they want to lead.

The evaluation found that there were significant challenges in designing and implementing the Demonstration as intended. It appeared there was limited change amongst schools and providers as a result of the Demonstration. Change amongst schools and providers takes time and requires investment consistent with achieving outcomes.

Most disabled people and families interviewed for the evaluation had positive experiences of EGL but there were suggested improvements to navigation and planning, funding, and the use of natural supports. There were some positive outcomes for disabled people interviewed as part of the evaluation but there is also room for improvement.

---

[1] The first evaluation was undertaken shortly after the Demonstration began in November 2013. See Anderson et al., 2014.

[2] The term natural support is not always clearly defined or understood. 'Natural supports' often refers to the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections.

[3] Navigation is the process by which participants identify and record what a good life looks like for them, and how they can achieve it. Participants can choose to undertake navigation with an EGL navigator, or with other people including wider family and friends, or with appropriate support they can choose to do it themselves. The output of navigation process is the development of a plan of action for the participant.

[4] Funding that disabled people are eligible for from the Ministries of Health, Education and Social Development is pooled into an EGL personal budget. Disabled people can choose, within guidelines, how that funding is used to support them to achieve their vision of a good life.

The evaluation used a mixed method approach similar to phase 1

The evaluation used a mixed method approach similar to phase 1 but with some additions. The methods used included:

- 10 case studies of disabled people in different contexts[5]
- a quality of life survey of 43 youth participating in EGL
- in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers (GMs), a representative from Manawanui InCharge (MIC)[6], the LAG as a group, EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
- analysis of existing administrative data to describe trends and patterns in use of navigators, use and management of the funding and use of supports and services
- analysis of documents on the Demonstration.

There were limitations associated with the evaluation. The key limitations were:

- *A comparison group could not be established:* The absence of a comparison group limits conclusions about the extent findings reflect all disabled young people and their families. It was not possible to randomly assign people to participate in the Demonstration. There was a plan to compare quality of life outcomes for participants with a group who had not participated in the Demonstration. However, it was not possible to gather enough responses from a comparison group to include them in the analysis.
- *The quality of life survey response rate was low (34%)*. The numbers of participants and proxies were small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth.
- *There were differences across several indicators between participants and proxies, highlighting challenges in combining participant and proxy responses*. Differences were likely to be due to either different perspectives of proxies and participants or to systematic differences in the circumstances of those who could respond for themselves and those who needed a proxy to respond for them. While the reporting of results from the survey generally combines responses of participants and proxies, these are reported separately where they are significantly different.

---

[5] There were three types of cases:

- Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care.
- Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
- Case type 3: Movement towards living a life in line with the EGL principles (opt-in)

[6] Manawanui is a company specialising in facilitating Individualised Funding and other self-directed services (see http://www.incharge.org.nz/interested-in-using-individualised-funding/what-we-do/)

Designing and implementing the Demonstration were challenging

There has been some improvement since the first evaluation of the EGL Demonstration in Christchurch. The mechanism for determining and allocating the funding to disabled people is now in place and functioning, the role of the navigators is clearer and systems are in place to pay providers. However, key elements of the Demonstration were not designed at all, or not designed until late in the Demonstration. This had an impact on what was implemented and when. For example:

- a wider range of options for managing the funding was needed
- the community development component was underdeveloped and received little attention in terms of design and resourcing
- providers and schools have an important role to play in helping disabled people achieve their outcomes. However, investment in changing practice in providers and schools was insufficient (see below).

The design of EGL proposes that disabled people be assisted to make more use of natural and universally available supports in their communities. The evaluation found that assumptions about the role that natural supports can play in supporting disabled people may be unrealistic, at least in the short term. Few families reported that they had significant natural supports outside of family and where these existed they appeared fragile. Further understanding is required about how natural supports can be developed and how they can be used alongside responsive formal supports and services.

Improving what was to be put in place in the Demonstration could have improved implementation.

- A more fully developed design was needed. Development of a detailed design was hindered by several factors. There were differing perspectives on the flexibility of the design, what co-design meant in practice in the context of the Demonstration and whether it had been co-designed. The co-design needed more time and resource. Better links between design and implementation were needed.
- Understanding of and buy-in to the EGL vision across stakeholders needed to improve.
- It would have improved the Demonstration if the leader on the ground and leaders in government had a common understanding about roles and responsibilities and the processes for resolving system issues as they affected the Demonstration.
- Accountability arrangements could be improved. There was a lack of focus on outcomes for disabled people and measuring outcomes at all levels. Accountability arrangements with providers and schools didn’t reflect the focus on outcomes for disabled people.

EGL highlights wider problems with the system which may have limited implementation and performance.

- The amount of funding disabled people receive may be insufficient to achieve their vision of a good life (eg for those who wanted to move out of home and live independently in the community).

- There is a limited range of housing options in Christchurch for disabled people. Several interviewees reported that the options appeared to be living at home with parents or in residential care.
- Some interviewees reported difficulties accessing appropriate supports and services for young disabled people ageing out of child services.

Families' and disabled people's experience of EGL was positive but there were some difficulties

Navigation and planning were largely a positive experience for most families interviewed

Case study data revealed families were often sceptical when they first heard about EGL, but people typically engaged with EGL because they wanted to improve outcomes for their young person. Families did not engage or were reluctant to engage in navigation where they had no opportunity to talk to the navigator, were not open to navigation, did not believe their family fitted with EGL and/or did not expect their young person to grow or develop further.

Where families did engage in planning, it was largely a positive experience. However, navigators were more beneficial for some families than for others. The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there.

There were practices that supported disabled people to engage in planning. These included making disabled people central to the planning process, building the capacity of disabled people and families to engage, and having other parents who had been through EGL to walk alongside new people. Having access to and use of independent facilitation was also reported as being important in assisting people to engage in planning, although alternatives were raised (eg provider-led navigation based on the EGL principles).

Challenges for planning and navigation included:

- engaging families who were in difficult and complex circumstances and struggled to envisage a good life for their young person
- finding workable solutions for disabled people without family support
- balancing what the young person wanted and what the family wanted.

Possible improvements for navigation involved providing better:

- support for disabled people and families when they get into difficulty implementing their plan
- support for vulnerable families to develop, put in place and maintain their vision of a good life
- links between new families and those families who have engaged with EGL
- clarity about the future of navigation.

Use of the funding

EGL personal budgets are made up from pooled funding from the Ministries of Health, Education and Social Development. Around 70-80% of the pooled funding is from Vote Health, with the remainder from the other two Votes. According to data collected by the EGL team, most participants had received their allocation of funding. This funding could be used flexibly to purchase supports and services. As at 9 October 2015, 129 of the 175 EGL participants had been allocated funding. People needed a plan to receive their funding. Most of those who had not been allocated their funding at this point had paused their engagement with EGL or were still working through the planning process (eg because they were new or had taken some time to decide what they wanted).

Being financially literate and well resourced assisted people to take up the funding and manage it. There were practices that supported disabled people and families but there was room to improve.

- Pooling the funding and having greater flexibility in the use of the funding was important. Some families expressed the desire for more flexibility.
- Managing the money was difficult for many families and disabled people. More options are needed to assist families to take up and manage the funding. Direct funding[7] to disabled people was not available in the Christchurch Demonstration. Flexible disability support contracts were due to be implemented at the time of the evaluation. These are now in place. It was anticipated that this would provide a less onerous option for families to manage the funding. Some people need agents but these are not always easy to find, leaving those people unable to take up the funding.
- The amount of funding was insufficient in some contexts. For example, the cost of living independently in the community with the appropriate supports was identified as a significant barrier and funding may have been insufficient for families on lower incomes. In addition the funding may have been insufficient to support disabled people’s choices where the family could not be involved in the day-to-day care of their young disabled person. Taking up Funded Family Care (FFC)[8] limited the overall pool of funding, but families did not always feel they had an alternative.
- Families had some useful sources of advice and guidance on how to use the funding but more is needed. MIC was instrumental in advising families and the purchasing advisory panel worked well but families were not always clear about why some services were funded and others were not. There was a need to clarify elements of the purchasing guidelines[9].

---

[7] Direct payments (either cash payments or a nominal budget) involve the funds being given directly to the person with a disability, who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations.

[8] Funded Family Care is Ministry of Health funding for some eligible disabled people over the age of 18 with high or very high needs. This means that if they are eligible for Disability Support Services funding they may be able to pay the people they live with to help them with their personal care and/or household tasks. http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care

[9] These have been updated since the evaluation.

The employment of staff could be improved

Families and EGL staff interviewed offered suggestions to make it easier to employ staff, including:

- undertaking more work to support families as employers, especially when disputes arise
- educating support workers about the home care environment
- establishing a group that could shoulder more of the employer responsibility for families
- using flexible disability support contracts between disabled people and providers. It would be useful to have a further evaluation of how well these contracts are working for disabled people and their families.

Some positive outcomes for disabled people and their families

Who were the participants?

As at 9 October 2015 there were 175 EGL participants. Most of these were school leavers (aged 18 to 21 years old) [10]: 135 were school leavers, 40 were opt-ins[11]. There were more male participants (100 males compared with 75 females). Most were Pākehā: the ethnicity of participants was primarily Pākehā (over 80 percent). Few participants were Māori or Asian (less than 10 percent each). Most (100) EGL participants had received high needs (HN) ORS funding. Sixty-one received very high needs (VHN) ORS funding, 10 received no ORS funding and four received no funding at all. Participants attended a mix of special[12] and mainstream schools.

EGL participants at 9 October 2015 had attended or were attending one of 27 schools. Most EGL participants (76%) had attended or were attending one of seven schools (Allenvale Special School, Ferndale High School, Hillmorton, Cashmere, Riccarton, Papanui or Van Asch Deaf Education Centre). Sixteen schools had only between one and three students who were EGL participants.

There was broad agreement amongst families and disabled people interviewed about what constituted a good life. Across the cases, families and disabled people agreed that a good life involved disabled people doing things that interested them and being included in the community. There was some distinction between those families who engaged with EGL and those who did not. Those who engaged with EGL had higher expectations of what their young person could do post-school.

---

[10] Young people students who are over 19 and whose exceptional needs mean that a secondary school is the best place for their education can stay at school until they are 21 years if they have a Section 9 Agreement. This is a formal agreement between the Ministry of Education and the parents/guardians of the disabled person allowing them to remain at school until they are 21. See http://www.education.govt.nz/school/student-support/special-education/entering-into-a-section-9-agreement-for-special-education-services/

[11] A small number of people in or near Christchurch who access disability supports but were not school leavers aged 18-21 were allowed to opt in at the discretion of the Director. Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support.

[12] Day special schools are part of the schooling network in New Zealand and offer specialist teaching to students who have a high level of need.

Quality of life outcomes

The Enabling Good Lives approach is ultimately about improving the quality of life of disabled people. A survey of 43 young people eligible to participate in the Christchurch Demonstration was conducted in late 2015 to assess quality of life outcomes. Respondents included 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). In the survey, the questions identified aspects of quality of life that many EGL participants and their proxies were positive about and aspects few thought mostly applied to their lives.

The Schalock Quality of Life framework was used as a foundation for developing quality of life indicators for the evaluation of the Enabling Good Lives Demonstration. Indicators relevant to the context were developed for each of the frameworks dimensions in consultation with the Local Advisory Group in Christchurch.

Wellbeing: physical and emotional wellbeing were good but material wellbeing was low

Analysis of the quality of life survey found that overall scores were higher for the physical (80) and emotional (81) wellbeing domains and lower for the material wellbeing domain (55).

In the case study research, the emotional wellbeing of the young people was reported as being good. Emotional wellbeing was reported as improved in all the cases where the young people had made changes in their lives following active engagement in EGL. In most of the cases no changes were reported in the physical wellbeing of disabled people interviewed. However, there were two cases where participating in EGL appears to have improved the young people's physical wellbeing (eg fewer doctors' visits, improved physical functioning). In both cases the families attributed this to having consistent carers they had chosen. As with the quality of life survey, evidence from the case studies indicates that material wellbeing is constrained for many young disabled people.

Social participation: interpersonal relationships with family were good but improvements could be made in the rights and social inclusion domains

Social inclusion could be improved. Analysis of the quality of life survey found that the social inclusion domain (63) had the lowest overall score within the social participation area. The survey found most respondents could go out in the community (eg shopping, movies) but fewer felt they belonged or had meaningful participation. The case studies revealed that young people's sense of belonging in their communities varied. There were factors that appeared to influence the degree of social inclusion. These included knowing and being known in the neighbourhood, having sufficient income to participate, having the ability to engage in social interactions in the community, and the attitudes of people in the community.

Improvement could be made in the rights domain. The rights domain is about being treated with respect, dignity and equality. It also encompasses citizenship, access and fair treatment. Analysis of the quality of life survey found the rights domain had a relatively low score (70). The survey found the highest-scoring indicators were use of the phone or internet when wanted, having someone trusted to ask for help and having choices respected. The lowest-scoring indicators were being able to go out when they wanted and getting time by themselves.

Interpersonal relationships with family were typically good. Analysis of the quality of life survey found the interpersonal domain had the highest overall score (81) within the social participation area. However, people's social networks were often limited. Factors that limited people's ability to spend time with the people that mattered to them and influenced the development and maintenance of relationships outside of the family included living in residential care, not being able to afford to go out, degree of assistance needed and received to build relationships, and the impact of individual conditions (eg level of functioning, self-motivation, confidence) on young people's ability to engage in and maintain personal relationships.

Independence: improvements could be made in personal development and self-determination outcomes

In the quality of life study the overall score for the personal development domain was 74. However, the overall score masks substantial differences between the underlying questions. High proportions reported their home had the things they needed day to day to help them (80%), they were doing some type of education or learning they were interested in (77%), and they had the things they needed to do what they wanted (71%). Smaller proportions responded that they mostly have had a chance to fix mistakes (49%), show people the things they are good at (40%) and learn to do new things that help with everyday life (29%). The case study data indicated greater personal development for young people engaged in EGL; for example, respondents reported being engaged in activities they wanted to do and being satisfied with the mix. However there was limited evidence the young people in residential care were engaged in personal development activities.

In the quality of life study the overall score for the self-determination domain was 71. As with the personal development domain, there were substantial differences between the underlying questions. Almost two-thirds of respondents (62%) reported that they *had a say about the important things in their life.* But a smaller proportion (35%) was positive about the *choice of who participants live with.* Analysis of the case study data found that families engaged in EGL reported their young person had greater choice and control over how they lived their life. However, the case data indicated that young people in the cases where they were in residential care had limited choice and control over various aspects of their lives (eg what activities they did, where they lived).

There appeared to be limited change to family outcomes

Based on analysis of case study data family emotional wellbeing had improved but not always because of EGL. There was no change in physical wellbeing. Family material wellbeing varied across families but changed little for individual families following participation in EGL. Limited change was reported in the quality of relationships between family members although there were some exceptions.

Family support networks and access to services could be improved. Few families reported that they had significant natural supports outside of family. Access to supports and services was problematic. The amount of use and experience of using disability support services varied.

Family personal development changed little. Family decisions about the care of their young person were influenced by and had an influence on parents' (especially mothers') choices regarding work and further education and training. In some of the cases EGL appeared to have opened up space for family members to engage in personal development but in most cases EGL appears to have had limited influence on parents' decisions in this area. Where the young person with the disability moved out of home or was cared for by a non-parental carer, there were more opportunities for both parents to engage in further work, education or training, or personal development.

Improvements are needed in the measurement of outcomes

Currently, only limited information is systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found that improvements could be made by:

- enhancing data collection (eg improving the response rate, the collection of information from people with communication challenges, and the collection of information from proxies)
- continuing to explore how to assess the impact of similar initiatives. Considering the difficulty in identifying and contacting a valid comparison group, the most useful comparison for future quality of life surveys may be as a measure of change over time within the same individual or group of participants. Other options could include exploring the use of quasi experimental designs although they would require considerable work both to develop design options and to assess ethical implications
- establishing a standard set of indicators that can be tracked over time and applied more widely
- developing family wellbeing indicators.

There was limited change in practice amongst schools and providers

Some schools and providers interviewed were working to support disabled people to live everyday lives in the community. However, provider and school alignment with the EGL approach could improve. The evaluation found that there was variation and room for improvement in:

- support for disabled people to make choices and tailoring of supports and services
- the way schools and providers assist disabled people and families to plan for the future and significant transitions, which was heavily influenced by their views of the life they saw disabled people leading post-school
- providers' and schools' understanding of social inclusion (eg being present versus meaningful inclusion) and their practices to support it
- support for disabled people to build and maintain relationships and develop natural supports in the community
- support amongst schools and providers for the concept of mainstream first

- support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed
- the ease with which disabled people get the support they want when they want it from schools and providers
- opportunities for disabled people to influence school and provider policies and practices. Schools and providers could improve their measurement of outcomes for disabled people and use the information to drive improvement in practice.

The following factors appear to have undermined the influence the Demonstration had on provider and school practice:

- Schools and providers did not see they needed to change significantly.
- Most of the providers and schools interviewed had had limited experience of EGL. Limited communication and inconsistent messages about EGL meant schools and providers lacked clarity about their role in EGL.
- There was underinvestment in school and provider development.
- The delayed development and implementation of key components of the Demonstration (eg the process for paying providers) undermined the Demonstration's credibility, particularly with providers.
- Some providers and schools reported limited capacity to fund changes to operate more in line with the EGL principles.

Factors that may have helped schools and providers include:

- engaging in consistent and clear communication with schools and providers over a longer time period before and during the Demonstration to assist in getting buy-in and ensure everyone is on the same page
- having a person schools knew and trusted liaise with them about the EGL approach. While there was a dedicated person to manage the EGL/provider relationship with providers, there was no such person for schools
- having readily available information on what EGL means in practice and advice on how to get there, including for the governing bodies of providers and schools; for example, providers wanted more advice on how to cost their services in an individualised way
- ensuring that contracts and funding arrangements with providers encouraged the outcomes sought by the EGL approach.

In future, specific provider (and school) development funding could help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools need to start by expanding their vision of what disabled people can achieve. An ongoing challenge will be addressing the financial sustainability of providers.

2. Evaluation purpose and Enabling Good Lives background

Purpose of the evaluation

This report details the findings from a second evaluation of the Enabling Good Lives (EGL) Demonstration. The Demonstration finished in June 2016. EGL is a new approach to supporting disabled people to live their vision of a good life. The Demonstration, developed to test this new approach, is a partnership between representatives of disabled people, families, providers, and government agencies.

The evaluation took place in late 2015 and will inform advice on the future direction of disability supports. The Ministries of Education, Health and Social Development, along with the Demonstration Director and the Local Advisory Group, wanted to understand how the Demonstration was being implemented and how it was working towards supporting disabled people to live the life they want to lead.

What is Enabling Good Lives and why change?

The current system of disability supports is problematic

The system of support for disabled people has often made it difficult for an individual to live an everyday life of their choice in their community. There has been pressure to change the current system of disability supports and services so that disabled people have greater choice and control. This pressure has arisen because:

- life outcomes for disabled people are poor compared with the general population[13]
- disabled people and their families report the current supports and services do not reflect their individual needs and preferences. The current system:
  - is very complicated for users. Disabled people and their families have to navigate complex bureaucracies in different agencies to access all the support they need. It is not person driven. Disabled people and their families struggle to get the assistance they need when they need it
  - focuses on funded specialist supports and services at the cost of mainstream services and other forms of support
  - typically allocates funding based on a medical model rather than on someone's strengths and what they could do. There is limited flexibility in the use of funding
- the current system is costly to government. Costs have increased but there is little evidence that the additional spending is resulting in better outcomes
- there is greater recognition that disabled people should have the same rights as non-disabled people eg as a result of the adoption of the United Nations Convention on

---

[13] People living with disability often experience poor social and economic outcomes. The New Zealand Disability Survey found that, compared to non-disabled people, disabled people had lower levels of employment; were less likely to hold formal educational qualifications; were more likely to experience discrimination; were more likely to feel lonely; were less likely to participate in popular leisure activities such as visiting friends, going to cafés and going on holiday; were less likely to be satisfied with their lives. See Statistics New Zealand, 2014b in The New Zealand Productivity Commission (2015).

the Rights of Persons with Disabilities (UNCRPD), wider acceptance of the social model of disability.

EGL is a principles-based approach to supporting disabled people

In September 2012 the Ministerial Committee on Disability Issues agreed to a long-term direction for change based on the Enabling Good Lives approach[14]. The vision for this approach is that disabled people and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports[15] in their communities.

Underpinning the EGL approach is a set of principles which Ministers agreed would guide the transformation of the disability support system. There are eight principles based on what is needed to improve the quality of life of disabled people. These are:

- *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
- *person-centred:* disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach
- *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:* relationships between disabled people, their whānau and their community are built and strengthened.

On 12 July 2013 Cabinet agreed to a three-year demonstration of the EGL approach in Christchurch in 2014 (CAB Min (13) 24/6 refers). The purpose of the Demonstration was to provide a group of disabled people with greater choice and control over their supports and lives, and to gather information about how the EGL approach works and how it might be possible to implement changes across the whole of the disability support system.

---

[14] See Ministerial Committee agreement to vision and principles for long-term change – September 2012 http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012/

[15] The term natural support is not always clearly defined or understood. 'Natural supports' often refers to the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections, but, over time, these connections can help an individual build a strong community network and support system that enhance their quality, and security, of life.

Implementation began during November 2013. The Demonstration ran until 30 June 2016 and was jointly supported by the Ministries of Health, Social Development and Education, with involvement from ACC.

EGL built on work already undertaken by the Government to give disabled people greater choice and control. For example:

- through the Ministry of Health disabled people can take up Individualised Funding
- Disability Support Services (DSS) at the Ministry of Health developed the New Model in consultation with disabled people, their families, providers and the wider disability sector. The New Model components give disabled people more flexible funding over some supports, information and support for disabled people to build networks in their communities. DSS piloted parts of the New Model in the Bay of Plenty but is now also demonstrating components of it in other areas eg Waikato, Auckland, Lakes, Hutt Valley and Otago/Southland regions
- Choices in Community Living is an alternative to residential services for people with significant disabilities[16]. It offers more choice and control over where they live, who they live with and how they are supported. It is part of the New Model demonstration and is available in Auckland, Waikato, the Hutt Valley and Otago/Southland.

EGL theory of change and components

The theory of change is that enabling disabled people to have more choice and control over their supports and services to live the life they want will improve their quality of life. The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design, planning and navigation, individualised flexible funding, provider and school development, and community development. How the mechanisms come together to bring about change for disabled people is outlined in an intervention logic developed as part of the evaluation (Figure 1).

The mechanisms (EGL components) are outlined in more detail below.

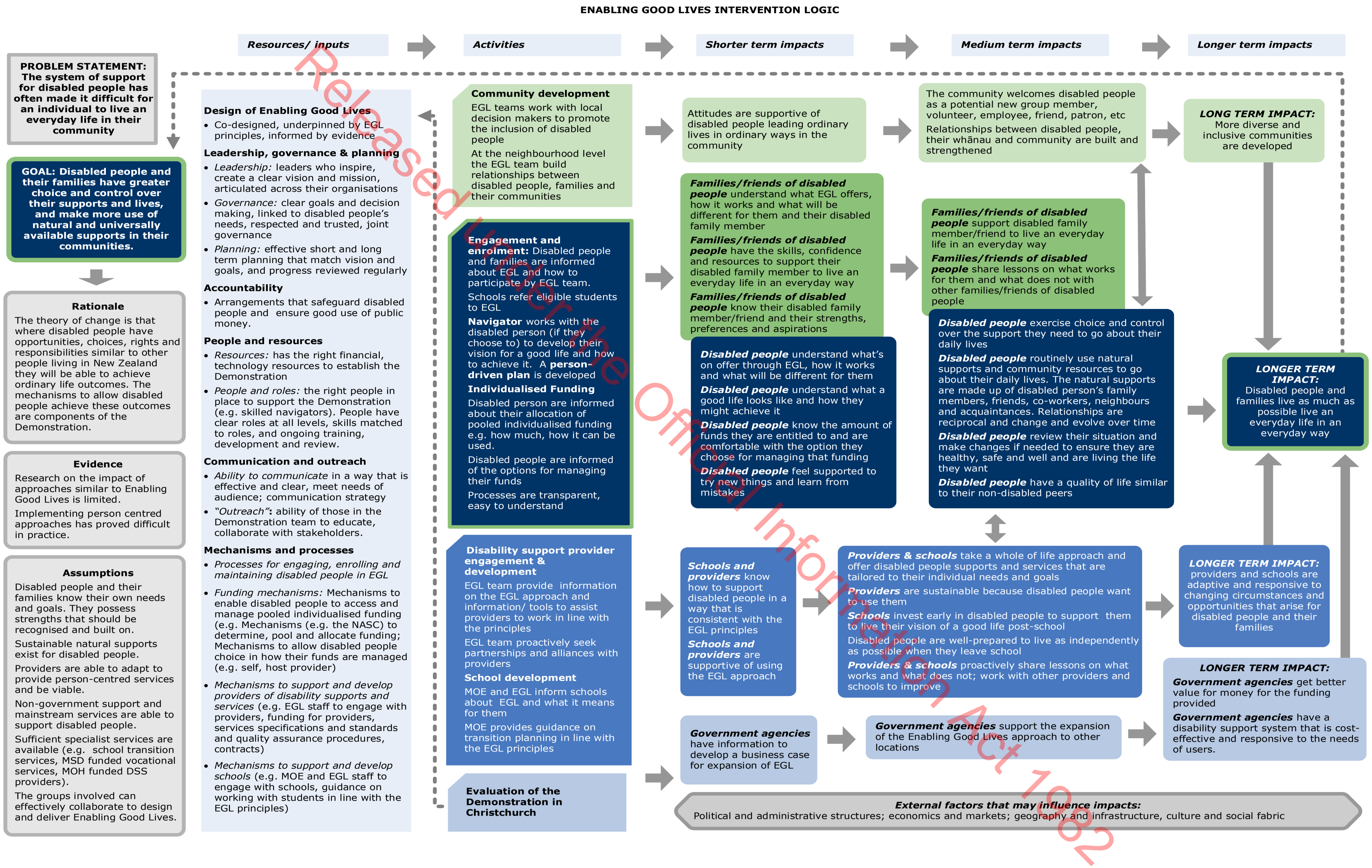
Co-design

A key feature of the Demonstration is the involvement of disabled people, families and providers in co-designing the changes and their cross-agency boundaries. While there is not an agreed definition of co-design internationally, it usually involves using collaborative relationships between public service professionals and citizens or users in the design process. Boyle and Harris (2009) believe these relationships need to demonstrate equality and reciprocity. There is also a focus on delivery of outcomes rather than just the service (OECD, 2011).

---

[16] See http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/new-model-supporting-disabled-people/choice-community-living

Figure 1. EGL intervention logic



ENABLING GOOD LIVES INTERVENTION LOGIC

Resources/ inputs → *Activities* → *Shorter term impacts* → *Medium term impacts* → *Longer term impacts*

PROBLEM STATEMENT: The system of support for disabled people has often made it difficult for an individual to live an everyday life in their community

GOAL: Disabled people and their families have greater choice and control over their supports and lives, and make more use of natural and universally available supports in their communities.

Rationale

The theory of change is that where disabled people have opportunities, choices, rights and responsibilities similar to other people living in New Zealand they will be able to achieve ordinary life outcomes. The mechanisms to allow disabled people achieve these outcomes are components of the Demonstration.

Evidence

Research on the impact of approaches similar to Enabling Good Lives is limited.

Implementing person centred approaches has proved difficult in practice.

Assumptions

Disabled people and their families know their own needs and goals. They possess strengths that should be recognised and built on.

Sustainable natural supports exist for disabled people.

Providers are able to adapt to provide person-centred services and be viable.

Non-government support and mainstream services are able to support disabled people.

Sufficient specialist services are available (e.g. school transition services, MSD funded vocational services, MOH funded DSS providers).

The groups involved can effectively collaborate to design and deliver Enabling Good Lives.

Design of Enabling Good Lives

- Co-designed, underpinned by EGL principles, informed by evidence

Leadership, governance & planning

- *Leadership:* leaders who inspire, create a clear vision and mission, articulated across their organisations
- *Governance:* clear goals and decision making, linked to disabled people's needs, respected and trusted, joint governance
- *Planning:* effective short and long term planning that match vision and goals, and progress reviewed regularly

Accountability

- Arrangements that safeguard disabled people and ensure good use of public money.

People and resources

- *Resources:* has the right financial, technology resources to establish the Demonstration
- *People and roles:* the right people in place to support the Demonstration (e.g. skilled navigators). People have clear roles at all levels, skills matched to roles, and ongoing training, development and review.

Communication and outreach

- *Ability to communicate* in a way that is effective and clear, meet needs of audience; communication strategy
- *"Outreach"*: ability of those in the Demonstration team to educate, collaborate with stakeholders.

Mechanisms and processes

- *Processes for engaging, enrolling and maintaining disabled people in EGL*
- *Funding mechanisms:* Mechanisms to enable disabled people to access and manage pooled individualised funding (e.g. Mechanisms (e.g. the NASC) to determine, pool and allocate funding; Mechanisms to allow disabled people choice in how their funds are managed (e.g. self, host provider)
- *Mechanisms to support and develop providers of disability supports and services* (e.g. EGL staff to engage with providers, funding for providers, services specifications and standards and quality assurance procedures, contracts)
- *Mechanisms to support and develop schools* (e.g. MOE and EGL staff to engage with schools, guidance on working with students in line with the EGL principles)

Community development

EGL teams work with local decision makers to promote the inclusion of disabled people

At the neighbourhood level the EGL team build relationships between disabled people, families and their communities

Engagement and enrolment: Disabled people and families are informed about EGL and how to participate by EGL team.

Schools refer eligible students to EGL

Navigator works with the disabled person (if they choose to) to develop their vision for a good life and how to achieve it. A **person-driven plan** is developed

Individualised Funding

Disabled person are informed about their allocation of pooled individualised funding e.g. how much, how it can be used.

Disabled people are informed of the options for managing their funds

Processes are transparent, easy to understand

Disability support provider engagement & development

EGL team provide information on the EGL approach and information/ tools to assist providers to work in line with the principles

EGL team proactively seek partnerships and alliances with providers

School development

MOE and EGL inform schools about EGL and what it means for them

MOE provides guidance on transition planning in line with the EGL principles

Evaluation of the Demonstration in Christchurch

Attitudes are supportive of disabled people leading ordinary lives in ordinary ways in the community

Families/friends of disabled people understand what EGL offers, how it works and what will be different for them and their disabled family member

Families/friends of disabled people have the skills, confidence and resources to support their disabled family member to live an everyday life in an everyday way

Families/friends of disabled people know their disabled family member/friend and their strengths, preferences and aspirations

Disabled people understand what's on offer through EGL, how it works and what will be different for them

Disabled people understand what a good life looks like and how they might achieve it

Disabled people know the amount of funds they are entitled to and are comfortable with the option they choose for managing that funding

Disabled people feel supported to try new things and learn from mistakes

Schools and providers know how to support disabled people in a way that is consistent with the EGL principles

Schools and providers are supportive of using the EGL approach

Government agencies have information to develop a business case for expansion of EGL

The community welcomes disabled people as a potential new group member, volunteer, employee, friend, patron, etc

Relationships between disabled people, their whānau and community are built and strengthened

Families/friends of disabled people support disabled family member/friend to live an everyday life in an everyday way

Families/friends of disabled people share lessons on what works for them and what does not with other families/friends of disabled people

Disabled people exercise choice and control over the support they need to go about their daily lives

Disabled people routinely use natural supports and community resources to go about their daily lives. The natural supports are made up of disabled person's family members, friends, co-workers, neighbours and acquaintances. Relationships are reciprocal and change and evolve over time

Disabled people review their situation and make changes if needed to ensure they are healthy, safe and well and are living the life they want

Disabled people have a quality of life similar to their non-disabled peers

Providers & schools take a whole of life approach and offer disabled people supports and services that are tailored to their individual needs and goals

Providers are sustainable because disabled people want to use them

Schools invest early in disabled people to support them to live their vision of a good life post-school

Disabled people are well-prepared to live as independently as possible when they leave school

Providers & schools proactively share lessons on what works and what does not; work with other providers and schools to improve

Government agencies support the expansion of the Enabling Good Lives approach to other locations

LONG TERM IMPACT: More diverse and inclusive communities are developed

LONGER TERM IMPACT: Disabled people and families live as much as possible live an everyday life in an everyday way

LONGER TERM IMPACT: providers and schools are adaptive and responsive to changing circumstances and opportunities that arise for disabled people and their families

LONGER TERM IMPACT:
Government agencies get better value for money for the funding provided
Government agencies have a disability support system that is cost-effective and responsive to the needs of users.

External factors that may influence impacts:
Political and administrative structures; economics and markets; geography and infrastructure, culture and social fabric

Individualised and flexible funding for disabled people

Funding that disabled people are eligible for from different agencies (eg the Ministries of Health, Education and Social Development) is pooled into an EGL personal budget. A disabled person's EGL personal budget can include relevant funding[17] from the:

- Ministry of Health: This includes funding as allocated by the local Needs Assessment and Service Coordination (NASC) organisation, which includes all disability support services such as residential care, home and community support, supported living, respite care and carer support – this funding may be used to purchase support from contracted providers, or can be accessed through an Individualised Funding arrangement
- Ministry of Social Development: This includes Participation and Inclusion funding, which covers specialist employment and community participation services and very high needs funding. There has been no change in the total amount of funding available
- Ministry of Education Ongoing Resourcing Scheme (ORS)[18] funding for students with high and very high needs[19], and flexible use of specialist support. Most ORS-funded students receive high needs funding[20]. ORS-funded students can remain at school until they are 21, but lose their funding if they leave earlier. The Demonstration made ORS funding available if a young person decided to leave school at 18. This funding was available to support them in their next step to create a foundation for their future life. Students were still able to choose to stay at school until 21 and would join the Demonstration once they left. There was no change in the total amount of funding available
- Transition Funding from the Ministry of Education: This was $2,150 and could only be accessed in their final year of school or if not accessed in this year it could be accessed in the following year.

Disabled people can choose how that funding is used to support them to achieve their vision of a good life. There are guidelines on the use of the funding for participants to follow. Currently, disabled people receiving funding under EGL need to use a host provider to manage their funding. However, the intention is that, over time, disabled people will have a choice about how their funding is managed (eg self-managed; partly self-managed; or managed by a third party, such as a host provider).

---

[17] This includes funding specifically targeted to the purchase of disability supports. Payments such as the Supported Living Payment administered through Work and Income have been excluded as they are classified as income.

[18] ORS provides funding for supports such as teacher time, teacher aides and specialists to help students whose disability is a barrier to their accessing the curriculum, whether because of hearing loss, visual impairment, difficulties with mobility, learning, or language use and social communication.

[19] In 2015 the funding rates were $18,209 for students with very high needs and $10,561 for students with high needs.

[20] As at 1 July 2015, 71% of ORS-funded students in the Christchurch City area received HN funding and 29% received VHN funding. Source: Indicators & Reporting Team, Ministry of Education (see https://www.educationcounts.govt.nz/statistics/special-education/ongoing-resourcing-scheme).

Planning and navigation with disabled people

Navigation is the process by which participants identify and record what a good life looks like for them, and how they can achieve it. It includes the disabled person's journey along their self-directed pathway (with support from natural and/or paid supports as and when the participant chooses). Participants can choose to undertake navigation with an EGL navigator, or with other people including wider family and friends, or with appropriate support they can choose to do it themselves.

It is intended that navigators work as allies of disabled people and supporting them to make their own decisions with all the resources and information required. Navigators are to facilitate the use of what is available in the community (eg mainstream services) and natural supports to assist disabled people to live the lives they want. 'Natural supports' were seen as the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports were seen as encompassing family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections, but, over time, these connections can help an individual build a strong community network and support system that enhance their quality, and security, of life.

Participants have access to an average of 25 hours navigator time for planning, and any ongoing support, recognising that some participants will be very clear and not need much and others may need more. The output of navigation process is the development of a plan of action for the participant.

The intention the participant and family will exit the process when they identify that their good life plan is in place and there is sufficient support and momentum for them to achieve their dreams and goals.

Individual and family capacity building

The Demonstration was to undertake initiatives that would build the capacity of disabled people and their families to help them to engage in planning and make use of the individualised, flexible funding.

Provider development and working with schools

Providers and schools have a role in supporting disabled people to achieve their vision of a good life by operating in line with the EGL principles. Giving disabled people choice and control over their funding is a mechanism to change provider practice. The expectation was that disabled people would choose personalised[21] supports and services in the community over traditional disability supports and services. This would encourage providers to adapt and offer supports and services tailored to individuals' preferences and situations. The Demonstration intended to influence schools and providers by engaging with them about the EGL approach. It was anticipated that schools and providers already operating in line with the principles would also share their knowledge and experience with other schools and providers.

---

[21] Personalisation is about enabling people to lead the lives that they choose and achieve the outcomes they want in ways that best suit them.

Community development to promote the inclusion of disabled people

Communities also have a role in supporting disabled people to achieve their vision of a good life. A key element of bringing about change for disabled people and their families is investing to build inclusive communities: to ensure communities, including businesses, workplaces, schools, and cultural, sport and recreational activities, are accessible and welcoming and recognise the contribution of disabled people[22].

The expectation is that as disabled people engage in everyday activities in everyday ways (eg going to work, doing mainstream leisure activities) the community will become more inclusive. The EGL team will support communities to become more inclusive of disabled people by working with local decision-makers to promote the inclusion of disabled people. At the neighbourhood level, the EGL team will help build relationships between disabled people, their families and their communities.

There are several assumptions underpinning this theory of change

The assumptions are that:

- increasing disabled people's choice and control over their lives will lead to improved quality of life. Research assessing the impact[23] of approaches similar to Enabling Good Lives is limited. However, reviews of international evidence suggest that community-based service models generally achieve better results for the people they serve than institutions (Mansell & Beadle-Brown, 2010). Evidence from multiple sources and from multiple countries (Australia, the UK, the US, the Netherlands, New Zealand) suggests that having a personal budget improves disabled people's quality of life, sense of empowerment, self-determination, and levels of choice and control. Indications are a personal budget also improves the quality of life of families, and changes the aspirations about what disabled people can achieve and how they can live their lives (Arksey & Baxter, 2012; Caldwell & Heller, 2007; Field et al., 2015; Fisher et al., 2010; Forder et al., 2012)
- disabled people and their families know their own needs and goals. They possess strengths that should be recognised and built on
- people understand what natural supports[24] are and that sustainable natural supports exist for disabled people in the Christchurch area
- schools and disability support providers will have or will adopt the beliefs and values that underpin an EGL approach and will be willing to ensure that these guide their organisation's relationship with disabled people
- non-government support and mainstream services are able to viably support disabled people

---

[22] Refer to http://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/

[23] For example, research using experimental or quasi experimental approaches to determine the difference the intervention made to outcomes.

[24] As mentioned earlier, the term is not always well understood. There is an implicit or explicit assumption in most understandings of natural supports that they are distinct from formal supports (ie support provided by paid workers). However, some authors suggest the distinction between natural supports and formal supports may be blurring (NDA, 2011; Newman et al., 2008).

- sufficient specialist services are available (eg school transition services, vocational services funded by Ministry of Social Development (MSD), disability support service providers funded by Ministry of Health (MOH))
- the groups involved in the Demonstration can effectively collaborate to design and deliver Enabling Good Lives
- resources will be in place to support an EGL approach. Considerable resources currently exist within the sector to support the change to an EGL approach
- the boundaries of the system are understood or can be understood. However, there is no clear definition for the term systems change. As Kendrick et al. (2006) state, human service and community systems usually are not single, unified entities. They are typically made up of many interconnected systems and sub-systems and include formal and informal elements. These elements (groups, organisations, families, individuals) are not always directly connected to one another.

The Demonstration focused primarily on school leavers

The Demonstration primarily focused on school leavers defined as those aged 18 to 21 years old with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education's ORS.

There was flexibility to allow some disabled people who did not meet the edibility criteria to opt into the Demonstration. This meant that in the first year the new elements of the system would be offered to all high and very high needs school leavers receiving ORS funding who were aged between 18 and 21 years in Christchurch City (approximately 40 to 50 people). Up to 10 further people who access disability supports in or near Christchurch would be allowed to opt in at the discretion of the Director. Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support, recognising that some participants will be very clear about what they want and not need much support and others may need more. The intention was that this would be tightly managed, but would still permit some flexibility in boundaries, and in the age and support needs of participants.

Initially the number and type of people involved in the Demonstration were expected to expand each year. The intention was to demonstrate EGL at different ages and stages of people's lives. However the expansion did not happen. To support the focus on system development work, the participant group for the Demonstration was limited to high and very high needs school leavers after the first year.

Leadership of the Demonstration

Several groups and individuals were involved in leading the Demonstration (Figure 2).

At a local level these included the:

- *Demonstration Director:* The Director was appointed to lead the implementation of the Demonstration in Christchurch. The intention was that the Director would be supported and advised by the Ministries and the Local Advisory Group. At the time of the evaluation the Director was also supported by the EGL team, which included a Manager of Families and Community Development, a Manager of Provider Relationships and Personalised Funding and a Demonstration Co-ordinator. This person was a key point of contact for disabled people, their families, providers and the wider EGL team during the Demonstration.

- *Local Advisory Group (LAG):* The LAG had a leadership role in that it represented disabled people, their families and providers in the development of the Demonstration. It was also intended to act as a vehicle for providing their networks with information on the Demonstration. The LAG included people who had personal experience of using flexible Individualised Funding and others who had been involved in bringing about changes towards more self-directed services for disabled people. Some also brought to the table an in-depth understanding of special education and the challenges facing youth and their families. Their experience encompassed a wide cross-section of disability and support organisations. The composition of the group has changed over the course of the Demonstration. Members included CCS Disability Action, Disabled Persons Assembly, SkillWise, the New Zealand Federation of Vocational and Support Services, Manawanui InCharge (MIC)[25], and the Canterbury branch of the Association of Blind Citizens of New Zealand Incorporated.

At a national level these included the:

- *Joint Agency Group (JAG) and the Ministerial Committee:* A Joint Agency Group of senior managers[26] from the Ministries of Health, Education and Social Development and ACC oversee the Demonstrations in Christchurch and the Waikato. The Director reported to the JAG. There was deliberately no single agency appointed as lead. Joint agency ownership was seen as more likely than a single lead agency to create the co-ordination and cooperation between government agencies that is necessary for an integrated and flexible disability support system.

  The JAG was responsible for achieving the Demonstration outcomes and making joint decisions that are within the agencies' delegated authority. This group reported to the Ministerial Committee on Disability Issues, and was advised by the National EGL Leadership Group. The Ministerial Committee on Disability Issues provides high-level ministerial oversight of the overall EGL work programme

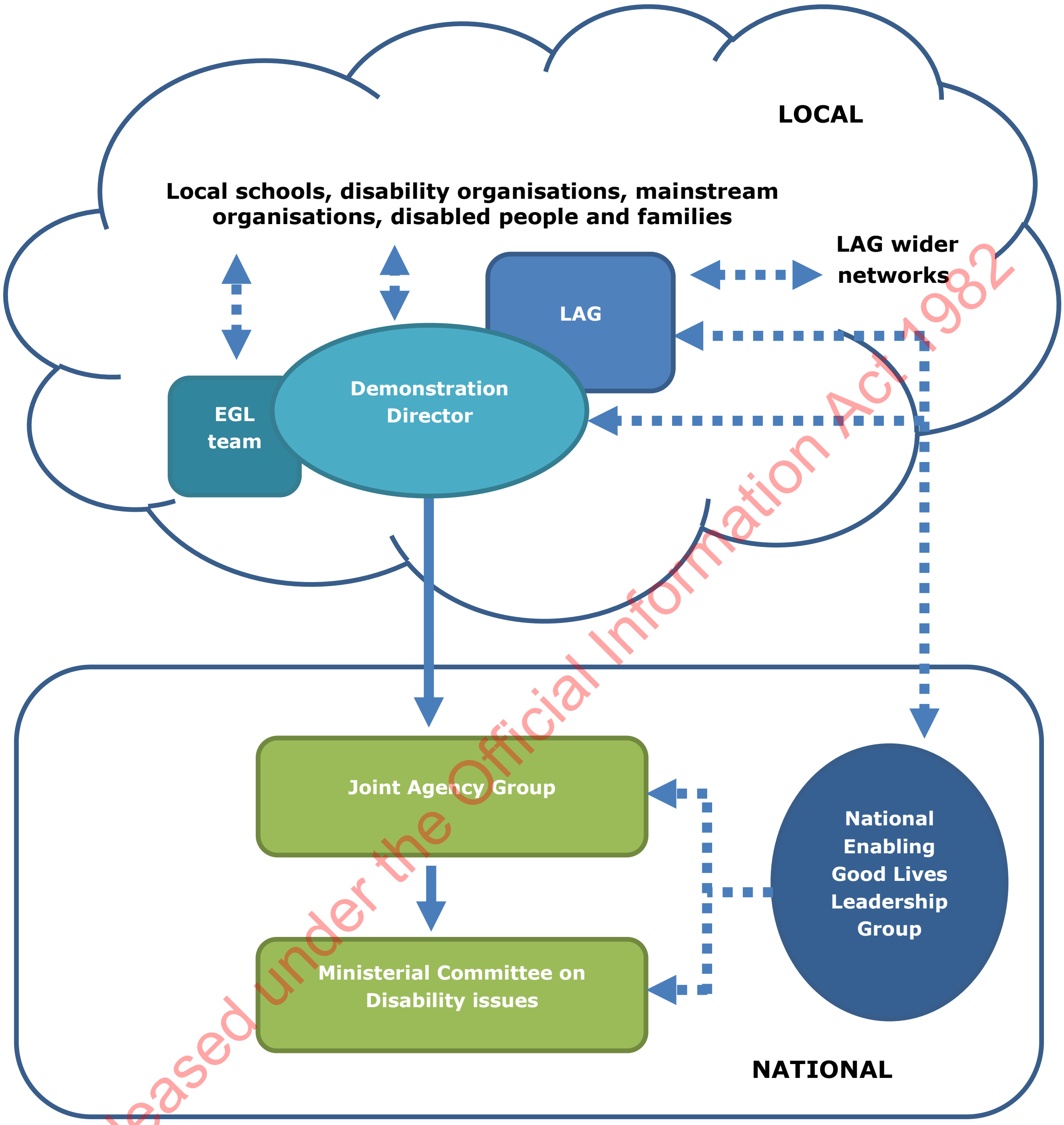
- *EGL Leadership Group:* The EGL Leadership Group is a national group that is responsible for promoting and protecting the overall vision and principles of Enabling Good Lives and for advising Ministers and senior officials. At least half the members are disabled people, and the group includes disability sector leaders and Māori and Pacific members.

---

[25] Manawanui is a company specialising in facilitating Individualised Funding and other self-directed services (see http://www.incharge.org.nz/interested-in-using-individualised-funding/what-we-do/)

[26] Deputy Chief Executives/Group Managers and General Managers.

Figure 2. Leadership and the Christchurch Demonstration



3. A mix of methods was used

Evaluation objectives and research questions

The evaluation objectives are outlined below.

- Objective 1: to understand what outcomes are being achieved by those participating in EGL and what contribution EGL has made to those outcomes
- Objective 2: to understand what constitutes a good life for disabled people involved in the Demonstration and how this understanding evolves over time
- Objective 3: to understand what is being implemented to enable disabled people to have good lives and how EGL is operating in practice
- Objective 4: to understand how schools, providers of disability support services and government agencies have positioned themselves to support disabled people to live a good life
- Objective 5: to examine what supports the success of the Demonstration as an approach to enable disabled people to have good lives, and what does not, and identify any lessons that could inform the scaling-up of the EGL approach.

The research questions for each evaluation objective are outlined Appendix 1.

The evaluation used a mixed method design

The evaluation used a mixed method approach similar to phase 1[27] but with some additions. As the phase 1 evaluation took place shortly after implementation began there was limited opportunity to look at outcomes for participants. Phase 2 was more focused on outcomes.

The methods used included:

- 10 case studies of disabled people in different contexts. The unit of analysis ('the case') is: *The young disabled person engaged in EGL who has recently left school or is planning to.* Here the focus is on the individual disabled person's journey towards building a life outside of school. There were three types of cases:
    - Case type 1: Limited change since being able to engage with EGL. While living circumstances were not a section variable in all these cases the young people were in residential care.
    - Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
    - Case type 3: Movement towards living a life in line with the EGL principles (opt-in)

---

[27] The focus of this initial evaluation, conducted in February 2014, was to understand how the Demonstration was being implemented and working towards supporting disabled people to have a good life. The evaluation involved 25 semi-structured interviews and one group interview with a broad cross section of people involved in the design and implementation of the Demonstration in Christchurch along with four disabled people and four parents from three families. In addition, descriptive data on the number and types of participants was included in the evaluation where it was available. The evaluation found that there have been some early positive outcomes from the EGL Demonstration, despite a problematic implementation.

- a quality of life survey of 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). The response rate was 34%.
- in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers, a representative from MIC, the LAG as a group, the EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
- analysis of existing administrative data to describe trends and patterns in the use of navigators, Individualised Funding, self-management of funding and supports and services
- analysis of documents on the Demonstration.

Methods were selected based on their capacity to answer evaluation objectives and research questions. The methods were applied concurrently but separately. This means the researchers implemented both the quantitative and qualitative strands during a single phase of the research study.

The rationale for using a mixed method design is as follows:

- Triangulation of findings allows them to be corroborated.
- Weaknesses in each method will be offset.
- Using a mix of methods allows for the development of a more complete picture.
- This approach is suitable in a context where the environment is very dynamic and pathways to change cannot be predetermined.

See Appendix 2: Evaluation methodology for further discussion of the rationale for the approach.

Limitations of the evaluation

The evaluation has the following limitations:

- *The observation period for the evaluation was too short for all outcomes to be fully achieved within it.* This may be particularly the case for the high-level outcomes of promoting wellbeing, participation and community connection. In some instances change may be too slow to be clearly observed and measured within the timeframe of the evaluation, especially when this timeframe is short (see Appendix 2, Quality of life survey).
- *A comparison group could not be established:* The absence of a comparison group limits conclusions about the extent findings reflect all disabled young people and their families. It was not possible to randomly assign people to participate in the Demonstration. There was a plan to compare quality of life outcomes for participants with a group who had not participated in the Demonstration. However, it was not possible to gather enough responses from a comparison group to include them in the analysis.
- *The quality of life survey response rate was low (34%).* The numbers of participants and proxies were small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth.

- *There were differences across several indicators between participants and proxies*[28]*, highlighting challenges in combining participant and proxy responses*. Proxies recorded responses on behalf of some participants. While having participants record their responses themselves is preferable, use of proxies is an appropriate way to include participants who are not able to do so. It is however important to note that while proxy responses have been found to be generally consistent with what people would record themselves, there can be differences, especially where the proxies are staff. For example, Claes et al. (2012) found no significant differences between self-reported responses and family member proxies, but did identify differences between self-reported responses and staff member proxies. The researchers conclude that quality of life scores obtained from self-reports are not the same as those obtained from family members or direct support staff. The differences are not necessarily indicative of bias or invalidity but reflect different perspectives.

  In this evaluation the proxies were all family members. The responses of participants and proxies sometimes differed and this was likely to be due to either different perspectives of proxies and participants or to systematic differences in the circumstances of those who could respond for themselves and those who needed a proxy to respond for them. While the reporting of results from the survey generally combines responses of participants and proxies, these are reported separately where they are significantly different.

- *Measuring quality of life is challenging.* There have been advances in the measurement of quality of life but there are still challenges. For example, there is broad agreement that an accurate quality of life assessment requires a combination of subjective well-being and social indicators approaches. However there is debate over the relative importance of objective versus subjective factors in determining quality of life, and about the relationship between the two. There are difficulties measuring quality of life for those with significant intellectual disabilities. Quality of life indicators can be realised in multiple ways. An individual's perception of their quality of life can be heavily influenced by one or a few aspects of their life which may or may not be amenable to change. People may report a high quality of life even where their circumstances are less desirable. This can because they do not know any different (Brown et al. 2013). Measuring changes in quality of life over time is challenging (Verdugo et al., 2015). The degree of change depends on the programme and approach to quality enhancement. The stability of quality of life scores is interactive, and is dependent on both personal characteristics and environmental factors (see Appendix 2: Evaluation methodology for further information on the quality of life survey).

- *The administrative systems captured little data on the quality of disabled people's experience of Enabling Good Lives.* The quality of life survey sought to address this but as mentioned above there were some limitations with this. The way in which administrative data were captured made it very difficult to examine what use participants had made of their funding and whether or not they were spending more or less than before the Demonstration.

---

[28] This difference was also reported by the *include Me*! team, who collected responses from two proxies and averaged them. This approach was not practical for the EGL evaluation as proxies were commonly parents.

- *The views expressed by schools and providers interviewed may not be representative of all schools and providers who had people participating in the Demonstration.* The evaluation team endeavoured to select a range of providers and schools and undertook in-depth interviews with five providers and three schools. All the schools and providers the team invited to participate in the evaluation accepted.

4. Design and implementation could have been improved

Summary

There was some improvement from the first evaluation but key components were not able to be implemented:

- Disabled people needed a wider range of funding options for managing their funding. Few options were available to disabled people to manage their funding. Additional options for managing the funding would have been useful for disabled people and their families.
- Assumptions about the role natural supports can play in supporting disabled people may be unrealistic.
- The community development component of the Demonstration was underdeveloped. It was unclear how community development was supposed to happen under EGL. The community development component received little attention in terms of design and resourcing.
- There was underinvestment in provider and school development to assist them to operate in line with the EGL principles.
- Accountability arrangements could be improved.

Improving inputs could have improved implementation:

- A more fully developed design was needed. Development of a detailed design was hindered by several factors.
- Understanding of and buy-in to the EGL vision across stakeholders needed to improve.
- Leadership could have better supported implementation.
- There were wider problems with the system which likely limited implementation and performance.

There was some improvement from the first evaluation, but key components were not implemented

For the Demonstration to be well placed to achieve the intended outcomes, the core components needed to be in place and operating as intended. The first evaluation found each of the agencies and the Local Advisory Group had a commitment to making the Demonstration happen. Those involved in implementing the Demonstration worked hard to put something in place by November 2013. Nevertheless key components of the Demonstration were not in place:

- The mechanism for pooling funding for individuals was not fully developed.
- The navigators were still being hired and the role of the navigator was still evolving.

- Work remained to be done on how providers would be paid and how they would be assisted to operate in line with the principles.
- Accountability mechanisms had not been developed and it was unclear how disabled people would be safeguarded.
- It was unclear what community development meant in the context of EGL as this work had not been done.
- The mechanisms for bringing about change in government systems were unclear.

There has been some improvement since the first evaluation. What was designed and ready to be implemented was implemented:

- There was a mechanism for pooling funding for individuals.
- The navigators were in place and their role was clearer according to the navigators, EGL team members, providers and schools interviewed.
- Systems were in place to pay providers.

However, key elements of the Demonstration were not designed at all, or not designed until late in the Demonstration. This influenced what was implemented and when.

A wider range of funding options for managing the funding was needed

Few options were available to disabled people to manage their funding

International evidence on personal budgeting models suggests that there is no 'one size fits all' approach and that disabled people, and their families, need a continuum of options – from self-management to contracting an agent or an organisation to manage the budget – to support them to manage their personal budget (Carter Anand et al., 2012; Forder et al., 2012; Glendinning et al., 2008). However, at the time of the evaluation, disabled people and their families had very few options for managing their funding allocation.

Everyone who received pooled funding had to go through MIC, who acted as the host provider. Unlike in the EGL Waikato Demonstration, there was no choice of host provider. Disabled people and families in the Christchurch Demonstration could then choose to:

- *self-manage with assistance from MIC:* Disabled people and their families could contract and employ individuals or organisations to provide supports or services (eg similar to employing a plumber). Disabled people and/or their families needed to invoice MIC for the number of hours they were using at the agreed rate. They then claimed the money from MIC to pay the individual or organisation. If they contracted someone, the contractor took care of their own tax and ACC; this was similar to Individualised Funding
- *use MIC's payroll system:* Disabled people and/or their families set this up with MIC, who paid the employees directly and sent the pay slip to the families because they were the employer. MIC took care of KiwiSaver, ACC levies (accrued out of their funding), holiday pay and payroll contingencies

- *use MIC to pay providers:* When the Demonstration began, people who were self-managing through a hosting mechanism (eg using MIC) were unable to access the GST inclusive portion of their EGL personal budget[29]. A workaround was put in place whereby the host was commissioned to purchase some supports on behalf of people. Families who wanted to carry on using providers as they had before the Demonstration and not manage the funding could enter into a third party payment (TPP) agreement between the agency, MIC and the disabled person. It enabled the family to deal directly with MIC, who also managed GST and paid providers. TPPs also meant that providers could be paid on time.

MIC reported that in October 2015 most people on EGL were using payroll through MIC, about 25 people had TPPs with service providers, and some people had a mix of some contracting and some payroll.

Additional options for managing the funding would have been useful for disabled people and their families

Direct payments were not available to disabled people in the Christchurch Demonstration

Direct funding for disability supports is not widely available in New Zealand but could suit some people. Direct payments (either cash payments or a nominal budget) involve the funds being given directly to the person with a disability, who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations. Direct funding can be used by disabled people to purchase services and supports of their choice to assist them with personal care, household chores, accommodation options, and getting around. In the UK, the US, Canada and Australia, direct funding approaches have been used. Fisher et al. (2010) indicate that direct funding is not for everyone and where it is available most people choose support organised through providers or financial facilitators rather than direct payments.

Proposed flexible disability support contracts could provide another option for managing the funding but there are some risks to manage

Flexible disability support contracts were due to be implemented at the time of the evaluation. It was anticipated that this option would make the management of the funding less onerous for families by allowing providers to take on the administrative burden of managing pooled funding. An EGL team member described the contracts as a game changer. He said:

> *Once we get that across the line that will be huge because it will allow providers to go into negotiations with people and say what would you like us to do for you – what do you need?*

He argued that the intention was that providers would design packages to meet the needs of disabled people. Examples could include using residential care funding to help people go flatting. There were also opportunities to be more creative in the provision of respite care. For example, a provider could use flexible contracts to offer respite care

---

[29] Initially the only way people could get their funding was directly through MIC. MIC charged disabled people GST even where not changing their arrangements with providers. As one EGL team member interviewed reported, participants were 15% worse off because of EGL. In the first year, the Ministry of Health added the GST onto the budgets of the 15 to 16 people affected.

that worked for families. The provider could potentially provide a carer to go on holiday with the disabled person or the parents could go away and the carer could provide the support in the home. This was reported to be difficult to achieve under existing contracts.

However, some concern was also expressed that there is a risk of provider capture if providers have access to disabled people's funding. A representative from MIC reported that some providers appeared very keen to sign the forms and seemed overly enthusiastic about spending the money. She felt uneasy about whose needs were driving the request. She said, *"It's just a gut feeling about what concerns me."* To manage the risk, MIC reported there needs to be ongoing communication with providers to reinforce the message that the contracts are all about what families want – not doing what is easy for the provider.

The EGL team was aware of this concern and the Demonstration required providers who wanted to provide flexible disability support contracts to engage in an organisational review process focused on the extent to which they were aligned with the EGL principles. However, an EGL team member acknowledged that changing mind-sets takes time and that there needed to be ongoing support that enabled disabled people to get the most out of flexible support funding. If there were problems between the disabled person and the provider, the funders of the flexible disability support contracts could step in and help resolve them.

Some people need agents but these are not always easy to find, leaving these people unable to take up the funding

People without the skills and abilities to manage the funding themselves need an agent to manage their funding. This role is typically filled by a family member. However, family members were not always in a position to take on the role for a variety of reasons (eg ill-health, substance use problems, relationship breakdown, poor financial skills). Where a family member cannot take on the agent role, it can be difficult for people to find a suitable agent. Members of the EGL team interviewed reported that few people wanted to take on the responsibilities associated with being an agent. Without an agent, disabled people cannot take up the pooled funding.

An EGL team member cited an example of a young person who ran away from home when they were setting up her personal budget. The foster mother withdrew from being the young person's agent. While the young person is now in Supported Independent Living (separately as external to the Enabling Good Lives budget), they do not have access to their very high needs ORS funding ($15,600) because they cannot be responsible for managing it. The EGL team member reported that the person could get access to it if they went to a day service as the provider could manage the funding, but that limits options. The EGL team member reported that not having an agent will become more of a problem as people age and their parents can no longer fill the role of agent.

One option could include paying people to be agents. Members of the EGL team interviewed suggested one option may be paying non-family members to be agents as an incentive for them to take up the role and to recognise the scale of the task they are taking on.

Assumptions the development of natural supports may be unrealistic

The use of natural supports was a key feature of the design. While the term 'natural support' is not always clearly defined or understood, it is often seen as encompassing the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. To this end, natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. Natural supports are based on personal ties rather than payment (Duggan & Linehan, 2013).

In the Demonstration there was an assumption that people may need help in developing these connections but that these connections could help an individual build a strong community network and support system that would enhance their quality, and security, of life. The implication was that the natural supports could be developed relatively quickly (eg within the timescale of the Demonstration). Moreover there was a view that disabled people could use natural supports instead of services.

The evaluation found that this assumption may be unrealistic.

- All the schools and several providers questioned the availability and sustainability of natural supports. Even those interviewed who were supportive of the idea of using natural supports reported that growing natural supports takes time and requires the right staff to facilitate their development (see Lack of support for the concept of natural supports, page 108, and Valuing natural supports, page 118).
- Families interviewed typically had no significant natural supports outside of family and where they did exist they appeared fragile. A common theme across the cases was high levels of parental stress and poor physical and/or mental health – especially amongst the mothers. This suggests that existing natural supports may already be stretched (see Few families had significant natural supports outside of family, page 94).

Further understanding is required about how natural supports can be developed and sustained and how they can be used alongside responsive formal supports and services.

Community development component was underdeveloped

It was unclear how community development was supposed to happen under EGL

It was unclear what the mechanism for change in the community was and what success would look like from whose perspective. In developing the intervention logic for Enabling Good Lives, it appeared that disabled people would be the main driver for changing attitudes, and experiences of people in the community and of community building would occur one person at a time. That is, as more disabled people participated in all aspects of 'mainstream' life, the general population would become more informed and less likely to hold negative stereotypes. The assumption was that positive attitudes would continue to grow as long as the presence of disabled people continued to increase and to expand in every area of life, thereby contributing to the development of more inclusive communities. EGL would facilitate this process by using a person-centred approach focusing on the use of mainstream services and community resources for assistance and not limiting assistance to what was available within specialist services.

There is some evidence that positive attitudes follow on from increased social contact between disabled and non-disabled people in the community (Abbott & McConkey, 2006). However, Hannon (2010) argues that attitudes to disability are complex and multifaceted and the attitudinal consequences of contact with disabled people are mediated by the characteristics of both the person with a disability and the person without a disability and the nature of the interaction between the two. Evidence of what works to change attitudes towards disabled people is very limited (Thompson et al., 2011). What research is available suggests that a broad approach targeting three levels (personal, organisational and structural) is required to change attitudes. However, increasing personal contact between disabled people and the general population by supporting them to access education, employment and social activities on an equal footing with everyone appears to be effective in reducing prejudice (Hannon, 2010).

The community development component received little attention in terms of design and resourcing

A national official stated that building welcoming, tolerant communities so that people can (a) have natural supports, and (b) be part of day-to-day life in their communities was a key element of the original concept of EGL. However, officials, the EGL team, the LAG and National EGL (NEGL) Leadership Group have all acknowledged that minimal attention has been paid to community development in the context of EGL. One LAG member reported:

> *I think what many of us were excited by was community development. And, you know, there's virtually nothing that's happened and there's some - and you could argue that community development, really, is the essence of Enabling Good Lives – in terms of, you know, the principles and the objectives. But it is disappointing that nothing really tangible's happened in that space.*

There was underinvestment in provider and school development to assist them to operate in line with the EGL principles

Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, providers and schools interviewed typically had had limited contact with EGL. The EGL resources dedicated to working with schools and providers on what EGL meant for their practice were limited:

- The EGL team had a person whose role it was to work with providers. Providers interviewed reported that this role was invaluable but more support was needed.
- While there was some EGL resource allocated to working with schools, the people in this role were primarily responsible for working with disabled people and families.
- Navigators had a role in changing provider and school behaviour but contact with them was limited. Some schools and providers had only a few people accessing support through EGL so had limited experience of the Demonstration. All the schools interviewed talked about including the navigators in the planning process. However, in practice the navigators had limited interaction with schools.
- The role of schools and providers was ambiguous when the Demonstration began. There was a perception, especially amongst providers, that the EGL approach promoted the use of natural supports over providers. It would have been more useful

to look at what was needed to better support disabled people to live the life they want and how providers could contribute.

The lack of contact with the Demonstration meant schools and providers were unclear of their role in the Demonstration and key concepts such as 'a good life', 'natural supports' and 'mainstream first' were not commonly understood (see section 6. Limited change amongst schools and providers, page 100).

Accountability arrangements could have been improved

Some arrangements were in place to ensure disabled people used pooled funding appropriately

In this evaluation interviewees reported that there were arrangements to ensure disabled people made appropriate use of the funding they received:

- MIC has been instrumental in advising families (see Families had some useful sources of advice and guidance but more was needed, page 63).
- Navigators have been able to provide guidance to disabled people and their families.
- The purchasing advisory panel (see The purchasing advisory panel worked well, page 64) and purchasing guidelines (see page 64) have provided assistance and guidance to disabled people and their families.

However, some interviewees involved in working with disabled people and families were concerned that they did not always fully appreciate the responsibilities they were taking on when they took up personalised funding or employed staff. An EGL team member reported that *"some people take on IF* [Individualised Funding] *and EGL with rose tinted spectacles and think great we've got money, we can employ who we want, we can go get this and that".*

Research indicates that building the capacity of disabled people and their families to manage the money needs to go hand in hand with Individualised Funding, especially where people have additional vulnerabilities or restricted capacity (Fisher et al., 2010). EGL did undertake capacity-building work with families but more may be needed (see Building the capacity of disabled people to engage in planning, page 55).

Arrangements to safeguard disabled people were not as clear as they could have been

Some interviewees raised questions about who is responsible for safeguarding[30] disabled people in the move towards greater personalisation of supports and services and individualised budgets. Some providers and schools interviewed questioned whether disabled people would be safe outside of their organisations. They questioned who would check that disabled people were being safely cared for in the community as not all families were well placed to meet their young person's needs.

---

[30] The term 'safeguard' is being increasingly used to describe ways to reduce the vulnerability of people with developmental disabilities. Intentional safeguards are things done on purpose to help reduce people's vulnerability. Intentional safeguarding, as part of person-directed planning and navigation, is about reducing risks and increasing someone's safety and wellbeing.

However, some interviewees suggested that for disabled people to develop and grow they need to be able to take risks. Not everything can be known or controlled. They suggested the way forward was a greater focus on risk enablement. This means empowering disabled people and their families to define and manage their own risks and to recognise, identify and report neglect and safeguarding issues (Carr, 2010). Empowering people to have more choice and control over what they do also means accepting that sometimes people will make mistakes or fail. *"This is what is meant by the dignity of risk"* (Reinders & Schalock, 2014: 293).

For the EGL team this meant asking disabled people and their families what they wanted and helping them work through what could be done safely (eg taking the bus with a friend, using their smart phone to take pictures of their location or text where they were). For example, the navigators sought to empower families to take reasonable risks within the bounds of what they were comfortable with. The EGL team found if they *"went with people's value systems and where they're at"* people were willing to try new activities they had initially perceived as riskier. Disabled people and their families were encouraged to talk with other families about how they managed risks.

Nevertheless some interviewees cautioned that service providers and families are not necessarily safe places for disabled people. The EGL team reported that there is a group of disabled people who are at risk because they don't have enough supports and they don't have enough people in their life who will help them manage risk.

The EGL team reported challenges in safeguarding vulnerable people, including the:

- difficulty determining what to do in situations where people's circumstances cross boundaries. For example, an EGL team member reported that it is difficult to get co-ordinated support where people have mental health concerns alongside an intellectual disability. Supports and services were fragmented and compartmentalised
- lack of clarity about what was the role of EGL staff and what was the role of other agencies
- limited number of hours navigators had to work with someone – for those in vulnerable situations it could take a long time working with them to set up safeguarding arrangements.

Accountability arrangements with providers and schools didn't reflect that focus on outcomes for disabled people

Schalock et al. (2016) suggest a key component of organisational accountability is the degree to which the organisation's intended results are achieved from the perspective of the client. There were some examples of organisations asking disabled people about their experience, with the aim of improving their practice. For example, the EGL team commissioned interviews with disabled people to understand their experience of EGL. MIC undertakes a survey of disabled people every two years. They reported that they often randomly call people to find out how things are going and if there is something that they could be doing. They also hold network meetings in different locations where people can come together to provide feedback on what the organisation could do better.

However, schools, providers, the EGL team, the LAG, the National EGL Leadership Group and officials all reported that it was difficult to tell whether or not what they were doing was making a difference for disabled people. Few of the organisations interviewed had formal systems in place to measure outcomes for disabled people from their perspective. There was reliance on anecdotal evidence of outcomes for disabled people, for example:

- hearing people's stories of what was working or not working
- assuming that if they did not hear complaints disabled people and their families were satisfied with the service they were receiving
- discussing with staff about how clients were progressing.

There were only limited examples of organisations attempting to systematically gather information on outcomes for disabled people to measure progress. For example, one provider was now requiring its staff to meet with disabled people and their families every six months to discuss progress against the goals and activities listed for them and what needed to change. This is a change from what they previously did. Before making this change, they had felt more accountable to the central government agencies whom they reported to, but now they felt they were more accountable to clients and family. *"I like that, that we are accountable to the person ... that is the correct philosophy."* The focus was on continuous improvement. Another provider was working to establish a formal system for collecting outcomes information.

There were few incentives for organisations to focus on delivering outcomes for disabled people. Several interviewees reported that:

- contracts between agencies and providers did not focus on outcomes for disabled people
- organisations working with disabled people were not necessarily required to report on what outcomes disabled people attending their service or purchasing their supports achieved
- there were few checks in place on what providers were doing: an interviewee who worked with providers reported that it was unclear who checked whether providers delivered what they said they would deliver, for example whether a one-to-one service was provided if that was what was promised to the disabled person. The interviewee questioned what help was available to support families trying to deal with providers who did not deliver what was promised. Similarly schools were encouraged to develop Individual Education Plans and all those interviewed reported undertaking them. However, an interviewee reported there were few checks to ensure what was in the plan was carried out. Schools were reviewed every three to five years by the Education Review Office ERO and they may see the plans, but an official reported that what schools say they do may not reflect what they actually do in practice.

At a national level, agency officials interviewed did not see themselves as accountable to disabled people. They typically reported that they were accountable to their managers and Ministers. In contrast, the EGL team, the LAG and the NEGL Leadership Group reported they were accountable to disabled people and their families.

Fully developing the components and improving support for the Demonstration could have strengthened implementation

A more fully developed design was needed

The Cabinet paper stated that the Demonstration would be a working model of how the cross-government disability support system could operate in line with the overall vision and principles of 'EGL'. At the time implementation began, this model was not in place because it was not possible within the timeframes allowed.

Key elements of the Demonstration were not designed before it began. These included:

- the range of options for disabled people to take up and manage their funding
- the role of schools and providers in enabling disabled people to have the life they want and how they can best support disabled people
- how providers would be paid
- accountability arrangements
- how community would be developed and how this would benefit disabled people.

Development of a detailed design was hindered by several factors

There was broad agreement that the co-design process[31] involved collaboration between government agencies and representatives of disabled people, their families and providers. However, over the course of the Demonstration it became clear that the participants had different understandings of the process.

There were two different perspectives on the flexibility of the design, both of which were problematic

There were different understandings of what the design would entail and the extent to which it should be allowed to develop. For example, the EGL team and some Ministry staff saw the Demonstration as a developmental model based on the principles. In this process the design was seen as something fluid that evolved over time. This requires that there is an initial detailed design but this is amended as feedback on implementation is gained. However, there were limited systems in place to support this feedback happening and being acted on.

Alternatively most Ministry staff interviewed stated that a fixed working model should be put in place and tested before making changes to scope or scale. This approach requires that the Demonstration be fully designed prior to implementation so that any evaluation can be an accurate test of performance. However, this was not the case as all the components of the Demonstration were not designed when implementation began. Design work carried on after the design phase had officially ended. The performance of elements not implemented until the end of the Demonstration could not be tested.

---

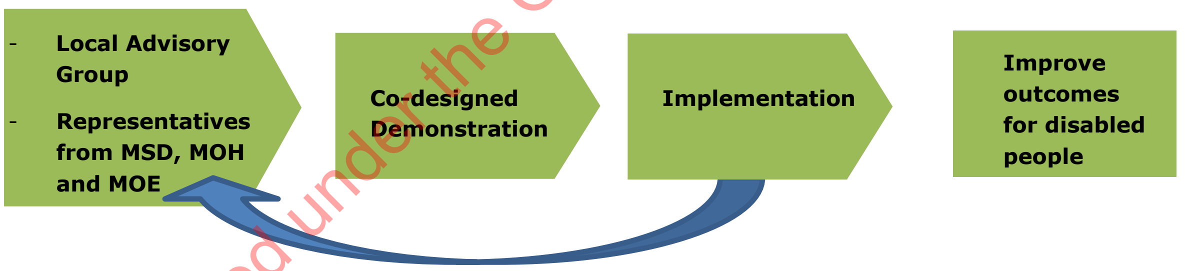
[31] While there is not an agreed definition of co-design internationally, it usually involves using collaborative relationships between public service professionals and citizens or users in the design process. Boyle and Harris (2009) believe these relationships need to demonstrate equality and reciprocity.

There was not a shared understanding of what co-design meant in practice in the context of the Demonstration and whether it had been co-designed

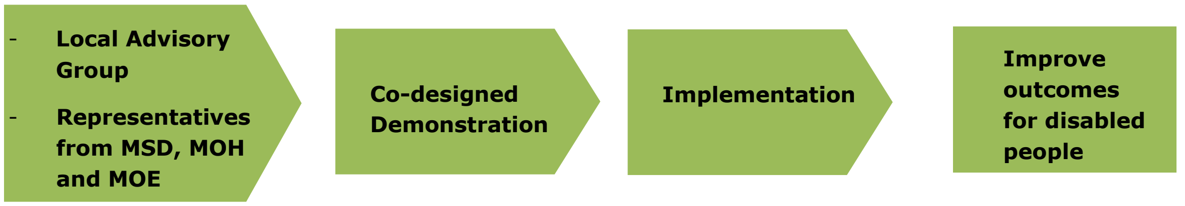
In the first evaluation, stakeholders interviewed reported that the Demonstration had been co-designed. In the second evaluation, stakeholders held different views. GMs and some Wellington officials were of the view the Demonstration was co-designed but at a local level officials and the EGL team were less convinced. The LAG, in particular, was strongly of the view the Demonstration was not co-designed.

These differing perspectives on whether the Demonstration was co-designed were driven by their different views of what constituted co-design. At a local level, co-design was reported to be about shared decision-making and partnership. There was an expectation that ideally no one partner would have any more power and control than the others. The co-design process was seen as more akin to co-development and as an ongoing process (see figure below). The 'co-development' approach ensures that all stakeholders' perspectives are present in the design, implementation and monitoring of the approach.

The NEGL indicated that the discrepancy arose because initial discussions about the design of EGL talked about sharing governance of cross-Ministries system reform as opposed to just 'co-design' (Boxhall & Benjamin, 2012). According to the NEGL, the 'co-design' term came later and in many respects is a sub-set of 'co-development'. In the case of an EGL approach, the identified groups included: disabled persons, disabled persons organisations, families, family networks, local service providers and provider networks and officials. The NEGL reported that, from their perspective, when some parties began to use the term 'co-design' there was some confusion, as the initial approach to the development of EGL had signalled something broader and had increased expectations.



At a national level amongst officials and GMs co-design was seen as a more linear process and separate from implementation. Their expectation was that co-design would involve disabled people, families (represented by the LAG) and government working together on the design only. They were clear that co-design was not the same as co-development.



From the perspective of GMs and officials interviewed they had involved the LAG in the design of the Demonstration. However, the GMs acknowledged the boundaries of co-design could have been clearer. They reported it would have been helpful to explain that agencies did not have to accept the advice put forward by the LAG. As one GM reported:

> *in terms of level of input and time for input from local people and disabled people, you'd give it a huge tick. And we also took real care and – when we were writing papers for the Ministers that we would put their voice in but we're really clear that we actually might even get other advice around that. So I think that was also an important point so that – it [the LAG] had the opportunity and Ministers had the opportunity to see their voice but we preserved the right to put our advice in the preliminary part of that.*

The GMs and the LAG agreed it would also have been helpful to clarify what the design could and could not include at the outset. For example, agencies could not negotiate on everything (eg carrying funding over from one year to the next, agency processes for employing someone, requirements of the Privacy Act).

Co-design needed more time and resource

Co-design processes typically take more time than a traditional design process (Brotchie, 2013). Some local officials and the GMs acknowledge that in hindsight expectations about the speed of change may have been unrealistic. The LAG considered that more preparation in the very early stages before the Demonstration started may have enabled everyone involved to:

- develop a shared and deep understanding of what they were trying to do and how. This would have included agreeing on what the principles and key concepts such as co-design and fiscal neutrality meant in practice
- develop the components (eg options for managing the funding) and have them ready to go prior to implementation
- identify potential problems and put steps in place to resolve them. For example, what are the downstream tax consequences of providing people with individualised budgets? How can people who do not have an agent take up individualised budgets? What implications does having a fiscally neutral Demonstration budget[32] have for the funding providers receive?

The evaluation found that some key people did not have enough time to contribute in the way they needed to. For the LAG and the GMs the design of EGL was in addition to their other work. They reported that they often did not have enough time to spend on the design. As one GM reported:

> *I think one of the challenges was that for us, it was part of our workload and so we couldn't invest the time, perhaps, that we needed to and also, for the Local Advisory Group, it was an add-on to whatever their other commitments were. I don't know; we could have managed that better maybe.*

Better links between design and implementation were needed

Once implementation began it was unclear if or how implementation should inform the design of the Demonstration. There were problems translating what had been agreed in

---

[32] The amount of funding available for personal budgets from the Ministry of Education and Ministry of Social Development did not change from what would have been spent if the Demonstration did not exist.

the design into practice. The GMs interviewed acknowledged that it would have been useful to have checked more with the LAG that the operationalisation of the design reflected what had been agreed on. For example, a GM reported:

> *I think the disaffection of the Local Advisory Group indicates that we might not have followed through with the co-design as well as we should have. They seem to have got a bit marginalised through the process and their voice wasn't being heard and we started having to make special trips down to talk with them and that shouldn't have happened. So something sort of went missing somewhere in the middle there and they – who were our key sort of co-design people as well got sort of left out of it.*

Understanding of and buy-in to the EGL vision across stakeholders needed to improve

Evidence from multiple sources suggests one of the key principles in bringing about change is creating and communicating a clear vision of the future (Duffy, 2004; Forder et al., 2012; Mitchell et al., 2015; Schalock & Verdugo, 2012). In the case of the Christchurch Demonstration this meant there needed to be widespread understanding of and buy-in to the EGL vision.

Steps were taken to build a common vision across stakeholders

Positive steps were taken to build a common vision across stakeholders. These included:

- *using the principles to unify stakeholders*: Stakeholders reported that having the principles helped to begin to build a common understanding and framework
- *using community meetings to build a common understanding:* The NEGL reported that the initial community meetings with disabled persons, families and providers were a good start to building a common vision and it would have been useful if this work had continued when the Demonstration got under way
- *undertaking ongoing work with stakeholders to build understanding* (eg schools, providers, local officials such as the NASC in Christchurch led to a better understanding of the EGL components and improved relationships. An EGL team member reported provider support for the EGL approach was improved by clearer communication with providers on their role in EGL undertaking provider development work. This included running workshops and holding monthly lunchbox sessions to talk about different aspects of the EGL approach. Two peak bodies New Zealand Disability Support Network (NZDSN) and Inclusive NZ are supportive of EGL and have also run workshops with providers.

Nevertheless there was not a deep and shared understanding of the EGL principles or the purpose of the Demonstration

More time was needed to build a common understanding of the Demonstration's purpose

The purpose of the Demonstration was not something all stakeholders interviewed agreed on. There was agreement amongst stakeholders interviewed that the Demonstration was about pooling funding and increased choice and control to improve the outcomes for disabled people. However, there was not agreement on whether or not the Demonstration was intended to transform the disability support system. Wellington officials typically reported that this was not the purpose of the Demonstration. Their view was that the Demonstration was intended to gather evidence to inform future government advice. In contrast, other stakeholders were of the view that the Demonstration was about system transformation and was the first stage in national roll-out. Taking more time initially to build understanding of the purpose amongst stakeholders including agencies would have helped. Some local officials and the GMs acknowledge that in hindsight expectations about the speed of change may have been unrealistic.

Understanding of the EGL principles and other key terms was not shared

While stakeholders typically reported they agreed with the EGL principles, there was not a shared understanding of what the principles and key terms related to the Demonstration meant in practice. For example, there was variable buy-in to and understanding of the EGL principles by providers and schools. Terms such as 'co-design' (see There was not a shared understanding of what co-design meant in practice in the context of the Demonstration, page 38), 'fiscally neutral', the 'EGL principles' (especially 'mainstream first') and 'independent facilitation' were not commonly understood by stakeholders.

The outcomes the Demonstration was focusing on were unclear

The vision for the EGL approach is that disabled people and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports in their communities. What the outcome of this would be for disabled people and their families was not clearly articulated.

Existing research indicates that a key element of effective partnerships is having a focus on shared outcomes rather than outputs and processes. All the stakeholders need to have a shared understanding of final outcomes. Measurable goals that can be clearly defined and evaluated, and an emphasis on the quality and distribution as well as the quantity of outcomes, are important. Without clearly defined goals and outcomes, there is a danger that partnerships can be drawn into the minutiae of the process, rather than focusing on implementing change (Ball & Maginn, 2005, in Lindsay et al., 2008; Brotchie, 2013).

Leadership could have better supported implementation

Literature looking at how to bring about social change identifies leadership as a critical factor in the process (Genio, 2014; Brotchie, 2013; Schalock et al., 2016).

There was lack of clarity about who was responsible for the Demonstration

Interviewees expressed different views on who was responsible for leadership of the Demonstration. The degree of responsibility the Director and the GMs had for the Demonstration was not something everyone agreed on.

GMs saw the Director as being solely accountable for the Demonstration's implementation and outcomes

From the perspective of the GMs, the Director was solely accountable for the Demonstration's implementation and outcomes. The GMs agreed that many would see accountability resting with the Joint Agency Group but in their view the GMs are only accountable for direction setting. The GMs reported that the Director's leadership was one of the reasons the Demonstration has struggled. They felt the Director was not able to adequately explain the Demonstration's vision to all the stakeholders involved, resulting in a less than coherent implementation. However, they agreed this was not a shared understanding and admitted that, if the Demonstration failed, it is unclear where people would see that failure sitting.

Schalock et al. (2016) argue that leadership needs to be transformational and strategic. However, this is also required at many levels. Genio (2014:10) adds:

> *While the presence of a charismatic and committed leader is very helpful, our learning indicates that multi-level leadership is at least as important. Multi-level leadership means there is 'a champion' at all levels of the organisation and in other key groups, who supports and drives the move to a new way of supporting those using the service.*

Many saw the GMs as the real leaders behind the Demonstration

The GMs reported that there was a high level of agreement between them and they worked well together. They felt they had a lot of commitment to and ownership of EGL. Others agreed with this perception. The Director, for example, reported that *"it feels that GMs are pretty well aligned".*

However, there was also concern expressed about the GM's leadership role. The Director reported that while the unity of the GMs was a strength it was experienced as exclusionary. He reported, *"They've worked it out and then I meet them. So I'm not part – so, that's the frustrating thing. I'm not part of that. Okay. Again, I feel I've got something to offer to that."* The LAG, the team in Christchurch and some officials reported that the GMs exerted too much control over the Demonstration and were in fact the real leaders behind the Demonstration. For example, one official reported that:

> *While the Demonstration Director was notionally responsible for leadership, in effect he had almost no authority. In practice, the unofficial General Managers Group, and to a lesser extent, Joint Agency Group, were the effective decision-makers on what did and not happen in the Demonstration.*

However, some officials felt the GMs were not involved enough

Some officials interviewed felt the GMs and JAG were not involved enough. Some officials felt the Demonstration needed more attention from the JAG and GMs so that they had a better understanding, greater support, and knowledge of what was happening on the ground. The GMs agreed that the Demonstration would have benefited from their greater input. They reported that they have learnt they probably sat back too much, especially during the co-design process and that *"officials needed to be equal partners – not just facilitators".* This was another example of the mismatch in expectations between the LAG and senior managers within the agencies.

Leadership from the Ministries did not appear transparent, joined up or consistent with achieving outcomes to those on the ground

Decision-making within the Ministries was difficult to navigate

Interviews with the team in Christchurch and the LAG revealed they were not always clear how decision-making worked within the Ministries. This was seen as being especially true of MSD. For example, the Director reported that with the Ministry of Health's DSS, it was clear where to go to get a decision made but this was not the case within MSD – *"In MSD it's just so – so big. And so many jobs that are very similar yet not quite the same. You think, 'I don't know where I'm going.'"* He added that the separation between policy and contracting and operations only added to the complexity.

Officials interviewed reported that part of the problem was that the team in Christchurch and the LAG did not always have a good understanding of the government processes. Unfamiliarity with the processes contributed to frustrations with government decision-making.

Agencies were seen as slow to act on matters that affected the implementation

Interviews with providers, the LAG and the Demonstration team in Christchurch reported that agencies were slow to identify potential problems and slow to make decisions that affected the implementation of the Demonstration. According to the Director, the time it took agencies to make decisions compromised the ability of the team in Christchurch to make changes quickly enough to minimise the impact on groups such as disabled people or providers. For example, the Demonstration began in late 2013 but it took until June 2014 to resolve the issue of disabled people being charged GST where they were not changing their arrangements and for providers to get paid on time. Interviewees reported that delays appeared to occur because of the need to consult with various agencies or because key people could not devote enough time to working on the problems.

The LAG felt issues such as this could have been anticipated. As one LAG member interviewed reported:

> *there didn't seem to be any kind of forward thinking in terms of okay, if we are seeking to make these changes in the system – in the current system, you know – what are the downstream effects of that? And, you know, the GST is a good example of that.*

Designing and putting in place a range of options for disabled people to take up and manage the money was also problematic. One EGL team member reported that sometimes the policies and bureaucracy seemed to get in the way. *"Often we feel as though we are being surrounded by a can't-do attitude rather than a can-do attitude."*

Agencies did not appear joined up in their actions

While the GMs considered that the EGL was one of the better examples of interagency cooperation, this was not the experience of those on the ground in Christchurch. Interviews with the team in Christchurch, the LAG and some providers revealed that:

- the Ministries' engagement in the Demonstration was perceived as variable, with some Ministries seen as taking a more active role than others

- communication within the Ministries was seen as problematic, especially MSD. As one EGL team member reported, *"within MSD it seems Policy don't talk to Contracts and vice versa then they go and do their own thing and boom. Policy and Contracts don't always to talk to us"*.

Decisions were made that did not appear to align with the EGL principles

The agencies reported that they supported the EGL principles. However, local officials, the EGL team and providers reported being frustrated that the Ministries made decisions that appeared to be at odds with the principles and what the design of the Demonstration was trying to achieve. For example, the Ministries were not seen by the LAG as acting in accordance with the principles when they decided to focus the purchasing guidelines on the purchase of services as opposed to things. The LAG had advocated for the guidelines to be broad and to enable a range of different purchasing options which they believed were consistent with the principles (eg mana enhancing, self-determination). As a LAG member reported:

> *To find that actually, that there was a view within officialdom that actually, we need to reduce the scope and we need to actually be really clear that it's about services and it's not about things. And so, I think it's difficult to make an argument other than that's not the right thing to do in respect of the principles. So I guess that's what I mean, in terms of selective application of the principles.*

An EGL team member suggested that one way the agencies could act more in accordance with the principles would be to require providers to provide information on how they are addressing the principles eg how they were helping people work towards greater self-determination. The view was that if contract managers gave providers feedback on the reports they completed this would encourage behaviour change in line with the principles. The team member added:

> *It's important for system change. I find it ironic that we talk about what others need to do to change but don't do it ourselves. Leadership comes from leading – not forcing. The Ministries need to lead by example.*

Schalock and Verdugo (2012) argue that to improve outcomes for disabled people it is crucial that system-level processes are aligned with the outcomes being sought.

LAG and National EGL Leadership Group reported their leadership in the Demonstration was constrained

LAG expected shared decision-making but the LAG was not set up for this

The LAG reported that in the initial stages the paperwork[33] described them as a governance group but that the documentation changed and they were referred to as an advisory group to provide advice to the Demonstration Director. The Terms of Reference for the LAG explicitly said that the LAG was not a decision-making group. Nevertheless the LAG expected to be involved as equal partners in decision-making about the shape of EGL and as result, they were frustrated by:

---

[33] See Ministerial Committee agreement to vision and principles for long-term change – September 2012 http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012/

- *their lack of power to make decisions.* The LAG reported that being only an advisory group limited the effectiveness of their input as officials could choose whether or not to listen to their advice
- *what they perceived as selective engagement by the Ministries:* There was a perception that the Ministries consulted with the LAG when it was beneficial to do so but avoided consultation when it was not
- *decisions affecting the Demonstration being made by agencies without consultation with the LAG:* The LAG reported that decision-making was not shared. They reported that as the conversations became perhaps more difficult, they started to be left out of decision-making and were just being told what to do
- *officials not understanding how to interact meaningfully with the LAG:* For example, officials set up 12 work streams to progress the Demonstration. For the LAG there was an overwhelming amount of paperwork associated with the work streams that they were expected to read and comment on within days of decisions being made. As one LAG member reported, *"really, with all the will in the world, with our day jobs, we haven't got time to go over that paperwork".* They would have preferred officials to develop options – having worked out what they can give and take on – and given them sufficient time to provide feedback.

National EGL Leadership Group had limited ability to exercise leadership

An NEGL representative reported that the National Leadership Group was not in a position to exercise leadership effectively in the Demonstration. His view was that if the National Leadership Group was to have been framed as providing leadership to the Demonstration, flows of information and decision-making should have been altered. In their experience they were sometimes participating in discussions well after key decisions had already been made – not an ideal situation if they were to demonstrate "leadership".

The EGL approach advocates "co-governance". The NEGL representative saw the current situation as a step towards this. His view of "co-governance" by a group comprising officials, disabled persons, families and providers is a valid aspiration. Ideally, there would be a clear link between a "co-governance" national body and a "co-governance" local body.

There were wider problems with the system which likely limited implementation and performance

The Demonstration, like any initiative, did not take place in a vacuum. There were external factors that influenced implementation and performance.

Limited range of housing options in Christchurch

Over the past two decades, research has consistently shown that living in the community is superior to living in institutions (Francis et al., 2014; Lakin et al., 2011). However, families interviewed reported that there are few housing options for disabled people in Christchurch other than living at home with family or in residential care. This is especially the case for disabled people who need considerable support with their day-to-day activities. For example, two families who had opted for residential care for their young person reported they would have preferred something else. For example, one parent said:

> *And, you know, even though I think, in a perfect world,* [we] *might have preferred something in between full-time care at* [residential provider] *and living at home, that sort of intermediate arrangements or arrangement isn't really feasible.*

At the time of the evaluation, Choices in Community Living was not available in Christchurch[34].

There were also difficulties for those with higher levels of functioning. A supported housing provider reported that they had leased places across Christchurch but landlords were not always willing to take on disabled people. With demand for rental accommodation high since the earthquake they could afford to turn people away. As the provider reported: *"It's a different situation here with the earthquake. It's hard to get landlords to take people with an intellectual disability and you need a guarantor for them"*. The provider had operated as the guarantor for disabled people in these situations.

Some reported difficulty accessing appropriate services

Difficulties for people who have mental health problems as well as disability

A provider and members of the EGL team reported that there were difficulties in meeting the needs of disabled people who also had mental health problems. The main difficulties were that:

- the mental health problems were not always diagnosed, at all or in a timely way, because the focus was on the person's disability
- service delivery was compartmentalised. For example, a provider and the EGL team both reported instances where they struggled to get mental health assistance for people with a disability who were threatening self-harm. The NASC funds support for disabled people but not mental health problems, which are dealt with by *"a whole other system"*.

A provider interviewed reported that the lack of co-ordination between mental health and disability services was becoming more of a problem because in their experience the incidence of people with dual diagnosis was increasing.

Access to appropriate services for young people ageing out of child services can be problematic

A supported housing provider reported that it was difficult getting services and supports for young disabled people once they were considered adults. In their experience once people are no longer attached to a service such as Child, Youth and Family (CYF) or a provider and have limited family support they receive limited assistance.

Some families reported difficulty accessing the right health services for their young person once they reached the age of 16. At this point they transferred to the adult health services, which were not always well set up to meet their needs. A parent

---

[34] The Ministry of Health's Choices in Community Living is an alternative to residential services for people with significant disabilities. It offers more choice and control over where they live, who they live with and how they are supported. It is part of the New Model demonstration and is only available in Auckland and Waikato at this time.

described these services as *"a big joke".* The young person had yearly check-ups with a paediatrician up until the age of 16. Once he was 16, however, the family lost this specialist support and were expected to access health services via their GP or the hospital's emergency department. It took some time to find a GP who specialised in people with special needs and the medication required. She reported that prior to this her son was overmedicated and had poor appetite.

Access to disability support services

Families interviewed reported difficulties in accessing the types of services they wanted when they wanted them (see Access to and experience of supports and services were problematic, page 95).

5. Families' and disabled people's experience of EGL was positive but there were some difficulties

Summary

Navigation and planning:

- Case study data revealed families were often sceptical about EGL when they first heard about it.
- Families did not engage or were reluctant to engage in navigation where they had no opportunity to talk to the navigator, were not open to navigation, did not believe their family fitted with EGL, or did not expect their young person to grow or develop further.
- Where families did engage in planning, it was largely a positive experience. The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there.
- Practices that supported engagement in navigation included making disabled people central to the planning process, building the capacity of disabled people and their families to engage, having independent facilitation (although alternatives were also raised), and having other parents who had been through EGL to walk alongside new people.

Use of the funding:

- Most participants had received funding. As at 9 October 2015, 129 of the 175 EGL participants had been allocated funding. This funding could be used flexibly to purchase supports and services.
- Being financially literate and well resourced assisted people to take up the funding and manage it. There were practices that supported disabled people and families but there was room to improve.
- The amount of funding may have been insufficient in some contexts. These included contexts where the young person wanted to live independently in the community but the cost was a significant barrier and where families were on lower incomes and the amount of funding they received may have been insufficient. The funding may be insufficient to support disabled people's choices where family cannot be involved in the day-to-day care of their young disabled. Some interviewees reported that taking up Funded Family Care limited the overall pool of funding but the families did not always feel they had an alternative.
- Families had some useful sources of advice and guidance but more was needed. MIC was instrumental in advising families, and the purchasing advisory panel worked well, but families were not always clear about why some services were funded and others were not. There was a need to clarify elements of the purchasing guidelines.

Engaging and planning with EGL was a largely positive experience

Across the Demonstration most EGL participants had a navigator

Most (152) of the 175 EGL participants as at 9 October 2015 had a navigator. Of this number, nine were listed as 'navigator only'; that is, they were not receiving EGL funding.

Not everyone who was eligible to be part of the Demonstration has engaged with a navigator. Of the 175 EGL participants as at 9 October 2015, 12 had chosen not to take up navigation but eight had taken up the EGL funding. A further nine people did not have navigators assigned to them because they were newly referred, were in the process of choosing a navigator, or were listed as not ready to engage with a navigator. In two more cases it was unclear why they did not have a navigator. An additional three EGL participants had an external navigator.

Rationale for whether or not to engage with EGL varied

The case study research explored disabled people's and their families' rationale for engaging or not with the navigators and the planning process.

Families were often sceptical about EGL when they first heard about it but those who engaged thought it might improve outcomes

Across the cases families typically reported viewing EGL with scepticism or wariness when they initially heard about the Demonstration. Concerns were specific to the individual families eg fear of the unknown, fear of managing the money, fear the good parts of the old system would be lost, cynicism EGL would live up to the hype. For example, one parent said her initial thoughts were *"oh no not another thing people are trying to make work that then falls flat on its face"*.

In the cases where families agreed to participate in EGL they did so because they believed EGL would allow them to create a life for their disabled person in the community with more choice and control over what they did and with whom. The families and, where possible, the disabled person expressed a desire for the disabled person to live as normal a life as possible in the community. For example, a parent of a young person with a profound intellectual disability said:

> *We just didn't – we couldn't imagine [our young person] going into like a day base or something like that – you know. And look, for some people the day base is a great network well, but for us, we just wanted – we wanted [our young person] to be out and about and doing and – so the timing of Enabling Good Lives for our family and the fact that we met the criteria was huge. And we're so thankful that we were able to jump on board.*

The families who engaged in planning shared some characteristics:

- The parents all had a strong sense of agency. All the parents interviewed described themselves as proactive in searching for something better for their young person.

- Parents all had an expectation that their young person would live in the community and learn and grow. They all felt this could happen with the right support. They wanted their young person to do something similar to what other young people their age were doing. For example, the mother of a young person with a profound intellectual disability felt it was important to think of what is possible. She said, "*You might think well my kid can't. No, your kid can. Anything is possible. Anything is possible.*" She added that others may not agree: "*I can recall we talked about flatting. There was some discussion at LifeLinks* [NASC] – *'oh if he goes flatting' – that sort of thing.*"
- They were unhappy with where life was at for their disabled person prior to EGL.

The mind-sets of the families who did not engage with EGL or had made limited change were different from those who did engage

All the families who placed their young person in residential care had a plan of action for their young person but this didn't necessarily involve EGL. Only one of the families had engaged with EGL and a navigator. All of the young people in these cases had previously attended special education schools.

When looking at the two cases where the families had not engaged or were reluctant to engage in navigation some common themes emerged.

Non-engagers had limited or no contact with navigators and were not open to navigation

In two of the cases the families were not open to navigation. In one case the family was offended by EGL offering a navigator. The family had actively sought out residential care. They stressed they were more than capable of deciding what was best for their young person – they had a strong sense of agency. They felt they could do it themselves and the navigator was a waste of money. They saw the need for navigation as a sign that the system was broken and overly complicated. They wanted to be able to take the money and spend it where they thought it would best benefit their young person. The parent commented:

> [We] *really felt affronted by this, I suppose, at one point, when they offered us a navigator. So part of me says Vote Health, Vote Disability spent on a person to help me – an intelligent person – wade through a system that is so complicated I can't work it out myself and we both felt pretty annoyed by that and so didn't agree to a navigator.*

In another case the young person was placed in residential care before Enabling Good Lives existed. The parent interviewed only half-heartedly reported that a navigator might have helped them to look at options for their young person post-school. The family wanted their young person to stay in residential care but to have something to do during the day when he left school. When the time came for the young person to leave school the family reported that they had received little information about EGL. The school had suggested a range of day services for the young person to attend post-school and the family had selected one of these. While the family expressed some misgivings about their current care arrangements it is unlikely they will change. The family reported that setting up a life in the community for their disabled person was too daunting and living at home was not an option.

Non-engagers did not expect their young person to grow or develop further

In two of the cases the families were looking to carry on with similar activities post-school to what the young person had done at school. They described the young person as if they were a child and had few expectations of any growth or change. We do not know if this would have changed had they had contact with a navigator.

The navigators had to work against such attitudes. As one EGL staff member reported:

> *And I think, you know, we're working against for most of these young people 20 years of families being told this is what, you know, just go for mediocre because that's what a disabled life should look like, and things like that. So, trying to do a massive culture change within families as well as – and this is just some families.*

Non-engagers and those that had made no change since engaging with EGL did not believe their family fitted with EGL

In all cases where the families had placed their young people in residential care they reported EGL had unrealistic expectations of families. They saw EGL as being about families actively supporting their young people to live in the community – often living at home.

In all of the cases the families did not believe they had the time and energy to plan or co-ordinate a life in the community for their young person. Reasons for this include:

- *work commitments*: In two of the cases both parents worked and the prospect of managing employees or activities in the community was daunting. In one case they had tried it prior to EGL and found managing work and their young person's carers too difficult
- *parental health problems*: In two of the cases the mothers reported their poor health made them reluctant to take on the role of co-ordinating a life in the community for their young person. They felt EGL was unrealistic for more vulnerable families
- *having their young person at home was not an option:* They saw EGL as being about young people living in the community. All the families wanted was their young person to be in an environment where they were cared for but they did not see that as being at home. However, housing options in the community for HN and VHN young people were limited.

However, looking across all the cases where EGL changed mind-sets, this change was long lasting

Almost all the disabled people and their families interviewed talked positively about the impact that EGL had had on how they thought about what was possible for their young person. For some it confirmed views they had already, whereas for others the change in mind-set was more profound. In any case this change was long lasting.

This was most evident in the case where EGL had not lived up to their expectations. The parent acknowledged that even though they were not using the navigator the process of thinking about what might be next for her young person had stayed with them. They were not using the plan that was developed under EGL as it was no longer useful but they were planning to find a carer. She reported that they wouldn't be where they were now without Enabling Good Lives and it had made them think more outside the square.

Use and experience of navigation and planning varied

Where families did engage in planning it was largely a positive experience

In cases where the navigator was involved, families were typically positive about that involvement. Families especially valued the navigators for broadened thinking about what was possible. Families also reported that the navigators were good at keeping them on track, providing reassurance, and being able to look at situations unemotionally. Parents commented:

> *[The navigator's] involvement meant we kept moving forward. He was great at giving us jobs to do to keep the momentum up. He was great when we got a bit discouraged. He also did his fair share of jobs too.*
>
> *Knowing the navigator is still there and you can call on them is fantastic.*

In one of the cases the family did not have a good experience with planning and navigation. They reported that EGL did not live up to their expectations. Their initial involvement in EGL was positive and their hopes were quite high but then *"it dropped away".* The parent and the disabled person felt the navigator built up their ideas of what they could do but this was not followed up with adequate support. Once engaged with EGL they reported difficulty re-engaging support services (eg CCS, IHC, IDEA services). Previously these organisations had supported them but once they were with EGL the family reported they were reluctant to help.

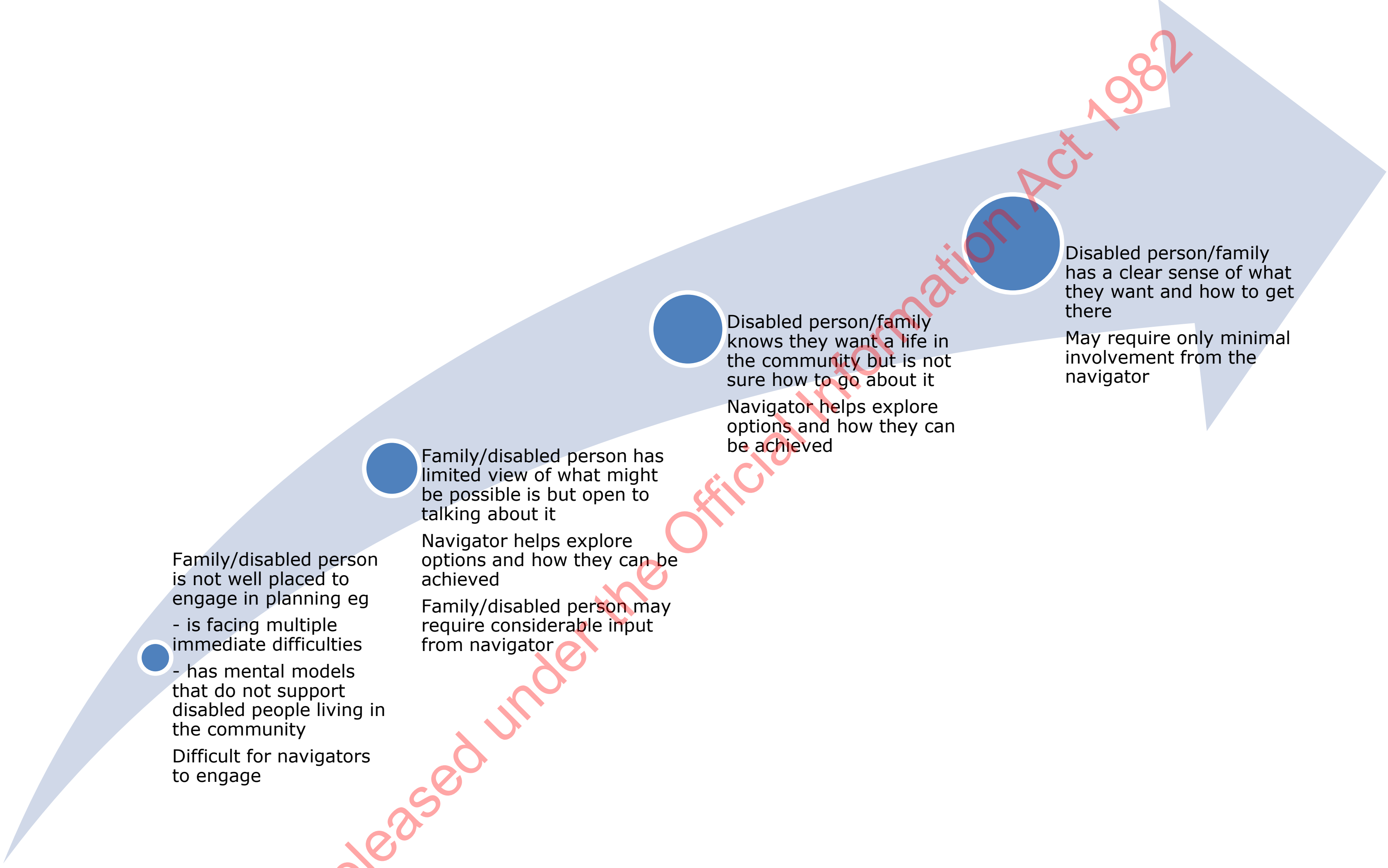
Navigators were more beneficial to some families than others

The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there (Figure 3). Based on their previous experiences, families sometimes had low expectations of what was possible for their young people and navigators could help change that. In this context the navigator could be a vehicle to explore ideas, suggest new possibilities and help shape a future. For example, one parent reported that in working with the navigator she realised and accepted *"how institutionalised I had become in my thinking"* and how she had normalised an awful situation. They had tried to make the decision to place their young person in residential care *"ok"* in their minds by pretending that the residential provider was doing a good job caring for their young person – *"that it isn't really that bad"*. She added that for many parents in her situation there may be resistance initially to looking at something different but the navigator had given her time to adjust, deal with her guilt and shift her thinking. Of EGL she now thinks *"what a good idea – let's do it"*.

Navigators were also especially helpful for families who wanted something different for their young person but were not sure how to go about it. As one parent reported:

> *I mean if we needed it we can ring her and talk to her and that but and so we know that, you know, that she's there. So, and initially that was, you know, really great and we really did need her for that initial … because we were going from having people, everybody doing it for us – to being, having to do it ourselves.*

Figure 3. Types of families navigators attempt to engage with



Family/disabled person is not well placed to engage in planning eg

- is facing multiple immediate difficulties

- has mental models that do not support disabled people living in the community

Difficult for navigators to engage

Family/disabled person has limited view of what might be possible is but open to talking about it

Navigator helps explore options and how they can be achieved

Family/disabled person may require considerable input from navigator

Disabled person/family knows they want a life in the community but is not sure how to go about it

Navigator helps explore options and how they can be achieved

Disabled person/family has a clear sense of what they want and how to get there

May require only minimal involvement from the navigator

However, where disabled people and families had a clear sense of what they wanted and how to get there, the influence of the navigators appeared more limited. In these cases the navigator was not always the only person guiding planning, or even very prominent in helping the family. This was especially so where families had opted into EGL. For example, in one case a family had pushed to be included in the Demonstration. From the outset the family had a very clear sense of what they wanted out of the process. Engaging in the planning process was seen as a necessary step in getting access to the EGL funding. Beyond that the planning process and meetings with the navigator did not mean a great deal to the family.

In another case the initial planning with the navigator appears to have been the beginning of an ongoing process of planning where to next. The navigator was involved in the initial planning process but the parent now discussed future plans for his young person with the carer employed to assist the family. The navigator had limited involvement.

Planning practices that supported disabled people and families

Making sure the disabled person is central to the planning process with the navigators

Most interviewees engaged in planning agreed having a navigator who was focused on the disabled person was useful. Interviews with navigators and families engaged in navigation revealed the following practices helped the navigators place the disabled person at the centre of the process:

- *building a relationship with the disabled person starting from where they were at:* Disabled people and their families were at different stages of readiness to think about what a good life looked like for them and planning how to achieve it. Navigators reported that they started by asking the disabled person questions about what they wanted and worked from there. For example, a navigator said they asked:

  > *"What are your dreams? Where do you want to be in 10 years' time?" And then write that vision. "What are some of the small steps we can take to get you there?" So we've got that and then we start to talk about, how can we make those small steps happen? We talk about natural support – "Who's around you that could help you get there?" And then we start talking about paid support*

- *having a fluid planning process where the content/layout of the plans is not fixed*: Not having a fixed process or plan type allows the navigator to work with where the person is at and how they want to engage. For example, some disabled people and families wanted detailed plans or to see them displayed visually. Others, according to a member of the EGL team, had limited willingness or ability to engage in the detail of their plans but there was an agreed broad direction.

Independent facilitation was seen as beneficial but alternatives were raised

The EGL team considered that independent navigators were beneficial because they focused on the disabled person – not an organisation's needs. As one EGL team member reported, *"they have no buy-in with any other organisation or any other group, truly there for that person. The only bias we have is that person has to be awesome".* Instead of being channelled down a certain direction, an EGL team member reported that disabled people and their families have the opportunity to engage with someone who is independent and is seen as an ally who thinks about the disabled person's whole life. He said traditionally organisations have been good at segmenting people’s lives. Blocks of activities have been found with the focus on filling up people’s lives rather than looking at their lives in a connected way. A navigator added that until disabled people were accepted as part of the community like everyone else, there would be a need for some disabled people to have an independent ally at key points in their lives.

However, others raised alternatives to independent facilitation. Some providers interviewed thought that they could undertake navigation and still be focused on the needs of the person. For example, one provider reported that the notion that providers could not provide person-centred navigation was untrue and based on false assumptions that providers would not look out for the best interests of the disabled person.

> *I think we’ve been able to demonstrate actually, you know, this - the function of navigation can actually sit quite comfortably in a provider organisation … That sort of navigation function could work within a provider organisation where people are being connected into, you know, a course at the Polytech or into a job … Some of that ongoing support would still be provided by that provider organisation but the actual function of navigation, which is, you know, facilitation and connection, whatever, call it what you will, you know, could still I think operate to a large degree within that sort of provider.*

A person who worked with disabled people commented that if providers did undertake navigation the navigators needed to be separate from the other functions. If they have other roles they will be spread too thinly.

The possibility of families acting as navigators was also raised (see below).

Having other parents who have been through EGL to walk alongside new people

Some families reported that having the support of other parents who had experienced EGL was valued and should be encouraged more. For example, a parent reported she felt very strongly that parents new to EGL should have other parents who had been through EGL to walk alongside them, along with the navigator. She reported she had seen people who *“were too scared to step out. It also brings those people into a community”*. She felt it was important to build the community so that families could share their experiences and build connections. She added that seeing others who were in similar situations who had built a life for their young person in the community reduced the fear of taking those steps – *“That encouraged me!” … “I thought, we can do this.”*

At the time of the evaluation the EGL team was exploring whether family members who had been involved in EGL wanted to take up the navigation role. These families had been given information on undertaking the role. Some families in the case study research reported that talking to other families who had been engaged in EGL was extremely useful and should be further encouraged.

Building the capacity of disabled people to engage in planning

The EGL team recognised that some families need assistance to get the most out of the planning process. The Demonstration got funding from Te Pou to support the Family Capacity Building Group. The group ran a series of workshops on topics such as housing, Circles of Support[35], employment and networking. Members of the team interviewed reported that workshops were an efficient way to convey information to families. As one navigator reported:

> *It's not particularly efficient to go through the whole process of every family that wants to have a Circle of Support or employment and networking. By providing the information to families in a group session they can possibly work together and develop these things.*

The workshops also gave families information about aspects of their young person's life they may want to address in the medium term (eg housing in the community).

Challenges associated with the planning process

The evaluation identified a number of challenges associated with the planning process. These are outlined below.

Engaging families in difficult and complex circumstances who struggled to envisage a good life for their young person

There is strong evidence in the literature that family support is needed to enable access to, or to get the best outcomes from, various elements of personalisation – including personal budgets. Those with no or limited support from family or friends are at a distinct disadvantage compared with those with extensive social networks, financial resources and skilled and knowledgeable family members (Harflett et al., 2015).

Members of the EGL team and navigators interviewed commented that it was difficult to engage some families who struggled to envisage a good life for their young person. For example, an EGL staff member reported that navigators frequently talked about coming across disabled people having "*so much potential and they're just sitting*". In working with the families, they were trying to bring about a cultural change within families. While some families understood the concept of a good life and how to get there, others had little idea. This was especially the case where the families had had difficult life experiences. A navigator reported:

> *If you have a fairly narrow life yourself and you don't have a particularly good life yourself then your ability to have a good life and have an imaginative and creative life for your children or child can be a bit limited. … Some people don't have the – I don't know – the confidence or cultural capital or whatever to actually go out and do stuff. So without – I don't think it's ever a conscious effort to try and limit the opportunities for their young person but sometimes the lack of horizon can sometimes mean that they're unwilling to try things.*

The EGL team commissioned research on disabled people in complex circumstances[36] who had met navigators. This research revealed that the participants were more difficult to engage because they were often fearful and vulnerable, lacked information about

---

[35] A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life.

[36] The EGL team in Christchurch engaged with a small number of participants who met the criteria of 'Category D' from the Productivity Commission Report into Social Services. Category D is defined as including individuals with complex needs who have difficulties navigating systems to co-ordinate services and supports (The New Zealand Productivity Commission, 2015).

options and systems that could help, had low expectations for themselves and their family, and had had mostly negative experiences with agencies. They had a limited concept of a future or 'next steps'. The participants were mostly focused on the present, what was happening in their lives now and how they got by each day. Thinking beyond their immediate circumstances and what they knew was difficult.

Some families who had engaged with EGL reported that EGL was not suitable for families in vulnerable circumstances. For example, a parent who had relished the planning process with her son said that *"it wouldn't suit families who are not good organisers or good with money or may be dysfunctional as there is some work involved".* This was echoed in the views of another parent, who reported she often had people asking her for advice on EGL eg which forms to use, how to fill them out. In her experience many have low literacy levels and they struggled with something like EGL that requires financial literacy as well as the ability to read.

The navigators and EGL staff were firmly of the view that the EGL approach could work for disabled people and families in complex circumstances. However, they reported that for people in these circumstances more time was needed to develop trusting relationships. From there it was possible to begin developing ideas about what a good life might look like and facilitate links to the appropriate supports and services. For example, some research undertaken by the EGL team with complex families found they were making progress within the EGL framework, albeit very slowly and with significant input from navigators and other support networks.

In other research there is evidence that, where local workers take the time to patiently build trusted relationships with 'hard to reach' individuals, their persistence pays off (Brotchie, 2013). Moreover there is some evidence that it is the role of staff, rather than family that is key to enabling person-centred plans (McConkey & Collins, 2010 and Robertson et al., 2007b cited in Harflett et al., 2015). Harflett et al. (2015) state that further research is needed to determine if having supportive and skilled staff can compensate for a lack of support from family or friends.

Finding workable solutions for disabled people without family support

Some young people do not have family to support them. The EGL team interviewed reported that this made making and implementing any plans more challenging. Those without family support were often more reliant on the navigators to make things happen. For example, a navigator put together a case to get driving lessons funded for a young disabled person because there was no parent to teach them or organise this for them. Without the navigator arranging for the lessons to happen, the person would not have got a driver's licence and would have had limited employment opportunities. The EGL team members and navigators interviewed were concerned about what will happen for people in these circumstances longer term.

Balancing what the young person wants and what the family wants

The navigators found that the needs of the family members do not always align with those of the disabled person. This is especially difficult when the young person might not use words to communicate. As one navigator reported:

> *I struggle with that a lot because the navigator is fundamentally allied to the disabled person but you also need to get the family on board as well. So there can be tension between the two. … But that's why that relationship building is so important, where you can get to that stage and say to them, "Your young person is really interested in this and you seem to have some different ideas."*

More support from navigators sought, especially when families faced difficulties after the planning stage

Interviews with the families and the EGL team revealed that the navigators typically worked with disabled people and their families to develop and implement their plans. Navigators were less involved once this had been done. In one case the family found that what they had planned was not working for them. They reported that they would have appreciated more help from EGL and the navigators at this point to find a way forward. The parent reported of EGL that the *"rhetoric doesn't live up to the reality".*

Lack of clarity about the future role of the navigators

The evaluation identified several aspects of the navigator role that it would be useful to clarify. For many families interviewed, their most immediate concern about the role of the navigators was whether or not the role would continue after the Demonstration.

If a navigation function continued to be available, the evaluation raises some questions about the navigator's role:

- What is the role of the navigator over the life course? In the Christchurch Demonstration navigators have been involved in the lives of young people transitioning from school to the life beyond that environment. However, it was unclear what involvement disabled people could expect from the navigator beyond this point. If navigators were to have an ongoing relationship with disabled people and their families, this would have implications for resourcing.
- What is the role of the navigator in addressing the often challenging needs of families independent of the disabled person? For example, the case studies revealed that family members, especially mothers, could have physical and/or mental health needs that impacted on their ability to support their young person.

Improvements suggested for navigation

Those interviewed offered suggestions for improving navigation, including:

- providing more support for people when they get into difficulty
- allowing more time to provide support for vulnerable families
- improving links with families who have engaged with EGL
- clarifying the role of the navigator.

Document 10

EGL personal budgets were valued but there was room to improve

About EGL personal budgets

EGL personal budgets, made up from pooled funding from the Ministries of Health, Education and Social Development, can be used flexibly to purchase supports and services. A disabled person's EGL personal budget can include funding from the Ministry of Health, Ministry of Education and Ministry of Social Development (see Individualised and flexible funding for disabled people page 18). In practice this has meant that around 70-80% of the pooled funding is from Vote Health, with the remainder from the other two Votes. The most common support services funding that was transferred to an EGL personal budget was Home and Community Support Services (HCSS).

All people who were allocated an EGL personal budget had the same responsibilities as a person using Individualised Funding to purchase their own Home and Community Support Services. These responsibilities included managing their budget and purchasing/commissioning their own support services. The latter often involved employing staff.

Most participants had taken up their funding

As at 9 October 2015 there were 175 EGL participants and 129 had been allocated funding (Table 1). People needed a plan to receive their funding. Most of those who had not been allocated their funding at this point had paused their engagement with EGL or were still working the planning process (eg because they were new or had taken some time to decide what they wanted). Other reasons for not receiving funding were that people were not eligible for Demonstration funding or did not have an agent who could manage the funding.

Table 1. Programme - EGL (participant count with allocated funding)

Types of participants		Number of EGL participants allocated funding
Opt-in	Phase 1	10
	Phase 2	9
	Total	**19**
School leavers	Phase 1	43
	Phase 2	39
	Phase 3	28
	Total	**110**
Grand Total		**129**

Source: Ministry of Health data

Some EGL participants opted to take the funding but not navigation (8 as at 9 October 2015). These participants tended to use their funding to attend day programmes and/or residential facilities.

Analysis of the case study data revealed a distinction between those in case type 1[37]and those in case types 2 and 3 in terms of use made of their EGL funding. Those in case type 1 all used their funding from all sources to attend day services and residential care.

However those in case types 2 and 3 were not using their funding to attend day services or residential care. They were mostly using their funding to employ their own staff to assist with personal care and support community engagement. Some were using it to engage in education and training and one had purchased equipment that supported their engagement in the community.

There were factors that supported disabled people and families in the use of the funding but there was room to improve

Being financially literate and well resourced assisted people to take up the funding and manage it

International research indicates that financially literate and better-resourced families with extensive social networks are best placed to make the most of personal budgets (Harflett et al., 2015). This appeared to be the case in this evaluation. The navigators interviewed reported that those who were most comfortable with taking up the funding were typically well placed to do so. One navigator said:

> *So the people who take it up are generally people who are well resourced – who are – who – their lives – their lives are – how do I say it? Their lives are already quite organised and – things are going well.*

Across the case studies, those who were most comfortable managing the funding either on their own or with some assistance from MIC had previously used Individualised Funding or had run their own business. For example, one family described themselves as completely comfortable managing the funding as they had *"used IF* [Individualised Funding] *for years"* and described it as a *"brilliant system"*. Another parent who had run her own business also reported that managing the funding had been straightforward and MIC had been available if there were any problems.

Pooling the funding and having greater flexibility in the use of the funding were important but there was a desire for more

Prior to EGL, families received different amounts of funding from different agencies. Having the funding all in one pool simplified arrangements for families. As one family reported, previously they had funding for Individualised Funding, personal care, MSD for hours and carer support through different agencies (MIC, CCS, IDEA). The parent reported that *"EGL has put all the funding together under IF* [Individualised Funding] *funding".*

---

[37] There were three types of cases:

- Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care.
- Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
- Case type 3: Movement towards living a life in line with the EGL principles (opt-in)

Refer to Appendix 2 for more information on the case studies.

An EGL team member interviewed reported that the change in funding is broader than just what families can purchase. Families have been able to purchase things for some time under Individualised Funding but the scope of what they can purchase under EGL is broader and this is the first time funding has been pooled across agencies. A family member who had used Individualised Funding for years summed this view up when she said *"EGL was the icing on the cake"*. The Individualised Funding is the base but the inclusion of the MSD funding and flexibility of use provided them with more options for meeting the needs of their young person.

Taking up Individualised Funding and managing the money was difficult for many families and disabled people

The evaluation found that not all families were comfortable with the responsibilities associated with managing their budget. The case study research and interviews with local officials and members of the EGL team revealed not all families had the skills, confidence or time to manage the funding. Those who were less financially literate, were facing multiple challenges, had not previously used Individualised Funding or had not run their own business typically found the prospect of taking up and managing the funding challenging. In the case studies there were examples where people had avoided taking on the management of the funding because it was daunting. A parent in one such case reported she admired the people who are able to manage the funding but she didn't think she was one of those people. She added that many parents of young disabled people were *"stressed and tired people".*

An official from MIC confirmed this view, stating that working with EGL participants can take longer than working with people just taking up Individualised Funding. This was because engaging with EGL combined with leaving school is a big change for disabled people and their families. She added that families have to be in the right place to make the best use of the funding and she spends more time coaching the EGL families. For example, with Individualised Funding recipients she would normally only take a couple of days to do the set-up but with EGL participants it takes a month or more.

Even some of those with previous experience of running their own business found the prospect of managing the funding daunting. For example, one family who had previously taken up Individualised Funding did not want to manage the funding because of the time commitment involved. In another case, the family had previously run their own business and were now comfortable managing the funding but admitted it had been a steep learning curve.

A local official reported that the navigators played an important role in building confidence to take up and manage the funding. However, it was not always just a matter of having the financial skills and confidence to manage the funding. Members of the EGL team interviewed reported that some families and disabled people were not in a position to manage the money. They cited the example of a family where no one in the household had a bank account, access to the internet or a reliable phone. In this example, the family also had problems with drug and alcohol misuse and ill-health. This is consistent with other research, which indicates that disabled people who do not have supportive social networks, financial resources and family with the skills and knowledge[38] to support them if they need it are less likely to take up individualised budgets (Harflett et al., 2015). Research indicates that support required for disabled people and their families in planning and spending the funds allocated needs to sit alongside the provision of a personal budget (Carter Anand et al., 2012).

The amount of funding was insufficient to cover what young people wanted to do

The contexts in which families reported the funding was insufficient to cover life in the community included the following. Carter Anand et al. (2012:36) indicate that having too little funding *"may ultimately deny disabled people any real choice".*

Where the young person wanted to live independently in the community, cost was a significant barrier

Across the cases, several families reported they wanted their young person to live more independently in the community but the cost of doing so was a significant barrier. Families reported there were few options apart from living at home or in residential care if the young person required significant assistance with daily living tasks. One parent whose young person was in residential care reported she gets cross when she hears people talk about all the things they could do with the funding. She felt this was only really the case for the more able bodied – *"It's not the case for people who need 24-hour care or have intellectual disabilities or the people who are not nice"* (eg have very challenging behaviours). Flatting with others was possible but difficult to set up and there were concerns about the sustainability of the arrangements. One young person who was profoundly disabled was flatting. However, the family were concerned that once the young person's sister could no longer live with him and receive Funded Family Care (FFC)[39] they would not be able to sustain the arrangements.

In another case, the young person was living at home and the family did not know how they would afford supporting him to live in a flat. In another case the young person wanted to go flatting but he and the family were unclear how that would happen. The young person said, *"I can't be going flatting – there are still big barriers."* He was fearful of ending up in a residential facility if he could no longer stay at home in the care of his family.

Purchasing a house with other disabled people has been raised as a possibility but families typically saw this as complex to set up, costly and not sustainable in the longer term. For example, one parent said: *"It seems like it is a really big leap from simply selecting a provider to actually going it alone and setting up a house for* [our son] *ourselves."*

---

[38] For example confidence, assertiveness, negotiation skills, being articulate, and money management (Harflett et al., 2015).

[39] Funded Family Care is Ministry of Health funding for some eligible disabled people over the age of 18 with high or very high needs. This means that if they are eligible for Disability Support Services funding they may be able to pay the people they live with to help them with their personal care and/or household tasks. http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care

Where families were on lower incomes, the amount of funding they received may have been insufficient

For example, for one family on a low income, there was not enough funding to enable their high needs young person to access social activities in the community, attend courses and go flatting (see Material wellbeing was constrained for many, page 80). In another case a low-income family where both parents worked reported they felt EGL was for the *"nice middle-income people".* They acknowledged that some have set up good solutions for their disabled family members but they have the income to support that.

International research indicates that having access to family financial resources is important as they are used to enable better outcomes for individuals by filling gaps or supplementing personal budgets (Harflett et al., 2015).

The funding may have been insufficient to support disabled people's choices where family could not be involved in the day-to-day care of their young disabled person

In all of the cases where the young person was actively engaged in EGL and doing something different, a parent or family member was available for significant parts of the day to assist the young person. One of these families commented that if parents were not involved with the care of their disabled young person the budget would be insufficient. For example, in this case the family was available and able to cover the cost of transporting their very high needs young person to and from activities but they were not sure how they would fund the transport if they were unavailable. Currently the purchasing guidelines do not allow the funding to be used to pay for transport.

Families had some useful sources of advice and guidance but more was needed

MIC was instrumental in advising families about management of the funding but more help was needed

Many families in the case study research cited MIC as an important source of advice and support in managing the funding. MIC is an Individualised Funding Agency appointed by the Ministry of Health to arrange Individualised Funding and support disabled people with that option. MIC provides budgeting advice, planning assistance, and advice on employing staff. A member of the EGL team in Christchurch reported that to date MIC has shouldered a lot of the responsibility for guiding and supporting people to manage their budgets and their own spending.

Nevertheless the evaluation concluded families needed more support to understand their roles and responsibilities regarding the management of the funding. An EGL team member and a representative from MIC reported that some disabled people and families did not always fully appreciate the responsibilities they were taking on when they took up personalised funding or employed staff. People who had previously employed someone understood more readily what they were accountable for but others *"say they understand when they don't".* Some families required more advice and support in this area.

Research indicates that building the capacity of disabled people and their families to manage the money needs to go hand in hand with Individualised Funding. This is particularly important where people have additional vulnerabilities or restricted capacity (Fisher et al., 2010).

Navigators were able to provide guidance to disabled people and their families

Some families interviewed reported that the navigators were an important source of advice about and support with EGL funding. Families did not always use the navigators for this purpose but liked that they were available if need be.

The purchasing advisory panel worked well

Those interviewed who were closely involved with the purchasing advisory panel reported it worked well. The panel met as needed. Where families were seeking to purchase something that may have been outside the guidelines or was a large purchase, they completed a form with assistance from MIC if needed. Their case was then presented to the panel, who decided what was funded. Representatives on the panel who were interviewed all reported that it was helpful having a range of people around the table as they all came at it from different points of view and could offer alternative solutions to problems raised. The panel often had to make difficult decisions and as one interviewee reported, *"it's good to have several heads around the table to make the decisions rather than such decisions falling on one person".*

There was a need to clarify elements of the purchasing guidelines[40]

A representative from MIC reported that the families all get a copy of the purchasing guidelines when they begin working with them. MIC stated that the guidelines were very important as they made it easier for families to understand what they could and could not purchase.

Nevertheless the case study research and interviews with members of the EGL team revealed that families were not always clear on what they could purchase with the funding and what they could not. This was especially the case in relation to purchasing items. For example, what is considered assistive technology is not always clear. The navigators, members of the EGL team and many of the families and some school representatives interviewed reported that disabled people used their smart phones for safety. If the disabled person was lost, for example, they could text a picture of their location to a caregiver. A family member who found it difficult to access communication technology for her young person to help with everyday life said: *"It's so a must. Having to apply for it is a barrier. He should just get this technology and it needs to work. He needs the right equipment to do his daily activities."*

Families and the members of the EGL team interviewed recommended greater clarity on what could be purchased. A member of the EGL team suggested:

> *I understand the nervousness. My view is, let's get on the front foot with it. Let's justify and really be clear about what we're doing. Let's have a behind-the-scenes conversation with the various parties, if that's really what will worry people so that we don't have to defend it because we agree this is the right thing for these circumstances, as long as there's a trade-off.*

---

[40] These have been updated since the evaluation.

Employing staff was largely a positive experience but there were challenges

Families valued being able to employ their own staff

The case study analysis revealed that in five of the ten cases, families had chosen to employ staff with their pooled funding. In one case the family employed seven staff to provide care for their young person. Across these cases employing staff had largely been a positive experience. The benefits of employing staff were reported as the following.

Families appreciated being able to choose who came into their home

Families reported that they did not have to accept who they were given. For example, in another case a parent with a disability relished being able to choose who came into his home. He explained that he had previously been sent support workers who did not meet his needs and in some cases treated him and his young person disrespectfully. The parent said:

> *They never did anything to help us. We needed – I wanted help with the tea like I have now. Sometimes I help her* [he gestured towards his carer who was preparing a meal] *and I want to know how to cook, how to cook different meals but they didn't show me.*

In another case the family also had had negative experiences using agency staff (eg inappropriate carers, limited flexibility). They reported they valued being able to choose who came into their home and that it was *"so much nicer for [their young people] to be in their own home, to be with the people that they trust, that they know really well"*.

Some parents also reported they appreciated the ability to dismiss someone who was unsuitable.

Families had greater flexibility to engage in activities in the community

For example, one parent employed a support worker because she wanted her son to get out in the community in a way that he would like to be in the community, using the Individualised Funding and not having to measure up to other people's criteria. She wanted him to be able to access a broader range of activities in the community (eg going to watch a rugby or soccer game with his support person and friends or go swimming at the beach). In their experience, services had restrictions about where they can take people; for example, they wouldn't go to the beach. She was happy they had found a good person who could do what her young person wanted.

Disabled people were able to receive more personalised care

Families reported that employing their own carers allowed them to choose carers who best met the needs of their disabled person. For example, in one case a mother reported that the carers they employed were more responsive to what her young person wanted to do on any given day. *"They can take him out and about but also if he wants to lie on the couch he can."*

One parent reported their young person received better care because they were able to hire people with a similar outlook:

> *They're not just doing – we don't feel – they're not just doing a job. They actually – you can see it in the interactions they love their job, they love being with* [our young people]. *It's actually – and we've said from day one it's not about – it's about* [our young people]. *It's not about anything else. It is about them and their good life. And they embrace that.*

Disabled people were able to receive better continuity of care

Having consistent carers was seen as a benefit of employing your own support workers. Families reported that the benefits of this were that:

- their young disabled people were more settled: In one case, the family employed several carers to look after their young person but there was a lot more continuity in his life and he was doing more for himself. Having the same regular carers now helped him feel more settled according to his mother. She explained that he tends to play up when he gets a new carer. When he attended a day service he had many different carers
- there was less risk of infection: One family found that before having consistent carers their young person had more infections and visits to the doctors.

There were factors that helped people employ staff

Families interviewed reported that in employing and managing staff they found it helped to:

- have had previous experience employing staff and be financially literate
- have support from MIC: MIC assisted families by making it clear to them what the employer role entailed. While some understood what was involved because they had previously employed staff, others said they understood when they didn't. They entered into employing someone and suddenly they had a personal grievance and were overwhelmed. MIC also provided liability insurance (see below)
- be able to employ staff on contract: This suited one parent because they avoided having to contend with PAYE. She sent the claim form, including expenses to MIC and paid her employee out of what she received. Her employee also preferred the contract arrangement as it gave him flexibility to take time off for his sport
- provide support to their staff (eg training).

Employing staff was not without its challenges

Interviews with disabled people and families and EGL staff revealed that families and disabled people faced several challenges employing staff. This is consistent with the experiences from evaluations from the UK and US, which strongly suggest that disabled people most need support and information in relation to being an employer (Jeon et al., 2015). The main challenges with employing people identified in this evaluation were as follows.

The prospect of managing staff and pay was too onerous for some families

Families with no experience of employing staff were daunted

A member of the EGL team in Christchurch reported that the employment of staff is challenging for some families:

> *The system is not easy, you know. If you want to employ people it's huge. Who do you employ? How do you get the contracts? Are they going to turn up? What happens if there is a grievance, you know? Do I want them in my house? Where do I send in the payroll? We've had that one. He'd never been paid for ages.*

Families who had employed staff reported that employing staff is not for everyone. A family member who was comfortable employing staff reported that she would recommend EGL to other people, but not to people who are not good organisers or may be dysfunctional as there is some work involved. She would not recommend it to people who are not used to paying people.

Australian research found that while people who managed their own workers enjoyed the flexibility and choice of their current arrangements, the additional administrative requirements of person-centred planning and support could be difficult (Fisher et al., 2010).

Juggling work commitments and managing carers was seen as too difficult for some

Some families were reluctant to employ staff to care for their young person because of the challenge of juggling work commitments and managing carers. A family who reported they were interested in employing staff at some point were concerned about how they would manage that and working as well. The mother explained she and her husband both work in minimum wage jobs and did not have the flexibility to also be organising her young person's life at the moment. She said: *"How do people who have to work full-time do this? They can't just drop everything and help out if a carer gets sick. It's unrealistic for some families to do all this."* She wanted EGL to put some more supports in place for working parents becoming employers.

Another parent commented that there is an assumption with EGL that parents have the time, inclination and ability to set up and manage the employment of carers but that is not always the case. In their case the parents worked and had recently stopped employing staff and placed their young person in residential care and with a day service, because it was less onerous than managing employees and work commitments. The parent reported:

> *I know that wasn't the idea of the exercise [EGL] but that's the reality of it for me and the hardest bit was not having a real choice and I'm constantly – I have to take the phone with me because things happen, just small things. Did she get picked up, did she get dropped off? One day I'm in a multi-disciplinary team meeting at [a hospital] and she's supposed to be horse riding and I get a text to say that the horse's feet are sore and I just think, "Far out man, what am I supposed to do now?", you know. No, it's a – and I just think – so I – you know, here I am trying to read out files to the [specialist] and, "The horse's feet are sore". It's just as well I've been here for a very long time on and off and they know her well.*

Employment disputes have added challenges in the context of a caring relationship

Employment disputes have added challenges in the context of a caring relationship. An EGL team member reported that disabled people can be vulnerable where they are the employer and are also the one receiving care or support. Employment dispute processes often assume that the employer has more power when the employment relationship breaks down but this may not be the case in a caring relationship. An EGL team member reported:

> *That can get very tricky because how do you performance manage the person who provides you with day-to-day support that you must have? Sometimes it's not that easy. In situations like that it's really helpful to have an ally. It's really tough to end things that aren't working.*

The normal employment processes are cumbersome in dealing with employment problems in this context. A family who had employed staff to care for their young person and faced an employment dispute reported that they found the dispute process very stressful. They felt there was a lack of clarity about what to do when an employment relationship involving personal care breaks down. The requirements to give several written and verbal warnings meant someone could be receiving care for some time from a carer who was unsuitable for them. Moreover while they had liability insurance through MIC, there was uncertainty about whether it applied to their situation. Even with liability insurance families still needed to pay the liability excess. For those without liability insurance the costs could be significant especially for those on low incomes. The parent added that this was a flaw with EGL and taking on the employer role is risky. She said, *"With what's happened, I can't look families in the face and say, 'Get on board Enabling Good Lives. It's great.' Because I said there's actually a few holes in the safety nets."*

Frustration at not being able to employ family at the same rate as non-family

Some families expressed frustration at not being able to employ family at the same rate as non-family. In the interviews undertaken with families, three disabled people had also taken up some hours of FFC as part of their support budget where they were employing their parent(s) who lived at home with them. The funding was taken up in the main because family were still required to provide support to their family member during the day and night.

For one family, moving to receiving some FFC meant they received less money than before. The FFC rate paid to family is lower than the rate paid to a person to provide support through Individualised Funding. They were frustrated as they reported that this had not been explained to them beforehand. However, the families reported that they had no choice but to take up FFC as their young person needed 24-hour care and the family needed income. The lack of support available meant a family member (usually the mother) could not engage in paid work. As they were doing the same work as support people, they would have liked to have been paid at the same rate for the shifts they were doing. In some situations a parent would fill in unexpectedly for a shift if a paid support person was sick and received no payment. Some reported that they were struggling financially as they found the combination of Individualised Funding and FFC was not enough to support their family.

Not being paid at the same rate as non-family carers also had a psychological impact. Family members reported feeling devalued when they were not paid at the same rate as non-family carers. This was the case for a family who was reluctantly considering taking up FFC for a daughter who flatted with their disabled sibling. The mother explained her daughter currently manages the house, which includes the seven people employed to care for her sibling, and his medical care in the house. She is not paid for this work but the mother felt FFC was a poor option because it undervalued the work done by the daughter whom she felt was *"worth more than $14.70 an hour!"*

These situations highlight the need for sufficient support cover over 24 hours, and the challenges faced by family with their reduced payment through FFC and the impact of this on their self-esteem and ability to make the budget work.

Finding the right staff could be challenging

An EGL staff member reported that some people are not able to use their funding because they are struggling to find staff. In one of the cases the family had not employed staff because they could not find the right people who were willing to provide assistance for a couple of hours a day. Many potential carers could not drive or did not have transport, were unwilling to assist with toileting or wanted more hours than they needed.

International evidence suggests that availability of qualified support workers for disability support is fundamental for implementing personal budgets (Carter Anand et al., 2012).

Suggestions to make it easier for families to employ staff

Families and EGL staff interviewed offered suggestions to make it easier to employ staff:

- *More work is needed to support families as employers, especially when disputes arise.* Several interviewees reported that MIC provided good advice about what was involved in employing someone. However, some interviewees reported there was not enough support if a dispute arose.
- *Education should be provided for support workers about the home care environment,* to take the support worker through a process that would teach them about the care environment in a home (eg home care support is not like working for an agency or working for The Warehouse or the supermarket as people are often vulnerable). Employees need to be aware that sometimes things can change quite quickly and they might find they don't have employment. Australian research indicates that having a successful working relationship between support workers and clients or their families, combined with ongoing support and training by the provider, best supported employee development and retention (Fisher et al., 2010).
- *Establishing a group that could shoulder more of employer responsibility* would mean that if employees were part of an agency the employee could be placed in another employment situation quickly if relations broke down. One interviewee reported that under this arrangement the disabled person would not shoulder the full responsibility of being an employer, it would be important that they retained control over who supported them, what they did, how and when.
- *The use of flexible disability support contracts between disabled people and providers may help* (see page 28). Providers could potentially support disabled people in

employing staff by assisting with human resource matters (eg interviewing, recruitment, the payment of wages, police vetting, and backup if a dispute arises). Disabled people could pay for that service if a fair and reasonable cost was determined.

6. Some positive outcomes for disabled people and their families

Summary

- As at 9 October 2015 there were 175 EGL participants. Most of these were school leavers. Participants had or were attending a mix of special and mainstream schools.
- There was broad agreement amongst those interviewed about what constituted a good life. A good life involved people doing things that interested them and doing meaningful activities and being included in the community. There was some distinction between those families who engaged with EGL and those who did not. Those who engaged with EGL had higher expectations of what their young person could do post-school.
- Findings from the research looking at quality of life found:
  - Wellbeing: physical and emotional wellbeing were good but material wellbeing was low
  - Social participation: interpersonal relationships with family were good but improvements could be made in the rights and social inclusion domains
  - Independence: improvements could be made in personal development and self-determination outcomes
- There appeared to be limited change to family outcomes.
- Improvements are needed in the measurement of outcomes for disabled people and their families.

Who was engaged with the Demonstration?

EGL was primarily targeted at school leavers defined as those aged 18-21 with high needs (HN) or very high needs (VHN) ORS funding in Christchurch. There was some scope to allow people with disabilities who did not meet the legibility criteria to opt into the Demonstration.

As at 9 October 2015 there were 175 EGL participants. Of this number:

- most were school leavers (aged 18 to 21 years old): 135 were school leavers and 40 were opt-ins. Examples of opt-ins were people who were between the ages of 13 – 18 and have high or very high needs ORS funding, recent school leavers who previously received ORS funding and are not satisfied with their current disability support arrangements and school leavers with significant needs but who are not in receipt of ORS funding.
- there were more male participants (100 males compared with 75 females). The majority of participants were aged 20 to 23 years but ages ranged from 14 to 48 years
- most were Pākehā: ethnicity of participants was primarily Pākehā (over 80%). Few participants were Māori or Asian (less than 10% each)

- most (100) EGL participants had received HN ORS funding in line with the eligibility criteria. Sixty-one received VHN ORS funding, 10 received no ORS funding and four received no funding at all.

Participants attended a mix of special and mainstream schools

EGL participants at 9 October 2015 had attended or were attending one of 27 schools. Most of the schools were mainstream schools which included staff and facilities to support students with learning difficulties. There were four day special schools that only catered to students with a high level of need. As at 9 October 2015:

- 34% of EGL participants had been or were enrolled in the specialist schools (Allenvale Special School, Ferndale High School, Van Asch Deaf Education Centre, Waitaha, Southern Regional Health School, Central Health School)
- 76% of EGL participants had attended or were attending one of seven schools (Allenvale Special School, Ferndale High School, Hillmorton, Cashmere, Riccarton, Papanui and Van Asch Deaf Education Centre)
- 16 schools had only had between 1 and 3 students who were EGL participants.

What is a good life?

Across the cases, families and disabled people agreed that a good life involved people doing things that interested them and doing meaningful activities in the community. The EGL team and navigators interviewed agreed but added that having a good life involved people having a sense of belonging and the ability to make choices about their lives.

While there was broad agreement amongst those interviewed about what constituted a good life, the EGL team and navigators interviewed cautioned that understanding of the concept was highly variable across the families they dealt with. Some disabled people and families had a clear idea of what a good life looked like for them, whereas others did not.

In the case study research there was some distinction between those who engaged with EGL and those who did not. In the cases where the families had opted to place their young person in residential care, there was a tendency to have a static view of what was a good life for their young person. The families who had had no contact with the navigators had few expectations of any growth or change in their young person. They described the young person as if they were a child. They reported that in transitioning to life beyond school the best option was for their young person to carry on doing similar activities in an institutional setting to what they had done at school. We do not know if this would have changed had they had contact with a navigator. However, in the other case in this group the family had had contact with a navigator. The conversations with the navigator had broadened their view of what was possible for their young person. They wanted their young person to be living away from home because that was the normal transition for young people reaching adulthood. There was an expectation that their young person would continue to grow and develop.

In all of the cases where the families and disabled people had engaged in EGL and were doing something different, the parents had an expectation that their young person would learn and grow as they got older. Their expectation was that their young person would have as normal a life as possible in the community. This meant doing everyday things in the community like their peers, for example getting a job, doing further study, going flatting, following their interests. It also meant avoiding residential care and specialist or segregated service providers.

Quality of life outcomes

The Enabling Good Lives approach is ultimately about improving the quality of life of disabled people. A survey of people eligible to participate in the Christchurch Demonstration was conducted to assess quality of life outcomes. The key objective of the quality of life survey was to understand what outcomes were being achieved by those participating in Enabling Good Lives and what contribution Enabling Good Lives has made to those outcomes.

Data were collected about 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). The response rate was low (34%).

The quality of life measures used were based on a framework developed by Robert Schalock. Quality of life is a multidimensional construct developed by Schalock and others (Schalock et al., 2002). It is composed of eight core domains: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and rights. These eight domains can be grouped into the three broad areas or factors outlined in Table 2 (below).

Table 2. Schalock's quality of life framework

Quality of life factors	Quality of life domains
Independence	**Self-Determination:** Autonomy/personal control; Goals and personal values (desires, expectations); Choices (opportunities, options, preferences) **Personal Development:** Education (achievements, education status); Performance (success, achievement, productivity); Personal competence (cognitive, social, practical skills)
Social participation	**Interpersonal Relations:** Interactions (social networks, social contacts); Relationships (family, friends, peers); Supports (emotional, physical, financial); Social activities **Social Inclusion:** Community integration and participation; Community roles (contributor, volunteer); Social supports (support networks, services) **Rights:** Human (respect, dignity, equality); Legal (citizenship, access, fair treatment)
Wellbeing	**Emotional Wellbeing:** Contentment; Self-concept; Lack of stress (predictability and control); Safety and security; Spirituality/culture **Physical Wellbeing:** Health and wellness; Activities of daily living; Physical activities including recreation **Material Wellbeing:** Financial status; Employment status; Housing status; Having possessions

In the survey, the quality of life questions identified aspects of quality of life that many EGL participants and their proxies were positive about and some that they were not. Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators. Indicators were classified as:

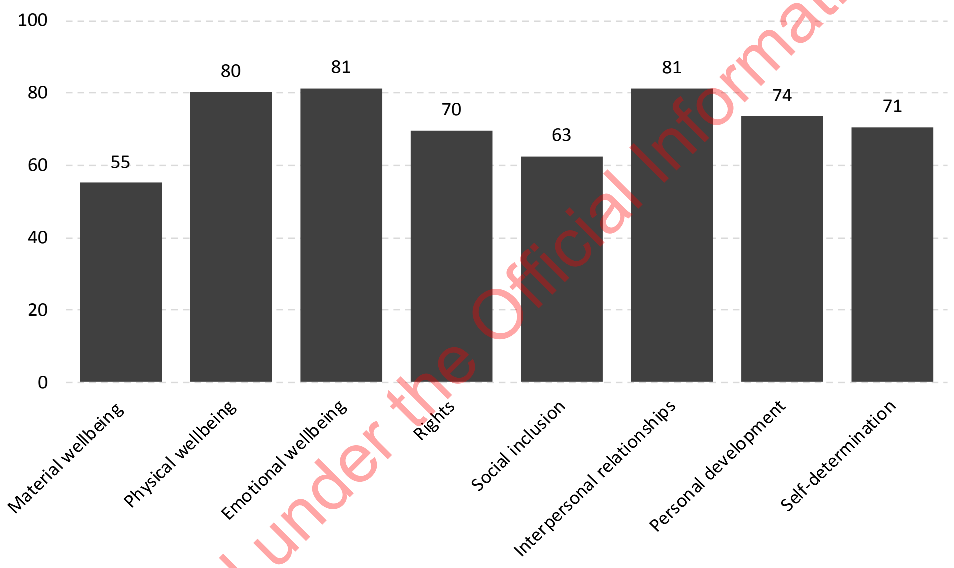
- foundational – indicators of core elements of quality of life expected for everyone, or
- aspirational – indicators of aspects of quality of life that the EGL programme aims to influence.

These indicators were developed in consultation with the Local Advisory Group in Christchurch.

Overall quality of life outcomes

The chart below provides an overview of scores in each of the quality of life domains (Figure 4).

Figure 4. Quality of life scores combining young survey respondents and proxy responses (n = 43)



Note: Scores are shown for overall indicators.

Across the overall scores for the different domains:

- the highest scores were recorded in physical wellbeing, emotional wellbeing and interpersonal relationships
- the aspect of quality of life where scores were lowest was material wellbeing.

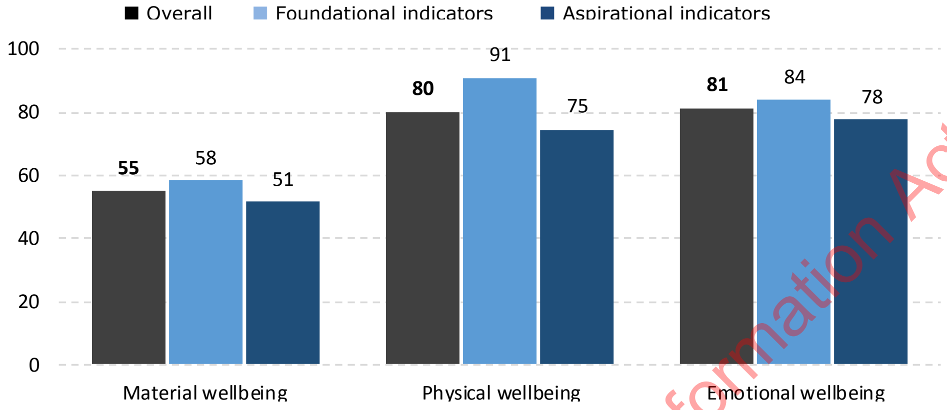
As expected, overall scores were consistently lower for the more aspirational indicators than for foundational indicators. Tracking some of these indicators over time has the potential to measure changes as a result of the EGL programme. However, it is important to recognise that in some areas the scores for the foundational indicators were also low (eg indicators of material wellbeing, and social inclusion).

There were differences between young survey respondent and proxy responses. Differences might reflect the degree to which different disabilities influence people's daily lives. Others might reflect differences between youth and parents that could be noted across the population as a whole.

Wellbeing

Wellbeing encompassed material, physical and emotional wellbeing. Analysis of the quality of life survey found that overall scores were highest for physical and emotional wellbeing and lowest for material wellbeing. Overall results combine young survey respondent and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators (Figure 5).

Figure 5. Wellbeing scores combining young survey respondents and proxy responses (n = 43)



Note: Scores are shown for overall, foundational indicators and aspirational indicators.

Emotional wellbeing was typically reported as being good

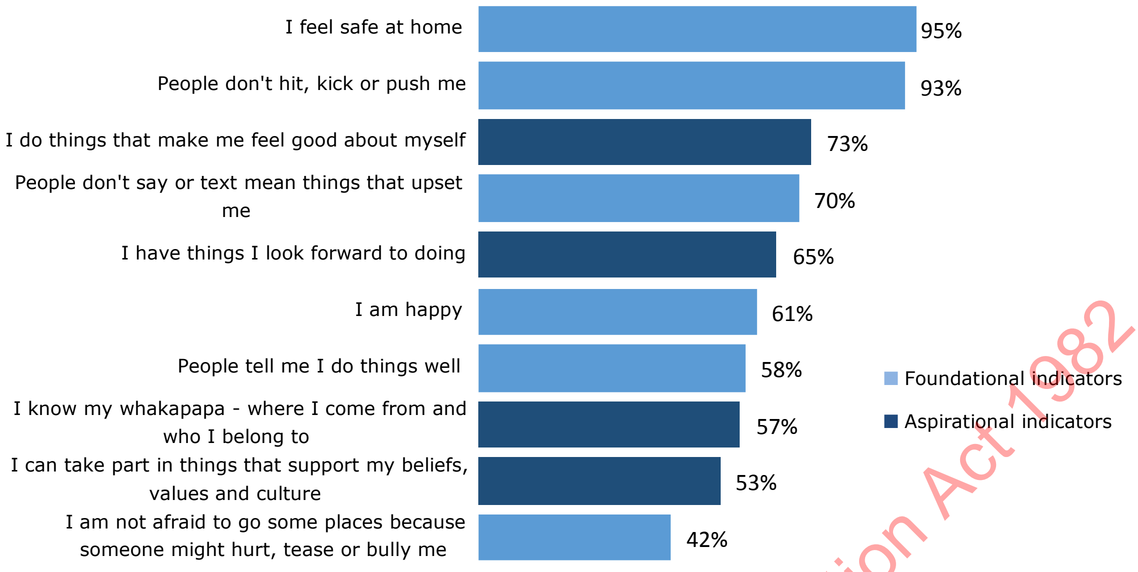
Overall emotional wellbeing was reported as high

Analysis of the quality of life survey found that foundational indicators for emotional wellbeing had a slightly higher overall score (84) than the more aspirational indicators (78). This pattern was evident for both young survey respondent and proxy responses.

As Figure 6 indicates, there was no clear distinction between the foundational and aspirational indicators with respect to the proportion of positive responses. However, the scores indicate that while people's basic needs may have been met (eg feeling safe at home, not being physically hurt) there was room for improvement on all the other indicators. In particular three of the foundational indicators were low, especially *feeling happy, being told they do things well* and *not feeling afraid to go some places.*

While the overall scores for proxies and young survey respondents for emotional wellbeing were consistent, there were some differences in their responses to individual questions. All of the proxies reported they felt *safe at home*, while one-tenth of the young survey respondents gave the neutral or negative answer. Young survey respondents were more positive than proxies about *feeling happy*, *knowing their whakapapa*, and *not feeling afraid to go some places*.

Figure 6. Emotional wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 38-43)



Case study research found overall emotional wellbeing was good

In the case study research the emotional wellbeing of the young people was reported as being good by young people, or parents where the young people could not answer. In the cases where the young people had moved into residential care the families all described their young people as usually cheerful and happy. However, the one young person who could answer only reported he was OK most of the time. There had not been any change for any of these young people over the course of the Demonstration.

By contrast, emotional wellbeing was reported as improved in all the cases where the young people had made changes in their lives following active engagement in EGL (as either opt-ins or core participants). The young people were reported as having more stability and being happier and more relaxed. For example, a parent reported that one young person who had a profound intellectual disability was now engaged in more self-soothing behaviour – *"He's settling himself more rather than seeking out others to make him feel better when agitated."* The mother gave a variety of reasons for this change: having consistent carers that they had chosen, living where they wanted to live and undertaking activities they chose.

Some young people interviewed who were engaged in EGL still experienced considerable stress but this was not related to the Demonstration

Examples of difficulties that caused stress included:

- *challenging family relationships:* For example, in one of the cases the young person had a difficult relationship with one of the parents and this was still an ongoing source of stress
- *uncertainty about future living arrangements:* In another case the young person was facing a number of challenges that impinged on their emotional wellbeing. While the young person was happy not using respite services and was enjoying tertiary studies, the uncertainty about where he would live in the future if his family could not care for him contributed to his anxiety. The parent reported that *"if it's hard work for the*

parents it's going to be harder work for our young people and some can't talk and he just frets about this stuff". The young person was adamant he did not want to be in an institutional setting

- *social isolation due to poverty:* The young person and the parent reported that he experienced a degree of social isolation which negatively influenced his wellbeing. Opportunities to socialise with his friends or meet new people were constrained by his dependence on a parent for transport and not being able to afford alternative forms of transport. For example, the parent reported a taxi typically cost $70 to transport him to where he needed to go and this was too much for their family, as they were *"living on a shoestring".*

Young people reported feeling safe at home but there were some concerns outside that environment

Safety was an important component of emotional wellbeing. In the quality of life survey almost all those who completed the survey considered they were or were considered to be *safe at home* and that *people did not kick or push me*. In the case study research, interviewees in all the cases reported the young people felt safe with the transport options they had, with their families and in their neighbourhoods.

However, both the survey and the case study identified safety concerns outside the home environment. For example, a substantial number of survey respondents were concerned about bullying. Bullying through texting and being afraid to go some places were issues for some young survey respondents and proxies. For example, 30% considered that sometimes or often *people said or texted things that upset them*. The majority response to a question about *being afraid to go some places because someone might hurt, tease or bully them* was the 'middle' option of 'sometimes' (56%). Research indicates that disabled people are at greater risk of bullying than their non-disabled peers (Blake et al., 2012; Chatzitheochari et al., 2014; Sentenac et al., 2012).

Some case study interviewees identified previous instances of problematic behaviour by residential facility staff and school staff. In several of the cases families gave examples of previous instances of distressing practices in the residential facilities the young people stayed in and in one case a school the young person attended. In two of the cases the young people were still attending these facilities. These practices included: carers providing young people with food that was not allowed, providers having too few carers to meet people's needs, young people being placed in residential care with inappropriate people and the young people getting hurt[41].

Physical wellbeing varied

Survey respondents could readily visit health professionals but few feel healthy

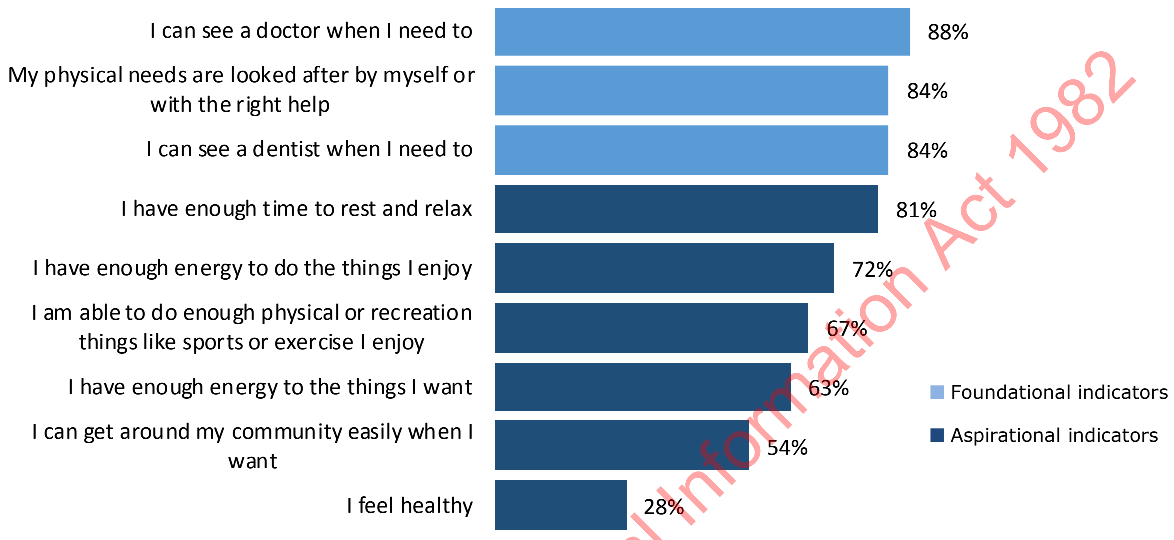
As Figure 7 illustrates, analysis of the quality of life survey found that the majority of survey respondents had high scores for the foundational indicators for physical wellbeing; for example, they considered their *physical needs were met* and they *could*

---

[41] Research indicates that influencing variables such as the characteristics of residents in a specific setting, the culture of a residence, the staff employed within a residence, and the size of the residential setting have a strong influence on the wellbeing of residents (Francis et al., 2014).

see a doctor[42] or *dentist*. Most respondents also reported having enough time to rest and relax (an EGL indicator). However, all the other scores for the more aspirational indicators were lower. Relatively low numbers reported being able to do enough physical or recreational activities[43], and get out in the community when they wanted, and having enough energy to do the things they wanted. *Feeling healthy* had a markedly lower score than other indicators.

Figure 7. Physical wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question on physical wellbeing (n = 43)



There were differences between young survey respondent and proxy responses to the foundational indicators that may reflect differences between those living independently and those living with their parents. The indicator where there was the most difference between proxy and young survey respondents was *I have enough time to rest and relax* (63% of young survey respondents compared with 96% of proxies).

It appeared EGL had little influence on their physical wellbeing but there were exceptions

In most of the cases, no changes were observed in EGL participants' health outcomes. There appear to be a number of reasons for this:

- *Some people were very healthy to start with, meaning EGL had little scope to improve their physical health.*
- *Some people had complex health problems that either have remained or were being addressed through the health system*. For example, a mother reported that her young person now had improved physical health but she attributed this to his health care rather than to EGL.
- *Some people were living in poverty, which negatively impacted on health, but this was something EGL had little control over*. Research indicates people living in

---

[42] This was higher than expected as a recent survey indicated that young disabled people in New Zealand have difficulty accessing health care (Peiris-John et al., 2015).

[43] The New Zealand Youth'12 national youth health and wellbeing survey found Christchurch students had less involvement in some positive daily activities. Christchurch students reported lower rates of participation (for an hour or more each day) in vigorous physical activity, or in music, arts, dance or drama (Fleming et al., 2013).

poverty, including those with disabilities, are at great risk of poor health (Emerson & Brigham, 2014). In one of the cases in this study, living in poverty appeared to contribute to the young person's poor health. For example, the family reported that the young person had poor health, especially in the winter, and this was in part related to their poor housing situation. They struggled to get the landlord to improve the house and could not afford a warmer place. Financial constraints also limited the young person's access to exercise facilities, which also contributed to their poor health. EGL had little scope to improve people's financial circumstances.

However, there were three cases where participating in EGL appears to have improved the young people's physical wellbeing. The improved health outcomes appeared to be related to changes in the quality of care and living environment:

- *Improved quality of care following the ability to choose caregivers:* In two situations regarding one family they reported that the quality of care had improved after they hired their own carers. In one situation, the family reported this move had led to health benefits for their young people. For example, prior to engaging in EGL the parent reported:

  > *we just had so much sickness in our household because – you'd have a person that had – that had been doing showers all day and they'd probably done five or six showers and the cross-contamination was just unbelievable. And we were always on antibiotics. The girls were always sick.*

  Once their young people were not attending facility-based respite care and had consistent carers they had chosen, the family reported that they were healthier, with fewer trips to the doctor. The parent reported that their doctor commented on the improved health of their disabled young people:

  > *she said, "My goodness", she said, "where have you been? We don't see you like we used to see you." So we told her about Enabling Good Lives and she said, "Well, it's working because … And the girls are thriving. That's the word. They are just absolutely thriving in every area of their life: health-wise, socially, just, we've watched them just really blossom.*

  There had been significant cost savings for the family associated with improved health outcomes for their young people.

- *Living in a chosen supported environment with non-disabled peers:* In another case, the young person started to walk again after going flatting. The mother attributed this to being around others his age who were all walking. She reported he used to walk but had stopped following a hip operation about four years ago. Nothing had worked to get him walking again. He initially only walked around the people in the flat and the carers but then he did it for her. She said she never thought he'd walk again and the experience opened her up to the benefits of flatting with non-disabled people.

- *Living at home rather than attending a residential service for respite care:* One family reported that their young person's physical health problems related to stress had improved since he stopped going to a residential service for respite care. The mother reported he did not go to the doctor as much. However, her own health was worse as she was now getting no respite.

An Australian evaluation found that levels of personal wellbeing and physical and mental health of most service users using Individualised Funding were similar to the Australian general population norm (Fisher et al., 2010). The evaluation reported participants believed these positive results were due to their increased control over the organisation of their disability support.

Material wellbeing was constrained for many

Evidence from the quality of life survey and the case studies indicates that material wellbeing is constrained for many young disabled people. In the quality of life survey, material wellbeing scores were considerably lower than the scores for emotional and physical wellbeing. The scores for foundational (58) and EGL (51) material wellbeing indicators were similar.

The case study research revealed the young people were financially reliant on their families

All of the young people were reliant on their families and/or government funding for financial support. Given disabled people's reliance on their families for financial support, the financial resources available to the family made a difference to their ability to access the community. In most of the cases the families were able to support their young person to access the community. However, in one of the cases the family was dependent on benefits and struggled much more than the others to access activities in the community. They were forced to choose between the young person attending a tertiary education course and attending activities in the community but they could not afford both.

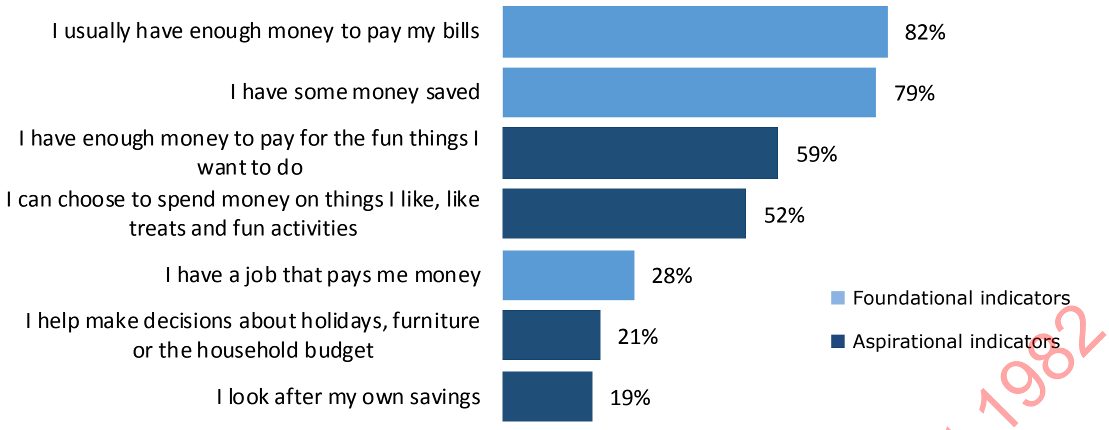
Young people's involvement in making financial decisions varied

Few young survey respondents or proxies scored positively for the measures of financial decision-making.

- Lowest scores were about participation in decision-making about holidays, furniture, the household budget and looking after savings (Figure 8).
- There were differences between young survey respondent and proxy responses, with more of those who completed the survey themselves responding positively to questions about financial independence. This may be related to their level of disability.

The case study research indicated that involvement in decisions about how the money was spent within the family was related to their capacity to understand discussions about how funding was spent. For example, across the cases, the parents of young people with profound intellectual disabilities reported they made the financial decisions because their young person could not. Where people were capable of making financial decisions, families did engage them in discussions about what to do with the funding. For example, one young person with an intellectual disability said he and his mother talked about how to spend the money and he was able to list where the money went (eg board, paying for the carer, transport).

Figure 8. Material wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



Getting paid work was a goal for some young people but it was not easy to achieve

None of the young people involved in the case study research had paid work but it was a goal for some. For example, some were attending Christchurch Polytechnic Institute of Technology (CPIT) with the aim of getting paid employment at the end of their studies.

The quality of life survey revealed few (28%) young people were engaged in some form of paid work. This is not surprising. In New Zealand, as in other developed countries, young disabled people tend to have lower rates of unemployment than their non-disabled peers[44] (Stevens et al., 2013). Eleven of the twelve people who were engaged in paid work liked their job. Of the 18 who did not have a paid job and answered the question, around one-quarter said they had support to get one.

Some young people were engaged in voluntary work

In the case studies some disabled people were engaged in voluntary work. They were typically doing less than five hours a week. For some, engaging in voluntary work was about undertaking something meaningful. For example, one young person volunteered at a wildlife centre, providing information to people about spider monkeys or giraffes, of which he said, *"It makes me proud."*

Some of the families involved in the case study research reported that getting paid work was not a realistic possibility for their young person because of their level of disability (eg they had profound intellectual disabilities). Families in these situations reported that they all wanted their young people to be engaged in something meaningful. Finding positions in the community was dependent on finding supportive people. In one case a family had found a local librarian who, despite the council being unenthusiastic, made a voluntary position for their autistic young person cleaning books. The parent commented:

> *So she was wiping the books, you know, the cardboard books that little kids dribble over and stuff like that. She was folding pamphlets and doing a little bit of*

---

[44] In Statistics New Zealand's 2006 New Zealand Disability Survey, youth aged 15 to 24 with a disability were found to be much less likely to be employed (39%) than those without disabilities (60%). Just 27% of young women aged 15 to 24 with disabilities were employed, compared with 61% of young women without disabilities (Stevens et al., 2013).

> *cataloguing. And she – it was great, I know. And that woman at that library, she was just like – it was going to happen regardless of what [the council] said.*

Some young people and their families saw engaging in voluntary work as a stepping stone to getting paid work. There was some evidence in this evaluation that some disabled young people may be vulnerable to exploitation by workplaces who take them on for extended periods of time in a voluntary capacity. For example, in one of the case studies a young person was working unpaid in a rest home for up to six days a week. Neither the young person nor the family talked about this being exploitative. Instead they were grateful for the opportunity to get work experience. The young person enjoyed the work but reported that ultimately "*I just want to get paid, find a house".* There are indications that this is not an isolated incident, as a teacher interviewed for this evaluation also gave examples of young disabled people working for no pay for considerable periods of time.

Microenterprises were an option for some

In the case study research one family with profoundly disabled young people was looking at establishing a microenterprise[45] to provide employment and a valued role for their young people.

> *We're looking at them starting up their own little microenterprise business which is clothing and accessories, second hand, and over winter lots of people have been donating clothes and bags and shoes. And then working in the summer months so that they go with caregivers, you know, for a few hours to the markets and actually sell their – sell their goods. So that's the plan for that.*

Research on microenterprises involving disabled people is limited but there is some evidence that suggests microenterprises offer opportunities for disabled people to engage in satisfying, meaningful, enjoyable work that may cost significantly less to implement than traditional sheltered workshops and adult day activity centres (Conroy et al., 2010).

Housing is an important part of material wellbeing but choices were limited

The case study research revealed that with the exception of one case, all of the young people in the case studies were living at home or in residential care. In several of the cases the families and the young people wanted to eventually live more independently in the community (eg go flatting).

Families reported that there were few alternatives to residential care or living at home for those with very high needs. For their young person to live in the community, families reported they would have to set it up (eg purchase a house, find flatmates and carers). This was seen as costly, difficult and possibly unsustainable (see The amount of funding was insufficient, page 62). The following quote from a parent sums up these concerns:

> *I'd have to get four other or five other families, buy a house, hire the staff, hope the hell it works, God knows what happens when I'm 80, that kind of thing and I – there's no answers to that and that's not just about Enabling Good Lives but that's – is that where things are headed? And I, you know – some parents think that's*

---

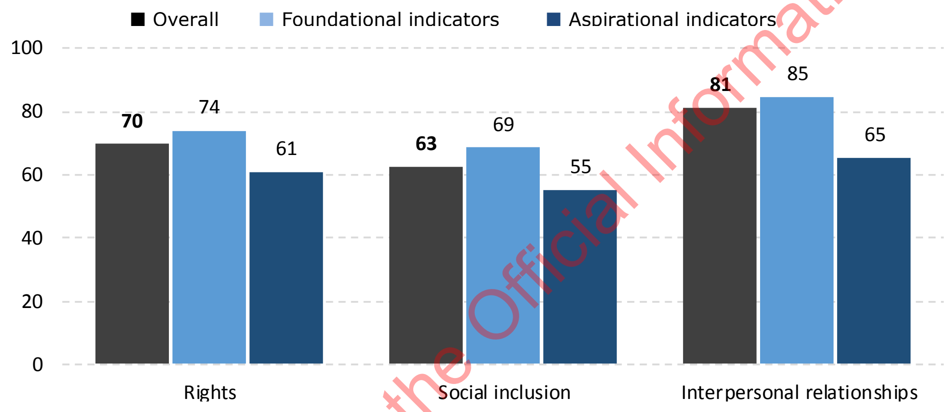
[45] These are very small enterprise owned and operated, usually in the informal sector. They have 10 or fewer workers, including the micro-entrepreneur and any unpaid family workers.

> *great but I wonder how they'll feel in five years' time and what happens when the strong point in a trust or a group of people drops away or you leave or ... it does require a reasonably intelligent, reasonably motivated organised parent, usually a mother, to keep – get it going and keep it going … Well I don't know where the money comes from to buy – to purchase the care, a collective resource of five or six people. I mean, how do you buy a six-bedroom home here? It would have to be seven because you have to have sleepover staff.*

Social participation

Social participation encompassed rights, social inclusion and interpersonal relationships. Analysis of the quality of life survey found overall scores[46] were higher for interpersonal relationships (81) than for rights (70) and social inclusion (63). The proportion of positive responses was lower for all aspirational indicators.

Figure 9. Scores (combining young survey respondents and proxy responses) for social participation (n = 43)



NOTE: Scores are shown for overall, foundational indicators and aspirational indicators.

Interpersonal relationships with family were typically good but social networks were often limited

Quality of life survey found family relationships were positive but relationships outside the family could improve

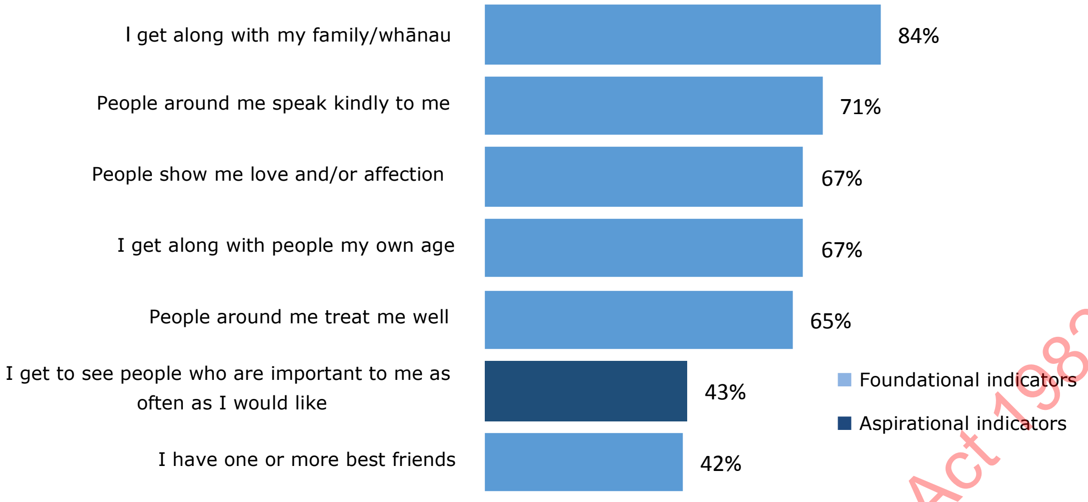
Analysis of the quality of life survey found that overall scores were generally high in this category. Scores were higher for foundational indicators (85) than for the more aspirational (65) EGL indicators (Figure 9 above).

Overall survey respondents were positive about getting along with their families and whānau (84%), friends and people their own age (67%). However, a smaller proportion reported they could see the people who were important to them as often as they would like (43%) or they had one or more best friends (42%) (Figure 10).

---

[46] Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators.

Figure 10. Interpersonal relationships – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



Young survey respondents' responses about their interpersonal relationships were broadly comparable with those of proxies on the foundational indicators, although they differed on some particular indicators. They differed in the proportion who reported they could see people who were important to them as often as they would like (58% of young survey respondents compared with 30% of proxies) and getting on with people their own age (79% of young survey respondents compared with 58% of proxies). They were also asked about their best friends. Two-thirds of young survey respondents reported they had *one or more best friends*, while only one in five of the proxies reported they had best friends.

The case study research also found disabled people had constrained social networks outside the family

In most of the cases the young people could spend time with the people that mattered in their life. However, the depth of young people's wider social networks varied. In cases where the young people were living in residential care their personal relationships mainly involved family and paid carers. In the cases where the young people had actively engaged in EGL (either as opt-ins or as core participants) it was more common for them to have friends who were not paid support staff.

Factors that limited people's ability to spend time with the people that mattered to them and influenced the development and maintenance of relationships outside of the family were:

- *living in residential care:* For example, a young person in residential care reported that he didn't see the people who mattered most in his life as often as he wanted to. His life was centred around attending a day service and being in his flat with a residential care provider
- *not being able to afford to go out*: For example, a young person who lived in a benefit-dependent household and was reliant on taxis could not afford to get out and about to meet friends. Interviews with families and schools indicated that the financial barriers to maintaining friendships were reported as being greater once the young person left school

- *degree of assistance needed and received to build relationships*: Those with profound intellectual disabilities or severe physical disabilities were also reliant on paid support or family to go anywhere and this limited opportunities to engage in personal relationships. However, there were examples of profoundly disabled young people building their social networks with the right support. For example, a parent of a young person with significant intellectual disabilities reported that her young person was now building a wider set of personal relationships because she had carers in her home who could take her to her chosen activities with other young people
- *impact of individual conditions (eg level of functioning, self-motivation, confidence) on young people's ability to engage in personal relationships*: Conditions which hindered people's ability to communicate constrained the building of personal relationships. For example, parents reported that their young people with profound intellectual disabilities were limited in their ability to develop and maintain personal relationships. One mother said of her son with a profound intellectual disability, *"He doesn't really have friends he can talk to about anything."* In another case a parent reported that it was not just her young person's condition that made interpersonal relationships more challenging. She said that while he had friends, many of them had disabilities that limited their ability to respond meaningfully to someone else's emotional needs (eg listening or talking to a friend about their problems). Mirfin-Veitch (2003) argues it is important not to gloss over the difficulties that disabled people can face in building and maintaining friendships, especially where communication is difficult.

Research has found that families with a disabled member often have fewer or smaller social networks and this makes them more dependent on paid services for support (Mirfin-Veitch, 2003; Orsmond et al., 2013; Pitonyak, 2002). Isolation is especially dangerous for vulnerable people. The more positive relationships a person has, the lower their odds of experiencing abuse (Pitonyak, 2013). Many disabled people and families need support to build relationships and valued roles within the community.

Social inclusion could be improved

There is not an agreed definition of what constitutes social inclusion. There are multiple and conflicting definitions (Simplican et al., 2015). Simplican et al. (2015) define social inclusion as encompassing two domains – interpersonal relationships and community participation. They argue they are both necessary for social inclusion and the two domains should overlap and mutually support one another. In this evaluation we have defined social inclusion as community participation, as there is another quality of life dimension focused on interpersonal relations.

There was a marked difference in the overall scores between foundational and aspirational indicators for social inclusion in the quality of life survey

There was a marked difference in the overall scores between foundational (69) and EGL (55) indicators for social inclusion. Overall most respondents (79%) reported that they did things in the community like shopping, going to the movies and eating out as often as they liked. The indicators with the lowest proportion of positive responses were the aspirational indicators of *belonging in the community (46%)* and *giving time to help others in the community (24%).*These are indicators of disabled people having more meaningful and sustained connections as opposed to just being present.

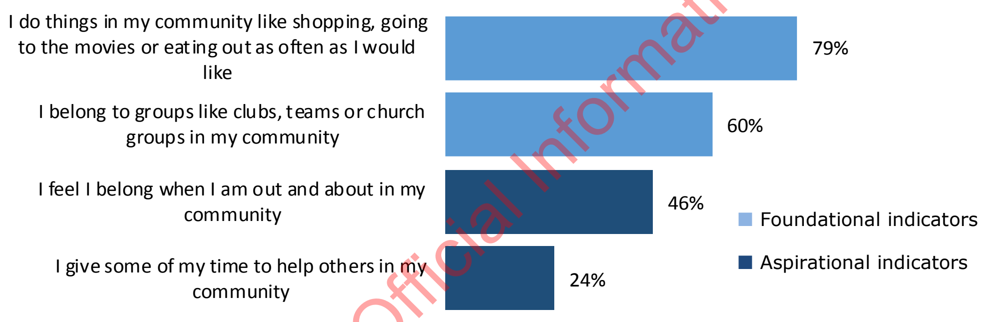
Document 10

When looking at the differences between young survey respondents and proxies:

- young survey respondents were most positive about doing things in their community and belonging to groups and least positive about feeling they belonged to their community and helping others in their community
- proxies were less positive than young survey respondents about three of the four indicators of social inclusion. The difference between foundational and aspirational indicators for social inclusion was driven by the proxies, fewer of whom were positive about the foundational (63% compared with 74%) and particularly the aspirational indicators (43% compared with 70%).

The differences between proxy responses and young survey respondents may reflect the challenges that those with more profound disabilities have in participating meaningfully in the community.

Figure 11. Social inclusion – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



The case studies revealed that young people's sense of belonging in their communities varied

In the case study research, several factors appeared to influence the degree of social inclusion. At the level of the individual, the evaluation identified the following as being important:

- *having the ability to engage in social interactions in the community*: In some cases the young people had profound intellectual disabilities. Family members who responded for their young person typically reported that their young person did not understand the concept of community
- *having family, friends or carers who supported their social inclusion*
- *having sufficient income to participate*: One young person felt his sense of belonging in his community was limited because he could not afford to get to or participate in activities in the community. However in another case the family had access to additional funding which enabled their young person to participate in a wide range of activities.

At the community level the following factors were important:

- *Knowing and being known in the neighbourhood*: In several of the cases the families had recently moved and these moves had contributed to a limited sense of belonging in their neighbourhood. It takes time to establish new relationships, especially where the young person has a disability. One family that had moved from a small, rural town to Christchurch reported it was easier to build relationships in the small town. The parent reported:

> *Locally like – look I've – all along over the years the public have been very good. It's better in [small town] but that's only because it's a small town. It's a one-school town so not only do everyone that she knows but [my young person's] friends also say hello, you know. Everyone knows – in fact in [small town] I'm not [X] I'm "that weird girl's mother".*
>
> *Yeah. So, you know, and that's fine. So everyone knows. But, yeah, it's different in the city, nobody says anything but that's only because it's a city. But in the local little pockets around where we live like – so yes, the local two or three cafes, the library, the swimming pool and the gym and the staff that have known me, yes very much so.*

In another case a young person with significant physical disabilities reported that he did not feel he belonged in his community and that most people around his neighbourhood were strangers to him. He and his family attributed this to the earthquakes, which had led many people he knew to leave the neighbourhood. At the same time, places he had previously frequented closed, limiting some of his opportunities to connect with people.

- *The attitudes of people in the community*: Family members and disabled people interviewed talked of people in their community being welcoming but some reported it was easier for those with less challenging behaviours or who did not look confronting. For example, when asked about how welcome his young person was in the community, one parent said:

> *I think in a general sense, yeah, all of the time. She is – she is welcomed. She's not – while she's very, very different, she generally doesn't have any behaviour that, you know, makes people drop what they're doing. And mostly the people in places that she likes to go are welcoming to her.*

Improvements could be made in the rights domain

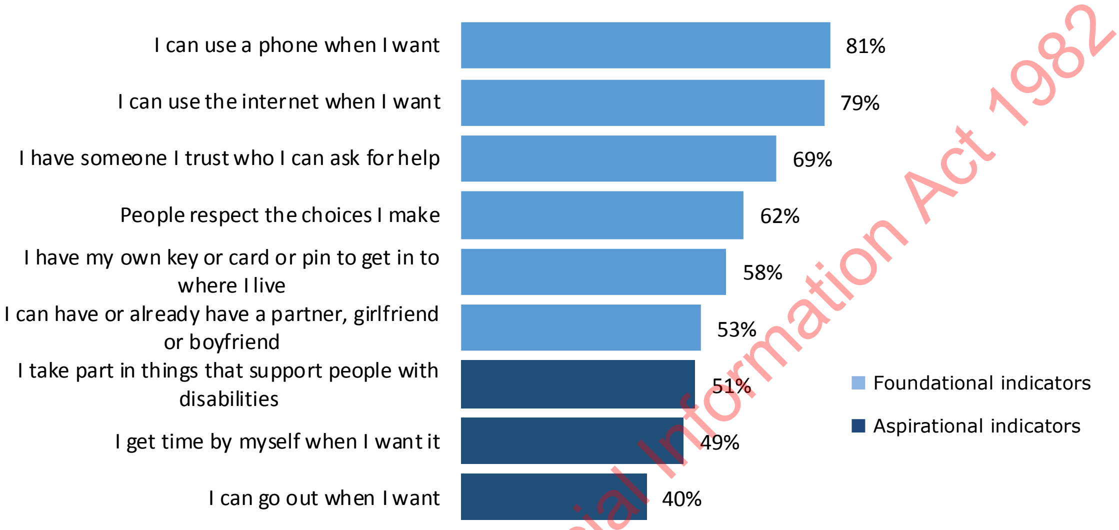
In the rights domain, the proportion of positive responses was lower for all aspirational indicators. Respondents indicated they were least likely to *have time alone when wanted (49%), take part in things that support disabled people (51%)* and be able to *go out when they want to (40%)* (Figure 12 below).However, some of the foundational indicators were also low (eg having their own key or card or pin number to get in and out of where they lived, being able to have a partner, girlfriend or boyfriend).

Responses of young survey respondent completions and proxy completions differed across many of the indicators relating to rights:

- Young survey respondents were more positive than proxies about the foundational rights indicators (81% compared with 68%).
- For young survey respondents, access to the phone and internet was mostly easy but fewer considered they had someone to trust or that people respected their choices.
- Proxies were more likely to consider their young disabled person could have time by themselves when they wanted.

Some differences are likely to relate to the extent of disability for those with proxy completions, for example having a partner, having a key, card or pin to enter their home. One notable difference between the two groups is the percentage who considered they get time by themselves when they need it. More proxies said this was mostly the case than young survey respondents. Young survey respondents were more likely to say they could go out when they wanted to although this was low for both groups.

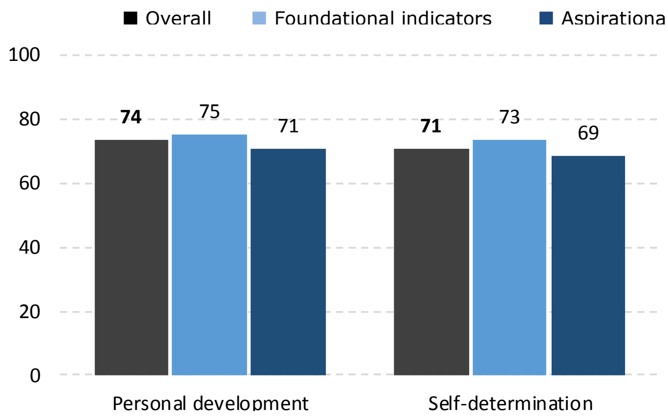
Figure 12. Rights – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



Independence

Independence encompassed personal development and self-determination. Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators. There was little difference in scores between foundational and aspirational indicators. This may reflect the EGL focus on personal development and self-determination; however, baseline measures are not known.

Figure 13. Independence scores combining young survey respondents and proxy responses (n = 43)



NOTE: Scores are shown for overall, foundational indicators and aspirational indicators.

Personal development

In the quality of life framework, personal development is about more than formal education, or cognitive learning in general. Reinders & Schalock (2014:294) argue that *"personal development occurs whenever people regardless of their level of functional limitations enlarge their world of experience".* They argue that anyone can experience personal development, including those with profound intellectual, sensory or motor limitations.

The survey revealed substantial differences between the personal development indicators

Analysis of the quality of life survey found that overall there was little difference in scores between foundational and aspirational indicators. However, there were substantial differences between the personal development indicators. Most people (80%) reported that their home had the things they needed to help them day to day. However, much smaller proportions responded they mostly had a chance to fix mistakes (49%), show people the things they were good at (40%) and learn to do new things that helped with everyday life (29%) (Figure 14).

Figure 14. Personal development - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)

There were few differences in overall scores between young survey respondents and proxies and between foundational and aspirational indicators. However, the overall scores mask substantial differences between indicators. For example:

- while most (88%) of the young survey respondents[47] were positive their home had the things they needed to help them day to day, fewer than half felt they mostly learnt new things, were able to show people what they were good at, and had a chance to fix mistakes

---

[47] Young survey respondents (n = 18-19).

- proxies[48] were more positive than participants about participation in education, learning or things of interest to them, and about having the things needed. They tended to be less positive that their home had the things needed to help day to day.

The case study data indicated greater personal development for young people engaged in EGL

In the seven cases where young people were actively engaged in EGL and living in the community, they were all involved in personal development activities. Three of the young people were involved in post-school education or training.

For those young people with very high needs, personal development was about trying new things and having new experiences with just enough help and support to experience success and thus develop their skills. The parents of the young people with very high needs reported that their young people were blossoming now that they had the flexibility to choose a mix of activities that interested them.

In cases where they were actively engaged in EGL and doing something different, almost all the young people and their families were satisfied with the mix of activities the young people were engaged in. There was one exception. One young person was satisfied with the activities he was doing but not the amount. Poverty meant he could not afford to engage in all activities he wanted to. He had limited natural supports and was reliant on family for transport.

However, there was no evidence of personal development for young people in cases where they were in residential care. In two of the cases the parents did not expect their young person would ever develop further. They were vague about whether their young person's daily life was filled with things that interested them. In the third case the young person stated he was not happy with the mix. The parents thought there might be changes if their young person was able to live in the community.

Self-determination

Overall the quality of life survey found similar scores for the foundational and the aspirational indicators for self-determination

Analysis of the quality of life survey found scores for foundational (73) and aspirational (69) indicators were similar. Overall almost two-thirds of respondents (62%) reported that they had a say about the important things in their life. Close to half of respondents answered positively each of the other questions focused on being listened to, being understood and having a choice about what they did each day (Figure 15). However, a smaller proportion was positive about *choice of who participants live with*, with answers evenly spread between positive (35%), neutral (36%) and negative (29%) responses. The variation may reflect some people's use of residential and respite services, age and stage of life and availability of appropriate supported living options.

There were some differences between young survey respondents and proxies:

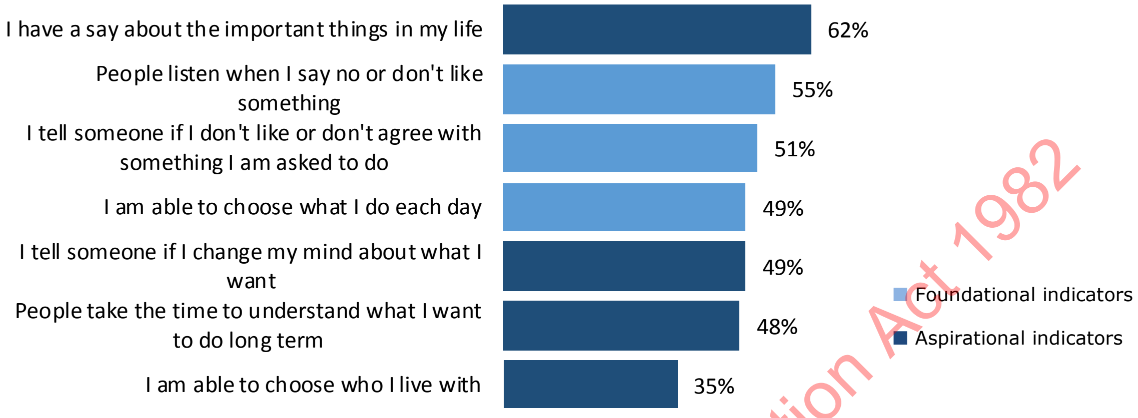
- More young survey respondents were positive about their ability to choose who they lived with (47% compared with 25% of proxies). Nevertheless choice was constrained for both.

---

[48] Proxies (n = 22-24).

- Fewer young survey respondents considered that people mostly *listened when they said no or didn’t like something* (37% compared with 70% of proxies).

Figure 15. Self-determination - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



Analysis of the case study data found that families engaged in EGL reported greater choice and control

Analysis of the case study data found that families engaged in EGL reported their young person had greater choice and control over how they lived their life. All of the families actively engaged in EGL had expectations their young person would be able to live the life they wanted in the community. For some families engaging in EGL reinforced their existing views about the importance of having choice and living in the community like non-disabled people. They were more focused on accessing and using the pooled funding to enact their choices. These families typically hired carers they chose to support their disabled person to do what they wanted (eg go flatting, participate in activities in the community when and where they wanted).

For others, engagement with EGL had broadened their view of what was possible for their young person. This change in mind-set was long-lasting – even where the experience of EGL was less positive. For example, one family interviewed who had engaged with EGL reported dissatisfaction with the level of support they had received from EGL. However, they had continued to focus on developing a life in the community for their young person.

While families engaged in EGL typically reported a greater degree of choice and control, there were constraints. In one of the cases the young person was doing more of what he wanted to than he would have been without EGL but his choices were constrained by financial circumstances and poor access to transport.

However, in the cases where the young people were in residential care they had limited choice and control over various aspects of their lives (eg activities they did, where they lived). In these cases the following factors applied:

- *Activities young people engaged in were typically in group settings, which limited choices and opportunities.* Satisfaction with the mix of activities varied. Two of the families reported that their young person was happy with the mix of activities they were engaged in. However, in one of these cases the parent was not entirely sure what the young person was doing with the provider. In both these cases the families had wanted the young person to be engaged with a provider doing similar activities to what they had undertaken at school. In the third case (the only one to have contact with a navigator) the young person and the family were unhappy with the provider's focus on group activities, the lack of personalisation and the limited opportunities for engagement with the wider community. However, they had yet to make any changes.

- *Family needs took precedence over what the young person may have chosen.* In all of the cases the parents had reached a point where they could not care for their young person at home anymore. However, the mother in one of the cases said the freedom of choice that EGL apparently gives is good for many people and their families as long as they understand the limits of it. She thought the focus of EGL was on the young person but *"this world here – we don't see children in isolation, they are in the context of their family"*. She said people like her daughter end up remaining in the context of their family so unless it works for the family it's not going to work for the young person and vice versa. She added:

  > *So it [EGL] kind of addresses that but not fully and again, I guess it depends on what else you want to achieve, yeah. And, you know, I have to come here [work] for financial reasons but I need to come here for myself as well.*

  These thoughts were echoed by the other families – especially in relation to undertaking paid work and their own health and wellbeing.

- *However, families' choices were also limited by what was available in terms of housing in the community*. All the families felt there was no other choice apart from residential care when the young person could not live at home. One family was beginning to look at alternatives to residential care but none of these families were confident they could sustainably support their young person's life in the community.

Family outcomes

Families have always been crucial to successful living for disabled children and adults. However, with the increased focus on disabled people living in community settings the importance of their role has increased. Successful outcomes for families are underpinned by assumptions that "*most families are both able and willing to act as the main caregivers and decision makers, and that family life will be enhanced as a result of their greater involvement* (Samuel et al., 2012:2). The capacity of families to undertake this role varies. Samuel et al. (2012) state that emerging evidence suggests family skill building and empowerment are a viable approach to addressing support needs of individuals with disabilities.

As part of the case study research the evaluation team looked at family outcomes. In particular the following outcomes were examined:

- emotional, physical and material wellbeing
- personal relationships
- support networks and access to services
- personal development.

Family emotional, physical and material wellbeing

Family emotional wellbeing had improved but not always because of EGL; no change in physical wellbeing

A common theme across the cases was high levels of parental stress and poor physical and/or mental health – especially amongst the mothers. This is consistent with the literature, which reveals that a substantial commitment to caregiving has a marked impact on the life of the caregiver (eg poorer mental and physical health, loss of social connectedness, negative impacts on financial circumstances and employment, concerns about the future of the care recipient) (Colombo et al., 2011; FaHCSIA, 2011; Goodhead & McDonald, 2007; Peer & Hillman, 2014). Mothers are more likely to suffer the negative impacts of caregiving as they are often the primary caregivers of disabled children.

This was true in all the cases where the young people were in residential care. Two of the three mothers reported poor health and the third had been very stressed juggling the care of their young person and work. For example, when asked what prompted them to move their young person into residential care a parent said:

> *Primarily, I think just the stresses and strains of looking after [our daughter] for 20-odd years. And [my wife], in particular, I think needing a bit of a break. That – a lot of things that we might otherwise do we can't do because [our daughter] needs to be looked after 24 hours a day, basically.*

Poor maternal health was common in families who had actively chosen to participate in EGL as well. In three of the four cases where the young people were core EGL participants, the mothers reported physical health problems that influenced their ability to work and/or care for their young person. Amongst the cases involving opt-ins, the mothers had experienced or still were experiencing poor health. In one of the cases the father had also experienced poor mental health.

There had been an improvement in the emotional wellbeing of many of the parents but not always because of EGL. In all of the cases where the young people went into residential care the mother's wellbeing improved afterwards. In two of the cases the family reported that having formal supports and services in place for their disabled person gave them greater peace of mind. This was organised independently of EGL. However, in one case, while having her young person in residential care had allowed her to recover physically, concern about the quality of care he received was a significant source of family stress. In this case the navigator had brought a sense of hope things could change.

In almost all the cases where families had decided to actively participate in EGL, family wellbeing was reported as improved. Family members reported feeling less stressed and more hopeful about the future since being engaged in EGL. For example:

> *PARENT: I think I'm more relaxed now, aren't I? DISABLED PERSON: Mm. PARENT: Because we can see things improving because I was getting quite frustrated when she was at school.*

However, a parent in one of the families reported being very stressed about managing the funding, the lack of suitable respite care, and how they would manage in the future. The parent felt let down by EGL.

Family material wellbeing varied across families but changed little for individual families

Across the cases, EGL appeared to have little influence on families' financial circumstances. In the cases where family incomes were low this did not change. Equally, those who had sufficient family income experienced no change in this situation.

EGL was not aimed at changing families' material wellbeing, but family material wellbeing does have an influence on young people's ability to achieve their goals. The evaluation found that families with more material resources were better placed to meet the needs of their young person with a disability. These families had greater flexibility and choice about how they met their young person's needs than those who had lower family incomes.

Where families were under financial stress it influenced their experience of EGL. While they valued the idea of disabled people having choice and control, they felt their choices were constrained by their financial circumstances. In cases where family incomes were low, they reported that accessing activities in the community was often a struggle because they could not afford it. Similarly, living independently in the community was seen as a far-off goal because of the high cost of housing.

Family personal relationships

Limited change was reported in the quality of relationships between family members but there were exceptions

Across the cases, the families typically did not report any change in the quality of relationships between family members since engaging in EGL. However, there were some exceptions and they highlight the role having the right supports can have in improving relationships:

- In a family where a young person with VHN ORS funding had gone flatting the mother reported improvements in her relationship with her partner and her young person. Without the daily stresses of looking after her young person she now had more time to spend with her partner, which she valued. When talking about her relationship with her son she emphatically described herself as his mum now – not his carer.
- The parents in another family, who had employed staff to come into their home rather than sending their child to respite care, reported being able to spend more time with their other children, who had left home; for example they could get away more easily. Before employing staff they had been reluctant to use respite care because of concerns about its quality.

Family support networks and access to services

Few families had significant natural supports outside of family

The use of natural supports to assist disabled people to live the life they want is a key element of the EGL approach. For families of disabled people, the literature indicates that having strong social networks outside of the immediate family can help to reduce stress by alleviating the physical and emotional toll often associated with substantial caregiving responsibilities (Peer & Hillman, 2014).

However, across the cases the consensus was there were not a lot of natural supports available. Several families commented that the expectation on families to provide more natural supports was not always realistic. For example, one mother of a son with a profound intellectual disability said that, although her son had many siblings, several *"had young families and it is not practical for them provide the support. Others don't have the inclination or their work makes supporting [her son] difficult".* These views were echoed by other families. She added that establishing a circle of support in the community has been very hard to achieve. *"People don't have the time or the inclination. Their lives are very busy. The pastor for example can't do more than he does because he has a church to run."*

Apart from family, friends or paid carers, none of the families interviewed received significant community support. One family who had previously lived in a small community reported that community support was easier to obtain in a place where everyone knew everyone. They had found it much more difficult to build that kind of support in Christchurch.

In all of the cases where the young people had gone into residential care, the family member reported they had someone they could talk to but no one had family or friends they could use to assist with the care of their young people in any sustained way. All reported that they had limited natural supports and felt it was unrealistic to expect families to develop and sustain them.

Amongst cases where people had actively chosen to engage with EGL and made changes, support networks largely consisted of family, friends or paid carers. In four of the cases EGL had strengthened their support networks (eg increased connection with other families; being able to choose who to hire to support their young people). However, in many of the cases the support networks were fragile. One family had extensive family support but stated it had been very difficult to build support beyond that. There was uncertainty about what would happen in a few years when the young person could not flat with a family member. Another family had developed a good support network in Christchurch but that would all disappear if they relocated. This was a real possibility. In another case the family relied heavily on their paid carer, who was essentially running the household.

Access to and experience of supports and services were problematic

Difficulty accessing services to support disabled people living in the community

Access to services to support disabled people living in the community was identified as a problem by families interviewed. In all the cases where the young people had moved into residential care the families reported they had little alternative. The young person staying at home was not seen as a viable option. One of the families had tried having their young person live with another family but this had fallen over prior to EGL. Two of the families felt there was not enough support available to help their young people live in the community.

In other jurisdictions the level of funding provided through individual packages is sometimes not sufficient to facilitate independent living, especially for those with significant cognitive disabilities (see, for example, Fisher et al., 2010).

Difficulty accessing affordable transport

Across the cases access to affordable transport when needed was an ongoing challenge identified by several of the families interviewed. Transporting their disabled young people to and from activities was costly, especially where the disabled people could not use public transport. To minimise costs some families did the transporting but it was time consuming to organise and tied the family to the disabled person's activities. For example, one parent took her young person to post-school education courses and stayed with him because they could not afford the transport and personal care costs. The family was reluctant to pay someone to take the young person to the course as they had had previous negative experiences (eg carers not turning up, using the family vehicle for their own needs, and/or damaging the vehicle).

Limited range of services to support people with high needs

The availability of, and access to, suitable activities for people with high needs was identified as a problem by some families interviewed. Families interviewed reported there were few activities available (eg following the 2011 earthquake one family reported limited access to swimming facilities suitable for people with significant physical disabilities) and insufficient funding to cover participation in the activities.

Access to suitable personal care services was a problem for some

A young male who needed assistance with personal care at particular points in the day reported he had struggled to find the right person(s). He said: *"There's nobody right around New Zealand – or not in Christchurch anyway."* His mother added they can get someone to look after her son *"but they won't do toileting"*. His mother currently provided the personal care but this was not sustainable long term as her health was suffering.

Experience of using formal disability support services and the amount of use varied

Amongst cases where people were actively engaged with EGL and not in a residential setting, the use of disability services in a segregated setting was limited. Several of the families used their EGL funding to employ carers instead of using formal disability support services. In many of these cases the families' past experience of using providers was negative, especially where they had used facility-based respite services.

Across the cases where families were using disability support services (eg residential care, respite care) their experience was variable. Some families reported they were satisfied with the services they received while others were highly dissatisfied. The main criticisms were:

- lack of choice eg about who cared for their young person, who lived with their young person if they were in respite or residential settings, what activities their young person did
- the quality of the service provided.

Family personal development

Family decisions about the care of their young person were influenced by and had influence on parents' (especially mothers') choices regarding work and further education and training. EGL appears to have had limited impact on these choices.

Parents were able to engage in further work, education or training, or personal development where the young person with the disability moved out of home. For example, where the young people were in residential care there was greater opportunity for the parents to concentrate on working.

Having carers come into the home can allow parents to work outside the home but it needs to be affordable. In one case the mother wanted to engage in paid work but could not afford the level of care needed. This meant she was still caring for her young person at home.

In some of the cases EGL appeared to have opened up space for family members to engage in personal development. For example:

- one family had used EGL to expand their work opportunities by facilitating family support for others
- in two cases the mothers reported an increase in time to pursue their own interests. In one case it was because the young person had moved out of home and in the other it was because the family had been able to employ a carer who was creating more space for the family.

Suggested improvements to measuring quality of life outcomes for individuals and families

There is currently limited information systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found that improvements could be made by:

- enhancing data collection (eg improving the response rate, collection of information from people with communication challenges, and collection of information from proxies)
- reconsidering the use of comparison groups.
- establishing a standard set of indicators that can be tracked over time.

Improvements could be made to data collection

The following improvements could be made:

- Including the peer interviewers[49] was a valuable aspect of data collection. Further work is needed to improve data collection from people who are more difficult to

---

[49] The evaluation employed peer interviewers to interview EGL participants who requested an in-person interview. Peer interviewers are disabled people who have been trained to undertake interviews with people with intellectual and other disabilities.

communicate with. Working in pairs and having support available when needed were essential for the interviewers.

- Email was not particularly effective in reaching participants as some did not have their own email address, or were not confident to reply to emails from someone they did not know. Where email addresses were family email addresses, on a few occasions parents appeared to complete the survey without forwarding it.
- Text messages seemed to be more effective in reaching participants. Improving the response rate would require promotion of the survey through the EGL programme, such as by the navigators, to endorse the value of the process.
- Collecting data from proxies is useful but problematic. Researchers have found that quality of life scores obtained from self-reports are not always the same as those obtained from family members or direct support staff. The differences are not necessarily indicative of bias or invalidity but reflect different perspectives (Claes et al., 2012). Development of a separate survey for proxies is recommended for future use of the quality of life survey. A separate survey should include some questions specifically for proxies to express their opinions and challenges. A separate response category may be needed to allow proxies to state whether an indicator is not applicable because of the disability of the participant. However, it is important to note that, as in all families, parents may have different expectations from their children about what is achievable.

Reconsidering the use of comparison groups

Considering the difficulty in identifying and contacting a valid comparison group, the future use of the quality of life survey is likely to be as a measure of change over time within the same individual or group of participants. Indicators can be selected that relate directly to a programme's aims and tracked over time. However this would not allow any conclusions to be drawn about impacts on participants and their families.

Other options could include exploring the use of quasi experimental designs. It may be possible to utilise a quasi-experimental design if a similar initiative is rolled out to elsewhere. However this would require considerable work both to develop design options and to assess ethical implications. A further possibility may be to use future Health and Disability Surveys (or possibly the General Social Survey) in a quasi-experimental design.

Establishing a standard set of evidence based indicators

A set of indicators has been developed. Some are generic and some are specific to EGL. Continuing to develop and use a standard set of indicators will over time result in a robust data set that could be used for analysis of sub-groups eg different demographic groups. A consistent approach to measuring quality of life also has the potential to develop a data set against which the results of new initiatives could be examined. A shorter survey, with fewer indicators, is recommended to reduce the burden on respondents.

Consideration could also be given to developing a set of indicators of family wellbeing. Families have always been crucial to successful living for children and adults with disabilities. However, with the increased focus on disabled people living in community settings, the importance of their role has increased. The capacity of families to undertake this role varies (Samuel et al., 2012).

7. Limited change amongst schools and providers

Summary

Some schools and providers interviewed were working to support disabled people to live everyday lives in the community. However, provider and school alignment with the EGL approach could improve. The evaluation found that there was variation and room for improvement in:

- support for disabled people to make choices and tailoring of supports and services
- the way schools and providers assist disabled people to plan for the future and significant transitions, which was heavily influenced by their views of the life they saw disabled people leading post-school
- providers' and schools' understanding of social inclusion and their practices to support it
- support for disabled people to build and maintain relationships and develop natural supports
- support for the concept of mainstream first
- support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed
- the ease with which disabled people get the support they want when they want it
- opportunities for disabled people to influence school/provider policies and practice and measurement of disabled people's outcomes.

The influence the Demonstration had on provider and school practice may have been improved by:

- ensuring the design and implementation incentivised providers and schools to change
- doing more work to change organisational beliefs and attitudes
- determining whether resourcing available to schools and providers was sufficient for them to operate in line with the principles
- ensuring individualised budgets did not reduce the ability of providers to respond to disabled people's preferences
- encouraging greater navigator engagement with schools and providers
- providing more encouragement for organisations to support disabled people to influence their policies and practice
- providing more assistance on developing ways to meet the needs of disabled people and families with multiple difficulties
- making further effort to change community attitudes and the environment where they were not supportive.

Interviews with schools and providers revealed practices that supported disabled people to live everyday lives, including:

- having beliefs and attitudes that supported life in the community
- being supportive of individualised planning and being person-centred
- having a strong focus on relationship building
- developing a network of organisations in the community to support disabled people
- providing learning in a way that worked for disabled people and supported them to

learn and grow
- developing disabled people’s functional life skills to enable independent life in the community
- changing resourcing to better support disabled people
- having some practices in place to support disabled people to influence how their organisation operated
- working on changing community attitudes.

Support expressed for the principles but limited change in practice reported

All the schools interviewed reported they liked the flexibility and holistic nature of the approach. All of the providers interviewed reported they agreed with the principles and philosophy of EGL. These were described as the *“glue really that holds the whole demonstration together”*, and as being *“a really good platform to build from”*. Almost all the providers and one of the schools reported the EGL approach was embedded in their organisation. However, few interviewed reported that they had changed their practices to work more in line with principles.

The evaluation found that:

- *There was variable support for disabled people to make choices and tailoring of supports and services to what people wanted.* A key element of the EGL approach is supporting disabled people to make choices about what they want to do and where needed having support and services tailored to meet their preferences. However, based on the interviews, there was room for schools and providers to improve their support for disabled people to make choices and tailoring of supports and services (see page 110).

- *How schools and providers assisted disabled people to plan for the future and significant transitions was heavily influenced by their views of the life they saw disabled people leading post-school.* The EGL approach encourages providers and schools adopt a whole of life approach[50] to supporting disabled people and to begin early. In this Demonstration this was particularly important as participants were transitioning from school to adulthood.

  However, transition typically did not begin early in schools. While the Ministry of Education’s National Transition Guidelines for students with special education needs state that schools should begin planning early – by age 14[51] – this was not typically the case in the schools interviewed. All the schools interviewed reported that transition started early but most of the activity appeared to happen in the last year of school. There appeared to be little emphasis in any of the schools on young disabled people leaving school at the same age as their non-disabled peers[52]. None of the

---

[50] This is the idea that someone’s life is made up of more than just what activities they do during the day. It is about considering the person in their wider context, not in the context of ‘funded support services’.

[51] See http://www.education.govt.nz/school/student-support/special-education/national-transition-guidelines-for-students-with-special-education-needs/

[52] Students who receive ORS funding or have exceptional needs can stay at secondary school until they are 21 years old.

schools interviewed reported any change in the age at which their special needs students were leaving school. Some school interviewees were sceptical about the benefits of such students leaving school earlier. For example, a school reported that some high-functioning disabled people may be ready to leave school with their peers but most were not.

Practices around planning for the future were heavily influenced by school and provider views of the life they saw disabled people leading post-school. For example, some schools and providers saw the main transition a person made as being from school to a provider (see page 106) and implemented practices that supported that. However, there was evidence some schools and providers interviewed were expecting young people to transition to a more independent life in the community (see page 117).

- *Providers and schools varied in their understanding of social inclusion and their practices to support it*. The EGL approach encourages disabled people to be supported to live an everyday life in everyday places and be regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life. It is about being meaningfully included in communities – not just having a physical presence in the community. Some schools and providers interviewed appeared to be aligned with this approach (see page 119) while others did not appear to be aligned (see page 108).
- *Support for disabled people to build and maintain relationships and develop natural supports*[53] *was variable.* Providers and schools interviewed understood what natural supports were. They considered natural supports to be relationships with people in the community such as employers, friends, and people in community organisations. It was wider than family. However, the extent to which the organisations interviewed supported the concept and worked to develop the supports with disabled people varied. Providers and schools who were supportive of the concept put more emphasis on building relationships between disabled people and people in the community (see 120). However, schools and providers interviewed who supported disabled people being in segregated environments appeared to do little to support the development or use of natural supports. They emphasised maintaining relationships within the environment of the specialist disability supports and services (see page 106).
- *There was varied support for the concept of mainstream first.* There was no common understanding of the mainstream first principle. Some schools and providers were supportive of the concept (see page 119) but others felt it devalued the role of specialist disability services (see page 107).
- *There was varied support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed.* Some organisations interviewed were very supportive (see page 117) while others were less so (see page 108).
- *The ease with which disabled people get the support they want when they want it could improve.* Amongst the organisations interviewed, an important practice that

---

[53] Natural supports are the relationships that occur in everyday life. They usually involve family members, co-workers, neighbours and acquaintances. Disabled people may need help in developing these relationships outside of family. However, the intention is that over time these connections can help people to build a strong community-based network and support system.

supported disabled people to get what they wanted was taking the time to find out what disabled people wanted to do by developing solid, ongoing relationships with disabled people so they could easily express preferences. Other supportive practices included having a can-do attitude towards getting disabled people what they wanted, having broad community networks to link disabled people into, and being upfront about what they can and can't offer. Organisations interviewed reported that it was difficult to easily meet people's preferences, expressed concerns about resourcing and the ability to keep disabled people safe, and had low expectations of disabled people's growth and development over the life course. However, most schools and providers also reported concerns about families and communities not always supporting disabled people to get what they wanted.

- *There were limited opportunities for disabled people and families to influence the policies and practices of the provider or school.* Interviews with schools and providers revealed that disabled people and families have only limited and indirect opportunities to influence policies and practices in providers or schools. Most schools and providers interviewed struggled to articulate how disabled people were able to influence their policies and practices (see page 114).

What may have improved the Demonstration's influence on provider and school practice?

There are several factors that could indicate why the Demonstration had a limited influence on wider provider and school practice. These included the need to:

- ensure the design and implementation created incentives for providers and schools to change
- undertake more work to change organisational beliefs and attitudes
- determine whether resourcing available to schools and providers was sufficient
- ensure individualised budgets did not reduce the ability of providers to respond to disabled people's preferences
- encourage greater navigator engagement with schools and providers
- encourage organisations to support disabled people more to influence their policies and practice
- give more assistance on developing ways to meet the needs of disabled people and families with multiple difficulties
- make further effort to change community attitudes and the environment where they are not supportive.

Further detail is provided below.

Ensuring the design and implementation created incentives for providers and schools to change

Aspects of the design and implementation undermined provider buy-in and incentives to change. The evaluation found that:

- the Demonstration underinvested in provider and school development to assist them to operate in line with the EGL principles
- the role of providers in the Demonstration was ambiguous
- design delays and late changes to provider funding undermined provider buy-in
- there was limited focus on outcomes sought from providers.

The Demonstration underinvested in provider and school development to assist them to operate in line with the EGL principles

Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, providers and schools interviewed typically had had limited experience of EGL. For example, the EGL resources dedicated to working with schools and providers on what EGL meant was limited:

- The EGL team had a person whose role it was to work with providers. Providers interviewed reported this role was invaluable but that more support was needed.
- While there was some EGL resource allocated to working with schools, the people in this role were primarily responsible for working with disabled people and families.
- Navigators had a role in changing behaviour but contact with providers and schools was limited. Some schools and providers had only a few people accessing support through EGL so had limited experience of the Demonstration. All the schools talked about including the navigators in the planning process; however, in practice the navigators had limited interaction in the school.

The lack of contact with the Demonstration meant schools and providers were unclear about their role in the Demonstration and key concepts such as 'a good life', 'natural supports', and 'mainstream first' were not commonly understood.

The role of providers in the Demonstration was ambiguous

Several interviewees reported that it would have helped to have clearer communication with providers on how they could contribute to improving the lives of disabled people in line with the EGL principles. As one interviewee reported, the initial messages didn't convey support for providers and their role was ambiguous. He believes it was due to the interpretation of the principle of mainstream first, which stated the need to look at all other options before settling on specialist disability support services. In his view, *"It raised the ire of some providers. But other documents talked about co-design and co-development. It was a real time of uncertainty for providers".*

Design delays and late changes to provider funding undermined provider buy-in

Not having the components of the Demonstration ready to go at the outset undermined provider buy-in, according to interviews with the EGL team, officials and providers. An EGL team member reported that initially provider commitment to the EGL approach was eroded by payments and funding difficulties which took time to resolve. He added, *"These side issues have then become real issues for some providers. They have focused on this instead of the real mahi, which is about them changing their ways."*

Progress was made with improving provider buy-in but MSD's decision to reduce the amount paid to its providers to ensure the Demonstration was fiscally neutral undermined this progress, according to several interviewees. A LAG member commented that the timing of the announcement was poor. Providers were developing a sense of what a different future might look like and were *"willing to take a bit of a risk and move out of their comfort zone but, I think what I've seen is a kind of a retreating back"* since MSD reduced the amount paid to providers.

This situation arose for a number of reasons. More people took up MSD funding than was expected. ORS status was used as a mechanism for determining eligibility for Demonstration funding. Typically not everyone who is eligible for ORS funding takes up MSD funding for community participation or vocational services. As services were fully subscribed, the only way to free up funding for personal budgets from within the existing funding was to reduce volumes elsewhere. Had there been a funding allocation mechanism tool in place at the outset of the Demonstration this problem may have been avoided.

Limited focus on outcomes sought from providers

The intent of the Demonstration was for providers and schools to focus on delivering the outcomes individuals wanted. At a systems level there were weak incentives for providers or schools to operate in a way that was consistent with achieving the desired outcomes for disabled people. For example, the Demonstration wanted providers to focus on individual outcomes, but MSD was still using bulk contracts with its providers. Under this system, MSD contracts for outputs (eg the number of people and the number of hours they are there) rather than outcomes achieved by disabled people. In addition, even where contracts encourage the employment of disabled people, a provider reported they don't necessarily encourage growth of the person. As the provider reported, *"we have seen overrepresentation of people with learning disabilities pushing trolleys, for example, because that's an easy win from a provider perspective"*. Schools completed Individual Education Plans for disabled people but were not required to report progress against these.

At an organisational level, the evaluation found that across schools and providers interviewed there was a limited focus on outcomes that would provide evidence of behaviour change in organisations. They typically reported there was no formal process for assessing the effectiveness of what they did with disabled people. Schools reported it was difficult to determine how effective they were at meeting the needs of disabled people as they did not know what happens to students once they leave school.

More work needed to change organisational beliefs and attitudes

The evaluation found more work was needed to change the beliefs and attitudes of schools and providers to make them more supportive of ensuring disabled people have greater choice and control over their lives. Amongst the schools and providers interviewed:

- none believed they needed to change significantly
- some exhibited beliefs and attitudes that did not support life in the community.

No schools and providers interviewed believed they needed to change

The evaluation found that the actions of some schools and providers interviewed were driven by their mental models or thinking about disabled people but the Demonstration appeared to have had little influence on them. Schalock et al. (2008:277) describe mental models as:

> *deeply ingrained assumptions, generalizations, and images we have to understand the world. They form the vision and culture of an organization and serve as the basis for leadership, values training, service delivery, outcomes evaluation, and quality improvement.*

None of the providers and schools interviewed reported that they needed to significantly change what they were doing to better align with the EGL principles. While the reported practices of schools and providers interviewed varied considerably, all those interviewed reported that the direction of their school or organisation aligned with the EGL approach.

For schools and providers interviewed who reported they supported the philosophy behind EGL and appeared to be operating more in line with the principles of EGL, the activities of the Demonstration confirmed to them that their approach was the right one. The Demonstration had little influence on their thinking and practice as they were already on this path before the EGL Demonstration began.

In contrast, schools and providers interviewed who were less supportive of the EGL approach typically displayed mental models that focused on people's deficits rather than human potential, and overemphasised safety. However, these schools and providers also reported that they were aligned with the EGL principles and did not need to change.

Some schools and providers interviewed had beliefs and attitudes that did not support disabled people living a life they chose in the community

The evaluation found that some schools and providers interviewed exhibited beliefs and attitudes that did not support life in the community. A belief that specialist disability supports and services were preferable was seen in the:

- expectation that disabled people would transition from school to a provider
- lack of support for the concept of mainstream first
- lack of support for the concept of natural supports
- low expectations of what disabled people can do
- overriding belief that disabled people needed to be kept safe
- little focus on tailoring supports and services to individual preferences.

These are explained below.

Expectation that disabled people would transition from school to a provider

Some interviewees saw the main life transition a disabled person made as being from school to a provider. All the staff interviewed at the schools visited saw themselves as providing a safe, nurturing environment and they wanted this to continue once people left school. However, those schools who supported transition to a provider reported that this was often the safest option for young disabled people with high or very high needs.

Transition was portrayed as the most stressful event in the lives of disabled people and their families. Transitioning to a provider was seen as minimising stress and disruption to disabled people and families and keeping disabled people safe and busy five days a week. As one school representative reported, *"going to a service provides structure and security to disabled people and their families"*.

Those interviewees that saw disabled people primarily being engaged with providers post-school expressed considerable concern that there was insufficient funding to support disabled people to attend a service five days a week. They reported that transition was a very stressful time for families because they were leaving a system which provided structure and certainty five days a week. In their view the stress on families would be reduced if they knew they had funding to cover a five-day-a-week service.

Once people had made the transition from school to a day service provider five days a week, there did not appear to be any discussion with providers about transitioning out of the service apart from for age-related reasons.

Lack of support for the concept of mainstream first

When asked about the concept of mainstream first, some providers and schools expressed concern the concept undermined the role and value of specialised services. Some schools and providers, especially those providing segregated services, reported feeling undervalued and alienated by the mainstream first principle. For example, a provider reported:

> *The impression I have is that some in EGL see themselves as crusaders against institutions. In the beginning we had psychopaedic hospitals and they were abolished. Now we need to get rid of day services to achieve genuine mainstream community participation.*

Some interviewees also queried the suitability of mainstream supports and services for all disabled people. For example, a provider reported that the concept of mainstream first was unrealistic and in their view parents wanted and needed support for their disabled family member for a whole day at a centre – a point they felt was not well understood by the Ministries. The provider argued that there would always need to be a range of service providers, including day services, and this needed to be recognised.

One school interviewed that was very supportive of the mainstream first principle cautioned there is a risk that focusing on mainstream first and building relationships with non-disabled people might undermine disabled people's connections with their disabled peers. The school reported that we need to be careful of the messaging to disabled people. They reported there is a need to be careful not to judge disabled people who choose to attend disability service providers. The school reported:

> *The social side of things is huge. It's very easy for the students to get isolated. Students want to do stuff with their friends and are happy doing that. It's important not to judge people's choices. For example, there are students who have gone to [Provider] four days a week and are very happy. They're with their friends doing activities they like eg art activities.*

There is research to suggest that some disabled people are more comfortable among 'segregated spaces' where only others with disabilities are present (Milner & Kelly, 2009 in Duggan & Linehan, 2013). Duggan and Linehan (2013) question *"whether* *involvement with others with disabilities has become a less valid form of community connection resulting in a devaluing of the relationships among disabled people".* Researchers have highlighted that the tendency to value disabled people's friendships with non-disabled people more highly than their friendships with other disabled people can leave them more isolated from their peers (Mirfin-Veitch, 2003).

Lack of support for the concept of natural supports

Some schools and providers interviewed conceptualised natural supports as an alternative to specialist disability supports and services rather than complementary. They highlighted their ability to meet the needs of disabled people and questioned whether others (eg natural support networks) would be able to safely do so. A special school and some providers reported that establishing and maintaining natural supports was especially challenging for families where both parents were working and/or the young person had VHN ORS funding. In these cases they believed families needed provider support, often in the form of a five-day-a-week day service. For example, a provider said:

> *Some families can do this and that's great. But some families have to go to work and they don't have natural supports to look after their disabled family member. … Also many of the families are borderline in the ability to cope with things anyway. They are not well placed to be able to organise and use natural supports. … When the young person comes to us the families get support. With this support some families have stepped up in other ways and this helps the disabled person.*

All the schools and several providers interviewed also questioned the availability and sustainability of natural supports. Schools and providers who supported disabled people being in segregated environments were particularly scathing of the availability and sustainability of natural supports. For example, one provider said:

> *Unfortunately people think, "Yes, let's tap into the natural supports, things that are out there and we'll go into the community and there'll be these wonderful welcoming people who include us automatically." Well, it doesn't happen.*

However, even those schools and providers who were supportive of the concept of natural supports reported that they take time to develop and require people with the right skill set to support disabled people. One such provider reported that having readily available natural supports in the community was *"a long way off".*

Lower expectations of what disabled people can do

Some schools and providers interviewed had low expectations of disabled people's growth and development over the life course and, related to this, there was a belief that staff were key to identifying what would be beneficial for the young person. There was an emphasis on keeping people stable. This made it difficult for them to help disabled people to identify their preferences and to grow, try new things and have new experiences.

A focus on having a presence in the community rather than meaningful social inclusion

It was evident from the interviews undertaken for the evaluation that social inclusion meant different things to different people. All providers and schools reported they supported people to have a presence in the community and doing everyday things but what this meant in practice varied considerably.

For some schools and providers, having a presence in the community meant engaging in segregated, group activities in the community rather than meaningful social inclusion with a range of people in a range of settings. Providers and schools who held this view tended to emphasise the need to protect disabled people, especially where they had significant intellectual disabilities. There was little evidence that they were supporting disabled people to make meaningful social connections with people in the wider community (eg active involvement in community activities that promote the development of interpersonal relationships; having valued social roles). Some schools and providers qualified their views by adding that having a life in the community was a more realistic option for higher-functioning disabled people.

This lack of agreement about the meaning of social inclusion is common. Research indicates that although social inclusion is central to disability policy, there is little clarity about its meaning largely because of multiple and conflicting definitions. Simplican et al. (2015:25) argue that:

> *The variation between definitions impedes effective service delivery and interventions, and leads to insufficient data about its effective implementation. Moreover, the conceptual ambiguity of social inclusion hinders communication across key stakeholders – such as individuals with disabilities, family members, service providers, researchers, and policymakers – who may disagree over the meaning and purpose of social inclusion.*

An overriding belief that disabled people needed to be kept safe and this was best done using specialist disability support services

The belief amongst some interviewees was that disabled people needed to be kept safe and this was best achieved in the care of specialist disability support services than out in the community. For example, two providers reported that they had staff who were skilled at being in the community with disabled people and making sure safety strategies were in place. They both questioned how safe it was for people using natural supports – the implication was people outside of the service may not be safe.

Some schools and providers interviewed highlighted the need to keep people safe, when asked about how they met disabled people's preferences or encouraged new experiences. While safety is important, it appeared that concern about the risks associated with disabled people engaging in everyday activities in non-segregated settings was limiting what they could do.

Research indicates that service organisations' risk assessments may hinder opportunities for community participation (Duggan & Linehan, 2013). International evidence suggests the focus should be on safeguarding[54] disabled people. Safeguards need to be thought about in a way that upholds the principles of person-centred approaches (eg a greater focus on risk enablement) (Ontario Ministry of Community and Social Services, 2013; Carr, 2010).

---

[54] The term 'safeguard' is being increasingly used to describe ways to reduce the vulnerability of people with developmental disabilities. Intentional safeguards are things done on purpose to help reduce people's vulnerability. Intentional safeguarding, as part of person-directed planning and facilitation, is about reducing risks and increasing someone's safety and wellbeing.

Little focus on tailoring supports and services to individual preferences

The evaluation found some schools and providers interviewed were continuing to deliver services the way they always had with little focus on tailoring supports and services to individual preferences outside a group setting. In these organisations there was a:

- greater reliance on the voices of the professionals and parents over disabled people
- preference for the use of specialist disability supports and services in group settings. If people did express choices, the school or provider would try to fit these in with what they had on offer. This typically meant undertaking activities as part of a group
- focus on risks and keeping people safe, which limited the extent to which people's preferences could be realised
- focus on people's deficits; for example, a school and some providers interviewed reported that determining preferences is more difficult where students are non-verbal.

Determining the adequacy of resourcing to schools and providers to operate in line with the principles

Insufficient resourcing was the most common challenge identified by schools and providers interviewed.

All providers reported they were underfunded and concerned about long-term sustainability

All providers interviewed indicated resources were tight owing to inadequate funding levels. Providers reliant on MSD funding in particular reported that they struggled as this funding was contributory and had not increased in 12 years. For example, one provider reported that their sustainability was questionable and they were currently kept afloat by Ministry of Health funding. The provider currently charged $40 per day, on a one:three staff/client ratio, which they described as "borderline in terms of sustainability". They reported that the only way they managed was by using the Health funding that came with the people who were deinstitutionalised to support the younger clients. The older Health-funded clients tended not to want to do the resource-intensive activities in the community that the young people liked. However, they reported that this situation is not sustainable as the older clients are ageing and retiring. Another provider reported that they had considered closing:

> *You can't expand services if you're not supporting the ones you have. This recent funding cut has pushed them to the wall – is that what government wants? MSD talks about contributory funding. The previous amount was very low but the current amount is too little – a slap in the face.*

Some providers interviewed reported that current funding levels made it difficult to attract the staff with the right skill set and to have the money to pay them sufficiently.

Christchurch providers are not alone in facing this challenge. Schalock et al. (2016:56) comment that in developed countries human service organisations are facing many challenges including *"adapting to an increased demand for services and supports within a shrinking financial base"*.

Insufficient funding attached to some disabled people was a challenge to delivering personalised supports and services

All providers interviewed identified insufficient funding as being the main barrier to providing personalised supports and services based on people's preferences. Providers interviewed reported that EGL does not address the issue of underfunding of the sector. Some reported that they changed how they used their resources to better support people's preferences (eg investing in staff rather than buildings) but the level of funding they received was still a challenge. All providers interviewed reported that providing supports and services for HN ORS-funded clients was particularly challenging as they received much less than those with VHN ORS funding ($2,600 per year compared with $15,600 per year for VHN ORS funding). This meant that most with HN ORS funding could only afford to go to a provider two to three days per week whereas those with VHN ORS funding could afford five days. Some providers interviewed expressed concern that those with less funding would be left *"sitting at home".*

Schools echoed the concerns of providers about the funding for HN ORS-funded students. They were concerned that the funding HN students received was not sufficient to support them to undertake activities in the community once they left school.

The mainstream schools reported that the teacher ratios they were currently funded for made it difficult to deliver on individualised plans for students. They struggled to find the time to develop the networks necessary to support young people's growth and development in the community and to search for new experiences. In one school, getting out in the community was seen as admirable but difficult to achieve within current resourcing. They commented that "*it's hard to fulfil the vision of Enabling Good Lives with the current funding arrangements*". They had managed this year because they had a student with ACC funding, which is higher than ORS funding. Another mainstream school was able to resource students' preferences but reported that the time taken juggling resources to do that and finding and building links with organisations in the community was significant. They wanted more help with this.

Funding transport to support personalisation

Transport is usually needed to support disabled people to access activities in the community. Some schools and providers reported that getting young people to off-site locations they wanted to go to could be difficult. A school and provider reported that their staff used their own transport or public transport. The provider reported that they could not afford to provide staff with cars but they did purchase bus passes for staff. The school reported that teachers at the school used their own cars to transport students when they could. However, they reported transport difficulties meant some students couldn't take up opportunities to engage in meaningful activities of their choice.

Some providers also reported that difficulties in transporting young people to individual activities made supporting individual choices challenging.

There may be insufficient resourcing to support engagement with mainstream organisations

Providers and schools all reported that funding was insufficient to support choices and participation in individualised activities in the community, particularly for HN students. They also reported it takes time and resources to build relationships with mainstream organisations eg employers, community groups, tertiary education organisations. One provider had taken five years to build a relationship with a tertiary provider. The mainstream schools reported they would like help building these networks. The mainstream schools interviewed also reported that finding resources (time and funding) to support individualised activities in the community leading up to transition was difficult. One school wanted a dedicated transition person to assist with the process.

Ensuring individualised budgets do not reduce the ability of providers to respond to disabled people's preferences

Some providers reported that individualised budgets as they were implemented did not make it easy to meet disabled people's preferences.

- *Some providers reported the move towards Individualised Funding reduced their flexibility to respond to disabled people's preferences.* A provider who supported the EGL approach felt this was an unintended consequence of individualising the funding. They reported that as much as it empowers the individual and provides more choice and control, it can limit options in terms of the supports that a person can purchase. In their experience the support they were able to provide for somebody through their bulk funding contract was greater than a person on an individualised budget. The provider commented:

  > *And so because under bulk funding you could be more responsive; – there's more flexibility so that, Johnny might need – because of a particular kind of issue or aspiration that he has, needs quite a lot of support, – over this next few weeks or months and so we could, – you can through a bulk-funded arrangement you had the ability – the flexibility and the ability to be able to just put a lot of resource into Johnny at that time. And that's not at the expense of others but it's just the way that you can allocate your resources.*

  Therefore although there is greater flexibility for the individual, there may be less flexibility for providers to allocate resources across individuals under an EGL approach.

- *Determining what to bill disabled people for when providing personalised services was difficult.* The EGL approach was about meeting people where they were at in a way that worked for them. Working this way presented billing challenges for some providers. For example, a provider reported that as they tried to operate in a more flexible and fluid way they found they were constrained by a funding system that required them to account for each hour of time spent with a person. The provider said it is easy to bill for a planning meeting held in an office but less so when meetings were less structured and in informal settings where time may be spent doing leisure activities and planning. For example, the provider said:

> *Like, how would people feel if we billed them for mountain biking – do you know what I mean? But, I would suggest that sort of process is – adds far more value than sitting down* [at a table]. *So, I think it's how you then quantify that.*

Greater navigator engagement needed with schools and providers

All the schools and many providers reported that they had had limited or variable contact with the navigators. One provider reported they never saw the navigators.

From the perspective of schools interviewed, the limited contact with the navigators led to the following problems:

- All schools interviewed reported that navigators became involved too late in the transition process. The navigators typically became involved in the last year a person was at school. By this stage the schools reported they were already working on transition from school to life post-school. As one school reported, they cannot afford to wait until the last six months of the year to think about transition from school. The school wanted earlier involvement from the navigators. Another school was concerned that having the navigators come in late in the process risked destabilising plans they had put in place for the young person and their family.
- Some schools interviewed reported that the lack of contact meant that the navigators did not understand enough about what their school offered. They felt the benefits of what they did with students were undervalued.
- Schools interviewed were concerned that the navigators didn't have the time to build an in-depth knowledge of the students. The schools reported that the navigators were good at finding options for people but because they didn't know the students well the options they suggested were not always appropriate or practical. A school gave the example of one of their students with muscular dystrophy being advised by the navigator he would be able to do more if he went to the gym and built up his strength. The school reported the mother was angry as she felt the navigator didn't understand the reality of her son's condition – that muscular dystrophy is an incurable, degenerative condition. Some providers echoed these concerns.

For providers interviewed, the limited contact with the navigators also led to problems. For providers who were active in promoting a life in the community, the limited contact with the navigators led to the following problems:

- The lack of contact meant that the navigators did not understand enough about what their service offered. For example, one provider reported they were set to provide an individualised service but navigators sent them disabled people expecting them to provide group-based activities.
- They received too little information about the disabled person before they came to the provider. For example, one provider reported that all their EGL clients came to them without plans. The provider wanted more involvement in the planning process with navigators so they knew the person better and could better organise what could be explored with the person. Without the plans there were delays in getting the service agreements in place. Moreover, if people weren't going to be a good fit with their organisation, they could let people know early.
- There was limited contact between the disabled person and the navigator once the disabled person was placed with the provider. A provider reported that the navigators

needed to follow up with disabled people to ensure people had made the right decision in attending the service. Providers who supported segregated services did not raise this concern.

Providers of segregated services interviewed also reported limited contact with the navigators. They were primarily concerned that the lack of contact with the navigator meant the navigator did not have a good understanding of the disabled person and their circumstances. They were also concerned that the navigators, when thinking about transition, did not understand enough about what their service offered and were therefore not able to give disabled people sound advice on the choices open to them.

More encouragement needed for organisations to support disabled people to influence their policies and practice

Interviews with schools and providers revealed that disabled people and families had only limited and indirect opportunities to influence policies and practices of providers or schools. Most schools and providers interviewed struggled to articulate how disabled people might be able to influence their policies and practices.

The evaluation identified the following challenges to disabled people being able to influence policies and practices of providers or schools:

- Schools and providers may not have processes that support disabled people and their families to express their views on how the service could be better. Several schools and providers had ways in which people involved with their organisation could express their dissatisfaction (eg being able to ring and complain). However, few mentioned actively asking disabled people and their families how they could better meet the needs of disabled people.
- The input of families or disabled people may not be valued. One provider reported that clients attending their service would be unable to participate in decision-making bodies and that it would be tokenistic to include them.
- Practices that work well in a small organisation to encourage involvement may not be as effective in a large organisation (eg relationship-focused practices).
- Disabled people may not have someone to advocate for them: a provider reported that they noticed parents became less involved in what was happening with their young person once they moved into residential care. He stated, *"So you lose the strength of advocacy because the residential carers will know something of them but they've got other people to look at, it's not quite – that don't have that single focus that a parent does."* This view is supported by the case study research. A family member who was advocating for change in a residential facility reported that there were people who were in situations similar to or worse than her young person – especially if they *"don't have mouthy parents"*.

More assistance needed on developing ways to meet the needs of disabled people and families with multiple difficulties

Schools and providers interviewed reported challenges in meeting the needs of those disabled people and families with multiple difficulties. Reasons include:

- families not supporting disabled people's preferences

- systems can struggle to support people with complex needs.

Families may not always support disabled people's preferences

Some schools and providers interviewed reported that families were not always able to support disabled people's preferences. Reasons cited included:

- *Parental attitudes may not support a disabled person's life of their choice in the community.* One school that was very supportive of assisting students to have a life in the community found that the attitudes of parents were not always supportive of this aim[55]. The school cited the example of a 17 year old who was encouraged by her family to leave school once she became eligible to go onto benefit in her own right. The school reported the young person had many skills but was at home in a benefit-dependent household doing housework for her mother, who was unsupportive of her daughter getting paid work. The school reported the young person *"used to live in care nearer the place of work but went home to live with mum and mum had cancelled the job as didn't see she needed to work. What can you do?"* In these situations the school found it difficult to have conversations with the family about working towards a better life for their young person. The school reported that this was not an uncommon scenario. She reported that students getting into and staying in work is dependent not just on an employer being willing to take the young person on but also on the family supporting the move. The school wanted more help with job coaching and changing the mind-sets of the parents (eg so they see work as an option for their young person).
- *They lacked the capability.* Some schools and providers interviewed reported that supporting a disabled person to live in the community required *"highly engaged, highly competent"* parents. They questioned whether families facing significant challenges would be able to provide this level of support (eg where parents had to work full-time or were experiencing family dysfunction).

Systems can struggle to support people with complex needs

A supported housing provider reported that in recent years the clients being referred to them had more complex needs. For example, they reported that more of their clients had dual diagnosis (such as mental health and intellectual or physical disabilities), had a CYF background and/or were from dysfunctional families. As a provider, they reported helping the more vulnerable young person get what they wanted was time-consuming and often not funded. For example, support workers were having to spend a considerable amount of time working with challenging families as well as the young people. The provider commented that the EGL concept is good but the amount of funding available to support people to live in the community is insufficient. They said: *"If they go on like this I think they are going to need to build another prison. And I'm very serious about that."*

---

[55] Researchers have found that the family's attitudes and expectations have a critical influence over a disabled person's level of independence and the extent to which they are involved in decisions about their lives (Mirfin-Veitch, 2003).

Further effort needed to change community attitudes and the environment where they are not supportive

Some schools and providers interviewed reported that the attitudes of those in the community were not always supportive of disabled people living the life they wanted. For example:

- *Potential partner organisations may not have had values consistent with delivering personalised services.* A provider and two schools reported that finding organisations that they could work with to provide what disabled people wanted was a challenge. One provider with an emphasis on placing disabled people in the community found that disability organisations who wanted to partner with them did not always share their values. For example, a progressive provider reported that they had chosen not to partner with disability organisations that had a preference for segregated services. Instead they had responded by partnering more with mainstream organisations. While these relationships were beneficial, they took time to develop.
- *Overcoming negative stereotypes in the community about disabled people was difficult.* Schools and providers cited examples of individuals and organisations in the community not wanting to accommodate disabled people. For example, a housing provider reported they frequently encountered resistance from neighbours to disabled people being housed in the community. A school also encountered resistance from some workplaces when seeking work experience for their students. For example, when approached about a young person in a wheelchair having some work experience, a large employer told the school they *"don't take people like that"*.
- *The wider environment was not necessarily supportive of disabled people's engagement in the community.* Some schools and providers reported that the environment in Christchurch is disabling; for example, bus services are not user friendly for disabled people.

Nevertheless some schools and providers were working to support disabled people to live everyday lives

Interviews with schools and providers revealed practices that supported disabled people to live everyday lives. These included:

- having beliefs and attitudes that supported life in the community
- being supportive of individualised planning and being person-centred
- having a strong focus on relationship building
- developing a network of organisations in the community that could be used to support disabled people
- providing learning in a way that worked for disabled people supported people to learn and grow
- developing disabled people's functional life skills to enable them to operate more independently in the community
- changing resourcing to better support disabled people
- having some practices in place to support disabled people to influence how their organisation operated

- working on changing community attitudes to better support disabled people to live in the community.

Beliefs and attitudes that supported life in the community were evident in some schools and providers

Some schools and providers interviewed displayed beliefs and attitudes that were supportive of disabled people having a life in the community. These included the following.

Seeing disabled people ultimately transitioning to live in the community

There was evidence some schools and providers interviewed were expecting young people to transition to a more independent life in the community. They saw their role as ultimately supporting people to live more independently in the community. They envisaged that their support would taper off over time as people were better able to manage for themselves or with the support of people in the community. For example, one provider reported that it was his aim that, with the right support, disabled people using his services would not need them in five years' time.

Schools who expressed the belief disabled people could live everyday lives in the community worked to support them to transition to the community by:

- having an expectation that people would learn and grow
- exploring what disabled people wanted to do in the community and helping to make that happen
- providing a range of experiences in the community to give people more options to choose between
- teaching life and social skills[56] to enable disabled people to more easily participate in life in the community.

For schools this was in line with the Ministry of Education National Transition Guidelines for students with special education needs, which have several references to engaging with the community. For example, they indicate schools should ensure goals for the transition plan are embedded in education and the community, use community settings, and build partnerships with communities[57].

Having an expectation that people can learn and grow over the life course but being flexible about the pathway

Some schools and providers interviewed had a strong expectation that disabled people would continue to learn and grow over the life course. They placed an emphasis on teaching skills that would allow people to be more independent in the community. One provider described his organisation as a bridge to the community. The provider's intention was that the young people coming to them would not be with them in five

---

[56] Literature supports the development of social skills as a means of improving quality of life for disabled people (Walker et al., 2011).

[57] See http://www.education.govt.nz/school/student-support/special-education/national-transition-guidelines-for-students-with-special-education-needs/

years' time because they were ready to move on after they had built up their skills and experience (eg through the RISK programme[58], referral to Catapult[59], work experience).

Another provider reported it was important to have an expectation that people can develop but to keep an open mind about what that pathway to growth might look like. Offering people choices and assisting them to develop their skills does not mean they need to stay with that choice. For example, if someone is placed in a job and they don't like it they should be able to leave – *"It's about the quality of the experience of the individual."*

Having a can-do attitude and being flexible supported disabled people to get what they wanted

All providers and schools considered the risks associated with disabled people participating in activities they wanted to undertake. However, some schools and providers had a strong 'can-do' attitude and focused on enabling people to do what they wanted and manage any risks. They had a culture of making things happen rather than a culture of risk aversion. When there was a concern about someone's safety, they worked through with the disabled person what needed to be done to manage the situation and enabled them to do it. For example, a provider who helped a disabled person fulfil their desire to race stock cars reflected:

> *I could have said, "Well, no, it's too risky, we're not going down that track." My arse is on the line here if –, but I stopped and I thought and, "Well, what would typically happen in that situation?" Well people would just work through a process of ticking off the boxes that needed to be ticked off in terms of managing the health and safety.*

If the family was worried about safety, they worked with them to allay their fears. When talking with the disabled person they discussed how they could do activities safely and what they would do if something unexpected happened (eg getting on the wrong bus). These interviewees reported that they believed expanding disabled people's experiences builds confidence, which enables them to do things more safely.

Valuing natural supports

Most providers and schools interviewed considered natural supports to be relationships with people in the community such as employers, friends, people in community organisations. Natural supports were seen to be wider than family. However, not all saw them as valuable. Providers interviewed who were supportive of disabled people living a life in the community typically saw natural supports as complementary to what they did, rather than as a lesser alternative.

---

[58] RISK (Recreation Inspires Strength & Knowledge) is a programme for people starting transition and uses recreation activities to build skills and confidence.

[59] See http://www.catapult.org.nz/ . This organisation helps people find work. The focus is on people who may have had time out of work or have not been able to get into work because of a disability, trauma or illness, raising a family, or personal reasons.

Valuing the concept of mainstream first

Under the EGL approach disabled people are supported to use mainstream and/or natural supports first, and supplement these with specialist supports where required. For some schools and providers interviewed, encouraging disabled people's participation and inclusion in mainstream activities and organisations was a core part of what they did.

They demonstrated that they were supportive of the concept of mainstream first by:

- supporting connections between disabled and non-disabled people
- teaching life skills that would support participation in mainstream activities
- building relationships between disabled people and those in mainstream organisations
- building relationships with mainstream organisations so that they had options to support disabled people.

Seeing social inclusion as being about building meaningful connections not just having a presence

Some providers and schools interviewed saw social inclusion as being about building meaningful connections in the community, not just having a presence. They supported disabled people to do, as much as possible, what their non-disabled peers were doing (eg work, volunteering, recreation). They typically had a goal of establishing more meaningful connections between disabled people and the wider community. They did this by, for example:

- using staff to establish relationships between disabled people and people in the community but stepping back as the relationships developed
- developing functional life skills to assist disabled people to be in the community
- working on changing community attitudes to better support disabled people to live in the community
- developing staff to support social inclusion.

Research indicates that people with intellectual disabilities living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than non-disabled and other disability groups (Verdonschot et al., 2009).

Some providers and schools were supportive of individualised planning and being person-centred

A key element of the EGL approach is that supporting disabled people to make choices about what they want to do and where needed having support and services tailored to meet their preferences. Some schools and providers interviewed were endeavouring to work in a personalised way by:

- *developing individualised plans with the disabled person:* All schools reported they developed Individual Education Plans as one of the means of identifying people's preferences and aspirations. However, the degree to which these were driven by disabled people rather than by what the school offered appeared to vary.

One school interviewed stood out as putting in place plans that were driven by what the students were interested in. The school had a strong emphasis on young people transitioning to a life in the community. They started talking with students early (eg when they were about 14) about what they were interested in and putting in place plans related to that. What they did depended on where students were at. For example, at the time of interviewing, many of the students were older so there had been an emphasis on sourcing work opportunities out in the community. Work opportunities were aligned with people's interests but were also used to allow people to explore activities they may want to pursue. In the following year, when they had more younger students, plans would have a greater emphasis on building functional life skills, relationships and self-care that supported life in the community. The school also offered people a range of experiences in the community so they had more ideas to draw on when thinking about what they liked.

Similarly, all providers reported that they developed individual plans with disabled people. However, as with the schools, only some were able to detail how they incorporated disabled people's preferences. In these organisations disabled people were also encouraged to be active players in decisions related to them and their development.

- *taking the time to build relationships and explore what disabled people wanted and how they could support that* (see page 120)
- *changing staff and resources to support personalisation (*see page 125)
- *sourcing options in the community that were aligned with people's choices*
- *being upfront with disabled people about what they could offer so they were clear about their choice:* Being upfront with disabled people about what they could offer to make choices more clearly supported disabled people to get what they wanted. Some providers reported that since the emergence of EGL they had been prompted to have more explicit discussions with disabled people and their families about what they could sustainably provide, and not overpromise
- *having a can-do attitude and being flexible to support disabled people to get what they wanted.*

Some providers and schools had a strong focus on relationship building

Building relationship between disabled person and school/provider

Schools and providers interviewed talked about the importance of building trusting relationships with families as a means of understanding disabled people's preferences. This was especially important where disabled people struggled to communicate their preferences. Having good relationships with disabled people and their families enabled schools and providers interviewed to keep up to date with what disabled people wanted. They reported they used this knowledge to better support individuals' learning and development.

Practices that helped build relationships included:

- *being less formal:* Having a relationship-based approach meant working with individuals and keeping formal processes to a minimum. One provider reported that it was beneficial to use informal approaches with disabled people and talk in environments that enabled meaningful conversations about what the disabled person wanted. For the provider it reduced assumptions they made about the person and made it easier for disabled people to be "*active players"* in the process
- *investing the time:* Schools and providers who placed a strong emphasis on relationship building reported that this took time. As one provider reported:

  > *It's about investing the time in those conversations but with a view of really trying to understand, what the person wants to do or what they don't want to do. That's not just about conversations. People will communicate through their actions and their behaviours so you need to be in tune with that as well. They might be saying this but actually their behaviour is telling us something quite different. For example, if one of the guys was regularly not turning up, well I'll say, "Well hang on, okay, so what's – let's explore that."*

  Another provider added that accepting that the relationship building will take time is particularly important where people have multiple challenges. She cited the example of a young person her organisation worked with who came to them because he could no longer live at home due to violent outbursts. His parents had rejected him and he had difficulty trusting people. The provider invested considerable time with the young person, including hiring someone to work one on one with him, to gain his trust and he was now calmer, respectful of boundaries, working, and developing friendships.
- *being aware of the various ways people communicated or expressed what they wanted to do but also whether they were enjoying what they were doing*.

Assisting disabled people to build relationships with people in the community

Some schools and providers were assisting disabled people to develop relationships with non-disabled people in the community by:

- *fostering links with people in the community such as employers who may eventually act as natural supports:* One provider firmly believed natural supports were available in the community for disabled people. The organisation used its staff to build disabled people's natural supports. The provider reported that natural supports take time to develop and require people with the right skill set to support people but "*once the dots start to join up it's amazing how things can then fall into place"*. The provider gave the example of a young person who, with the use of natural supports fostered by the provider, went on to get a driver's licence and employment (see Box 1, page 124). A school interviewed adopted a similar approach with local employers (see page 123)
- *stepping back as the relationships in the community developed:* Having a staff person present initially was seen as important for both the disabled person and the community organisation or workplace to assist in establishing a relationship. When possible, staff left people to maintain the relationships but were there for them to fall back on if there were any concerns. For example, one school built relationships with workplaces who were willing to provide work experience for disabled people. They

provided support in the form of teacher aides but this could be reduced as the people in the workplace became more confident in supporting the disabled person.

While beneficial, the process can be time-consuming, as the following example illustrates. The school got one of their students into a supermarket working 40 hours a week after the teacher met with the supermarket and built up the relationship with them. It took two years to establish the position. The school used the teacher aide resource to support the young person initially in the job and gradually the supermarket took over that role until finally the person was employed.

A provider interviewed undertook similar practices. The provider explained that as the relationship between the disabled person and person(s) in the community (eg employer) developed he expected that the role of the provider would be more in the background:

> *I think that kind of captures it for me, really, that new relationships would develop for people, that there would be more natural supports around that person. But there would still be a provider would still be there, maybe more in the background than foreground, so – the support wouldn't be – I mean, as much as it would be structured to a degree and formalised, – it would be more in the background, yeah.*

Supporting a disabled person's relationships with peers

Providers and schools interviewed reported they were supporting disabled people to build relationships with their peers. However, some explicitly talked about helping people to build longer-lasting connections. For example, two schools worked to develop students' social networks in the community so that they had support once they left school. In another example a provider assisted a young person with no friends to build up relationships by supporting him to go to social activities of his choice in the community. The activities were with disabled people (eg youth groups, a ball) and without disabilities (eg nightclubs, musicals).

Developing connections between disabled and non-disabled people by supporting participation in mainstream activities

Some schools and providers supported connections between disabled and non-disabled people. For example, mainstream schools supported connections between disabled and non-disabled students by:

- encouraging disabled people's participation in mainstream classes and activities where this was possible. For example, at one school all the students in the special needs class spent time in mainstream classes, sometimes with teacher aides and sometimes not. Several students participated in mainstream dance activities at the school; and all the special needs students attended form time in a mainstream class
- amending mainstream events so that disabled people could participate, for example changing the lighting so visually impaired students could participate in the end of year prize giving
- opening up mainstream roles to disabled people. For example, at one of the schools a past student with special needs had been deputy head boy. The teacher reported that

> he had had help with his end of year speech but it was really well received by the students – that support was genuine. He took the job seriously and did all his tasks.

Developing a network of organisations in the community that can be used to support disabled people

Some schools and providers worked to develop networks with mainstream organisations so that they could assist disabled people to build strong connections with them and more easily fulfil their choices. They actively encouraged their staff to build these networks. For example, one provider reported that, while there was value in disability organisations collaborating with each other, the real value for disabled people came in such providers connecting more with mainstream organisations. He stated:

> *thinking about the principles of Enabling Good Lives – it's actually about disability providers becoming part of the mainstream and connecting with a whole range of different people and organisations ... And so we, we've been quite intentional about [it]. … You know, we don't want to kind of isolate ourselves but we see the future more about becoming part of the community.*

The provider believed this approach opened up more mainstream opportunities for disabled people to participate in everyday life and build relationships. The provider had established links with art galleries, mainstream employers, and tertiary education organisations, which had in turn provided opportunities for disabled people to participate in mainstream activities they were interested in. As the provider reported:

> *And that's enabled us to move out of the disability space and into the art space. So, our philosophy is that this is not about disabilities. This is about art. This is about recognising that we have a group of talented artists here that really have a passion for art and so then flowing from that.*

A school with strong connections to several mainstream organisations expressed similar sentiments. For example, the school went to considerable effort to build relationships with employers who could provide work experience that fitted with people's preferences. For example, the school interviewee reported that she used her existing relationship with her local vet to create a work opportunity for one of her students. She had a student who really liked cats and wanted to work at the vet clinic. *"It's about finding the right people – I have managed to find quite a few."*

Providing learning in a way that worked for disabled people supported people to learn and grow

A provider interviewed supported disabled people to grow through experiential learning[60]. For example, the provider ran a course for learners with intellectual disability who wanted to work. The course was shaped around people's employment goals. The

---

[60] Experiential learning is seen as a dynamic process in which people are constantly able to construct their own learning and development by moving through a learning cycle. Experience is constantly reviewed and impressions challenged or confirmed. For example, a person's life experiences form the basis for his/her observation, and reflection on what has been encountered encourages learning. This in turn becomes assimilated into what is already known, providing a new conceptual map on which further actions will be based, thus forming a new experience. To complete the cycle, people also need to be able to practise skills learned if the training is to have any true meaning for them.

classroom-based work was shaped by the work experience people would be involved with and vice versa. The provider reported that:

> *an employment outcome is more likely if there's an opportunity for a person to connect with an employer through work experience early on in the process and not only does that allow for the necessary skills to then develop but it's about those relationships. And so the employer gets to know the person and that makes a big difference. … So that's kind of – we're hoping that we can demonstrate through that actually the role that work experience plays in terms of the learning process but then ultimately an employment outcome.*

The provider had an example of where providing a young person with the opportunities to gain confidence, build skills, and learn from experience had resulted in an employment outcome (see Box 1). This approach required the provider to have the right staff to facilitate experiential learning.

Box 1: Stock car racing

A provider was supporting a young person who was passionate about stock cars. The provider found him work with a car dismantler who had a private race track. The relationship between the disabled person and the car wrecker flourished. After a few months one of the team came to the head of the provider and said:

> *"There's been a bit of a change in plan." And I'm, "Yeah." They said, "William wants to race the car at Woodford Glen," and so I'm thinking, "Okay" you know, probably 101 sort of health and safety issues that – and I said, "Okay." So I mean that kind of challenged me a little bit and so I'm like, "Yeah, okay, well let's just take it one step at a time and see what's required." So, a lot of really good support from the car wrecker guy and then, we liaised with the raceway and all the health and safety things and just ticked them off one thing at a time. And then it's like, "Hang on, he hasn't got a driver's licence."*

The provider supported this decision and got some funding for six driving lessons. Once the driving instructor got to know the young person and what he was trying to do, he donated another 10 driving lessons to help him pass. In addition the car wrecker supplied much of the safety equipment and allowed him to practise on the private track. All his work culminated in the young man racing in a stock car at the local speedway. His confidence significantly increased in the time he was with the car wrecker. The provider said:

> *We hardly ever see him and so, he's now got a full-time job working as a car groomer, passion for cars again, he's bought his own car. … And I've just recently heard that he's bought his own old wreck of a car to build as a stock car.*

Developing functional life skills to enable people to operate more independently in the community

All the schools reported they taught their students life skills[61] to participate in the community. For example, one of the mainstream schools interviewed had a particularly strong emphasis on teaching functional life skills that would support young people to live as independently as possible in the community post-school. They taught students about managing money and time, how to communicate, using transport, health, sexuality, and keeping safe.

There was an emphasis on disabled people practising the skills they learned in the community. For example, when teaching students how to buy clothes at the mall the teacher aide made sure the students knew how to try the clothes on, wrote down their

---

[61] Teaching a wide range of functional life skills (eg banking, self-management, leisure, personal health) and teaching employment and career development skills are among the 63 evidence-based practices that show moderate to high levels of evidence of effectiveness in terms of improved post-school outcomes for students with disabilities (Morningstar & Mazzotti, 2014).

sizes so they knew what to get next time, and showed them how to pay for the clothing. The school also taught students to buy and cook healthy food by undertaking these activities. The school provided visual recipes for hot dogs, pizza, noodles, as not everyone could read. Students were encouraged to cook at home and put pictures on Facebook to showcase their efforts.

What the schools taught depended on the needs of the students. For example, at the school mentioned above, where students were older and closer to leaving school, the focus was more on strengthening the skills needed post-school. Where students were younger the focus was more on developing basic life skills. At another school where the students were higher functioning the emphasis was less on basic life skills and more about supporting them with equipment and establishing back-up plans (eg what to do if they had a technical malfunction with their technology such as their Segway or phone).

Some providers were also involved in teaching life skills and/or vocational skills to allow people to engage on their own terms in the community. For example, this included building disabled people's skills to take the bus by themselves, do shopping and cooking so they could live independently, and keep safe including using technology.

Changing resourcing to better support disabled people

Research indicates that staff practice and organisational process are both important for ensuring personal outcomes (Claes et al., 2012). This evaluation found all schools and providers had concerns about the adequacy of the resources available to them. However, some schools and providers reported that part of the answer lies in better use of resources. A school and two providers who were very supportive of the EGL approach reported that, while more resourcing would be useful, it was also a matter of thinking differently about how the resources they had were used. For example, some were:

- *moving resources away from away from investing in buildings to investing in staff who could work with disabled people in a community setting:* One provider interviewed who had done this reported that the earthquake provided an opportunity to use their funding differently and fitted with their move to providing more individualised and flexible support to disabled people. Rather than leasing or owning a building with all the associated costs, they utilised community spaces and developed partnerships with organisations who let the provider use their buildings at minimal or no cost
- *using staff differently to better support the delivery of a personalised approach:* Some schools and providers were doing this. For example, a provider who had moved away from group activities now required staff to work more flexibly with individuals on a one-to-one basis to build people's confidence and skills and undertake activities of their choice in the community. A school interviewed undertook a similar approach. It sometimes meant they had higher than normal teacher: student ratios in the classroom (eg 1:6) while the teacher aides were out but they reported that so far this had not been a problem
- *up-skilling staff:* The move to a more personalised approach required some providers to up-skill staff to work in a personalised way. Two providers reported they had worked to educate staff on how to work in a more personalised way. While some staff were not able to make the adjustment and left, those that remained had changed the way they worked. As one provider reported:

> *I think that was probably one of the factors that saw some of our team leave – they had a fairly sort of – how can I say this respectfully? You know, sort of a boxed-up view of what it looked like. But I think we've got the right – more or less the right team now that understands the principles that we work from and see evidence of those principles, hopefully, on a day-to-day basis.*

- *using leadership to promote change:* The evaluation found leadership and values were important to support staff to respond to specific issues and continual challenges regarding risk. Leadership was essential in supporting staff with the approach and situations, to build a culture of learning and confidence. The expanding of disabled people's experiences and confidence meant staff were continuing to be challenged and needing to work through situations as they presented to ensure any risks to individuals were well thought through (see Box 2).

Box 2: Supported housing

One supported housing provider commented that they needed to be able to manage the risks and allow people the freedom to live their lives. Achieving this balance with staff was at times stressful but possible. She had given the clear direction to her staff that the people they supported were adults and needed to be treated as such (eg flexibility about bedtimes rather than having to be in bed by 8.30pm because that time suited the staff).

She gave the example of a young person whom they were providing supported housing for. The young person sometimes tried to re-negotiate curfews while out. While it was later than agreed he would eventually come back, she reported that one staff member was keen on reprimanding his behaviour. She talked to the staff member concerned, saying they needed to focus on the fact he came back and that needed to be said was, "Oh, good you're back."

She said the change in approach at the organisation had been challenging for some staff. In line with their philosophy of treating people as the adults they were, people were encouraged to negotiate when they wanted to stay out late. For example, a young person they were supporting wanted to come back one night at 11.30pm. She advised him to negotiate with the sleepover woman to make sure it was ok for her to wait up for him as she officially finished at 10.30pm. She gave the responsibility to the young person to ask her and sort out how he'd get in. She checked it out as well but the young person managed it.

Had some practices in place to support disabled people to influence how their organisation operated

Some practices were identified that supported disabled people to influence the policies and practices of the provider or school.

- *building relationships:* Some schools and providers reported building good relationships with disabled people so they felt comfortable raising concerns
- *having disabled people represented on boards or other decision-making bodies:* This was not common. However, two providers reported that they had disabled people represented in decision-making. For example, a provider had a monthly group meeting with staff and families where they talked about how the service could be improved. The provider reported that they had made changes as a result of the input from families. The provider also had a client representative on the Board of Trustees and this influenced purchases. Another provider reported they had a client representative group and these representatives attended the provider's board meetings. The provider reported it meant that the people they worked with had a direct connection with their Board of Trustees

- *having complaints processes:* Several providers and all the schools reported that they had a complaints process whereby disabled people and/or their families could express concerns.

Working on changing community attitudes to better support disabled people to live in the community

Some providers and schools worked to get people in the community to value what disabled people have to offer and the skills they have. For example, a teacher in one mainstream school did this by building connections between her students and people in the community (eg work experience opportunities). Connections were also built with mainstream students by encouraging students with disabilities to participate in mainstream activities in the school and mainstream students to interact with them (eg year 12 mainstream students attending camp with students from the special unit). The teacher said:

> *That kind of contact and experience helps change attitudes. You hope that when they get jobs they might become managers and they might give these guys [disabled students] opportunities.*

Some schools and providers reported using their staff to build relationships with organisations and encourage them to be inclusive and accepting of disabled people. A provider reported that by building relationships between disabled people and those in the community prejudices can be lessened and natural supports developed.

Some providers worked to allay the fears of people in the community about disabled people. A housing provider believed having more disabled people live successfully in the community would help change attitudes. To overcome resistance to having disabled people as neighbours, the provider spent time reassuring them they had nothing to worry about and sometimes they also guaranteed bonds. A vocational provider reported there were ways to use staff to reduce the nervousness of mainstream people when disabled people visited community facilities. When the staff member was acting as part of the group, rather than standing off to the side and observing the other group members, it seemed to normalise the situation, and put other people more at ease.

More investment may be needed to bring about sustained change

More investment may be needed to bring about sustained change in schools and providers. When asked whether EGL had brought about sustained or superficial change in providers and schools, those working with schools and providers reported the changes were superficial. They reported they had seen the beginnings of change in how providers and schools operated but felt there was a risk that providers and schools would stop progressing once the Demonstration ended. As one EGL team member reported, *"Providers could take their foot off the pedal and say see I told you it would go away"*. Of schools, another team member said:

> *I think if we didn't turn up next year the schools would be like, "Oh well. That was a waste of time." … And the others would, you know, it's sort of – there would be that – that element of "I told you so".*

Specific provider (and school) development funding could help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools need to start by expanding their vision of what disabled people can achieve.

8. Where to next?

Suggested improvements to implementation and the design process

Improving what was to be put in place in the Demonstration could have improved implementation.

- A more fully developed design was needed. Development of a detailed design was hindered by several factors. There were differing perspectives on the flexibility of the design, what co-design meant in practice in the context of the Demonstration and whether it had been co-designed. The co-design needed more time and resource. Better links between design and implementation were needed.
- Understanding of and buy-in to the EGL vision across stakeholders needed to improve.
- It would have improved the Demonstration if the leader on the ground and leaders in government had a common understanding about roles and responsibilities and the processes for resolving system issues as they affected the Demonstration.
- Accountability arrangements could be improved. Focus on outcomes and measuring outcomes was problematic at all levels. Accountability arrangements with providers and schools don’t yet reflect that focus on outcomes for disabled people.

EGL highlights wider problems with the system which limit implementation and performance.

- The amount of funding disabled people received may have been insufficient to achieve their vision of a good life. For example, those who wanted to move out of home and live independently in the community.

The design of what was implemented could have been improved.

- A wider range of funding options for managing the funding was needed.
- There is a need to look at the assumptions about the role natural supports can play in supporting disabled people, as they may be unrealistic. Few families reported that they had significant natural supports outside of family and where they existed they appeared fragile. Further understanding is required about how natural supports can be developed and how they can be used alongside responsive formal supports and services.
- The community development component was underdeveloped. It was unclear how community development was supposed to happen under EGL. The community development component received little attention in terms of design and resourcing.
- Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, investment in changing practice in providers and schools was insufficient (see below).

Suggested improvements to navigation and planning, personal budgets and employment of staff by families

Possible improvements for navigation and planning include providing:

- more support for disabled people and families when they get into difficulty implementing their plan
- more support for vulnerable families to develop, put in place and maintain their vision of a good life
- improved links between new families and those families who have engaged with EGL
- clarity about the future of navigation.

There were practices that supported disabled people and families but there was room to improve.

- Pooling the funding and having greater flexibility in the use of the funding have been important. Some families expressed the desire for more flexibility in the use of the funding.
- Managing the money was difficult for many families and disabled people. More options were needed to assist individuals and families to take up and manage the funding.
- The amount of funding appeared to be insufficient in some contexts. These included where the young person wanted to live independently in the community the cost was a significant barrier and where families were on lower incomes the amount of funding they received may have been insufficient. The funding may have been insufficient to support disabled people's choices where family could not be involved in the day-to-day care of their young disabled. Taking up FFC limited the overall pool of funding but families did not always feel they had an alternative.
- Families had some useful sources of advice on how to use the funding and guidance but more was needed.

The employment of staff could be improved. Families and EGL staff interviewed offered suggestions to make it easier to employ staff, including:

- doing more work to support families as employers, especially when disputes arise
- providing education for support workers about the home care environment
- establishing a group that could shoulder more employer responsibility for families
- using flexible disability support contracts between disabled people and providers. These are now in place, but it would be useful to have further evaluation of how well they are working for disabled people and families.

Suggested improvements to measuring quality of life outcomes

There is currently limited information systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found improvements could be made by:

- enhancing data collection (eg improving the response rate, the collection of information from people with communication challenges, and the collection of information from proxies)
- reconsidering the use of comparison groups. It may be a better use of scarce resources to track participant outcomes over time. However this would not allow any conclusions to be drawn about impacts on participants and their families.
- establishing a standard set of evidence based indicators for individuals that can be tracked over time and applied more widely
- developing family wellbeing indicators.

Suggested improvements to engaging with and changing the behaviour of schools and providers

In future similar initiatives, factors that may help schools and providers include:

- engaging in consistent and clear communication with schools and providers over a longer time period prior to and during a Demonstration to assist in getting buy-in and ensure that everyone is on the same page
- having a person schools know and trust to liaise with them about the approach
- having readily available information on what the approach means in practice and advice on how to get there, including for the governing bodies of providers and schools (eg, more advice on how to cost their services in an individualised way)
- ensuring that contracts and funding arrangements with providers encourage the outcomes sought by the EGL approach
- providing specific provider (and school) development funding to help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools needs to start by expanding their vision of what disabled people can achieve.

An ongoing challenge will be addressing the financial sustainability of providers.

References

Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities,* 10(3), 275–287. http://journals.sagepub.com/doi/pdf/10.1177/1744629506067618

Anderson, D., Ferguson, B., & Janes, R. (2014). *Enabling Good Lives Christchurch Demonstration: Phase 1 evaluation report.* Wellington, New Zealand: Ministry of Social Development, Ministry of Health and Ministry of Education.

Arksey, H., & Baxter, K. (2012). Exploring the temporal aspects of direct payments. *British Journal of Social Work*, *42*(1), 147–164.

Ball, M and Maginn, P. J (2005), Urban Change and Conflict: Evaluating the Role of Partnerships in Urban Regeneration in the UK. Housing Studies, *20*(1), 9-28.

Blake, J., Lund, E., Zhou, Q., Kwok, O., & Benz, M. (2012). National prevalence rates of bully victimization among students with disabilities in the United States. *School Psychology Quarterly*, *27*(4), 210–222. https://www.apa.org/pubs/journals/features/spq-0000008.pdf

Boxhall, G., & Benjamin, M. (2012). *Enabling Good Lives in Canterbury.* A report collated by Gordon Boxall and Mark Benjamin for the "Steering Group" for the Enabling Good Lives Canterbury Project. http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/the-canterbury-plan-june-2012/

Boyle, D., & Harris, M. (2009). *The challenge of co-production: How equal partnerships between professionals and the public are crucial to improving public services*. NESTA. http://www.nesta.org.uk/publications/challenge-co-production

Brotchie, J. (2013). *The enabling state: From rhetoric to reality. Case studies of contemporary practice*. London: Carnegie UK Trust. http://www.bsc.scot/uploads/1/9/0/5/19054171/carnegieuk_trust_-_the_enabling_state_from_rhetoric_to_reality.pdf

Browder, D. M., Wood, L., Thompson, J., & Ribuffo, C. (2014). *Evidence-based practices for students with severe disabilities* (Document No. IC-3). University of Florida, Collaboration for Effective Educator, Development, Accountability, and Reform Center website: http://ceedar.education.ufl.edu/wp-content/uploads/2014/09/IC-3_FINAL_03-03-15.pdf

Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities, 51*(5), 316–332.

Caldwell, J., & Heller, T. (2007). Longitudinal outcomes of a consumer-directed program supporting adults with developmental disabilities and their families. *Intellectual and Developmental Disabilities*, *45*(3), 161–173.

Cameron, A., Lart, R., Bostock, L., & Coomber, C. (2012). Factors that promote and hinder joint and integrated working between health and social care services. *SCIE Research Briefing 41.* London. http://www.scie.org.uk/publications/briefings/files/briefing41.pdf

Carr, S. (2010). *Enabling risk, ensuring safety: Self-directed support and personal budgets* (Adults' Services SCIE Report No.36). London, UK: SCIE.

Carter Anand, J., Davidson, G., Macdonald, G., Kelly, B., Clift-Matthews, V., Martin, A., & Rizzo, M. (2012). *The transition to personal budgets for people with disabilities: A review of practice in specified jurisdictions* (National Disability Authority Working Paper). Dublin, Ireland: NDA. http://www.inis.gov.ie/website/nda/cntmgmtnew.nsf/0/F6E10844509D45B780257B3C00517FB4/$File/personal_budgets_state_of_evidence_nov_2012.htm

Chatzitheochari, S., Parsons, S., & Platt, L. (2014*). Bullying experiences among disabled children and young people in England: Evidence from two longitudinal studies* (Working Paper No. 14–11). London, UK: Department of Quantitative Social Science, Institute of Education, University of London. http://repec.ioe.ac.uk/REPEc/pdf/qsswp1411.pdf

Claes, C., Vandevelde, S., Van Hove, G., van Loon, J., Verschelden, G., & Schalock, R. (2012). Relationship between self-report and proxy ratings on assessed personal quality of life-related outcomes. *Journal of Policy and Practice in Intellectual Disabilities, 9*(3), 159–165.

Claes, C., Van Hove, G., van Loon, J., Vandevelde, S., & Schalock, R. (2010). Quality of life measurement in the field of intellectual disabilities: Eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research*, *98*(1), 61–72.

Colombo, F., Llena-Nozal, A., Mercier, J., & Tjadens, F. (2011). *Help wanted? Providing and paying for long-term care*. OECD Publishing, Paris.

http://www.oecd-ilibrary.org/social-issues-migration-health/help-wanted_9789264097759-en

Conroy, J., Ferris, C., & Irvine, R. (2010). Microenterprise options for people with intellectual and developmental disabilities: An outcome evaluation. *Journal of Policy and Practice in Intellectual Disabilities, 7*(4), 269–277.

Cummins, R.A., Lau, A.L.D. (2005). Personal Wellbeing Index- School Children (PWI-SC) (3rd-ed.). Deakin University, Melbourne.

Duffy, S. (2004). Person centred planning and system change. *Learning Disability Practice, 7*(8), 15–19.

Duggan, C., & Linehan, C. (2013). The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature. *British Journal of Learning Disabilities, 41*(3), 199–207. doi:10.1111/bld.12040

Emerson, E., & Brigham, P. (2014). The developmental health of children of parents with intellectual disabilities: Cross sectional study. *Research in Developmental Disabilities,* 35(4):917-21.

FaHCSIA (2011). *National Carer Strategy: Evidence base.* Canberra: Department of Families, Housing, Community Services and Indigenous Affairs. http://www.fahcsia.gov.au/sites/default/files/documents/06_2012/nat_carer_strat_ev_base.pdf

Field, A., McGechie, M., & King, J. (2015). MIC Individualised Funding Analysis: Report for Manawanui InCharge. New Zealand: Dovetail. http://www.incharge.org.nz/wp-content/uploads/2014/01/Dovetail-IF-cost-analysis-Final-Updated-15102.pdf

Fisher, K., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., … Thompson, D. (2010). *Effectiveness of individual funding approaches for disability support* (Occasional Paper No. 29). Canberra: FaHCSIA. https://www.dss.gov.au/sites/default/files/documents/05_2012/op29.pdf

Fleming, T., Clark, T., Denny, S., Robinson, E., Rossen, F., Bullen, P., … The Adolescent Health Research Group (2013). *The health and wellbeing of secondary school students in Christchurch: Findings from the Youth'12 national youth health and wellbeing survey*. Auckland, New Zealand: The University of Auckland. https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/ahrg/docs/christchurch-%20report.pdf

Forder, J., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., … Dolan, P. (2012). *Evaluation of the personal health budget pilot programme* (Discussion Paper No. 2840_2). London, UK: Department of Health.

Francis, G., Blue-Banning, M., & Turnbull, R. (2014). Variables within a household that influence quality-of-life outcomes for individuals with intellectual and developmental disabilities living in the community: Discovering the gaps. *Research and Practice for Persons with Severe Disabilities*, *39*(1), 3–10. http://journals.sagepub.com/doi/pdf/10.1177/1540796914534632

Genio (2014). Supporting people to live self-directed lives in the community: Learning from 54 Irish projects. Dublin, Ireland: Genio. http://www.genio.ie/system/files/publications/GENIO_LEARNING_PAPER_MOVE_TO_COMMUNITY.pdf

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., … Wilberforce, M. (2008). *Evaluation of the Individual Budgets Pilot Programme: Final report*. York, UK: Social Policy Research Unit, University of York.

Goodhead, A., & McDonald, J. (2007). *Informal caregivers literature review: A report prepared for the National Health Committee*. Wellington, New Zealand: Health Services Research Centre, Victoria University of Wellington.

Hannon, F. (2010). *Literature review on attitudes towards disability* (Disability Research Series No. 9). Dublin, Ireland: National Disability Authority. http://www.ucd.ie/issda/static/documentation/nda/nda-literature-review.pdf

Harflett, N., Turner, S., & Bown, H. (2015). *The impact of personalisation on the lives of the most isolated people with learning disabilities: A review of the evidence*. Bath, UK: National Development Team for Inclusion. http://www.ndti.org.uk/uploads/files/Isolation_and_personalisation_evidence_review_final_02_06_15.pdf

Jeon, H., Mahoney, K., Loughlin, D., & Simon-Rusinowitz, L. (2015). Multi-state survey of support brokers in cash and counseling programs: Perceived roles and training needs. *Journal of Disability Policy Studies*, *26*(1), 24–32.

Kendrick, M., Jones, D., Bezanson, L., & Petty, R. (2006). *Key components of systems change.* Houston, TX: Independent Living Research Utilization. http://www.ilru.org/sites/default/files/Systems_Change_Key_Components1.pdf

Lakin, C., Larson, S., & Kim, S. (2011). *Behavioral outcomes of deinstitutionalization for people with intellectual and/or developmental disabilities: Third decennial review of U.S. studies, 1977-2010* (Policy Research Brief Vol. 21, No. 2). Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, College of Education and Human Development, University of Minnesota. https://ici.umn.edu/products/prb/212/212.pdf

Lindsay, C., McQuaid, R., & Dutton, M. (2008) Inter-agency Cooperation and New Approaches to Employability. *Social Policy & Administration 42*(7) 715-732.

Mansell, J., & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities. *Journal of Intellectual Disability Research*, *54*(2), 104–112.

Milner, P., & Kelly, B. (2009). Community participation and inclusion: people with disabilities defining their place. *Disability & Society, 24*(1), 47-62

Ministry of Community and Social Services. (2013). *Person-directed and facilitation planning guid*e. Ministry of Community and Social Services Community and Developmental Services Branch, Canada

Mirfin-Veitch, B. (2003). *Relationships and adults with an intellectual disability: Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for people with an intellectual disability.* Wellington, New Zealand: National Health Committee. http://www.donaldbeasley.org.nz/assets/Uploads/publications/NHC-Relations.pdf

Mitchell, W., Brooks, J., & Glendinning, C. (2015). Carers' roles in personal budgets: Tensions and dilemmas in front line practice. *British Journal of Social Work*, *45*(5), 1433–1450.

Morningstar, M., & Mazzotti, V. (2014). *Teacher preparation to deliver evidence-based transition planning and services to youth with disabilities* (CEEDAR Document No. IC-1). Gainesville, FL: CEEDAR Center, University of Florida. http://ceedar.education.ufl.edu/wp-content/uploads/2014/08/transition-planning.pdf

Newman, J., Glendinning, C., & Hughes, M. (2008). Beyond modernisation? Social care and the transformation of welfare governance. *Journal of Social Policy, 37*(4), 531–557.

NDA (2011). A review of literature on natural community supports: A contemporary developments in disability services paper. Dublin, Ireland: National Disability Authority.

OECD (2011). *Together for better public services: Partnering with citizens and civil society* (OECD Public Governance Reviews). OECD Publishing. Paris

Orsmond, G., Shattuck, P., Cooper, B., Sterzing, P., & Anderson, K. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(11), 2710–2719.

Peer, J., & Hillman, S. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: a review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 92–98.

Peiris-John, R., Ameratunga, S., Lee, A., Al-Ani, H., Fleming, T., & Clark, T. (2015). Adolescents with disability report higher rates of injury but lower rates of receiving care: Findings from a national school-based survey in New Zealand. *Injury Prevention 22*(1), 40-45. http://injuryprevention.bmj.com/content/early/2015/06/30/injuryprev-2015-041636.abstract

Pitonyak, D. (2002). Opening the door. In J. O'Brien & C. L. O'Brien (Eds.), *Implementing person-centred planning* (pp. 99–120). Toronto, Canada: Inclusion Press.

Pitonyak, D. (2013). Loneliness is the only real disability: Implications and recommendations for policy makers. http:// www.dimgine.com/NASDDS.pdf

Reinders, H.S., & Schalock, R.L. (2014). How Organizations Can Enhance the Quality of Life of Their Clients and Assess Their Results: The Concept of QOL Enhancement. *American Journal on Intellectual and Developmental Disabilities. 119* (4). 291-302.

Samuel, P.S., Rillotta, F., & Brown, I. (2012). The development of family quality of life concepts and measures. *Journal of Intellectual Disability Research.56* (1). 1-16.

Schalock, R., & Verdugo, M. (2012). A conceptual and measurement framework to guide policy development and systems change. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(1), 63–72.

Schalock, R., & Verdugo, M. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities*, *51*(4), 273–286.

Schalock, R. L., Verdugo, M. A., Gomez, L. E., & Reinders, H. S. (2016). Moving Us Toward a Theory of Individual Quality of Life. *American Journal on Intellectual and Developmental Disabilities. 121* (1). 1-12.

Schalock, R., Verdugo, M., & Lee, T. (2016). A systematic approach to an organization's sustainability. *Evaluation and Program Planning, 56*, 56–63. http://dx.doi.org/10.1016/j.evalprogplan.2016.03.005

Schalock, R., Brown, I., Brown, R., Cummins, R., Felce, D., Matikka, L., … Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation, 40*(6), 457–470. http://www.viauc.dk/psykomotorikuddannelsen/oekonomi/documents/quality of life%20and%20IDD%20schalock%20et%20al%202002.pdf

Schalock, R., Verdugo, M., Bonham, G., Fantova, F., & van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities*, *5*(4), 276–285.

Schalock, R., Bonham, G., & Verdugo, M. (2008). The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities*. Evaluation and Program Planning, 31*(2): 181–190.

Schalock, R., Verdugo, M., Jenaro, C., Wang, M., Wehmeyer, M., Xu, J., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, *110*(4), 298–311.

Sentenac, M., Gavin, A., Nic Gabhainn, S., Molcho, M., Due, P., Ravens-Sieberer, U., … Godeau, E. (2012). Peer victimization and subjective health among students reporting disability or chronic illness in 11 Western countries. *European Journal of Public Health, 23*(3), 421–426. http://eurpub.oxfordjournals.org/content/eurpub/23/3/421.full.pdf

Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities*, *38*, 18–29. http://www.doctrid.ie/adminbackend/resources/s-clifforddefining-social-inclusionridd.pdf

Simpson, B. (2010). *Practical approaches to safeguarding and personalisation*. London, UK: Department of Health. http://www.communitylivingbc.ca/wp-content/uploads/Practical-approaches-to-safeguarding-and-personalisation.pdf

Stevens, K., Munford, R., Sanders, J., Dewhurst, K., Youthline Auckland, Henaghan, M. … Mirfin-Veitch, B. (2013). *Pathways to youth resilience: Youth health and disability services in New Zealand: A policy overview.* New Zealand: Massey University Resilience Research Centre. https://www.massey.ac.nz/massey/fms/Resilience/Documents/Youth%20Health%20and%20Disability%20Service.pdf

The New Zealand Productivity Commission (2015) More effective social services. Appendix D Services for people with disabilities. Wellington, NZ. http://www.productivity.govt.nz/sites/default/files/social-services-final-report-appendix-d.pdf

Thompson, D., Fisher, K., Purcal, C., Deeming, C., & Sawrikar, P. (2011). *Community attitudes to people with disability: Scoping project* (Occasional Paper No. 39). Sydney, Australia: Social Policy Research Centre, Disability Studies and Research Centre, University of New South Wales. https://www.sprc.unsw.edu.au/media/SPRCFile/Australian_community_attitudes_to_disability.pdf

Townsend-White, C., Pham, A., & Vassos. M. (2012). A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours. *Journal of Intellectual Disability Research*, *56*(3), 270–284. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2011.01427.x/pdf

Verdonschot, M., de Witte, L., Reichrath, E., Buntinx, W., & Curfs, L. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303–318.

Verdugo, M., Schalock, R, Keith, K., & Stancliffe, R. (2005) Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research,*49(10):707–717 https://www.researchgate.net/publication/39585074_Quality_of_life_and_its_measurement_important_principles_and_guidelines

Walker, H., Calkins, C., Wehmeyer, M., Walker, L., Bacon, A., Palmer, S., Johnson, D. (2011). *A series of papers on scaling-up efforts to promote self-determination. Paper 1: A social-ecological approach to promote self-determination*. Washington, D.C.: US Department of Health and Human Services, Administration on Developmental Disabilities http://www.aucd.org/docs/ScalingUpPaper1Final.pdf

Yin, R. (1994). *Case study research: Design and methods*. Thousand Oaks, CA: Sage Publications.

Appendix 1: Evaluation objectives and research questions

Objective 1: to understand what outcomes are being achieved by those participating in EGL and what contribution EGL has made to those outcomes

- Who develops a vision for a good life? To what extent are disabled people's visions for a good life being realised?
- What life outcomes does the Demonstration contribute to for participants? What outcomes originated, and were sustained, outside of the Demonstration? What outcomes mattered to disabled people and their families? How do the life outcomes of disabled people who are participating in the Demonstration compare with those who are not?
- How easy do disabled people find it to get and sustain the life they want? What is assisting them to do this and what is a barrier?
- What perceptions do participants have of outcomes, so far? To what extent do disabled people believe they have real choice and control over their lives?
- What is the level of community access, participation and connection? What impact on or contribution to the community is the disabled person making? How does the community (eg structures, attitudes, culture, people) change as a result?
- Has the Demonstration had any unintended effects for disabled people and families?

Objective 2: to understand what constitutes a good life for disabled people involved in the Demonstration and how this understanding evolves over time

- How do disabled people and their families conceptualise a good life? How does this change over time? What commonalities and differences exist in the descriptions of what constitutes a good life?
- To what extent does the EGL approach support disabled people to identify what constitutes a good life for them and what it would take to achieve it? What is working well and for whom? What could be improved upon and how? Are there any unintended consequences?

Objective 3: to understand what is being implemented to enable disabled people to have good lives and how it is operating in practice

- What do the results reveal about the expected progress of the different components of the Demonstration? How are the components of the Demonstration operating in practice? What seems to be working and not working and why? What innovations have been developed? What improvements could be made?
- What supported and what hindered the implementation of the Demonstration? Where there have been problems, how significant are they, and are they transient or likely to remain? What can be done to resolve any continuing problems?
- What has been the experience of disabled people and their families participating in the Demonstration? What are the most valuable and least valuable aspects of their participation in the Demonstration? What changes would they make?
- What has been the experience of providers and schools participating in the Demonstration? What are the most valuable and least valuable aspects of their participation in the Demonstration? What changes would they make?

Objective 4: to understand how schools, providers of disability support services and government agencies have positioned themselves to support disabled people to live a good life

Providers

- What are providers doing to support disabled people to be healthy, safe and well and live the life they want? What, if any, changes have they made to their practice in this area following the introduction of EGL?
- What is influencing the way providers support disabled people? What influence has EGL had on their practice?
- What is impeding or facilitating the capacity of providers to support disabled people to be healthy, safe and well and live the life they want?

Schools

- What are schools doing to support disabled people to be healthy, safe and well and live the life they want post-school? What is influencing the way schools support disabled people?
- How have schools responded to the EGL approach? What influences their support or otherwise of the Demonstration? What, if any, changes have they made to their practice in this area following the introduction of EGL?
- What do schools like about the EGL approach and what would they change?

Government agencies, EGL team, LAG

- To what extent are government systems supporting disabled people to be healthy, safe and well and live the life they want within the Demonstration?
- What contribution have government agencies, the EGL team and the Local Advisory Group made to the development and implementation of Enabling Good Lives? What has worked well? What is limiting progress?

Objective 5: to examine what supports the success of the Demonstration as an approach to enable disabled people to have good lives, and what does not, and identify any lessons that could inform the scaling-up of the Demonstration

- What is getting in the way of the Demonstration achieving the desired outcomes?
- What adaptations are needed to achieve the outcomes?
- What would inform the scaling-up of the Demonstration?

Appendix 2: Evaluation methodology

Evaluation approach

The evaluation used a mixed method approach similar to phase 1 but with some additions. As the phase 1 evaluation took place shortly after implementation began there was limited opportunity to look at outcomes for participants. Phase 2 was more focused on outcomes.

The methods used in Phase 2 included:

- 10 case studies of disabled people in different contexts
- a quality of life survey of 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). While comparable with many youth surveys, the response rate was low (34%).
- in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers, a representative from MIC, the LAG as a group, the EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
- analysis of existing administrative data to describe trends and patterns in use of navigators, Individualised Funding, self-management of funding and supports and services
- analysis of documents on the Demonstration.

Methods were selected based on their capacity to answer evaluation objectives and research questions. The methods were applied concurrently but separately. This means the researchers implemented both the quantitative and qualitative strands during a single phase of the research study.

The rationale for using a mixed method design is as follows:

- *Triangulation of findings allows them to be corroborated.* Triangulation is a technique that facilitates validation of data through cross verification from two or more sources. In particular, it refers to the application and combination of several research methods in the study of the same phenomenon.
- *Weaknesses in each method will be offset.* All methods have their strengths and weaknesses. Combining methods allows us to offset the weaknesses of each method and to draw on the strengths of each method.
- *Using a mix of methods allows for the development of a more complete picture*. By having a mix of methods we are seeking to provide a more complete picture of the Demonstration than is possible using a single method within the timeframe and resources available. Quantitative and qualitative research can each answer different research questions. This evaluation approach allows us insight into which aspects of the Demonstration are working and which are not and why, along with whether or not there are unexpected consequences.
- *This approach is suitable in a context where the environment is very dynamic and pathways to change cannot be predetermined*. EGL has evolved in Christchurch over

the course of the Demonstration. A mixed method evaluation can support this evolution by providing timely and actionable data about how a complex system is responding to the Demonstration.

Ethics

Ethical approval was obtained

Ethical approval to undertake the quality of life survey was obtained by going through the Ministry of Social Development's ethics process. The evaluation plan was also sent to the Chief Science Advisors in the Ministries of Education and Social Development, who both approved the proposed approach.

Ethical considerations

Obtaining consent to be interviewed

Wherever possible, written informed consent was obtained from each participant. Care was taken to ensure that potential participants clearly understood the implications of their involvement and that: (1) they could withdraw their consent at any time; (2) refusal or withdrawal of consent would have no impact on the support they received; and (3) they would still be able to take part in EGL even if they did not give consent for involvement in the evaluation.

Some interviewees had learning disabilities. Care was been taken to ensure that potential participants clearly understood the implications of their involvement (eg having consent forms written in plain, simple language; using assistive technology where available and people who know the disabled person well to assist with understanding).

Where potential participants were unable to give informed consent due to the severity of their intellectual impairments we sought agreement for participation from either: (1) the person's independent advocate; or (2) the closest family member who was in regular contact with the person.

Use of proxies when disabled cannot be interviewed

Some disabled people were not be able to undertake the quality of life survey. It has been well established that people who have a severe or profound level of intellectual disability cannot respond validly to a scale of subjective wellbeing (Cummins & Lau, 2005).

Where disabled people are unable to respond to interview questions proxies were used. A proxy was someone who knew the person with a disability well. The use of a proxy or third party response is considered more reliable for reporting objective measurements than subjective feelings. Measurement of a person's quality of life from another person's perspective is not ideal[62] but can be useful in some instances where people are not able

---

[62] The only known method of measurement for those with a severe or profound level of intellectual disability is through behavioural observation but this is resource intensive.

to communicate or make life decisions, but the results should not be treated as the perception of the person with disability.

Ensuring confidentiality of research participants

The evaluation reporting did not contain personal identifiers but may contain professional or role identifiers (eg disabled person, navigator, Ministry of Social Development official). Evaluation reporting may make use of short quotes to illustrate points. These quotes were attributed to roles (eg a disabled person, a family member, a navigator) rather than individuals. Any information which might lead to an interviewee being identified was only to be published with their permission.

Privacy and data storage

Any audio-recordings and interview notes would only be available to the research team, and be stored securely until the project is completed, and then destroyed. No information that identifies the research participants personally would be given to people outside the research team. The evaluation reporting would not contain personal identifiers but may contain professional or role identifiers (eg disabled person, navigator, Ministry of Social Development official).

Ensuring disabled people have a voice

A key element of the EGL approach is to ensure disabled people have a voice. This is being done by:

- involving disabled people in the design of the evaluation and where possible in carrying out the research
- interviewing disabled people as part of the case study research
- undertaking a quality of life survey with disabled people. Wherever possible disabled people completed the survey. They were given the option of completing it via email, telephone or face to face. However, some people with significant disabilities were not be able to complete the survey. Where disabled people were unable to respond to interview questions proxies were be used. A proxy was be someone who knew the person with a disability well. There are drawbacks to using proxies[63]. However, not allowing the use of proxies would mean some people with significant disabilities would not have a voice in the evaluation. Research indicates that measurement of a person's quality of life from another person's perspective could be useful in some instances where people are not able to communicate or make life decisions, but the results should not be treated as the perception of the person with disability.

---

[63] The use of a proxy or third party response is considered more reliable for reporting objective measurements than subjective feelings. It has been well established that people who have a severe or profound level of intellectual disability cannot respond validly to a scale of subjective wellbeing (Cummins & Lau, 2005).

Openness and transparency of the research

There has been considerable consultation with stakeholders about the design of the evaluation. Initial results were discussed with stakeholders to get their feedback and to be open about what is emerging.

As agreed to with the Enabling Good Lives Local Advisory Group, the final report would be available on the Office for Disability Issues website – http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/

Ensuring the research is beneficial

Ministers want to know whether or not the Enabling Good Lives approach is improving outcomes for participants. They are using the evaluation to gather information about how the EGL approach works, and how it might be possible to implement changes across the whole of the disability support system.

There is some concern that disabled people have been over-surveyed/interviewed. However, in the case of the quality of life survey we cannot obtain the information on outcomes for participants from existing data bases. Similarly with the case study research, interviewing disabled people is necessary to understand their perspective of how the Demonstration is working for them. Moreover there is likely to be a positive impact on policy thinking from having the voices of young disabled people represented. This is preferable to taking decisions without having their voices represented.

Risk to participants

Ensuring disabled people have a voice

See earlier.

Ensuring disabled people understand what involvement in the evaluation means

Disabled people would be informed of the risk prior to the evaluation and this would be reiterated at the time of the interview. Where the disabled person has a learning disability we would provide caregivers with information to relay to them. Every effort would be made to use plain, simple language. The purpose of the report and intended audience will be made clear from the outset.

Risk that interviewees will be distressed by the interviewing process

Interviewers will be alert to signs of distress when conducting interviews and, if these occur, ask the participant if he or she wishes to continue. It would be made clear that they do not have to continue or answer questions if they don't want to. Where proxies are interviewed face to face, the disabled young person may be present. If that is the case, proxies would be asked to be alert to any signs of stress in the young people that may indicate their discomfort in continuing with the interview.

Risk that negative stereotypes are perpetuated

This would be mitigated by:

- using researchers with expertise in undertaking research with disabled people (eg Malatest[64] was contracted to undertake the quality of life survey)
- involving disabled people in the research:
  - the EGL Local Advisory Group, which includes disabled people, has been involved in the design of the evaluation
  - with regard to the quality of life survey the Canadian approach has been to support a disabled person(s) to complete some or all of the in-person interviews. The same will be done in Christchurch
- discussing key findings and implications of the evaluation with the agencies and the EGL Advisory Group prior to preparing a final report
- consulting on the design of the evaluation with national and international disability researchers and people with experience of the disability sector (eg the Local Advisory Group, the National EGL Leadership Group).

Methods of data collection

Quality of life survey[65]

The Schalock Quality of Life framework

The Schalock Quality of Life framework has been used as a foundation for developing quality of life measures for the evaluation of the Enabling Good Lives Demonstration. Quality of life is a multidimensional construct developed by Schalock and others (Schalock et al., 2002). It is composed of eight core domains: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights. These eight domains were developed and validated through an extensive review of the international quality of life literature across the areas of intellectual and developmental disabilities, special education, behavioural and mental health, and ageing. The eight domains can be grouped together under three broad quality of life factors – wellbeing, social participation and independence (Table 1). The framework is supported by over 25 years of scientific research that confirms its validity and practical applicability (Townsend-White et al., 2012; Schalock et al., 2015; Claes et al., 2010).

Schalock recommends that the eight quality of life domains are measured via the assessment of relevant indicators. The indicators are quality of life-related perceptions, behaviours and conditions that define operationally each quality of life domain. Various quality of life indicators can be used to quantitatively measure changes in individuals' quality of life.

---

[64] Malatest NZ developed and administered the survey in New Zealand. R.A. Malatest & Associates Ltd has conducted the evaluation of the *include Me!* initiative for Community Living British Columbia in Canada. The *include Me!* survey was developed to administer to people with learning disabilities and is similar to the survey that was run in Christchurch. The project leader, Joanne Barry (Malatest Canada), provided advice to the New Zealand evaluation.

[65] The JAG agreed at its December 2014 meeting to fund the survey.

Document 10

Development of the indicators

Questions used to measure quality of life that have been assessed and validated in Canada were adapted for the EGL and New Zealand contexts through the following steps:

- A draft set of indicators was developed, based on the indicators used in the Canadian *Include Me!* survey[66] and the New Zealand Youth Survey[67].
- Indicators were categorised as foundational – expected to apply to all participants and aspirational – expected to improve as a result of the EGL programme.
- Draft indicators were discussed with the EGL Local Advisory Group, including youth representatives.
- The indicators were modified after feedback from the advisory group.
- Questions were developed based on the indicators and reviewed by the EGL Local Advisory Group and the EGL evaluation team.
- A final review of the questions was included as part of the training for peer interviewers.

Questions were based on three-point scales with categories such as: lots/mostly/little or none; or yes/sort of/no; or yes/no/not sure. Three-point scales were used because although extended scales are more sensitive they are also more complicated to read and comprehend. Smiley face emoticons were used to illustrate the three responses (Table 3). A summary of the questions is appended (Appendix 1).

Table 3. An example of questionnaire formatting

How much choice do you have about who you live with? (Click one answer)	**lots**	**some**	**little or none**
	☺	😐	☹

Ethics

Ethical approval to undertake the quality of life survey was obtained by going through the Ministry of Social Development's ethics process (see Ethics, page 141).

Research population

EGL participants

The survey was to compare outcomes for EGL participants with a group of disabled people who do not have access to the Enabling Good Lives approach.

Participants were school leavers (aged 18 to 21 years old) with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education's ORS. There was

---

[66] Community Living British Columbia in Canada run the *include Me!* initiative aimed at people with learning disabilities. The *include Me!* quality of life survey was developed to administer to people with learning disabilities and is similar to that was run in Christchurch. See http://www.communitylivingbc.ca/projects/quality-of-life/

[67] The Youth 2012 questionnaire is available at: https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/ahrg/docs/youth12-questionnaire.pdf

flexibility to allow some disabled people outside these criteria to opt into the Demonstration (eg in the first year up to 10 further people who access disability supports in or near Christchurch were allowed to opt in at the discretion of the Director). A list of 125 EGL participants was sent to the survey company.

Comparison group

The original plan was to include responses from a comparison group. The comparison group was to be those in Christchurch aged 17 to 21 who received VHN and HN ORS funding and left school in 2011 and 2012. There were 120 ORS students with high or very high needs who left school in the Canterbury region.

However, it was difficult to gain agreement on the source of a comparison group, on consent processes and on access to comparison group details. Delays in obtaining a sample, and a two-step consent process, resulted in little time to collect survey responses before the Christmas break.

Responses were received from a total of nine of the comparison group: six from individuals and three from proxies (a response rate of 20%). The number of responses was too small to include in the analysis.

Considering the difficulty in identifying and contacting a valid comparison group, the most useful comparison for future quality of life surveys is as a measure of change over time within the same individual or group of EGL participants.

Data collection

Data collection provided several ways for EGL participants to participate in the evaluation.

Insights MSD provided a list of EGL participants, which included a combination of email addresses, phone numbers, mobile phone numbers and/or names and contact details for parents or caregivers. The participant list included young people who had been involved in EGL for some time and others who were beginning their involvement.

The survey was developed so EGL participants could complete it online or with an interviewer. An email was sent to the contact email address held by EGL for each participant. In some cases, the email address was the participant’s personal email address. In other cases, it was a family or parent’s email address.

The invitation email explained the purpose of the survey. It provided options for EGL participants (or a proxy) to complete the survey online, or to request an interview. Participants could also select an option to decline to take part, in which case no further contact was made.

Following the initial email, participants who did not complete the survey online and did not decline were telephoned, sent a reminder email and sent a text. Telephone calls were made by two qualified[68] members of the team.

The evaluation employed peer interviewers to interview EGL participants who requested an in-person interview. Peer interviewers are disabled people who have been trained to

---

[68] One holds a social science and policy degree with a focus on disability and community care and is an expert in interviewing disabled people. The other has a Master’s degree in psychology.

undertake interviews with people with intellectual and other disabilities. In previous studies, participants with developmental disabilities said they felt more comfortable being asked questions by an interviewer who also had a disability[69].

Three peer interviewers were recommended by the EGL advisory group. At the start of the project, our team trained the interviewers in a half-day workshop. Interviewers were provided with extensive support before any interviews and debriefs following each interview. When a participant asked for a face-to-face interview, we arranged a time with the participant and the interviewer.

Peer interviewers had a point of contact who was available at any time to answer their calls. They were paid a wage for their training, travel time and the time to complete interviews (including discussions).

Data collection took place between mid-September and the end of December 2015.

Response rates

A total of 43 EGL participants and proxies from the list of 125 contacts completed the survey – a response rate of 34%, with:

- total responses from EGL participants – 19 responses
- total responses from proxies – 24 responses.

The numbers and mode of responses are summarised below (Table 4).

Table 4. Response numbers

	Numbers of responses		
Response type	**Total responses**	**Online**	**In-person**
EGL participants – self-completion	19	10	9
EGL participants – proxy	24	24	-

Interviewing challenges

Confidentiality was important to allow the EGL participants to respond freely to questions. In the training, the interviewers anticipated difficulty in arranging time to speak alone with the EGL participants without a parent present. In practice, this was a problem for some of the interviews. The training manual for the interviewers included a scenario about someone else wanting to stay in the room with the interview participants. We were clear in the training about the importance of doing everything we could to capture the voice of the participant.

To make sure that the interviewers felt safe while doing the face-to-face interviews, the interviewers always worked in pairs and checked in before and after each interview. If they were asked any questions they could not answer, they gave business cards of the team members to the participant or participant's caregiver so they could call us directly.

---

[69] Personal communication with *include Me!* project lead Joanne Barry.

Scenario: A staff member or a relative/friend of the participant wants to be part of the discussion.

- The discussion is private. A participant should be able to tell you their answers without anyone else knowing what they said. If someone else is in the room, then the discussion is no longer confidential!
- Ask the participant if they would feel comfortable having the discussion with just you alone. If the participant says **"yes" then** you can politely ask for privacy. Here is an example of what you **could say:**
- "Are you comfortable talking to us alone? *If the participant says yes, then say:* **We** need a private space to have our discussion. It needs to be a place where we won't be disturbed and nobody else can hear what we say. If you could please wait outside or in the reception area, [*participant's name*] will come and meet you when we are done."

A service staff member or relative/friend can stay in the room if the participant does not want to be left alone.

Enhancing response rates

A number of different strategies were tried to enhance response rates. Further enhancing response rates would require wider communication about the survey, perhaps through the EGL navigators.

Reflection on data collection strategies

Phone-based recruitment was the most successful; however, the approach had to be individualised rather than scripted. Some of the contact calls were answered by the EGL participants and others by a parent or family member. The recruiter had to be prepared to speak to both, often in the one phone call.

On some occasions the parent disclosed a disability themselves. The most important thing was being adaptive and flexible on the phone, changing the language used to suit the dynamic of the family. The recruiter took care to identify what the concerns are for the parent. These could be family dynamics, being too busy, or thinking it will be too hard for their child. It has been important to demonstrate quickly that we are prepared to work with what will suit the participant and the parent by:

- taking the time to listen and understand their situation
- breaking down barriers and showing how the interview process can work.

The phone calls generally follow this pattern:

1) **Building initial rapport:** Quickly identifying Enabling Good Lives as the reason for the call and building enthusiasm about the opportunity for the participant to give feedback. This could include saying that other people have valued the opportunity to give their feedback. Checking whether they received any information (by text or email) about the evaluation.
2) **Providing information about the questionnaire:** Explaining that the questions are as accessible as possible (eg using multi-choice answers and symbols) and that they focus on quality of life. This step could include providing information about the symbol sheet and reading out a couple of question examples. The goal was to communicate that the questionnaire is accessible, easy and not daunting, so that the parent was reassured the participant was able to complete the questionnaire alone and it would be a positive experience.
3) **Introducing the interviewers:** Explaining that the interviewers we employed are disabled people who are excited to do the interviews and help other disabled people. Being able to meet and interact with other disabled people was a selling point. When speaking to the participants, the recruiter described it as an opportunity to connect, have their say and be listened to.
4) **Giving the opportunity to share their disability:** The recruiter giving the parent and/or participant the choice to share information about the participant's disability so that we could prepare the interviewers to accommodate the participant's needs.
5) **Concluding:** Telling the parent/participant that we really value their time.

Survey analysis

Results of the EGL survey are reported two ways in this report: scored and percentage positive.

The questions in the EGL survey have two or three response options:

- two answers (positive and negative) plus not applicable
- three answers (positive, negative or neutral) plus not applicable.

For percentage of positive reporting, we have reported the proportion of respondents who provided either of positive responses (excluding missing and not applicable responses).

For scored questions, we have assigned a value of two to every positive response, a score of one to every neutral response and a score of zero to every negative response. Scores are calculated by dividing the respondent's score across a group of questions by the total score available, then multiplying by 100. Scored analyses include all responses to all indicators.

Charts of positive responses do not include sub-questions following 'filter' questions. For example, the question about whether a respondent has a paid job is included but not subsequent questions about whether they like their job.

Malatest identified and reported relationships between indicators as correlations between responses to questions in the same subject grouping. Only significant correlations between related questions have been reported. The value of the correlations is in making decisions about which questions to include or omit to shorten the length of the survey and reduce the burden on respondents. Questions that are similar in content and strongly correlated could be deleted.

Strengths and limitations of the survey

The quality of life survey provided an opportunity to develop a series of indicators within an established and validated framework. Indicators were developed with the EGL advisory group, representing participants in the EGL demonstration.

The resulting survey was too lengthy but the Demonstration provided an opportunity to refine the survey by identifying correlations between questions to provide guidance on questions that could be eliminated in future surveys. The length of the survey appeared not to affect response rates, as no participants stopped partway through. However, a shorter survey would reduce the burden on participants and peer interviewers.

Although the peer interviewers did not complete a large number of interviews, their insight was valuable in developing the data collection process and in interviewing EGL participants. Their experience as interviewers may be valuable in future work.

Although the survey response rate was comparable with or better than other surveys of youth, the numbers of participants and proxies are small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth. Caution should be taken in comparing responses of proxies and participants, and in examining the combined results of proxies and participants. There can be differences between proxy responses and self-reported responses. Differences may be a result of differences in perspective rather than invalidity or bias (Claes et al., 2012).

Absence of a comparison group – either of other disabled youth or of youth in the general population – limits conclusions about the extent findings reflect this group of youth, a wider group of disabled youth or all youth.

Case studies

The purpose of the case studies was to understand better how the EGL approach contributes to disabled people having greater choice and control over their lives. A multiple case study approach was used because a cross-case analysis will allow us to explore the effects of using the EGL approach and identify major patterns. Multiple cases also allow us to test the extent to which the overall pattern of results matches the behaviour we expected to see and to build on the theory of change underpinning the Demonstration. As Yin (1994) has noted, the case study method generalises to theory and the goal is therefore to obtain replication, not enumeration. In analysing multiple cases, replication can be achieved within the types (or 'families') of cases, with predicted variation across groups.

The unit of analysis ('the case') is: *The young disabled person engaged in EGL who has recently left school or is planning to.* Here the focus is on the individual disabled person's journey towards building a life outside of school.

There were three types of cases, outlined in more detail in Table 5 below:

- Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care. While living circumstances were not a section variable in all these cases the young people were in residential care.
- Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
- Case type 3: Movement towards living a life in line with the EGL principles (opt-in)[70].

Ten cases with differing characteristics were selected across the three case types to provide diverse points of view. Interviewees were selected from the EGL database compiled by the Demonstration team. The EGL team assisted the evaluators in gaining access to some participants. Three of the cases involved respondents interviewed in phase one of the evaluation.

Any common patterns emerging from the variant cases can capture the core experiences and shared aspects of transitioning from school to post-school life. Across the cases we will attempt to get a mix of disability types, gender and ethnicity.

Interviewees were asked about their experience of being part of the Demonstration, in particular:

- what a good life looked like for them
- what was influencing their achievement of a good life

---

[70] Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support, recognising that some participants will be very clear and not need much and others may need more.

- their experience of the Demonstration – what was working well or presenting difficulties.

In each case effort was made to interview the disabled person and a parent or parents. In some cases a caregiver was also interviewed. Where the disabled person was unable to answer the questions (eg because they had a profound intellectual disability) the parent(s) responded for them.

Table 5. Case types

Case type	Selection variables	Number of cases
Case type 1: Limited change since coming into EGL to live in line with the EGL principles	• Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs • Non-opt-in • Limited engagement in planning for a good life • Traditional use of funding (eg attendance at a day programme) as opposed to doing something different in the community.	3
Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)	• Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs • Non-opt-in • Developed a plan with a navigator • Choosing to use their funding for supports differently • One or more of the following ○ living in the community eg flatting with support; living at home with support instead of residential care ○ engagement in meaningful activities in the community ○ engagement in meaningful work or education	4
Case type 3: Movement towards living a life in line with the EGL principles (opt-in)	• Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs. • Opt-in • Developed a plan with a navigator • Choosing to use their funding for supports differently • One or more of the following ○ living in the community eg flatting with support; living at home with support instead of residential care ○ engagement in meaningful activities in the community ○ engagement in meaningful work or education	3

Analysis

The analytical process was iterative and aimed at identifying patterns, differences and puzzles across the cases.

Analysis of the information collected in case studies occurred both during the data collection phase (eg discussion with the other interviewer after the interview while in the field) and at the completion of all the interviewing (eg in structured analytical workshops, during the writing phase).

Within and between cases we used inductive thematic analysis combined with triangulation. The process consisted of reading through textual data, identifying themes in the data, coding those themes, and then interpreting the structure and content of the themes.

Causal linkages which held good across these diverse settings were considered robust and capable of 'analytical generalisation'.

Weakness of case study research

The primary weakness is the assertion that it is impossible to generalise from these cases to the wider population.

While the evaluation team sought to capture the views of a range of participants, the views expressed by interviewees may not be representative of all participants in the Demonstration. Obtaining the views of people facing multiple challenges[71] was particularly difficult.

In-depth interviews with key stakeholders involved in the Demonstration

Purpose, rationale and scope

Talking with key stakeholders allowed us to detail what shaped the design, implementation and operation of EGL and how this has evolved over time.

The design of the EGL Demonstration is intended to evolve over time and also involved collaboration between the disability sector and government agencies. There is interest in how this process operated.

Interviews took place with:

- the Demonstration Director and members of the EGL team in Christchurch
- Members of the LAG
- local and national officials from the Ministry of Social Development, Ministry of Education and Ministry of Health
- Manawanui InCharge representatives
- representatives from selected providers and schools. We were able to interview most representatives from schools and providers we talked to in phase 1.

Data collection and recruitment

Data collection

Some stakeholders answered the questions via email but most were interviewed face to face. Stakeholders included selected providers, selected schools, selected navigators, representatives from LifeLinks and Manawanui InCharge, officials from the Ministries of Education, Health and Social Development, the Local Advisory Group, members of the EGL team in Christchurch, the National EGL Leadership Group, and the Joint Agency Group.

Interviewees were asked about their experience of being part of the Demonstration, in particular:

---

[71] For example, those who had chosen not to engage or were struggling to engage with the Demonstration because they lived in difficult family circumstances or had no family support.

- what was influencing Demonstration participants' achievement of a good life
- their experience of how the Demonstration is contributing to disabled people obtaining good lives
- what schools, providers of disability support services and government agencies were doing to support disabled people to live a good life and what was working well or presenting difficulties.

Recruitment

People were contacted via telephone. Those interviewed in phase 1 were, where possible, re-interviewed. In some cases this was not possible as people had moved on or were not available at the time the interviewing took place.

When: Interviews took place in August and September 2015.

Ethics

See ethics section earlier.

Analysis

Thematic analysis: The process consisted of reading through textual data, identifying themes in the data, coding those themes, and then interpreting the structure and content of the themes.

Limitations

The views expressed by schools and providers interviewed may not be representative of all schools and providers who had people participating in the Demonstration. The evaluation team sought to interview a range of providers and schools but there were only five providers and three schools.

Analysis of administrative data

Purpose, rationale and scope

To describe trends and patterns in use of navigators, Individualised Funding, self-management of funding, and supports and services amongst participants using data collected by the EGL team and the three agencies.

Ethics

See ethics section earlier.

Analysis

A descriptive analysis of data from the Ministries of Social Development, Education and Health and the EGL team in Christchurch.

Limitations

The administrative systems captured little data on the quality of disabled people's experience of Enabling Good Lives. The quality of life survey sought to address this but, as mentioned above, there were some limitations with this.

The way in which data was captured made it very difficult to examine what use participants had made of their funding and whether they were spending more or less than before the Demonstration.