CARE MATTERS

LEARNING & WELLBEING

Update & MidCentral Prototype

Update for carers/ family/whānau

The information in the following document includes key decisions from the April 2018 Cabinet paper and appendices two, three and four. Alternatively visit the Enabling Good Lives (EGL) website for up-to-date information.

The new system has been designed together with disabled people, whānau, and others in the disability sector, and is based on the Enabling Good Lives vision and principles (for more detailed information refer to The Principles in Action).

The objective of transforming the disability support system ('system transformation') is to give disabled people and their whānau more options and decision-making authority about their supports and lives, to improve their outcomes, and to create a more cost-effective disability support system.

This is a cross-government initiative that includes the Ministry of Health, Ministry of Social Development, Ministry of Education, Oranga Tamariki, ACC and the Ministry of Transport.

Two small-scale demonstrations on the EGL vision and principles were undertaken in Christchurch (2013 – 2016) and Waikato (2015 – now). EGL will continue, with current arrangements in Christchurch and the Waikato until the full transformation starts in those areas.

On 1 October 2018, there will be a new prototype (disability support system) trialled in the MidCentral region. Learnings from this prototype will be taken to Christchurch and the Waikato before roll-out throughout New Zealand. Decisions on the final model and expansion beyond MidCentral will be sought from Cabinet in late 2020. MidCentral includes Palmerston North, Horowhenua, Manawatu, Otaki, and Tararua districts in the North Island.

Some features agreed so far include:

a Funding will be available to help disabled people and family/whānau be prepared and feel confident

b An independent Connector/Kaitūhono may walk alongside to help plan a positive future and how to get there (your choice)

c Regional and national leadership groups will protect the original intent of the Enabling Good Lives principles and vision, contribute to the new way of doing things and monitor changes

d Resources will be based on people's strengths and what they need

e Personal budgets will allow people to have more control over resources

f Disabled people, their families and whānau will have access to a range of ways to use their personal budgets.

Below outlines some key questions carers/family/whānau have asked...

1 **Carers/family/whānau will have to change, even though they are happy with their current supports and services**

This is NOT the case. There are, in fact, a range of ways you can use the resource, from supports remaining the same to exploring new options. From total self-management of the personal budget to having someone else manage it for you (refer to the continuum on p4).

2 **That disability supports and services will change on the 1st of October (in MidCentral)**

In MidCentral, as of the 1st of October everything you have will remain the same. You can either wait until your annual review date and decide to change things then (or leave things as they are), or if you want to instigate change now you can contact a Connector or disability information specialist to explore change from 1st of October.

3 **The personalised budget is a new version of Individualised Funding**

This is incorrect. The personal budget includes cross-government funding and has more flexibility and less restrictions.

4 **What will be the ongoing role of the NASC (Needs Assessment Service Coordination Service)?**
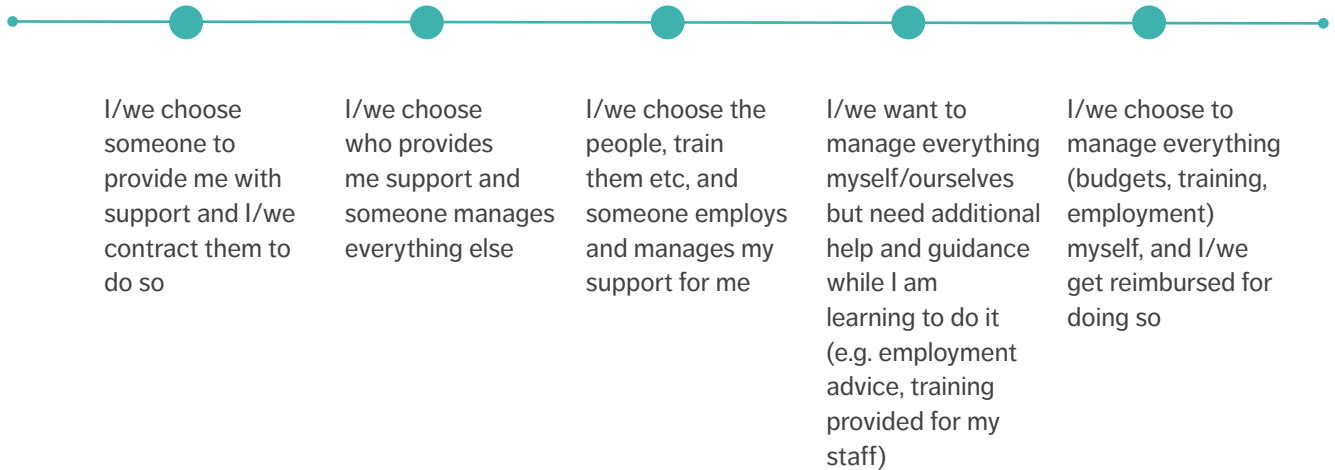
Following an internal restructure, the NASC in the MidCentral is being used for this prototype (as the Systems Enabling team). However, no decision has been made regarding what the final organisation structure or form will look like, and this won't be decided until the completion of the prototype and recommendations to Cabinet (in late 2020). Recommendations about future organisational arrangements will be based on the monitoring and evaluation findings that take place throughout the prototype.

5 **Will we need to use a host agency?**

You can use a host agency, or someone else like an accountant or person who is good with figures. It will be up to you as to how you want this managed. Some collective arrangements have been explored by family/whānau in the Waikato. There may be new employment opportunities created from having more choice in the new system.

Managing resources choice continuum: from total self-management to total contractor management

I/we choose someone to provide me with support and I/we contract them to do so

I/we choose who provides me support and someone manages everything else

I/we choose the people, train them etc, and someone employs and manages my support for me

I/we want to manage everything myself/ourselves but need additional help and guidance while I am learning to do it (e.g. employment advice, training provided for my staff)

I/we choose to manage everything (budgets, training, employment) myself, and I/we get reimbursed for doing so

The six steps of the new approach:
(refer to Appendix One, High Level Experience of the Transformed System)

1   I know what support is available

2   I am listened to and respected

3   We decide what we want to do, and how we want to do it

4   We make it happen

5   We live the life we want, and

6   The system responds.

The key features of the new system
(as outlined in the April 2018 Cabinet paper)

a   **People are welcomed into the system** in multiple ways, and can then be provided with information, linked with a Connector, peer network, government agency or disability organisation.

b   **Access to Connectors** who can walk alongside disabled people and whānau if they choose, to help them identify what they want in their lives, how to build their life, and the range of supports available to live their life.

c   **Easy to use information and processes** that meet the diverse needs of disabled people and their whānau.

d   **Seamless support across government,** with Government Liaison supporting people in the background to access other government services (e.g., benefit applications), and to build positive relationships with other parts of government (e.g., learning support in school).

e   **A straightforward process for accessing funding,** with flexibility about what can be purchased and how it can be administered, and easy reporting on how funding has been used. The intention is for this to integrate multiple sources of funding from across government following Cabinet consideration in June 2018.

f   **Capability funding** for disabled people and whānau with decisions made by the Regional Governance Group.

g   **Greater system accountability to disabled people and their whānau** so that disabled people and whānau are involved in monitoring and evaluating the system, and making recommendations to Ministers about changes to the system.

A **'try, learn and adjust'** approach will be taken in MidCentral to refine and finalise the model for roll-out across New Zealand. Feedback from disabled people and whānau will help improve and finalise the system before it is rolled out across New Zealand. Advice will be provided to Cabinet on the final model and expanding the transformed system beyond the MidCentral region in late 2020.

Refer to Appendix Two - A Visual Representation of the MidCentral Prototype
Refer to Appendix Three - Key Features of the MidCentral Prototype

EGL Connector/ Kaitūhono

The following provides some information on what some of the roles and responsibilities will be for the Connector/Kaitūhono. The Connector/Kaitūhono is a new role established for the MidCentral prototype, based on feedback from disabled people and whānau who expressed the need for an independent person to walk alongside them to help plan a positive future.

Role

- Walks alongside disabled people and whānau to support them to think about possibilities, and supports action.

- Be one point of contact for disabled people and whānau.

- Ensures the disabled person's voice is listened to and their rights respected and upheld, and

- Ensures that the context and needs and aspirations of the disabled person's whānau are understood and respected.

Responsibilities

- Mirrors the diversity of the community.

- Builds trusted relationships with disabled people and whānau.

- Understands people in their context – holistic view of disabled people and whānau including cultural and spiritual dimensions.

- Ongoing reflection and professional development including culturally responsive practice.

- Supports disabled people and whānau to think about opportunities and possibilities, to be innovative and creative about support.

- Supports disabled people's will and preference to be listened to and actioned within the context of the needs and aspirations of whānau.

- Ensures disabled people and whānau have information to make informed choices, and supports people to make those choices a reality once decisions have been made (without judgment).

- Supports disabled people and whānau through processes to access disability support including being proactive about connections to other government systems and removing barriers.

- May have specific knowledge in one or more area (e.g., disabled parents, young people in transition).

- May be involved in outreach with a community (e.g., rural Māori, people in residential care).

- May proactively contact disabled people and whānau following an initial diagnosis.

- Continues to have an ongoing role in proactively checking in with disabled people and whānau.

- Is impartial about support options.

Key shifts

- Support is person-directed, builds trust, reflects manaakitanga* and is culturally responsive.

- Support is available to ensure equity of outcomes.

- The Connector invests the time needed to build trust with disabled people and their whānau.

- The intensity of support provided to a disabled person and whānau changes in response to what they need at the time.

- The disabled person's aspirations drive conversations, not the funding.

Manaakitanga refers to the process of showing respect, generosity and care for others

Keeping track of it all

Disabled people and family/whānau will be involved in governance arrangements, monitoring and evaluation.

A range of governance and advisory groups have been put in place to ensure that a wide range of perspectives are heard and taken-into-account in the design of the new disability support system and implementation of the MidCentral prototype.

The voices of disabled people and family/whānau are part of each governance and advisory group at all levels of leadership and decision-making.

A Developmental Evaluation approach will be used to provide frequent feedback and insight to affirm or inform meaningful change in the prototype.

Guidance and authority

- Government Ministers

- Governance Group – system transformation

- Enabling Good Lives National Leadership Group

- Regional Leadership Groups

- Regional Governance (sub-group of the Regional Leadership Group in MidCentral).
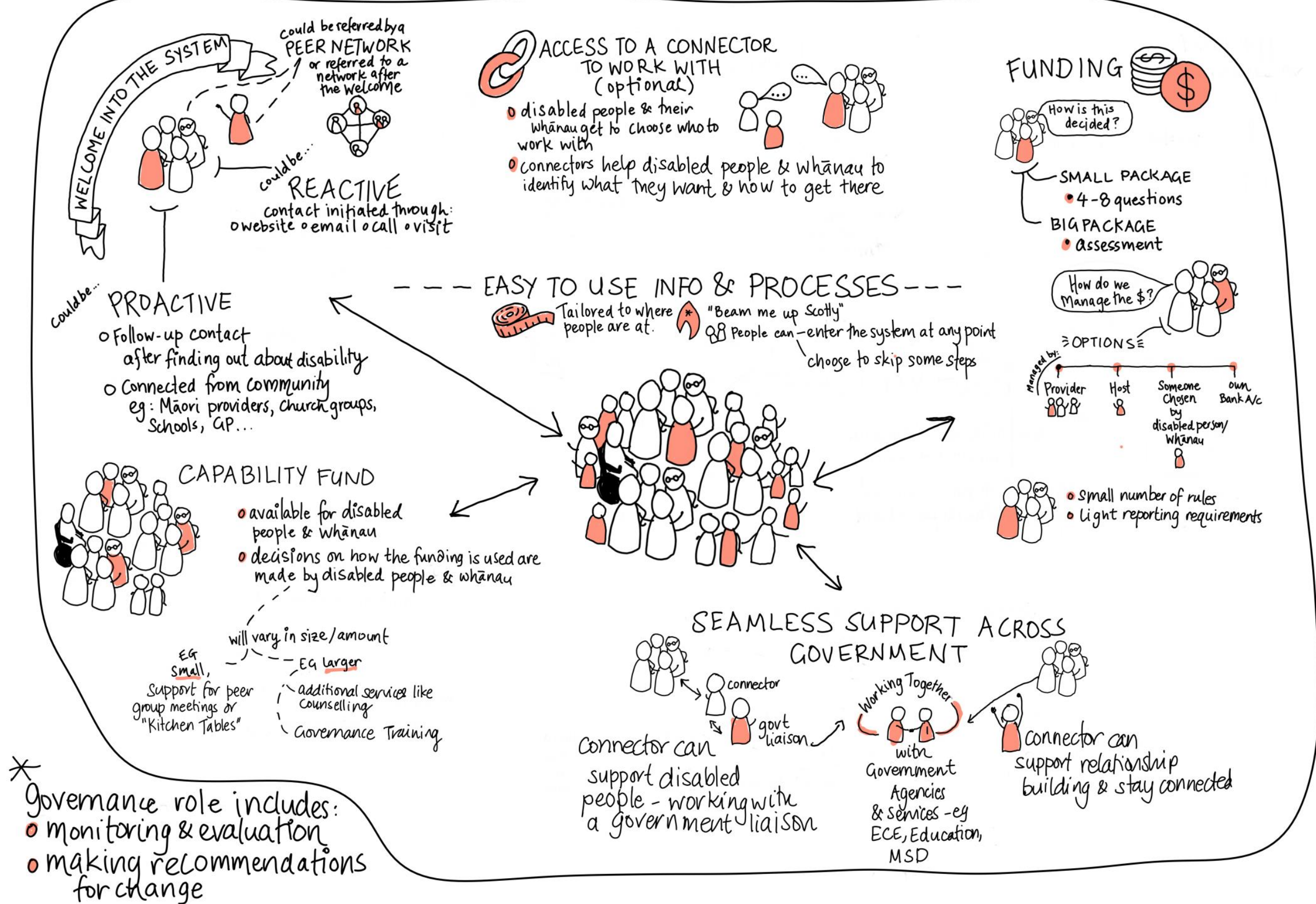
Appendix One

High Level Experience
of the Transformed
System

Enabling Good Lives Principles: self determination, beginning early, person-centered, ordinary life outcomes, mainstream first, mana enhancing, easy to use, relationship building						
	0.0 Catalyst	**1.0 Awareness** I/we know what support and assistance is available	**2.0 Entry** I/we are listened to and respected	**3.0 Immersion** I/we develop my aspirations and an approach	**4.0 Transitioning** I/we enable my aspirations	**5.0 Extension** I/we live my aspirations
Overview	A person finds out they, or a family member, have an impairment and want to know more	It is easy to find out about disability support and there is widespread awareness at whānau, community and the system level	There are proactive and responsive entry points for everyone	The Enabling Good Lives team provides a space for thinking about possibilities, and responds in a way that enables the life that the disabled person and whānau wants	The Enabling Good Lives team assists the disabled person and whānau to put support in place that works for them	Disabled people continue to live the lives they want, have new experiences and connect with others
Gateway		I am looking for information and support	I would like someone to assist me	I am ready to talk about what I want in my life	I know what I want to achieve and how to get there	I have the support to do the things I want	Things have changed – I might need something else
Disabled Person	"Something has changed or I could have more in my life."	"I know there is support for me and I know there is someone to walk alongside me and help me work things out, on my terms."	"I am listened to, respected and responded to in a way that works for me."	"I'm making decisions about my life and I'm supported to do this in a way that builds the life I want. I have mana."	"I am in control of my supports and am connected with people and places I enjoy."	"I am continuing to build the life I want and have flexible support to assist me"
Whānau	"We are facing some challenges or life could be better for us."	"We know there is support for our whole whānau. I know who to talk to about getting support."	"We are listened to, respected and responded to in a way that works for all of the whānau."	"Our whānau know where we are heading and have supports in place to build the life we want together."	"We are in control of our support, and our disabled family member, along with our whānau, are stronger."	"We know that if things change for our whānau and disabled family member our supports are flexible and can change with us."
Other People	"I can see someone might benefit from some information or support."	""I know what support, resources and information is available and am going to offer this. I know what my role is, I'm confident and capable. I'm going to actively help."	"I have the time, skills and the resources to truly listen and respond in a way that works for you and your whānau."	"I'm there to assist you and your whānau, work out what you want to achieve and how to get the supports and resources you need to make this a reality. I'm the 'support crew' while you are in the driving seat."	" I am alongside to assist as you manage your supports, try new experiences and deal with difficult times".	"I reflect and learn from the opportunities I have to support disabled people and their whanau".
Critical System Shifts	• Strengths-based social awareness • The EGL team reaches out to people • Support is available to ensure equity of outcomes	• Support is directed by the person, builds trust, reflects manaakitanga and is culturally responsive • Support is available to cover an immediate crisis • Disabled people are welcomed with warmth and respect in a way that matches where they are at and what they want • The EGL team is pro-active in supporting disabled people and their whānau and connecting those who don't have someone in their lives • When support is needed from other places, communication is open and transparent with the disabled person deciding what information is shared	• The EGL team takes the time to listen and get to know each person and learn about what is happening and what is important in their lives • The EGL team invests the time needed to build trust with disabled people and their whānau • Disabled people and whānau own and can access their records, and decide who else can see them • The intensity and type of support provided changes quickly in response to what the disabled person and their whānau need at the time	• Disabled people and their whānau are in control and direct their support and lives • EGL practice is informed by disabled peoples' lived experiences and uses these learnings to continually develop better ways of working • There is flexibility in how resources are used at a system and an individual level • The disabled person's aspirations drive the conversation, not the funding • Support across government is seamless to the disabled person and whānau	• Control over support has shifted from the system to disabled people and their whānau • Each disabled person's Enabling Good Lives proposal is flexible and changes with them as they do • Disabled people and their whānau have choices about their support with very few rules • The EGL team trusts that disabled people will use their funding for the purpose it was intended (and doesn't require much detail about expenditure in return) • Disabled people and whānau have a range of options for managing their support and can be reimbursed for costs if they take on administration	• Each disabled person's support is flexible and changes with them as they do • The EGL team keeps in regular contact to see how things are going for people

System Building Blocks	
• **Investing in disabled people and whānau capability** • **Self-managed information and resources** • **Tools, resources and processes to support the Enabling Good Lives journey** • **The Enabling Good Lives team and investing in system capability and capacity**	• **Multi-channel disability information** • **Self determined pathways and support, tailored to the disabled person and their whānau** • **Funding allocation (including funding model, allocation and processes)**

Appendix Two

Visual Representation
of the MidCentral
Prototype

Disabled people & whānau involved in ≋ GOVERNANCE ≋ over the System *

WELCOME INTO THE SYSTEM

could be referred by a **PEER NETWORK** or referred to a network after the Welcome

could be...

REACTIVE
contact initiated through:
o website o email o call o visit

could be...

PROACTIVE
o Follow-up contact after finding out about disability
o Connected from community
  eg: Māori providers, church groups, Schools, GP...

CAPABILITY FUND
o available for disabled people & whānau
o decisions on how the funding is used are made by disabled people & whānau

will vary in size/amount

EG small, Support for peer group meetings or "Kitchen Tables"

EG larger
- additional services like Counselling
- Governance Training

ACCESS TO A CONNECTOR
TO WORK WITH (optional)
o disabled people & their whānau get to choose who to work with
o connectors help disabled people & whānau to identify what they want & how to get there

- - - EASY TO USE INFO & PROCESSES - - -
Tailored to where people are at.
"Beam me up Scotty"
People can enter the system at any point
choose to skip some steps

FUNDING $
How is this decided?
SMALL PACKAGE
  • 4-8 questions
BIG PACKAGE
  • assessment

How do we Manage the $?

≋ OPTIONS ≋
Managed by:
Provider | Host | Someone chosen by disabled person/whānau | own Bank A/c

o small number of rules
o Light reporting requirements

SEAMLESS SUPPORT ACROSS GOVERNMENT
connector
govt liaison
Working Together
with Government Agencies & services - eg ECE, Education, MSD

Connector can support disabled people - working with a government liaison

connector can support relationship building & stay connected

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

Appendix Three

Key Features of the
MidCentral Prototype

Disabled people and whānau make decisions about their lives and supports

	People are welcomed into the system	Connectors	Seamless support across government	A straightforward process for accessing funding	Capability funding	Greater system accountability to disabled people and their whānau
Disabled people and whānau will:	**be welcomed in multiple ways** with information that is easy to use, and have access to: ○ a Connector ○ peer networks ○ disability organisations	**have access to someone who can walk alongside them** to help them to identity what they want in their lives, and what supports are available to achieve this	**be supported by government liaison** who will work in the background to access other government services (e.g. benefit applications), and to build positive relationships (e.g. learning support in schools)	**have the ability to make decisions about what can be purchased** and how it can be administered, and easy reporting on how the funding has been used	**have the opportunity to develop skills** through a fund to help develop leadership and community capability	**be involved in monitoring and evaluation, and making recommendations to Ministers** about changes to the system
The system will have:	• • someone to talk with face-to-face, on the phone, online • an accessible website with useful and accurate information • self-directed pathways through the system based on where an individual is • an outreach function to connect with disabled people and whānau when they first learn about an impairment • outreach to communities and groups who have not had contact with disability support services	• connectors employed by the Disabled People Supporting organisation • a simple process for people to be validated as a connector • contracts with organisations (that do not provide disability support services) to provide connectors e.g. Whānau Ora	• processes with government agencies on how they work together • a transparent, easy to use process to access government funding for whole of life	• a clear process to make an application for funding • transparent purchasing guidelines • a simple funding allocation process • clearly stated monitoring requirements • range of options for other people to manage the personal budget • processes for: ○ getting the funding into a disabled person's bank account ○ monitoring the funding	• pool of funding for disabled people capability building • pool of funding for whānau capability building • criteria for funding applications • transparent process for making funding applications • clear and multiple ways to inform people about the funding • clear communication process about funding decisions	• a monitoring and evaluation framework • multiple ways for disabled people and whānau to give their views about what is working and what needs to be improved • a Governance Group with 60% disabled people • a process for the Governance Group to communicate its decisions to the disability sector
Disabled people and whānau will have tools and resources These will be in multiple formats, languages and easy to use	**Resources** • welcome pack and orientation • the Enabling Good Lives principles and approach • information about: ○ what government support is available and how to access it ○ local and national service providers (disability and universal) ○ community-based activities such as sports, recreation, clubs **Tools** • who to contact with any concerns or feedback	**Resources** • the role of connectors – what they can and cannot do • profiles of connectors • stories from disabled people who have worked with a connector • Code of Ethics **Tools** • validation process for connectors • how to contact a connector	**Resources** • information about what supports are available	**Resources** • information about what funding is available • purchasing guidelines • how to request a review of a decision about funding allocation • how to manage a personal budget (rights and obligations) • how to employ or contract support people (including health and safety, taxation, training) • options for someone else to manage a personal budget **Tools** • funding allocation tool	**Resources** • simple, clear and easy to use funding application • some examples of funding applications • information about the process for making decisions, including timeframes	**Resources** • training and support for the Governance Group