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| arrow-greyEnabling Good Lives Christchurch Demonstration: Phase 1 Evaluation report | | | | |
| December 2014 | | | | |
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| 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. | | |

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# Executive summary

This report details the findings from an initial evaluation of the Enabling Good Lives (EGL) Demonstration in Christchurch.

EGL is a new approach to supporting disabled people to live their vision of a good life. Under the approach, disabled people and their families are offered planning and facilitation along with greater choice and control over how resources are used to support the life they want to lead. The approach encourages the use of natural and universally available supports in the community. The EGL Demonstration has been established as a working model in Christchurch so that we can learn whether and how to implement the approach more widely.

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 will inform the next stage of the Demonstration design.

The evaluation found that there have been some early positive outcomes from the EGL Demonstration, despite a problematic implementation. Key findings are outlined below.

### Enabling Good Lives is a new approach to supporting disabled people

The theory of change underpinning this approach 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 (e.g. having opportunities for learning, employment, having a home and family, and social participation). Being respected and appreciated as a citizen, like everyone else, is crucial.

The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design[[1]](#footnote-1), planning and facilitation using navigators[[2]](#footnote-2), funding for individuals that is pooled and portable, provider and school development and community development.

Representatives of disabled people, families, providers and government agencies have worked together to develop and implement the Demonstration. The Ministries of Health, Social Development and Education, with involvement from the Accident Compensation Corporation (ACC) are jointly supporting the Demonstration. Implementation began during November 2013. The Demonstration will run until 30 June 2016.

The Demonstration has started by focusing on school leavers aged 18 to 21 years old with High Needs and Very High Needs On-going Resourcing Scheme (ORS) funding. Over the course of the Demonstration, the number and type of people involved in it is expected to expand.

### A good life meant different things to each person but there were commonalities

The evaluation found a good life meant different things to each person but there were commonalities (e.g. having opportunities for valued relationships, security for the future, choices, contribution and challenge). For some people this included doing similar things to their peers such as socialising with friends, having a relationship, and having a job or work experience, getting a flat or getting to do things each week they like to do.

Understanding and articulating the concept of a good life is difficult for some disabled people. The ability to communicate varied between individuals. Navigators played an important role in helping disabled people articulate their vision of a good life. They reported that families usually understood the concept but it can take time to lift their expectations of what is possible. However, some schools, providers and ministry staff interviewed believed there were limitations to the application of the concept (e.g. that it could not be applied to everyone).

### Some early outcomes are evident

Uptake was as expected with 52 people participating in EGL by the end of February 2013. Some early outcomes were evident for a small number of disabled people and their families interviewed. However, the Demonstration is still in its early days and these interviewees were early adopters of the EGL approach. Their experiences and early outcomes may be different from those yet to be involved in the Demonstration.

The early outcomes identified by the evaluation have been organised using the EGL principles as a framework.

*Principle 1: Self determination – tino rangitiratanga.*A shift in the attitudes of individuals and their families was clear and there was evidence of disabled people and their families exercising greater choice and control. Combined with individualised funding, this greater choice and control was seen as transformative. However, there are still potential barriers to disabled people achieving greater choice and control (e.g. organisations not supporting disabled people’s choices; transport barriers; having few support options to choose between). Some providers interviewed also reported that having a free navigation function through EGL constrained disabled people’s choice as they would be less inclined to use similar services provided at a cost by disability support providers.

*Principle 2: Timatanga (beginning early).*It was too early to comment on this principle.

*Principle 3: Person-centred.* Interviews with navigators, disabled people and their families revealed disabled people were being supported to imagine what a good life for them might look like and how this can be achieved. The planning process was inclusive and focused on disabled people’s needs and goals. Disabled people and families valued the whole of life approach to planning taken by the navigators. Planning for whole of life gave families reassurance their relative would be cared for when they were no longer around.

*Principle 4: Achieving Ordinary Life Outcomes.* The disabled people interviewed were taking opportunities to do what others at similar stages of life are doing (e.g. leaving school earlier, further education, training or work experience, planning on living away from home).

*Principle 5: Mainstream is the default.* While there is an emphasis on disabled people accessing mainstream supports, this does not mean they will not also need disability support services. In February 2014 most disabled people in EGL were accessing disability support services. However, there was some evidence that the disabled people interviewed were choosing alternatives to the disability support services they had previously used. Some providers, schools and ministry staff felt mainstream supports and services would not suit many disabled people with very high needs.

*Principle 6: Mana Enhancing, Empowerment.*Disabled people and their families interviewed are becoming more knowledgeable and confident in sorting things for themselves. Support from the navigator was important to the disabled person and families. Families interviewed did not feel they were working on their own anymore.

*Principle 7: Easy to use.* Making supports simple is not straightforward in practice. Further work is needed to make supports simple and easy to access. Modifying the existing system, as opposed to a radical transformation, requires the development of workarounds and may be increasing complexity.

*Principle 8: Relationship building.* This means supports are based around relationships. Supportive relationships were developing, but amongst disabled people interviewed, family were the key people in their lives providing support. Wider circles of support were being considered by families. It was too early to comment on the extent to which the Demonstration developed communities. The next phase of the Demonstration will focus more on community building but little had been done at the time of the evaluation.

At the time of the evaluation there was strong commitment to principles that underpin the design from those closely involved in the Demonstration but wider buy-in is needed if EGL is to become business as usual. EGL is likely to have had limited impact on schools and providers so far.

### Aspects of the design process worked well but there are areas for improvement

Some practices facilitated the co-design process. There was a strong commitment to the EGL Principles, co-design and doing something different. The design built on work that had already occurred. Considerable thinking had been undertaken on what EGL could look like before the Demonstration began. Existing knowledge and experience helped with development of systems and processes (e.g. the Ministry of Health’s experience with the New Model[[3]](#footnote-3) was useful in developing the navigator role).

Christchurch was a good place to locate the Demonstration according to Wellington ministry staff, the Local Advisory Group and the EGL team. However, Christchurch based ministry staff, providers and schools had reservations. They were primarily concerned about overburdening people coping with the changes brought about by the Canterbury earthquakes.

#### Suggested improvements to the design process

The following could improve the design process:

* *Having greater clarity about what co-design means in the context of the Demonstration.* There were different understandings of what co-design meant in practice. Sharing of information in a way that enables equal participation was a challenge. The concept of co-design implies shared decision-making responsibilities but this was not the case in the Demonstration. Some interviewees involved in the design process reported more could be done to take advantage of learnings from elsewhere in the design process.
* *Allowing sufficient time to develop the components of the Demonstration.* Not doing this has meant that some of the changes so far have focused on modifying the existing system (e.g. developing workarounds) rather than transforming it. For example, the rush to implement the Demonstration meant there was a reliance on less than ideal temporary solutions for disabled people to receive and manage their allocation of pooled funding.
* *Having the right people involved in the design process.* The design and implementation would have benefited from the earlier involvement of operational people from the Ministries.
* *Developing a shared understanding of the design.* There was not a shared understanding of what the Demonstration design entailed. Some saw the design as something fluid that evolved over time whereas others saw it as something that was fixed and only changed after the three years of evaluation.

### The implementation of EGL could have been better

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.

#### Suggested improvements to the implementation

The following may have improved the implementation of the Demonstration:

* *Having the Demonstration’s key components designed and in place:* The implementation would have been improved by having the key components of the Demonstration ready to implement in November 2013.
* *Better implementation planning:* International evidence suggests it is crucial that for the implementation or roll out of initiatives like EGL to be successful they need to have a realistic action plan and clear implementation procedures. This was not the case with the Demonstration. There was a perception that the preparation to implement EGL had been developed in an organic or ad hoc manner.
* *More time to implement the Demonstration:*Implementation was rushed and placed considerable pressure on ministry staff. The workload to implement the Demonstration was higher than expected, in a short time frame and on top of existing workloads.
* *Implementing earlier in the school year to better engage with disabled students and families:* The implementation was poorly timed. Going live at the end of the school year was difficult for schools, only compounding the problems the Demonstration team had in contacting students. Some students missed out on receiving information on EGL.
* *Timelier communication, with the right people and in the right way:* Engagement and communication with schools and providers was limited. External factors may also have negatively influenced how much schools and providers engaged with EGL. As a consequence, schools and providers interviewed had a limited understanding of what the Demonstration would mean in practice for them.

### The role of the navigators was pivotal but still evolving

At the time of the evaluation, eight EGL navigators were in place and working with 35 EGL participants. Two members of the Going Places team employed by NZCare took on board EGL navigator roles in February 2014 for the 17 EGL participants they were already working with. These young people were included as EGL participants when Going Places was merged with EGL.

The navigator role was seen as pivotal to making EGL work. Navigators saw themselves as allies of disabled people who assisted them to develop their vision of a good life and how to achieve it. Families valued the role navigators played in assisting them to work towards their vision of a good life. Person-centred practices enabled navigators to work well with disabled people and their families.

#### Suggested improvements to the navigation function

The evaluation identified some improvements that could be made to the navigator role and understanding of it:

* navigators wanted greater clarity on the boundaries of their role and more guidance on the planning process
* schools and providers need a better understanding of the role of the navigator
* the long-term future and sustainability of the navigator role is uncertain.

### Leadership and collaboration are important in bringing about change

Leadership of the Demonstration is important but not straightforward as several groups and individuals had leadership roles. The roles and interrelationships between these groups and individuals could have been clearer. Bringing about the changes the Demonstration is seeking requires a collaborative effort. Barriers to collaboration included:

* not having a shared understanding of the Demonstration and what it is trying to achieve
* difficult team dynamics
* not understanding the perspective of others working on the design and implementation
* a lack of clarity about roles and responsibilities and how partnerships should operate
* not communicating in a way that engages stakeholders.

Enablers of collaboration included having a shared belief in the principles, opportunities to come together, good communication between those working together, time to develop connections and trust, and examples of the benefits of collaboration.

#### Suggested improvements to leadership and collaboration

The following may improve leadership and collaboration:

* *Addressing challenges facing the Director:* The Director role was challenging especially holding all the components of the Demonstration together, and trying to quickly bring about change for disabled people while also working with large and complex government agencies. However, the Director reported he was assisted in the role by a supportive Local Advisory Group, a committed and competent EGL team in Christchurch and the drive from senior ministry staff in Wellington.
* *Consider whether there are gaps in who is on the Local Advisory Group* (e.g. representation from those with intellectual disabilities; local ministry staff).
* *Clarifying leadership roles within the Ministries.* It was not always clear to ministry staff what their roles and responsibilities were in designing and implementing the Demonstration. Several ministry staff reported that there did not appear to be a formal plan of action. Not all the agencies have been equally represented all the time during the design and implementation of EGL. Some ministry staff reported that their agencies needed to take greater ownership of their role in the process of developing the Demonstration. There needed to be greater visibility and understanding of EGL within the Ministries.
* *Building on the enablers of collaboration and working to address the barriers*.

### Conclusion

There was a strong a commitment amongst those involved in the Demonstration in Christchurch and ministry staff in Wellington to develop and make the EGL approach work. There was early evidence that the approach was working for the disabled people and their families interviewed. They were experiencing increased choice and control in their life and were very supportive of the EGL approach.

Nevertheless the implementation could have been better. To test the effectiveness of the EGL approach and build a strong case for its wider use, the Demonstration’s components need to be fully implemented. Consideration needs to be given as to how implementation can be improved especially as other groups of disabled people are included in the Demonstration.

Leadership at all levels was important in bringing about the changes sought by the Demonstration. However, leadership of the Demonstration was not straightforward. Some further clarity about the various roles, responsibilities and interrelationships of the groups involved in the Demonstration would assist people’s understanding and engagement. Bringing about the changes sought by the Demonstration requires a collaborative effort. To improve collaboration further, work is needed to build trusting relationships and to develop a common understanding of what the Demonstration is trying to achieve.

# Introduction

## Purpose of the evaluation

This report details the findings from an initial evaluation of the Enabling Good Lives (EGL) Demonstration. 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 February 2014 and will inform the further development of the Demonstration based in Christchurch. 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 working towards supporting disabled people to live the life they want to lead.

## Background: What is Enabling Good Lives?

### EGL is a blueprint to transform the disability support system

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. The current system focuses on specialist funded supports at the cost of mainstream services and other forms of support. Disabled people and their families have to navigate complex bureaucracies in different agencies to access all the support they need.

In September 2012, the Ministerial Committee on Disability Issues agreed to a long-term direction for change to the disability support system, based on the EGL approach. 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 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 community are built and strengthened.

The EGL Demonstration has been established as a working model in Christchurch so that government agencies can learn whether and how to implement the approach more widely. Implementation began during November 2013. The Demonstration will run until 30 June 2016 and is jointly supported by the Ministries of Health, Social Development and Education, with involvement from ACC.

EGL builds on work already undertaken by the Government to give disabled people greater choice and control. For example, the Ministry of Health has introduced individualised funding and its New Model[[4]](#footnote-4) pilot in Bay of Plenty has trialled more flexible funding, information and support for disabled people to build networks in their communities.

### EGL theory of change and components

The theory of change[[5]](#footnote-5) is that this approach will enable disabled people to achieve ordinary life outcomes and to participate in and contribute meaningfully to their communities (Figure 1). Being respected and appreciated as a citizen, like everyone else, is crucial.

The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design, planning and facilitation, individualised portable funding, provider and school development and community development. These are outlined in more detail below. 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 2).

Figure 1: EGL Demonstration Pathway



#### Co-design

A key feature of the Demonstration is the involvement of disabled people, families and providers in co-designing the changes and their across 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).

#### Planning and facilitation with disabled people

The intention is that disabled people and their families will work with a navigator if they choose to. The navigator will assist the disabled person to develop their vision of a good life and a plan of how that could be achieved. The emphasis is on working as an ally of disabled people and supporting them to make their own decisions with all the resources and information required. Navigators will facilitate the use of natural supports[[6]](#footnote-6) and what is available in the community (e.g. mainstream services) to assist disabled people.

Figure 2: EGL intervention logic

#### Individualised and portable funding for disabled people

Funding that disabled people are eligible for from different agencies (e.g. the Ministries of Health, Education and Social Development) is pooled. Disabled people can choose how that funding is used to support them to achieve their vision of a good life. 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 they manage their funding (e.g. self-managed; partly self-managed; or a third party, such as a host provider, managing the 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 is that disabled people will choose personalised supports and services in the community over traditional disability supports and services. The Demonstration intends to influence schools and providers through engaging with them about the EGL approach. Schools and providers already operating in line with the principles could also share their knowledge and experience with other schools and providers.

#### 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. The expectation is that as disabled people engage in everyday activities in every day ways (e.g. 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, families and their communities.

#### Who EGL targets will change over the course of the Demonstration.

The number and type of people involved in it is expected to expand each year. The Demonstration started by focusing on school leavers (aged 18 to 21 years old) with High Needs and Very High Needs On-going Resourcing Scheme (ORS)[[7]](#footnote-7) funding.

### Leadership of the Demonstration

There are several groups and individuals involved in leading the Demonstration (see Figure 3).

Figure 3: Governance arrangements for the Demonstration



#### The 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 ministry staff 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 Coordinator[[8]](#footnote-8).

#### The Local Advisory Group

The Local Advisory Group has a leadership role in that they represent disabled people, their families and providers in the development of the Demonstration. The Local Advisory Group includes people who have had personal experience of using flexible Individualised Funding and others who have been involved in bringing about changes for more self-directed services for disabled people. Some also bring to the table an in-depth understanding of special education and the challenges facing youth and their families. Their experience encompasses a wide cross-section of disability and support organisations[[9]](#footnote-9).

#### Joint Agency Group (JAG) and the Ministerial Committee

The Director reports to the JAG which is responsible for achieving the Demonstration outcomes and making joint decisions that are within agencies’ delegated authority. The JAG is made up of senior managers[[10]](#footnote-10) from the Ministries of Health, Social Development, and Education along with ACC. 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 coordination and cooperation between government agencies that is necessary for an integrated and flexible disability support system. The JAG reports to the Ministerial Committee on Disability Issues.

#### 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[[11]](#footnote-11). At least half the members are disabled people, and includes disability sector leaders and Māori and Pacific members.

## Evaluation scope

Evaluating the Demonstration will provide the Ministries with the information they need to make the case for wider changes in the disability support system. On-going monitoring and formative evaluations will inform decisions on broadening the target group and allowing more people to opt in.

### There are five evaluation objectives that shape the evaluation of EGL

The evaluation objectives, developed in consultation with the Local Advisory Group, are:

* Objective 1: to describe who is receiving what funding and support under the Demonstration
* 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 influences the disabled people’s achievement of a good life and the how these influences change over time
* 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 does and does not support the success of the Demonstration as an approach to enable disabled people to have good lives, what does not and identify any lessons that could inform the scaling up of the Demonstration.

### This report details phase one of the evaluation

This phase of the evaluation was conducted at the end of February 2014. Phase one of 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. Interviews were undertaken by a team of three evaluators from the Ministry of Social Development, Ministry of Education and Ministry of Health, along with a person with a lived experience of disability from People First New Zealand. In addition, descriptive data on the number and types of participants was included in the evaluation where it was available (see Appendix 1). We also examined documents about EGL.

### Evaluation limitations and caveats

This phase of the evaluation focused on the implementation of EGL and providing a description of early outcomes. At this stage, the evaluation does not address questions of impact e.g. whether the approach makes a difference to disabled people‘s outcomes.

This evaluation was carried out very early following the implementation of EGL in Christchurch. This decision was made to ensure the evaluation could feed into the next stage of the Demonstration design. However, it meant the evaluation had a limited pool of disabled people and their families to talk to as only a few had had significant interaction with the Demonstration at that stage. For the same reason there was also limited data on who and how people were participating in the Demonstration.

For this phase of the evaluation there was a heavy reliance on in-depth interviews. However, where possible this was supplemented with analysis of administrative data.

The disabled people and their families interviewed for the evaluation are likely different from those not involved in EGL or those who will come later to the Demonstration. These families were early adopters of the EGL approach.

## Outline for the report

This report discusses:

* what is meant by the concept of a good life
* early outcomes evident from the evaluation
* what worked well and what did not in relation to the design process
* the early implementation of the Demonstration
* the role of the navigators in the Demonstration
* the importance of leadership and collaboration in bringing about change.

# What does a ‘good life’ mean?

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| --- |
| Summary The evaluation found a good life meant different things to each person but there were commonalities. These included having opportunities for valued relationships, security for the future, choices, and opportunities to make a meaningful contribution and have challenges. For some people this included doing similar things to their peers such as socialising with friends, having a relationship, and having a job or work experience, getting a flat or getting to do things each week they like to do.  Understanding and articulating the concept of a good life is difficult for some disabled people. The ability to communicate varied between individuals. Navigators played an important role in helping disabled people articulate their vision of a good life. Navigators reported that families usually understood the concept but it can take time to lift their expectations of what is possible. However, some schools, providers and ministry staff interviewed believed there were limitations to the application of the concept (e.g. that it could not be applied to everyone). |

## A good life meant different things to each person but there were commonalities

The evaluation found developing a vision for a good life is a personal and individual matter. Consistent with other similar research (see for example, Duffy 2003) the concept of having a good life was described by young disabled people in terms of what was important for them personally, and this meant different things to each person.

Nevertheless, there are commonalities to people’s visions of a good life. Duffy (2003) refers to it being structured around seven elements called the ‘keys to citizenship’. These elements include: purpose, freedom, money, home, help, gifts and love. Several of these elements were raised by people interviewed for the evaluation in commenting about what a good life means to them. Disabled people and their families interviewed expressed their view that a good life in the local community requires opportunities for valued relationships, security for the future, choices, contribution and challenge. However, each person had different priorities about what was important to them based on their individual circumstances.

## There are several elements of a good life

Disabled people, their families and the navigators were asked what a good life for disabled people entailed.

### It can mean opportunities for engagement in meaningful work or activities

Those interviewed typically reported that a good life for disabled people included undertaking work - be it paid or unpaid. Families and navigators reported that work and work experience, like other community activities such as sport, provided people with social interactions and ability to feel included and interact with others at an equal level. They believed participation in work experience could lead to employment and further support people to realise their goals.

### It means being able to have meaningful relationships with peers

Developing and maintaining friendships with peers was identified by those interviewed as an integral part of a good life for disabled people. This could be harder to achieve once disabled people left school. Families interviewed were particularly keen to encourage and support regular contact with friends, and people that mattered to their family member. For example, one parent with a daughter who had very high needs reported:

We were at a recent event and [Will[[12]](#footnote-12)], who went through school with our daughter, was there as well. Our daughter had not seen [Will], for some time and there was this connection. They were holding hands and she was smiling. They really need this just like us. Relationships like this are really important to keep and for them to get to see each other often, or go out together.

For the disabled people interviewed, having a significant other was important. They liked to be in contact with their girlfriend or boyfriend and meet up regularly, while others wanted to have a girlfriend or boyfriend.

### It means being well supported and treated with respect

In interviews, disabled people and their families each expressed their care and support for the other. Both indicated how they wanted the other to have support or time for themselves. Interviews with the disabled people and the navigators revealed that the young people were very aware of the impact of their care on their parents. Family members played the key role in supporting the disabled people interviewed to do the things that were important to them. At times, the parent(s) provided 24 hour care without much of a break. All the disabled people interviewed needed help with many routine tasks like dishes, laundry, and personal care which could be provided by someone else. Families interviewed conveyed how they were or would be looking to involve other people (including younger people) who could support their family member(s) to catch up with friends and socialise.

Disabled people and their families wanted support from people who wanted to be there and not just because they were paid. Families interviewed wanted their disabled family member to be treated with respect and dignity by those supporting them.

For family members interviewed, the health and safety and future wellbeing of their disabled family member was very important. As some disabled people are unable to talk or express their concerns, families never wanted them to be placed in a position where they were vulnerable. Parents also wanted suitable support in place that would carry on when they were not around.

### It means disabled people having a home of their choice

Interviews with disabled people, their families and the navigators revealed that the opportunity to live independently in a flat or home of their choice was a common desire. For example, a navigator reported that:

People want living situations that work for them. Families want opportunities for the young person to live independently. Families don’t want to be 70 with a 50-year-old child at home. Young people also want to do what their peers are doing.

There was, however, acknowledgement that for some people realising this goal was some time away as there were various options that needed to be explored in regard to living independently. Some people spoke of the need to have a job first and for others it was *“one step at a time”* and *“maybe not right now but in the future”*.

### It means doing what others at similar stages of life are doing

Analysis of interviews with family members, disabled people and navigators revealed that they saw participation in a range of cultural activities, recreation and sport like others at similar stages of life was a key element of a good life. Family members did not want their son or daughter isolated from the wider community. For example, one family member explained that they had two older children who at the same age they hardly saw because they were out with friends*.* They wanted their disabled young people to have a similar experience. *“That’s our vision for* [them] *– out and about with their friends and certainly not sitting in front of a computer all day or at* [respite care] *on a 26 degree hot day watching motor sport*”.

## Articulating and understanding the concept of a good life is difficult for some

### Ability to communicate what a good life is varied between individuals

Some people are better able to articulate what a good life would mean for themselves than others. In some situations families/whānau or friends who know a person well, and are aware of their likes, dislikes, strengths and interests can be supportive in describing what a ‘good life’ would mean for their family member. The navigator was providing a supportive role in listening to and understanding what a ‘good life’ could mean to people and exploring this with them. This gave people a voice in expressing what was important to them, and was described as empowering.

### Changing the attitudes and mindsets of some families may be needed

A navigator reported that she had never had to challenge disabled people or their family members on the idea of getting a good life, just lift expectations of what life after school might look like. The navigators had not worked with families who were less enthusiastic about being involved in the Demonstration or had more challenges. They acknowledged that more time may need to be spent with families facing additional challenges to develop the relationships and a vision for a good life. One navigator added this is where the EGL principle of starting early was really important.

### Some interviewees believed there were limitations to the application of the concept

Other interviewees (e.g. schools, providers, ministry staff) had different perceptions about the concept of ‘a good life’. Some ministry staff acknowledged understanding the concept of a good life required a change of mind set and this was hard. For example, one ministry staff member commented:

It’s really hard to drag yourself out of how things have been done before. The hardest thing was dragging yourself out of the old paradigm and putting yourself in the new one. Once you’re in the new one it’s easier to see alternative options. The new paradigm is talking about people’s lives rather than people’s needs. It’s about giving people choice and control.

However, some interviewees believed there were limitations to the application of the concept. For some people, the current system involves meetings, often with a wide range of services, to get an assessment and funding for support. A ‘good life’ for people was described as simplifying this process so that access was much easier and less stressful so people could get on with what they want in their life.

Some interviewed were concerned that the concept would be interpreted as having fun or doing what you want and not grounded in the realities of life. They were concerned that some people may not take up opportunities to extend themselves and learn new skills. They suggested it would be better to refer to disabled people getting a real life rather than a good life.

Others were concerned the concept would seem unattainable to some families who were struggling with multiple challenges. As one interviewee explained, some families she saw are overwhelmed by living. They have a young person with a disability and they themselves have minimal job prospects. She said:

For a woman on a benefit with a disabled child it’s hard for them to get work. They’re stuck in the role for the rest of their lives. How do they get beyond that to thinking about something different? …. It’s so damn hard.

Some ministry staff and providers suggested it was a great concept but would not suit all disabled people as not everyone had the ability to achieve it (e.g. people with learning disabilities).

# Some early outcomes are evident

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| Summary Uptake was as expected with 52 people participating in EGL by the end of February 2014. Some early outcomes were evident for a small number of disabled people and their families. However, the Demonstration is still in its early days. The disabled people and their families interviewed for the evaluation were early adopters so results may be different from those for people not yet involved in EGL.  The early outcomes identified by the evaluation have been organised using the EGL principles as a framework.  *Principle 1: Self determination*A shift in the attitudes of individuals and their families was clear. There was evidence of disabled people and their families exercising greater choice and control which when combined with individualised funding appeared to be transformative. However, there are still potential barriers to disabled people achieving greater choice and control.  *Principle 2: Beginning early.*It was too early to comment on this principle.  *Principle 3: Person-centred.* Interviews with navigators, disabled people and their families revealed disabled people were being supported to imagine what a good life for them might look like and how this can be achieved. The planning process was inclusive and focused on disabled people’s needs and goals. Disabled people and families valued the whole of life approach taken by the navigators. Planning for the whole of life gave families reassurance their disabled person would be cared for when they were no longer around.  *Principle 4: Achieving Ordinary Life Outcomes.* The disabled people interviewed were taking opportunities to do what others at similar stages of life are doing (e.g. leaving school earlier, further education, training or work experience, planning on living away from home)  *Principle 5: Mainstream is the default.* While there is an emphasis on disabled people accessing mainstream supports, this does not mean they will not also need disability support services. Most disabled people in the Demonstration were accessing disability support services. However, there was some evidence that the disabled people interviewed were choosing alternatives to the disability support services they had previously used. Some providers, schools and ministry staff felt mainstream supports and services could not be the default for all, especially those with very high needs.  *Principle 6: Mana Enhancing.* Disabled people and their families interviewed are becoming more knowledgeable and confident in sorting things for themselves. They reported that support from the navigator was important. Families interviewed did not feel they were working on their own anymore. |

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| *Principle 7: Easy to use.* Making supports simple is not straightforward in practice. Further work is needed to make supports simple and easy to access. Modifying the existing system, as opposed to a radical transformation, requires the development of workarounds and may be increasing complexity.  *Principle 8: Relationship building.* This means supports are based around relationships. Supportive relationships were developing but families were the central people in disabled people’s lives providing support. Wider circles of support[[13]](#footnote-13) were being considered by families. It was too early to comment on the extent to which the Demonstration developed communities. The next phase of the Demonstration will focus more on community building but little had been done at the time of the evaluation.  There was strong commitment to principles that underpin the design from those closely involved in the Demonstration, but wider buy-in is needed. EGL is likely to have had limited impact on schools and providers at the time of the evaluation. |

## Uptake for the Demonstration was as expected

In February 2014, 52 disabled people were engaged with EGL. This is in line with what was expected in the first year. In the first year it was expected the Demonstration would offer the new elements of the system to all high and very high need schools leavers as verified by the Ministry of Education’s Ongoing Resourcing Scheme (ORS) who are aged between 18 and 21 years in Christchurch City (approximately 40 – 50 people).

In the first year, the Demonstration could allow up to ten further people who access disability supports in or near Christchurch to opt in at the discretion of the Director. The intention was that while this would be tightly managed it would allow some flexibility in boundaries, and in the age and support needs of participants. At the time of the evaluation five of the 52 were opt-ins.

Most of the 52 EGL participants were receiving High Needs or Very High Needs ORS funding – 23 and 26 respectively. One person was receiving High and Complex Needs funding[[14]](#footnote-14) and two were non-funded. Most (39) of the disabled people engaged in EGL were school leavers under the age of 21. Nine were still at school and the status of four was unclear at the time of the evaluation.

As at February 2014, the EGL participants were at or came from one of 17 schools. The schools were a mix of special schools and regular high schools. Most (28) of the young people were at or had gone to three schools. Of the 52 disabled people engaged in EGL, 17 were part of the Going Places[[15]](#footnote-15) initiative which following an agreement with the service provider, was to be absorbed into the Demonstration by end of June 2014 (see page 54).

## Some early outcomes aligned to the Enabling Good Lives principles were evident

The evaluation looked at some emerging outcomes for a small number of EGL participants. All of the individuals with disabilities interviewed had very high support needs and were living at home with their parents. Two individuals had left school last year while two were still at school with the likelihood this would be their last year. Families reported having had a history of poor service provision and supports. When they became involved in EGL they were concerned about the long-term support for their disabled young people and were becoming tired from the care they provided.

There are some limitations on the findings on outcomes:

* The disabled people and their families interviewed are likely to hold different views from those not yet involved in EGL. They were all early adopters of the EGL approach and had large support networks and were connected with other families with a disabled child/family member. The family members interviewed described themselves as fighters, visionaries, or people who *“think outside the square”.* They were interested in trying a new approach to support their family member. There was some concern expressed that families without this background may find aspects of EGL challenging.
* It is early days in terms of outcomes. When the evaluation took place, aspects of the Demonstration were still being implemented, the number of disabled people engaged in the Demonstration was low, and many of those who were engaged had only had initial meetings with their navigator. However, some early outcomes were starting to emerge during the evaluation.

The early outcomes identified by the evaluation have been organised using the EGL principles as a framework. The EGL Principles focus on self-determination, beginning early, being person-centred, achieving ordinary life outcomes, mainstream first, empowerment of disabled people and their families, simple to use supports, and relationship building.

### Principle 1: Self determination – tino rangitiratanga

This means disabled people are in control of their lives.

#### A shift in the attitudes was an important step towards achieving greater choice and control

Amongst the disabled people and families interviewed EGL was creating a different type of thinking as they explored what was possible. In starting EGL some families found it *“exciting but scary*” and *“a shift of their mind-set”* to think differently and beyond what had been previously accepted. The support from the navigator was important in providing reassurance and encouragement to *“tell you you’re right and keep going”.* This was important for people who at times felt they were reverting back to the old way of thinking.

Interviews with disabled people and their families and navigators revealed that once people had started thinking more broadly about what a good life might entail they were better placed to plan and make decisions about their life and the supports required. Disabled people with support from the navigator and family were now deciding what they wanted to do in their life, and choosing how they could be supported to make it work. As a result individuals were expressing their wishes; and were feeling listened to. The plans centred on the individual and their life. As one interviewee commented, *“The plan this time is what he wants to do. We had no help on previous plans, now we have a huge amount of help and direction”.*

#### Evidence of disabled people and their families exercising greater choice and control

All the families reported their choice of support options before EGL were often limited and they had to use services they didn’t like or choose. As part of the planning process, people were exercising more choice over supports that would work for them. For some people with high health needs this meant planning a flexible week that was at their own pace, and involved the things they wanted to do. An increased focus was being given to personal interests rather than a weekly routine of activities not of their choosing.

For others it meant choosing alternatives to facility-based care that better met the needs of the disabled young person. For example, at the time of the evaluation a family participating in EGL was in the process of changing the care arrangements for their disabled young person. They were using their pooled funding to employ caregivers they had chosen to come into their home which they saw as preferable to the respite care they had previously used. Another parent who had chosen in-home care said:

If we had not had EGL it would have been respite for the rest of X’s life –it’s been once a month to give me a rest. We’re now breaking out of this as we don’t really need it and can do it differently now with me still getting a rest. It’s [respite care place] not a place to put our young people, and cruel to have to put our young people there.

#### Changed attitudes combined with individualised funding are important to achieving greater choice and control

The disabled people and their families interviewed reported they were using or going to use their funding allocation differently because their mindset had changed. They had higher expectations and saw themselves as having real choice and control over how the money was to be used. A parent interviewed reported that her son had previously taken up individualised funding through the Ministry of Health but “*that was still in the old mind thinking. Carers would come in and do what they want. Now it’s changed as carers are employed and paid to do a job and they are not a babysitter – this has been a real help*”.

Another family interviewed had also begun to employ their own support workers who would better meet the needs of their disabled family member. Individuals and families were determined the people they employed would be required to do the work they wanted. Those who had yet to receive their combined funding allocation were hopeful that it would make a real difference in their lives.

#### There are still potential barriers to disabled people achieving greater choice and control

The evaluation identified a number of barriers:

* *Organisations that disabled people interact with can make achieving greater choice and control harder:*Under EGL, disabled people may choose not to use disability support providers. However, where disabled people attend school or need support from a provider, the degree of choice and control they have will depend on the approach of the organisations they have access to. Families gave several examples of organisations (e.g. schools, providers) not always supporting their choices. Some interviewees cited examples of schools not supporting the disabled person in the classroom or taking account of their level of ability. In some situations young people did not participate with their peers in the mainstream school which had an effect on their ability to create friends and networks. This also impacted on people’s learning and development both academically and socially. Navigators, individuals and families also described past experiences of providers not respecting their choices. For instance, one family gave the example of their disabled family member in respite care being *“forced to go to bed at 7pm when he wanted to watch a movie”.* Another example is outlined in Box 1.
* *A belief that greater choice and control was not appropriate for some groups:* Some providers, schools and ministry staff interviewed were of the view that the EGL approach would not be appropriate for everyone, especially those with learning disabilities. These interviewees expressed concern that disabled people would be more vulnerable to abuse. According to Manthorpe et al. (2011) several international studies have found provider staff believe approaches like EGL will not work for some groups. They add that underlying this view is usually a concern disabled people will be at greater risk of abuse, exploitation and general distress, or lack of wellbeing arising from the ‘hassle’ of managing new relationships associated with individualised budgets. However, evidence about the actual risk of abuse, neglect or fraud associated with personal budgets is very limited (Carr, 2010).
* *Limited options mean there may not always be real choice:* The respite options available for young disabled people, for example, appeared limited and while they would not have been the choice for some families there was no alternative to use them as they needed the break (see Box 1). As one parent said “*Respite, this was a physical rest for us but not a mental rest*”.
* *Transport can be problematic and may limit choice:* the disabled people in this evaluation have access to transport. However, families and providers raised concerns about the cost of transport and how this would be funded to support disabled people to have good life. Some possible solutions identified for assistance with transport included using the Supported Living Payment, the Disability Allowance, mobility vouchers, and public transport or private vehicles. Transport could also impact on families who may not have a vehicle for use for their family member.
* *Some interviewees perceived that the navigator’s role could constrain people’s choice:*The navigation service is fully funded by EGL for the duration of the Demonstration. Having a free navigation function was perceived by some as constraining disabled people’s choice as they would be less inclined to use similar services provided at a cost by disability support providers. For example, a provider reported *“The navigation system is actually restraining people’s choice when it is understood it was actually going to be about extending people’s choice.”*

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| Box 1: Organisations can be unresponsive to the needs of disabled people and their families |
| Until EGL, the family interviewed felt they had no alternative but to use a respite care service they were extremely unhappy with. They described the service as *“awful”.* The parents reported that the provider rarely asked questions about their disabled family member. For example, they reported they wrote in the diary every week what was happening with their disabled family member but the provider only rang once in 18 months. *“The scary thing was [Mary\*] had two seizures and they didn’t ring us and didn’t ring an ambulance because it would have cost them. I explained to them the ambulance for [Mary] is free. We found out through another person that was staying at the service that [Mary] had a seizure”*.  The parents reported the provider was unresponsive to their attempts to improve the situation. For example, they provided the service with a visual book outlining what life looked like for their disabled young person. When the parents asked staff two months later if they had read it they said they were told the staff hadn’t looked at it.  ⃰Not their real name |

### Principle 2: Timatanga (beginning early)

This means investing 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, skilled adults. It was too early to comment on this principle.

### Principle 3: Person-centred

This means disabled people have supports that are tailored to their individual needs and goals, and that take a whole of life approach rather than being split across programmes.

#### Disabled people were being supported to imagine what a good life for them might look like and how this can be achieved

Disabled people and their families reported that the navigators were widening their expectations of what a good life might look like and how it could be achieved. The families and disabled people interviewed reported feeling hopeful. One family member spoke of EGL having given them the ability to *“dream again”.*

The navigators assisted the disabled people and families interviewed to work out how the disabled person’s vision of a good life could be achieved. Families and disabled people interviewed experienced this assistance as the navigator walking alongside them offering suggestions, but not telling them what to do.

#### The planning process was inclusive and focused on disabled people’s needs and goals

The intention of EGL was that people’s aspirations and personal preferences for what they wanted to do in life would drive the supports they require. This was evident with the increased focus being given in planning to *“what people can do, their abilities and combining of ideas”* for the future. Supports were also coordinated and tailored to people’s specific needs.

Individuals and their families spoke positively of the planning process as empowering and enabling them to have a voice. EGL was described by a disabled person as *“Happy impact”, “Awesome ride”, “Over the moon about it”.*

Family members reported seeing the value of their disabled family member being included in the planning process. As one parent said:

I had ideas before this about what he would do but they were different like training, arts. Since EGL [Tom[[16]](#footnote-16)] has talked about what he wants to do. It’s different to how I saw it but not by much. It has opened my mind. I would not have thought of it and parents aren’t always right. I always said I would listen to him but as a parent you don’t.

The planning experience under EGL was in contrast to their past experience of planning services and supports which had left some family members and individuals feeling demotivated, stressed and even depressed by inaction and slow progress. As one family member reported they *“kept coming up with ideas and nothing ever happened”.*

#### Navigators were taking a whole of life approach to planning which was appreciated by disabled people and families

Navigators and families commented that the plans for people covered activities throughout the week, weekends and when individuals or parents were away, including long-term plans. Navigators and families interviewed talked about the importance of thinking ahead. The focus in setting up supports to take a whole of life approach gave families reassurance their disabled person would be cared for when they were no longer around. All the parents interviewed had had concerns about what would happen to their son or daughter as they aged.

“Yes we have had a weight lifted from our shoulders and we want to make sure that when we die things are in place so they are set up for life”.

“[He] is excited seeing the future he can have, he’s going to be safe which is the biggest thing, lot of support around him to keep him that way. Someone else knows what his plan is”

Navigators and families also talked of the importance of supporting disabled people to participate in activities or make changes at a time and pace that suited them. For example, one disabled person had a longer term goal of living independently of his family but he was not ready for it yet. There was acceptance by navigators of people’s everyday life situation and their need to concentrate on matters outside EGL sometimes. For example, one parent reported it was difficult to focus on planning a good life until her sons health was sorted out.

### Principle 4: Achieving ordinary life outcomes

This means disabled people are supported to live an everyday life in everyday places. They are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation like others at similar stages of life.

#### Disabled people were doing what others at similar stages of life are doing

Like others at similar stages of life, disabled people are getting opportunities to contribute, learn, have relationships, have a home, take part in their culture, and participate in recreation and sport. For example:

* *Some disabled people chose to leave school at similar age to their peers.* With EGL starting in November 2013 some disabled people who could have stayed at school until they were 21-year-old[[17]](#footnote-17) chose not to return.
* *Increasing networks and more involvement in the local community.* Interviews with disabled people, their families and navigators revealed that circles of friends for disabled people appeared to be increasing. There was an emphasis on meeting new people, building relationships and making friends. For example, a parent reported that her disabled son had a much wider circle of friends and was enjoying going to meet new people at groups and making friends. Another parent said *“We’ve put in place for the school holidays that the carers will come in at different times to take the* [her] *bowling and catch up with friends.* [She] *needs to keep up relationships with* [her] *friends. That’s really important”*.
* *Some people were involved in attending courses and work experience.* A navigator reported that getting work support is often important, and many have done work experience. For example, one client has done work experience at an animal park, but now feels like he knows the job and wants to get paid for the work. It has become one of his goals for achieving a good life. One of the young people interviewed said he wanted a job and was now getting some training.
* *Some were planning to live away from home in the community.* For example, one of the young people interviewed had a longer term goal of going flatting.

### Principle 5: Mainstream is the default

This means disabled people are supported to access mainstream services before specialist disability services. While there is an emphasis on disabled people accessing mainstream supports this does not mean they will not need disability support services.

#### Most disabled people in EGL are accessing disability support services

Administrative data indicates that in February 2014, 32 participants were accessing disability support services (e.g. day services, respite care) and 20 were not.

It is early days but there was some evidence that disabled people were choosing alternatives to the disability support services they had previously used. All the families interviewed were choosing to use natural supports or employ staff rather than use day services or respite care. There was some evidence of families using social networks for support.

#### Some interviewees felt mainstream supports and services could not be the default for all

As mentioned earlier some providers and some ministry staff stated that EGL would work best for disabled people who were higher functioning. They did not believe it would work for those with an intellectual disability and/or who may need 24-hour care and support (also see page 25). Associated with this was the belief that disabled people could become socially isolated being reliant on natural supports. For example, the view was they would have less contact other people with disabilities if they were not attending a day service or living in residential facility.

### Principle 6: Mana enhancing, empowerment

This means the abilities and contributions of disabled people and their families are recognised and respected.

#### Confidence and self-esteem of disabled people and their families was increasing

EGL appeared to be supporting people to become more knowledgeable and confident. There had been meetings held that supported people to learn about using natural supports and individualised funding, along with courses on microenterprises and going flatting. Navigators encouraged people to get their own information on how they might achieve a good life but were also a source of information. The navigators reported that disabled people and families who were more comfortable managing for themselves sought less help from them.

The opportunity EGL provided to think about what life could offer appeared to be improving the confidence of disabled people and their families. The families interviewed reported feeling more empowered to plan and create the life they wanted for their disabled family member. As one parent reported: *“EGL has enabled us to do better as we’re thinking differently – X doesn’t have to be where he doesn’t want to be”.*

A positive consequence of the increased confidence was families being more willing to say no to bad service (see Box 2). Previously families interviewed felt they should be grateful for whatever hand-outs they received and powerless to effect change. This was relayed as *“you would ask for something, you know you’re not going to get it and you wait and may not get it.”*

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| Box 2: Increased confidence in dealing with bad service |
| A parent described a situation where they said no to unsatisfactory service. Their disabled family member had attended a respite care where they were kicked and attacked. At a meeting the provider assured the parent that this person would not be there when he was staying there. However, the parent found that a couple of weeks later the person was back in the same house. She rang and told the provider who suggested they move her disabled family member. “*I said sorry that doesn’t suit me. Before I wouldn’t have said that. It’s* (EGL) *given me the confidence to say things.* |

An example of disabled people and their families confidence in EGL was that they have also been recommending EGL to others. Several interviewees were excited for other families, particularly young parents just receiving a diagnosis and starting the journey, and for disabled people and their families in other parts of the country. One disabled person said EGL should be *“for all NZ”.*

#### Disabled people and their families did not feel on their own with the navigators support

Individuals and families felt well supported by the navigator. Many had not previously had this support and described feeling on their own and challenged by barriers.

We really need a navigator to run things by her, you bounce things off her, text back and forward, run it by her, run it by [partner] and it’s nice having [the navigators] support, it’s massive. It’s very, very important. Since EGL has come into our lives it’s the first time we don’t feel as though we’re on our own.

They experienced the navigator as someone they trusted, who walks alongside them and genuinely wanted to be there. This was evident from the regular communication between people and the navigator. While some found the planning process could be difficult and time consuming they valued having the navigator to help them through it.

### Principle 7: Easy to use

This means disabled people have supports that are simple to use and flexible.

#### Making supports easy to access is not straightforward in practice

Further work is needed to make supports easy to access. For supports to be simple and easy to access and responsive to disabled people, government systems and processes need to change. Making supports simple has proved harder to achieve in practice and those working on the design acknowledged this remained a significant challenge for the Demonstration.

The government agencies were working together but operationalising EGL within the existing system was difficult and time-consuming. For example, Lifelinks in Christchurch had to develop a means of pooling and allocating the funding EGL participants were eligible for, and this sat alongside their existing processes for non-EGL participants – the vast majority of people they dealt with. Developing the new approach for the EGL participants was difficult and time-consuming as it rubbed up against Lifelinks’ existing processes and guidelines.

In another example, a navigator reported that some people were employing their own staff now. However, the staff are having to pay secondary tax because they are working for three different families on separate contracts. She reported that the families were trying to think through ways they could work it out amongst themselves so the staff they employed did not pay the secondary tax but this was *“not simple and easy”.*

#### Modifying the existing system may be increasing complexity

There was some concern that supports could be being made more complicated. Creating completely new and simple ways for people to access supports takes time. However, adding new ways of doing things onto an existing system, while quicker, did not reduce the complexity. Moreover, the Local Advisory Group and ministry staff were concerned that modifying the existing system may actually be making it more difficult for disabled people to access supports and services. For example, at the time of the evaluation there was concern that under EGL some disabled people who were not changing their supports and services would lose some funding because they needed to pay a host provider a fee (see Box 3). A work around had to be developed to ensure disabled people were not disadvantaged.

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| Box 3: The payment of host provider fees were an example of increased complexity for disabled people |
| Currently disabled people receiving funding under EGL need to use a host provider to manage their funding. At the time of the evaluation, Manawanui In Charge was the only host provider involved although the intention was that in time a range of host providers would be available for disabled people and their families to choose between.  Host providers charge disabled people a fee for managing their funds. This was considered fair and reasonable where disabled people and families wanted to use their funding differently. Families and others interviewed were very complimentary of the work that Manawanui In Charge had done to assist disabled people and their families in this way. However, there was concern that some disabled people were being disadvantaged by the need to use a host provider. For example, where disabled people opted not to change the support they received from a disability support provider organisation that is contracted by a Government agency, they needed a support agreement[[18]](#footnote-18) that was separate from that contract. Host organisations were proposing taking a percentage of the funding allocation where payments were made to the provider by a host organisation operating on behalf of the disabled person. While it was acknowledged that host providers have a right to be paid for work they undertook, many of those interviewed felt it was unfair to take a large percentage (e.g. 5%) when nothing was changing for the disabled person. Some also felt it would discourage people from trying something different.  Still a bit of work to do with the funding pathway – the fact that people have to go to a host provider to clip the ticket first reduces the amount of money they have left to spend – especially people who want to continue to purchase more traditional services rather than be more creative, as under the old system they wouldn’t have had to do this. We don’t want to overcomplicate it for these people and make them say that it was easier the old way.  Since the interviews were undertaken, host providers have agreed disabled people can pay a fixed payment where there is no change in the support they are receiving. |

A number of those working on the design of EGL felt it would be useful to have a discussion about what “making supports simple” means. International evidence suggests that where supports are not simple to access there is a risk that disabled people will be less likely to take up personalised approaches (Fisher et al. 2010).

### Principle 7: Kotahitangatatou- whānaungatanga; relationship building

This means supports are based around relationships - a unified partnership connecting disabled people and their family and whānau with communities, building supportive relationships, and encouraging community responsibility.

#### Supportive relationships were developing but families were key in people’s lives

Families were important in the lives of disabled people, providing support and ensuring people were connected with extended family and their community. It was evident that parents were the key people who enabled disabled people to spend time with people important to them. This role appeared to be changing as families were realising they could get a break. Individuals were developing rapport with support people they liked and who were able to take them to places where they wanted to go to and meet friends and/or new people. For example, one parent described being tired and not being able *“to physically keep up with X now and I don’t want to go partying with them”*. However, with the support provided, the disabled person was able to enjoy life with their peers.

#### Wider circles of support were being considered

Some families were beginning to look into establishing circles of support. Circles of support are a groups of people (e.g. family, friends and maybe supportive workers) who come together to give support and friendship to a person to help them do the things they would like to do (e.g. day to day things in a person’s life, such as going out in the evening, meeting new people or going shopping or possibly big things, such as going on a holiday, finding a job or moving house).

Although some disabled people had friends, extended family, and associates who cared for them in addition to their immediate family, they had never approached them for support. Asking for support can be challenging for many people. An interviewee had heard of a way to approach this where *“a parent writing on behalf of their child for a person’s support in their circle of friends had a positive outcome with the person being really pleased to be asked”.*

#### It is too early to tell if community development activities are having an impact

The intention is that accessible communities will be created by engaging and supporting them to be more welcoming and inclusive of disabled people. It was too early to comment on this aspect of EGL.

## There was a strong commitment to the principles but wider buy-in is needed

The design is underpinned by a strong commitment to the principles. All the interviewees stated support for the principles of EGL. Those working in the design – the EGL team, most Wellington ministry staff and the Local Advisory Group – wholeheartedly supported the principles. However, other interviewees – typically providers, schools and local ministry staff – were more likely to qualify their support for the principles. They more commonly reported that the practical application of the principles was problematic. As one provider said of the principles *“They’re fine – but where is the detail about how it will work”*.

Those interviewees who were strong advocates for EGL added that getting wider buy-in to the principles remains an on-going challenge. They reported that greater buy-in to the principles is needed within the Ministries and amongst schools and providers in Christchurch. However, an interviewee who was a strong advocate of the principles cautioned that getting that buy-in needed to be done carefully:

I think it’s really important with all of these things, like with providers who might not be on board with the principles is that we don’t make people wrong – we actually try to take them along with us. Instead of getting all like crusaders around it – there’s a real danger of becoming self-righteous around it and they need to respect where people are at, and move with them through that. There are good people working at all of the places – but because it’s such a big community, there’s a lot of work for them to do.

## EGL is likely to have had limited impact on schools and providers so far

#### The Demonstration appears to have had limited impact on the schools interviewed

The schools interviewed reported they wanted EGL to be a positive experience for their school leavers, and were committed to working alongside EGL in order for this to happen. However, at the early stage at which interviews took place, schools had had very limited exposure to EGL and in reality had made minimal changes to their practices. Schools were taking a ‘wait and see’ approach to EGL.

#### The Demonstration appears to have increased provider uncertainty

Providers interviewed in Christchurch were uncertain what the Demonstration would mean for them. Overall, all providers thought that EGL had been implemented too early, and because it was not fully developed and the infrastructure to support it was not in place, it had impacted certain providers in a negative way in terms of funding arrangements.

#### Some providers had started to prepare for EGL while others thought they had been working this way for some time

EGL appears to have had limited impact on provider practice and behaviour at this stage but it’s very early days. Providers interviewed typically reported that they had been doing something similar to EGL for years and it wasn’t new.

We already plan with individuals about their aims, aspirations and goals. We tend to be working 1:1 with people already.

We are very aware of the principles surrounding EGL – and were doing these things anyway, they’re not new.

There is a heightened awareness around the need of individuals and what we are doing is essentially the same as EGL.

They saw EGL was about enhancing what they were already doing, with some indicating they had a heightened awareness around the needs of individuals. Some providers had started to prepare for EGL, in terms of staff they may require and being able to support people in transition.

At the early stage of the interviews, providers were unsure what the impact of EGL would be for them, and were not doing anything measurably different. As one provider said *‘what is still unknown is how it’s going to work. Embrace the idea of it, but don’t know how it’s actually going to work....It’s all just uncertain at the moment.”* The lack of certainty and details made it difficult for providers to plan and make any changes to their service. One provider reflected *“in terms of where we are going – it is the status quo.”* However, whilst not doing anything differently as yet, some were beginning to think about options and were discussing ways they may be able to market and price services for potential clients to offer them more flexibility and choice. One provider reflected:

we are looking at new things, but again, it all comes down to resources, we don’t know where the money is going to come from and how much this will be so can’t plan for it.

# The design process could be improved

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| Summary: Some practices facilitated the co-design process:   * A strong commitment to the EGL Principles, co-design and doing something different. * The design built on work that had already occurred. Considerable thinking had been undertaken on what EGL could look like before the Demonstration began. Existing knowledge and experience helped with development of systems and processes (e.g. The Ministry of Health’s experience with the New Model was useful in developing the navigator role). * Christchurch was a good place to locate the Demonstration according to Wellington ministry staff, the Local Advisory Group and the EGL team. However, local ministry staff, providers and schools had reservations. They were primarily concerned about overburdening people coping with the changes brought about by the Canterbury earthquakes.   There were challenging aspects to the co-design process and areas for improvement:   * There was not a shared understanding what co-design meant in practice in the context of the Demonstration. Sharing of information in a way that enables equal participation was a challenge. The concept of co-design implies shared decision-making responsibilities, but this was not the case in the Demonstration. Some reported more could be done to take advantage of learnings from elsewhere in the design process. * Too little time was allowed to develop the components of the Demonstration. This has meant the changes so far have focused on modifying the existing system (e.g. developing workarounds) rather than transforming it. * The design and implementation would have benefited from the earlier involvement of operational people from the Ministries. * There was not a shared understanding of what the Demonstration design entailed. |

## Some practices facilitated the co-design process

### There was a strong commitment to the principles of EGL

The intention was that the design and operation of EGL would be based on the EGL principles. Within the group working on the design of the Demonstration there was a high degree of support for the principles. As one interviewee said *“The Principles are great, fabulous! They should underpin all our work”.* This is important as a key component of achieving a collective impact – having a shared vision for change (Kania and Kramer, 2011).

### The design built on work that had already occurred

Considerable thinking had been undertaken on what EGL could look like before the Demonstration began. Before approval was given for the Demonstration to progress in Christchurch many of those involved in developing the design had already undertaken work in the area. The design process built on this knowledge and experience.

We all had a good understanding of and commitment to the Demonstration. We had been talking about doing something like this for some time before the LAG [Local Advisory Group] was established and the Demonstration began. They weren’t starting from scratch.

Existing knowledge and experience helped with development of systems and processes. For example, the Ministry of Health’s experience of developing and implementing the New Model in the Bay of Plenty informed the development of the Demonstration, especially the role of the navigator. In another example, Manawanui In Charge’s past experience of working with the Ministry of Health on implementing individualised funding assisted them to prepare for the Demonstration. Manawanui In Charge reported while they had to change some of their internal processes and forms, the way in which they work with EGL participants is similar to how they are working with the Ministry of Health’s individualised funding recipients.

### Christchurch was seen by many as a good place to locate the Demonstration but others had reservations

Wellington ministry staff, the Local Advisory Group and the EGL team were of the view that Christchurch was the right place for the Demonstration to be based. One reason included the existence of motivated locals who had put considerable thought into how life for disabled people and their families could be different. For example, a Wellington ministry staff member reported *“having people who will stand up and say we’ll do it or we don’t like that, is something to appreciate. It’s a strength, a real asset”*. Another reason given was that providers of services and supports were already coming together and working in different ways in the aftermath of the earthquake. As one interviewee said:

Things had to change in Christchurch anyway. There’s services here that have changed after the earthquakes anyway and have proved that the world didn’t end because they went for a slightly more individualised approach and not so much focus on bricks and mortar.

A member of the EGL team suggested that the location of the Demonstration was not an issue as EGL was about applying the principles and these could be applied anywhere. His view was that each location would have its own particular challenges but that principles could be applied regardless.

However, some interviewees had reservations about Christchurch as a location for the Demonstration. Local ministry staff, providers, schools and families interviewed spoke about the effect of the earthquakes and the impact on Christchurch. The effect was both at a personal level for people and their families, and at a community level with the environmental changes, closure and merging of schools, and providers needing assistance for repairs or to relocate their facilities.

Local ministry staff, providers and schools interviewed tended to have mixed views about the Demonstration being in Christchurch. They acknowledged that while there was some logic to placing the Demonstration in Christchurch, there was also a risk of overburdening families, schools and providers with change. For example, a provider reported:

It’s ironic that they seem to say that Christchurch is doing things differently – let’s do some more. The Demonstration is being trialled in an area already under a lot of pressure. I don’t mind – maybe we’ve got a chance of shaping it. But I find it really ironic that no one seems to have challenged the government on its decision to put the Demonstration in Christchurch. People are already really stressed, schools are closing!

## The co-design process could be improved

### There was a strong commitment to co-design but a lack of clarity about what it meant in the context of the Demonstration

Interviewees involved in the design of EGL typically reported that the Demonstration had been co-designed. This was particularly the case amongst Wellington ministry staff. They expressed a strong commitment to what they understood the concept of co-design was. As one interviewee reported:

The co-design process is integral to the Demonstration. I think it has been co-designed and the Local Advisory Group has driven much of the design. They know the people in their area and their aspirations. It’s quite right they should drive it.

Interviewees involved in the design process reported that the Local Advisory Group members had engaged enthusiastically in the process and were committed to bringing about change.

While there was a commitment to co-design, there was no stated definition or agreed understanding of what it meant in the context of the Demonstration. People involved had different ideas about what co-designed entailed. While there was agreement that the design process involved the three Ministries and the Local Advisory Group, there was not agreement how they contribute to the process. Some ministry staff saw themselves as being part of a genuine two-way design process. They constructed the process as both the Local Advisory Group and themselves raising ideas, discussing them and agreeing on a way forward. However, other ministry staff saw their role only as enabling what the Local Advisory Group came up with and not drawing on their own knowledge and experience. For example, one ministry staff member said:

Sometimes it’s a challenge to keep my mouth shut on things that I know haven’t worked in the past. But my role is just to be there and advise, not to lead. I offer information where it’s needed and not offer an opinion. They’re leading and driving it. I just want to support them.

### Sharing of information in a way that enables equal participation was a challenge

It is useful to think about what kind of environments foster the useful sharing of knowledge and experience from all participants in the process. The Local Advisory Group members reported being overwhelmed by the number of papers they were expected to read and provide comment on. For example, members of the Local Advisory Group commented that:

Meetings with ministry staff from Wellington were difficult at times. We were overwhelmed by the complexity of their systems and processes. … There was an assumption that we were bureaucrats and able to absorb all the papers. It was too much. We have other lives.

Wellington ministry staff interviewed acknowledged that while they were well intentioned, the process of sharing papers with the Local Advisory Group had not worked and there was a need for a different approach.

At the same time the Local Advisory Group also reported a lack of information in some areas made it difficult for them to make informed decisions. For example, they reported being unclear on how much money was available for the EGL Demonstration and that this made it difficult to provide good advice. One member of the Local Advisory Group commented “*How can we provide good advice to* [the Director] *and ministry staff when we don’t know what the budget is?”* and another said “*We need to know how much money is available and what is expected of us with a project like this”*.

### The concept of co-design implies shared decision-making responsibilities but this was not the case in the Demonstration

Ministry staff and Local Advisory Group members acknowledged that the relationship between the Local Advisory Group and the Ministries was not an equal one. While the Ministries actively sought the input of the Local Advisory Group during the design phase, it was the Ministries who ultimately had the decision-making power. As one Local Advisory Group member said of their experience of the process: “*It has been complex and frustrating. We have to remember it’s about the power shift. We’re not anywhere near that happening yet*”.

Ministry staff acknowledged the imbalance and some reported that more thought needs to be given to how the Ministries can share power in the Demonstration. For example, one ministry staff member reported:

In terms of what might have been better – it’s more about local control now; not just co-design. Phase two will be more about local control. We need to be more open. We can provide advice and guidance and make it happen but we need to be more confident in their ability to know what to do and to trust them. … I’d like to see it more locally driven this time.

The Director added:

Co-governance – needs to be carefully thought through distinguishing between what is considered advice (to be weighed) and what is direction (to be actioned). The process whereby people are elected or selected is also important. It may be as much about the how as the who or the what. However, there is no perfect system.

This point is reinforced by Bovaird (2007:856) who states that when co-producing services the community or *“service user has to trust professional advice and support, but the professional also has to be prepared to trust the decisions and behaviours of service users, and the communities in which they live, rather than dictate them”.* The interdependence of decision-making is important. No one actor or group should dominate.

### Some reported more could be done to take advantage of learnings from elsewhere

Some ministry staff reported that the design could have been more informed by research on the experiences of similar initiatives in other countries (e.g. the Local Area Coordination initiative[[19]](#footnote-19) in Australia; direct funding in the UK) and New Zealand (e.g. the New Model implemented by the Ministry of Health).The Director reported that it is difficult to know how much the design should be informed by international experience versus designing as you go based on the considerable experience of those in Christchurch and Wellington. He said:

Can we pick and mix from existing models or do we develop our own? For example, we have the principles and are developing a model from there. What is making the principles work? This is a developmental model. What makes it work? Is it the principles or is it the structures? Other models only go so far then get overwhelmed by decisions about funding and contracts and so on. There hasn't yet been a sustainable model developed.

However, he thought the Demonstration needed to take on the learnings from international models and look at how they could collaborate with people who understand initiatives like EGL.

### Too little time was allowed to develop the Demonstration’s components

Once Cabinet agreed in July 2013 to having the Demonstration in Christchurch, ministry staff and the Local Advisory Group had until November 2013 to put the Demonstration in place. All the ministry staff, EGL staff, and representatives from schools and providers interviewed were of the view the time for preparing to implement EGL was too short. Key components of the Demonstration were not developed.

The time pressure meant that the emphasis was on getting something in place rather than redesigning the system, and even this was a challenge. As one ministry staff member reported:

What’s been done to date is the best that could be done at the time. There are lots of things we could do. The challenging part is not coming up with the ideas. The challenging part is do you go with what we’ve got because coming up with something completely different will take such a long time? For example the funding allocation – there are options. If we go with something different to what the Ministry has already done that’s likely to take twice as long as what we’ve got. How we deal with that is difficult. Do you go with what the Ministry has come up with now and expand it across agencies even though it’s not perfect or do you try to do something even better? What’s the trade-off in choices?

However, Brotchie (2013) argues that is critical to set aside sufficient time and resources to dismantle and rebuild supports and services in an enabling manner.

This reduces the pressures to rush new approaches through in top-down fashion and allows service users and other stakeholders to be properly involved in the design and development stage. Frontline staff and their managers must also be equipped and ready to work in a new way, and new deeper relationships with individuals and communities must be built so that citizens can be properly engaged in the design, delivery and development of services (Brotchie 2013:15).

### Questions about who else should have been involved in the design process

#### Operational staff from the Ministries needed to be included much earlier in the design process

There was a strong view that the design of EGL would have benefited from the inclusion of operational people from the Ministries much earlier in the design process. The design process included the Local Advisory Group in Christchurch and representatives from each of the Ministries. However, the representatives from the ministries were almost all policy people.

Policy and operational people interviewed acknowledged that not having operational people involved earlier in preparing to implement EGL undermined the implementation. It was not clear why operational people were not involved earlier, but it meant the practical details such as how the Demonstration would be operationalised were underdeveloped (e.g. paying providers, allocating funding to disabled people).

When operational staff did become involved, the timeframe to the go live date was very tight. They had to rapidly catch up with where the Demonstration was at. This was challenging as there was little documentation about how the Demonstration might work in practice. For example, ministry staff said:

The challenge has really been trying to make sense of it operationally. Thinking about what it can mean, what's up and running and what needs to be constructed from scratch.

We had something that went live before it was really designed. So we’re now having to scramble to get the operational policies, processes and procedures in place for something that’s already happening.

#### Providers felt excluded from the design process

Providers are represented on the Local Advisory Group. However, some providers interviewed felt the voice of providers was not adequately included in the design process. Respect was held for the people in the EGL team by providers interviewed. However, they voiced concern about not receiving communication or not being kept informed about the Demonstration, and any issues arising. The wanted a more collective approach to implementation and to feel they had a place in EGL.

#### Greater involvement from ACC would have been useful

ACC were represented at the initial design workshops and at the JAG but have had little involvement beyond that. According to one interviewee this was significant as they have approaches that would align well with EGL. The interviewee said:

It’s really significant that they’re not involved. They have an actuarial, whole of life approach. We don’t ever do that with our children or disabled adults. We focus on the cost of the here and now – not what would happen if we got our act together and looked at what they need and want to achieve positive outcomes. It would probably cost half of what it does now and you’d have improved quality of life.

### No shared understanding of what the Demonstration design entailed

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’. The paper stated, in the first year, the Demonstration was to be tightly targeted at school leavers with high needs and very high needs but there was flexibility to allow up to ten disabled people to opt-in.[[20]](#footnote-20) The Demonstration would expand after the first year to include a cross-section of the disability population.

The EGL team and some ministry staff saw the Demonstration as a developmental model based on the principles. This meant the design was seen as something fluid that evolved over time. However, others interviewed felt strongly that the Demonstration should not deviate from the initial cohort outlined in the Cabinet paper until it was clear what works and what does not. Local ministry staff and some national ministry staff interviewed conceptualised the Demonstration as something fixed that would test how EGL worked for the initial cohort of disabled people in receipt of ORS funding who were transitioning from school before expanding to other groups. They expressed considerable frustration at attempts to expand the Demonstration beyond this group, as the following quote from a local ministry staff member illustrates:

In a Demonstration model you need to focus on a particular cohort/ group – a group with good data, who are learning, getting good skills, have support – that would be ideal. We could learn from that, and then can measure outcomes of EGL. I don’t understand why they are looking at so many different cohorts of people.

They were concerned that the Demonstration was *“trying to go too wide too far too fast”*. There is a concern that the impacts of the Demonstration will be diluted if the target groups are too broad.

Local ministry staff and some national ministry staff also reported that an evolving design posed considerable operational challenges. They reported that they found it difficult to develop a response to EGL when from their perspective the design kept changing. They wanted greater clarity on the criteria for who should and should not be part of the Demonstration.

# Key parts of the Demonstration were not fully implemented

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| Summary The implementation of EGL could have been better. Each of the agencies and the Local Advisory Group had a commitment to making the Demonstration happen and they each worked very 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 agencies were unclear. |

Each of the agencies and the Local Advisory Group had a commitment to making the Demonstration happen. Those involved in implementing the Demonstration worked very hard to put something in place by November 2013. Nevertheless key components of the Demonstration were not in place.

## Funding mechanisms were not in place or fully developed

### The mechanism for pooling funding for individuals was not fully developed

At the time of the evaluation the mechanism and processes to deliver a total package of funds to EGL recipients was still being developed. Ministry staff acknowledged this was not ideal and it undermined the credibility of Wellington ministry staff in particular with the Director and the Local Advisory Group. As one Wellington ministry staff member said:

We put our hands on our public service hearts and said this is our business we’ll fix it, and we didn’t. It put [the Director] in a very extraordinarily difficult position at the end of last year. He had made a commitment to families that they would know what funds their son or daughter could get and he was looking like he wasn’t going to be able to do that. Happily we were able to solve it at the eleventh hour. But the reality is that the mechanics are not sorted. It’s held together with band aids and twine at the moment. That’s not good enough. That has undermined our credibility … I’m not saying it’s not hard but we just haven’t sorted it in a timely way.

Internationally, integrating funding streams has proved difficult to achieve according to Manthorpe et al. (2011).

### Reliance on less than ideal temporary solutions for disabled people to receive and manage their allocation of pooled funding

As the final funding mechanism was not going to be in place in November, the agencies agreed that Lifelinks (also referred to as “the NASC” – the Needs Assessment and Service Coordination organisation in Canterbury) would manage the funding allocation process in the short term. The existing processes used by Lifelinks were modified to pool and allocate the funding from the three agencies. Several interviewees commented that the NASC had worked very hard to put in place a process for allocating the funding. For example, an EGL staff member when asked about what worked well said: *“The NASC getting on board – they were charged with a pretty huge role to pull all the funding streams together. That took a while but once it came together this has worked really well”*.

Nevertheless, there was a perception amongst some involved in the Demonstration that Lifelinks was not an ideal organisation to allocate the funding for EGL participants. They perceived Lifelinks as conservative, inflexible and focused on cost containment.

#### Lifelinks faced very real challenges in pooling the funding

Lifelinks staff interviewed were aware of these perceptions but felt that their critics did not always understand the work of Lifelinks and the constraints on what they could do. Lifelinks ministry staff interviewed reported that combining funding from the three agencies and allowing disabled people to choose how it is used posed a number of very real challenges for Lifelinks outlined below:

Firstly, it was not entirely clear what funding is included in EGL (see Box 4). Secondly, Lifelinks had to work within its existing systems. As one NASC official reported: *“it’s not that easy for us. We have to work in with our systems”.* The guidelines and processes they as NASC ministry staff had to follow reduced their ability to be flexible. Thirdly, the current funding allocation criteria are based on assessed need – not achievement of a good life. Lifelinks and others questioned whether funding allocated to a person based on a specific need can or should be used for something else? Do they still have that need? (See Box 4). Fourthly, Lifelinks were concerned about cost pressures. EGL is not supposed to cost more but Lifelinks reported there was real pressure on their budget as it was uncapped unlike the Ministries of Social Development and Education. For example, Lifelinks ministry staff interviewed reported that

The implications are much greater for us than for Education or MSD [Ministry of Social Development] where there is a ceiling and a set amount of funding. For example, MSD has a set amount of money for vocational services. The MSD funding hasn’t changed for the last three years. So where does all the pressure come from when these kids need more funding? It comes on Health. It’s not what we’re supposed to be funding. There is real pressure on our budgets.

The pressure came about because support package allocation determined by Lifelinks did not fit well with how EGL participants wanted to use the funding. Within the Lifelinks system, people were assessed as having a particular level of support need but there was a dollar amount attached to that under EGL. Lifelinks reported that this created an incentive for families to focus on the “dollars”. To help with managing the pressure on their budget Lifelinks suggested using a system similar to that used by Lifelinks in the Bay of Plenty.

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| Box 4: Example of a young person in residential care who wants to live elsewhere |
| An EGL staff member gave the following example. A young person in a residential service wants to use his MSD and ORS funding differently. He wants to use it for something other than a day service. For now he wants to stay in his residential service but he’s unlikely to need that long term.  This creates a problem as the services and supports are not designed for what disabled people aspire to. The differences between someone living at home and living in residential care are extreme, but it was the interviewees opinion there are few alternatives in between those two options. It is therefore a huge decision for families to opt for residential services. Families make that decision because they cannot cope at home without additional support.  An interviewee reported that a decision to use the funding disabled people would get for residential services to live in the community raises a number of questions:   * Does the funding for residential services become part of EGL and how much does that involve? Currently Lifelinks pays providers and families do not know how much is paid. * If the money is part of the disabled person’s personal budget, who is the contract for any supports and services provided between? Is it between the provider and the disabled person, or is it between the residential provider and the Ministry of Health? * Where is the duty of care? Who is accountable? What happens if something goes wrong? * If the person wants to live in the community, does that then trigger a reassessment of their need for residential services funding? |

### Under the EGL approach some providers were unclear how they would be paid or how to cost their services

Some providers had taken on people with EGL funding in good faith and were placed in a difficult situation. One provider remarked *“why should it be that we’re waiting to be paid? It shouldn’t be like that. Providers were the last to be considered.”*

Providers were uncertain how to cost their services out, especially where they have been paid as part of a bulk contract. Some of these providers are part of a national organisation which had national contracts. It was unclear how the funding for individuals would be extricated from such contracts and how this would impact on the money for the rest of the service.

## Arrangements for safeguarding disabled people and families needed more work

### Questions arose as to how disabled people would be safeguarded

Several interviewees questioned how disabled people would be protected against abuse, neglect, exploitation and injury. They were unclear how this would happen under EGL. Some providers were concerned that where disabled people remained at home rather than with a provider they could become more isolated and more vulnerable to exploitation. As one provider reported “*Families are not uniformly virtuous. With individualised funding there is a resource that some may exploit to their own end”*.

Alternatively, some interviewees were concerned about families being disadvantaged. A provider was concerned families would feel pressured under EGL to use individualised funding in a way that did not suit them. This provider felt more needed to be done to make families aware of the implications of their choices.

Families need to be made aware of the realities of the choices they make – the consequences of decisions. For example, if you choose that, this means that you can't do this. We worry that these aren't being well articulated and question whether these have been considered. Will we have to say sorry but you can’t do your full-time job anymore because you will be providing this part of the care package? There may be too much focus on the individual – but it may have a huge impact on family. That’s the reality of it and I don’t think it’s been thought about. I’m concerned about the impact on families.

This is a concern that providers have commonly raised in other research (Manthorpe et al. 2011).

### International evidence suggests the focus should be on safeguarding disabled people

The Ontario Ministry of Community and Social Services (2013) argue that safeguards[[21]](#footnote-21) need to be thought about in a way that upholds the principles of person-centred approaches. To this end, Carr (2010) suggests there is a need to change the way risk is understood, managed and negotiated where disabled people have greater choice and control over the supports and services they use. Carr (2010) suggest there needs to be greater focus on risk enablement (e.g. supporting disabled people and their families to define their own risks and to recognise, identify and report abuse, neglect and safeguarding issues as well as incorporating it into on-going reviews of outcomes). She concludes:

A supportive system is one which clearly incorporates self-directed support with safeguarding policy and practice, abuse detection and prevention. Risk enablement and safeguarding training for staff, people using services, carers and families is important (Carr 2010: 51).

This view was supported by Fisher et al. (2010) who concluded that building the capacity[[22]](#footnote-22) of disabled people and their families to manage the money needed to go hand in hand with individualised funding. This is particularly important where people have additional vulnerabilities or restricted capacity.

## Accountability arrangements were unclear

### It was unclear who was accountable for how personal budgets were spent

A range of interviewees stated it was not clear who was accountable for how personal budgets are spent, particularly if there are problems. A concern expressed by many interviewees was that disabled people will be left unsupported in organising their own services and will have to take full responsibility for managing risk alone. For example, questions raised included:

* What happens if a disabled person or their family member misspends the money?
* How will ministry staff know if the money is misspent?
* What happens to the disabled persons supports and services if the money is misspent? For example, if the money allocated to the disabled person for their care at home is used inappropriately, who will pay for the disabled person’s care?

These are important questions to address.

International research suggests the level of monitoring should be comparable with level of risk and resources allocated and should be non-intrusive to avoid reducing creativity and flexibility (Fisher et al. 2010, Robertson et al. 2005). Fisher et al. (2010) suggest there are a range of options available for ensuring funds are used appropriately[[23]](#footnote-23). However, they also suggest that the risk of money being misspent may be low. For example, Western Australia has had direct payments for twenty years and in that time there had been very few cases of funds not being used as intended. *“Consumers have a vested interest in using the money wisely, as they need it to provide disability support for such basic requirements as assistance to get out of bed in the morning”* (Fisher et al. 2010:37).

### Provider accountability arrangements were unclear

Some ministry staff and providers had some questions about how a provider would be held accountable for the services they provided to disabled people. Where the provider is already contracted to a Ministry there is an existing relationship and a means of discussing issues as they arise. However, some ministry staff and providers were unclear what the accountability arrangements were in situations where disabled people chose an organisation not contracted to a Ministry. Questions raised included:

* How would the funders (the Ministries) know or check that the provider was reputable and viable?
* Who is accountable if something goes wrong? Do providers wear the risk or do disabled people?

Some providers interviewed wanted greater clarity about what they would be responsible for delivering.

### Greater clarity was needed on who is responsible for disabled people’s personal information

At the time of the evaluation, the Director reported that sufficient systems for managing shared information were not in place but the team was working with the Ministries to resolve the problem. He was of the view that greater collaboration between government agencies means difficulties around information sharing will need to be resolved. He would like to see *“a system where the families own the information. They’re fine with the sharing of information”.* However, he acknowledged there were risks that needed to be mitigated.

## Navigators were in place but the role was still evolving and poorly understood

Refer to page 56 for more on the navigation role.

## How communities will be developed and government agencies transformed is unclear

It was unclear what community development meant in the context of EGL as this work had not been done. The emphasis in this phase was on getting in place the other aspects of the Demonstration, particularly the navigator role and the funding pathways. The EGL team reported that the next phase of the Demonstration would focus more on community building but little had been done at the time of the evaluation.

The mechanisms for bringing about change in government agencies were unclear. A goal of the Demonstration is to encourage transformation of government agencies to better support disabled people. The evaluation of the Demonstration is to provide evidence for a wider transformation of the system that supports disabled people. Following analysis of documents and interviews with people involved in the design of the Demonstration it was unclear what the boundaries of the system were and what mechanisms were to bring about change in government systems.

# Reasons the implementation was problematic

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| Summary The evaluation identified several reasons the implementation was less than ideal:  Implementation planning could have been better. International evidence suggests that it is crucial that for the implementation or roll-out of initiatives like EGL to be successful they need to have a realistic action plan and clear implementation procedures. This was not the case with the Demonstration. There was a perception that the preparation to implement EGL had been developed in an organic or ad hoc manner.  Implementation was rushed and this placed considerable pressure on ministry staff. The workload to implement the Demonstration was higher than expected, in a short time frame and on top of existing workloads.  The implementation was poorly timed. Going live at the end of the school year is a difficult time for schools and only compounded the problems the Demonstration team had in contacting students. Some students missed out on receiving information on what EGL might mean for them.  Communication needed to be timelier, with the right people and in the right way. Engagement and communication with schools and providers was limited. External factors may also have negatively influenced school and providers engagement. As a consequence schools and providers interviewed had a limited understanding of what the Demonstration would mean in practice for them. |

## Implementation planning could have been better

International evidence suggests that it is crucial that for the implementation or roll-out of initiatives like EGL to be successful they need to have a realistic action plan and clear implementation procedures (see for example, Manthorpe et al. 2011, Kania and Kramer, 2011).

Some ministry staff reported that the design process and the preparation to implement EGL appeared to have been developed in an organic or ad hoc manner. Several interviewees reported that the process would have benefited from better project management. They felt there was a lack of clarity about what was going to happen and when. As two ministry staff reported:

The key lesson is that slow is sometimes better. If we were to do this in the Waikato – then we should take the time to get the people together, figure out what it is your trying to do, work through an implementation design, and have everything in place before go live.

There were some ideas early on but there isn’t any plan saying you have to do this by this date. And there is nothing written that says this will happen if you don’t do it by this date. It’s not clear what happens if things don’t all happen.

While it is not possible to plan for every eventuality, especially when designing something new, the more organic approach created uncertainty for providers, schools and local ministry staff. For example, providers were taking on people who were part of EGL but were unsure how they would be funded under EGL and if they would have enough. As one person involved in the design of the Demonstration reported:

One of the big difficulties with doing things on the hoof is transparency – but in reality they do have limited funds, problems are cropping up and getting ticked off as they go rather than being planned for. This approach isn’t helpful for providers. We can’t say to them everything will be fine when they’ve just had their funding cut. They had two cheques a year and MSD just stopped paying them but didn’t have anything else in place. There is also nothing in place to replace MSD.

## Implementation was rushed

Almost everyone interviewed acknowledged the implementation of EGL was too rushed. The rushed implementation placed considerable pressure on ministry staff. The pressure came on ministry staff for two main reasons.

### Workloads associated with implementing the Demonstration in a short space of time were high

Several interviewees in Christchurch and Wellington reported that the workload associated with preparing to implement the Demonstration was higher than anticipated and this placed considerable pressure on staff. For example, there was urgency from within the Ministry of Education to inform schools of EGL, identify 2013 school leavers, as well as contact parents to gain their permission for EGL to contact them directly. Education ministry staff interviewed described the process as very resource intensive and ‘frantic’. They believed this could have been avoided or at least reduced with more lead in time. For example, at the time the Demonstration went live, a process was not in place for easily identifying school leavers eligible to participate in it, resulting in the need for checking and ringing around schools.

### The work came on top of existing workloads

For many of the ministry staff involved, EGL was not their sole task. For example, the local ministry staff typically had jobs that covered large parts of the South Island. The work required to implement EGL came on top of existing workloads. At a national level, members of the working group[[24]](#footnote-24) also reported that EGL was in addition to their other responsibilities.

Ministry staff reported that the implementation happened to the degree it did due to a lot of people working very hard.

The people down there [in Christchurch] are amazing! It’s only because people have been prepared to scramble and work hard to get it in place that we’ve got as far as we have. You’d hate to put anyone in this position again.

## The implementation was poorly timed

The time of the year was a factor that worked against the early implementation. The Demonstration went live quickly at the end of term four in 2013. The Demonstration team only had four weeks to try and contact all those who could participate in the Demonstration. The fact that the end of the school year is a difficult time for schools only compounded the problems the Demonstration team had in contacting students.

The EGL team went to extraordinary lengths to contact students. For example, one of the meetings to inform young disabled people and their parents about EGL took place on Christmas Eve. A member of the EGL team reported *“We were not well prepared. It was the wrong time of year to do it. We had a meeting with families on Christmas Eve. It was ok – I just wore my Christmas stuff. It was well attended”*.

As a consequence of implementing the Demonstration towards the end of the school year some students missed out on receiving information on what EGL might mean for them. An EGL team member reported that the Demonstration had 40 school leavers they could not engage with at the end of the year because they did not have the time and capacity. He commented that where these young people went to providers it was not clear if that is what they wanted or if it was the default option. For those students they were able to contact, there was little time to work with them and get something in place before the beginning of the following year.

## Communication needed to be more timely, with the right people and in the right way

The evaluation identified several areas where communication and engagement was problematic. The EGL team acknowledged they could have communicated better with schools and providers about what was expected of them.

### Engagement with providers was problematic but may improve

#### Providers interviewed were grappling to varying degrees with the practical application of the principles

For the Demonstration to work well, providers need to operate in line with the EGL principles. While the EGL team report some providers are being innovative and operating more in line with the principles others have some way to go change to from *“providing a service as opposed to being of service”*.

While providers reported being aware of EGL and its overall aims, purpose and principles they were unclear on what the Demonstration was about and what it meant in practice for them. All providers reported that they did not have any real detail about how EGL would work in practice, and would like to know more. As one provider said *“I do not feel I am articulate about EGL... I would like to see it more concrete.’*

#### Providers reported they had had limited engagement with the Demonstration team

One of the key mechanisms in the Demonstration to bring about this change is the EGL team engaging with providers. However, at the time of interviews, the main contact with EGL had been at a meeting for providers as well as through the EGL newsletter. All providers reported that they would have liked more contact with the EGL team to better understand what was expected of them.

Two providers in particular reported that the lack of engagement and collaboration with providers left them feeling excluded from the process. They questioned the motives behind EGL with one provider saying: *‘you think, is there an anti-provider bias? It’s not a healthy situation for the sector that really needs to be collaborative. Flexibility has been done to us, not with us.’* Another provider agreed reflecting that for them, with the introduction of EGL the sector was becoming more competitive and disparate. They felt the provider voice was not being listened to and they were not being engaged seriously.

Reasons for the lack of engagement with providers appear to be:

* *The rushed implementation.* When the Demonstration began there had been little time to engage with providers. The focus was on engaging with disabled people and their families.
* *The Manager, Provider Relationships and Funding, was only appointed in November 2013.* Until this point the EGL team did not have a dedicated resource to engage with providers. However, with his appointment, the EGL team and providers expected the relationship between the Demonstration and providers would improve. The team were planning to talk to providers about practice in line with the principles and were putting together tools and resources to assist providers.

### Engagement and communication with schools was limited

There was also limited engagement with schools. Despite the fact the first cohort for the Demonstration was school leavers the two schools interviewed reported having had little direct contact from the EGL team; however, what interactions they did have they felt positive about. One school had taken a more proactive approach and been in contact with EGL directly. For the other school interviewed, their engagement with EGL at the time of their interview was mostly via the Ministry of Education. Engagement and communication with schools was problematic for several reasons outlined below.

#### No coherent plan of engagement

Ministry staff and the EGL team confirmed there was no coherent or deliberate strategy for engaging with schools, and at the time the Demonstration went live, there was not a person in place whose role it was to lead this engagement. The EGL team interaction with schools was split between two roles – the Manager of Families and Community Development and the Manager of Provider Relationships and Personalised Funding.

#### Barriers to sharing information meant the Demonstration team struggled to contact school leavers before the end of 2013

As part of putting disabled people first, the Demonstration team wanted to provide disabled people thinking of leaving school and their families with the information first rather than going through the schools. However, for privacy reasons the Ministry of Education and schools were not able to give the Demonstration team the names of the students without first gaining their consent.

#### The purpose of some meetings was not clear to schools

A series of information meetings for each of the groups involved in EGL were held in December 2013. However, the intention of these meetings, and who should attend was unclear to schools and families. This proved to be problematic as some families had invited Ministry special education staff and teachers to attend the school leavers and family meeting as their support people. However, as this was not the intended purpose of the meetings, all non-family members were asked to leave. This caused upset and distress for the family members who had wanted the support people there to attend. Again, if the rationale for the approach along with the purpose and intent of the meetings had been clearly communicated such confusion and upset may have been avoided.

#### Schools had a lot of unanswered questions

As one ministry staff member said, at the time EGL was being communicated to schools, information was particularly ‘fluffy’, and they were asked some specific questions by schools, which at the time they didn’t have the answers to. Of most concern to schools was a lack of clarity about the role of the navigator, and how they would work alongside schools in the transition process (for more on navigation see page 56).

#### The practice of talking to groups separately created uncertainty and frustration

The EGL team providing disabled people and their families with the information directly rather than going through the schools upset some schools and ministry staff. They reported that when families came to them with questions they did not have the information to answer them.

## External factors may have influenced engagement with EGL

### Past experience with other initiatives and change associated with the Canterbury earthquakes may have influenced school engagement

There were several changes external to the Demonstration that impacted on the way the schools interviewed saw EGL. For example, there was uncertainty about the absorption of “Going Places” by EGL. The pilot of the Going Places programme was running in parallel to the Demonstration when in 2013 it was signalled it would end in June 2014. An agreement was made between the service provider and the Demonstration to collaborate for the remainder of the contract at which point it would be absorbed into the Demonstration. For one of the schools interviewed, this was particularly frustrating, as in their opinion Going Places was beginning to work well. Ministry staff also mentioned the impact of the discontinuation of Going Places, stating that the difference between EGL and Going Places for some schools and parents was potentially confusing and unclear. The fact that some Going Places staff became temporary EGL navigators to provide some consistency for individuals they were already working with under Going Places exacerbated the sense of confusion.

In addition, prior to Going Places ending, the funding for the lead school transition service, an initiative also being piloted in Christchurch, had been discontinued. Some providers had been involved in an earlier pilot of a transition service and when it was just getting going the funding was stopped with little communication to those involved. There were fears expressed by providers that EGL also may not last. There was also frustration that the experience gained from being part of other developments and learning from these was not recognised.

Moreover, Christchurch schools are also undergoing the Greater Christchurch Renewal Programme which has meant more potential change for schools. Given the amount of change in the transition area for schools, one ministry staff member reported that some schools are sceptical saying *‘another initiative – will see how long that lasts.’*

### Implementation of the Demonstration has occurred in a context where providers were already under considerable pressure

Financial pressure on providers came from a range of sources. For example, there were reports the sector had been underfunded for years. Providers of vocational services and some ministry staff reported years of underfunding prior to EGL. This appeared to have put a lot of pressure on providers and their ability to retain staff, keep up with rents and provide a quality service.

Providers reported that some funding criteria had had changed reducing the amount providers of community activities received. Eligibility criteria for the transition resource funding package from the Ministry of Social Development for people transitioning from school was changed which meant it was no longer available to some providers. The funding changed to being only available for people leaving school who chose to go on to further education or employment. Moreover, the Ministry of Health had recently withdrawn funding for new people who require vocational support. This has added to the pressure providers are under at a time of financial constraint, and potential change in service delivery with EGL. Some ministry staff and some in the Demonstration team were concerned that in this context, the EGL Demonstration may be seen as the last straw for some providers. Unlike most schools, providers rely heavily on disability-focused funding from the Ministries.

# Navigation role is pivotal but could be improved

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| Summary: At the time of the evaluation eight EGL navigators were in place and working with 35 EGL participants. There were also two Going Places navigators employed by NZ Care who were working with 17 EGL participants in February 2014.  The navigator role was seen as pivotal to making EGL work. Navigators saw themselves as allies of disabled people who assisted them to develop their vision of a good life and how to achieve it. Families valued the role navigators had played in assisting them to work towards their vision of a good life. Person-centred practices enabled navigators to work well with disabled people and their families.  The evaluation identified some improvements that could be made to the navigator role and understanding of it:  Navigators want greater clarity on the boundaries of their role and more guidance on the planning process.  Schools and providers need a better understanding of the role of the navigator.  The long-term future and sustainability of the navigator role is uncertain. |

In the design of EGL, the intention was that navigators would facilitate and support disabled people and their families to develop their vision of a good life and a plan for how they might achieve it. As the focus for Phase 1 has been on young disabled people, navigation at this stage has been linked to transitioning out of school.

## Eight Enabling Good Lives navigators were in place

At the time of the evaluation eight navigators were working with 35 young people. The other 17 young people were part of the Going Places initiative which was being merged into EGL. Two people from Going Places were invited to take on board the broader EGL navigator role for the students they were working with already. This recognised the existing relationship that they had with school leavers and extended it to include a wider view of what is possible for these young people for the future. They continued to work with these students up until the end of June 2014. During this time they continued to be employed by NZ Care[[25]](#footnote-25) but in relation to their work with young disabled people and their family members, they also reported to the Manager – Families and Community Development, EGL.

## The navigator role was seen as pivotal to making EGL work

There was a widespread view that the navigators were pivotal to making EGL work. The navigators are seen as the key person assisting disabled people to have their needs met and achieve their vision of a good life.

### Navigators described themselves as allies of disabled people

Navigators, the EGL team and the Local Advisory Group referred to the navigators as “an ally first and foremost” of the disabled person and then their family. The navigators identified two key aspects of their role.

The first aspect was assisting disabled people to develop a vision of what a good life might entail. A key part of this process was broadening and lifting people’s expectations of what a good life involved. One navigator described it as encouraging disabled people and their families to *“believe in better”.*

The second aspect was assisting disabled people with the practicalities of achieving their vision of good life. The navigators saw themselves as enabling disabled people and their families to do as much as possible themselves to achieve their vision. However, some disabled people and their families needed more assistance than others. Disabled people and families who were confident and capable of putting in place the steps needed to achieve their vision of a good life needed less assistance than those who were less confident and capable. As one navigator said: *“I try not to do any more for any family than they need but what I do for one family might look quite different from what I do for another”.* Nevertheless, the navigators expected their involvement with each disabled person and their family would lessen over time as their confidence and capability to achieve their vision grew.

### Person-centred practices enabled navigators to work well with disabled people and their families

How the navigators worked with disabled people and their families was an important aspect of the planning process. Navigators and families particularly valued the following practices.

### Building trust and empowering people to act is crucial

Navigators and the EGL team reported that building trusting relationships with families is critical. Trust building can take time. Navigators have to demonstrate they mean what they say. As one parent said *“Everything [the navigator] has said, she has done, so that’s been huge.”* To build trust the navigators need to have the ability to assist families and disabled people to overcome past disappointments in support provision. For example, a navigator said *“a big part of my job is building up trust. Many families have been let down in the past and are easily deflated by rejections”.*

### Sorting out crises before engaging in planning

A navigator reported that it is difficult for disabled people and their families to think about and plan for the future when they are preoccupied by immediate crises. The navigator said in these situations her priority is to help them respond to the crisis before starting to talk about what a good life might look like. She gave the example of a family who were extremely unhappy with the respite care provider their disabled child was using. They could not see an alternative. The navigator assisted them to use the funding that would have gone to the respite care provider to employ support staff of their choice in their own home. Once the respite care problem was resolved they were able to engage in planning for the longer term.

### Including the disabled person’s views is central to the planning process

Navigators stressed the importance of ensuring the voice of the disabled person was heard and was central in the planning process. While parents and caregivers usually want what is best for their disabled family member, it was not always the same as what the disabled person wanted. Family members were not always aware that their disabled family member held different views to themselves. For example, one family member reported that through the planning process with the navigator she discovered that what her son wanted to do with his life was different to how she saw it. She said: *“it has opened my mind. I would not have thought of it and parents aren’t always right”*.

However, obtaining the views of the disabled person was not always easy to achieve. Some disabled people were reluctant to express their thoughts in front of their parent(s). Navigators reported that in these instances they had to look for ways to help disabled people get their ideas out. This included meeting with young people separately from their parents. In other cases disabled people had difficulty communicating their ideas. Where it was appropriate navigators used assistive technologies (e.g. talking mats) to help disabled people express their ideas. However, such technologies were not helpful if the disabled person did not have the cognitive ability to use them. In these cases the navigators relied on the parents or caregivers to voice what the disabled person liked or disliked.

### Seeing the disabled person is part of a family with needs as well

The navigators and families were clear that the views of disabled people should be central in the planning process. However, navigators reported that it was also important to understand that disabled people are part of a family. The family have important insights into what the disabled person wants, and the needs of the family members should be taken into account too. A navigator gave the example of a young person who said that he didn’t like horse riding. Later the navigator talked to the mother who provided some context. She said he normally loved horse riding but the previous week he’d seen his cousin get bitten by a horse and that had put him off for the moment.

Sometimes the needs of the disabled person and the family member appeared to be in conflict. When this happened, the navigators worked to create *“win win”* solutions to problems. For example, a navigator gave the example of a family where the young person was very vocal about not wanting to be placed in respite care but the mother was exhausted and needed a break. The navigator worked with the family to find out what they each wanted and how that might be accommodated. The solution in the end was to find a different respite care provider where the young person was happy.

### Being open to new ideas and ways of operating

The Manager of Families and Communities and the navigators reported that they were sharing ideas on how the navigation role could best work. They reported this was important as the navigation role was new and still developing. More experienced navigators were sharing their experience with newer navigators.

### The planning process is iterative but valued

#### Plans were not formal documents and the process was iterative and inclusive

Planning was described by those involved as an iterative and inclusive process (see Box 5). The navigators stressed the importance of the disabled person and their families owning the plan. Both navigators interviewed explained the plans were a series of notes outlining the outcome of meetings with disabled people and their families. They detailed what was discussed and who was going to do what. The navigators usually wrote up the notes and families were given a copy and encouraged to make changes if needed. This approach appears to foster disabled people and families owning the plans.

The navigators reported that there is no standard way of undertaking and recording the outcome of the planning they did with disabled people and their families. For example, one navigator said: *“I have developed my own system of writing up notes, case notes, which go to the family to check. … At the moment a plan is a series of notes, there isn't a format for a plan”*.

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| Box 5: Iterative planning process |
| A mother and her disabled son worked on the plan together. *“It changed lots but came right”.* The navigator wrote what her son wanted to do – a job and a hobby and gave them information about what he could do to achieve his goal. The navigator said she likes to get the families to do as much for themselves as they can.  The mother and son checked the information and checked some things out for themselves. They looked at training courses. *“It’s just brilliant if you can get into something but it’s ok if you can’t as well”*. The mother reported that nothing like this has ever been written into a plan before. She said that previously the goals for her son had been much lower level e.g. going to the toilet by himself or passing an NCEA examination. He said “*Wipe my bottom by myself – excuse me!”* His mother added these are not real goals. For example, it didn’t matter if he passed his exam as he could do it again the next year.  The mother and son don’t want to change anything in the plan but like that they can change it if they want*. “If* [he] *doesn’t want to do it that’s ok as its* [his] *decision”.* The mother reported her son is excited seeing the future he can have. He described it as *“super exciting”*. |

#### Families valued the navigators role

The disabled people and their families interviewed reported they were satisfied with this approach to planning. Families reported the process gave them time to think through what a good life might entail and how they might get there.

Some family members interviewed found this process challenging at times but valuable nonetheless. One family member reported that the navigator had empowered them by allowing them to “dream again” and encouraging them to “think outside the square”. Another family member reported that initially it was challenging to think of a life for her disabled son other than the one she had experienced but she valued the navigator for encouraging her to think about his future differently.

## Navigation role and how it could be improved

### Navigators wanted greater clarity on the boundaries of their role

The navigators interviewed reported that when the navigation role was established how it was to operate in practice was not entirely clear. The practice has evolved as more navigators have come on board and they have interacted with more disabled people and their families. However, the navigators expressed a need for greater clarity on the boundaries between the role of the navigator and others working with the disabled person and their family. For example, one navigator reported some families were straightforward to work with but he was less certain about what to do when

there are lots of different professionals involved. I have a family which is already working with two Educational psychologists …, a high and complex needs coordinator, someone from the Ministry of Education’s head office, and they’ve had Teacher's Aides involved. And then you’re adding a navigator on top of this – it is quite tricky, and hard to know where as a navigator to add value.

The navigators interviewed were not suggesting that the navigator role becomes prescriptive. They both valued the flexibility the role gave them to respond to the variability of what disabled people and their families wanted and needed. They added that as time went on they expected the role to become clearer.

### More guidance on planning would be welcomed by navigators

While navigators were comfortable with their approach to planning they reported some concern that they had each developed their own approach to planning and recording the outcomes in the absence of more formal guidelines. As one navigator said *“It would be good to have some guidelines and a common way of doing things across navigators. At the moment a lot is left to our own judgement”.* They were also concerned their plans were not in a form others could follow if they were no longer involved. The EGL team reported that they were working to put in place more guidance in this area.

### Better communication with schools and providers about the role of the navigator was needed

Providers and schools needed a better understanding of the role of the navigator. Most interviewees from the providers and schools had had little involvement with the EGL navigators. They were unclear how the navigators would operate and what the existence of the navigators meant for their organisations.

### Schools did not know how the navigator would work with them

Neither of the schools visited had met a navigator at the time of the evaluation. They were apprehensive about how the navigators would be involved with disabled students at their schools. Interviewees from the schools visited felt they provided very good support to the disabled students who attended their schools. They felt strongly that the navigators should complement the work they had done with students and were worried this would not be the case. For example, an interviewee from a special school said they were initially worried that EGL would take over what the school had been doing and possibly undo what they had worked carefully with the student and family to develop. However, this concern had faded.

We were reassured by [Demonstration official] that where we have things in place at the level we have the navigators would use the lightest touch and they would work alongside us and – this is my expression – not throw the baby out with the bath water. (School)

The interviewee from the other school had had minimal information about EGL and the navigators. She stressed the importance of navigators having the right set of skills and was concerned this would not be the case.

### Education officials were concerned about how schools would interpret the navigator role

Education officials were concerned that in the absence of clear information on the navigation role schools would place their own interpreation on the role. The Ministry of Education was working with schools to improve transition from school and they were concerned that some schools may see the existence of navigators as a sign they do not have to be as involved in transition planning.

### Providers were unclear about the role of navigators and how it would impact on them

All three providers expressed similar concerns to schools about the navigator role. For some, the navigator role was viewed as a step backwards. For example, one provider believed the navigator role was actually taking choice away from individuals about where they go to for support around transition and that for them this undermined one of the principles of EGL. Providers also reported that they spent considerable time getting to know the disabled people and families they were involved with. They expressed scepticism about the time available to navigators to really get to know someone and address their needs and develop their plans. For example, one provider said:

We wonder about how much time navigators can spend with individuals – they would need to spend up to a year getting to know them and their family to set up a good programme. We would work for the school, families and individuals for a year or more to set up a programme.

Concern was also raised around the knowledge of navigators and the importance of them understanding providers, contracts and the sector generally.

### There was uncertainty about the role of navigators over the life course

Providers and schools interviewed were unclear how or if the navigators would be involved with disabled people over the life course. However, they commonly reported that navigators should be involved with disabled people over the life course because people’s needs change over time (e.g. when parents are no longer able to provide support or care).

### There was some criticism of the part-time status of the navigators

Some providers and schools were critical of the navigator’s part-time status. They were concerned that it would mean the best people would not be attracted to the role and it would be difficult to retain them because people preferred full-time roles. They also expressed concern that the navigators would not have sufficient time to work with disabled people.

The EGL team and the Local Advisory Group were clear that navigation should be a part-time role. The rationale for this was that having a range of navigators allowed the team to match disabled people to navigators based on geographic area and the disabled persons interests. There was a recognition that the part-time status of the navigators may change as the Demonstration develops. The hours of the navigators could grow if the capacity for navigation grows. There was also concern that making the position full-time sent the message that the navigator was yet another professional involved in the lives of disabled people.

### The long-term future of the navigator role was uncertain

A common theme across the interviews was a concern about the future of the navigator role. Providers, schools, families, EGL staff and ministry staff interviewed were unclear what the future of the navigators was post the Demonstration. In particular, they raised concerns about whether the navigator role would exist beyond the Demonstration and how it would be funded.For example, a navigator reported *“After three years there is no budget for the navigator role. Families ask me how long I’m going to be around. I tell them I don’t know.”*

Some providers and ministry staff expressed concern about the ability of navigators to work intensively with disabled people if their case load expanded significantly. One ministry staff member said that caseloads were:

something to think about for the future of EGL. They may get good outcomes with caseloads at these low levels but can we continue to resource it at those levels? Can it be resourced enough to work?

# Leadership and collaboration to bring about change

|  |
| --- |
| Summary Leadership of the Demonstration is important but not straightforward as several groups and individuals had leadership roles. The roles and interrelationships between these groups and individuals could have been clearer.  Bringing about the changes the Demonstration is seeking requires a collaborative effort. Barriers to collaboration included not having a shared understanding of the Demonstration and what it was trying to achieve, difficult team dynamics, not understanding the perspective of others working in the design and implementation, not being clear about how partnerships should operate and what people’s roles and responsibilities are, and not communicating in a way that engages stakeholders. Enablers of collaboration included having a shared belief in the principles, opportunities to come together, good communication between those working together, time to develop connections and trust, and examples of the benefits of collaboration.  Suggested improvements to leadership and collaboration:   * Addressing challenges facing the Director: The Director role was challenging especially holding all the components of the Demonstration together, and trying to quickly bring about change for disabled people while also working with large and complex government agencies. * Consider whether there are gaps in who is on the Local Advisory Group (e.g. representation from those with intellectual disabilities; local ministry staff). * Clarifying leadership within the Ministries. It was not always clear to ministry staff what their roles and responsibilities were in designing and implementing the Demonstration. Several ministry staff reported that there did not appear to be a formal plan of action. Not all the agencies have been equally represented all the time during the design and implementation of EGL. Some ministry staff reported that their agencies needed to take greater ownership of their role in the process of developing the Demonstration. * Building on the enablers of collaboration and working to address the barriers. |

## Leadership is important but not straightforward

International research suggests that where organisations are collaborating to achieve social impacts leadership is critical (Kania and Kramer, 2011; Manthorpe et al. 2011). The leadership of the EGL Demonstration is not straightforward. There are several involved in leading the Demonstration (see Figure 2, earlier). Interviews with those involved in the design and implementation of EGL revealed there were some considerable challenges associated with this way of leading the Demonstration.

### The Director’s role was challenging but there were sources of support

The Director was appointed to lead the implementation of the Demonstration in Christchurch. The Director described his role as:

To be true to the principles of EGL, and take the essence of what is being asked for by the Local Advisory Group and to try and make sure the participating Ministries understand what that means locally and nationally. I work with the ministry staff to try and take the current system and in the first instance re-adjust it and then redesign it so people in the cohort of EGL can have as easy a life as possible.

Several aspects of the Directors role were identified as particularly challenging.

#### Understanding the boundaries of the role took time

Several interviewees commented that it was not clear initially what the boundaries of the Director’s role were (e.g. with the various groups involved and what he had authority over). One ministry staff member commented that it would be better if the Director had responsibility for the whole disability sector in Christchurch because *‘it’s confusing at the moment trying to do stuff across three agencies”*.

#### Holding all the components of the Demonstration together was difficult

The Director was familiar with EGL and had previously been involved introducing a person-centred approach in the UK. However, he reported that in the Demonstration *“holding and linking all the elements of Enabling Good Lives together”* was particularly challenging. He wanted to create a *“win-win”* situation for all the groups involved – disabled people and families, schools, providers, government agencies and the Local Advisory Group. He wants everyone to be part of the solution. *“We’re trying to keep everyone involved. My role is to keep everyone there”.* International research suggests this is difficult as views about increased choice and control in social services can become polarised (Glasby, 2014).

#### Difficult bringing about change while working with large and complex government agencies

The size and complexity of the Ministries made them difficult to navigate and bring about change for disabled people. The Director reported that the large government agencies were made up of so many parts that it was often difficult to know what was happening. He said of the Ministry of Social Development, for example:

It’s huge, 10,000 people. So even within MSD there are initiatives going on that are directly relevant to Enabling Good Lives that I don’t know about. I stumble across. That feels uncomfortable.

Moreover, the level of bureaucracy within government agencies (e.g. rules about how and when people are paid, hired, what can be done and when) made it difficult to *“be quick and flexible”* according to the Director. Transforming large organisations, such as the Ministries, so that the EGL approach was a central focus is likely to be an on-going challenge. International research indicates that public sector organisations tend to be hierarchical with an emphasis on control and stability over innovation and risk-taking (Drumm, 2012). Internationally systems barriers have often impeded the successful implementation of individualised funding (Lord and Hutchison, 2008). Good working relationships and trust are essential across agencies to move forward and change culture and processes (Personal Health Budgets Delivery Team, 2012).

#### Despite the challenges there were sources of support

The Director reported that the Local Advisory Group were supportive and held him to account – *“they feel like my bosses”.* He felt supported and trusted by them.

The Director reported that having a committed and competent EGL team in Christchurch was supported his role. The Director felt that the management set up of the EGL team (e.g. the Director, a Manager of Families and Community Development, and a Manager of Provider Relationships and Personalised Funding) worked very well. He felt the two managers could fully support their constituents and as Director he could arbitrate and maintain oversight. It enabled him to manage the natural tensions. *“We have the right fit structurally for EGL and great people on board. They’re professional people working constructively”.*

The drive from senior ministry staff has been important according to the Director. He particularly valued their commitment to the Demonstration, the space they had given him to try out different ideas, and that he could escalate problems to them where necessary. *“They’re strong leaders. It could have become a competition about who was leading but it hasn’t”*.

### Questions were raised about the representativeness of the Local Advisory Group

Some interviewees questioned the representativeness of the Local Advisory Group. One suggestion was to include representation for those with an intellectual disability as they are a large group within the disability population in Christchurch.

Another interviewee questioned whether it may be better to have people who represent a group of people rather than individuals as they have somewhere to go to debate issues and have a mandate.

Local ministry staff are not represented on the Local Advisory Group. They were not asking to be on the group but they reported that closer links with the group would be useful. They felt it would improve communication and understanding between themselves and the Local Advisory Group.

### Within the Ministries leadership was at times unclear to ministry staff

The Ministries were required to work together on the design and implementation of EGL. This process was organic and ministry staff talked about being on the working group *“to get things done”*. However there were a number of challenges and these are outlined below:

#### The course of action and who was doing what were not always clear

It was not always clear to ministry staff what their roles and responsibilities were in designing and implementing the Demonstration. The roles of the working group were not clearly defined but have evolved with the Demonstration. The lack of role clarity was unsettling for ministry staff. For example, a ministry staff member said:

It’s not clear whose role is what, especially between the Local Advisory Group and the national working group. It’s not clear how issues should be resolved. It works often because of relationships rather than anything else.

Several ministry staff reported that there did not appear to be a formal plan of action (see earlier: Implementation planning could have been better, page 50). As one official reported: *“There is no coherent work programme for EGL – that’s not just for the Wellington working group but also for the local one. Without it it’s hard to know what you’re working towards”*.

#### Agency representation varied

Not all the agencies have been equally represented all the time during the design and implementation of EGL. Some ministry staff reported that their agencies needed to take greater ownership of their role in the process of developing the Demonstration.

#### Agencies needed to take greater ownership of their role in developing the Demonstration

Some ministry staff interviewed reported that there needed to be greater visibility and understanding of EGL within organisations. Those working in the design and implementation of EGL had bought into the principles of EGL but there was concern this was not the case beyond this group. If the intention was for EGL to become business as usual they felt wider buy-in from the ministries was needed.

## Collaboration is necessary to bring about change

Under EGL collaboration between agencies, providers, families and disabled people was seen as a means of bringing about improved outcomes for disabled people[[26]](#footnote-26). There was some overlap between the factors that enable collaboration and those that hinder it.

### There were barriers to collaboration

Barriers to collaboration were identified in the evaluation and these are outlined below.

#### Not having a shared understanding of the Demonstration’s purpose

Cameron et al. (2012:11) argue that “without a shared understanding of aims and objectives, partnerships may struggle to develop a sense of purpose at the operational level”. In the case of EGL maintaining a shared understanding of what the Demonstration is trying to achieve has been a challenge, especially as new people have become involved. For example, the ministry staff involved in the design and implementation of EGL had changed over time. There was concern that those who came later to the initiative did not have the same understanding of the intent of the Demonstration as those who had been involved from the outset. As one ministry staff member said:

The Local Advisory Group has been there all the way through but there have been shifts in the ministry staff. I wonder if it was a bit like one of those whispering games – if we spoke it out loud now would we hear the same thing that the ministry staff said in the beginning. And given that this is a Cabinet-mandated process if there is any distortion of message that’s a fairly serious thing. How have we safeguarded decisions so that everyone knows what they are? New people have come in as the role has changed but how well have we passed on the messages. Is the story about EGL consistent?

This may have been resolved by better communication. Kania and Kramer (2011) stress the importance of continuous communication amongst groups striving to achieve a collective impact. It is central to building trust between the groups but is challenging and takes time.

#### Difficult team dynamics

Within any group there will at times be difficult dynamics that undermine effectiveness. Some interviewees reported that the national ministry staff working group could function better if these dynamics improved. They felt that within the working group there was a hierarchy of personalities and opinions and some views were seen as more valuable than others.

#### Not understanding the perspective of those collaborating

Lifelinks, for example, reported that they felt their views were taken on board in discussions with the EGL team in Christchurch. However, they also indicated they believed the process was made more difficult because the Local Advisory Group did not fully understand Lifelinks processes.

#### Lack of clarity about how partnerships should operate and what people’s roles and responsibilities are

Ministry staff interviewed were clear about their role within their organisation and who they reported to. However, they commonly reported they were less clear on their role in the Demonstration and what the boundaries were with other organisations such as the EGL team. For example, a local ministry staff member said at the local level all three government agencies *“think similarly as we work for government and know the boundaries – but EGL steps outside these boundaries to challenge what’s happened in the past”*. Similar concerns were expressed at the national working group level.

#### Not communicating in a way that engages stakeholders

The strategy of not involving local ministry staff in discussions with providers was not seen as collaborative by some. Some operational staff felt they were placed in a difficult position in terms of being able to address provider questions and being uncertain what their role was with providers and the Demonstration.

### There were enablers of collaboration

There were enablers of collaboration. These are outlined below.

#### Having a shared goal assists collaboration

Those working on the design and implementation of the Demonstration expressed a shared belief in the EGL principles (see page 36).

#### Collaborative working relationships required good communication

Manawanui In Charge reported that that they had established good working relationship with Lifelinks and the EGL team. This was put down to good communication – picking up the phone and talking to someone before something became an issue. In another example, Lifelinks reported that they had had some difficult conversations as part of their involvement with EGL but they still felt they were able to put their point of view across. They reported that *“at the end of day that relationship is still there – which is great”*.

#### Having time and opportunities to develop connections and trust is important

Having opportunities to come together assists collaboration. Regular meetings provided an opportunity to develop relationships necessary to then develop the policies and processes related to the Demonstration. The meetings also provided a setting to resolve problems and review practice. For example, one ministry staff member reported that:

Over time, and initially not without some pain, we have developed an ability to have robust discussions with ourselves and disagree and work things through. You can’t be a good cross agency group and put forward your best ideas without being able to do this. It’s important for being innovative.

The Director reported that the Local Advisory Group was a good example of how a group could operate when the connections were there. He said *“the Local Advisory* Group *is really gelling and it’s not a homogenous group. It’s a diverse group. Providers and parents have come from very different positions. It’s a model of good practice”.* The Director reported that the relationship between ministry staff and the Local Advisory Group was evolving, trust was building and he was hopeful about the process.

#### Seeing the benefits of collaboration encouraged more collaboration

Those involved in designing and implementing the Demonstration saw the benefits of organisations collaborating. A common theme was that the Demonstration drew organisations together and that it was beneficial. At the national level, ministry staff also saw the value of collaborating. Some mentioned that increased collaboration had had additional benefits outside of EGL. For example, one ministry staff member reported that coming together for EGL had improved working relationships with the other agencies to the point where they were now picking up the phone about matters not related to the Demonstration. They now had a mechanism (e.g. weekly meetings) to communicate. Without this they tended not to communicate because they were so busy.

The local ministry staff reported that at the local level the Ministries of Education and Social Development and Lifelinks worked very well together. In their view *“EGL has pulled the ministries together”* and that historically they had not worked closely together. This meant better sharing of information and ideas.

# Where to next?

There have been some early positive outcomes despite a problematic implementation.

The evaluation identified aspects of the following that could be improved – design process, implementation, navigation function and leadership and collaboration.

### Suggested improvements to the design process

* *Developing greater clarity about what co-design is in the context of the EGL Demonstration.* There were different understandings of what co-design was. Sharing of information in a way that enables equal participation was a challenge. The concept of co-design implies shared decision-making responsibilities but this was not the case in the Demonstration. Some reported more could be done to take advantage of learnings from elsewhere in the design process.
* *Having the right people involved in the design process.* There were some questions about whether the right people were at the table. The design and implementation would have benefited from the earlier involvement of operational people from the Ministries.
* *Allowing sufficient time to develop the components of the Demonstration.* Not doing this has meant the changes so far have tinkered with the existing system rather than transforming it. For example, the rush to implement the Demonstration meant there was a reliance on less than ideal temporary solutions for disabled people to receive and manage their allocation of pooled funding.
* *Developing a shared understanding of the design.* There was not a shared understanding of what the Demonstration design entailed. Some saw the design as something fluid that evolved over time whereas others saw it as something that was fixed and only changed after the three years of evaluation.

### Suggested improvements to the implementation

* Having the key components designed before implementation.
* *Having a realistic action plan and clear implementation procedures.* This was not the case with the Demonstration. There was a perception that the preparation to implement EGL had been developed in an organic or ad hoc manner.
* *Having sufficient time to implement the Demonstration.* Implementation was rushed and placed considerable pressure on ministry staff. The workload to implement the Demonstration was higher than expected, in a short time frame and on top of existing workloads.
* *Implementing the Demonstration at the right time*. The implementation was poorly timed. Going live at the end of the school year is a difficult time for schools – only compounding the problems the Demonstration team had in contacting students. Some students missed out on receiving information on what EGL might mean for them.
* *Timelier communication with the right people and in the right way.* For example, engagement with schools and providers was limited and unclear. As a consequence they had a limited understanding of what the Demonstration would mean in practice for them. Communication about the Demonstration within the Ministries could be improved. Ministry staff interviewed reported that there needed to be greater visibility and understanding of EGL within their organisations.

### Suggested improvements to the navigation function

Navigators are pivotal to the Demonstration but their role is still evolving. The evaluation identified some improvements that could be made to the navigation role and all parties understanding of it. Navigators wanted greater clarity on the boundaries of their role and more guidance on the planning process. Schools and providers need a better understanding of the role of the navigator. The long-term future and sustainability of the navigator role is uncertain. This needs to be clarified.

### Suggested improvements to leadership and collaboration

* *Addressing challenges facing the Director*. The Director role was challenging especially holding all the components of the Demonstration together, and trying to quickly bring about change for disabled people while also working with large and complex government agencies. However, the Director also added he was assisted in the role by a supportive Local Advisory Group, a committed and competent EGL team in Christchurch and the drive from senior ministry staff in Wellington.
* *Consider whether there are gaps in who is on the Local Advisory Group had a leadership* (e.g. representation from those with intellectual disabilities; local ministry staff).
* *Clarifying leadership roles within the Ministries*. It was not always clear to ministry staff what their roles and responsibilities were in designing and implementing the Demonstration. Several ministry staff reported that there did not appear to be a formal plan of action. Not all the agencies have been equally represented all the time during the design and implementation of EGL. Some ministry staff reported that their agencies needed to take greater ownership of their role in the process of developing the Demonstration.
* *Building on the enablers of collaboration and working to address the barriers*. Collaboration between the Local Advisory Group, offcials, schools and providers is a necessary part of designing and implementing the Demonstration.

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# Appendix 1: Methodology

### Overall design

This is a multi-phase concurrent mixed method design. The rationale for using this design was:

* *Triangulation of findings allows them to be corroborated.* Triangulation refers to the view that quantitative and qualitative research might be combined to triangulate findings in order that they may be mutually corroborated.
* *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 EGL than is possible using a single method within the timeframe and resources available. Quantitative and qualitative research can each answer different research questions.
* The methods could be applied concurrently*[[27]](#footnote-27)* but separately.

Methods have been selected based on their capacity to answer evaluation objectives and research questions.

This evaluation approach allowed 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 will evolve in Christchurch over the next three years. A mixed method evaluation can support this evolution by providing timely and actionable data about how a complex system is responding to the Demonstration.

### Phase one design

Phase one relied heavily on interviews with a broad cross section of people involved in the design and implementation of the Demonstration in Christchurch along with a small number of disabled people and their families.

The participants in the evaluation included:

* four disabled people from three families (All received Very High Needs ORS funding)
* four family members from three families
* two navigators
* five representatives from three vocational providers
* four representatives from two schools (a mainstream and a special school)
* five members of the national EGL working group
* a group interview with five representatives of the Local Advisory Group. Those who could not attend this interview were given the opportunity to provide written feedback. One person did this.
* key members of the EGL team in Christchurch (Demonstration Director, Manager of Provider Relationships and Personalised Funding, Manager of Families and Community Development)
* three local ministry staff from the Ministries of Education and Social Development
* two representatives from Lifelinks (also referred to as the Needs Assessment and Service Coordination Service (NASC))
* one representative from Manawanui In Charge (MIC).

There were 25 semi-structured interviews but some of the interviews were with two people from the same organisation or family.

#### Limitations

For this phase of the evaluation there was a heavy reliance on in-depth interviews. However, where possible this was supplemented with analysis of administrative data.

We had intended to analyse disabled people’s plans but this was not possible as the plans were not formal documents.

The disabled people and their families interviewed were early adopters of the EGL approach and are likely different from those not involved in EGL or those who will come later to the Demonstration.

This phase of the evaluation focused on the implementation of EGL and does not address questions of impact e.g. did the approach make a difference to disabled people‘s outcomes.

### Analysis was guided by the principles of EGL and the intervention logic

Thematic analysis was used to identify, analyse, and report patterns (themes) within the data. The analysis sought to report the experiences, meanings and the reality of participants with regard to the early implementation of the Demonstration.

The analysis of outcomes for disabled people was accomplished by adopting an organising framework for analysis. The EGL Principles (outlined below) were used as an organising framework along with the intervention logic (refer to Figure 2: EGL intervention logic).

|  |  |
| --- | --- |
| Principles | What will this look like? |
| Self determination | This means disabled people are in control of their lives |
| Beginning early | This means:  investing early in families and whānau  supporting families and whānau to be aspirational for their disabled child;  building community and natural supports;  supporting disabled children to become independent, |
| Person-centred | This means:  disabled people have supports that are tailored to their individual needs and goals  a whole of life approach is taken to supporting disabled people |
| Achieving ordinary life outcomes | This means disabled people are  supported to live an everyday life in everyday places  regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life |
| Mainstream is the default | This means disabled people are supported to access mainstream services before specialist disability services. |
| Mana enhancing | This means the abilities and contributions of disabled people and their families are recognised and respected. |
| Easy to use | This means disabled people have supports that are simple to use and flexible. |
| Relationship building | This means supports build and strengthen relationships between disabled people, their whānau and community. |

1. 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. [↑](#footnote-ref-1)
2. A navigator facilitates and supports the disabled person and their family to find out what a good life looks like for them and then work out how best to achieve this. Navigators, funded through the Demonstration, are a free resource for disabled people and their families to use. [↑](#footnote-ref-2)
3. The New Model, introduced by the Ministry of Health in selected areas, gives people more choice and control over support and funding in their everyday lives. See <http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people>. [↑](#footnote-ref-3)
4. The Report of the Social Services Select Committee’s [“Inquiry into the Quality of Care and Service Provision for People with Disabilities (www.parliament.nz)”](http://www.parliament.nz/en-NZ/PB/SC/Documents/Reports/9/6/7/48DBSCH_SCR4194_1-Inquiry-into-the-quality-of-care-and-service-provision.htm) in September 2008 outlined a number of recommendations that the Government needed to respond to. [The Government Response to the Select Committee’s Report (www.parliament.nz)](http://www.parliament.nz/en-NZ/PB/Presented/Papers/3/1/d/49DBHOH_PAP17698_1-Government-Response-to-Report-of-the-Social-Services.htm) in February 2009 accepted the Committee’s conclusion that improvements should be made to disability services.

   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. DSS piloted parts of the New Model in the Bay of Plenty but is now also demonstrating it other areas e.g. Waikato, Auckland, Lakes, Hutt Valley and Otago/Southland regions. The New Model gives people more choice and control over support and funding in their everyday lives. See <http://www.health.govt.nz/our-work/disability-services/new-model-supporting-disabled-people>. [↑](#footnote-ref-4)
5. A theory of change outlines the rationale for the Demonstration, the changes that are expected, and how change is to be achieved [↑](#footnote-ref-5)
6. Natural supports are the relationships that occur in everyday life. 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 enhances their quality, and security, of life. [↑](#footnote-ref-6)
7. ORS provides funding for supports such as teacher time, teacher aides and specialists to help students whose disability is a barrier to them accessing the curriculum, whether because of hearing loss, visual impairment, difficulties with mobility, learning, or language use and social communication. [↑](#footnote-ref-7)
8. This person is a key point of contact for disabled people, their families, providers and the wider EGL team. [↑](#footnote-ref-8)
9. This includes CCS Disability Action, Disabled Persons Assembly, SkillWise, the New Zealand Federation of Vocational and Support Services, Manawanui In Charge, and the Canterbury branch of the Association of Blind Citizens. [↑](#footnote-ref-9)
10. Deputy Chief Executives/ Group Managers and General Managers. [↑](#footnote-ref-10)
11. Refer to following for their terms of reference: <http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/terms-of-reference-leadership-group-july-2013.html> [↑](#footnote-ref-11)
12. Not their real name. [↑](#footnote-ref-12)
13. 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. [↑](#footnote-ref-13)
14. This comes from the Ministry of Social Development’s Child, Youth and Family service line. [↑](#footnote-ref-14)
15. The Going Places initiative was put in Christchurch (a collaboration of the Ministries of Education and Social Development and local communities) to better support learners with special education needs when they transition from school into employment, training, further education or community settings. [↑](#footnote-ref-15)
16. Not his real name. [↑](#footnote-ref-16)
17. Young people receiving ORS can stay at school until the end of the year they turn 21 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. [↑](#footnote-ref-17)
18. A Support Agreement is between a disabled person and an individual or organisation that provides them with support. It sets out the level and type of support the disabled person will receive and from whom, along with how much of the disabled person’s allocation will be paid to the individual or provider for delivering that support. [↑](#footnote-ref-18)
19. Local Area Co-ordination (LAC) started in Western Australia in 1988. It is now used to support social care in most Australian states and has been successfully adopted in Scotland, Ireland, New Zealand, Canada and England. Local Area Coordinators support practical, creative and informal ways of meeting people‘s aspirations and needs, increasing the control and range of choices for individuals, their carers and families whilst contributing to systems and structure reform. LAC helps people plan, select and receive a range of supports and services to achieve their vision for a good life. [↑](#footnote-ref-19)
20. This meant the new elements of the system would be offered to all high and very high need schools leavers in receipt of ORS funding who are aged between 18 and 21 years in Christchurch City (approximately 40-50 people), and 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. In the first year, this would be tightly managed, but will still permit some flexibility in boundaries, and in the age and support needs of participants. [↑](#footnote-ref-20)
21. 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 well-being. [↑](#footnote-ref-21)
22. Mechanisms can include networks of family members, guardians for friends, facilitators, brokers, network builders, financial intermediaries, advocacy and consumer organisations, micro boards, or independent living centres. [↑](#footnote-ref-22)
23. For example, use of advisers, contracted management support, training, and resources and simplified clear guidelines, including exclusions such as the employment of family members. [↑](#footnote-ref-23)
24. This refers to officials in Wellington and the EGL team. [↑](#footnote-ref-24)
25. These navigators were employed by NZCare under Going Places. NZCare Group Ltd is a provider of services for people with disabilities. NZCare provided the "Going Places" transitional service for young people with very high ORS funding who were leaving school. [↑](#footnote-ref-25)
26. Internationally evidence on the effectiveness of joint and integrated working is limited (Cameron et al. 2012). [↑](#footnote-ref-26)
27. This means the researcher implements both the quantitative and qualitative strands during a single phase of the research study. [↑](#footnote-ref-27)