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EGL Christchurch Demonstration

Phase two evaluation report

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**Acknowledgements**

We wish to thank all those involved in the Enabling Good Lives Demonstration who gave us their time to be interviewed for assisting with the data collection. We also thank everyone who provided feedback on the design of the evaluation and on this report.

**Disclaimer**

The views and interpretations expressed in this report are those of the researchers and are not an official position of the Ministry of Social Development, the Ministry of Education or the Ministry of Health.

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# Executive summary

This report details the findings from a second evaluation[[1]](#footnote-1) of the Enabling Good Lives (EGL) Demonstration in Christchurch. The Demonstration finished in June 2016. EGL is a principles-based approach to supporting disabled people to live their vision of a good life. The Demonstration, developed to test this approach, is a partnership between representatives of disabled people, families, providers, and government agencies. The Demonstration primarily focused on school leavers (aged 18 to 21 years old) with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education’s Ongoing Resourcing Scheme (ORS).

The theory of change is that enabling disabled people to have more choice and control over their supports and services to live the life they want will improve their quality of life. It is anticipated that disabled people will make more use of natural[[2]](#footnote-2) and universally available supports in their communities. The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design, planning and navigation[[3]](#footnote-3), individualised flexible funding[[4]](#footnote-4), provider and school development, and community development.

The evaluation took place in late 2015 and will inform advice on the future direction of disability supports. The Ministries of Education (MoE), Ministry of Health (MoH) and Ministry of Social Development (MSD), along with the Demonstration Director and the Local Advisory Group (LAG), wanted to understand how the Demonstration was being implemented and how it was working towards supporting disabled people to live the life they want to lead.

The evaluation found that there were significant challenges in designing and implementing the Demonstration as intended. It appeared there was limited change amongst schools and providers as a result of the Demonstration. Change amongst schools and providers takes time and requires investment consistent with achieving outcomes.

Most disabled people and families interviewed for the evaluation had positive experiences of EGL but there were suggested improvements to navigation and planning, funding, and the use of natural supports. There were some positive outcomes for disabled people interviewed as part of the evaluation but there is also room for improvement.

### The evaluation used a mixed method approach similar to phase 1

The evaluation used a mixed method approach similar to phase 1 but with some additions. The methods used included:

* 10 case studies of disabled people in different contexts[[5]](#footnote-5)
* a quality of life survey of 43 youth participating in EGL
* in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers (GMs), a representative from Manawanui InCharge (MIC)[[6]](#footnote-6), the LAG as a group, EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
* analysis of existing administrative data to describe trends and patterns in use of navigators, use and management of the funding and use of supports and services
* analysis of documents on the Demonstration.

There were limitations associated with the evaluation. The key limitations were:

* *A comparison group could not be established:* The absence of a comparison group limits conclusions about the extent findings reflect all disabled young people and their families. It was not possible to randomly assign people to participate in the Demonstration. There was a plan to compare quality of life outcomes for participants with a group who had not participated in the Demonstration. However, it was not possible to gather enough responses from a comparison group to include them in the analysis.
* *The quality of life survey response rate was low (34%)*. The numbers of participants and proxies were small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth.
* *There were differences across several indicators between participants and proxies, highlighting challenges in combining participant and proxy responses*. Differences were likely to be due to either different perspectives of proxies and participants or to systematic differences in the circumstances of those who could respond for themselves and those who needed a proxy to respond for them. While the reporting of results from the survey generally combines responses of participants and proxies, these are reported separately where they are significantly different.

### Designing and implementing the Demonstration were challenging

There has been some improvement since the first evaluation of the EGL Demonstration in Christchurch. The mechanism for determining and allocating the funding to disabled people is now in place and functioning, the role of the navigators is clearer and systems are in place to pay providers. However, key elements of the Demonstration were not designed at all, or not designed until late in the Demonstration. This had an impact on what was implemented and when. For example:

* a wider range of options for managing the funding was needed
* the community development component was underdeveloped and received little attention in terms of design and resourcing
* providers and schools have an important role to play in helping disabled people achieve their outcomes. However, investment in changing practice in providers and schools was insufficient (see below).

The design of EGL proposes that disabled people be assisted to make more use of natural and universally available supports in their communities. The evaluation found that assumptions about the role that natural supports can play in supporting disabled people may be unrealistic, at least in the short term. Few families reported that they had significant natural supports outside of family and where these existed they appeared fragile. Further understanding is required about how natural supports can be developed and how they can be used alongside responsive formal supports and services.

Improving what was to be put in place in the Demonstration could have improved implementation.

* A more fully developed design was needed. Development of a detailed design was hindered by several factors. There were differing perspectives on the flexibility of the design, what co-design meant in practice in the context of the Demonstration and whether it had been co-designed. The co-design needed more time and resource. Better links between design and implementation were needed.
* Understanding of and buy-in to the EGL vision across stakeholders needed to improve.
* It would have improved the Demonstration if the leader on the ground and leaders in government had a common understanding about roles and responsibilities and the processes for resolving system issues as they affected the Demonstration.
* Accountability arrangements could be improved. There was a lack of focus on outcomes for disabled people and measuring outcomes at all levels. Accountability arrangements with providers and schools didn’t reflect the focus on outcomes for disabled people.

EGL highlights wider problems with the system which may have limited implementation and performance.

* The amount of funding disabled people receive may be insufficient to achieve their vision of a good life (eg for those who wanted to move out of home and live independently in the community).
* There is a limited range of housing options in Christchurch for disabled people. Several interviewees reported that the options appeared to be living at home with parents or in residential care.
* Some interviewees reported difficulties accessing appropriate supports and services for young disabled people ageing out of child services.

### Families’ and disabled people’s experience of EGL was positive but there were some difficulties

#### Navigation and planning were largely a positive experience for most families interviewed

Case study data revealed families were often sceptical when they first heard about EGL, but people typically engaged with EGL because they wanted to improve outcomes for their young person. Families did not engage or were reluctant to engage in navigation where they had no opportunity to talk to the navigator, were not open to navigation, did not believe their family fitted with EGL and/or did not expect their young person to grow or develop further.

Where families did engage in planning, it was largely a positive experience. However, navigators were more beneficial for some families than for others. The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there.

There were practices that supported disabled people to engage in planning. These included making disabled people central to the planning process, building the capacity of disabled people and families to engage, and having other parents who had been through EGL to walk alongside new people. Having access to and use of independent facilitation was also reported as being important in assisting people to engage in planning, although alternatives were raised (eg provider-led navigation based on the EGL principles).

Challenges for planning and navigation included:

* engaging families who were in difficult and complex circumstances and struggled to envisage a good life for their young person
* finding workable solutions for disabled people without family support
* balancing what the young person wanted and what the family wanted.

Possible improvements for navigation involved providing better:

* support for disabled people and families when they get into difficulty implementing their plan
* support for vulnerable families to develop, put in place and maintain their vision of a good life
* links between new families and those families who have engaged with EGL
* clarity about the future of navigation.

#### Use of the funding

EGL personal budgets are made up from pooled funding from the Ministries of Health, Education and Social Development. Around 70-80% of the pooled funding is from Vote Health, with the remainder from the other two Votes. According to data collected by the EGL team, most participants had received their allocation of funding. This funding could be used flexibly to purchase supports and services. As at 9 October 2015, 129 of the 175 EGL participants had been allocated funding. People needed a plan to receive their funding. Most of those who had not been allocated their funding at this point had paused their engagement with EGL or were still working through the planning process (eg because they were new or had taken some time to decide what they wanted).

Being financially literate and well resourced assisted people to take up the funding and manage it. There were practices that supported disabled people and families but there was room to improve.

* Pooling the funding and having greater flexibility in the use of the funding was important. Some families expressed the desire for more flexibility.
* Managing the money was difficult for many families and disabled people. More options are needed to assist families to take up and manage the funding. Direct funding[[7]](#footnote-7) to disabled people was not available in the Christchurch Demonstration. Flexible disability support contracts were due to be implemented at the time of the evaluation. These are now in place. It was anticipated that this would provide a less onerous option for families to manage the funding. Some people need agents but these are not always easy to find, leaving those people unable to take up the funding.
* The amount of funding was insufficient in some contexts. For example, the cost of living independently in the community with the appropriate supports was identified as a significant barrier and funding may have been insufficient for families on lower incomes. In addition the funding may have been insufficient to support disabled people’s choices where the family could not be involved in the day-to-day care of their young disabled person. Taking up Funded Family Care (FFC)[[8]](#footnote-8) limited the overall pool of funding, but families did not always feel they had an alternative.
* Families had some useful sources of advice and guidance on how to use the funding but more is needed. MIC was instrumental in advising families and the purchasing advisory panel worked well but families were not always clear about why some services were funded and others were not. There was a need to clarify elements of the purchasing guidelines[[9]](#footnote-9).

#### The employment of staff could be improved

Families and EGL staff interviewed offered suggestions to make it easier to employ staff, including:

* undertaking more work to support families as employers, especially when disputes arise
* educating support workers about the home care environment
* establishing a group that could shoulder more of the employer responsibility for families
* using flexible disability support contracts between disabled people and providers. It would be useful to have a further evaluation of how well these contracts are working for disabled people and their families.

### Some positive outcomes for disabled people and their families

#### Who were the participants?

As at 9 October 2015 there were 175 EGL participants. Most of these were school leavers (aged 18 to 21 years old) [[10]](#footnote-10): 135 were school leavers, 40 were opt-ins[[11]](#footnote-11). There were more male participants (100 males compared with 75 females). Most were Pākehā: the ethnicity of participants was primarily Pākehā (over 80 percent). Few participants were Māori or Asian (less than 10 percent each). Most (100) EGL participants had received high needs (HN) ORS funding. Sixty-one received very high needs (VHN) ORS funding, 10 received no ORS funding and four received no funding at all. Participants attended a mix of special[[12]](#footnote-12) and mainstream schools.

EGL participants at 9 October 2015 had attended or were attending one of 27 schools. Most EGL participants (76%) had attended or were attending one of seven schools (Allenvale Special School, Ferndale High School, Hillmorton, Cashmere, Riccarton, Papanui or Van Asch Deaf Education Centre). Sixteen schools had only between one and three students who were EGL participants.

There was broad agreement amongst families and disabled people interviewed about what constituted a good life. Across the cases, families and disabled people agreed that a good life involved disabled people doing things that interested them and being included in the community. There was some distinction between those families who engaged with EGL and those who did not. Those who engaged with EGL had higher expectations of what their young person could do post-school.

#### Quality of life outcomes

The Enabling Good Lives approach is ultimately about improving the quality of life of disabled people. A survey of 43 young people eligible to participate in the Christchurch Demonstration was conducted in late 2015 to assess quality of life outcomes. Respondents included 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). In the survey, the questions identified aspects of quality of life that many EGL participants and their proxies were positive about and aspects few thought mostly applied to their lives.

The Schalock Quality of Life framework was used as a foundation for developing quality of life indicators for the evaluation of the Enabling Good Lives Demonstration. Indicators relevant to the context were developed for each of the frameworks dimensions in consultation with the Local Advisory Group in Christchurch.

##### Wellbeing: physical and emotional wellbeing were good but material wellbeing was low

Analysis of the quality of life survey found that overall scores were higher for the physical (80) and emotional (81) wellbeing domains and lower for the material wellbeing domain (55).

In the case study research, the emotional wellbeing of the young people was reported as being good. Emotional wellbeing was reported as improved in all the cases where the young people had made changes in their lives following active engagement in EGL. In most of the cases no changes were reported in the physical wellbeing of disabled people interviewed. However, there were two cases where participating in EGL appears to have improved the young people’s physical wellbeing (eg fewer doctors’ visits, improved physical functioning). In both cases the families attributed this to having consistent carers they had chosen. As with the quality of life survey, evidence from the case studies indicates that material wellbeing is constrained for many young disabled people.

##### Social participation: interpersonal relationships with family were good but improvements could be made in the rights and social inclusion domains

Social inclusion could be improved.Analysis of the quality of life survey found that the social inclusion domain (63) had the lowest overall score within the social participation area. The survey found most respondents could go out in the community (eg shopping, movies) but fewer felt they belonged or had meaningful participation. The case studies revealed that young people’s sense of belonging in their communities varied. There were factors that appeared to influence the degree of social inclusion. These included knowing and being known in the neighbourhood, having sufficient income to participate, having the ability to engage in social interactions in the community, and the attitudes of people in the community.

Improvement could be made in the rights domain. The rights domain is about being treated with respect, dignity and equality. It also encompasses citizenship, access and fair treatment. Analysis of the quality of life survey found the rights domain had a relatively low score (70). The survey found the highest-scoring indicators were use of the phone or internet when wanted, having someone trusted to ask for help and having choices respected. The lowest-scoring indicators were being able to go out when they wanted and getting time by themselves.

Interpersonal relationships with family were typically good. Analysis of the quality of life survey found the interpersonal domain had the highest overall score (81) within the social participation area. However, people’s social networks were often limited. Factors that limited people’s ability to spend time with the people that mattered to them and influenced the development and maintenance of relationships outside of the family included living in residential care, not being able to afford to go out, degree of assistance needed and received to build relationships, and the impact of individual conditions (eg level of functioning, self-motivation, confidence) on young people’s ability to engage in and maintain personal relationships.

##### Independence: improvements could be made in personal development and self-determination outcomes

In the quality of life study the overall score for the personal development domain was 74. However, the overall score masks substantial differences between the underlying questions. High proportions reported their home had the things they needed day to day to help them (80%), they were doing some type of education or learning they were interested in (77%), and they had the things they needed to do what they wanted (71%). Smaller proportions responded that they mostly have had a chance to fix mistakes (49%), show people the things they are good at (40%) and learn to do new things that help with everyday life (29%)*.* The case study data indicated greater personal development for young people engaged in EGL; for example, respondents reported being engaged in activities they wanted to do and being satisfied with the mix. However there was limited evidence the young people in residential care were engaged in personal development activities.

In the quality of life study the overall score for the self-determination domain was 71. As with the personal development domain, there were substantial differences between the underlying questions. Almost two-thirds of respondents (62%) reported that they *had a say about the important things in their life.* But a smaller proportion (35%) was positive about the *choice of who participants live with.* Analysis of the case study data found that families engaged in EGL reported their young person had greater choice and control over how they lived their life. However, the case data indicated that young people in the cases where they were in residential care had limited choice and control over various aspects of their lives (eg what activities they did, where they lived).

#### There appeared to be limited change to family outcomes

Based on analysis of case study data family emotional wellbeing had improved but not always because of EGL. There was no change in physical wellbeing. Family material wellbeing varied across families but changed little for individual families following participation in EGL. Limited change was reported in the quality of relationships between family members although there were some exceptions.

Family support networks and access to services could be improved. Few families reported that they had significant natural supports outside of family. Access to supports and services was problematic. The amount of use and experience of using disability support services varied.

Family personal development changed little. Family decisions about the care of their young person were influenced by and had an influence on parents’ (especially mothers’) choices regarding work and further education and training. In some of the cases EGL appeared to have opened up space for family members to engage in personal development but in most cases EGL appears to have had limited influence on parents’ decisions in this area. Where the young person with the disability moved out of home or was cared for by a non-parental carer, there were more opportunities for both parents to engage in further work, education or training, or personal development.

#### Improvements are needed in the measurement of outcomes

Currently, only limited information is systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found that improvements could be made by:

* enhancing data collection (eg improving the response rate, the collection of information from people with communication challenges, and the collection of information from proxies)
* continuing to explore how to assess the impact of similar initiatives. Considering the difficulty in identifying and contacting a valid comparison group, the most useful comparison for future quality of life surveys may be as a measure of change over time within the same individual or group of participants. Other options could include exploring the use of quasi experimental designs although they would require considerable work both to develop design options and to assess ethical implications
* establishing a standard set of indicators that can be tracked over time and applied more widely
* developing family wellbeing indicators.

### There was limited change in practice amongst schools and providers

Some schools and providers interviewed were working to support disabled people to live everyday lives in the community. However, provider and school alignment with the EGL approach could improve. The evaluation found that there was variation and room for improvement in:

* support for disabled people to make choices and tailoring of supports and services
* the way schools and providers assist disabled people and families to plan for the future and significant transitions, which was heavily influenced by their views of the life they saw disabled people leading post-school
* providers’ and schools’ understanding of social inclusion (eg being present versus meaningful inclusion) and their practices to support it
* support for disabled people to build and maintain relationships and develop natural supports in the community
* support amongst schools and providers for the concept of mainstream first
* support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed
* the ease with which disabled people get the support they want when they want it from schools and providers
* opportunities for disabled people to influence school and provider policies and practices. Schools and providers could improve their measurement of outcomes for disabled people and use the information to drive improvement in practice.

The following factors appear to have undermined the influence the Demonstration had on provider and school practice:

* Schools and providers did not see they needed to change significantly.
* Most of the providers and schools interviewed had had limited experience of EGL. Limited communication and inconsistent messages about EGL meant schools and providers lacked clarity about their role in EGL.
* There was underinvestment in school and provider development.
* The delayed development and implementation of key components of the Demonstration (eg the process for paying providers) undermined the Demonstration’s credibility, particularly with providers.
* Some providers and schools reported limited capacity to fund changes to operate more in line with the EGL principles.

Factors that may have helped schools and providers include:

* engaging in consistent and clear communication with schools and providers over a longer time period before and during the Demonstration to assist in getting buy-in and ensure everyone is on the same page
* having a person schools knew and trusted liaise with them about the EGL approach. While there was a dedicated person to manage the EGL/provider relationship with providers, there was no such person for schools
* having readily available information on what EGL means in practice and advice on how to get there, including for the governing bodies of providers and schools; for example, providers wanted more advice on how to cost their services in an individualised way
* ensuring that contracts and funding arrangements with providers encouraged the outcomes sought by the EGL approach.

In future, specific provider (and school) development funding could help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools need to start by expanding their vision of what disabled people can achieve. An ongoing challenge will be addressing the financial sustainability of providers.

# Evaluation purpose and Enabling Good Lives background

## Purpose of the evaluation

This report details the findings from a second evaluation of the Enabling Good Lives (EGL) Demonstration. The Demonstration finished in June 2016. EGL is a new approach to supporting disabled people to live their vision of a good life. The Demonstration, developed to test this new approach, is a partnership between representatives of disabled people, families, providers, and government agencies.

The evaluation took place in late 2015 and will inform advice on the future direction of disability supports. The Ministries of Education, Health and Social Development, along with the Demonstration Director and the Local Advisory Group, wanted to understand how the Demonstration was being implemented and how it was working towards supporting disabled people to live the life they want to lead.

## What is Enabling Good Lives and why change?

### The current system of disability supports is problematic

The system of support for disabled people has often made it difficult for an individual to live an everyday life of their choice in their community. There has been pressure to change the current system of disability supports and services so that disabled people have greater choice and control. This pressure has arisen because:

* life outcomes for disabled people are poor compared with the general population[[13]](#footnote-13)
* disabled people and their families report the current supports and services do not reflect their individual needs and preferences. The current system:
* is very complicated for users. Disabled people and their families have to navigate complex bureaucracies in different agencies to access all the support they need. It is not person driven. Disabled people and their families struggle to get the assistance they need when they need it
* focuses on funded specialist supports and services at the cost of mainstream services and other forms of support
* typically allocates funding based on a medical model rather than on someone’s strengths and what they could do. There is limited flexibility in the use of funding
* the current system is costly to government. Costs have increased but there is little evidence that the additional spending is resulting in better outcomes
* there is greater recognition that disabled people should have the same rights as non-disabled people eg as a result of the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), wider acceptance of the social model of disability.

### EGL is a principles-based approach to supporting disabled people

In September 2012 the Ministerial Committee on Disability Issues agreed to a long-term direction for change based on the Enabling Good Lives approach[[14]](#footnote-14). The vision for this approach is that disabled people and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports[[15]](#footnote-15) in their communities.

Underpinning the EGL approach is a set of principles which Ministers agreed would guide the transformation of the disability support system. There are eight principles based on what is needed to improve the quality of life of disabled people. These are:

* *self-determination:* disabled people are in control of their lives
* *beginning early:* invest early in families and whānau to support them to be aspirational for their disabled child, to build community and natural supports and to support disabled children to become independent
* *person-centred:* disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach
* *ordinary life outcomes:* disabled people are supported to live an everyday life in everyday places, and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life
* *mainstream first:* disabled people are supported to access mainstream services before specialist disability services
* *mana enhancing:* the abilities and contributions of disabled people and their families are recognised and respected
* *easy to use:* disabled people have supports that are simple to use and flexible
* *relationship building:* relationships between disabled people, their whānau and their community are built and strengthened.

On 12 July 2013 Cabinet agreed to a three-year demonstration of the EGL approach in Christchurch in 2014 (CAB Min (13) 24/6 refers). The purpose of the Demonstration was to provide a group of disabled people with greater choice and control over their supports and lives, and to gather information about how the EGL approach works and how it might be possible to implement changes across the whole of the disability support system.

Implementation began during November 2013. The Demonstration ran until 30 June 2016 and was jointly supported by the Ministries of Health, Social Development and Education, with involvement from ACC.

EGL built on work already undertaken by the Government to give disabled people greater choice and control. For example:

* through the Ministry of Health disabled people can take up Individualised Funding
* Disability Support Services (DSS) at the Ministry of Health developed the New Model in consultation with disabled people, their families, providers and the wider disability sector. The New Model components give disabled people more flexible funding over some supports, information and support for disabled people to build networks in their communities. DSS piloted parts of the New Model in the Bay of Plenty but is now also demonstrating components of it in other areas eg Waikato, Auckland, Lakes, Hutt Valley and Otago/Southland regions
* Choices in Community Living is an alternative to residential services for people with significant disabilities[[16]](#footnote-16). It offers more choice and control over where they live, who they live with and how they are supported. It is part of the New Model demonstration and is available in Auckland, Waikato, the Hutt Valley and Otago/Southland.

### EGL theory of change and components

The theory of change is that enabling disabled people to have more choice and control over their supports and services to live the life they want will improve their quality of life. The mechanisms in the Demonstration to bring about change for disabled people and their families include co-design, planning and navigation, individualised flexible funding, provider and school development, and community development. How the mechanisms come together to bring about change for disabled people is outlined in an intervention logic developed as part of the evaluation (Figure 1).

The mechanisms (EGL components) are outlined in more detail below.

#### Co-design

A key feature of the Demonstration is the involvement of disabled people, families and providers in co-designing the changes and their cross-agency boundaries. While there is not an agreed definition of co-design internationally, it usually involves using collaborative relationships between public service professionals and citizens or users in the design process. Boyle and Harris (2009) believe these relationships need to demonstrate equality and reciprocity. There is also a focus on delivery of outcomes rather than just the service (OECD, 2011).

Figure 1. EGL intervention logic



#### Individualised and flexible funding for disabled people

Funding that disabled people are eligible for from different agencies (eg the Ministries of Health, Education and Social Development) is pooled into an EGL personal budget. A disabled person’s EGL personal budget can include relevant funding[[17]](#footnote-17) from the:

* Ministry of Health: This includes funding as allocated by the local Needs Assessment and Service Coordination (NASC) organisation, which includes all disability support services such as residential care, home and community support, supported living, respite care and carer support – this funding may be used to purchase support from contracted providers, or can be accessed through an Individualised Funding arrangement
* Ministry of Social Development: This includes Participation and Inclusion funding, which covers specialist employment and community participation services and very high needs funding. There has been no change in the total amount of funding available
* Ministry of Education Ongoing Resourcing Scheme (ORS)[[18]](#footnote-18) funding for students with high and very high needs[[19]](#footnote-19), and flexible use of specialist support. Most ORS-funded students receive high needs funding[[20]](#footnote-20). ORS-funded students can remain at school until they are 21, but lose their funding if they leave earlier. The Demonstration made ORS funding available if a young person decided to leave school at 18. This funding was available to support them in their next step to create a foundation for their future life. Students were still able to choose to stay at school until 21 and would join the Demonstration once they left. There was no change in the total amount of funding available
* Transition Funding from the Ministry of Education: This was $2,150 and could only be accessed in their final year of school or if not accessed in this year it could be accessed in the following year.

Disabled people can choose how that funding is used to support them to achieve their vision of a good life. There are guidelines on the use of the funding for participants to follow. Currently, disabled people receiving funding under EGL need to use a host provider to manage their funding. However, the intention is that, over time, disabled people will have a choice about how their funding is managed (eg self-managed; partly self-managed; or managed by a third party, such as a host provider).

#### Planning and navigation with disabled people

Navigation is the process by which participants identify and record what a good life looks like for them, and how they can achieve it. It includes the disabled person’s journey along their self-directed pathway (with support from natural and/or paid supports as and when the participant chooses). Participants can choose to undertake navigation with an EGL navigator, or with other people including wider family and friends, or with appropriate support they can choose to do it themselves.

It is intended that navigators work as allies of disabled people and supporting them to make their own decisions with all the resources and information required. Navigators are to facilitate the use of what is available in the community (eg mainstream services) and natural supports to assist disabled people to live the lives they want. ‘Natural supports’ were seen as the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports were seen as encompassing family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections, but, over time, these connections can help an individual build a strong community network and support system that enhance their quality, and security, of life.

Participants have access to an average of 25 hours navigator time for planning, and any ongoing support, recognising that some participants will be very clear and not need much and others may need more. The output of navigation process is the development of a plan of action for the participant.

The intention the participant and family will exit the process when they identify that their good life plan is in place and there is sufficient support and momentum for them to achieve their dreams and goals.

#### Individual and family capacity building

The Demonstration was to undertake initiatives that would build the capacity of disabled people and their families to help them to engage in planning and make use of the individualised, flexible funding.

#### Provider development and working with schools

Providers and schools have a role in supporting disabled people to achieve their vision of a good life by operating in line with the EGL principles. Giving disabled people choice and control over their funding is a mechanism to change provider practice. The expectation was that disabled people would choose personalised[[21]](#footnote-21) supports and services in the community over traditional disability supports and services. This would encourage providers to adapt and offer supports and services tailored to individuals’ preferences and situations. The Demonstration intended to influence schools and providers by engaging with them about the EGL approach. It was anticipated that schools and providers already operating in line with the principles would also share their knowledge and experience with other schools and providers.

#### Community development to promote the inclusion of disabled people

Communities also have a role in supporting disabled people to achieve their vision of a good life. A key element of bringing about change for disabled people and their families is investing to build inclusive communities: to ensure communities, including businesses, workplaces, schools, and cultural, sport and recreational activities, are accessible and welcoming and recognise the contribution of disabled people[[22]](#footnote-22).

The expectation is that as disabled people engage in everyday activities in everyday ways (eg going to work, doing mainstream leisure activities) the community will become more inclusive. The EGL team will support communities to become more inclusive of disabled people by working with local decision-makers to promote the inclusion of disabled people. At the neighbourhood level, the EGL team will help build relationships between disabled people, their families and their communities.

#### There are several assumptions underpinning this theory of change

The assumptions are that:

* increasing disabled people’s choice and control over their lives will lead to improved quality of life. Research assessing the impact[[23]](#footnote-23) of approaches similar to Enabling Good Lives is limited. However, reviews of international evidence suggest that community-based service models generally achieve better results for the people they serve than institutions (Mansell & Beadle-Brown, 2010). Evidence from multiple sources and from multiple countries (Australia, the UK, the US, the Netherlands, New Zealand) suggests that having a personal budget improves disabled people’s quality of life, sense of empowerment, self-determination, and levels of choice and control. Indications are a personal budget also improves the quality of life of families, and changes the aspirations about what disabled people can achieve and how they can live their lives (Arksey & Baxter, 2012; Caldwell & Heller, 2007; Field et al., 2015; Fisher et al., 2010; Forder et al., 2012)
* disabled people and their families know their own needs and goals. They possess strengths that should be recognised and built on
* people understand what natural supports[[24]](#footnote-24) are and that sustainable natural supports exist for disabled people in the Christchurch area
* schools and disability support providers will have or will adopt the beliefs and values that underpin an EGL approach and will be willing to ensure that these guide their organisation’s relationship with disabled people
* non-government support and mainstream services are able to viably support disabled people
* sufficient specialist services are available (eg school transition services, vocational services funded by Ministry of Social Development (MSD), disability support service providers funded by Ministry of Health (MOH))
* the groups involved in the Demonstration can effectively collaborate to design and deliver Enabling Good Lives
* resources will be in place to support an EGL approach. Considerable resources currently exist within the sector to support the change to an EGL approach
* the boundaries of the system are understood or can be understood. However, there is no clear definition for the term systems change. As Kendrick et al. (2006) state, human service and community systems usually are not single, unified entities. They are typically made up of many interconnected systems and sub-systems and include formal and informal elements. These elements (groups, organisations, families, individuals) are not always directly connected to one another.

### The Demonstration focused primarily on school leavers

The Demonstration primarily focused on school leavers defined as those aged 18 to 21 years old with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education’s ORS.

There was flexibility to allow some disabled people who did not meet the edibility criteria to opt into the Demonstration. This meant that in the first year the new elements of the system would be offered to all high and very high needs school leavers receiving ORS funding who were aged between 18 and 21 years in Christchurch City (approximately 40 to 50 people). Up to 10 further people who access disability supports in or near Christchurch would be allowed to opt in at the discretion of the Director. Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support, recognising that some participants will be very clear about what they want and not need much support and others may need more. The intention was that this would be tightly managed, but would still permit some flexibility in boundaries, and in the age and support needs of participants.

Initially the number and type of people involved in the Demonstration were expected to expand each year. The intention was to demonstrate EGL at different ages and stages of people’s lives. However the expansion did not happen. To support the focus on system development work, the participant group for the Demonstration was limited to high and very high needs school leavers after the first year.

### Leadership of the Demonstration

Several groups and individuals were involved in leading the Demonstration (Figure 2).

At a local level these included the:

* *Demonstration Director:* The Director was appointed to lead the implementation of the Demonstration in Christchurch. The intention was that the Director would be supported and advised by the Ministries and the Local Advisory Group. At the time of the evaluation the Director was also supported by the EGL team, which included a Manager of Families and Community Development, a Manager of Provider Relationships and Personalised Funding and a Demonstration Co-ordinator. This person was a key point of contact for disabled people, their families, providers and the wider EGL team during the Demonstration.
* *Local Advisory Group (LAG):* The LAG had a leadership role in that it represented disabled people, their families and providers in the development of the Demonstration. It was also intended to act as a vehicle for providing their networks with information on the Demonstration. The LAG included people who had personal experience of using flexible Individualised Funding and others who had been involved in bringing about changes towards more self-directed services for disabled people. Some also brought to the table an in-depth understanding of special education and the challenges facing youth and their families. Their experience encompassed a wide cross-section of disability and support organisations. The composition of the group has changed over the course of the Demonstration. Members included CCS Disability Action, Disabled Persons Assembly, SkillWise, the New Zealand Federation of Vocational and Support Services, Manawanui InCharge (MIC)[[25]](#footnote-25), and the Canterbury branch of the Association of Blind Citizens of New Zealand Incorporated.

At a national level these included the:

* *Joint Agency Group (JAG) and the Ministerial Committee:* A Joint Agency Group of senior managers[[26]](#footnote-26) from the Ministries of Health, Education and Social Development and ACC oversee the Demonstrations in Christchurch and the Waikato. The Director reported to the JAG. There was deliberately no single agency appointed as lead. Joint agency ownership was seen as more likely than a single lead agency to create the co-ordination and cooperation between government agencies that is necessary for an integrated and flexible disability support system.

TheJAGwas responsible for achieving the Demonstration outcomes and making joint decisions that are within the agencies’ delegated authority. This group reported to the Ministerial Committee on Disability Issues, and was advised by the National EGL Leadership Group. The Ministerial Committee on Disability Issues provides high-level ministerial oversight of the overall EGL work programme

* *EGL Leadership Group:* The EGL Leadership Group is a national group that is responsible for promoting and protecting the overall vision and principles of Enabling Good Lives and for advising Ministers and senior officials. At least half the members are disabled people, and the group includes disability sector leaders and Māori and Pacific members.

Figure 2. Leadership and the Christchurch Demonstration

**LOCAL**

**Local schools, disability organisations, mainstream organisations, disabled people and families**

**LAG wider networks**

**LAG**

**EGL team**

**Joint Agency Group**

**Ministerial Committee on Disability issues**

**NATIONAL**

# A mix of methods was used

## Evaluation objectives and research questions

The evaluation objectives are outlined below.

* Objective 1: to understand what outcomes are being achieved by those participating in EGL and what contribution EGL has made to those outcomes
* Objective 2: to understand what constitutes a good life for disabled people involved in the Demonstration and how this understanding evolves over time
* Objective 3: to understand what is being implemented to enable disabled people to have good lives and how EGL is operating in practice
* Objective 4: to understand how schools, providers of disability support services and government agencies have positioned themselves to support disabled people to live a good life
* Objective 5: to examine what supports the success of the Demonstration as an approach to enable disabled people to have good lives, and what does not, and identify any lessons that could inform the scaling-up of the EGL approach.

The research questions for each evaluation objective are outlined Appendix 1.

## The evaluation used a mixed method design

The evaluation used a mixed method approach similar to phase 1[[27]](#footnote-27) but with some additions. As the phase 1 evaluation took place shortly after implementation began there was limited opportunity to look at outcomes for participants. Phase 2 was more focused on outcomes.

The methods used included:

* 10 case studies of disabled people in different contexts. The unit of analysis (‘the case’) is: *The young disabled person engaged in EGL who has recently left school or is planning to.* Here the focus is on the individual disabled person’s journey towards building a life outside of school. There were three types of cases:
* Case type 1: Limited change since being able to engage with EGL. While living circumstances were not a section variable in all these cases the young people were in residential care.
* Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
* Case type 3: Movement towards living a life in line with the EGL principles (opt-in)
* a quality of life survey of 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). The response rate was 34%.
* in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers, a representative from MIC, the LAG as a group, the EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
* analysis of existing administrative data to describe trends and patterns in the use of navigators, Individualised Funding, self-management of funding and supports and services
* analysis of documents on the Demonstration.

Methods were selected based on their capacity to answer evaluation objectives and research questions. The methods were applied concurrently but separately. This means the researchers implemented both the quantitative and qualitative strands during a single phase of the research study.

The rationale for using a mixed method design is as follows:

* Triangulation of findings allows them to be corroborated.
* Weaknesses in each method will be offset.
* Using a mix of methods allows for the development of a more complete picture.
* This approach is suitable in a context where the environment is very dynamic and pathways to change cannot be predetermined.

See Appendix 2: Evaluation methodology for further discussion of the rationale for the approach.

### Limitations of the evaluation

The evaluation has the following limitations:

* *The observation period for the evaluation was too short for all outcomes to be fully achieved within it.* This may be particularly the case for the high-level outcomes of promoting wellbeing, participation and community connection. In some instances change may be too slow to be clearly observed and measured within the timeframe of the evaluation, especially when this timeframe is short (see Appendix 2, Quality of life survey).
* *A comparison group could not be established:* The absence of a comparison group limits conclusions about the extent findings reflect all disabled young people and their families. It was not possible to randomly assign people to participate in the Demonstration. There was a plan to compare quality of life outcomes for participants with a group who had not participated in the Demonstration. However, it was not possible to gather enough responses from a comparison group to include them in the analysis.
* *The quality of life survey response rate was low (34%).* The numbers of participants and proxies were small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth.
* *There were differences across several indicators between participants and proxies*[[28]](#footnote-28)*, highlighting challenges in combining participant and proxy responses*. Proxies recorded responses on behalf of some participants. While having participants record their responses themselves is preferable, use of proxies is an appropriate way to include participants who are not able to do so. It is however important to note that while proxy responses have been found to be generally consistent with what people would record themselves, there can be differences, especially where the proxies are staff. For example, Claes et al. (2012) found no significant differences between self-reported responses and family member proxies, but did identify differences between self-reported responses and staff member proxies. The researchers conclude that quality of life scores obtained from self-reports are not the same as those obtained from family members or direct support staff. The differences are not necessarily indicative of bias or invalidity but reflect different perspectives.

In this evaluation the proxies were all family members. The responses of participants and proxies sometimes differed and this was likely to be due to either different perspectives of proxies and participants or to systematic differences in the circumstances of those who could respond for themselves and those who needed a proxy to respond for them. While the reporting of results from the survey generally combines responses of participants and proxies, these are reported separately where they are significantly different.

* *Measuring quality of life is challenging.* There have been advances in the measurement of quality of life but there are still challenges. For example, there is broad agreement that an accurate quality of life assessment requires a combination of subjective well-being and social indicators approaches. However there is debate over the relative importance of objective versus subjective factors in determining quality of life, and about the relationship between the two. There are difficulties measuring quality of life for those with significant intellectual disabilities. Quality of life indicators can be realised in multiple ways. An individual’s perception of their quality of life can be heavily influenced by one or a few aspects of their life which may or may not be amenable to change. People may report a high quality of life even where their circumstances are less desirable. This can because they do not know any different (Brown et al. 2013). Measuring changes in quality of life over time is challenging (Verdugo et al., 2015). The degree of change depends on the programme and approach to quality enhancement. The stability of quality of life scores is interactive, and is dependent on both personal characteristics and environmental factors (see Appendix 2: Evaluation methodology for further information on the quality of life survey).
* *The administrative systems captured little data on the quality of disabled people’s experience of Enabling Good Lives.* The quality of life survey sought to address this but as mentioned above there were some limitations with this. The way in which administrative data were captured made it very difficult to examine what use participants had made of their funding and whether or not they were spending more or less than before the Demonstration.
* *The views expressed by schools and providers interviewed may not be representative of all schools and providers who had people participating in the Demonstration.* The evaluation team endeavoured to select a range of providers and schools and undertook in-depth interviews with five providers and three schools. All the schools and providers the team invited to participate in the evaluation accepted.

# Design and implementation could have been improved

|  |
| --- |
| Summary There was some improvement from the first evaluation but key components were not able to be implemented:   * Disabled people needed a wider range of funding options for managing their funding. Few options were available to disabled people to manage their funding. Additional options for managing the funding would have been useful for disabled people and their families. * Assumptions about the role natural supports can play in supporting disabled people may be unrealistic. * The community development component of the Demonstration was underdeveloped. It was unclear how community development was supposed to happen under EGL. The community development component received little attention in terms of design and resourcing. * There was underinvestment in provider and school development to assist them to operate in line with the EGL principles. * Accountability arrangements could be improved.   Improving inputs could have improved implementation:   * A more fully developed design was needed. Development of a detailed design was hindered by several factors. * Understanding of and buy-in to the EGL vision across stakeholders needed to improve. * Leadership could have better supported implementation. * There were wider problems with the system which likely limited implementation and performance. |

## There was some improvement from the first evaluation, but key components were not implemented

For the Demonstration to be well placed to achieve the intended outcomes, the core components needed to be in place and operating as intended. The first evaluation found each of the agencies and the Local Advisory Group had a commitment to making the Demonstration happen. Those involved in implementing the Demonstration worked hard to put something in place by November 2013. Nevertheless key components of the Demonstration were not in place:

* The mechanism for pooling funding for individuals was not fully developed.
* The navigators were still being hired and the role of the navigator was still evolving.
* Work remained to be done on how providers would be paid and how they would be assisted to operate in line with the principles.
* Accountability mechanisms had not been developed and it was unclear how disabled people would be safeguarded.
* It was unclear what community development meant in the context of EGL as this work had not been done.
* The mechanisms for bringing about change in government systems were unclear.

There has been some improvement since the first evaluation. What was designed and ready to be implemented was implemented:

* There was a mechanism for pooling funding for individuals.
* The navigators were in place and their role was clearer according to the navigators, EGL team members, providers and schools interviewed.
* Systems were in place to pay providers.

However, key elements of the Demonstration were not designed at all, or not designed until late in the Demonstration. This influenced what was implemented and when.

### A wider range of funding options for managing the funding was needed

#### Few options were available to disabled people to manage their funding

International evidence on personal budgeting models suggests that there is no ‘one size fits all’ approach and that disabled people, and their families, need a continuum of options – from self-management to contracting an agent or an organisation to manage the budget – to support them to manage their personal budget (Carter Anand et al., 2012; Forder et al., 2012; Glendinning et al., 2008). However, at the time of the evaluation, disabled people and their families had very few options for managing their funding allocation.

Everyone who received pooled funding had to go through MIC, who acted as the host provider. Unlike in the EGL Waikato Demonstration, there was no choice of host provider. Disabled people and families in the Christchurch Demonstration could then choose to:

* *self-manage with assistance from MIC:* Disabled people and their families could contract and employ individuals or organisations to provide supports or services (eg similar to employing a plumber). Disabled people and/or their families needed to invoice MIC for the number of hours they were using at the agreed rate. They then claimed the money from MIC to pay the individual or organisation. If they contracted someone, the contractor took care of their own tax and ACC; this was similar to Individualised Funding
* *use MIC’s payroll system:* Disabled people and/or their families set this up with MIC, who paid the employees directly and sent the pay slip to the families because they were the employer. MIC took care of KiwiSaver, ACC levies (accrued out of their funding), holiday pay and payroll contingencies
* *use MIC to pay providers:* When the Demonstration began, people who were self-managing through a hosting mechanism (eg using MIC) were unable to access the GST inclusive portion of their EGL personal budget[[29]](#footnote-29). A workaround was put in place whereby the host was commissioned to purchase some supports on behalf of people. Families who wanted to carry on using providers as they had before the Demonstration and not manage the funding could enter into a third party payment (TPP) agreement between the agency, MIC and the disabled person. It enabled the family to deal directly with MIC, who also managed GST and paid providers. TPPs also meant that providers could be paid on time.

MIC reported that in October 2015 most people on EGL were using payroll through MIC, about 25 people had TPPs with service providers, and some people had a mix of some contracting and some payroll.

#### Additional options for managing the funding would have been useful for disabled people and their families

Direct payments were not available to disabled people in the Christchurch Demonstration

Direct funding for disability supports is not widely available in New Zealand but could suit some people. Direct payments (either cash payments or a nominal budget) involve the funds being given directly to the person with a disability, who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations. Direct funding can be used by disabled people to purchase services and supports of their choice to assist them with personal care, household chores, accommodation options, and getting around. In the UK, the US, Canada and Australia, direct funding approaches have been used. Fisher et al. (2010) indicate that direct funding is not for everyone and where it is available most people choose support organised through providers or financial facilitators rather than direct payments.

Proposed flexible disability support contracts could provide another option for managing the funding but there are some risks to manage

Flexible disability support contracts were due to be implemented at the time of the evaluation. It was anticipated that this option would make the management of the funding less onerous for families by allowing providers to take on the administrative burden of managing pooled funding. An EGL team member described the contracts as a game changer. He said:

Once we get that across the line that will be huge because it will allow providers to go into negotiations with people and say what would you like us to do for you – what do you need?

He argued that the intention was that providers would design packages to meet the needs of disabled people. Examples could include using residential care funding to help people go flatting. There were also opportunities to be more creative in the provision of respite care. For example, a provider could use flexible contracts to offer respite care that worked for families. The provider could potentially provide a carer to go on holiday with the disabled person or the parents could go away and the carer could provide the support in the home. This was reported to be difficult to achieve under existing contracts.

However, some concern was also expressed that there is a risk of provider capture if providers have access to disabled people’s funding. A representative from MIC reported that some providers appeared very keen to sign the forms and seemed overly enthusiastic about spending the money.She felt uneasy about whose needs were driving the request. She said, *“It’s just a gut feeling about what concerns me.”* To manage the risk, MIC reported there needs to be ongoing communication with providers to reinforce the message that the contracts are all about what families want – not doing what is easy for the provider.

The EGL team was aware of this concern and the Demonstration required providers who wanted to provide flexible disability support contracts to engage in an organisational review process focused on the extent to which they were aligned with the EGL principles. However, an EGL team member acknowledged that changing mind-sets takes time and that there needed to be ongoing support that enabled disabled people to get the most out of flexible support funding. If there were problems between the disabled person and the provider, the funders of the flexible disability support contracts could step in and help resolve them.

Some people need agents but these are not always easy to find, leaving these people unable to take up the funding

People without the skills and abilities to manage the funding themselves need an agent to manage their funding. This role is typically filled by a family member. However, family members were not always in a position to take on the role for a variety of reasons (eg ill-health, substance use problems, relationship breakdown, poor financial skills). Where a family member cannot take on the agent role, it can be difficult for people to find a suitable agent. Members of the EGL team interviewed reported that few people wanted to take on the responsibilities associated with being an agent. Without an agent, disabled people cannot take up the pooled funding.

An EGL team member cited an example of a young person who ran away from home when they were setting up her personal budget. The foster mother withdrew from being the young person’s agent. While the young person is now in Supported Independent Living (separately as external to the Enabling Good Lives budget), they do not have access to their very high needs ORS funding ($15,600) because they cannot be responsible for managing it. The EGL team member reported that the person could get access to it if they went to a day service as the provider could manage the funding, but that limits options. The EGL team member reported that not having an agent will become more of a problem as people age and their parents can no longer fill the role of agent.

One option could include paying people to be agents. Members of the EGL team interviewed suggested one option may be paying non-family members to be agents as an incentive for them to take up the role and to recognise the scale of the task they are taking on.

### Assumptions the development of natural supports may be unrealistic

The use of natural supports was a key feature of the design. While the term ‘natural support’ is not always clearly defined or understood, it is often seen as encompassing the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. To this end, natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. Natural supports are based on personal ties rather than payment (Duggan & Linehan, 2013).

In the Demonstration there was an assumption that people may need help in developing these connections but that these connections could help an individual build a strong community network and support system that would enhance their quality, and security, of life. The implication was that the natural supports could be developed relatively quickly (eg within the timescale of the Demonstration). Moreover there was a view that disabled people could use natural supports instead of services.

The evaluation found that this assumption may be unrealistic.

* All the schools and several providers questioned the availability and sustainability of natural supports. Even those interviewed who were supportive of the idea of using natural supports reported that growing natural supports takes time and requires the right staff to facilitate their development (see Lack of support for the concept of natural supports, page 108, and Valuing natural supports, page 118).
* Families interviewed typically had no significant natural supports outside of family and where they did exist they appeared fragile. A common theme across the cases was high levels of parental stress and poor physical and/or mental health – especially amongst the mothers. This suggests that existing natural supports may already be stretched (see Few families had significant natural supports outside of family, page 94).

Further understanding is required about how natural supports can be developed and sustained and how they can be used alongside responsive formal supports and services.

### Community development component was underdeveloped

#### It was unclear how community development was supposed to happen under EGL

It was unclear what the mechanism for change in the community was and what success would look like from whose perspective. In developing the intervention logic for Enabling Good Lives, it appeared that disabled people would be the main driver for changing attitudes, and experiences of people in the community and of community building would occur one person at a time. That is, as more disabled people participated in all aspects of ‘mainstream’ life, the general population would become more informed and less likely to hold negative stereotypes. The assumption was that positive attitudes would continue to grow as long as the presence of disabled people continued to increase and to expand in every area of life, thereby contributing to the development of more inclusive communities. EGL would facilitate this process by using a person-centred approach focusing on the use of mainstream services and community resources for assistance and not limiting assistance to what was available within specialist services.

There is some evidence that positive attitudes follow on from increased social contact between disabled and non-disabled people in the community (Abbott & McConkey, 2006). However, Hannon (2010) argues that attitudes to disability are complex and multifaceted and the attitudinal consequences of contact with disabled people are mediated by the characteristics of both the person with a disability and the person without a disability and the nature of the interaction between the two. Evidence of what works to change attitudes towards disabled people is very limited (Thompson et al., 2011). What research is available suggests that a broad approach targeting three levels (personal, organisational and structural) is required to change attitudes. However, increasing personal contact between disabled people and the general population by supporting them to access education, employment and social activities on an equal footing with everyone appears to be effective in reducing prejudice (Hannon, 2010).

#### The community development component received little attention in terms of design and resourcing

A national official stated that building welcoming, tolerant communities so that people can (a) have natural supports, and (b) be part of day-to-day life in their communities was a key element of the original concept of EGL. However, officials, the EGL team, the LAG and National EGL (NEGL) Leadership Group have all acknowledged that minimal attention has been paid to community development in the context of EGL. One LAG member reported:

I think what many of us were excited by was community development. And, you know, there’s virtually nothing that’s happened and there’s some - and you could argue that community development, really, is the essence of Enabling Good Lives –in terms of, you know, the principles and the objectives. But it is disappointing that nothing really tangible’s happened in that space.

### There was underinvestment in provider and school development to assist them to operate in line with the EGL principles

Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, providers and schools interviewed typically had had limited contact with EGL. The EGL resources dedicated to working with schools and providers on what EGL meant for their practice were limited:

* The EGL team had a person whose role it was to work with providers. Providers interviewed reported that this role was invaluable but more support was needed.
* While there was some EGL resource allocated to working with schools, the people in this role were primarily responsible for working with disabled people and families.
* Navigators had a role in changing provider and school behaviour but contact with them was limited. Some schools and providers had only a few people accessing support through EGL so had limited experience of the Demonstration. All the schools interviewed talked about including the navigators in the planning process. However, in practice the navigators had limited interaction with schools.
* The role of schools and providers was ambiguous when the Demonstration began. There was a perception, especially amongst providers, that the EGL approach promoted the use of natural supports over providers. It would have been more useful to look at what was needed to better support disabled people to live the life they want and how providers could contribute.

The lack of contact with the Demonstration meant schools and providers were unclear of their role in the Demonstration and key concepts such as ‘a good life’, ‘natural supports’ and ‘mainstream first’ were not commonly understood (see section 6. Limited change amongst schools and providers, page 100).

### Accountability arrangements could have been improved

#### Some arrangements were in place to ensure disabled people used pooled funding appropriately

In this evaluation interviewees reported that there were arrangements to ensure disabled people made appropriate use of the funding they received:

* MIC has been instrumental in advising families (see Families had some useful sources of advice and guidance but more was needed, page 63).
* Navigators have been able to provide guidance to disabled people and their families.
* The purchasing advisory panel (see The purchasing advisory panel worked well, page 64) and purchasing guidelines (see page 64) have provided assistance and guidance to disabled people and their families.

However, some interviewees involved in working with disabled people and families were concerned that they did not always fully appreciate the responsibilities they were taking on when they took up personalised funding or employed staff. An EGL team member reported that *“some people take on IF* [Individualised Funding] *and EGL with rose tinted spectacles and think great we’ve got money, we can employ who we want, we can go get this and that”.*

Research indicates that building the capacity of disabled people and their families to manage the money needs to go hand in hand with Individualised Funding, especially where people have additional vulnerabilities or restricted capacity (Fisher et al., 2010). EGL did undertake capacity-building work with families but more may be needed (see Building the capacity of disabled people to engage in planning, page 55).

#### Arrangements to safeguard disabled people were not as clear as they could have been

Some interviewees raised questions about who is responsible for safeguarding[[30]](#footnote-30) disabled people in the move towards greater personalisation of supports and services and individualised budgets. Some providers and schools interviewed questioned whether disabled people would be safe outside of their organisations. They questioned who would check that disabled people were being safely cared for in the community as not all families were well placed to meet their young person’s needs.

However, some interviewees suggested that for disabled people to develop and grow they need to be able to take risks. Not everything can be known or controlled. They suggested the way forward was a greater focus on risk enablement. This means empowering disabled people and their families to define and manage their own risks and to recognise, identify and report neglect and safeguarding issues (Carr, 2010). Empowering people to have more choice and control over what they do also means accepting that sometimes people will make mistakes or fail. *“This is what is meant by the dignity of risk”* (Reinders & Schalock, 2014: 293).

For the EGL team this meant asking disabled people and their families what they wanted and helping them work through what could be done safely (eg taking the bus with a friend, using their smart phone to take pictures of their location or text where they were). For example, the navigators sought to empower families to take reasonable risks within the bounds of what they were comfortable with. The EGL team found if they *“went with people’s value systems and where they’re at”* people were willing to try new activities they had initially perceived as riskier. Disabled people and their families were encouraged to talk with other families about how they managed risks.

Nevertheless some interviewees cautioned that service providers and families are not necessarily safe places for disabled people. The EGL team reported that there is a group of disabled people who are at risk because they don’t have enough supports and they don’t have enough people in their life who will help them manage risk.

The EGL team reported challenges in safeguarding vulnerable people, including the:

* difficulty determining what to do in situations where people’s circumstances cross boundaries. For example, an EGL team member reported that it is difficult to get co-ordinated support where people have mental health concerns alongside an intellectual disability. Supports and services were fragmented and compartmentalised
* lack of clarity about what was the role of EGL staff and what was the role of other agencies
* limited number of hours navigators had to work with someone – for those in vulnerable situations it could take a long time working with them to set up safeguarding arrangements.

#### Accountability arrangements with providers and schools didn’t reflect that focus on outcomes for disabled people

Schalock et al. (2016) suggest a key component of organisational accountability is the degree to which the organisation’s intended results are achieved from the perspective of the client. There were some examples of organisations asking disabled people about their experience, with the aim of improving their practice. For example, the EGL team commissioned interviews with disabled people to understand their experience of EGL. MIC undertakes a survey of disabled people every two years. They reported that they often randomly call people to find out how things are going and if there is something that they could be doing. They also hold network meetings in different locations where people can come together to provide feedback on what the organisation could do better.

However, schools, providers, the EGL team, the LAG, the National EGL Leadership Group and officials all reported that it was difficult to tell whether or not what they were doing was making a difference for disabled people. Few of the organisations interviewed had formal systems in place to measure outcomes for disabled people from their perspective. There was reliance on anecdotal evidence of outcomes for disabled people, for example:

* hearing people’s stories of what was working or not working
* assuming that if they did not hear complaints disabled people and their families were satisfied with the service they were receiving
* discussing with staff about how clients were progressing.

There were only limited examples of organisations attempting to systematically gather information on outcomes for disabled people to measure progress. For example, one provider was now requiring its staff to meet with disabled people and their families every six months to discuss progress against the goals and activities listed for them and what needed to change. This is a change from what they previously did. Before making this change, they had felt more accountable to the central government agencies whom they reported to, but now they felt they were more accountable to clients and family. *“I like that, that we are accountable to the person ... that is the correct philosophy.”* The focus was on continuous improvement. Another provider was working to establish a formal system for collecting outcomes information.

There were few incentives for organisations to focus on delivering outcomes for disabled people. Several interviewees reported that:

* contracts between agencies and providers did not focus on outcomes for disabled people
* organisations working with disabled people were not necessarily required to report on what outcomes disabled people attending their service or purchasing their supports achieved
* there were few checks in place on what providers were doing: an interviewee who worked with providers reported that it was unclear who checked whether providers delivered what they said they would deliver, for example whether a one-to-one service was provided if that was what was promised to the disabled person. The interviewee questioned what help was available to support families trying to deal with providers who did not deliver what was promised. Similarly schools were encouraged to develop Individual Education Plans and all those interviewed reported undertaking them. However, an interviewee reported there were few checks to ensure what was in the plan was carried out. Schools were reviewed every three to five years by the Education Review Office ERO and they may see the plans, but an official reported that what schools say they do may not reflect what they actually do in practice.

At a national level, agency officials interviewed did not see themselves as accountable to disabled people. They typically reported that they were accountable to their managers and Ministers. In contrast, the EGL team, the LAG and the NEGL Leadership Group reported they were accountable to disabled people and their families.

## Fully developing the components and improving support for the Demonstration could have strengthened implementation

### A more fully developed design was needed

The Cabinet paper stated that the Demonstration would be a working model of how the cross-government disability support system could operate in line with the overall vision and principles of ‘EGL’. At the time implementation began, this model was not in place because it was not possible within the timeframes allowed.

Key elements of the Demonstration were not designed before it began. These included:

* the range of options for disabled people to take up and manage their funding
* the role of schools and providers in enabling disabled people to have the life they want and how they can best support disabled people
* how providers would be paid
* accountability arrangements
* how community would be developed and how this would benefit disabled people.

#### Development of a detailed design was hindered by several factors

There was broad agreement that the co-design process[[31]](#footnote-31) involved collaboration between government agencies and representatives of disabled people, their families and providers. However, over the course of the Demonstration it became clear that the participants had different understandings of the process.

There were two different perspectives on the flexibility of the design, both of which were problematic

There were different understandings of what the design would entail and the extent to which it should be allowed to develop. For example, the EGL team and some Ministry staff saw the Demonstration as a developmental model based on the principles. In this process the design was seen as something fluid that evolved over time. This requires that there is an initial detailed design but this is amended as feedback on implementation is gained. However, there were limited systems in place to support this feedback happening and being acted on.

Alternatively most Ministry staff interviewed stated that a fixed working model should be put in place and tested before making changes to scope or scale. This approach requires that the Demonstration be fully designed prior to implementation so that any evaluation can be an accurate test of performance. However, this was not the case as all the components of the Demonstration were not designed when implementation began. Design work carried on after the design phase had officially ended. The performance of elements not implemented until the end of the Demonstration could not be tested.

There was not a shared understanding of what co-design meant in practice in the context of the Demonstration and whether it had been co-designed

In the first evaluation, stakeholders interviewed reported that the Demonstration had been co-designed. In the second evaluation, stakeholders held different views. GMs and some Wellington officials were of the view the Demonstration was co-designed but at a local level officials and the EGL team were less convinced. The LAG, in particular, was strongly of the view the Demonstration was not co-designed.

These differing perspectives on whether the Demonstration was co-designed were driven by their different views of what constituted co-design. At a local level, co-design was reported to be about shared decision-making and partnership. There was an expectation that ideally no one partner would have any more power and control than the others. The co-design process was seen as more akin to co-development and as an ongoing process (see figure below). The ‘co-development’ approach ensures that all stakeholders’ perspectives are present in the design, implementation and monitoring of the approach.

The NEGL indicated that the discrepancy arose because initial discussions about the design of EGL talked about sharing governance of cross-Ministries system reform as opposed to just ‘co-design’ (Boxhall & Benjamin, 2012). According to the NEGL, the ‘co-design’ term came later and in many respects is a sub-set of ‘co-development’. In the case of an EGL approach, the identified groups included: disabled persons, disabled persons organisations, families, family networks, local service providers and provider networks and officials. The NEGL reported that, from their perspective, when some parties began to use the term ‘co-design’ there was some confusion, as the initial approach to the development of EGL had signalled something broader and had increased expectations.

**Improve outcomes for disabled people**

**Implementation**

**Co-designed Demonstration**

* **Local Advisory Group**
* **Representatives from MSD, MOH and MOE**

At a national level amongst officials and GMs co-design was seen as a more linear process and separate from implementation. Their expectation was that co-design would involve disabled people, families (represented by the LAG) and government working together on the design only. They were clear that co-design was not the same as co-development.

**Improve outcomes for disabled people**

**Implementation**

**Co-designed Demonstration**

* **Local Advisory Group**
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From the perspective of GMs and officials interviewed they had involved the LAG in the design of the Demonstration. However, the GMs acknowledged the boundaries of co-design could have been clearer. They reported it would have been helpful to explain that agencies did not have to accept the advice put forward by the LAG. As one GM reported:

in terms of level of input and time for input from local people and disabled people, you’d give it a huge tick. And we also took real care and – when we were writing papers for the Ministers that we would put their voice in but we’re really clear that we actually might even get other advice around that. So I think that was also an important point so that – it [the LAG] had the opportunity and Ministers had the opportunity to see their voice but we preserved the right to put our advice in the preliminary part of that.

The GMs and the LAG agreed it would also have been helpful to clarify what the design could and could not include at the outset. For example, agencies could not negotiate on everything (eg carrying funding over from one year to the next, agency processes for employing someone, requirements of the Privacy Act).

Co-design needed more time and resource

Co-design processes typically take more time than a traditional design process (Brotchie, 2013). Some local officials and the GMs acknowledge that in hindsight expectations about the speed of change may have been unrealistic. The LAG considered that more preparation in the very early stages before the Demonstration started may have enabled everyone involved to:

* develop a shared and deep understanding of what they were trying to do and how. This would have included agreeing on what the principles and key concepts such as co-design and fiscal neutrality meant in practice
* develop the components (eg options for managing the funding) and have them ready to go prior to implementation
* identify potential problems and put steps in place to resolve them. For example, what are the downstream tax consequences of providing people with individualised budgets? How can people who do not have an agent take up individualised budgets? What implications does having a fiscally neutral Demonstration budget[[32]](#footnote-32) have for the funding providers receive?

The evaluation found that some key people did not have enough time to contribute in the way they needed to. For the LAG and the GMs the design of EGL was in addition to their other work. They reported that they often did not have enough time to spend on the design. As one GM reported:

I think one of the challenges was that for us, it was part of our workload and so we couldn’t invest the time, perhaps, that we needed to and also, for the Local Advisory Group, it was an add-on to whatever their other commitments were. I don’t know; we could have managed that better maybe.

Better links between design and implementation were needed

Once implementation began it was unclear if or how implementation should inform the design of the Demonstration. There were problems translating what had been agreed in the design into practice. The GMs interviewed acknowledged that it would have been useful to have checked more with the LAG that the operationalisation of the design reflected what had been agreed on. For example, a GM reported:

I think the disaffection of the Local Advisory Group indicates that we might not have followed through with the co-design as well as we should have. They seem to have got a bit marginalised through the process and their voice wasn’t being heard and we started having to make special trips down to talk with them and that shouldn’t have happened. So something sort of went missing somewhere in the middle there and they – who were our key sort of co-design people as well got sort of left out of it.

### Understanding of and buy-in to the EGL vision across stakeholders needed to improve

Evidence from multiple sources suggests one of the key principles in bringing about change is creating and communicating a clear vision of the future (Duffy, 2004; Forder et al., 2012; Mitchell et al., 2015; Schalock & Verdugo, 2012). In the case of the Christchurch Demonstration this meant there needed to be widespread understanding of and buy-in to the EGL vision.

#### **Steps were taken to build a common vision across stakeholders**

Positive steps were taken to build a common vision across stakeholders. These included:

* *using the principles to unify stakeholders*: Stakeholders reported that having the principles helped to begin to build a common understanding and framework
* *using community meetings to build a common understanding:* The NEGL reported that the initial community meetings with disabled persons, families and providers were a good start to building a common vision and it would have been useful if this work had continued when the Demonstration got under way
* *undertaking ongoing work with stakeholders to build understanding* (eg schools, providers, local officials such as the NASC in Christchurch led to a better understanding of the EGL components and improved relationships. An EGL team member reported provider support for the EGL approach was improved by clearer communication with providers on their role in EGL undertaking provider development work. This included running workshops and holding monthly lunchbox sessions to talk about different aspects of the EGL approach. Two peak bodies New Zealand Disability Support Network (NZDSN) and Inclusive NZ are supportive of EGL and have also run workshops with providers.

#### Nevertheless there was not a deep and shared understanding of the EGL principles or the purpose of the Demonstration

More time was needed to build a common understanding of the Demonstration’s purpose

The purpose of the Demonstration was not something all stakeholders interviewed agreed on. There was agreement amongst stakeholders interviewed that the Demonstration was about pooling funding and increased choice and control to improve the outcomes for disabled people. However, there was not agreement on whether or notthe Demonstration was intended to transform the disability support system. Wellington officials typically reported that this was not the purpose of the Demonstration. Their view was that the Demonstration was intended to gather evidence to inform future government advice. In contrast, other stakeholders were of the view that the Demonstration was about system transformation and was the first stage in national roll-out. Taking more time initially to build understanding of the purpose amongst stakeholders including agencies would have helped. Some local officials and the GMs acknowledge that in hindsight expectations about the speed of change may have been unrealistic.

Understanding of the EGL principles and other key terms was not shared

While stakeholders typically reported they agreed with the EGL principles, there was not a shared understanding of what the principles and key terms related to the Demonstration meant in practice. For example, there was variable buy-in to and understanding of the EGL principles by providers and schools. Terms such as ‘co-design’ (see There was not a shared understanding of what co-design meant in practice in the context of the Demonstration, page 38), ‘fiscally neutral’, the ‘EGL principles’ (especially ‘mainstream first’) and ‘independent facilitation’ were not commonly understood by stakeholders.

The outcomes the Demonstration was focusing on were unclear

The vision for the EGL approach is that disabled people and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports in their communities. What the outcome of this would be for disabled people and their families was not clearly articulated.

Existing research indicates that a key element of effective partnerships is having a focus on shared outcomes rather than outputs and processes. All the stakeholders need to have a shared understanding of final outcomes. Measurable goals that can be clearly defined and evaluated, and an emphasis on the quality and distribution as well as the quantity of outcomes, are important. Without clearly defined goals and outcomes, there is a danger that partnerships can be drawn into the minutiae of the process, rather than focusing on implementing change (Ball & Maginn, 2005, in Lindsay et al., 2008; Brotchie, 2013).

### Leadership could have better supported implementation

Literature looking at how to bring about social change identifies leadership as a critical factor in the process (Genio, 2014; Brotchie, 2013; Schalock et al., 2016).

#### There was lack of clarity about who was responsible for the Demonstration

Interviewees expressed different views on who was responsible for leadership of the Demonstration. The degree of responsibility the Director and the GMs had for the Demonstration was not something everyone agreed on.

GMs saw the Director as being solely accountable for the Demonstration’s implementation and outcomes

From the perspective of the GMs, the Director was solely accountable for the Demonstration’s implementation and outcomes. The GMs agreed that many would see accountability resting with the Joint Agency Group but in their view the GMs are only accountable for direction setting. The GMs reported that the Director’s leadership was one of the reasons the Demonstration has struggled. They felt the Director was not able to adequately explain the Demonstration’s vision to all the stakeholders involved, resulting in a less than coherent implementation. However, they agreed this was not a shared understanding and admitted that, if the Demonstration failed, it is unclear where people would see that failure sitting.

Schalock et al. (2016) argue that leadership needs to be transformational and strategic. However, this is also required at many levels. Genio (2014:10) adds:

*While the presence of a charismatic and committed leader is very helpful, our learning indicates that multi-level leadership is at least as important. Multi-level leadership means there is ‘a champion’ at all levels of the organisation and in other key groups, who supports and drives the move to a* new way of supporting those using the service.

Many saw the GMs as the real leaders behind the Demonstration

The GMs reported that there was a high level of agreement between them and they worked well together. They felt they had a lot of commitment to and ownership of EGL. Others agreed with this perception. The Director, for example, reported that *“it feels that GMs are pretty well aligned”.*

However, there was also concern expressed about the GM’s leadership role. The Director reported that while the unity of the GMs was a strength it was experienced as exclusionary. He reported, *“They’ve worked it out and then I meet them. So I’m not part – so, that’s the frustrating thing. I’m not part of that. Okay. Again, I feel I’ve got something to offer to that.”* The LAG, the team in Christchurch and some officials reported that the GMs exerted too much control over the Demonstration and were in fact the real leaders behind the Demonstration. For example, one official reported that:

While the Demonstration Director was notionally responsible for leadership, in effect he had almost no authority. In practice, the unofficial General Managers Group, and to a lesser extent, Joint Agency Group, were the effective decision-makers on what did and not happen in the Demonstration.

However, some officials felt the GMs were not involved enough

Some officials interviewed felt the GMs and JAG were not involved enough. Some officials felt the Demonstration needed more attention from the JAG and GMs so that they had a better understanding, greater support, and knowledge of what was happening on the ground. The GMs agreed that the Demonstration would have benefited from their greater input. They reported that they have learnt they probably sat back too much, especially during the co-design process and that *“officials needed to be equal partners – not just facilitators”.* This was another example of the mismatch in expectations between the LAG and senior managers within the agencies.

#### Leadership from the Ministries did not appear transparent, joined up or consistent with achieving outcomes to those on the ground

Decision-making within the Ministries was difficult to navigate

Interviews with the team in Christchurch and the LAG revealed they were not always clear how decision-making worked within the Ministries. This was seen as being especially true of MSD. For example, the Director reported that with the Ministry of Health’s DSS, it was clear where to go to get a decision made but this was not the case within MSD – *“In MSD it’s just so – so big. And so many jobs that are very similar yet not quite the same. You think, ‘I don’t know where I’m going.’”* He added that the separation between policy and contracting and operations only added to the complexity.

Officials interviewed reported that part of the problem was that the team in Christchurch and the LAG did not always have a good understanding of the government processes. Unfamiliarity with the processes contributed to frustrations with government decision-making.

Agencies were seen as slow to act on matters that affected the implementation

Interviews with providers, the LAG and the Demonstration team in Christchurch reported that agencies were slow to identify potential problems and slow to make decisions that affected the implementation of the Demonstration. According to the Director, the time it took agencies to make decisions compromised the ability of the team in Christchurch to make changes quickly enough to minimise the impact on groups such as disabled people or providers. For example, the Demonstration began in late 2013 but it took until June 2014 to resolve the issue of disabled people being charged GST where they were not changing their arrangements and for providers to get paid on time. Interviewees reported that delays appeared to occur because of the need to consult with various agencies or because key people could not devote enough time to working on the problems.

The LAG felt issues such as this could have been anticipated. As one LAG member interviewed reported:

there didn’t seem to be any kind of forward thinking in terms of okay, if we are seeking to make these changes in the system – in the current system, you know – what are the downstream effects of that? And, you know, the GST is a good example of that.

Designing and putting in place a range of options for disabled people to take up and manage the money was also problematic. One EGL team member reported that sometimes the policies and bureaucracy seemed to get in the way. *“Often we feel as though we are being surrounded by a can’t-do attitude rather than a can-do attitude.”*

Agencies did not appear joined up in their actions

While the GMs considered that the EGL was one of the better examples of interagency cooperation, this was not the experience of those on the ground in Christchurch. Interviews with the team in Christchurch, the LAG and some providers revealed that:

* the Ministries’ engagement in the Demonstration was perceived as variable, with some Ministries seen as taking a more active role than others
* communication within the Ministries was seen as problematic, especially MSD. As one EGL team member reported, *“within MSD it seems Policy don’t talk to Contracts and vice versa then they go and do their own thing and boom. Policy and Contracts don’t always to talk to us”*.

Decisions were made that did not appear to align with the EGL principles

The agencies reported that they supported the EGL principles. However, local officials, the EGL team and providers reported being frustrated that the Ministries made decisions that appeared to be at odds with the principles and what the design of the Demonstration was trying to achieve. For example, the Ministries were not seen by the LAG as acting in accordance with the principles when they decided to focus the purchasing guidelines on the purchase of services as opposed to things. The LAG had advocated for the guidelines to be broad and to enable a range of different purchasing options which they believed were consistent with the principles (eg mana enhancing, self-determination). As a LAG member reported:

To find that actually, that there was a view within officialdom that actually, we need to reduce the scope and we need to actually be really clear that it’s about services and it’s not about things. And so, I think it’s difficult to make an argument other than that’s not the right thing to do in respect of the principles. So I guess that's what I mean, in terms of selective application of the principles.

An EGL team member suggested that one way the agencies could act more in accordance with the principles would be to require providers to provide information on how they are addressing the principles eg how they were helping people work towards greater self-determination. The view was that if contract managers gave providers feedback on the reports they completed this would encourage behaviour change in line with the principles. The team member added:

It’s important for system change. I find it ironic that we talk about what others need to do to change but don’t do it ourselves. Leadership comes from leading – not forcing. The Ministries need to lead by example.

Schalock and Verdugo (2012) argue that to improve outcomes for disabled people it is crucial that system-level processes are aligned with the outcomes being sought.

#### LAG and National EGL Leadership Group reported their leadership in the Demonstration was constrained

LAG expected shared decision-making but the LAG was not set up for this

The LAG reported that in the initial stages the paperwork[[33]](#footnote-33) described them as a governance group but that the documentation changed and they were referred to as an advisory group to provide advice to the Demonstration Director. The Terms of Reference for the LAG explicitly said that the LAG was not a decision-making group. Nevertheless the LAG expected to be involved as equal partners in decision-making about the shape of EGL and as result, they were frustrated by:

* *their lack of power to make decisions.* The LAG reported that being only an advisory group limited the effectiveness of their input as officials could choose whether or not to listen to their advice
* *what they perceived as selective engagement by the Ministries:* There was a perception that the Ministries consulted with the LAG when it was beneficial to do so but avoided consultation when it was not
* *decisions affecting the Demonstration being made by agencies without consultation with the LAG:* The LAG reported that decision-making was not shared. They reported that as the conversations became perhaps more difficult, they started to be left out of decision-making and were just being told what to do
* *officials not understanding how to interact meaningfully with the LAG:* For example, officials set up 12 work streams to progress the Demonstration. For the LAG there was an overwhelming amount of paperwork associated with the work streams that they were expected to read and comment on within days of decisions being made. As one LAG member reported, *“really, with all the will in the world, with our day jobs, we haven’t got time to go over that paperwork”.* They would have preferred officials to develop options – having worked out what they can give and take on – and given them sufficient time to provide feedback.

National EGL Leadership Group had limited ability to exercise leadership

An NEGL representative reported that the National Leadership Group was not in a position to exercise leadership effectively in the Demonstration. His view was that if the National Leadership Group was to have been framed as providing leadership to the Demonstration, flows of information and decision-making should have been altered. In their experience they were sometimes participating in discussions well after key decisions had already been made – not an ideal situation if they were to demonstrate “leadership”.

The EGL approach advocates “co-governance”. The NEGL representative saw the current situation as a step towards this. His view of “co-governance” by a group comprising officials, disabled persons, families and providers is a valid aspiration. Ideally, there would be a clear link between a “co-governance” national body and a “co-governance” local body.

### There were wider problems with the system which likely limited implementation and performance

The Demonstration, like any initiative, did not take place in a vacuum. There were external factors that influenced implementation and performance.

#### Limited range of housing options in Christchurch

Over the past two decades, research has consistently shown that living in the community is superior to living in institutions (Francis et al., 2014; Lakin et al., 2011). However, families interviewed reported that there are few housing options for disabled people in Christchurch other than living at home with family or in residential care. This is especially the case for disabled people who need considerable support with their day-to-day activities. For example, two families who had opted for residential care for their young person reported they would have preferred something else. For example, one parent said:

And, you know, even though I think, in a perfect world, [we] might have preferred something in between full-time care at [residential provider] and living at home, that sort of intermediate arrangements or arrangement isn’t really feasible.

At the time of the evaluation, Choices in Community Living was not available in Christchurch[[34]](#footnote-34).

There were also difficulties for those with higher levels of functioning. A supported housing provider reported that they had leased places across Christchurch but landlords were not always willing to take on disabled people. With demand for rental accommodation high since the earthquake they could afford to turn people away. As the provider reported: *“It’s a different situation here with the earthquake. It’s hard to get landlords to take people with an intellectual disability and you need a guarantor for them”*. The provider had operated as the guarantor for disabled people in these situations.

#### Some reported difficulty accessing appropriate services

Difficulties for people who have mental health problems as well as disability

A provider and members of the EGL team reported that there were difficulties in meeting the needs of disabled people who also had mental health problems. The main difficulties were that:

* the mental health problems were not always diagnosed, at all or in a timely way, because the focus was on the person’s disability
* service delivery was compartmentalised. For example, a provider and the EGL team both reported instances where they struggled to get mental health assistance for people with a disability who were threatening self-harm. The NASC funds support for disabled people but not mental health problems, which are dealt with by *“a whole other system”*.

A provider interviewed reported that the lack of co-ordination between mental health and disability services was becoming more of a problem because in their experience the incidence of people with dual diagnosis was increasing.

Access to appropriate services for young people ageing out of child services can be problematic

A supported housing provider reported that it was difficult getting services and supports for young disabled people once they were considered adults. In their experience once people are no longer attached to a service such as Child, Youth and Family (CYF) or a provider and have limited family support they receive limited assistance.

Some families reported difficulty accessing the right health services for their young person once they reached the age of 16. At this point they transferred to the adult health services, which were not always well set up to meet their needs. A parent described these services as *“a big joke”.* The young person had yearly check-ups with a paediatrician up until the age of 16. Once he was 16, however, the family lost this specialist support and were expected to access health services via their GP or the hospital’s emergency department. It took some time to find a GP who specialised in people with special needs and the medication required. She reported that prior to this her son was overmedicated and had poor appetite.

Access to disability support services

Families interviewed reported difficulties in accessing the types of services they wanted when they wanted them (see Access to and experience of supports and services were problematic, page 95).

# Families’ and disabled people’s experience of EGL was positive but there were some difficulties

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| **Summary**  Navigation and planning:   * Case study data revealed families were often sceptical about EGL when they first heard about it. * Families did not engage or were reluctant to engage in navigation where they had no opportunity to talk to the navigator, were not open to navigation, did not believe their family fitted with EGL, or did not expect their young person to grow or develop further. * Where families did engage in planning, it was largely a positive experience. The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there. * Practices that supported engagement in navigation included making disabled people central to the planning process, building the capacity of disabled people and their families to engage, having independent facilitation (although alternatives were also raised), and having other parents who had been through EGL to walk alongside new people.   Use of the funding:   * Most participants had received funding. As at 9 October 2015, 129 of the 175 EGL participants had been allocated funding. This funding could be used flexibly to purchase supports and services. * Being financially literate and well resourced assisted people to take up the funding and manage it. There were practices that supported disabled people and families but there was room to improve. * The amount of funding may have been insufficient in some contexts. These included contexts where the young person wanted to live independently in the community but the cost was a significant barrier and where families were on lower incomes and the amount of funding they received may have been insufficient. The funding may be insufficient to support disabled people’s choices where family cannot be involved in the day-to-day care of their young disabled. Some interviewees reported that taking up Funded Family Care limited the overall pool of funding but the families did not always feel they had an alternative. * Families had some useful sources of advice and guidance but more was needed. MIC was instrumental in advising families, and the purchasing advisory panel worked well, but families were not always clear about why some services were funded and others were not. There was a need to clarify elements of the purchasing guidelines. |

## Engaging and planning with EGL was a largely positive experience

### Across the Demonstration most EGL participants had a navigator

Most (152) of the 175 EGL participants as at 9 October 2015 had a navigator. Of this number, nine were listed as ‘navigator only’; that is, they were not receiving EGL funding.

Not everyone who was eligible to be part of the Demonstration has engaged with a navigator. Of the 175 EGL participants as at 9 October 2015, 12 had chosen not to take up navigation but eight had taken up the EGL funding. A further nine people did not have navigators assigned to them because they were newly referred, were in the process of choosing a navigator, or were listed as not ready to engage with a navigator. In two more cases it was unclear why they did not have a navigator. An additional three EGL participants had an external navigator.

### Rationale for whether or not to engage with EGL varied

The case study research explored disabled people’s and their families’ rationale for engaging or not with the navigators and the planning process.

#### Families were often sceptical about EGL when they first heard about it but those who engaged thought it might improve outcomes

Across the cases families typically reported viewing EGL with scepticism or wariness when they initially heard about the Demonstration. Concerns were specific to the individual families eg fear of the unknown, fear of managing the money, fear the good parts of the old system would be lost, cynicism EGL would live up to the hype. For example, one parent said her initial thoughts were *“oh no not another thing people are trying to make work that then falls flat on its face”*.

In the cases where families agreed to participate in EGL they did so because they believed EGL would allow them to create a life for their disabled person in the community with more choice and control over what they did and with whom. The families and, where possible, the disabled person expressed a desire for the disabled person to live as normal a life as possible in the community. For example, a parent of a young person with a profound intellectual disability said:

We just didn’t – we couldn’t imagine [our young person] going into like a day base or something like that –you know. And look, for some people the day base is a great network well, but for us, we just wanted – we wanted [our young person] to be out and about and doing and – so the timing of Enabling Good Lives for our family and the fact that we met the criteria was huge. And we’re so thankful that we were able to jump on board.

The families who engaged in planning shared some characteristics:

* The parents all had a strong sense of agency. All the parents interviewed described themselves as proactive in searching for something better for their young person.
* Parents all had an expectation that their young person would live in the community and learn and grow. They all felt this could happen with the right support. They wanted their young person to do something similar to what other young people their age were doing. For example, the mother of a young person with a profound intellectual disability felt it was important to think of what is possible. She said, “*You might think well my kid can’t. No, your kid can. Anything is possible. Anything is possible.”* She added that others may not agree: “*I can recall we talked about flatting. There was some discussion at LifeLinks* [NASC] *– ‘oh if he goes flatting’ – that sort of thing.”*
* They were unhappy with where life was at for their disabled person prior to EGL.

#### The mind-sets of the families who did not engage with EGL or had made limited change were different from those who did engage

All the families who placed their young person in residential care had a plan of action for their young person but this didn’t necessarily involve EGL. Only one of the families had engaged with EGL and a navigator. All of the young people in these cases had previously attended special education schools.

When looking at the two cases where the families had not engaged or were reluctant to engage in navigation some common themes emerged.

Non-engagers had limited or no contact with navigators and were not open to navigation

In two of the cases the families were not open to navigation. In one case the family was offended by EGL offering a navigator. The family had actively sought out residential care. They stressed they were more than capable of deciding what was best for their young person – they had a strong sense of agency. They felt they could do it themselves and the navigator was a waste of money. They saw the need for navigation as a sign that the system was broken and overly complicated. They wanted to be able to take the money and spend it where they thought it would best benefit their young person. The parent commented:

[We] really felt affronted by this, I suppose, at one point, when they offered us a navigator. So part of me says Vote Health, Vote Disability spent on a person to help me – an intelligent person – wade through a system that is so complicated I can’t work it out myself and we both felt pretty annoyed by that and so didn’t agree to a navigator.

In another case the young person was placed in residential care before Enabling Good Lives existed. The parent interviewed only half-heartedly reported that a navigator might have helped them to look at options for their young person post-school. The family wanted their young person to stay in residential care but to have something to do during the day when he left school. When the time came for the young person to leave school the family reported that they had received little information about EGL. The school had suggested a range of day services for the young person to attend post-school and the family had selected one of these. While the family expressed some misgivings about their current care arrangements it is unlikely they will change. The family reported that setting up a life in the community for their disabled person was too daunting and living at home was not an option.

Non-engagers did not expect their young person to grow or develop further

In two of the cases the families were looking to carry on with similar activities post- school to what the young person had done at school. They described the young person as if they were a child and had few expectations of any growth or change. We do not know if this would have changed had they had contact with a navigator.

The navigators had to work against such attitudes. As one EGL staff member reported:

And I think, you know, we’re working against for most of these young people 20 years of families being told this is what, you know, just go for mediocre because that’s what a disabled life should look like, and things like that. So, trying to do a massive culture change within families as well as – and this is just some families.

Non-engagers and those that had made no change since engaging with EGL did not believe their family fitted with EGL

In all cases where the families had placed their young people in residential care they reported EGL had unrealistic expectations of families. They saw EGL as being about families actively supporting their young people to live in the community – often living at home.

In all of the cases the families did not believe they had the time and energy to plan or co-ordinate a life in the community for their young person. Reasons for this include:

* *work commitments*: In two of the cases both parents worked and the prospect of managing employees or activities in the community was daunting. In one case they had tried it prior to EGL and found managing work and their young person’s carers too difficult
* *parental health problems*: In two of the cases the mothers reported their poor health made them reluctant to take on the role of co-ordinating a life in the community for their young person. They felt EGL was unrealistic for more vulnerable families
* *having their young person at home was not an option:* They saw EGL as being about young people living in the community. All the families wanted was their young person to be in an environment where they were cared for but they did not see that as being at home. However, housing options in the community for HN and VHN young people were limited.

However, looking across all the cases where EGL changed mind-sets, this change was long lasting

Almost all the disabled people and their families interviewed talked positively about the impact that EGL had had on how they thought about what was possible for their young person. For some it confirmed views they had already, whereas for others the change in mind-set was more profound. In any case this change was long lasting.

This was most evident in the case where EGL had not lived up to their expectations. The parent acknowledged that even though they were not using the navigator the process of thinking about what might be next for her young person had stayed with them. They were not using the plan that was developed under EGL as it was no longer useful but they were planning to find a carer. She reported that they wouldn’t be where they were now without Enabling Good Lives and it had made them think more outside the square.

### Use and experience of navigation and planning varied

#### Where families did engage in planning it was largely a positive experience

In cases where the navigator was involved, families were typically positive about that involvement. Families especially valued the navigators for broadened thinking about what was possible. Families also reported that the navigators were good at keeping them on track, providing reassurance, and being able to look at situations unemotionally. Parents commented:

[The navigator’s] involvement meant we kept moving forward. He was great at giving us jobs to do to keep the momentum up. He was great when we got a bit discouraged. He also did his fair share of jobs too.

Knowing the navigator is still there and you can call on them is fantastic.

In one of the cases the family did not have a good experience with planning and navigation. They reported that EGL did not live up to their expectations. Their initial involvement in EGL was positive and their hopes were quite high but then *“it dropped away”.* The parent and the disabled person felt the navigator built up their ideas of what they could do but this was not followed up with adequate support. Once engaged with EGL they reported difficulty re-engaging support services (eg CCS, IHC, IDEA services). Previously these organisations had supported them but once they were with EGL the family reported they were reluctant to help.

#### Navigators were more beneficial to some families than others

The evaluation found navigators were especially helpful for disabled people and their families who struggled to think about a good life and/or how to get there (Figure 3). Based on their previous experiences, families sometimes had low expectations of what was possible for their young people and navigators could help change that. In this context the navigator could be a vehicle to explore ideas, suggest new possibilities and help shape a future. For example, one parent reported that in working with the navigator she realised and accepted *“how institutionalised I had become in my thinking”* and how she had normalised an awful situation. They had tried to make the decision to place their young person in residential care *“ok”* in their minds by pretending that the residential provider was doing a good job caring for their young person – *“that it isn’t really that bad”*. She added that for many parents in her situation there may be resistance initially to looking at something different but the navigator had given her time to adjust, deal with her guilt and shift her thinking. Of EGL she now thinks *“what a good idea – let’s do it”*.

Navigators were also especially helpful for families who wanted something different for their young person but were not sure how to go about it. As one parent reported:

I mean if we needed it we can ring her and talk to her and that but and so we know that, you know, that she’s there. So, and initially that was, you know, really great and we really did need her for that initial … because we were going from having people, everybody doing it for us – to being, having to do it ourselves.

Figure 3. Types of families navigators attempt to engage with

However, where disabled people and families had a clear sense of what they wanted and how to get there, the influence of the navigators appeared more limited. In these cases the navigator was not always the only person guiding planning, or even very prominent in helping the family. This was especially so where families had opted into EGL. For example, in one case a family had pushed to be included in the Demonstration. From the outset the family had a very clear sense of what they wanted out of the process. Engaging in the planning process was seen as a necessary step in getting access to the EGL funding. Beyond that the planning process and meetings with the navigator did not mean a great deal to the family.

In another case the initial planning with the navigator appears to have been the beginning of an ongoing process of planning where to next. The navigator was involved in the initial planning process but the parent now discussed future plans for his young person with the carer employed to assist the family. The navigator had limited involvement.

### Planning practices that supported disabled people and families

Making sure the disabled person is central to the planning process with the navigators

Most interviewees engaged in planning agreed having a navigator who was focused on the disabled person was useful. Interviews with navigators and families engaged in navigation revealed the following practices helped the navigators place the disabled person at the centre of the process:

* *building a relationship with the disabled person starting from where they were at:* Disabled people and their families were at different stages of readiness to think about what a good life looked like for them and planning how to achieve it. Navigators reported that they started by asking the disabled person questions about what they wanted and worked from there. For example, a navigator said they asked:

“What are your dreams? Where do you want to be in 10 years’ time?” And then write that vision. “What are some of the small steps we can take to get you there?” So we’ve got that and then we start to talk about, how can we make those small steps happen? We talk about natural support – “Who’s around you that could help you get there?” And then we start talking about paid support

* *having a fluid planning process where the content/layout of the plans is not fixed*: Not having a fixed process or plan type allows the navigator to work with where the person is at and how they want to engage. For example, some disabled people and families wanted detailed plans or to see them displayed visually. Others, according to a member of the EGL team, had limited willingness or ability to engage in the detail of their plans but there was an agreed broad direction.

Independent facilitation was seen as beneficial but alternatives were raised

The EGL team considered that independent navigators were beneficial because they focused on the disabled person – not an organisation’s needs. As one EGL team member reported, *“they have no buy-in with any other organisation or any other group, truly there for that person. The only bias we have is that person has to be awesome”.* Instead of being channelled down a certain direction, an EGL team member reported that disabled people and their families have the opportunity to engage with someone who is independent and is seen as an ally who thinks about the disabled person’s whole life. He said traditionally organisations have been good at segmenting people’s lives. Blocks of activities have been found with the focus on filling up people’s lives rather than looking at their lives in a connected way. A navigator added that until disabled people were accepted as part of the community like everyone else, there would be a need for some disabled people to have an independent ally at key points in their lives.

However, others raised alternatives to independent facilitation. Some providers interviewed thought that they could undertake navigation and still be focused on the needs of the person. For example, one provider reported that the notion that providers could not provide person-centred navigation was untrue and based on false assumptions that providers would not look out for the best interests of the disabled person.

I think we’ve been able to demonstrate actually, you know, this - the function of navigation can actually sit quite comfortably in a provider organisation … That sort of navigation function could work within a provider organisation where people are being connected into, you know, a course at the Polytech or into a job … Some of that ongoing support would still be provided by that provider organisation but the actual function of navigation, which is, you know, facilitation and connection, whatever, call it what you will, you know, could still I think operate to a large degree within that sort of provider.

A person who worked with disabled people commented that if providers did undertake navigation the navigators needed to be separate from the other functions. If they have other roles they will be spread too thinly.

The possibility of families acting as navigators was also raised (see below).

Having other parents who have been through EGL to walk alongside new people

Some families reported that having the support of other parents who had experienced EGL was valued and should be encouraged more. For example, a parent reported she felt very strongly that parents new to EGL should have other parents who had been through EGL to walk alongside them, along with the navigator. She reported she had seen people who *“were too scared to step out. It also brings those people into a community”*. She felt it was important to build the community so that families could share their experiences and build connections. She added that seeing others who were in similar situations who had built a life for their young person in the community reduced the fear of taking those steps – *“That encouraged me!” … “I thought, we can do this.”*

At the time of the evaluation the EGL team was exploring whether family members who had been involved in EGL wanted to take up the navigation role. These families had been given information on undertaking the role. Some families in the case study research reported that talking to other families who had been engaged in EGL was extremely useful and should be further encouraged.

Building the capacity of disabled people to engage in planning

The EGL team recognised that some families need assistance to get the most out of the planning process. The Demonstration got funding from Te Pou to support the Family Capacity Building Group. The group ran a series of workshops on topics such as housing, Circles of Support[[35]](#footnote-35), employment and networking. Members of the team interviewed reported that workshops were an efficient way to convey information to families. As one navigator reported:

It’s not particularly efficient to go through the whole process of every family that wants to have a Circle of Support or employment and networking. By providing the information to families in a group session they can possibly work together and develop these things.

The workshops also gave families information about aspects of their young person’s life they may want to address in the medium term (eg housing in the community).

### Challenges associated with the planning process

The evaluation identified a number of challenges associated with the planning process. These are outlined below.

#### Engaging families in difficult and complex circumstances who struggled to envisage a good life for their young person

There is strong evidence in the literature that family support is needed to enable access to, or to get the best outcomes from, various elements of personalisation – including personal budgets. Those with no or limited support from family or friends are at a distinct disadvantage compared with those with extensive social networks, financial resources and skilled and knowledgeable family members (Harflett et al., 2015).

Members of the EGL team and navigators interviewed commented that it was difficult to engage some families who struggled to envisage a good life for their young person. For example, an EGL staff member reported that navigators frequently talked about coming across disabled people having *“so much potential and they’re just sitting”*. In working with the families, they were trying to bring about a cultural change within families. While some families understood the concept of a good life and how to get there, others had little idea. This was especially the case where the families had had difficult life experiences. A navigator reported:

If you have a fairly narrow life yourself and you don’t have a particularly good life yourself then your ability to have a good life and have an imaginative and creative life for your children or child can be a bit limited. … Some people don’t have the – I don’t know – the confidence or cultural capital or whatever to actually go out and do stuff. So without – I don’t think it’s ever a conscious effort to try and limit the opportunities for their young person but sometimes the lack of horizon can sometimes mean that they’re unwilling to try things.

The EGL team commissioned research on disabled people in complex circumstances[[36]](#footnote-36) who had met navigators. This research revealed that the participants were more difficult to engage because they were often fearful and vulnerable, lacked information about options and systems that could help, had low expectations for themselves and their family, and had had mostly negative experiences with agencies. They had a limited concept of a future or ‘next steps’. The participants were mostly focused on the present, what was happening in their lives now and how they got by each day. Thinking beyond their immediate circumstances and what they knew was difficult.

Some families who had engaged with EGL reported that EGL was not suitable for families in vulnerable circumstances. For example, a parent who had relished the planning process with her son said that *“it wouldn’t suit families who are not good organisers or good with money or may be dysfunctional as there is some work involved”.* This was echoed in the views of another parent, who reported she often had people asking her for advice on EGL eg which forms to use, how to fill them out. In her experience many have low literacy levels and they struggled with something like EGL that requires financial literacy as well as the ability to read.

The navigators and EGL staff were firmly of the view that the EGL approach could work for disabled people and families in complex circumstances. However, they reported that for people in these circumstances more time was needed to develop trusting relationships. From there it was possible to begin developing ideas about what a good life might look like and facilitate links to the appropriate supports and services. For example, some research undertaken by the EGL team with complex families found they were making progress within the EGL framework, albeit very slowly and with significant input from navigators and other support networks.

In other research there is evidence that, where local workers take the time to patiently build trusted relationships with ‘hard to reach’ individuals, their persistence pays off (Brotchie, 2013). Moreover there is some evidence that it is the role of staff, rather than family that is key to enabling person-centred plans (McConkey & Collins, 2010 and Robertson et al., 2007b cited in Harflett et al., 2015). Harflett et al. (2015) state that further research is needed to determine if having supportive and skilled staff can compensate for a lack of support from family or friends.

#### Finding workable solutions for disabled people without family support

Some young people do not have family to support them. The EGL team interviewed reported that this made making and implementing any plans more challenging. Those without family support were often more reliant on the navigators to make things happen. For example, a navigator put together a case to get driving lessons funded for a young disabled person because there was no parent to teach them or organise this for them. Without the navigator arranging for the lessons to happen, the person would not have got a driver’s licence and would have had limited employment opportunities. The EGL team members and navigators interviewed were concerned about what will happen for people in these circumstances longer term.

#### **Balancing what the young person wants and what the family wants**

The navigators found that the needs of the family members do not always align with those of the disabled person. This is especially difficult when the young person might not use words to communicate. As one navigator reported:

I struggle with that a lot because the navigator is fundamentally allied to the disabled person but you also need to get the family on board as well. So there can be tension between the two. … But that’s why that relationship building is so important, where you can get to that stage and say to them, “Your young person is really interested in this and you seem to have some different ideas.”

#### More support from navigators sought, especially when families faced difficulties after the planning stage

Interviews with the families and the EGL team revealed that the navigators typically worked with disabled people and their families to develop and implement their plans. Navigators were less involved once this had been done. In one case the family found that what they had planned was not working for them. They reported that they would have appreciated more help from EGL and the navigators at this point to find a way forward. The parent reported of EGL that the *“rhetoric doesn’t live up to the reality”.*

#### Lack of clarity about the future role of the navigators

The evaluation identified several aspects of the navigator role that it would be useful to clarify. For many families interviewed, their most immediate concern about the role of the navigators was whether or not the role would continue after the Demonstration.

If a navigation function continued to be available, the evaluation raises some questions about the navigator’s role:

* What is the role of the navigator over the life course? In the Christchurch Demonstration navigators have been involved in the lives of young people transitioning from school to the life beyond that environment. However, it was unclear what involvement disabled people could expect from the navigator beyond this point. If navigators were to have an ongoing relationship with disabled people and their families, this would have implications for resourcing.
* What is the role of the navigator in addressing the often challenging needs of families independent of the disabled person? For example, the case studies revealed that family members, especially mothers, could have physical and/or mental health needs that impacted on their ability to support their young person.

### Improvements suggested for navigation

Those interviewed offered suggestions for improving navigation, including:

* providing more support for people when they get into difficulty
* allowing more time to provide support for vulnerable families
* improving links with families who have engaged with EGL
* clarifying the role of the navigator.

## EGL personal budgets were valued but there was room to improve

### About EGL personal budgets

EGL personal budgets, made up from pooled funding from the Ministries of Health, Education and Social Development, can be used flexibly to purchase supports and services. A disabled person’s EGL personal budget can include funding from the Ministry of Health, Ministry of Education and Ministry of Social Development (see Individualised and flexible funding for disabled people page 18). In practice this has meant that around 70-80% of the pooled funding is from Vote Health, with the remainder from the other two Votes. The most common support services funding that was transferred to an EGL personal budget was Home and Community Support Services (HCSS).

All people who were allocated an EGL personal budget had the same responsibilities as a person using Individualised Funding to purchase their own Home and Community Support Services. These responsibilities included managing their budget and purchasing/commissioning their own support services. The latter often involved employing staff.

### Most participants had taken up their funding

As at 9 October 2015 there were 175 EGL participants and 129 had been allocated funding (Table 1). People needed a plan to receive their funding. Most of those who had not been allocated their funding at this point had paused their engagement with EGL or were still working the planning process (eg because they were new or had taken some time to decide what they wanted). Other reasons for not receiving funding were that people were not eligible for Demonstration funding or did not have an agent who could manage the funding.

Table 1. Programme - EGL (participant count with allocated funding)

|  |  |  |
| --- | --- | --- |
| **Types of participants** | | **Number of EGL participants allocated funding** |
| **Opt-in** | Phase 1 | 10 |
|  | Phase 2 | 9 |
|  | **Total** | **19** |
| **School leavers** | Phase 1 | 43 |
|  | Phase 2 | 39 |
|  | Phase 3 | 28 |
|  | **Total** | **110** |
| **Grand Total** |  | **129** |

Source: Ministry of Health data

Some EGL participants opted to take the funding but not navigation (8 as at 9 October 2015). These participants tended to use their funding to attend day programmes and/or residential facilities.

Analysis of the case study data revealed a distinction between those in case type 1[[37]](#footnote-37)and those in case types 2 and 3 in terms of use made of their EGL funding. Those in case type 1 all used their funding from all sources to attend day services and residential care.

However those in case types 2 and 3 were not using their funding to attend day services or residential care. They were mostly using their funding to employ their own staff to assist with personal care and support community engagement. Some were using it to engage in education and training and one had purchased equipment that supported their engagement in the community.

### There were factors that supported disabled people and families in the use of the funding but there was room to improve

#### Being financially literate and well resourced assisted people to take up the funding and manage it

International research indicates that financially literate and better-resourced families with extensive social networks are best placed to make the most of personal budgets (Harflett et al., 2015). This appeared to be the case in this evaluation. The navigators interviewed reported that those who were most comfortable with taking up the funding were typically well placed to do so. One navigator said:

So the people who take it up are generally people who are well resourced – who are – who – their lives – their lives are – how do I say it? Their lives are already quite organised and – things are going well.

Across the case studies, those who were most comfortable managing the funding either on their own or with some assistance from MIC had previously used Individualised Funding or had run their own business. For example, one family described themselves as completely comfortable managing the funding as they had *“used IF* [Individualised Funding] *for years”* and described it as a *“brilliant system”*. Another parent who had run her own business also reported that managing the funding had been straightforward and MIC had been available if there were any problems.

#### Pooling the funding and having greater flexibility in the use of the funding were important but there was a desire for more

Prior to EGL, families received different amounts of funding from different agencies. Having the funding all in one pool simplified arrangements for families. As one family reported, previously they had funding for Individualised Funding, personal care, MSD for hours and carer support through different agencies (MIC, CCS, IDEA). The parent reported that *“EGL has put all the funding together under IF* [Individualised Funding] *funding”.*

An EGL team member interviewed reported that the change in funding is broader than just what families can purchase. Families have been able to purchase things for some time under Individualised Funding but the scope of what they can purchase under EGL is broader and this is the first time funding has been pooled across agencies. A family member who had used Individualised Funding for years summed this view up when she said *“EGL was the icing on the cake”*. The Individualised Funding is the base but the inclusion of the MSD funding and flexibility of use provided them with more options for meeting the needs of their young person.

#### Taking up Individualised Funding and managing the money was difficult for many families and disabled people

The evaluation found that not all families were comfortable with the responsibilities associated with managing their budget. The case study research and interviews with local officials and members of the EGL team revealed not all families had the skills, confidence or time to manage the funding. Those who were less financially literate, were facing multiple challenges, had not previously used Individualised Funding or had not run their own business typically found the prospect of taking up and managing the funding challenging. In the case studies there were examples where people had avoided taking on the management of the funding because it was daunting. A parent in one such case reported she admired the people who are able to manage the funding but she didn’t think she was one of those people. She added that many parents of young disabled people were *“stressed and tired people”.*

An official from MIC confirmed this view, stating that working with EGL participants can take longer than working with people just taking up Individualised Funding. This was because engaging with EGL combined with leaving school is a big change for disabled people and their families. She added that families have to be in the right place to make the best use of the funding and she spends more time coaching the EGL families. For example, with Individualised Funding recipients she would normally only take a couple of days to do the set-up but with EGL participants it takes a month or more.

Even some of those with previous experience of running their own business found the prospect of managing the funding daunting. For example, one family who had previously taken up Individualised Funding did not want to manage the funding because of the time commitment involved. In another case, the family had previously run their own business and were now comfortable managing the funding but admitted it had been a steep learning curve.

A local official reported that the navigators played an important role in building confidence to take up and manage the funding. However, it was not always just a matter of having the financial skills and confidence to manage the funding. Members of the EGL team interviewed reported that some families and disabled people were not in a position to manage the money. They cited the example of afamily where no one in the household had a bank account, access to the internet or a reliable phone. In this example, the family also had problems with drug and alcohol misuse and ill-health. This is consistent with other research, which indicates that disabled people who do not have supportive social networks, financial resources and family with the skills and knowledge[[38]](#footnote-38) to support them if they need it are less likely to take up individualised budgets (Harflett et al., 2015). Research indicates that support required for disabled people and their families in planning and spending the funds allocated needs to sit alongside the provision of a personal budget (Carter Anand et al., 2012).

#### The amount of funding was insufficient to cover what young people wanted to do

The contexts in which families reported the funding was insufficient to cover life in the community included the following. Carter Anand et al. (2012:36) indicate that having too little funding *“may ultimately deny disabled people any real choice”.*

Where the young person wanted to live independently in the community, cost was a significant barrier

Across the cases, several families reported they wanted their young person to live more independently in the community but the cost of doing so was a significant barrier. Families reported there were few options apart from living at home or in residential care if the young person required significant assistance with daily living tasks. One parent whose young person was in residential care reported she gets cross when she hears people talk about all the things they could do with the funding. She felt this was only really the case for the more able bodied – *“It’s not the case for people who need 24-hour care or have intellectual disabilities or the people who are not nice”* (eg have very challenging behaviours). Flatting with others was possible but difficult to set up and there were concerns about the sustainability of the arrangements. One young person who was profoundly disabled was flatting. However, the family were concerned that once the young person’s sister could no longer live with him and receive Funded Family Care (FFC)[[39]](#footnote-39) they would not be able to sustain the arrangements.

In another case, the young person was living at home and the family did not know how they would afford supporting him to live in a flat. In another case the young person wanted to go flatting but he and the family were unclear how that would happen. The young person said, *“I can’t be going flatting – there are still big barriers.”* He was fearful of ending up in a residential facility if he could no longer stay at home in the care of his family.

Purchasing a house with other disabled people has been raised as a possibility but families typically saw this as complex to set up, costly and not sustainable in the longer term. For example, one parent said: *“It seems like it is a really big leap from simply selecting a provider to actually going it alone and setting up a house for* [our son] *ourselves.”*

Where families were on lower incomes, the amount of funding they received may have been insufficient

For example, for one family on a low income, there was not enough funding to enable their high needs young person to access social activities in the community, attend courses and go flatting (see Material wellbeing was constrained for many, page 80). In another case a low-income family where both parents worked reported they felt EGL was for the *“nice middle-income people”.* They acknowledged that some have set up good solutions for their disabled family members but they have the income to support that.

International research indicates that having access to family financial resources is important as they are used to enable better outcomes for individuals by filling gaps or supplementing personal budgets (Harflett et al., 2015).

The funding may have been insufficient to support disabled people’s choices where family could not be involved in the day-to-day care of their young disabled person

In all of the cases where the young person was actively engaged in EGL and doing something different, a parent or family member was available for significant parts of the day to assist the young person. One of these families commented that if parents were not involved with the care of their disabled young person the budget would be insufficient. For example, in this case the family was available and able to cover the cost of transporting their very high needs young person to and from activities but they were not sure how they would fund the transport if they were unavailable. Currently the purchasing guidelines do not allow the funding to be used to pay for transport.

#### Families had some useful sources of advice and guidance but more was needed

MIC was instrumental in advising families about management of the funding but more help was needed

Many families in the case study research cited MIC as an important source of advice and support in managing the funding. MIC is an Individualised Funding Agency appointed by the Ministry of Health to arrange Individualised Funding and support disabled people with that option. MIC provides budgeting advice, planning assistance, and advice on employing staff. A member of the EGL team in Christchurch reported that to date MIC has shouldered a lot of the responsibility for guiding and supporting people to manage their budgets and their own spending.

Nevertheless the evaluation concluded families needed more support to understand their roles and responsibilities regarding the management of the funding. An EGL team member and a representative from MIC reported that some disabled people and families did not always fully appreciate the responsibilities they were taking on when they took up personalised funding or employed staff. People who had previously employed someone understood more readily what they were accountable for but others *“say they understand when they don’t”.* Some families required more advice and support in this area.

Research indicates that building the capacity of disabled people and their families to manage the money needs to go hand in hand with Individualised Funding. This is particularly important where people have additional vulnerabilities or restricted capacity (Fisher et al., 2010).

Navigators were able to provide guidance to disabled people and their families

Some families interviewed reported that the navigators were an important source of advice about and support with EGL funding. Families did not always use the navigators for this purpose but liked that they were available if need be.

The purchasing advisory panel worked well

Those interviewed who were closely involved with the purchasing advisory panel reported it worked well. The panel met as needed. Where families were seeking to purchase something that may have been outside the guidelines or was a large purchase, they completed a form with assistance from MIC if needed. Their case was then presented to the panel, who decided what was funded. Representatives on the panel who were interviewed all reported that it was helpful having a range of people around the table as they all came at it from different points of view and could offer alternative solutions to problems raised. The panel often had to make difficult decisions and as one interviewee reported, *“it’s good to have several heads around the table to make the decisions rather than such decisions falling on one person”.*

There was a need to clarify elements of the purchasing guidelines[[40]](#footnote-40)

A representative from MIC reported that the families all get a copy of the purchasing guidelines when they begin working with them. MIC stated that the guidelines were very important as they made it easier for families to understand what they could and could not purchase.

Nevertheless the case study research and interviews with members of the EGL team revealed that families were not always clear on what they could purchase with the funding and what they could not. This was especially the case in relation to purchasing items. For example, what is considered assistive technology is not always clear. The navigators, members of the EGL team and many of the families and some school representatives interviewed reported that disabled people used their smart phones for safety. If the disabled person was lost, for example, they could text a picture of their location to a caregiver. A family member who found it difficult to access communication technology for her young person to help with everyday life said: *“It’s so a must. Having to apply for it is a barrier. He should just get this technology and it needs to work. He needs the right equipment to do his daily activities.”*

Families and the members of the EGL team interviewed recommended greater clarity on what could be purchased. A member of the EGL team suggested:

I understand the nervousness. My view is, let’s get on the front foot with it. Let’s justify and really be clear about what we’re doing. Let’s have a behind-the-scenes conversation with the various parties, if that’s really what will worry people so that we don’t have to defend it because we agree this is the right thing for these circumstances, as long as there’s a trade-off.

## Employing staff was largely a positive experience but there were challenges

### Families valued being able to employ their own staff

The case study analysis revealed that in five of the ten cases, families had chosen to employ staff with their pooled funding. In one case the family employed seven staff to provide care for their young person. Across these cases employing staff had largely been a positive experience. The benefits of employing staff were reported as the following.

Families appreciated being able to choose who came into their home

Families reported that they did not have to accept who they were given. For example, in another case a parent with a disability relished being able to choose who came into his home. He explained that he had previously been sent support workers who did not meet his needs and in some cases treated him and his young person disrespectfully. The parent said:

They never did anything to help us. We needed – I wanted help with the tea like I have now. Sometimes I help her [he gestured towards his carer who was preparing a meal] and I want to know how to cook, how to cook different meals but they didn’t show me.

In another case the family also had had negative experiences using agency staff (eg inappropriate carers, limited flexibility). They reported they valued being able to choose who came into their home and that it was *“so much nicer for [their young people] to be in their own home, to be with the people that they trust, that they know really well”*.

Some parents also reported they appreciated the ability to dismiss someone who was unsuitable.

Families had greater flexibility to engage in activities in the community

For example, one parent employed a support worker because she wanted her son to get out in the community in a way that he would like to be in the community, using the Individualised Funding and not having to measure up to other people’s criteria. She wanted him to be able to access a broader range of activities in the community (eg going to watch a rugby or soccer game with his support person and friends or go swimming at the beach). In their experience, services had restrictions about where they can take people; for example, they wouldn’t go to the beach. She was happy they had found a good person who could do what her young person wanted.

Disabled people were able to receive more personalised care

Families reported that employing their own carers allowed them to choose carers who best met the needs of their disabled person. For example, in one case a mother reported that the carers they employed were more responsive to what her young person wanted to do on any given day. *“They can take him out and about but also if he wants to lie on the couch he can.*”

One parent reported their young person received better care because they were able to hire people with a similar outlook:

They’re not just doing – we don’t feel – they’re not just doing a job. They actually – you can see it in the interactions they love their job, they love being with [our young people]. It’s actually – and we’ve said from day one it’s not about – it’s about [our young people]. It’s not about anything else. It is about them and their good life. And they embrace that.

Disabled people were able to receive better continuity of care

Having consistent carers was seen as a benefit of employing your own support workers. Families reported that the benefits of this were that:

* their young disabled people were more settled: In one case, the family employed several carers to look after their young person but there was a lot more continuity in his life and he was doing more for himself. Having the same regular carers now helped him feel more settled according to his mother. She explained that he tends to play up when he gets a new carer. When he attended a day service he had many different carers
* there was less risk of infection: One family found that before having consistent carers their young person had more infections and visits to the doctors.

### There were factors that helped people employ staff

Families interviewed reported that in employing and managing staff they found it helped to:

* have had previous experience employing staff and be financially literate
* have support from MIC: MIC assisted families by making it clear to them what the employer role entailed. While some understood what was involved because they had previously employed staff, others said they understood when they didn’t. They entered into employing someone and suddenly they had a personal grievance and were overwhelmed. MIC also provided liability insurance (see below)
* be able to employ staff on contract: This suited one parent because they avoided having to contend with PAYE. She sent the claim form, including expenses to MIC and paid her employee out of what she received. Her employee also preferred the contract arrangement as it gave him flexibility to take time off for his sport
* provide support to their staff (eg training).

### Employing staff was not without its challenges

Interviews with disabled people and families and EGL staff revealed that families and disabled people faced several challenges employing staff. This is consistent with the experiences from evaluations from the UK and US, which strongly suggest that disabled people most need support and information in relation to being an employer (Jeon et al., 2015). The main challenges with employing people identified in this evaluation were as follows.

#### The prospect of managing staff and pay was too onerous for some families

Families with no experience of employing staff were daunted

A member of the EGL team in Christchurch reported that the employment of staff is challenging for some families:

The system is not easy, you know. If you want to employ people it’s huge. Who do you employ? How do you get the contracts? Are they going to turn up? What happens if there is a grievance, you know? Do I want them in my house? Where do I send in the payroll? We’ve had that one. He’d never been paid for ages.

Families who had employed staff reported that employing staff is not for everyone. A family member who was comfortable employing staff reported that she would recommend EGL to other people, but not to people who are not good organisers or may be dysfunctional as there is some work involved. She would not recommend it to people who are not used to paying people.

Australian research found that while people who managed their own workers enjoyed the flexibility and choice of their current arrangements, the additional administrative requirements of person‑centred planning and support could be difficult (Fisher et al., 2010).

Juggling work commitments and managing carers was seen as too difficult for some

Some families were reluctant to employ staff to care for their young person because of the challenge of juggling work commitments and managing carers. A family who reported they were interested in employing staff at some point were concerned about how they would manage that and working as well. The mother explained she and her husband both work in minimum wage jobs and did not have the flexibility to also be organising her young person’s life at the moment. She said: *“How do people who have to work full-time do this? They can’t just drop everything and help out if a carer gets sick. It’s unrealistic for some families to do all this.”* She wanted EGL to put some more supports in place for working parents becoming employers.

Another parent commented that there is an assumption with EGL that parents have the time, inclination and ability to set up and manage the employment of carers but that is not always the case. In their case the parents worked and had recently stopped employing staff and placed their young person in residential care and with a day service, because it was less onerous than managing employees and work commitments. The parent reported:

I know that wasn’t the idea of the exercise [EGL] but that’s the reality of it for me and the hardest bit was not having a real choice and I’m constantly – I have to take the phone with me because things happen, just small things. Did she get picked up, did she get dropped off? One day I’m in a multi-disciplinary team meeting at [a hospital] and she’s supposed to be horse riding and I get a text to say that the horse’s feet are sore and I just think, “Far out man, what am I supposed to do now?”, you know. No, it’s a – and I just think – so I – you know, here I am trying to read out files to the [specialist] and, “The horse’s feet are sore”. It’s just as well I’ve been here for a very long time on and off and they know her well.

#### Employment disputes have added challenges in the context of a caring relationship

Employment disputes have added challenges in the context of a caring relationship. An EGL team member reported that disabled people can be vulnerable where they are the employer and are also the one receiving care or support. Employment dispute processes often assume that the employer has more power when the employment relationship breaks down but this may not be the case in a caring relationship. An EGL team member reported:

That can get very tricky because how do you performance manage the person who provides you with day-to-day support that you must have? Sometimes it’s not that easy. In situations like that it’s really helpful to have an ally. It’s really tough to end things that aren’t working.

The normal employment processes are cumbersome in dealing with employment problems in this context. A family who had employed staff to care for their young person and faced an employment dispute reported that they found the dispute process very stressful. They felt there was a lack of clarity about what to do when an employment relationship involving personal care breaks down. The requirements to give several written and verbal warnings meant someone could be receiving care for some time from a carer who was unsuitable for them. Moreover while they had liability insurance through MIC, there was uncertainty about whether it applied to their situation. Even with liability insurance families still needed to pay the liability excess. For those without liability insurance the costs could be significant especially for those on low incomes. The parent added that this was a flaw with EGL and taking on the employer role is risky. She said, *“With what’s happened, I can’t look families in the face and say, ‘Get on board Enabling Good Lives. It’s great.’ Because I said there’s actually a few holes in the safety nets.”*

#### Frustration at not being able to employ family at the same rate as non-family

Some families expressed frustration at not being able to employ family at the same rate as non-family. In the interviews undertaken with families, three disabled people had also taken up some hours of FFC as part of their support budget where they were employing their parent(s) who lived at home with them. The funding was taken up in the main because family were still required to provide support to their family member during the day and night.

For one family, moving to receiving some FFC meant they received less money than before. The FFC rate paid to family is lower than the rate paid to a person to provide support through Individualised Funding. They were frustrated as they reported that this had not been explained to them beforehand. However, the families reported that they had no choice but to take up FFC as their young person needed 24-hour care and the family needed income. The lack of support available meant a family member (usually the mother) could not engage in paid work. As they were doing the same work as support people, they would have liked to have been paid at the same rate for the shifts they were doing. In some situations a parent would fill in unexpectedly for a shift if a paid support person was sick and received no payment. Some reported that they were struggling financially as they found the combination of Individualised Funding and FFC was not enough to support their family.

Not being paid at the same rate as non-family carers also had a psychological impact. Family members reported feeling devalued when they were not paid at the same rate as non-family carers. This was the case for a family who was reluctantly considering taking up FFC for a daughter who flatted with their disabled sibling. The mother explained her daughter currently manages the house, which includes the seven people employed to care for her sibling, and his medical care in the house. She is not paid for this work but the mother felt FFC was a poor option because it undervalued the work done by the daughter whom she felt was *“worth more than $14.70 an hour!”*

These situations highlight the need for sufficient support cover over 24 hours, and the challenges faced by family with their reduced payment through FFC and the impact of this on their self-esteem and ability to make the budget work.

#### Finding the right staff could be challenging

An EGL staff member reported that some people are not able to use their funding because they are struggling to find staff. In one of the cases the family had not employed staff because they could not find the right people who were willing to provide assistance for a couple of hours a day. Many potential carers could not drive or did not have transport, were unwilling to assist with toileting or wanted more hours than they needed.

International evidence suggests that availability of qualified support workers for disability support is fundamental for implementing personal budgets (Carter Anand et al., 2012).

### Suggestions to make it easier for families to employ staff

Families and EGL staff interviewed offered suggestions to make it easier to employ staff:

* *More work is needed to support families as employers, especially when disputes arise.* Several interviewees reported that MIC provided good advice about what was involved in employing someone. However, some interviewees reported there was not enough support if a dispute arose.
* *Education should be provided for support workers about the home care environment,* to take the support worker through a process that would teach them about the care environment in a home (eg home care support is not like working for an agency or working for The Warehouse or the supermarket as people are often vulnerable). Employees need to be aware that sometimes things can change quite quickly and they might find they don’t have employment. Australian research indicates that having a successful working relationship between support workers and clients or their families, combined with ongoing support and training by the provider, best supported employee development and retention (Fisher et al., 2010).
* *Establishing a group that could shoulder more of employer responsibility* would mean that if employees were part of an agency the employee could be placed in another employment situation quickly if relations broke down. One interviewee reported that under this arrangement the disabled person would not shoulder the full responsibility of being an employer, it would be important that they retained control over who supported them, what they did, how and when.
* *The use of flexible disability support contracts between disabled people and providers may help* (see page 28). Providers could potentially support disabled people in employing staff by assisting with human resource matters (eg interviewing, recruitment, the payment of wages, police vetting, and backup if a dispute arises). Disabled people could pay for that service if a fair and reasonable cost was determined.

# Some positive outcomes for disabled people and their families

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| --- |
| Summary  * As at 9 October 2015 there were 175 EGL participants. Most of these were school leavers. Participants had or were attending a mix of special and mainstream schools. * There was broad agreement amongst those interviewed about what constituted a good life. A good life involved people doing things that interested them and doing meaningful activities and being included in the community. There was some distinction between those families who engaged with EGL and those who did not. Those who engaged with EGL had higher expectations of what their young person could do post-school. * Findings from the research looking at quality of life found:   + Wellbeing: physical and emotional wellbeing were good but material wellbeing was low   + Social participation: interpersonal relationships with family were good but improvements could be made in the rights and social inclusion domains   + Independence: improvements could be made in personal development and self-determination outcomes * There appeared to be limited change to family outcomes. * Improvements are needed in the measurement of outcomes for disabled people and their families. |

## Who was engaged with the Demonstration?

EGL was primarily targeted at school leavers defined as those aged 18-21 with high needs (HN) or very high needs (VHN) ORS funding in Christchurch. There was some scope to allow people with disabilities who did not meet the legibility criteria to opt into the Demonstration.

As at 9 October 2015 there were 175 EGL participants. Of this number:

* most were school leavers (aged 18 to 21 years old): 135 were school leavers and 40 were opt-ins. Examples of opt-ins were people who were between the ages of 13 – 18 and have high or very high needs ORS funding, recent school leavers who previously received ORS funding and are not satisfied with their current disability support arrangements and school leavers with significant needs but who are not in receipt of ORS funding.
* there were more male participants (100 males compared with 75 females). The majority of participants were aged 20 to 23 years but ages ranged from 14 to 48 years
* most were Pākehā: ethnicity of participants was primarily Pākehā (over 80%). Few participants were Māori or Asian (less than 10% each)
* most (100) EGL participants had received HN ORS funding in line with the eligibility criteria. Sixty-one received VHN ORS funding, 10 received no ORS funding and four received no funding at all.

### Participants attended a mix of special and mainstream schools

EGL participants at 9 October 2015 had attended or were attending one of 27 schools. Most of the schools were mainstream schools which included staff and facilities to support students with learning difficulties. There were four day special schools that only catered to students with a high level of need. As at 9 October 2015:

* 34% of EGL participants had been or were enrolled in the specialist schools (Allenvale Special School, Ferndale High School, Van Asch Deaf Education Centre, Waitaha, Southern Regional Health School, Central Health School)
* 76% of EGL participants had attended or were attending one of seven schools (Allenvale Special School, Ferndale High School, Hillmorton, Cashmere, Riccarton, Papanui and Van Asch Deaf Education Centre)
* 16 schools had only had between 1 and 3 students who were EGL participants.

## What is a good life?

Across the cases, families and disabled people agreed that a good life involved people doing things that interested them and doing meaningful activities in the community. The EGL team and navigators interviewed agreed but added that having a good life involved people having a sense of belonging and the ability to make choices about their lives.

While there was broad agreement amongst those interviewed about what constituted a good life, the EGL team and navigators interviewed cautioned that understanding of the concept was highly variable across the families they dealt with. Some disabled people and families had a clear idea of what a good life looked like for them, whereas others did not.

In the case study research there was some distinction between those who engaged with EGL and those who did not. In the cases where the families had opted to place their young person in residential care, there was a tendency to have a static view of what was a good life for their young person. The families who had had no contact with the navigators had few expectations of any growth or change in their young person. They described the young person as if they were a child. They reported that in transitioning to life beyond school the best option was for their young person to carry on doing similar activities in an institutional setting to what they had done at school. We do not know if this would have changed had they had contact with a navigator. However, in the other case in this group the family had had contact with a navigator. The conversations with the navigator had broadened their view of what was possible for their young person. They wanted their young person to be living away from home because that was the normal transition for young people reaching adulthood. There was an expectation that their young person would continue to grow and develop.

In all of the cases where the families and disabled people had engaged in EGL and were doing something different, the parents had an expectation that their young person would learn and grow as they got older. Their expectation was that their young person would have as normal a life as possible in the community. This meant doing everyday things in the community like their peers, for example getting a job, doing further study, going flatting, following their interests. It also meant avoiding residential care and specialist or segregated service providers.

## Quality of life outcomes

The Enabling Good Lives approach is ultimately about improving the quality of life of disabled people. A survey of people eligible to participate in the Christchurch Demonstration was conducted to assess quality of life outcomes. The key objective of the quality of life survey was to understand what outcomes were being achieved by those participating in Enabling Good Lives and what contribution Enabling Good Lives has made to those outcomes.

Data were collected about 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). The response rate was low (34%).

The quality of life measures used were based on a framework developed by Robert Schalock. Quality of life is a multidimensional construct developed by Schalock and others (Schalock et al., 2002). It is composed of eight core domains: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion, and rights. These eight domains can be grouped into the three broad areas or factors outlined in Table 2 (below).

Table 2. Schalock’s quality of life framework

|  |  |
| --- | --- |
| **Quality of life factors** | **Quality of life domains** |
| **Independence** | **Self-Determination:** Autonomy/personal control; Goals and personal values (desires, expectations); Choices (opportunities, options, preferences)  **Personal Development:** Education (achievements, education status); Performance (success, achievement, productivity); Personal competence (cognitive, social, practical skills) |
| **Social participation** | **Interpersonal Relations:** Interactions (social networks, social contacts); Relationships (family, friends, peers); Supports (emotional, physical, financial); Social activities  **Social Inclusion:** Community integration and participation; Community roles (contributor, volunteer); Social supports (support networks, services)  **Rights:** Human (respect, dignity, equality); Legal (citizenship, access, fair treatment) |
| **Wellbeing** | **Emotional Wellbeing:** Contentment; Self-concept; Lack of stress (predictability and control); Safety and security; Spirituality/culture  **Physical Wellbeing:** Health and wellness; Activities of daily living; Physical activities including recreation  **Material Wellbeing:** Financial status; Employment status; Housing status; Having possessions |

In the survey, the quality of life questions identified aspects of quality of life that many EGL participants and their proxies were positive about and some that they were not. Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators. Indicators were classified as:

* foundational – indicators of core elements of quality of life expected for everyone, or
* aspirational – indicators of aspects of quality of life that the EGL programme aims to influence.

These indicators were developed in consultation with the Local Advisory Group in Christchurch.

### Overall quality of life outcomes

The chart below provides an overview of scores in each of the quality of life domains (Figure 4).

Figure 4. Quality of life scores combining young survey respondents and proxy responses (n = 43)



Note: Scores are shown for overall indicators.

Across the overall scores for the different domains:

* the highest scores were recorded in physical wellbeing, emotional wellbeing and interpersonal relationships
* the aspect of quality of life where scores were lowest was material wellbeing.

As expected, overall scores were consistently lower for the more aspirational indicators than for foundational indicators. Tracking some of these indicators over time has the potential to measure changes as a result of the EGL programme. However, it is important to recognise that in some areas the scores for the foundational indicators were also low (eg indicators of material wellbeing, and social inclusion).

There were differences between young survey respondent and proxy responses. Differences might reflect the degree to which different disabilities influence people’s daily lives. Others might reflect differences between youth and parents that could be noted across the population as a whole.

### Wellbeing

Wellbeing encompassed material, physical and emotional wellbeing. Analysis of the quality of life survey found that overall scores were highest for physical and emotional wellbeing and lowest for material wellbeing. Overall results combine young survey respondent and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators (Figure 5).

Figure 5. Wellbeing scores combining young survey respondents and proxy responses (n = 43)

■ Overall ■ Foundational indicators ■ Aspirational indicators



Note: Scores are shown for overall, foundational indicators and aspirational indicators.

#### Emotional wellbeing was typically reported as being good

Overall emotional wellbeing was reported as high

Analysis of the quality of life survey found that foundational indicators for emotional wellbeing had a slightly higher overall score (84) than the more aspirational indicators (78). This pattern was evident for both young survey respondent and proxy responses.

As Figure 6 indicates, there was no clear distinction between the foundational and aspirational indicators with respect to the proportion of positive responses. However, the scores indicate that while people’s basic needs may have been met (eg feeling safe at home, not being physically hurt) there was room for improvement on all the other indicators. In particular three of the foundational indicators were low, especially *feeling happy, being told they do things well* and *not* *feeling afraid to go some places.*

While the overall scores for proxies and young survey respondents for emotional wellbeing were consistent, there were some differences in their responses to individual questions. All of the proxies reported they felt *safe at home*, while one-tenth of the young survey respondents gave the neutral or negative answer. Young survey respondents were more positive than proxies about *feeling happy*, *knowing their whakapapa*, and *not* *feeling afraid to go some places*.

Figure 6. Emotional wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 38-43)

■ Foundational indicators

■ Aspirational indicators

42%

53%

57%

58%

61%

65%

70%

73%

93%

95%

I am not afraid to go some places because

someone might hurt, tease or bully me

I can take part in things that support my beliefs,

values and culture

I know my whakapapa - where I come from and

who I belong to

People tell me I do things well

I am happy

I have things I look forward to doing

People don't say or text mean things that upset

me

I do things that make me feel good about myself

People don't hit, kick or push me

I feel safe at home

Case study research found overall emotional wellbeing was good

In the case study research the emotional wellbeing of the young people was reported as being good by young people, or parents where the young people could not answer. In the cases where the young people had moved into residential care the families all described their young people as usually cheerful and happy. However, the one young person who could answer only reported he was OK most of the time. There had not been any change for any of these young people over the course of the Demonstration.

By contrast, emotional wellbeing was reported as improved in all the cases where the young people had made changes in their lives following active engagement in EGL (as either opt-ins or core participants). The young people were reported as having more stability and being happier and more relaxed. For example, a parent reported that one young person who had a profound intellectual disability was now engaged in more self-soothing behaviour – *“He’s settling himself more rather than seeking out others to make him feel better when agitated.”* The mother gave a variety of reasons for this change: having consistent carers that they had chosen, living where they wanted to live and undertaking activities they chose.

Some young people interviewed who were engaged in EGL still experienced considerable stress but this was not related to the Demonstration

Examples of difficulties that caused stress included:

* *challenging family relationships:* For example, in one of the cases the young person had a difficult relationship with one of the parents and this was still an ongoing source of stress
* *uncertainty about future living arrangements:* In another case the young person was facing a number of challenges that impinged on their emotional wellbeing. While the young person was happy not using respite services and was enjoying tertiary studies, the uncertainty about where he would live in the future if his family could not care for him contributed to his anxiety. The parent reported that *“if it’s hard work for the parents it’s going to be harder work for our young people and some can’t talk and he just frets about this stuff”.* The young person was adamant he did not want to be in an institutional setting
* *social isolation due to poverty:* The young person and the parent reported that he experienced a degree of social isolation which negatively influenced his wellbeing. Opportunities to socialise with his friends or meet new people were constrained by his dependence on a parent for transport and not being able to afford alternative forms of transport. For example, the parent reported a taxi typically cost $70 to transport him to where he needed to go and this was too much for their family, as they were *“living on a shoestring”.*

Young people reported feeling safe at home but there were some concerns outside that environment

Safety was an important component of emotional wellbeing. In the quality of life survey almost all those who completed the survey considered they were or were considered to be *safe at home* and that *people did not kick or push me*. In the case study research, interviewees in all the cases reported the young people felt safe with the transport options they had, with their families and in their neighbourhoods.

However, both the survey and the case study identified safety concerns outside the home environment. For example, a substantial number of survey respondents were concerned about bullying. Bullying through texting and being afraid to go some places were issues for some young survey respondents and proxies. For example, 30% considered that sometimes or often *people said or texted things that upset them*. The majority response to a question about *being afraid to go some places because someone might hurt, tease or bully them* was the ‘middle’ option of ‘sometimes’ (56%). Research indicates that disabled people are at greater risk of bullying than their non-disabled peers (Blake et al., 2012; Chatzitheochari et al., 2014; Sentenac et al., 2012).

Some case study interviewees identified previous instances of problematic behaviour by residential facility staff and school staff. In several of the cases families gave examples of previous instances of distressing practices in the residential facilities the young people stayed in and in one case a school the young person attended. In two of the cases the young people were still attending these facilities. These practices included: carers providing young people with food that was not allowed, providers having too few carers to meet people’s needs, young people being placed in residential care with inappropriate people and the young people getting hurt[[41]](#footnote-41).

#### Physical wellbeing varied

Survey respondents could readily visit health professionals but few feel healthy

As Figure 7 illustrates, analysis of the quality of life survey found that the majority of survey respondents had high scores for the foundational indicators for physical wellbeing; for example, they considered their *physical needs were met* and they *could see a doctor*[[42]](#footnote-42) or *dentist*. Most respondents also reported having enough time to rest and relax (an EGL indicator). However, all the other scores for the more aspirational indicators were lower. Relatively low numbers reported being able to do enough physical or recreational activities[[43]](#footnote-43), and get out in the community when they wanted, and having enough energy to do the things they wanted. *Feeling healthy* had a markedly lower score than other indicators.

Figure 7. Physical wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question on physical wellbeing (n = 43)



■ Foundational indicators

■ Aspirational indicators

There were differences between young survey respondent and proxy responses to the foundational indicators that may reflect differences between those living independently and those living with their parents. The indicator where there was the most difference between proxy and young survey respondents was *I have enough time to rest and relax* (63% of young survey respondents compared with 96% of proxies).

It appeared EGL had little influence on their physical wellbeing but there were exceptions

In most of the cases, no changes were observed in EGL participants’ health outcomes. There appear to be a number of reasons for this:

* *Some people were very healthy to start with, meaning EGL had little scope to improve their physical health.*
* *Some people had complex health problems that either have remained or were being addressed through the health system*. For example, a mother reported that her young person now had improved physical health but she attributed this to his health care rather than to EGL.
* *Some people were living in poverty, which negatively impacted on health, but this was something EGL had little control over*. Research indicates people living in poverty, including those with disabilities, are at great risk of poor health (Emerson & Brigham, 2014). In one of the cases in this study, living in poverty appeared to contribute to the young person’s poor health. For example, the family reported that the young person had poor health, especially in the winter, and this was in part related to their poor housing situation. They struggled to get the landlord to improve the house and could not afford a warmer place. Financial constraints also limited the young person’s access to exercise facilities, which also contributed to their poor health. EGL had little scope to improve people’s financial circumstances.

However, there were three cases where participating in EGL appears to have improved the young people’s physical wellbeing. The improved health outcomes appeared to be related to changes in the quality of care and living environment:

* *Improved quality of care following the ability to choose caregivers:* In two situations regarding one family they reported that the quality of care had improved after they hired their own carers. In one situation, the family reported this move had led to health benefits for their young people. For example, prior to engaging in EGL the parent reported:

we just had so much sickness in our household because –you’d have a person that had – that had been doing showers all day and they’d probably done five or six showers and the cross-contamination was just unbelievable. And we were always on antibiotics. The girls were always sick.

Once their young people were not attending facility-based respite care and had consistent carers they had chosen, the family reported that they were healthier, with fewer trips to the doctor. The parent reported that their doctor commented on the improved health of their disabled young people:

she said, “My goodness”, she said, “where have you been? We don’t see you like we used to see you.” So we told her about Enabling Good Lives and she said, “Well, it’s working because … And the girls are thriving. That’s the word. They are just absolutely thriving in every area of their life: health-wise, socially, just, we’ve watched them just really blossom.

There had been significant cost savings for the family associated with improved health outcomes for their young people.

* *Living in a chosen supported environment with non-disabled peers:* In another case, the young person started to walk again after going flatting. The mother attributed this to being around others his age who were all walking. She reported he used to walk but had stopped following a hip operation about four years ago. Nothing had worked to get him walking again. He initially only walked around the people in the flat and the carers but then he did it for her. She said she never thought he’d walk again and the experience opened her up to the benefits of flatting with non-disabled people.
* *Living at home rather than attending a residential service for respite care:* One family reported that their young person’s physical health problems related to stress had improved since he stopped going to a residential service for respite care. The mother reported he did not go to the doctor as much. However, her own health was worse as she was now getting no respite.

An Australian evaluation found that levels of personal wellbeing and physical and mental health of most service users using Individualised Funding were similar to the Australian general population norm (Fisher et al., 2010). The evaluation reported participants believed these positive results were due to their increased control over the organisation of their disability support.

#### Material wellbeing was constrained for many

Evidence from the quality of life survey and the case studies indicates that material wellbeing is constrained for many young disabled people. In the quality of life survey, material wellbeing scores were considerably lower than the scores for emotional and physical wellbeing. The scores for foundational (58) and EGL (51) material wellbeing indicators were similar.

The case study research revealed the young people were financially reliant on their families

All of the young people were reliant on their families and/or government funding for financial support. Given disabled people’s reliance on their families for financial support, the financial resources available to the family made a difference to their ability to access the community. In most of the cases the families were able to support their young person to access the community. However, in one of the cases the family was dependent on benefits and struggled much more than the others to access activities in the community. They were forced to choose between the young person attending a tertiary education course and attending activities in the community but they could not afford both.

Young people’s involvement in making financial decisions varied

Few young survey respondents or proxies scored positively for the measures of financial decision-making.

* Lowest scores were about participation in decision-making about holidays, furniture, the household budget and looking after savings (Figure 8).
* There were differences between young survey respondent and proxy responses, with more of those who completed the survey themselves responding positively to questions about financial independence. This may be related to their level of disability.

The case study research indicated that involvement in decisions about how the money was spent within the family was related to their capacity to understand discussions about how funding was spent. For example, across the cases, the parents of young people with profound intellectual disabilities reported they made the financial decisions because their young person could not. Where people were capable of making financial decisions, families did engage them in discussions about what to do with the funding. For example, one young person with an intellectual disability said he and his mother talked about how to spend the money and he was able to list where the money went (eg board, paying for the carer, transport).

Figure 8. Material wellbeing - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



■ Foundational indicators

■ Aspirational indicators

Getting paid work was a goal for some young people but it was not easy to achieve

None of the young people involved in the case study research had paid work but it was a goal for some. For example, some were attending Christchurch Polytechnic Institute of Technology (CPIT) with the aim of getting paid employment at the end of their studies.

The quality of life survey revealed few (28%) young people were engaged in some form of paid work. This is not surprising. In New Zealand, as in other developed countries, young disabled people tend to have lower rates of unemployment than their non-disabled peers[[44]](#footnote-44) (Stevens et al., 2013). Eleven of the twelve people who were engaged in paid work liked their job. Of the 18 who did not have a paid job and answered the question, around one-quarter said they had support to get one.

Some young people were engaged in voluntary work

In the case studies some disabled people were engaged in voluntary work. They were typically doing less than five hours a week. For some, engaging in voluntary work was about undertaking something meaningful. For example, one young person volunteered at a wildlife centre, providing information to people about spider monkeys or giraffes, of which he said, *“It makes me proud.”*

Some of the families involved in the case study research reported that getting paid work was not a realistic possibility for their young person because of their level of disability (eg they had profound intellectual disabilities). Families in these situations reported that they all wanted their young people to be engaged in something meaningful. Finding positions in the community was dependent on finding supportive people. In one case a family had found a local librarian who, despite the council being unenthusiastic, made a voluntary position for their autistic young person cleaning books. The parent commented:

So she was wiping the books, you know, the cardboard books that little kids dribble over and stuff like that. She was folding pamphlets and doing a little bit of cataloguing.And she – it was great, I know. And that woman at that library, she was just like – it was going to happen regardless of what [the council] said.

Some young people and their families saw engaging in voluntary work as a stepping stone to getting paid work. There was some evidence in this evaluation that some disabled young people may be vulnerable to exploitation by workplaces who take them on for extended periods of time in a voluntary capacity. For example, in one of the case studies a young person was working unpaid in a rest home for up to six days a week. Neither the young person nor the family talked about this being exploitative. Instead they were grateful for the opportunity to get work experience. The young person enjoyed the work but reported that ultimately “I just want to get paid, find a house”. There are indications that this is not an isolated incident, as a teacher interviewed for this evaluation also gave examples of young disabled people working for no pay for considerable periods of time.

Microenterprises were an option for some

In the case study research one family with profoundly disabled young people was looking at establishing a microenterprise[[45]](#footnote-45) to provide employment and a valued role for their young people.

We’re looking at them starting up their own little microenterprise business which is clothing and accessories, second hand, and over winter lots of people have been donating clothes and bags and shoes. And then working in the summer months so that they go with caregivers, you know, for a few hours to the markets and actually sell their – sell their goods. So that’s the plan for that.

Research on microenterprises involving disabled people is limited but there is some evidence that suggests microenterprises offer opportunities for disabled people to engage in satisfying, meaningful, enjoyable work that may cost significantly less to implement than traditional sheltered workshops and adult day activity centres (Conroy et al., 2010).

Housing is an important part of material wellbeing but choices were limited

The case study research revealed that with the exception of one case, all of the young people in the case studies were living at home or in residential care. In several of the cases the families and the young people wanted to eventually live more independently in the community (eg go flatting).

Families reported that there were few alternatives to residential care or living at home for those with very high needs. For their young person to live in the community, families reported they would have to set it up (eg purchase a house, find flatmates and carers). This was seen as costly, difficult and possibly unsustainable (see The amount of funding was insufficient, page 62). The following quote from a parent sums up these concerns:

I’d have to get four other or five other families, buy a house, hire the staff, hope the hell it works, God knows what happens when I’m 80, that kind of thing and I – there’s no answers to that and that’s not just about Enabling Good Lives but that’s – is that where things are headed? And I, you know – some parents think that’s great but I wonder how they’ll feel in five years’ time and what happens when the strong point in a trust or a group of people drops away or you leave or ... it does require a reasonably intelligent, reasonably motivated organised parent, usually a mother, to keep – get it going and keep it going … Well I don’t know where the money comes from to buy – to purchase the care, a collective resource of five or six people. I mean, how do you buy a six-bedroom home here? It would have to be seven because you have to have sleepover staff.

### Social participation

Social participation encompassed rights, social inclusion and interpersonal relationships. Analysis of the quality of life survey found overall scores[[46]](#footnote-46) were higher for interpersonal relationships (81) than for rights (70) and social inclusion (63). The proportion of positive responses was lower for all aspirational indicators.

Figure 9. Scores (combining young survey respondents and proxy responses) for social participation (n = 43)



■ Overall ■ Foundational indicators ■ Aspirational indicators

NOTE: Scores are shown for overall, foundational indicators and aspirational indicators.

#### Interpersonal relationships with family were typically good but social networks were often limited

Quality of life survey found family relationships were positive but relationships outside the family could improve

Analysis of the quality of life survey found that overall scores were generally high in this category. Scores were higher for foundational indicators (85) than for the more aspirational (65) EGL indicators (Figure 9 above).

Overall survey respondents were positive about getting along with their families and whānau (84%), friends and people their own age (67%). However, a smaller proportion reported they could see the people who were important to them as often as they would like (43%) or they had one or more best friends (42%) (Figure 10).

Figure 10. Interpersonal relationships – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)

■ Foundational indicators

■ Aspirational indicators

42%

43%

65%

67%

67%

71%

84%

I have one or more best friends

I get to see people who are important to me as

often as I would like

People around me treat me well

I get along with people my own age

People show me love and/or affection

People around me speak kindly to me

I get along with my family/whānau

Young survey respondents’ responses about their interpersonal relationships were broadly comparable with those of proxies on the foundational indicators, although they differed on some particular indicators. They differed in the proportion who reported they could see people who were important to them as often as they would like (58% of young survey respondents compared with 30% of proxies) and getting on with people their own age (79% of young survey respondents compared with 58% of proxies). They were also asked about their best friends. Two-thirds of young survey respondents reported they had *one or more best friends*, while only one in five of the proxies reported they had best friends.

The case study research also found disabled people had constrained social networks outside the family

In most of the cases the young people could spend time with the people that mattered in their life. However, the depth of young people’s wider social networks varied. In cases where the young people were living in residential care their personal relationships mainly involved family and paid carers. In the cases where the young people had actively engaged in EGL (either as opt-ins or as core participants) it was more common for them to have friends who were not paid support staff.

Factors that limited people’s ability to spend time with the people that mattered to them and influenced the development and maintenance of relationships outside of the family were:

* *living in residential care:* For example, a young person in residential care reported that he didn’t see the people who mattered most in his life as often as he wanted to. His life was centred around attending a day service and being in his flat with a residential care provider
* *not being able to afford to go out*: For example, a young person who lived in a benefit-dependent household and was reliant on taxis could not afford to get out and about to meet friends. Interviews with families and schools indicated that the financial barriers to maintaining friendships were reported as being greater once the young person left school
* *degree of assistance needed and received to build relationships*: Those with profound intellectual disabilities or severe physical disabilities were also reliant on paid support or family to go anywhere and this limited opportunities to engage in personal relationships. However, there were examples of profoundly disabled young people building their social networks with the right support. For example, a parent of a young person with significant intellectual disabilities reported that her young person was now building a wider set of personal relationships because she had carers in her home who could take her to her chosen activities with other young people
* *impact of individual conditions (eg level of functioning, self-motivation, confidence) on young people’s ability to engage in personal relationships*: Conditions which hindered people’s ability to communicate constrained the building of personal relationships. For example, parents reported that their young people with profound intellectual disabilities were limited in their ability to develop and maintain personal relationships. One mother said of her son with a profound intellectual disability, *“He doesn’t really have friends he can talk to about anything.”* In another case a parent reported that it was not just her young person’s condition that made interpersonal relationships more challenging. She said that while he had friends, many of them had disabilities that limited their ability to respond meaningfully to someone else’s emotional needs (eg listening or talking to a friend about their problems). Mirfin-Veitch (2003) argues it is important not to gloss over the difficulties that disabled people can face in building and maintaining friendships, especially where communication is difficult.

Research has found that families with a disabled member often have fewer or smaller social networks and this makes them more dependent on paid services for support (Mirfin-Veitch, 2003; Orsmond et al., 2013; Pitonyak, 2002). Isolation is especially dangerous for vulnerable people. The more positive relationships a person has, the lower their odds of experiencing abuse (Pitonyak, 2013). Many disabled people and families need support to build relationships and valued roles within the community.

#### Social inclusion could be improved

There is not an agreed definition of what constitutes social inclusion. There are multiple and conflicting definitions (Simplican et al., 2015). Simplican et al. (2015) define social inclusion as encompassing two domains – interpersonal relationships and community participation. They argue they are both necessary for social inclusion and the two domains should overlap and mutually support one another. In this evaluation we have defined social inclusion as community participation, as there is another quality of life dimension focused on interpersonal relations.

There was a marked difference in the overall scores between foundational and aspirational indicators for social inclusion in the quality of life survey

There was a marked difference in the overall scores between foundational (69) and EGL (55) indicators for social inclusion. Overall most respondents (79%) reported that they did things in the community like shopping, going to the movies and eating out as often as they liked. The indicators with the lowest proportion of positive responses were the aspirational indicators of *belonging in the community (46%)* and *giving time to help others in the community (24%).*These are indicators of disabled people having more meaningful and sustained connections as opposed to just being present.

When looking at the differences between young survey respondents and proxies:

* young survey respondents were most positive about doing things in their community and belonging to groups and least positive about feeling they belonged to their community and helping others in their community
* proxies were less positive than young survey respondents about three of the four indicators of social inclusion. The difference between foundational and aspirational indicators for social inclusion was driven by the proxies, fewer of whom were positive about the foundational (63% compared with 74%) and particularly the aspirational indicators (43% compared with 70%).

The differences between proxy responses and young survey respondents may reflect the challenges that those with more profound disabilities have in participating meaningfully in the community.

Figure 11. Social inclusion – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



■ Foundational indicators

■ Aspirational indicators

The case studies revealed that young people’s sense of belonging in their communities varied

In the case study research, several factors appeared to influence the degree of social inclusion. At the level of the individual, the evaluation identified the following as being important:

* *having the ability to engage in social interactions in the community*: In some cases the young people had profound intellectual disabilities. Family members who responded for their young person typically reported that their young person did not understand the concept of community
* *having family, friends or carers who supported their social inclusion*
* *having sufficient income to participate*: One young person felt his sense of belonging in his community was limited because he could not afford to get to or participate in activities in the community. However in another case the family had access to additional funding which enabled their young person to participate in a wide range of activities.

At the community level the following factors were important:

* *Knowing and being known in the neighbourhood*: In several of the cases the families had recently moved and these moves had contributed to a limited sense of belonging in their neighbourhood. It takes time to establish new relationships, especially where the young person has a disability. One family that had moved from a small, rural town to Christchurch reported it was easier to build relationships in the small town. The parent reported:

Locally like – look I’ve – all along over the years the public have been very good. It’s better in [small town] but that’s only because it’s a small town. It’s a one-school town so not only do everyone that she knows but [my young person’s] friends also say hello, you know. Everyone knows – in fact in [small town] I’m not [X] I’m “that weird girl’s mother”.

Yeah. So, you know, and that’s fine. So everyone knows. But, yeah, it’s different in the city, nobody says anything but that’s only because it’s a city. But in the local little pockets around where we live like – so yes, the local two or three cafes, the library, the swimming pool and the gym and the staff that have known me, yes very much so.

In another case a young person with significant physical disabilities reported that he did not feel he belonged in his community and that most people around his neighbourhood were strangers to him. He and his family attributed this to the earthquakes, which had led many people he knew to leave the neighbourhood. At the same time, places he had previously frequented closed, limiting some of his opportunities to connect with people.

* *The attitudes of people in the community*: Family members and disabled people interviewed talked of people in their community being welcoming but some reported it was easier for those with less challenging behaviours or who did not look confronting. For example, when asked about how welcome his young person was in the community, one parent said:

I think in a general sense, yeah, all of the time. She is – she is welcomed. She’s not – while she’s very, very different, she generally doesn’t have any behaviour that, you know, makes people drop what they’re doing. And mostly the people in places that she likes to go are welcoming to her.

#### Improvements could be made in the rights domain

In the rights domain, the proportion of positive responses was lower for all aspirational indicators. Respondents indicated they were least likely to *have time alone when wanted (49%), take part in things that support disabled people (51%)* andbe able to *go out when they want to (40%)* (Figure 12 below)*.*However, some of the foundational indicators were also low (eg having their own key or card or pin number to get in and out of where they lived, being able to have a partner, girlfriend or boyfriend).

Responses of young survey respondent completions and proxy completions differed across many of the indicators relating to rights:

* Young survey respondents were more positive than proxies about the foundational rights indicators (81% compared with 68%).
* For young survey respondents, access to the phone and internet was mostly easy but fewer considered they had someone to trust or that people respected their choices.
* Proxies were more likely to consider their young disabled person could have time by themselves when they wanted.

Some differences are likely to relate to the extent of disability for those with proxy completions, for example having a partner, having a key, card or pin to enter their home. One notable difference between the two groups is the percentage who considered they get time by themselves when they need it. More proxies said this was mostly the case than young survey respondents. Young survey respondents were more likely to say they could go out when they wanted to although this was low for both groups.

Figure 12. Rights – percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



■ Foundational indicators

■ Aspirational indicators

### Independence

Independence encompassed personal development and self-determination. Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators. There was little difference in scores between foundational and aspirational indicators. This may reflect the EGL focus on personal development and self-determination; however, baseline measures are not known.

Figure 13. Independence scores combining young survey respondents and proxy responses (n = 43)



■ Overall ■ Foundational indicators ■ Aspirational indicators

NOTE: Scores are shown for overall, foundational indicators and aspirational indicators.

#### Personal development

In the quality of life framework, personal development is about more than formal education, or cognitive learning in general. Reinders & Schalock (2014:294) argue that *“personal development occurs whenever people regardless of their level of functional limitations enlarge their world of experience”.* They argue that anyone can experience personal development, including those with profound intellectual, sensory or motor limitations.

The survey revealed substantial differences between the personal development indicators

Analysis of the quality of life survey found that overall there was little difference in scores between foundational and aspirational indicators. However, there were substantial differences between the personal development indicators. Most people (80%) reported that their home had the things they needed to help them day to day. However, much smaller proportions responded they mostly had a chance to fix mistakes (49%), show people the things they were good at (40%) and learn to do new things that helped with everyday life (29%) (Figure 14).

Figure 14. Personal development - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



■ Foundational indicators

■ Aspirational indicators

There were few differences in overall scores between young survey respondents and proxies and between foundational and aspirational indicators. However, the overall scores mask substantial differences between indicators. For example:

* while most (88%) of the young survey respondents[[47]](#footnote-47) were positive their home had the things they needed to help them day to day, fewer than half felt they mostly learnt new things, were able to show people what they were good at, and had a chance to fix mistakes
* proxies[[48]](#footnote-48) were more positive than participants about participation in education, learning or things of interest to them, and about having the things needed. They tended to be less positive that their home had the things needed to help day to day.

The case study data indicated greater personal development for young people engaged in EGL

In the seven cases where young people were actively engaged in EGL and living in the community, they were all involved in personal development activities. Three of the young people were involved in post-school education or training.

For those young people with very high needs, personal development was about trying new things and having new experiences with just enough help and support to experience success and thus develop their skills. The parents of the young people with very high needs reported that their young people were blossoming now that they had the flexibility to choose a mix of activities that interested them.

In cases where they were actively engaged in EGL and doing something different, almost all the young people and their families were satisfied with the mix of activities the young people were engaged in. There was one exception. One young person was satisfied with the activities he was doing but not the amount. Poverty meant he could not afford to engage in all activities he wanted to. He had limited natural supports and was reliant on family for transport.

However, there was no evidence of personal development for young people in cases where they were in residential care. In two of the cases the parents did not expect their young person would ever develop further. They were vague about whether their young person’s daily life was filled with things that interested them. In the third case the young person stated he was not happy with the mix. The parents thought there might be changes if their young person was able to live in the community.

#### Self-determination

Overall the quality of life survey found similar scores for the foundational and the aspirational indicators for self-determination

Analysis of the quality of life survey found scores for foundational (73) and aspirational (69) indicators were similar. Overall almost two-thirds of respondents (62%) reported that they had a say about the important things in their life. Close to half of respondents answered positively each of the other questions focused on being listened to, being understood and having a choice about what they did each day (Figure 15). However, a smaller proportion was positive about *choice of who participants live with*, with answers evenly spread between positive (35%), neutral (36%) and negative (29%) responses. The variation may reflect some people’s use of residential and respite services, age and stage of life and availability of appropriate supported living options.

There were some differences between young survey respondents and proxies:

* More young survey respondents were positive about their ability to choose who they lived with (47% compared with 25% of proxies). Nevertheless choice was constrained for both.
* Fewer young survey respondents considered that people mostly *listened when they said no or didn’t like something* (37% compared with 70% of proxies)*.*

Figure 15. Self-determination - Percent of young survey respondent and proxy responses that gave the positive answer to each question (n = 43)



■ Foundational indicators

■ Aspirational indicators

Analysis of the case study data found that families engaged in EGL reported greater choice and control

Analysis of the case study data found that families engaged in EGL reported their young person had greater choice and control over how they lived their life. All of the families actively engaged in EGL had expectations their young person would be able to live the life they wanted in the community. For some families engaging in EGL reinforced their existing views about the importance of having choice and living in the community like non-disabled people. They were more focused on accessing and using the pooled funding to enact their choices. These families typically hired carers they chose to support their disabled person to do what they wanted (eg go flatting, participate in activities in the community when and where they wanted).

For others, engagement with EGL had broadened their view of what was possible for their young person. This change in mind-set was long-lasting – even where the experience of EGL was less positive. For example, one family interviewed who had engaged with EGL reported dissatisfaction with the level of support they had received from EGL. However, they had continued to focus on developing a life in the community for their young person.

While families engaged in EGL typically reported a greater degree of choice and control, there were constraints. In one of the cases the young person was doing more of what he wanted to than he would have been without EGL but his choices were constrained by financial circumstances and poor access to transport.

However, in the cases where the young people were in residential care they had limited choice and control over various aspects of their lives (eg activities they did, where they lived). In these cases the following factors applied:

* *Activities young people engaged in were typically in group settings, which limited choices and opportunities.* Satisfaction with the mix of activities varied. Two of the families reported that their young person was happy with the mix of activities they were engaged in. However, in one of these cases the parent was not entirely sure what the young person was doing with the provider. In both these cases the families had wanted the young person to be engaged with a provider doing similar activities to what they had undertaken at school. In the third case (the only one to have contact with a navigator) the young person and the family were unhappy with the provider’s focus on group activities, the lack of personalisation and the limited opportunities for engagement with the wider community. However, they had yet to make any changes.
* *Family needs took precedence over what the young person may have chosen.* In all of the cases the parents had reached a point where they could not care for their young person at home anymore. However, the mother in one of the cases said the freedom of choice that EGL apparently gives is good for many people and their families as long as they understand the limits of it. She thought the focus of EGL was on the young person but *“this world here – we don’t see children in isolation, they are in the context of their family”*. She said people like her daughter end up remaining in the context of their family so unless it works for the family it’s not going to work for the young person and vice versa. She added:

So it [EGL] kind of addresses that but not fully and again, I guess it depends on what else you want to achieve, yeah. And, you know, I have to come here [work] for financial reasons but I need to come here for myself as well.

These thoughts were echoed by the other families – especially in relation to undertaking paid work and their own health and wellbeing.

* *However, families’ choices were also limited by what was available in terms of housing in the community*. All the families felt there was no other choice apart from residential care when the young person could not live at home. One family was beginning to look at alternatives to residential care but none of these families were confident they could sustainably support their young person’s life in the community.

## Family outcomes

Families have always been crucial to successful living for disabled children and adults. However, with the increased focus on disabled people living in community settings the importance of their role has increased. Successful outcomes for families are underpinned by assumptions that *“most families are both able and willing to act as the main caregivers and decision makers, and that family life will be enhanced as a result of their greater involvement* (Samuel et al., 2012:2). The capacity of families to undertake this role varies. Samuel et al. (2012) state that emerging evidence suggests family skill building and empowerment are a viable approach to addressing support needs of individuals with disabilities.

As part of the case study research the evaluation team looked at family outcomes. In particular the following outcomes were examined:

* emotional, physical and material wellbeing
* personal relationships
* support networks and access to services
* personal development.

### Family emotional, physical and material wellbeing

#### Family emotional wellbeing had improved but not always because of EGL; no change in physical wellbeing

A common theme across the cases was high levels of parental stress and poor physical and/or mental health – especially amongst the mothers. This is consistent with the literature, which reveals that a substantial commitment to caregiving has a marked impact on the life of the caregiver (eg poorer mental and physical health, loss of social connectedness, negative impacts on financial circumstances and employment, concerns about the future of the care recipient) (Colombo et al., 2011; FaHCSIA, 2011; Goodhead & McDonald, 2007; Peer & Hillman, 2014). Mothers are more likely to suffer the negative impacts of caregiving as they are often the primary caregivers of disabled children.

This was true in all the cases where the young people were in residential care. Two of the three mothers reported poor health and the third had been very stressed juggling the care of their young person and work. For example, when asked what prompted them to move their young person into residential care a parent said:

Primarily, I think just the stresses and strains of looking after [our daughter] for 20-odd years. And [my wife], in particular, I think needing a bit of a break. That – a lot of things that we might otherwise do we can’t do because [our daughter] needs to be looked after 24 hours a day, basically.

Poor maternal health was common in families who had actively chosen to participate in EGL as well. In three of the four cases where the young people were core EGL participants, the mothers reported physical health problems that influenced their ability to work and/or care for their young person. Amongst the cases involving opt-ins, the mothers had experienced or still were experiencing poor health. In one of the cases the father had also experienced poor mental health.

There had been an improvement in the emotional wellbeing of many of the parents but not always because of EGL. In all of the cases where the young people went into residential care the mother’s wellbeing improved afterwards. In two of the cases the family reported that having formal supports and services in place for their disabled person gave them greater peace of mind. This was organised independently of EGL. However, in one case, while having her young person in residential care had allowed her to recover physically, concern about the quality of care he received was a significant source of family stress. In this case the navigator had brought a sense of hope things could change.

In almost all the cases where families had decided to actively participate in EGL, family wellbeing was reported as improved. Family members reported feeling less stressed and more hopeful about the future since being engaged in EGL. For example:

PARENT: I think I’m more relaxed now, aren’t I? DISABLED PERSON: Mm. PARENT: Because we can see things improving because I was getting quite frustrated when she was at school.

However, a parent in one of the families reported being very stressed about managing the funding, the lack of suitable respite care, and how they would manage in the future. The parent felt let down by EGL.

#### Family material wellbeing varied across families but changed little for individual families

Across the cases, EGL appeared to have little influence on families’ financial circumstances. In the cases where family incomes were low this did not change. Equally, those who had sufficient family income experienced no change in this situation.

EGL was not aimed at changing families’ material wellbeing, but family material wellbeing does have an influence on young people’s ability to achieve their goals. The evaluation found that families with more material resources were better placed to meet the needs of their young person with a disability. These families had greater flexibility and choice about how they met their young person’s needs than those who had lower family incomes.

Where families were under financial stress it influenced their experience of EGL. While they valued the idea of disabled people having choice and control, they felt their choices were constrained by their financial circumstances. In cases where family incomes were low, they reported that accessing activities in the community was often a struggle because they could not afford it. Similarly, living independently in the community was seen as a far-off goal because of the high cost of housing.

### Family personal relationships

#### Limited change was reported in the quality of relationships between family members but there were exceptions

Across the cases, the families typically did not report any change in the quality of relationships between family members since engaging in EGL. However, there were some exceptions and they highlight the role having the right supports can have in improving relationships:

* In a family where a young person with VHN ORS funding had gone flatting the mother reported improvements in her relationship with her partner and her young person. Without the daily stresses of looking after her young person she now had more time to spend with her partner, which she valued. When talking about her relationship with her son she emphatically described herself as his mum now – not his carer.
* The parents in another family, who had employed staff to come into their home rather than sending their child to respite care, reported being able to spend more time with their other children, who had left home; for example they could get away more easily. Before employing staff they had been reluctant to use respite care because of concerns about its quality.

### Family support networks and access to services

#### Few families had significant natural supports outside of family

The use of natural supports to assist disabled people to live the life they want is a key element of the EGL approach. For families of disabled people, the literature indicates that having strong social networks outside of the immediate family can help to reduce stress by alleviating the physical and emotional toll often associated with substantial caregiving responsibilities (Peer & Hillman, 2014).

However, across the cases the consensus was there were not a lot of natural supports available. Several families commented that the expectation on families to provide more natural supports was not always realistic. For example, one mother of a son with a profound intellectual disability said that, although her son had many siblings, several *“had young families and it is not practical for them provide the support. Others don’t have the inclination or their work makes supporting [her son] difficult”.* These views were echoed by other families. She added that establishing a circle of support in the community has been very hard to achieve. *“People don’t have the time or the inclination. Their lives are very busy. The pastor for example can’t do more than he does because he has a church to run.”*

Apart from family, friends or paid carers, none of the families interviewed received significant community support. One family who had previously lived in a small community reported that community support was easier to obtain in a place where everyone knew everyone. They had found it much more difficult to build that kind of support in Christchurch.

In all of the cases where the young people had gone into residential care, the family member reported they had someone they could talk to but no one had family or friends they could use to assist with the care of their young people in any sustained way. All reported that they had limited natural supports and felt it was unrealistic to expect families to develop and sustain them.

Amongst cases where people had actively chosen to engage with EGL and made changes, support networks largely consisted of family, friends or paid carers. In four of the cases EGL had strengthened their support networks (eg increased connection with other families; being able to choose who to hire to support their young people). However, in many of the cases the support networks were fragile. One family had extensive family support but stated it had been very difficult to build support beyond that. There was uncertainty about what would happen in a few years when the young person could not flat with a family member. Another family had developed a good support network in Christchurch but that would all disappear if they relocated. This was a real possibility. In another case the family relied heavily on their paid carer, who was essentially running the household.

#### Access to and experience of supports and services were problematic

Difficulty accessing services to support disabled people living in the community

Access to services to support disabled people living in the community was identified as a problem by families interviewed. In all the cases where the young people had moved into residential care the families reported they had little alternative. The young person staying at home was not seen as a viable option. One of the families had tried having their young person live with another family but this had fallen over prior to EGL. Two of the families felt there was not enough support available to help their young people live in the community.

In other jurisdictions the level of funding provided through individual packages is sometimes not sufficient to facilitate independent living, especially for those with significant cognitive disabilities (see, for example, Fisher et al., 2010).

Difficulty accessing affordable transport

Across the cases access to affordable transport when needed was an ongoing challenge identified by several of the families interviewed. Transporting their disabled young people to and from activities was costly, especially where the disabled people could not use public transport. To minimise costs some families did the transporting but it was time consuming to organise and tied the family to the disabled person’s activities. For example, one parent took her young person to post-school education courses and stayed with him because they could not afford the transport and personal care costs. The family was reluctant to pay someone to take the young person to the course as they had had previous negative experiences (eg carers not turning up, using the family vehicle for their own needs, and/or damaging the vehicle).

Limited range of services to support people with high needs

The availability of, and access to, suitable activities for people with high needs was identified as a problem by some families interviewed. Families interviewed reported there were few activities available (eg following the 2011 earthquake one family reported limited access to swimming facilities suitable for people with significant physical disabilities) and insufficient funding to cover participation in the activities.

Access to suitable personal care services was a problem for some

A young male who needed assistance with personal care at particular points in the day reported he had struggled to find the right person(s). He said: *“There’s nobody right around New Zealand – or not in Christchurch anyway.”* His mother added they can get someone to look after her son *“but they won’t do toileting”*. His mother currently provided the personal care but this was not sustainable long term as her health was suffering.

Experience of using formal disability support services and the amount of use varied

Amongst cases where people were actively engaged with EGL and not in a residential setting, the use of disability services in a segregated setting was limited. Several of the families used their EGL funding to employ carers instead of using formal disability support services. In many of these cases the families’ past experience of using providers was negative, especially where they had used facility-based respite services.

Across the cases where families were using disability support services (eg residential care, respite care) their experience was variable. Some families reported they were satisfied with the services they received while others were highly dissatisfied. The main criticisms were:

* lack of choice eg about who cared for their young person, who lived with their young person if they were in respite or residential settings, what activities their young person did
* the quality of the service provided.

### Family personal development

Family decisions about the care of their young person were influenced by and had influence on parents’ (especially mothers’) choices regarding work and further education and training. EGL appears to have had limited impact on these choices.

Parents were able to engage in further work, education or training, or personal development where the young person with the disability moved out of home. For example, where the young people were in residential care there was greater opportunity for the parents to concentrate on working.

Having carers come into the home can allow parents to work outside the home but it needs to be affordable. In one case the mother wanted to engage in paid work but could not afford the level of care needed. This meant she was still caring for her young person at home.

In some of the cases EGL appeared to have opened up space for family members to engage in personal development. For example:

* one family had used EGL to expand their work opportunities by facilitating family support for others
* in two cases the mothers reported an increase in time to pursue their own interests. In one case it was because the young person had moved out of home and in the other it was because the family had been able to employ a carer who was creating more space for the family.

### Suggested improvements to measuring quality of life outcomes for individuals and families

There is currently limited information systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found that improvements could be made by:

* enhancing data collection (eg improving the response rate, collection of information from people with communication challenges, and collection of information from proxies)
* reconsidering the use of comparison groups.
* establishing a standard set of indicators that can be tracked over time.

#### Improvements could be made to data collection

The following improvements could be made:

* Including the peer interviewers[[49]](#footnote-49) was a valuable aspect of data collection. Further work is needed to improve data collection from people who are more difficult to communicate with. Working in pairs and having support available when needed were essential for the interviewers.
* Email was not particularly effective in reaching participants as some did not have their own email address, or were not confident to reply to emails from someone they did not know. Where email addresses were family email addresses, on a few occasions parents appeared to complete the survey without forwarding it.
* Text messages seemed to be more effective in reaching participants. Improving the response rate would require promotion of the survey through the EGL programme, such as by the navigators, to endorse the value of the process.
* Collecting data from proxies is useful but problematic. Researchers have found that quality of life scores obtained from self-reports are not always the same as those obtained from family members or direct support staff. The differences are not necessarily indicative of bias or invalidity but reflect different perspectives (Claes et al., 2012). Development of a separate survey for proxies is recommended for future use of the quality of life survey. A separate survey should include some questions specifically for proxies to express their opinions and challenges. A separate response category may be needed to allow proxies to state whether an indicator is not applicable because of the disability of the participant. However, it is important to note that, as in all families, parents may have different expectations from their children about what is achievable.

#### Reconsidering the use of comparison groups

Considering the difficulty in identifying and contacting a valid comparison group, the future use of the quality of life survey is likely to be as a measure of change over time within the same individual or group of participants. Indicators can be selected that relate directly to a programme’s aims and tracked over time. However this would not allow any conclusions to be drawn about impacts on participants and their families.

Other options could include exploring the use of quasi experimental designs. It may be possible to utilise a quasi-experimental design if a similar initiative is rolled out to elsewhere. However this would require considerable work both to develop design options and to assess ethical implications. A further possibility may be to use future Health and Disability Surveys (or possibly the General Social Survey) in a quasi-experimental design.

#### Establishing a standard set of evidence based indicators

A set of indicators has been developed. Some are generic and some are specific to EGL. Continuing to develop and use a standard set of indicators will over time result in a robust data set that could be used for analysis of sub-groups eg different demographic groups. A consistent approach to measuring quality of life also has the potential to develop a data set against which the results of new initiatives could be examined. A shorter survey, with fewer indicators, is recommended to reduce the burden on respondents.

Consideration could also be given to developing a set of indicators of family wellbeing. Families have always been crucial to successful living for children and adults with disabilities. However, with the increased focus on disabled people living in community settings, the importance of their role has increased. The capacity of families to undertake this role varies (Samuel et al., 2012).

# Limited change amongst schools and providers

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| --- |
| **Summary**  Some schools and providers interviewed were working to support disabled people to live everyday lives in the community. However, provider and school alignment with the EGL approach could improve. The evaluation found that there was variation and room for improvement in:   * support for disabled people to make choices and tailoring of supports and services * the way schools and providers assist disabled people to plan for the future and significant transitions, which was heavily influenced by their views of the life they saw disabled people leading post-school * providers’ and schools’ understanding of social inclusion and their practices to support it * support for disabled people to build and maintain relationships and develop natural supports * support for the concept of mainstream first * support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed * the ease with which disabled people get the support they want when they want it * opportunities for disabled people to influence school/provider policies and practice and measurement of disabled people’s outcomes.   The influence the Demonstration had on provider and school practice may have been improved by:   * ensuring the design and implementation incentivised providers and schools to change * doing more work to change organisational beliefs and attitudes * determining whether resourcing available to schools and providers was sufficient for them to operate in line with the principles * ensuring individualised budgets did not reduce the ability of providers to respond to disabled people’s preferences * encouraging greater navigator engagement with schools and providers * providing more encouragement for organisations to support disabled people to influence their policies and practice * providing more assistance on developing ways to meet the needs of disabled people and families with multiple difficulties * making further effort to change community attitudes and the environment where they were not supportive.   Interviews with schools and providers revealed practices that supported disabled people to live everyday lives, including:   * having beliefs and attitudes that supported life in the community * being supportive of individualised planning and being person-centred * having a strong focus on relationship building * developing a network of organisations in the community to support disabled people * providing learning in a way that worked for disabled people and supported them to learn and grow * developing disabled people’s functional life skills to enable independent life in the community * changing resourcing to better support disabled people * having some practices in place to support disabled people to influence how their organisation operated * working on changing community attitudes. |

## Support expressed for the principles but limited change in practice reported

All the schools interviewed reported they liked the flexibility and holistic nature of the approach. All of the providers interviewed reported they agreed with the principles and philosophy of EGL. These were described as the *“glue really that holds the whole demonstration together”*, and as being *“a really good platform to build from”*. Almost all the providers and one of the schools reported the EGL approach was embedded in their organisation. However, few interviewed reported that they had changed their practices to work more in line with principles.

The evaluation found that:

* *There was variable support for disabled people to make choices and tailoring of supports and services to what people wanted.* A key element of the EGL approach is supporting disabled people to make choices about what they want to do and where needed having support and services tailored to meet their preferences. However, based on the interviews, there was room for schools and providers to improve their support for disabled people to make choices and tailoring of supports and services (see page 110).
* *How schools and providers assisted disabled people to plan for the future and significant transitions was heavily influenced by their views of the life they saw disabled people leading post-school.* The EGL approach encourages providers and schools adopt a whole of life approach[[50]](#footnote-50) to supporting disabled people and to begin early. In this Demonstration this was particularly important as participants were transitioning from school to adulthood.

However, transition typically did not begin early in schools. While the Ministry of Education’s National Transition Guidelines for students with special education needs state that schools should begin planning early – by age 14[[51]](#footnote-51) – this was not typically the case in the schools interviewed. All the schools interviewed reported that transition started early but most of the activity appeared to happen in the last year of school. There appeared to be little emphasis in any of the schools on young disabled people leaving school at the same age as their non-disabled peers[[52]](#footnote-52). None of the schools interviewed reported any change in the age at which their special needs students were leaving school. Some school interviewees were sceptical about the benefits of such students leaving school earlier. For example, a school reported that some high-functioning disabled people may be ready to leave school with their peers but most were not.

Practices around planning for the future were heavily influenced by school and provider views of the life they saw disabled people leading post-school. For example, some schools and providers saw the main transition a person made as being from school to a provider (see page 106) and implemented practices that supported that. However, there was evidence some schools and providers interviewed were expecting young people to transition to a more independent life in the community (see page 117).

* *Providers and schools varied in their understanding of social inclusion and their practices to support it*. The EGL approach encourages disabled people to be supported to live an everyday life in everyday places and be regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life. It is about being meaningfully included in communities – not just having a physical presence in the community. Some schools and providers interviewed appeared to be aligned with this approach (see page 119) while others did not appear to be aligned (see page 108).
* *Support for disabled people to build and maintain relationships and develop natural supports[[53]](#footnote-53) was variable.* Providers and schools interviewed understood what natural supports were. They considered natural supports to be relationships with people in the community such as employers, friends, and people in community organisations. It was wider than family. However, the extent to which the organisations interviewed supported the concept and worked to develop the supports with disabled people varied. Providers and schools who were supportive of the concept put more emphasis on building relationships between disabled people and people in the community (see 120). However, schools and providers interviewed who supported disabled people being in segregated environments appeared to do little to support the development or use of natural supports. They emphasised maintaining relationships within the environment of the specialist disability supports and services (see page 106).
* *There was varied support for the concept of mainstream first.* There was no common understanding of the mainstream first principle.Some schools and providers were supportive of the concept (see page 119) but others felt it devalued the role of specialist disability services (see page 107).
* *There was varied support for disabled people to learn, grow, try new things and have new experiences from schools and providers interviewed.* Some organisations interviewed were very supportive (see page 117) while others were less so (see page 108).
* *The ease with which disabled people get the support they want when they want it could improve.* Amongst the organisations interviewed, an important practice that supported disabled people to get what they wanted was taking the time to find out what disabled people wanted to do by developing solid, ongoing relationships with disabled people so they could easily express preferences. Other supportive practices included having a can-do attitude towards getting disabled people what they wanted, having broad community networks to link disabled people into, and being upfront about what they can and can’t offer. Organisations interviewed reported that it was difficult to easily meet people’s preferences, expressed concerns about resourcing and the ability to keep disabled people safe, and had low expectations of disabled people’s growth and development over the life course. However, most schools and providers also reported concerns about families and communities not always supporting disabled people to get what they wanted.
* *There were limited opportunities for disabled people and families to influence the policies and practices of the provider or school.* Interviews with schools and providers revealed that disabled people and families have only limited and indirect opportunities to influence policies and practices in providers or schools. Most schools and providers interviewed struggled to articulate how disabled people were able to influence their policies and practices (see page 114).

## What may have improved the Demonstration’s influence on provider and school practice?

There are several factors that could indicate why the Demonstration had a limited influence on wider provider and school practice. These included the need to:

* ensure the design and implementation created incentives for providers and schools to change
* undertake more work to change organisational beliefs and attitudes
* determine whether resourcing available to schools and providers was sufficient
* ensure individualised budgets did not reduce the ability of providers to respond to disabled people’s preferences
* encourage greater navigator engagement with schools and providers
* encourage organisations to support disabled people more to influence their policies and practice
* give more assistance on developing ways to meet the needs of disabled people and families with multiple difficulties
* make further effort to change community attitudes and the environment where they are not supportive.

Further detail is provided below.

### Ensuring the design and implementation created incentives for providers and schools to change

Aspects of the design and implementation undermined provider buy-in and incentives to change. The evaluation found that:

* the Demonstration underinvested in provider and school development to assist them to operate in line with the EGL principles
* the role of providers in the Demonstration was ambiguous
* design delays and late changes to provider funding undermined provider buy-in
* there was limited focus on outcomes sought from providers.

#### The Demonstration underinvested in provider and school development to assist them to operate in line with the EGL principles

Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, providers and schools interviewed typically had had limited experience of EGL. For example, the EGL resources dedicated to working with schools and providers on what EGL meant was limited:

* The EGL team had a person whose role it was to work with providers. Providers interviewed reported this role was invaluable but that more support was needed.
* While there was some EGL resource allocated to working with schools, the people in this role were primarily responsible for working with disabled people and families.
* Navigators had a role in changing behaviour but contact with providers and schools was limited. Some schools and providers had only a few people accessing support through EGL so had limited experience of the Demonstration. All the schools talked about including the navigators in the planning process; however, in practice the navigators had limited interaction in the school.

The lack of contact with the Demonstration meant schools and providers were unclear about their role in the Demonstration and key concepts such as ‘a good life’, ‘natural supports’, and ‘mainstream first’ were not commonly understood.

#### The role of providers in the Demonstration was ambiguous

Several interviewees reported that it would have helped to have clearer communication with providers on how they could contribute to improving the lives of disabled people in line with the EGL principles. As one interviewee reported, the initial messages didn’t convey support for providers and their role was ambiguous. He believes it was due to the interpretation of the principle of mainstream first, which stated the need to look at all other options before settling on specialist disability support services. In his view, *“It raised the ire of some providers. But other documents talked about co-design and co-development. It was a real time of uncertainty for providers”.*

#### Design delays and late changes to provider funding undermined provider buy-in

Not having the components of the Demonstration ready to go at the outset undermined provider buy-in, according to interviews with the EGL team, officials and providers. An EGL team member reported that initially provider commitment to the EGL approach was eroded by payments and funding difficulties which took time to resolve. He added, *“These side issues have then become real issues for some providers. They have focused on this instead of the real mahi, which is about them changing their ways.”*

Progress was made with improving provider buy-in but MSD’s decision to reduce the amount paid to its providers to ensure the Demonstration was fiscally neutral undermined this progress, according to several interviewees. A LAG member commented that the timing of the announcement was poor. Providers were developing a sense of what a different future might look like and were *“willing to take a bit of a risk and move out of their comfort zone but, I think what I’ve seen is a kind of a retreating back”* since MSD reduced the amount paid to providers.

This situation arose for a number of reasons. More people took up MSD funding than was expected. ORS status was used as a mechanism for determining eligibility for Demonstration funding. Typically not everyone who is eligible for ORS funding takes up MSD funding for community participation or vocational services. As services were fully subscribed, the only way to free up funding for personal budgets from within the existing funding was to reduce volumes elsewhere. Had there been a funding allocation mechanism tool in place at the outset of the Demonstration this problem may have been avoided.

#### Limited focus on outcomes sought from providers

The intent of the Demonstration was for providers and schools to focus on delivering the outcomes individuals wanted. At a systems level there were weak incentives for providers or schools to operate in a way that was consistent with achieving the desired outcomes for disabled people. For example, the Demonstration wanted providers to focus on individual outcomes, but MSD was still using bulk contracts with its providers. Under this system, MSD contracts for outputs (eg the number of people and the number of hours they are there) rather than outcomes achieved by disabled people. In addition, even where contracts encourage the employment of disabled people, a provider reported they don’t necessarily encourage growth of the person. As the provider reported, *“we have seen overrepresentation of people with learning disabilities pushing trolleys, for example, because that’s an easy win from a provider perspective”*. Schools completed Individual Education Plans for disabled people but were not required to report progress against these.

At an organisational level, the evaluation found that across schools and providers interviewed there was a limited focus on outcomes that would provide evidence of behaviour change in organisations. They typically reported there was no formal process for assessing the effectiveness of what they did with disabled people. Schools reported it was difficult to determine how effective they were at meeting the needs of disabled people as they did not know what happens to students once they leave school.

### More work needed to change organisational beliefs and attitudes

The evaluation found more work was needed to change the beliefs and attitudes of schools and providers to make them more supportive of ensuring disabled people have greater choice and control over their lives. Amongst the schools and providers interviewed:

* none believed they needed to change significantly
* some exhibited beliefs and attitudes that did not support life in the community.

#### No schools and providers interviewed believed they needed to change

The evaluation found that the actions of some schools and providers interviewed were driven by their mental models or thinking about disabled people but the Demonstration appeared to have had little influence on them. Schalock et al. (2008:277) describe mental models as:

deeply ingrained assumptions, generalizations, and images we have to understand the world. They form the vision and culture of an organization and serve as the basis for leadership, values training, service delivery, outcomes evaluation, and quality improvement.

None of the providers and schools interviewed reported that they needed to significantly change what they were doing to better align with the EGL principles. While the reported practices of schools and providers interviewed varied considerably, all those interviewed reported that the direction of their school or organisation aligned with the EGL approach.

For schools and providers interviewed who reported they supported the philosophy behind EGL and appeared to be operating more in line with the principles of EGL, the activities of the Demonstration confirmed to them that their approach was the right one. The Demonstration had little influence on their thinking and practice as they were already on this path before the EGL Demonstration began.

In contrast, schools and providers interviewed who were less supportive of the EGL approach typically displayed mental models that focused on people’s deficits rather than human potential, and overemphasised safety. However, these schools and providers also reported that they were aligned with the EGL principles and did not need to change.

#### Some schools and providers interviewed had beliefs and attitudes that did not support disabled people living a life they chose in the community

The evaluation found that some schools and providers interviewed exhibited beliefs and attitudes that did not support life in the community. A belief that specialist disability supports and services were preferable was seen in the:

* expectation that disabled people would transition from school to a provider
* lack of support for the concept of mainstream first
* lack of support for the concept of natural supports
* low expectations of what disabled people can do
* overriding belief that disabled people needed to be kept safe
* little focus on tailoring supports and services to individual preferences.

These are explained below.

##### Expectation that disabled people would transition from school to a provider

Some interviewees saw the main life transition a disabled person made as being from school to a provider. All the staff interviewed at the schools visited saw themselves as providing a safe, nurturing environment and they wanted this to continue once people left school. However, those schools who supported transition to a provider reported that this was often the safest option for young disabled people with high or very high needs. Transition was portrayed as the most stressful event in the lives of disabled people and their families. Transitioning to a provider was seen as minimising stress and disruption to disabled people and families and keeping disabled people safe and busy five days a week. As one school representative reported, “*going to a service provides structure and security to disabled people and their families”*.

Those interviewees that saw disabled people primarily being engaged with providers post-school expressed considerable concern that there was insufficient funding to support disabled people to attend a service five days a week. They reported that transition was a very stressful time for families because they were leaving a system which provided structure and certainty five days a week. In their view the stress on families would be reduced if they knew they had funding to cover a five-day-a-week service.

Once people had made the transition from school to a day service provider five days a week, there did not appear to be any discussion with providers about transitioning out of the service apart from for age-related reasons.

##### Lack of support for the concept of mainstream first

When asked about the concept of mainstream first, *s*ome providers and schools expressed concern the concept undermined the role and value of specialised services. Some schools and providers, especially those providing segregated services, reported feeling undervalued and alienated by the mainstream first principle. For example, a provider reported:

The impression I have is that some in EGL see themselves as crusaders against institutions. In the beginning we had psychopaedic hospitals and they were abolished. Now we need to get rid of day services to achieve genuine mainstream community participation.

Some interviewees also queried the suitability of mainstream supports and services for all disabled people. For example, a provider reported that the concept of mainstream first was unrealistic and in their view parents wanted and needed support for their disabled family member for a whole day at a centre – a point they felt was not well understood by the Ministries. The provider argued that there would always need to be a range of service providers, including day services, and this needed to be recognised.

One school interviewed that was very supportive of the mainstream first principle cautioned there is a risk that focusing on mainstream first and building relationships with non-disabled people might undermine disabled people’s connections with their disabled peers. The school reported that we need to be careful of the messaging to disabled people. They reported there is a need to be careful not to judge disabled people who choose to attend disability service providers. The school reported:

The social side of things is huge. It’s very easy for the students to get isolated. Students want to do stuff with their friends and are happy doing that. It’s important not to judge people’s choices. For example, there are students who have gone to [Provider] four days a week and are very happy. They’re with their friends doing activities they like eg art activities.

There is research to suggest that some disabled people are more comfortable among ‘segregated spaces’ where only others with disabilities are present (Milner & Kelly, 2009 in Duggan & Linehan, 2013). Duggan and Linehan (2013) question *“whether involvement with others with disabilities has become a less valid form of community connection resulting in a devaluing of the relationships among disabled people”.* Researchers have highlighted that the tendency to value disabled people’s friendships with non-disabled people more highly than their friendships with other disabled people can leave them more isolated from their peers (Mirfin-Veitch, 2003).

##### Lack of support for the concept of natural supports

Some schools and providers interviewed conceptualised natural supports as an alternative to specialist disability supports and services rather than complementary. They highlighted their ability to meet the needs of disabled people and questioned whether others (eg natural support networks) would be able to safely do so. A special school and some providers reported that establishing and maintaining natural supports was especially challenging for families where both parents were working and/or the young person had VHN ORS funding. In these cases they believed families needed provider support, often in the form of a five-day-a-week day service. For example, a provider said:

Some families can do this and that’s great. But some families have to go to work and they don’t have natural supports to look after their disabled family member. … Also many of the families are borderline in the ability to cope with things anyway. They are not well placed to be able to organise and use natural supports. … When the young person comes to us the families get support. With this support some families have stepped up in other ways and this helps the disabled person.

All the schools and several providers interviewed also questioned the availability and sustainability of natural supports. Schools and providers who supported disabled people being in segregated environments were particularly scathing of the availability and sustainability of natural supports. For example, one provider said:

Unfortunately people think, “Yes, let’s tap into the natural supports, things that are out there and we’ll go into the community and there’ll be these wonderful welcoming people who include us automatically.” Well, it doesn’t happen.

However, even those schools and providers who were supportive of the concept of natural supports reported that they take time to develop and require people with the right skill set to support disabled people. One such provider reported that having readily available natural supports in the community was *“a long way off”.*

##### Lower expectations of what disabled people can do

Some schools and providers interviewed had low expectations of disabled people’s growth and development over the life course and, related to this, there was a belief that staff were key to identifying what would be beneficial for the young person. There was an emphasis on keeping people stable. This made it difficult for them to help disabled people to identify their preferences and to grow, try new things and have new experiences.

##### A focus on having a presence in the community rather than meaningful social inclusion

It was evident from the interviews undertaken for the evaluation that social inclusion meant different things to different people. All providers and schools reported they supported people to have a presence in the community and doing everyday things but what this meant in practice varied considerably.

For some schools and providers, having a presence in the community meant engaging in segregated, group activities in the community rather than meaningful social inclusion with a range of people in a range of settings. Providers and schools who held this view tended to emphasise the need to protect disabled people, especially where they had significant intellectual disabilities. There was little evidence that they were supporting disabled people to make meaningful social connections with people in the wider community (eg active involvement in community activities that promote the development of interpersonal relationships; having valued social roles). Some schools and providers qualified their views by adding that having a life in the community was a more realistic option for higher-functioning disabled people.

This lack of agreement about the meaning of social inclusion is common. Research indicates that although social inclusion is central to disability policy, there is little clarity about its meaning largely because of multiple and conflicting definitions. Simplican et al. (2015:25) argue that:

The variation between definitions impedes effective service delivery and interventions, and leads to insufficient data about its effective implementation. Moreover, the conceptual ambiguity of social inclusion hinders communication across key stakeholders – such as individuals with disabilities, family members, service providers, researchers, and policymakers – who may disagree over the meaning and purpose of social inclusion.

##### An overriding belief that disabled people needed to be kept safe and this was best done using specialist disability support services

The belief amongst some interviewees was that disabled people needed to be kept safe and this was best achieved in the care of specialist disability support services than out in the community. For example, two providers reported that they had staff who were skilled at being in the community with disabled people and making sure safety strategies were in place. They both questioned how safe it was for people using natural supports – the implication was people outside of the service may not be safe.

Some schools and providers interviewed highlighted the need to keep people safe, when asked about how they met disabled people’s preferences or encouraged new experiences. While safety is important, it appeared that concern about the risks associated with disabled people engaging in everyday activities in non-segregated settings was limiting what they could do.

Research indicates that service organisations’ risk assessments may hinder opportunities for community participation (Duggan & Linehan, 2013). International evidence suggests the focus should be on safeguarding[[54]](#footnote-54) disabled people. Safeguards need to be thought about in a way that upholds the principles of person-centred approaches (eg a greater focus on risk enablement) (Ontario Ministry of Community and Social Services, 2013; Carr, 2010).

##### Little focus on tailoring supports and services to individual preferences

The evaluation found some schools and providers interviewed were continuing to deliver services the way they always had with little focus on tailoring supports and services to individual preferences outside a group setting. In these organisations there was a:

* greater reliance on the voices of the professionals and parents over disabled people
* preference for the use of specialist disability supports and services in group settings. If people did express choices, the school or provider would try to fit these in with what they had on offer. This typically meant undertaking activities as part of a group
* focus on risks and keeping people safe, which limited the extent to which people’s preferences could be realised
* focus on people’s deficits; for example, a school and some providers interviewed reported that determining preferences is more difficult where students are non-verbal.

### Determining the adequacy of resourcing to schools and providers to operate in line with the principles

Insufficient resourcing was the most common challenge identified by schools and providers interviewed.

#### All providers reported they were underfunded and concerned about long-term sustainability

All providers interviewed indicated resources were tight owing to inadequate funding levels. Providers reliant on MSD funding in particular reported that they struggled as this funding was contributory and had not increased in 12 years. For example, one provider reported that their sustainability was questionable and they were currently kept afloat by Ministry of Health funding. The provider currently charged $40 per day, on a one:three staff/client ratio, which they described as “borderline in terms of sustainability”. They reported that the only way they managed was by using the Health funding that came with the people who were deinstitutionalised to support the younger clients. The older Health-funded clients tended not to want to do the resource-intensive activities in the community that the young people liked. However, they reported that this situation is not sustainable as the older clients are ageing and retiring. Another provider reported that they had considered closing:

You can’t expand services if you’re not supporting the ones you have. This recent funding cut has pushed them to the wall – is that what government wants? MSD talks about contributory funding. The previous amount was very low but the current amount is too little – a slap in the face.

Some providers interviewed reported that current funding levels made it difficult to attract the staff with the right skill set and to have the money to pay them sufficiently.

Christchurch providers are not alone in facing this challenge. Schalock et al. (2016:56) comment that in developed countries human service organisations are facing many challenges including *“adapting to an increased demand for services and supports within a shrinking financial base”*.

#### Insufficient funding attached to some disabled people was a challenge to delivering personalised supports and services

All providers interviewed identified insufficient funding as being the main barrier to providing personalised supports and services based on people’s preferences. Providers interviewed reported that EGL does not address the issue of underfunding of the sector. Some reported that they changed how they used their resources to better support people’s preferences (eg investing in staff rather than buildings) but the level of funding they received was still a challenge. All providers interviewed reported that providing supports and services for HN ORS-funded clients was particularly challenging as they received much less than those with VHN ORS funding ($2,600 per year compared with $15,600 per year for VHN ORS funding). This meant that most with HN ORS funding could only afford to go to a provider two to three days per week whereas those with VHN ORS funding could afford five days. Some providers interviewed expressed concern that those with less funding would be left *“sitting at home”.*

Schools echoed the concerns of providers about the funding for HN ORS-funded students. They were concerned that the funding HN students received was not sufficient to support them to undertake activities in the community once they left school.

The mainstream schools reported that the teacher ratios they were currently funded for made it difficult to deliver on individualised plans for students. They struggled to find the time to develop the networks necessary to support young people’s growth and development in the community and to search for new experiences. In one school, getting out in the community was seen as admirable but difficult to achieve within current resourcing. They commented that “*it’s hard to fulfil the vision of Enabling Good Lives with the current funding arrangements”.* They had managed this year because they had a student with ACC funding, which is higher than ORS funding. Another mainstream school was able to resource students’ preferences but reported that the time taken juggling resources to do that and finding and building links with organisations in the community was significant. They wanted more help with this.

#### **Funding transport to support personalisation**

Transport is usually needed to support disabled people to access activities in the community. Some schools and providers reported that getting young people to off-site locations they wanted to go to could be difficult. A school and provider reported that their staff used their own transport or public transport. The provider reported that they could not afford to provide staff with cars but they did purchase bus passes for staff. The school reported that teachers at the school used their own cars to transport students when they could. However, they reported transport difficulties meant some students couldn’t take up opportunities to engage in meaningful activities of their choice.

Some providers also reported that difficulties in transporting young people to individual activities made supporting individual choices challenging.

#### There may be insufficient resourcing to support engagement with mainstream organisations

Providers and schools all reported that funding was insufficient to support choices and participation in individualised activities in the community, particularly for HN students. They also reported it takes time and resources to build relationships with mainstream organisations eg employers, community groups, tertiary education organisations. One provider had taken five years to build a relationship with a tertiary provider. The mainstream schools reported they would like help building these networks. The mainstream schools interviewed also reported that finding resources (time and funding) to support individualised activities in the community leading up to transition was difficult. One school wanted a dedicated transition person to assist with the process.

### Ensuring individualised budgets do not reduce the ability of providers to respond to disabled people’s preferences

Some providers reported that individualised budgets as they were implemented did not make it easy to meet disabled people’s preferences.

* *Some providers reported the move towards Individualised Funding reduced their flexibility to respond to disabled people’s preferences.* A provider who supported the EGL approach felt this was an unintended consequence of individualising the funding. They reported that as much as it empowers the individual and provides more choice and control, it can limit options in terms of the supports that a person can purchase. In their experience the support they were able to provide for somebody through their bulk funding contract was greater than a person on an individualised budget. The provider commented:

And so because under bulk funding you could be more responsive; – there’s more flexibility so that, Johnny might need – because of a particular kind of issue or aspiration that he has, needs quite a lot of support, – over this next few weeks or months and so we could, – you can through a bulk-funded arrangement you had the ability – the flexibility and the ability to be able to just put a lot of resource into Johnny at that time. And that’s not at the expense of others but it’s just the way that you can allocate your resources.

Therefore although there is greater flexibility for the individual, there may be less flexibility for providers to allocate resources across individuals under an EGL approach.

* *Determining what to bill disabled people for when providing personalised services was difficult.* The EGL approach was about meeting people where they were at in a way that worked for them. Working this way presented billing challenges for some providers. For example, a provider reported that as they tried to operate in a more flexible and fluid way they found they were constrained by a funding system that required them to account for each hour of time spent with a person. The provider said it is easy to bill for a planning meeting held in an office but less so when meetings were less structured and in informal settings where time may be spent doing leisure activities and planning. For example, the provider said:

Like, how would people feel if we billed them for mountain biking – do you know what I mean? But, I would suggest that sort of process is – adds far more value than sitting down [at a table]. So, I think it’s how you then quantify that.

### Greater navigator engagement needed with schools and providers

All the schools and many providers reported that they had had limited or variable contact with the navigators. One provider reported they never saw the navigators.

From the perspective of schools interviewed, the limited contact with the navigators led to the following problems:

* All schools interviewed reported that navigators became involved too late in the transition process. The navigators typically became involved in the last year a person was at school. By this stage the schools reported they were already working on transition from school to life post-school. As one school reported, they cannot afford to wait until the last six months of the year to think about transition from school. The school wanted earlier involvement from the navigators. Another school was concerned that having the navigators come in late in the process risked destabilising plans they had put in place for the young person and their family.
* Some schools interviewed reported that the lack of contact meant that the navigators did not understand enough about what their school offered. They felt the benefits of what they did with students were undervalued.
* Schools interviewed were concerned that the navigators didn’t have the time to build an in-depth knowledge of the students. The schools reported that the navigators were good at finding options for people but because they didn’t know the students well the options they suggested were not always appropriate or practical. A school gave the example of one of their students with muscular dystrophy being advised by the navigator he would be able to do more if he went to the gym and built up his strength. The school reported the mother was angry as she felt the navigator didn’t understand the reality of her son’s condition – that muscular dystrophy is an incurable, degenerative condition. Some providers echoed these concerns.

For providers interviewed, the limited contact with the navigators also led to problems. For providers who were active in promoting a life in the community, the limited contact with the navigators led to the following problems:

* The lack of contact meant that the navigators did not understand enough about what their service offered. For example, one provider reported they were set to provide an individualised service but navigators sent them disabled people expecting them to provide group-based activities.
* They received too little information about the disabled person before they came to the provider. For example, one provider reported that all their EGL clients came to them without plans. The provider wanted more involvement in the planning process with navigators so they knew the person better and could better organise what could be explored with the person. Without the plans there were delays in getting the service agreements in place. Moreover, if people weren’t going to be a good fit with their organisation, they could let people know early.
* There was limited contact between the disabled person and the navigator once the disabled person was placed with the provider. A provider reported that the navigators needed to follow up with disabled people to ensure people had made the right decision in attending the service. Providers who supported segregated services did not raise this concern.

Providers of segregated services interviewed also reported limited contact with the navigators. They were primarily concerned that the lack of contact with the navigator meant the navigator did not have a good understanding of the disabled person and their circumstances. They were also concerned that the navigators, when thinking about transition, did not understand enough about what their service offered and were therefore not able to give disabled people sound advice on the choices open to them.

### More encouragement needed for organisations to support disabled people to influence their policies and practice

Interviews with schools and providers revealed that disabled people and families had only limited and indirect opportunities to influence policies and practices of providers or schools. Most schools and providers interviewed struggled to articulate how disabled people might be able to influence their policies and practices.

The evaluation identified the following challenges to disabled people being able to influence policies and practices of providers or schools:

* Schools and providers may not have processes that support disabled people and their families to express their views on how the service could be better. Several schools and providers had ways in which people involved with their organisation could express their dissatisfaction (eg being able to ring and complain). However, few mentioned actively asking disabled people and their families how they could better meet the needs of disabled people.
* The input of families or disabled people may not be valued. One provider reported that clients attending their service would be unable to participate in decision-making bodies and that it would be tokenistic to include them.
* Practices that work well in a small organisation to encourage involvement may not be as effective in a large organisation (eg relationship-focused practices).
* Disabled people may not have someone to advocate for them: a provider reported that they noticed parents became less involved in what was happening with their young person once they moved into residential care. He stated, *“So you lose the strength of advocacy because the residential carers will know something of them but they’ve got other people to look at, it’s not quite – that don’t have that single focus that a parent does.*” This view is supported by the case study research. A family member who was advocating for change in a residential facility reported that there were people who were in situations similar to or worse than her young person – especially if they *“don’t have mouthy parents”*.

### More assistance needed on developing ways to meet the needs of disabled people and families with multiple difficulties

Schools and providers interviewed reported challenges in meeting the needs of those disabled people and families with multiple difficulties. Reasons include:

* families not supporting disabled people’s preferences
* systems can struggle to support people with complex needs.

#### Families may not always support disabled people’s preferences

Some schools and providers interviewed reported that families were not always able to support disabled people’s preferences. Reasons cited included:

* *Parental attitudes may not support a disabled person’s life of their choice in the community.* One school that was very supportive of assisting students to have a life in the community found that the attitudes of parents were not always supportive of this aim[[55]](#footnote-55). The school cited the example of a 17 year old who was encouraged by her family to leave school once she became eligible to go onto benefit in her own right. The school reported the young person had many skills but was at home in a benefit-dependent household doing housework for her mother, who was unsupportive of her daughter getting paid work. The school reported the young person *“used to live in care nearer the place of work but went home to live with mum and mum had cancelled the job as didn’t see she needed to work. What can you do?”* In these situations the school found it difficult to have conversations with the family about working towards a better life for their young person. The school reported that this was not an uncommon scenario. She reported that students getting into and staying in work is dependent not just on an employer being willing to take the young person on but also on the family supporting the move. The school wanted more help with job coaching and changing the mind-sets of the parents (eg so they see work as an option for their young person).
* *They lacked the capability.* Some schools and providers interviewed reported that supporting a disabled person to live in the community required *“highly engaged, highly competent”* parents. They questioned whether families facing significant challenges would be able to provide this level of support (eg where parents had to work full-time or were experiencing family dysfunction).

#### Systems can struggle to support people with complex needs

A supported housing provider reported that in recent years the clients being referred to them had more complex needs. For example, they reported that more of their clients had dual diagnosis (such as mental health and intellectual or physical disabilities), had a CYF background and/or were from dysfunctional families. As a provider, they reported helping the more vulnerable young person get what they wanted was time-consuming and often not funded. For example, support workers were having to spend a considerable amount of time working with challenging families as well as the young people. The provider commented that the EGL concept is good but the amount of funding available to support people to live in the community is insufficient. They said: *“If they go on like this I think they are going to need to build another prison. And I’m very serious about that.”*

### Further effort needed to change community attitudes and the environment where they are not supportive

Some schools and providers interviewed reported that the attitudes of those in the community were not always supportive of disabled people living the life they wanted. For example:

* *Potential partner organisations may not have had values consistent with delivering personalised services.* A provider and two schools reported that finding organisations that they could work with to provide what disabled people wanted was a challenge. One provider with an emphasis on placing disabled people in the community found that disability organisations who wanted to partner with them did not always share their values. For example, a progressive provider reported that they had chosen not to partner with disability organisations that had a preference for segregated services. Instead they had responded by partnering more with mainstream organisations. While these relationships were beneficial, they took time to develop.
* *Overcoming negative stereotypes in the community about disabled people was difficult.* Schools and providers cited examples of individuals and organisations in the community not wanting to accommodate disabled people. For example, a housing provider reported they frequently encountered resistance from neighbours to disabled people being housed in the community. A school also encountered resistance from some workplaces when seeking work experience for their students. For example, when approached about a young person in a wheelchair having some work experience, a large employer told the school they *“don’t take people like that”*.
* *The wider environment was not necessarily supportive of disabled people’s engagement in the community.* Some schools and providers reported that the environment in Christchurch is disabling; for example, bus services are not user friendly for disabled people.

## Nevertheless some schools and providers were working to support disabled people to live everyday lives

Interviews with schools and providers revealed practices that supported disabled people to live everyday lives. These included:

* having beliefs and attitudes that supported life in the community
* being supportive of individualised planning and being person-centred
* having a strong focus on relationship building
* developing a network of organisations in the community that could be used to support disabled people
* providing learning in a way that worked for disabled people supported people to learn and grow
* developing disabled people’s functional life skills to enable them to operate more independently in the community
* changing resourcing to better support disabled people
* having some practices in place to support disabled people to influence how their organisation operated
* working on changing community attitudes to better support disabled people to live in the community.

### Beliefs and attitudes that supported life in the community were evident in some schools and providers

Some schools and providers interviewed displayed beliefs and attitudes that were supportive of disabled people having a life in the community. These included the following.

#### Seeing disabled people ultimately transitioning to live in the community

There was evidence some schools and providers interviewed were expecting young people to transition to a more independent life in the community. They saw their role as ultimately supporting people to live more independently in the community. They envisaged that their support would taper off over time as people were better able to manage for themselves or with the support of people in the community. For example, one provider reported that it was his aim that, with the right support, disabled people using his services would not need them in five years’ time.

Schools who expressed the belief disabled people could live everyday lives in the community worked to support them to transition to the community by:

* having an expectation that people would learn and grow
* exploring what disabled people wanted to do in the community and helping to make that happen
* providing a range of experiences in the community to give people more options to choose between
* teaching life and social skills[[56]](#footnote-56) to enable disabled people to more easily participate in life in the community.

For schools this was in line with the Ministry of Education National Transition Guidelines for students with special education needs, which have several references to engaging with the community. For example, they indicate schools should ensure goals for the transition plan are embedded in education and the community, use community settings, and build partnerships with communities[[57]](#footnote-57).

#### Having an expectation that people can learn and grow over the life course but being flexible about the pathway

Some schools and providers interviewed had a strong expectation that disabled people would continue to learn and grow over the life course. They placed an emphasis on teaching skills that would allow people to be more independent in the community. One provider described his organisation as a bridge to the community. The provider’s intention was that the young people coming to them would not be with them in five years’ time because they were ready to move on after they had built up their skills and experience (eg through the RISK programme[[58]](#footnote-58), referral to Catapult[[59]](#footnote-59), work experience).

Another provider reported it was important to have an expectation that people can develop but to keep an open mind about what that pathway to growth might look like. Offering people choices and assisting them to develop their skills does not mean they need to stay with that choice. For example, if someone is placed in a job and they don’t like it they should be able to leave – *“It’s about the quality of the experience of the individual.”*

#### Having a can-do attitude and being flexible supported disabled people to get what they wanted

All providers and schools considered the risks associated with disabled people participating in activities they wanted to undertake. However, some schools and providers had a strong ‘can-do’ attitude and focused on enabling people to do what they wanted and manage any risks. They had a culture of making things happen rather than a culture of risk aversion. When there was a concern about someone’s safety, they worked through with the disabled person what needed to be done to manage the situation and enabled them to do it. For example, a provider who helped a disabled person fulfil their desire to race stock cars reflected:

I could have said, “Well, no, it’s too risky, we’re not going down that track.” My arse is on the line here if –, but I stopped and I thought and, “Well, what would typically happen in that situation?” Well people would just work through a process of ticking off the boxes that needed to be ticked off in terms of managing the health and safety.

If the family was worried about safety, they worked with them to allay their fears. When talking with the disabled person they discussed how they could do activities safely and what they would do if something unexpected happened (eg getting on the wrong bus). These interviewees reported that they believed expanding disabled people’s experiences builds confidence, which enables them to do things more safely.

#### Valuing natural supports

Most providers and schools interviewed considered natural supports to be relationships with people in the community such as employers, friends, people in community organisations. Natural supports were seen to be wider than family. However, not all saw them as valuable. Providers interviewed who were supportive of disabled people living a life in the community typically saw natural supports as complementary to what they did, rather than as a lesser alternative.

#### Valuing the concept of mainstream first

Under the EGL approach disabled people are supported to use mainstream and/or natural supports first, and supplement these with specialist supports where required. For some schools and providers interviewed, encouraging disabled people’s participation and inclusion in mainstream activities and organisations was a core part of what they did.

They demonstrated that they were supportive of the concept of mainstream first by:

* supporting connections between disabled and non-disabled people
* teaching life skills that would support participation in mainstream activities
* building relationships between disabled people and those in mainstream organisations
* building relationships with mainstream organisations so that they had options to support disabled people.

#### Seeing social inclusion as being about building meaningful connections not just having a presence

Some providers and schools interviewed saw social inclusion as being about building meaningful connections in the community, not just having a presence. They supported disabled people to do, as much as possible, what their non-disabled peers were doing (eg work, volunteering, recreation). They typically had a goal of establishing more meaningful connections between disabled people and the wider community. They did this by, for example:

* using staff to establish relationships between disabled people and people in the community but stepping back as the relationships developed
* developing functional life skills to assist disabled people to be in the community
* working on changing community attitudes to better support disabled people to live in the community
* developing staff to support social inclusion.

Research indicates that people with intellectual disabilities living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than non-disabled and other disability groups (Verdonschot et al., 2009).

### Some providers and schools were supportive of individualised planning and being person-centred

A key element of the EGL approach is that supporting disabled people to make choices about what they want to do and where needed having support and services tailored to meet their preferences. Some schools and providers interviewed were endeavouring to work in a personalised way by:

* *developing individualised plans with the disabled person:* All schools reported they developed Individual Education Plans as one of the means of identifying people’s preferences and aspirations. However, the degree to which these were driven by disabled people rather than by what the school offered appeared to vary.

One school interviewed stood out as putting in place plans that were driven by what the students were interested in. The school had a strong emphasis on young people transitioning to a life in the community. They started talking with students early (eg when they were about 14) about what they were interested in and putting in place plans related to that. What they did depended on where students were at. For example, at the time of interviewing, many of the students were older so there had been an emphasis on sourcing work opportunities out in the community. Work opportunities were aligned with people’s interests but were also used to allow people to explore activities they may want to pursue. In the following year, when they had more younger students, plans would have a greater emphasis on building functional life skills, relationships and self-care that supported life in the community. The school also offered people a range of experiences in the community so they had more ideas to draw on when thinking about what they liked.

Similarly, all providers reported that they developed individual plans with disabled people. However, as with the schools, only some were able to detail how they incorporated disabled people’s preferences. In these organisations disabled people were also encouraged to be active players in decisions related to them and their development.

* *taking the time to build relationships and explore what disabled people wanted and how they could support that* (see page 120)
* *changing staff and resources to support personalisation (*see page 125)
* *sourcing options in the community that were aligned with people’s choices*
* *being upfront with disabled people about what they could offer so they were clear about their choice:* Being upfront with disabled people about what they could offer to make choices more clearly supported disabled people to get what they wanted. Some providers reported that since the emergence of EGL they had been prompted to have more explicit discussions with disabled people and their families about what they could sustainably provide, and not overpromise
* *having a can-do attitude and being flexible to support disabled people to get what they wanted.*

### Some providers and schools had a strong focus on relationship building

#### Building relationship between disabled person and school/provider

Schools and providers interviewed talked about the importance of building trusting relationships with families as a means of understanding disabled people’s preferences. This was especially important where disabled people struggled to communicate their preferences. Having good relationships with disabled people and their families enabled schools and providers interviewed to keep up to date with what disabled people wanted. They reported they used this knowledge to better support individuals’ learning and development.

Practices that helped build relationships included:

* *being less formal:* Having a relationship-based approach meant working with individuals and keeping formal processes to a minimum. One provider reported that it was beneficial to use informal approaches with disabled people and talk in environments that enabled meaningful conversations about what the disabled person wanted. For the provider it reduced assumptions they made about the person and made it easier for disabled people to be “*active players”* in the process
* *investing the time:* Schools and providers who placed a strong emphasis on relationship building reported that this took time. As one provider reported:

It’s about investing the time in those conversations but with a view of really trying to understand, what the person wants to do or what they don’t want to do. That’s not just about conversations. People will communicate through their actions and their behaviours so you need to be in tune with that as well. They might be saying this but actually their behaviour is telling us something quite different. For example, if one of the guys was regularly not turning up, well I’ll say, “Well hang on, okay, so what’s – let’s explore that.”

Another provider added that accepting that the relationship building will take time is particularly important where people have multiple challenges. She cited the example of a young person her organisation worked with who came to them because he could no longer live at home due to violent outbursts. His parents had rejected him and he had difficulty trusting people. The provider invested considerable time with the young person, including hiring someone to work one on one with him, to gain his trust and he was now calmer, respectful of boundaries, working, and developing friendships.

* *being aware of the various ways people communicated or expressed what they wanted to do but also whether they were enjoying what they were doing*.

#### Assisting disabled people to build relationships with people in the community

Some schools and providers were assisting disabled people to develop relationships with non-disabled people in the community by:

* *fostering links with people in the community such as employers who may eventually act as natural supports:* One provider firmly believed natural supports were available in the community for disabled people. The organisation used its staff to build disabled people’s natural supports. The provider reported that natural supports take time to develop and require people with the right skill set to support people but *“once the dots start to join up it’s amazing how things can then fall into place”*. The provider gave the example of a young person who, with the use of natural supports fostered by the provider, went on to get a driver’s licence and employment (see Box 1, page 124). A school interviewed adopted a similar approach with local employers (see page 123)
* *stepping back as the relationships in the community developed:* Having a staff person present initially was seen as important for both the disabled person and the community organisation or workplace to assist in establishing a relationship. When possible, staff left people to maintain the relationships but were there for them to fall back on if there were any concerns. For example, one school built relationships with workplaces who were willing to provide work experience for disabled people. They provided support in the form of teacher aides but this could be reduced as the people in the workplace became more confident in supporting the disabled person.

While beneficial, the process can be time-consuming, as the following example illustrates. The school got one of their students into a supermarket working 40 hours a week after the teacher met with the supermarket and built up the relationship with them. It took two years to establish the position. The school used the teacher aide resource to support the young person initially in the job and gradually the supermarket took over that role until finally the person was employed.

A provider interviewed undertook similar practices. The provider explained that as the relationship between the disabled person and person(s) in the community (eg employer) developed he expected that the role of the provider would be more in the background:

I think that kind of captures it for me, really, that new relationships would develop for people, that there would be more natural supports around that person. But there would still be a provider would still be there, maybe more in the background than foreground, so – the support wouldn’t be – I mean, as much as it would be structured to a degree and formalised, – it would be more in the background, yeah.

#### Supporting a disabled person’s relationships with peers

Providers and schools interviewed reported they were supporting disabled people to build relationships with their peers. However, some explicitly talked about helping people to build longer-lasting connections. For example, two schools worked to develop students’ social networks in the community so that they had support once they left school. In another example a provider assisted a young person with no friends to build up relationships by supporting him to go to social activities of his choice in the community. The activities were with disabled people (eg youth groups, a ball) and without disabilities (eg nightclubs, musicals).

#### Developing connections between disabled and non-disabled people by supporting participation in mainstream activities

Some schools and providers supported connections between disabled and non-disabled people. For example, mainstream schools supported connections between disabled and non-disabled students by:

* encouraging disabled people’s participation in mainstream classes and activities where this was possible. For example, at one school all the students in the special needs class spent time in mainstream classes, sometimes with teacher aides and sometimes not. Several students participated in mainstream dance activities at the school; and all the special needs students attended form time in a mainstream class
* amending mainstream events so that disabled people could participate, for example changing the lighting so visually impaired students could participate in the end of year prize giving
* opening up mainstream roles to disabled people. For example, at one of the schools a past student with special needs had been deputy head boy. The teacher reported that he had had help with his end of year speech but it was really well received by the students – that support was genuine. He took the job seriously and did all his tasks.

### Developing a network of organisations in the community that can be used to support disabled people

Some schools and providers worked to develop networks with mainstream organisations so that they could assist disabled people to build strong connections with them and more easily fulfil their choices. They actively encouraged their staff to build these networks. For example, one provider reported that, while there was value in disability organisations collaborating with each other, the real value for disabled people came in such providers connecting more with mainstream organisations. He stated:

thinking about the principles of Enabling Good Lives – it’s actually about disability providers becoming part of the mainstream and connecting with a whole range of different people and organisations ... And so we, we’ve been quite intentional about [it]. … You know, we don’t want to kind of isolate ourselves but we see the future more about becoming part of the community.

The provider believed this approach opened up more mainstream opportunities for disabled people to participate in everyday life and build relationships. The provider had established links with art galleries, mainstream employers, and tertiary education organisations, which had in turn provided opportunities for disabled people to participate in mainstream activities they were interested in. As the provider reported:

And that’s enabled us to move out of the disability space and into the art space. So, our philosophy is that this is not about disabilities. This is about art. This is about recognising that we have a group of talented artists here that really have a passion for art and so then flowing from that.

A school with strong connections to several mainstream organisations expressed similar sentiments. For example, the school went to considerable effort to build relationships with employers who could provide work experience that fitted with people’s preferences. For example, the school interviewee reported that she used her existing relationship with her local vet to create a work opportunity for one of her students. She had a student who really liked cats and wanted to work at the vet clinic. *“It’s about finding the right people – I have managed to find quite a few.”*

### Providing learning in a way that worked for disabled people supported people to learn and grow

A provider interviewed supported disabled people to grow through experiential learning[[60]](#footnote-60). For example, the provider ran a course for learners with intellectual disability who wanted to work. The course was shaped around people’s employment goals. The classroom-based work was shaped by the work experience people would be involved with and vice versa. The provider reported that:

an employment outcome is more likely if there’s an opportunity for a person to connect with an employer through work experience early on in the process and not only does that allow for the necessary skills to then develop but it’s about those relationships. And so the employer gets to know the person and that makes a big difference. … So that’s kind of – we’re hoping that we can demonstrate through that actually the role that work experience plays in terms of the learning process but then ultimately an employment outcome.

The provider had an example of where providing a young person with the opportunities to gain confidence, build skills, and learn from experience had resulted in an employment outcome (see Box 1). This approach required the provider to have the right staff to facilitate experiential learning.

Box 1: Stock car racing

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| A provider was supporting a young person who was passionate about stock cars. The provider found him work with a car dismantler who had a private race track. The relationship between the disabled person and the car wrecker flourished. After a few months one of the team came to the head of the provider and said:  “*There’s been a bit of a change in plan.” And I’m, “Yeah.” They said, “William wants to race the car at Woodford Glen,” and so I’m thinking, “Okay” you know, probably 101 sort of health and safety issues that – and I said, “Okay.”* So I mean that kind of challenged me a little bit and so I’m like, “Yeah, okay, well let’s just take it one step at a time and see what’s required.” So, a lot of really good support from the car wrecker guy and then, we liaised with the raceway and all the health and safety things and just ticked them off one thing at a time. And then it’s like, “Hang on, he hasn’t got a driver’s licence.”  The provider supported this decision and got some funding for six driving lessons. Once the driving instructor got to know the young person and what he was trying to do, he donated another 10 driving lessons to help him pass. In addition the car wrecker supplied much of the safety equipment and allowed him to practise on the private track. All his work culminated in the young man racing in a stock car at the local speedway. His confidence significantly increased in the time he was with the car wrecker. The provider said:  We hardly ever see him and so, he’s now got a full-time job working as a car groomer, passion for cars again, he’s bought his own car. … And I’ve just recently heard that he’s bought his own old wreck of a car to build as a stock car. |

### Developing functional life skills to enable people to operate more independently in the community

All the schools reported they taught their students life skills[[61]](#footnote-61) to participate in the community. For example, one of the mainstream schools interviewed had a particularly strong emphasis on teaching functional life skills that would support young people to live as independently as possible in the community post-school. They taught students about managing money and time, how to communicate, using transport, health, sexuality, and keeping safe.

There was an emphasis on disabled people practising the skills they learned in the community. For example, when teaching students how to buy clothes at the mall the teacher aide made sure the students knew how to try the clothes on, wrote down their sizes so they knew what to get next time, and showed them how to pay for the clothing. The school also taught students to buy and cook healthy food by undertaking these activities. The school provided visual recipes for hot dogs, pizza, noodles, as not everyone could read. Students were encouraged to cook at home and put pictures on Facebook to showcase their efforts.

What the schools taught depended on the needs of the students. For example, at the school mentioned above, where students were older and closer to leaving school, the focus was more on strengthening the skills needed post-school. Where students were younger the focus was more on developing basic life skills. At another school where the students were higher functioning the emphasis was less on basic life skills and more about supporting them with equipment and establishing back-up plans (eg what to do if they had a technical malfunction with their technology such as their Segway or phone).

Some providers were also involved in teaching life skills and/or vocational skills to allow people to engage on their own terms in the community. For example, this included building disabled people’s skills to take the bus by themselves, do shopping and cooking so they could live independently, and keep safe including using technology.

### Changing resourcing to better support disabled people

Research indicates that staff practice and organisational process are both important for ensuring personal outcomes (Claes et al., 2012). This evaluation found all schools and providers had concerns about the adequacy of the resources available to them. However, some schools and providers reported that part of the answer lies in better use of resources. A school and two providers who were very supportive of the EGL approach reported that, while more resourcing would be useful, it was also a matter of thinking differently about how the resources they had were used. For example, some were:

* *moving resources away from away from investing in buildings to investing in staff who could work with disabled people in a community setting:* One provider interviewed who had done this reported that the earthquake provided an opportunity to use their funding differently and fitted with their move to providing more individualised and flexible support to disabled people. Rather than leasing or owning a building with all the associated costs, they utilised community spaces and developed partnerships with organisations who let the provider use their buildings at minimal or no cost
* *using staff differently to better support the delivery of a personalised approach:* Some schools and providers were doing this. For example, a provider who had moved away from group activities now required staff to work more flexibly with individuals on a one-to-one basis to build people’s confidence and skills and undertake activities of their choice in the community. A school interviewed undertook a similar approach. It sometimes meant they had higher than normal teacher: student ratios in the classroom (eg 1:6) while the teacher aides were out but they reported that so far this had not been a problem
* *up-skilling staff:* The move to a more personalised approach required some providers to up-skill staff to work in a personalised way. Two providers reported they had worked to educate staff on how to work in a more personalised way. While some staff were not able to make the adjustment and left, those that remained had changed the way they worked. As one provider reported:

I think that was probably one of the factors that saw some of our team leave – they had a fairly sort of – how can I say this respectfully? You know, sort of a boxed-up view of what it looked like. But I think we’ve got the right – more or less the right team now that understands the principles that we work from and see evidence of those principles, hopefully, on a day-to-day basis.

* *using leadership to promote change:* The evaluation found leadership and values were important to support staff to respond to specific issues and continual challenges regarding risk. Leadership was essential in supporting staff with the approach and situations, to build a culture of learning and confidence. The expanding of disabled people’s experiences and confidence meant staff were continuing to be challenged and needing to work through situations as they presented to ensure any risks to individuals were well thought through (see Box 2).

Box 2: Supported housing

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| One supported housing provider commented that they needed to be able to manage the risks and allow people the freedom to live their lives. Achieving this balance with staff was at times stressful but possible. She had given the clear direction to her staff that the people they supported were adults and needed to be treated as such (eg flexibility about bedtimes rather than having to be in bed by 8.30pm because that time suited the staff).  She gave the example of a young person whom they were providing supported housing for. The young person sometimes tried to re-negotiate curfews while out. While it was later than agreed he would eventually come back, she reported that one staff member was keen on reprimanding his behaviour. She talked to the staff member concerned, saying they needed to focus on the fact he came back and that needed to be said was, “Oh, good you’re back.”  She said the change in approach at the organisation had been challenging for some staff. In line with their philosophy of treating people as the adults they were, people were encouraged to negotiate when they wanted to stay out late. For example, a young person they were supporting wanted to come back one night at 11.30pm. She advised him to negotiate with the sleepover woman to make sure it was ok for her to wait up for him as she officially finished at 10.30pm. She gave the responsibility to the young person to ask her and sort out how he’d get in. She checked it out as well but the young person managed it. |

### Had some practices in place to support disabled people to influence how their organisation operated

Some practices were identified that supported disabled people to influence the policies and practices of the provider or school.

* *building relationships:* Some schools and providers reported building good relationships with disabled people so they felt comfortable raising concerns
* *having disabled people represented on boards or other decision-making bodies:* This was not common. However, two providers reported that they had disabled people represented in decision-making. For example, a provider had a monthly group meeting with staff and families where they talked about how the service could be improved. The provider reported that they had made changes as a result of the input from families. The provider also had a client representative on the Board of Trustees and this influenced purchases. Another provider reported they had a client representative group and these representatives attended the provider’s board meetings. The provider reported it meant that the people they worked with had a direct connection with their Board of Trustees
* *having complaints processes:* Several providers and all the schools reported that they had a complaints process whereby disabled people and/or their families could express concerns.

### Working on changing community attitudes to better support disabled people to live in the community

Some providers and schools worked to get people in the community to value what disabled people have to offer and the skills they have. For example, a teacher in one mainstream school did this by building connections between her students and people in the community (eg work experience opportunities). Connections were also built with mainstream students by encouraging students with disabilities to participate in mainstream activities in the school and mainstream students to interact with them (eg year 12 mainstream students attending camp with students from the special unit). The teacher said:

That kind of contact and experience helps change attitudes. You hope that when they get jobs they might become managers and they might give these guys [disabled students] opportunities.

Some schools and providers reported using their staff to build relationships with organisations and encourage them to be inclusive and accepting of disabled people.A provider reported that by building relationships between disabled people and those in the community prejudices can be lessened and natural supports developed.

Some providers worked to allay the fears of people in the community about disabled people. A housing provider believed having more disabled people live successfully in the community would help change attitudes. To overcome resistance to having disabled people as neighbours, the provider spent time reassuring them they had nothing to worry about and sometimes they also guaranteed bonds. A vocational provider reported there were ways to use staff to reduce the nervousness of mainstream people when disabled people visited community facilities. When the staff member was acting as part of the group, rather than standing off to the side and observing the other group members, it seemed to normalise the situation, and put other people more at ease.

## More investment may be needed to bring about sustained change

More investment may be needed to bring about sustained change in schools and providers. When asked whether EGL had brought about sustained or superficial change in providers and schools, those working with schools and providers reported the changes were superficial. They reported they had seen the beginnings of change in how providers and schools operated but felt there was a risk that providers and schools would stop progressing once the Demonstration ended. As one EGL team member reported, *“Providers could take their foot off the pedal and say see I told you it would go away”*. Of schools, another team member said:

I think if we didn’t turn up next year the schools would be like, “Oh well. That was a waste of time.” … And the others would, you know, it’s sort of – there would be that – that element of “I told you so”.

Specific provider (and school) development funding could help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools need to start by expanding their vision of what disabled people can achieve.

# Where to next?

### Suggested improvements to implementation and the design process

Improving what was to be put in place in the Demonstration could have improved implementation.

* A more fully developed design was needed. Development of a detailed design was hindered by several factors. There were differing perspectives on the flexibility of the design, what co-design meant in practice in the context of the Demonstration and whether it had been co-designed. The co-design needed more time and resource. Better links between design and implementation were needed.
* Understanding of and buy-in to the EGL vision across stakeholders needed to improve.
* It would have improved the Demonstration if the leader on the ground and leaders in government had a common understanding about roles and responsibilities and the processes for resolving system issues as they affected the Demonstration.
* Accountability arrangements could be improved. Focus on outcomes and measuring outcomes was problematic at all levels. Accountability arrangements with providers and schools don’t yet reflect that focus on outcomes for disabled people.

EGL highlights wider problems with the system which limit implementation and performance.

* The amount of funding disabled people received may have been insufficient to achieve their vision of a good life. For example, those who wanted to move out of home and live independently in the community.

The design of what was implemented could have been improved.

* A wider range of funding options for managing the funding was needed.
* There is a need to look at the assumptions about the role natural supports can play in supporting disabled people, as they may be unrealistic. Few families reported that they had significant natural supports outside of family and where they existed they appeared fragile. Further understanding is required about how natural supports can be developed and how they can be used alongside responsive formal supports and services.
* The community development component was underdeveloped. It was unclear how community development was supposed to happen under EGL. The community development component received little attention in terms of design and resourcing.
* Providers and schools have an important role to play in helping disabled people achieve their outcomes. However, investment in changing practice in providers and schools was insufficient (see below).

### Suggested improvements to navigation and planning, personal budgets and employment of staff by families

Possible improvements for navigation and planning include providing:

* more support for disabled people and families when they get into difficulty implementing their plan
* more support for vulnerable families to develop, put in place and maintain their vision of a good life
* improved links between new families and those families who have engaged with EGL
* clarity about the future of navigation.

There were practices that supported disabled people and families but there was room to improve.

* Pooling the funding and having greater flexibility in the use of the funding have been important. Some families expressed the desire for more flexibility in the use of the funding.
* Managing the money was difficult for many families and disabled people. More options were needed to assist individuals and families to take up and manage the funding.
* The amount of funding appeared to be insufficient in some contexts. These included where the young person wanted to live independently in the community the cost was a significant barrier and where families were on lower incomes the amount of funding they received may have been insufficient. The funding may have been insufficient to support disabled people’s choices where family could not be involved in the day-to-day care of their young disabled. Taking up FFC limited the overall pool of funding but families did not always feel they had an alternative.
* Families had some useful sources of advice on how to use the funding and guidance but more was needed.

The employment of staff could be improved. Families and EGL staff interviewed offered suggestions to make it easier to employ staff, including:

* doing more work to support families as employers, especially when disputes arise
* providing education for support workers about the home care environment
* establishing a group that could shoulder more employer responsibility for families
* using flexible disability support contracts between disabled people and providers. These are now in place, but it would be useful to have further evaluation of how well they are working for disabled people and families.

### Suggested improvements to measuring quality of life outcomes

There is currently limited information systematically collected on outcomes for disabled people who engage in government-funded interventions. The quality of life framework and indicators were adapted for use in New Zealand and with input from the EGL Christchurch Local Advisory Group. Review of the usefulness of the approach to collecting quality of life information was an important aspect of the evaluation. The evaluation found improvements could be made by:

* enhancing data collection (eg improving the response rate, the collection of information from people with communication challenges, and the collection of information from proxies)
* reconsidering the use of comparison groups. It may be a better use of scarce resources to track participant outcomes over time. However this would not allow any conclusions to be drawn about impacts on participants and their families.
* establishing a standard set of evidence based indicators for individuals that can be tracked over time and applied more widely
* developing family wellbeing indicators.

### Suggested improvements to engaging with and changing the behaviour of schools and providers

In future similar initiatives, factors that may help schools and providers include:

* engaging in consistent and clear communication with schools and providers over a longer time period prior to and during a Demonstration to assist in getting buy-in and ensure that everyone is on the same page
* having a person schools know and trust to liaise with them about the approach
* having readily available information on what the approach means in practice and advice on how to get there, including for the governing bodies of providers and schools (eg, more advice on how to cost their services in an individualised way)
* ensuring that contracts and funding arrangements with providers encourage the outcomes sought by the EGL approach
* providing specific provider (and school) development funding to help move more of them to a more personalised approach in line with the EGL principles, but a shift in attitudes and expectations is required before they can make practical changes in that direction. Any efforts to develop providers and schools needs to start by expanding their vision of what disabled people can achieve.

An ongoing challenge will be addressing the financial sustainability of providers.

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# Appendix 1: Evaluation objectives and research questions

**Objective 1: to understand what outcomes are being achieved by those participating in EGL and what contribution EGL has made to those outcomes**

* Who develops a vision for a good life? To what extent are disabled people’s visions for a good life being realised?
* What life outcomes does the Demonstration contribute to for participants? What outcomes originated, and were sustained, outside of the Demonstration? What outcomes mattered to disabled people and their families? How do the life outcomes of disabled people who are participating in the Demonstration compare with those who are not?
* How easy do disabled people find it to get and sustain the life they want? What is assisting them to do this and what is a barrier?
* What perceptions do participants have of outcomes, so far? To what extent do disabled people believe they have real choice and control over their lives?
* What is the level of community access, participation and connection? What impact on or contribution to the community is the disabled person making? How does the community (eg structures, attitudes, culture, people) change as a result?
* Has the Demonstration had any unintended effects for disabled people and families?

**Objective 2: to understand what constitutes a good life for disabled people involved in the Demonstration and how this understanding evolves over time**

* How do disabled people and their families conceptualise a good life? How does this change over time? What commonalities and differences exist in the descriptions of what constitutes a good life?
* To what extent does the EGL approach support disabled people to identify what constitutes a good life for them and what it would take to achieve it? What is working well and for whom? What could be improved upon and how? Are there any unintended consequences?

**Objective 3: to understand what is being implemented to enable disabled people to have good lives and how it is operating in practice**

* What do the results reveal about the expected progress of the different components of the Demonstration? How are the components of the Demonstration operating in practice? What seems to be working and not working and why? What innovations have been developed? What improvements could be made?
* What supported and what hindered the implementation of the Demonstration? Where there have been problems, how significant are they, and are they transient or likely to remain? What can be done to resolve any continuing problems?
* What has been the experience of disabled people and their families participating in the Demonstration? What are the most valuable and least valuable aspects of their participation in the Demonstration? What changes would they make?
* What has been the experience of providers and schools participating in the Demonstration? What are the most valuable and least valuable aspects of their participation in the Demonstration? What changes would they make?

**Objective 4: to understand how schools, providers of disability support services and government agencies have positioned themselves to support disabled people to live a good life**

Providers

* What are providers doing to support disabled people to be healthy, safe and well and live the life they want? What, if any, changes have they made to their practice in this area following the introduction of EGL?
* What is influencing the way providers support disabled people? What influence has EGL had on their practice?
* What is impeding or facilitating the capacity of providers to support disabled people to be healthy, safe and well and live the life they want?

Schools

* What are schools doing to support disabled people to be healthy, safe and well and live the life they want post-school? What is influencing the way schools support disabled people?
* How have schools responded to the EGL approach? What influences their support or otherwise of the Demonstration? What, if any, changes have they made to their practice in this area following the introduction of EGL?
* What do schools like about the EGL approach and what would they change?

Government agencies, EGL team, LAG

* To what extent are government systems supporting disabled people to be healthy, safe and well and live the life they want within the Demonstration?
* What contribution have government agencies, the EGL team and the Local Advisory Group made to the development and implementation of Enabling Good Lives? What has worked well? What is limiting progress?

**Objective 5: to examine what supports the success of the Demonstration as an approach to enable disabled people to have good lives, and what does not, and identify any lessons that could inform the scaling-up of the Demonstration**

* What is getting in the way of the Demonstration achieving the desired outcomes?
* What adaptations are needed to achieve the outcomes?
* What would inform the scaling-up of the Demonstration?

# Appendix 2: Evaluation methodology

## Evaluation approach

The evaluation used a mixed method approach similar to phase 1 but with some additions. As the phase 1 evaluation took place shortly after implementation began there was limited opportunity to look at outcomes for participants. Phase 2 was more focused on outcomes.

The methods used in Phase 2 included:

* 10 case studies of disabled people in different contexts
* a quality of life survey of 43 youth participating in EGL: 19 EGL participants completed the survey themselves and 24 surveys were completed by someone else on their behalf (proxies). While comparable with many youth surveys, the response rate was low (34%).
* in-depth interviews with stakeholders (five providers, three schools, two navigators, 13 local and national officials – including the General Managers, a representative from MIC, the LAG as a group, the EGL team). Some officials (3) and the National EGL Leadership Group responded via email to the interview questions
* analysis of existing administrative data to describe trends and patterns in use of navigators, Individualised Funding, self-management of funding and supports and services
* analysis of documents on the Demonstration.

Methods were selected based on their capacity to answer evaluation objectives and research questions. The methods were applied concurrently but separately. This means the researchers implemented both the quantitative and qualitative strands during a single phase of the research study.

The rationale for using a mixed method design is as follows:

* *Triangulation of findings allows them to be corroborated.* Triangulation is a technique that facilitates validation of data through cross verification from two or more sources. In particular, it refers to the application and combination of several research methods in the study of the same phenomenon.
* *Weaknesses in each method will be offset.* All methods have their strengths and weaknesses. Combining methods allows us to offset the weaknesses of each method and to draw on the strengths of each method.
* *Using a mix of methods allows for the development of a more complete picture*. By having a mix of methods we are seeking to provide a more complete picture of the Demonstration than is possible using a single method within the timeframe and resources available. Quantitative and qualitative research can each answer different research questions. This evaluation approach allows us insight into which aspects of the Demonstration are working and which are not and why, along with whether or not there are unexpected consequences.
* *This approach is suitable in a context where the environment is very dynamic and pathways to change cannot be predetermined*. EGL has evolved in Christchurch over the course of the Demonstration. A mixed method evaluation can support this evolution by providing timely and actionable data about how a complex system is responding to the Demonstration.

## Ethics

### Ethical approval was obtained

Ethical approval to undertake the quality of life survey was obtained by going through the Ministry of Social Development’s ethics process. The evaluation plan was also sent to the Chief Science Advisors in the Ministries of Education and Social Development, who both approved the proposed approach.

### Ethical considerations

#### Obtaining consent to be interviewed

Wherever possible, written informed consent was obtained from each participant. Care was taken to ensure that potential participants clearly understood the implications of their involvement and that: (1) they could withdraw their consent at any time; (2) refusal or withdrawal of consent would have no impact on the support they received; and (3) they would still be able to take part in EGL even if they did not give consent for involvement in the evaluation.

Some interviewees had learning disabilities. Care was been taken to ensure that potential participants clearly understood the implications of their involvement (eg having consent forms written in plain, simple language; using assistive technology where available and people who know the disabled person well to assist with understanding).

Where potential participants were unable to give informed consent due to the severity of their intellectual impairments we sought agreement for participation from either: (1) the person’s independent advocate; or (2) the closest family member who was in regular contact with the person.

#### Use of proxies when disabled cannot be interviewed

Some disabled people were not be able to undertake the quality of life survey. It has been well established that people who have a severe or profound level of intellectual disability cannot respond validly to a scale of subjective wellbeing (Cummins & Lau, 2005).

Where disabled people are unable to respond to interview questions proxies were used. A proxy was someone who knew the person with a disability well. The use of a proxy or third party response is considered more reliable for reporting objective measurements than subjective feelings. Measurement of a person’s quality of life from another person’s perspective is not ideal[[62]](#footnote-62) but can be useful in some instances where people are not able to communicate or make life decisions, but the results should not be treated as the perception of the person with disability.

#### Ensuring confidentiality of research participants

The evaluation reporting did not contain personal identifiers but may contain professional or role identifiers (eg disabled person, navigator, Ministry of Social Development official). Evaluation reporting may make use of short quotes to illustrate points. These quotes were attributed to roles (eg a disabled person, a family member, a navigator) rather than individuals. Any information which might lead to an interviewee being identified was only to be published with their permission.

#### Privacy and data storage

Any audio-recordings and interview notes would only be available to the research team, and be stored securely until the project is completed, and then destroyed. No information that identifies the research participants personally would be given to people outside the research team. The evaluation reporting would not contain personal identifiers but may contain professional or role identifiers (eg disabled person, navigator, Ministry of Social Development official).

#### Ensuring disabled people have a voice

A key element of the EGL approach is to ensure disabled people have a voice. This is being done by:

* involving disabled people in the design of the evaluation and where possible in carrying out the research
* interviewing disabled people as part of the case study research
* undertaking a quality of life survey with disabled people. Wherever possible disabled people completed the survey. They were given the option of completing it via email, telephone or face to face. However, some people with significant disabilities were not be able to complete the survey. Where disabled people were unable to respond to interview questions proxies were be used. A proxy was be someone who knew the person with a disability well. There are drawbacks to using proxies[[63]](#footnote-63). However, not allowing the use of proxies would mean some people with significant disabilities would not have a voice in the evaluation. Research indicates that measurement of a person’s quality of life from another person’s perspective could be useful in some instances where people are not able to communicate or make life decisions, but the results should not be treated as the perception of the person with disability.

#### Openness and transparency of the research

There has been considerable consultation with stakeholders about the design of the evaluation. Initial results were discussed with stakeholders to get their feedback and to be open about what is emerging.

As agreed to with the Enabling Good Lives Local Advisory Group, the final report would be available on the Office for Disability Issues website – <http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/>

#### Ensuring the research is beneficial

Ministers want to know whether or not the Enabling Good Lives approach is improving outcomes for participants. They are using the evaluation to gather information about how the EGL approach works, and how it might be possible to implement changes across the whole of the disability support system.

There is some concern that disabled people have been over-surveyed/interviewed. However, in the case of the quality of life survey we cannot obtain the information on outcomes for participants from existing data bases. Similarly with the case study research, interviewing disabled people is necessary to understand their perspective of how the Demonstration is working for them. Moreover there is likely to be a positive impact on policy thinking from having the voices of young disabled people represented. This is preferable to taking decisions without having their voices represented.

#### Risk to participants

Ensuring disabled people have a voice

See earlier.

Ensuring disabled people understand what involvement in the evaluation means

Disabled people would be informed of the risk prior to the evaluation and this would be reiterated at the time of the interview. Where the disabled person has a learning disability we would provide caregivers with information to relay to them. Every effort would be made to use plain, simple language. The purpose of the report and intended audience will be made clear from the outset.

Risk that interviewees will be distressed by the interviewing process

Interviewers will be alert to signs of distress when conducting interviews and, if these occur, ask the participant if he or she wishes to continue. It would be made clear that they do not have to continue or answer questions if they don’t want to. Where proxies are interviewed face to face, the disabled young person may be present. If that is the case, proxies would be asked to be alert to any signs of stress in the young people that may indicate their discomfort in continuing with the interview.

Risk that negative stereotypes are perpetuated

This would be mitigated by:

* using researchers with expertise in undertaking research with disabled people (eg Malatest[[64]](#footnote-64) was contracted to undertake the quality of life survey)
* involving disabled people in the research:
  + the EGL Local Advisory Group, which includes disabled people, has been involved in the design of the evaluation
  + with regard to the quality of life survey the Canadian approach has been to support a disabled person(s) to complete some or all of the in-person interviews. The same will be done in Christchurch
* discussing key findings and implications of the evaluation with the agencies and the EGL Advisory Group prior to preparing a final report
* consulting on the design of the evaluation with national and international disability researchers and people with experience of the disability sector (eg the Local Advisory Group, the National EGL Leadership Group).

## Methods of data collection

### Quality of life survey[[65]](#footnote-65)

#### The Schalock Quality of Life framework

The Schalock Quality of Life framework has been used as a foundation for developing quality of life measures for the evaluation of the Enabling Good Lives Demonstration. Quality of life is a multidimensional construct developed by Schalock and others (Schalock et al., 2002). It is composed of eight core domains: emotional wellbeing, interpersonal relationships, material wellbeing, personal development, physical wellbeing, self-determination, social inclusion and rights. These eight domains were developed and validated through an extensive review of the international quality of life literature across the areas of intellectual and developmental disabilities, special education, behavioural and mental health, and ageing. The eight domains can be grouped together under three broad quality of life factors – wellbeing, social participation and independence (Table 1). The framework is supported by over 25 years of scientific research that confirms its validity and practical applicability (Townsend-White et al., 2012; Schalock et al., 2015; Claes et al., 2010).

Schalock recommends that the eight quality of life domains are measured via the assessment of relevant indicators. The indicators are quality of life-related perceptions, behaviours and conditions that define operationally each quality of life domain. Various quality of life indicators can be used to quantitatively measure changes in individuals’ quality of life.

#### Development of the indicators

Questions used to measure quality of life that have been assessed and validated in Canada were adapted for the EGL and New Zealand contexts through the following steps:

* A draft set of indicators was developed, based on the indicators used in the Canadian *Include Me!* survey[[66]](#footnote-66) and the New Zealand Youth Survey[[67]](#footnote-67).
* Indicators were categorised as foundational – expected to apply to all participants and aspirational – expected to improve as a result of the EGL programme.
* Draft indicators were discussed with the EGL Local Advisory Group, including youth representatives.
* The indicators were modified after feedback from the advisory group.
* Questions were developed based on the indicators and reviewed by the EGL Local Advisory Group and the EGL evaluation team.
* A final review of the questions was included as part of the training for peer interviewers.

Questions were based on three-point scales with categories such as: lots/mostly/little or none; or yes/sort of/no; or yes/no/not sure. Three-point scales were used because although extended scales are more sensitive they are also more complicated to read and comprehend. Smiley face emoticons were used to illustrate the three responses (Table 3). A summary of the questions is appended (Appendix 1).

Table 3. An example of questionnaire formatting

|  |  |  |  |
| --- | --- | --- | --- |
| How much choice do you have about who you live with? (Click one answer) | lots | some | little or none |
|  |  |  |

#### Ethics

Ethical approval to undertake the quality of life survey was obtained by going through the Ministry of Social Development’s ethics process (see Ethics, page 141).

#### Research population

##### EGL participants

The survey was to compare outcomes for EGL participants with a group of disabled people who do not have access to the Enabling Good Lives approach.

Participants were school leavers (aged 18 to 21 years old) with high needs (HN) and very high needs (VHN) – as verified through the Ministry of Education’s ORS. There was flexibility to allow some disabled people outside these criteria to opt into the Demonstration (eg in the first year up to 10 further people who access disability supports in or near Christchurch were allowed to opt in at the discretion of the Director). A list of 125 EGL participants was sent to the survey company.

##### Comparison group

The original plan was to include responses from a comparison group. The comparison group was to be those in Christchurch aged 17 to 21 who received VHN and HN ORS funding and left school in 2011 and 2012. There were 120 ORS students with high or very high needs who left school in the Canterbury region.

However, it was difficult to gain agreement on the source of a comparison group, on consent processes and on access to comparison group details. Delays in obtaining a sample, and a two-step consent process, resulted in little time to collect survey responses before the Christmas break.

Responses were received from a total of nine of the comparison group: six from individuals and three from proxies (a response rate of 20%). The number of responses was too small to include in the analysis.

Considering the difficulty in identifying and contacting a valid comparison group, the most useful comparison for future quality of life surveys is as a measure of change over time within the same individual or group of EGL participants.

#### Data collection

Data collection provided several ways for EGL participants to participate in the evaluation.

Insights MSD provided a list of EGL participants, which included a combination of email addresses, phone numbers, mobile phone numbers and/or names and contact details for parents or caregivers. The participant list included young people who had been involved in EGL for some time and others who were beginning their involvement.

The survey was developed so EGL participants could complete it online or with an interviewer. An email was sent to the contact email address held by EGL for each participant. In some cases, the email address was the participant’s personal email address. In other cases, it was a family or parent’s email address.

The invitation email explained the purpose of the survey. It provided options for EGL participants (or a proxy) to complete the survey online, or to request an interview. Participants could also select an option to decline to take part, in which case no further contact was made.

Following the initial email, participants who did not complete the survey online and did not decline were telephoned, sent a reminder email and sent a text. Telephone calls were made by two qualified[[68]](#footnote-68) members of the team.

The evaluation employed peer interviewers to interview EGL participants who requested an in-person interview. Peer interviewers are disabled people who have been trained to undertake interviews with people with intellectual and other disabilities. In previous studies, participants with developmental disabilities said they felt more comfortable being asked questions by an interviewer who also had a disability[[69]](#footnote-69).

Three peer interviewers were recommended by the EGL advisory group. At the start of the project, our team trained the interviewers in a half-day workshop. Interviewers were provided with extensive support before any interviews and debriefs following each interview. When a participant asked for a face-to-face interview, we arranged a time with the participant and the interviewer.

Peer interviewers had a point of contact who was available at any time to answer their calls. They were paid a wage for their training, travel time and the time to complete interviews (including discussions).

Data collection took place between mid-September and the end of December 2015.

#### Response rates

A total of 43 EGL participants and proxies from the list of 125 contacts completed the survey – a response rate of 34%, with:

* total responses from EGL participants – 19 responses
* total responses from proxies – 24 responses.

The numbers and mode of responses are summarised below (Table 4).

Table 4. Response numbers

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Numbers of responses** | | |
| **Response type** | **Total responses** | **Online** | **In-person** |
| **EGL participants – self-completion** | 19 | 10 | 9 |
| **EGL participants – proxy** | 24 | 24 | - |

Interviewing challenges

Confidentiality was important to allow the EGL participants to respond freely to questions. In the training, the interviewers anticipated difficulty in arranging time to speak alone with the EGL participants without a parent present. In practice, this was a problem for some of the interviews. The training manual for the interviewers included a scenario about someone else wanting to stay in the room with the interview participants. We were clear in the training about the importance of doing everything we could to capture the voice of the participant.

To make sure that the interviewers felt safe while doing the face-to-face interviews, the interviewers always worked in pairs and checked in before and after each interview. If they were asked any questions they could not answer, they gave business cards of the team members to the participant or participant’s caregiver so they could call us directly.

|  |
| --- |
| Scenario: A staff member or a relative/friend of the participant wants to be part of the discussion.   * The discussion is private. A participant should be able to tell you their answers without anyone else knowing what they said. If someone else is in the room, then the discussion is no longer confidential! * Ask the participant if they would feel comfortable having the discussion with just you alone. If the participant says “yes” then you can politely ask for privacy. Here is an example of what you could say: * C:\Documents and Settings\Sherry\Local Settings\Temporary Internet Files\Content.IE5\U3OWVL4A\MC900283365[1].wmf“Are you comfortable talking to us alone? *If the participant says yes, then say:* We need a private space to have our discussion. It needs to be a place where we won’t be disturbed and nobody else can hear what we say. If you could please wait outside or in the reception area, [*participant’s name*] will come and meet you when we are done.”   A service staff member or relative/friend can stay in the room if the participant does not want to be left alone. |

Enhancing response rates

A number of different strategies were tried to enhance response rates. Further enhancing response rates would require wider communication about the survey, perhaps through the EGL navigators.

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| **Reflection on data collection strategies**  Phone-based recruitment was the most successful; however, the approach had to be individualised rather than scripted. Some of the contact calls were answered by the EGL participants and others by a parent or family member. The recruiter had to be prepared to speak to both, often in the one phone call.  On some occasions the parent disclosed a disability themselves. The most important thing was being adaptive and flexible on the phone, changing the language used to suit the dynamic of the family. The recruiter took care to identify what the concerns are for the parent. These could be family dynamics, being too busy, or thinking it will be too hard for their child. It has been important to demonstrate quickly that we are prepared to work with what will suit the participant and the parent by:   * taking the time to listen and understand their situation * breaking down barriers and showing how the interview process can work.   The phone calls generally follow this pattern:   1. **Building initial rapport:** Quickly identifying Enabling Good Lives as the reason for the call and building enthusiasm about the opportunity for the participant to give feedback. This could include saying that other people have valued the opportunity to give their feedback. Checking whether they received any information (by text or email) about the evaluation. 2. **Providing information about the questionnaire:** Explaining that the questions are as accessible as possible (eg using multi-choice answers and symbols) and that they focus on quality of life. This step could include providing information about the symbol sheet and reading out a couple of question examples. The goal was to communicate that the questionnaire is accessible, easy and not daunting, so that the parent was reassured the participant was able to complete the questionnaire alone and it would be a positive experience. 3. **Introducing the interviewers:** Explaining that the interviewers we employed are disabled people who are excited to do the interviews and help other disabled people. Being able to meet and interact with other disabled people was a selling point. When speaking to the participants, the recruiter described it as an opportunity to connect, have their say and be listened to. 4. **Giving the opportunity to share their disability:** The recruiter giving the parent and/or participant the choice to share information about the participant’s disability so that we could prepare the interviewers to accommodate the participant’s needs. 5. **Concluding:** Telling the parent/participant that we really value their time. |

#### Survey analysis

Results of the EGL survey are reported two ways in this report: scored and percentage positive.

The questions in the EGL survey have two or three response options:

* two answers (positive and negative) plus not applicable
* three answers (positive, negative or neutral) plus not applicable.

For percentage of positive reporting, we have reported the proportion of respondents who provided either of positive responses (excluding missing and not applicable responses).

For scored questions, we have assigned a value of two to every positive response, a score of one to every neutral response and a score of zero to every negative response. Scores are calculated by dividing the respondent’s score across a group of questions by the total score available, then multiplying by 100. Scored analyses include all responses to all indicators.

Charts of positive responses do not include sub-questions following ‘filter’ questions. For example, the question about whether a respondent has a paid job is included but not subsequent questions about whether they like their job.

Malatest identified and reported relationships between indicators as correlations between responses to questions in the same subject grouping. Only significant correlations between related questions have been reported. The value of the correlations is in making decisions about which questions to include or omit to shorten the length of the survey and reduce the burden on respondents. Questions that are similar in content and strongly correlated could be deleted.

#### Strengths and limitations of the survey

The quality of life survey provided an opportunity to develop a series of indicators within an established and validated framework. Indicators were developed with the EGL advisory group, representing participants in the EGL demonstration.

The resulting survey was too lengthy but the Demonstration provided an opportunity to refine the survey by identifying correlations between questions to provide guidance on questions that could be eliminated in future surveys. The length of the survey appeared not to affect response rates, as no participants stopped partway through. However, a shorter survey would reduce the burden on participants and peer interviewers.

Although the peer interviewers did not complete a large number of interviews, their insight was valuable in developing the data collection process and in interviewing EGL participants. Their experience as interviewers may be valuable in future work.

Although the survey response rate was comparable with or better than other surveys of youth, the numbers of participants and proxies are small. There is limited information about the differences between responding and non-responding youth so caution should be exercised in extrapolating the results of the survey to a wider group of disabled youth. Caution should be taken in comparing responses of proxies and participants, and in examining the combined results of proxies and participants. There can be differences between proxy responses and self-reported responses. Differences may be a result of differences in perspective rather than invalidity or bias (Claes et al., 2012).

Absence of a comparison group – either of other disabled youth or of youth in the general population – limits conclusions about the extent findings reflect this group of youth, a wider group of disabled youth or all youth.

### Case studies

The purpose of the case studies was to understand better how the EGL approach contributes to disabled people having greater choice and control over their lives. A multiple case study approach was used because a cross-case analysis will allow us to explore the effects of using the EGL approach and identify major patterns. Multiple cases also allow us to test the extent to which the overall pattern of results matches the behaviour we expected to see and to build on the theory of change underpinning the Demonstration. As Yin (1994) has noted, the case study method generalises to theory and the goal is therefore to obtain replication, not enumeration. In analysing multiple cases, replication can be achieved within the types (or ‘families’) of cases, with predicted variation across groups.

The unit of analysis (‘the case’) is: *The young disabled person engaged in EGL who has recently left school or is planning to.* Here the focus is on the individual disabled person’s journey towards building a life outside of school.

There were three types of cases, outlined in more detail in Table 5 below:

* Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care. While living circumstances were not a section variable in all these cases the young people were in residential care.
* Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
* Case type 3: Movement towards living a life in line with the EGL principles (opt-in)[[70]](#footnote-70).

Ten cases with differing characteristics were selected across the three case types to provide diverse points of view. Interviewees were selected from the EGL database compiled by the Demonstration team. The EGL team assisted the evaluators in gaining access to some participants. Three of the cases involved respondents interviewed in phase one of the evaluation.

Any common patterns emerging from the variant cases can capture the core experiences and shared aspects of transitioning from school to post-school life. Across the cases we will attempt to get a mix of disability types, gender and ethnicity.

Interviewees were asked about their experience of being part of the Demonstration, in particular:

* what a good life looked like for them
* what was influencing their achievement of a good life
* their experience of the Demonstration – what was working well or presenting difficulties.

In each case effort was made to interview the disabled person and a parent or parents. In some cases a caregiver was also interviewed. Where the disabled person was unable to answer the questions (eg because they had a profound intellectual disability) the parent(s) responded for them.

Table 5. Case types

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| --- | --- | --- |
| **Case type** | **Selection variables** | **Number of cases** |
| **Case type 1:** Limited change since coming into EGL to live in line with the EGL principles | * Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs * Non-opt-in * Limited engagement in planning for a good life * Traditional use of funding (eg attendance at a day programme) as opposed to doing something different in the community. | 3 |
| **Case type 2:** Movement towards living a life in line with the EGL principles (non-opt-in) | * Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs * Non-opt-in * Developed a plan with a navigator * Choosing to use their funding for supports differently * One or more of the following * living in the community eg flatting with support; living at home with support instead of residential care * engagement in meaningful activities in the community * engagement in meaningful work or education | 4 |
| **Case type 3:** Movement towards living a life in line with the EGL principles (opt-in) | * Significant disability-related needs – all will have previously received ORS funding or have significant disability-related needs. * Opt-in * Developed a plan with a navigator * Choosing to use their funding for supports differently * One or more of the following * living in the community eg flatting with support; living at home with support instead of residential care * engagement in meaningful activities in the community * engagement in meaningful work or education | 3 |

#### Analysis

The analytical process was iterative and aimed at identifying patterns, differences and puzzles across the cases.

Analysis of the information collected in case studies occurred both during the data collection phase (eg discussion with the other interviewer after the interview while in the field) and at the completion of all the interviewing (eg in structured analytical workshops, during the writing phase).

Within and between cases we used inductive thematic analysis combined with triangulation. The process consisted of reading through textual data, identifying themes in the data, coding those themes, and then interpreting the structure and content of the themes.

Causal linkages which held good across these diverse settings were considered robust and capable of ‘analytical generalisation’.

#### Weakness of case study research

The primary weakness is the assertion that it is impossible to generalise from these cases to the wider population.

While the evaluation team sought to capture the views of a range of participants, the views expressed by interviewees may not be representative of all participants in the Demonstration. Obtaining the views of people facing multiple challenges[[71]](#footnote-71) was particularly difficult.

### In-depth interviews with key stakeholders involved in the Demonstration

#### Purpose, rationale and scope

Talking with key stakeholders allowed us to detail what shaped the design, implementation and operation of EGL and how this has evolved over time.

The design of the EGL Demonstration is intended to evolve over time and also involved collaboration between the disability sector and government agencies. There is interest in how this process operated.

Interviews took place with:

* the Demonstration Director and members of the EGL team in Christchurch
* Members of the LAG
* local and national officials from the Ministry of Social Development, Ministry of Education and Ministry of Health
* Manawanui InCharge representatives
* representatives from selected providers and schools. We were able to interview most representatives from schools and providers we talked to in phase 1.

#### Data collection and recruitment

##### Data collection

Some stakeholders answered the questions via email but most were interviewed face to face. Stakeholders included selected providers, selected schools, selected navigators, representatives from LifeLinks and Manawanui InCharge, officials from the Ministries of Education, Health and Social Development, the Local Advisory Group, members of the EGL team in Christchurch, the National EGL Leadership Group, and the Joint Agency Group.

Interviewees were asked about their experience of being part of the Demonstration, in particular:

* what was influencing Demonstration participants’ achievement of a good life
* their experience of how the Demonstration is contributing to disabled people obtaining good lives
* what schools, providers of disability support services and government agencies were doing to support disabled people to live a good life and what was working well or presenting difficulties.

##### Recruitment

People were contacted via telephone. Those interviewed in phase 1 were, where possible, re-interviewed. In some cases this was not possible as people had moved on or were not available at the time the interviewing took place.

**When:** Interviews took place in August and September 2015.

#### Ethics

See ethics section earlier.

#### Analysis

**Thematic analysis:** The process consisted of reading through textual data, identifying themes in the data, coding those themes, and then interpreting the structure and content of the themes.

#### Limitations

The views expressed by schools and providers interviewed may not be representative of all schools and providers who had people participating in the Demonstration. The evaluation team sought to interview a range of providers and schools but there were only five providers and three schools.

### Analysis of administrative data

#### Purpose, rationale and scope

To describe trends and patterns in use of navigators, Individualised Funding, self-management of funding, and supports and services amongst participants using data collected by the EGL team and the three agencies.

#### Ethics

See ethics section earlier.

#### Analysis

A descriptive analysis of data from the Ministries of Social Development, Education and Health and the EGL team in Christchurch.

#### Limitations

The administrative systems captured little data on the quality of disabled people’s experience of Enabling Good Lives. The quality of life survey sought to address this but, as mentioned above, there were some limitations with this.

The way in which data was captured made it very difficult to examine what use participants had made of their funding and whether they were spending more or less than before the Demonstration.

1. The first evaluation was undertaken shortly after the Demonstration began in November 2013. See Anderson et al., 2014. [↑](#footnote-ref-1)
2. The term natural support is not always clearly defined or understood. ‘Natural supports’ often refers to the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections. [↑](#footnote-ref-2)
3. Navigation is the process by which participants identify and record what a good life looks like for them, and how they can achieve it. Participants can choose to undertake navigation with an EGL navigator, or with other people including wider family and friends, or with appropriate support they can choose to do it themselves. The output of navigation process is the development of a plan of action for the participant. [↑](#footnote-ref-3)
4. Funding that disabled people are eligible for from the Ministries of Health, Education and Social Development is pooled into an EGL personal budget. Disabled people can choose, within guidelines, how that funding is used to support them to achieve their vision of a good life. [↑](#footnote-ref-4)
5. There were three types of cases:

   * Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care.
   * Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
   * Case type 3: Movement towards living a life in line with the EGL principles (opt-in)

   [↑](#footnote-ref-5)
6. Manawanui is a company specialising in facilitating Individualised Funding and other self-directed services (see <http://www.incharge.org.nz/interested-in-using-individualised-funding/what-we-do/>) [↑](#footnote-ref-6)
7. Direct payments (either cash payments or a nominal budget) involve the funds being given directly to the person with a disability, who then self-manages this money to meet their individual needs, capabilities, life circumstances and aspirations. [↑](#footnote-ref-7)
8. Funded Family Care is Ministry of Health funding for some eligible disabled people over the age of 18 with high or very high needs. This means that if they are eligible for Disability Support Services funding they may be able to pay the people they live with to help them with their personal care and/or household tasks. <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care> [↑](#footnote-ref-8)
9. These have been updated since the evaluation. [↑](#footnote-ref-9)
10. Young people students who are over 19 and whose exceptional needs mean that a secondary school is the best place for their education can stay at school until they are 21 years if they have a Section 9 Agreement. This is a formal agreement between the Ministry of Education and the parents/guardians of the disabled person allowing them to remain at school until they are 21. See http://www.education.govt.nz/school/student-support/special-education/entering-into-a-section-9-agreement-for-special-education-services/ [↑](#footnote-ref-10)
11. A small number of people in or near Christchurch who access disability supports but were not school leavers aged 18-21 were allowed to opt in at the discretion of the Director. Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support. [↑](#footnote-ref-11)
12. Day special schools are part of the schooling network in New Zealand and offer specialist teaching to students who have a high level of need. [↑](#footnote-ref-12)
13. People living with disability often experience poor social and economic outcomes. The New Zealand Disability Survey found that, compared to non-disabled people, disabled people had lower levels of employment; were less likely to hold formal educational qualifications; were more likely to experience discrimination; were more likely to feel lonely; were less likely to participate in popular leisure activities such as visiting friends, going to cafés and going on holiday; were less likely to be satisfied with their lives. See Statistics New Zealand, 2014b in The New Zealand Productivity Commission (2015). [↑](#footnote-ref-13)
14. See Ministerial Committee agreement to vision and principles for long-term change – September 2012 <http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012/> [↑](#footnote-ref-14)
15. The term natural support is not always clearly defined or understood. ‘Natural supports’ often refers to the resources inherent in community environments including personal associations and relationships that enhance the quality, and security, of life for people. Natural supports usually involve family members, friends, co-workers, neighbours and acquaintances. People may need help in developing these connections, but, over time, these connections can help an individual build a strong community network and support system that enhance their quality, and security, of life. [↑](#footnote-ref-15)
16. See <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/new-model-supporting-disabled-people/choice-community-living> [↑](#footnote-ref-16)
17. This includes funding specifically targeted to the purchase of disability supports. Payments such as the Supported Living Payment administered through Work and Income have been excluded as they are classified as income. [↑](#footnote-ref-17)
18. ORS provides funding for supports such as teacher time, teacher aides and specialists to help students whose disability is a barrier to their accessing the curriculum, whether because of hearing loss, visual impairment, difficulties with mobility, learning, or language use and social communication. [↑](#footnote-ref-18)
19. In 2015 the funding rates were $18,209 for students with very high needs and $10,561 for students with high needs. [↑](#footnote-ref-19)
20. As at 1 July 2015, 71% of ORS-funded students in the Christchurch City area received HN funding and 29% received VHN funding. Source: Indicators & Reporting Team, Ministry of Education (see <https://www.educationcounts.govt.nz/statistics/special-education/ongoing-resourcing-scheme>). [↑](#footnote-ref-20)
21. Personalisation is about enabling people to lead the lives that they choose and achieve the outcomes they want in ways that best suit them. [↑](#footnote-ref-21)
22. Refer to <http://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/> [↑](#footnote-ref-22)
23. For example, research using experimental or quasi experimental approaches to determine the difference the intervention made to outcomes. [↑](#footnote-ref-23)
24. As mentioned earlier, the term is not always well understood. There is an implicit or explicit assumption in most understandings of natural supports that they are distinct from formal supports (ie support provided by paid workers). However, some authors suggest the distinction between natural supports and formal supports may be blurring (NDA, 2011; Newman et al., 2008). [↑](#footnote-ref-24)
25. Manawanui is a company specialising in facilitating Individualised Funding and other self-directed services (see http://www.incharge.org.nz/interested-in-using-individualised-funding/what-we-do/ ) [↑](#footnote-ref-25)
26. Deputy Chief Executives/Group Managers and General Managers. [↑](#footnote-ref-26)
27. The focus of this initial evaluation, conducted in February 2014, was to understand how the Demonstration was being implemented and working towards supporting disabled people to have a good life. The evaluation involved 25 semi-structured interviews and one group interview with a broad cross section of people involved in the design and implementation of the Demonstration in Christchurch along with four disabled people and four parents from three families. In addition, descriptive data on the number and types of participants was included in the evaluation where it was available. The evaluation found that there have been some early positive outcomes from the EGL Demonstration, despite a problematic implementation. [↑](#footnote-ref-27)
28. This difference was also reported by the *include Me*! team, who collected responses from two proxies and averaged them. This approach was not practical for the EGL evaluation as proxies were commonly parents. [↑](#footnote-ref-28)
29. Initially the only way people could get their funding was directly through MIC. MIC charged disabled people GST even where not changing their arrangements with providers. As one EGL team member interviewed reported, participants were 15% worse off because of EGL. In the first year, the Ministry of Health added the GST onto the budgets of the 15 to 16 people affected. [↑](#footnote-ref-29)
30. The term ‘safeguard’ is being increasingly used to describe ways to reduce the vulnerability of people with developmental disabilities. Intentional safeguards are things done on purpose to help reduce people’s vulnerability. Intentional safeguarding, as part of person-directed planning and navigation, is about reducing risks and increasing someone’s safety and wellbeing. [↑](#footnote-ref-30)
31. While there is not an agreed definition of co-design internationally, it usually involves using collaborative relationships between public service professionals and citizens or users in the design process. Boyle and Harris (2009) believe these relationships need to demonstrate equality and reciprocity. [↑](#footnote-ref-31)
32. The amount of funding available for personal budgets from the Ministry of Education and Ministry of Social Development did not change from what would have been spent if the Demonstration did not exist. [↑](#footnote-ref-32)
33. See Ministerial Committee agreement to vision and principles for long-term change – September 2012 <http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012/> [↑](#footnote-ref-33)
34. The Ministry of Health’s Choices in Community Living is an alternative to residential services for people with significant disabilities. It offers more choice and control over where they live, who they live with and how they are supported. It is part of the New Model demonstration and is only available in Auckland and Waikato at this time. [↑](#footnote-ref-34)
35. A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. [↑](#footnote-ref-35)
36. The EGL team in Christchurch engaged with a small number of participants who met the criteria of ‘Category D’ from the Productivity Commission Report into Social Services. Category D is defined as including individuals with complex needs who have difficulties navigating systems to co-ordinate services and supports (The New Zealand Productivity Commission, 2015). [↑](#footnote-ref-36)
37. There were three types of cases:

    * Case type 1: Limited change towards living a life in line with the EGL principles since being able to engage with EGL. In all these cases the young people were in residential care.
    * Case type 2: Movement towards living a life in line with the EGL principles (non-opt-in)
    * Case type 3: Movement towards living a life in line with the EGL principles (opt-in)

    Refer to Appendix 2 for more information on the case studies. [↑](#footnote-ref-37)
38. For example confidence, assertiveness, negotiation skills, being articulate, and money management (Harflett et al., 2015). [↑](#footnote-ref-38)
39. Funded Family Care is Ministry of Health funding for some eligible disabled people over the age of 18 with high or very high needs. This means that if they are eligible for Disability Support Services funding they may be able to pay the people they live with to help them with their personal care and/or household tasks. <http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/funded-family-care> [↑](#footnote-ref-39)
40. These have been updated since the evaluation. [↑](#footnote-ref-40)
41. Research indicates that influencing variables such as the characteristics of residents in a specific setting, the culture of a residence, the staff employed within a residence, and the size of the residential setting have a strong influence on the wellbeing of residents (Francis et al., 2014). [↑](#footnote-ref-41)
42. This was higher than expected as a recent survey indicated that young disabled people in New Zealand have difficulty accessing health care (Peiris-John et al., 2015). [↑](#footnote-ref-42)
43. The New Zealand Youth’12 national youth health and wellbeing survey found Christchurch students had less involvement in some positive daily activities. Christchurch students reported lower rates of participation (for an hour or more each day) in vigorous physical activity, or in music, arts, dance or drama (Fleming et al., 2013). [↑](#footnote-ref-43)
44. In Statistics New Zealand’s 2006 New Zealand Disability Survey, youth aged 15 to 24 with a disability were found to be much less likely to be employed (39%) than those without disabilities (60%). Just 27% of young women aged 15 to 24 with disabilities were employed, compared with 61% of young women without disabilities (Stevens et al., 2013). [↑](#footnote-ref-44)
45. These are very small enterprise owned and operated, usually in the informal sector. They have 10 or fewer workers, including the micro-entrepreneur and any unpaid family workers. [↑](#footnote-ref-45)
46. Overall results combine participant and proxy responses, and report overall scores alongside those for the foundational and aspirational indicators. [↑](#footnote-ref-46)
47. Young survey respondents (n = 18-19). [↑](#footnote-ref-47)
48. Proxies (n = 22-24). [↑](#footnote-ref-48)
49. The evaluation employed peer interviewers to interview EGL participants who requested an in-person interview. Peer interviewers are disabled people who have been trained to undertake interviews with people with intellectual and other disabilities. [↑](#footnote-ref-49)
50. This is the idea that someone’s life is made up of more than just what activities they do during the day. It is about considering the person in their wider context, not in the context of ‘funded support services’. [↑](#footnote-ref-50)
51. See <http://www.education.govt.nz/school/student-support/special-education/national-transition-guidelines-for-students-with-special-education-needs/> [↑](#footnote-ref-51)
52. Students who receive ORS funding or have exceptional needs can stay at secondary school until they are 21 years old. [↑](#footnote-ref-52)
53. Natural supports are the relationships that occur in everyday life. They usually involve family members, co-workers, neighbours and acquaintances. Disabled people may need help in developing these relationships outside of family. However, the intention is that over time these connections can help people to build a strong community-based network and support system. [↑](#footnote-ref-53)
54. The term ‘safeguard’ is being increasingly used to describe ways to reduce the vulnerability of people with developmental disabilities. Intentional safeguards are things done on purpose to help reduce people’s vulnerability. Intentional safeguarding, as part of person-directed planning and facilitation, is about reducing risks and increasing someone’s safety and wellbeing. [↑](#footnote-ref-54)
55. Researchers have found that the family’s attitudes and expectations have a critical influence over a disabled person’s level of independence and the extent to which they are involved in decisions about their lives (Mirfin-Veitch, 2003). [↑](#footnote-ref-55)
56. Literature supports the development of social skills as a means of improving quality of life for disabled people (Walker et al., 2011). [↑](#footnote-ref-56)
57. See <http://www.education.govt.nz/school/student-support/special-education/national-transition-guidelines-for-students-with-special-education-needs/> [↑](#footnote-ref-57)
58. RISK (Recreation Inspires Strength & Knowledge) is a programme for people starting transition and uses recreation activities to build skills and confidence. [↑](#footnote-ref-58)
59. See <http://www.catapult.org.nz/> . This organisation helps people find work. The focus is on people who may have had time out of work or have not been able to get into work because of a disability, trauma or illness, raising a family, or personal reasons. [↑](#footnote-ref-59)
60. Experiential learning is seen as a dynamic process in which people are constantly able to construct their own learning and development by moving through a learning cycle. Experience is constantly reviewed and impressions challenged or confirmed. For example, a person’s life experiences form the basis for his/her observation, and reflection on what has been encountered encourages learning. This in turn becomes assimilated into what is already known, providing a new conceptual map on which further actions will be based, thus forming a new experience. To complete the cycle, people also need to be able to practise skills learned if the training is to have any true meaning for them. [↑](#footnote-ref-60)
61. Teaching a wide range of functional life skills (eg banking, self-management, leisure, personal health) and teaching employment and career development skills are among the 63 evidence-based practices that show moderate to high levels of evidence of effectiveness in terms of improved post-school outcomes for students with disabilities (Morningstar & Mazzotti, 2014). [↑](#footnote-ref-61)
62. The only known method of measurement for those with a severe or profound level of intellectual disability is through behavioural observation but this is resource intensive. [↑](#footnote-ref-62)
63. The use of a proxy or third party response is considered more reliable for reporting objective measurements than subjective feelings. It has been well established that people who have a severe or profound level of intellectual disability cannot respond validly to a scale of subjective wellbeing (Cummins & Lau, 2005). [↑](#footnote-ref-63)
64. Malatest NZ developed and administered the survey in New Zealand. R.A. Malatest & Associates Ltd has conducted the evaluation of the *include Me!* initiative for Community Living British Columbia in Canada. The *include Me!* survey was developed to administer to people with learning disabilities and is similar to the survey that was run in Christchurch. The project leader, Joanne Barry (Malatest Canada), provided advice to the New Zealand evaluation. [↑](#footnote-ref-64)
65. The JAG agreed at its December 2014 meeting to fund the survey. [↑](#footnote-ref-65)
66. Community Living British Columbia in Canada run the *include Me!* initiative aimed at people with learning disabilities. The *include Me!* quality of life survey was developed to administer to people with learning disabilities and is similar to that was run in Christchurch. See <http://www.communitylivingbc.ca/projects/quality-of-life/> [↑](#footnote-ref-66)
67. The Youth 2012 questionnaire is available at: <https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/ahrg/docs/youth12-questionnaire.pdf> [↑](#footnote-ref-67)
68. One holds a social science and policy degree with a focus on disability and community care and is an expert in interviewing disabled people. The other has a Master’s degree in psychology. [↑](#footnote-ref-68)
69. Personal communication with *include Me!* project lead Joanne Barry. [↑](#footnote-ref-69)
70. Opt-in participants have access to an average of 25 hours (navigator time) available for planning, and any ongoing support, recognising that some participants will be very clear and not need much and others may need more. [↑](#footnote-ref-70)
71. For example, those who had chosen not to engage or were struggling to engage with the Demonstration because they lived in difficult family circumstances or had no family support. [↑](#footnote-ref-71)