Enabling Good Lives
Waikato Demonstration

Phase Three Evaluation Report

Prepared for: EGL Governance Group
EGL Waikato Leadership Group
EGL Waikato Evaluation Reference Group

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Tēnēi te mihi atu ki a koutou. Many thanks to you all.

Accessible and easy-to-read versions

Accessible and easy-to-read versions will be developed with EGL Waikato.

Disclaimer

The information in this report is presented in good faith using the information available at the time of preparation. It is provided on the basis that the authors of the report are not liable to any person or organisation for any damage or loss that may occur in relation to taking or not taking action in respect of any information or advise within this report.

Contents

Contents

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Table of Figures

___

Executive Summary

Enabling Good Lives (EGL) is an approach that seeks to form partnerships between the disability sector – that is, disabled people, families, whānau, providers of disability support – and government agencies. EGL has been trialled in Waikato since 2015 through the EGL Waikato Demonstration (the Demonstration).

This report presents the findings from the Phase Three evaluation of the Demonstration, commissioned by the EGL National Governance Group, aimed to understand how, and to what extent, disabled people, families and whānau achieved anticipated outcomes. This phase of the evaluation ran from April to November 2018 and also explored how, and to what extent the Demonstration contributed to those outcomes. To address these points three Key Evaluation Questions (KEQ's) were developed and agreed. Fifty-five disabled people, families and whānau shared their experiences of the Demonstration. Findings from the two earlier phases of the evaluation, undertaken between 2015 and 2018, have also been considered in this report.

Key finding
Participants are clearly experiencing success and achieving their outcomes through the EGL Waikato Demonstration, which is generally well delivered but with some opportunities for further refinement and improvement.

Overall, the EGL Waikato Demonstration has successfully contributed to 91% of participants achieving at least half or more of their desired outcomes, through enabling self-determination, choice and control over their lives. The Demonstration, as identified through interviews and reviews, has done so by:
- creating flexibility and freedom,
- providing adaptable, individualised funding and supports,
- supporting self-management of personal budgets,
- building Tūhono/Connector relationships, facilitation and support.

Participants shared experiences of their sense of independence, building confidence, expanding

friendships and being able to make choices about who comes into their home and when. They talked about greater access to environments previously not accessible, particularly education and sporting activities, and also re-establishing connections with whānau, marae and other culturally significant spaces. Reportedly, several factors outside the Demonstration also contributed to their success, including;

- support and encouragement from whānau,
- empathetic and empowering relationships with trusted people in the community, including other disabled people and whānau,
- the chance to take part in sports, learning and other activities,
- connecting with other agencies such as schools and service providers.

A few participants were still progressing to meet their goals. Core EGL systems, as well as external factors outside the control of the Demonstration (e.g., the participant's general wellness and energy, other agencies not following through, challenges with finding and keeping the right supports, etc.) contributed to slower progress – and the overall evaluation reflects all those aspects.

Almost all participants believed the Demonstration made 'a lot of difference' to them and their whānau. Over half the participants achieved most of their plans or goals during the past 12-24 months. They noted that the Demonstration was flexible and responsive when they wished to change their plans and goals along their journey. Across all three phases of evaluation the majority of participants self-managed their personal budget, and this arrangement worked well for them.

Almost all participants found, and continue to find, taking part in EGL a positive experience and recognised the Demonstration's commitment to improve these. Those taking part thought all improvements or adaptations, such as more focused or additional contact with Tūhono/Connectors, were important, even those affecting only one participant or whānau.

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¹ To support the three phases of evaluation, success and performance criteria were developed with the EGL Waikato Evaluation Reference Group. They provide a framework to make overall evaluative judgements as well as guide data collection, analysis and collective sense making. The performance criteria help us to answer our key evaluation questions (KEQ's). Refer to Appendix One for more information.

Insight from the workforce: a small sample

An online workforce survey, undertaken outside the phase three evaluation, added insight from the perspective of support workers who are working with EGL participants. While timely and useful, the survey was distinct from the original phase three evaluation plan. It received only a small sample,[2] therefore limited analysis was possible within this project scope. While there is a need for further engagement and evaluation with the workforce, we include here a few top line results of note for the evaluation.[3]

The workforce, comprised of people both new and experienced to the sector undertake multiple activities and roles for participants, and have a range of employment relationships in place. This includes people with lived experience of disability as whānau members providing that support. There is mainly understanding and practice of the EGL principles, with further training sought to continue to strengthen their practice.

In summary

The Demonstration shows strong, consistent and continuing delivery towards participant outcomes. Participants value the contributions it makes to their lives.

In addition to this success, the evaluators recommend continuing fine-tuning in key areas such as facilitating ongoing and supportive engagement between EGL participants and Tūhono/Connectors, EGL Systems and Community Connectedness - to continue to improve and increase performance and the experience for participants. Going forward, the evaluators expect the Demonstration will be able to preserve their strong delivery as they have done over the nearly four-year period since the beginning of the Demonstration. However, with the continued rising volume demand over this period, the sustainability of the Demonstration and its staff is a critical consideration.

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[2] *All promotion of the survey was undertaken with EGL participants and service providers, as the EGL workforce are independently employed.*

[3] *The top line results from the online workforce survey are outlined in a separate document to this evaluation report.*

1

Introduction

1.1. Enabling Good Lives

Enabling Good Lives (EGL) is an approach first developed in 2012 that seeks to form partnerships between the disability sector – that is, disabled people, families, whānau, providers of disability support – and government agencies.[4] EGL is based on eight principles that guide all decisions and actions, from the system level to the individual. [5]

The vision of EGL is, "in the future, disabled children and adults and their families will have greater choice and control over their supports and lives and make more use of natural and universally available supports". (Office of the Minister for Disability Issues and Associate Minister of Health, 2017, p. 18).[6]

EGL is an innovative approach: this means it uses new ideas and new ways to do things, and was trialled or demonstrated in two places; Christchurch and Waikato. The wider disability sector has also been trialling a range of relatively small-scale initiatives such as Enhanced Individualised Funding and Choice in Community Living (Office of the Minister for Disability Issues and Associate Minister of Health, 2017). More recently Mana Whaikaha, the prototype of a transformed disability system has recently begun (October 2018) in the MidCentral region.

The EGL Waikato Demonstration (the Demonstration) is now into its fourth year of delivery. Over this period, it is important to note that the Demonstration has exceeded their intended 200 participants with 291 active participants as at 1 February 2018. It also has had an extensive waiting list of approximately 100 possible participants, with the Waikato Demonstration confirmed to continue until June 2020.

1.2. The evaluation [7]

This is the third phase of the evaluation of the Demonstration. Phase one focused on the first six months of

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[4] *Government recognised the need and broad direction for change to the disability support system. In January 2009, the Government established a work programme to address long-standing concerns with it. In 2012, the Ministries of Social Development and Health worked in consultation with disability sector organisations to test the Enabling Good Lives approach in Wellington, Christchurch and Hamilton (Office of Disability Issues, 2016). Refer to Appendix One for more detail on the origins of the approach.*

[5] *The EGL Principles are self-determination, person-centred, mana enhancing, beginning early, easy to use, relationship building, ordinary life outcomes and mainstream first.*

[6] *Office of the Minister for Disability Issues and Associate Minister of Health, 2017, Disability Support System Transformation: Overall Approach. Retrieved from http://www.enablinggoodlives.co.nz/system-transformation/*

[7] *For more detailed information, please refer to EGL Waikato Demonstration Phase Three evaluation plan.*

implementation of the Demonstration (July-December 2016), with phase two focusing on the formative period, or the first year of implementation (July 2015 – June 2016).

1.2.1.　Evaluation purpose

Exploring experiences and outcomes from both the perspectives of disabled people and their families and whānau is vital. As such, the purpose of the phase three evaluation is to understand how and to what extent disabled people, families and whānau are achieving the outcomes that matter to them, and the extent to which the Demonstration is contributing to those outcomes.

1.2.2.　Key Evaluation Questions

The key evaluation questions (KEQs) were agreed by the EGL Waikato Evaluation Reference Group and EGL Governance Group to provide the framework for inquiry undertaken through the evaluation. Following a review of the questions developed and utilised in the previous EGL Waikato evaluations, the following KEQs and sub-questions were used for phase three:

KEQ 1: How and to what extent are disabled people, families and whānau effectively achieving their outcomes? Have there been any unexpected outcomes?
- What are the experiences of Tāngata Whaikaha [8] and their whānau?
- What are the experiences of Tagata Pasifika and their families?

KEQ 2: How and to what extent does the EGL Waikato Demonstration contribute to disabled people, families and whānau achieving their outcomes and living the lives they want?
- What, if any, are the other factors outside of EGL Waikato that contribute to disabled people, families and whānau achieving their outcomes?
- What are factors that help or hinder people achieving their outcomes?

KEQ 3: How well is the EGL Waikato Demonstration being delivered and how might things be improved?
- What are the most valuable and least valuable aspects of engaging with EGL Waikato for participants, their families and whānau?
- What is working well? What challenges have arisen and how have these been tackled?
- What changes could be made?

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[8] *Through the revision of Whaia Te Ao Marama – the Māori Disability Action Plan 2017-2022 – a significant change in the plan was the introduction of the term Tangata Whaikaha to describe a Māori disabled person (Tāngata Whaikaha used to describe Māori disabled people). Whaikaha can be translated as "to have ability or to be enabled". For more information, please refer to https://www.heiwhakapikimauri.co.nz/s/Whaia-te-ao-Marama-2017-2022.docx.*

1.2.3.   Evaluation Approach

The approach to evaluation over the three phases is unique to EGL Waikato as it has drawn on and embedded the EGL principles and ways of working to provide an evaluation framework. The approach also recognises that the Demonstration is happening in a complex system. That is, there are many different and connected parts to how disabled people, families and whānau get support, and these are not constant. Aspects of innovation, change and complexity present within the Demonstration are recognised by applying and reflecting on developmental evaluation principles throughout the evaluation.

1.2.4.   Ethical considerations

The evaluation and evaluation team recognises that it is operating within multiple cultural contexts – disability, Māori, Pasifika, rural, urban, for example. As such the evaluation needs to be responsive to these. According to Barnes and Mercer (2001, p.517), medical discourse in the past has placed disabled people in the context of other. However, many have been actively working to eliminate the stigmatisation and 'othering' of disabled people, and what has emerged is a disability culture that provides disabled people with a positive identity. The Demonstration and the evaluation team draw on this strength-based approach and by having an evaluation team that not only understands disability culture but also lives that culture, the risk of stigmatisation is minimised. [9] The team brings together experienced evaluators, and in the first instance will draw on and utilise this breadth of knowledge and experience.

The team is committed to working in ways that are honest, respectful, meet the needs of people who use EGL Waikato, and will ensure those involved can clearly see what the evaluation is aiming to do. We have a strong value of care for those we work with, and for, in the evaluation of EGL Waikato.

Also important to the evaluation, is honouring the UN Convention on the Rights of Persons with Disabilities, Te Tiriti o Waitangi, the principles of EGL and ethical evaluation practices set out in the Aotearoa New Zealand Evaluation Standards, Aotearoa New Zealand Evaluation Association (ANZEA) Evaluator Competencies, and Kaupapa Māori research practices. The team abides by their respective code of ethics when undertaking evaluation and research.

1.2.5.   Privacy, confidentiality and informed consent

The evaluation team protected the privacy and confidentiality of all those who volunteered to participate, sought their informed consent, and ensured all participants felt safe and confident to share their valued experiences and information with the evaluation team. This means that when people chose to share their information and experiences, the evaluation team kept it confidential, stored it safely and only used or shared it in the ways people had agreed to.

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[9] *Barnes, C., Mercer, G. (2001). Disability Culture. Handbook of disability Studies, 515-534*

Seeking informed consent is a critical step, and as such, the consent process has been built into the wider Demonstration consent process. Easy to read information about the evaluation was shared, and disabled people could have the support of trusted people to assist with communication and understanding. It is acknowledged that each phase of the evaluation requires information to be shared with participants as participants may change over time as they enter and leave the Demonstration, some time may pass between phases, and data collection methods may be altered. It is important that participants understand the evaluation process and reconfirm their consent to participate.

1.2.6.   Limitations

There are potential risks and limitations to any evaluation. In summary, the possible limitations for this evaluation centred on the ability to meaningfully assess outcomes and impacts for participants. This was mainly due to the time needed to fulfil outcomes through the Demonstration, as well as the difficulties of measuring quality of life within a very diverse, voluntary group of participants. However, on reflection, the mitigation strategies put in place for this evaluation were effective in minimising the impact of these limitations on the ability of the evaluation to make valid conclusions. Examples of these mitigation strategies were: utilising an outcomes framework co-created with the evaluation reference group to have a shared understanding of outcomes, using a range of evaluative methods and tools to gather data, and to look at outcomes over time.

1.2.7.   Gathering data

This evaluation used various methods, triangulating multiple sources of data to answer the key evaluation questions. The data sources included:

- participant interviews which included open-ended questions as well as Likert scales,
- participant file review,
- an online survey of a small sample of the workforce.

1.2.8.   Iterative evaluation analysis

The approach to analysis was not one single process, but a combination of analysis, synthesis, and sense making. The qualitative data were analysed utilising a range of tools and processes to identify themes and patterns, as well as identifying exceptions, contradictions and unexpected consequences. [10]

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[10] *We wish to acknowledge the use of Bob Williams' ideas about data analysis, in particular the Qualitative Data Analysis Tool as contained on his website http://www.bobwilliams.co.nz/Tools.html and http://www.bobwilliams.co.nz/Tools_files/analysis2.pdf*

1.2.9.   Evaluative framework used in analysis

To help develop a shared understanding of how well something has been done and define the aspects that are important to success, an evaluative framework or rubric[11] was designed in phase one, and utilised with adaptions in phase two and three. This tool is a way of being explicit about evaluative conclusions. For example, it helps determine what are the important or essential aspects for the success of a policy, approach or programme, how well a policy or approach has been implemented, or if outcomes, intended and unexpected, have been realised.

The EGL principles provide both the guiding framework for the Waikato Demonstration and the high-level framework for the success criteria. This ensures that the principles provide the initial measure of quality.

The evaluative framework both defines what success looks like (outcomes and delivery criteria) as well as determines how well or successful something has been developed, implemented or delivered (performance criteria).

For further information see Appendix One for the Evaluative Framework for the Demonstration, and Appendix Two on data collection methods and demographic analysis.

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[11] *A rubric sets out clearly criteria and standards for assessing different levels of performance. See http://betterevaluation.org/en/ evaluation-options/rubrics*

2

Findings from the evaluation

This part of the report provides findings from the evaluation and is structured to respond to the three KEQs. Each section presents a detailed summary of the findings for each of the KEQs.

2.1. KEQ1: How and to what extent are disabled people, families and whānau effectively achieving their outcomes? Have there been any unexpected outcomes?

The majority of disabled people, families and whānau are effectively achieving their self-determined outcomes, as well as agreed EGL outcomes.

2.1.1. Experiences of all participants show the majority are effectively achieving their outcomes

The evaluators found that 91% (37 out of 41 respondents) thought that they achieved at least half or more of the things they had set out to achieve in the past year or two (see Figure 1). Some participants, who had not achieved most of the things they wanted to, identified that they were still making progress towards their goals, but felt it was slow progress. When asked about each of the EGL outcomes, on average 90% of participants agreed that they experienced each of the EGL outcomes (see Figure 2). The things that hinder participants' achievement of their goals are explored later in the report.

91% of EGL participants had achieved half or more of their own outcomes
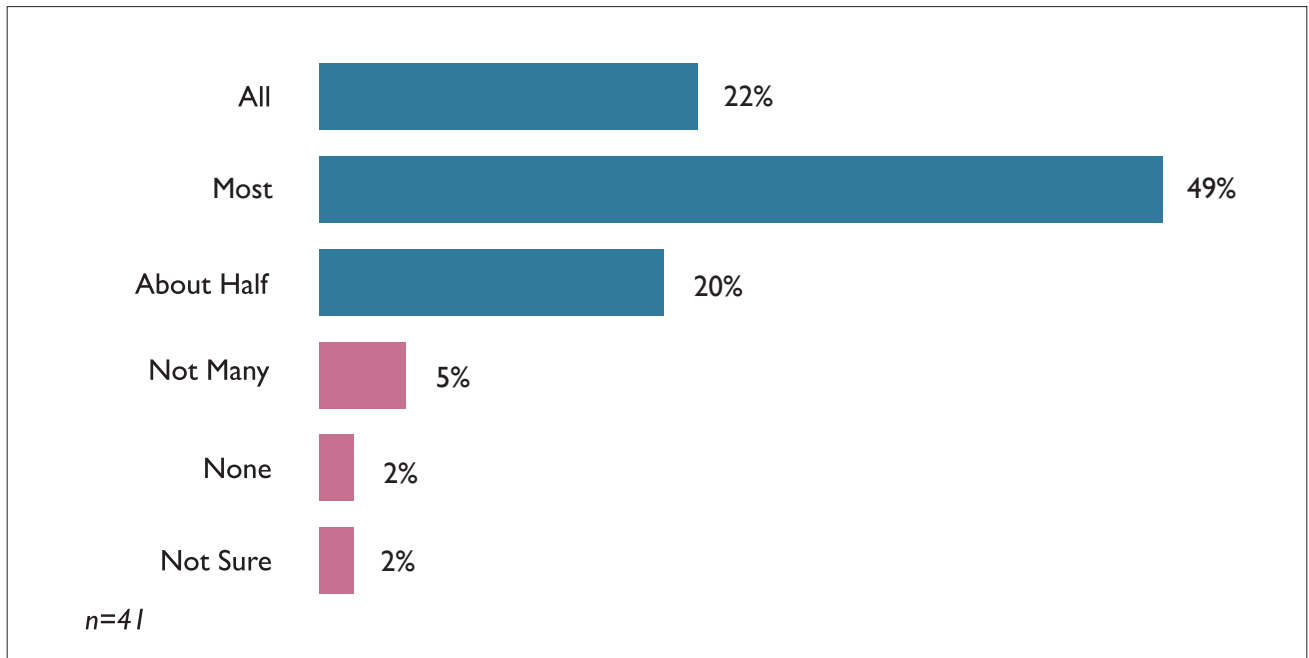
The vast majority of EGL participants agreed they were achieving EGL outcomes.

Outcome	%
I am known and connected in my community	91%
I have supports I need, they work for me, when and how I need them	91%
I can choose who can assist me with my ongoing support	91%
I control and direct the support I need	91%
I have ideas and goals for my future and plan for them	91%
I can do things important to me	91%
I am in control of my life and what happens to me	91%
I make choices and decisions that direct my life	91%
I can build strong relationships that are important to me	89%
I know how to, and I can access information, support and funding at the time I need it	89%
I have rights	89%
I can use community options, connections and services that are for everyone before I have to use specialised disability services	87%
The contribution I make is recognised and respected	87%
I can contribute to the lives of others and to my community in ways I want to	87%
I can choose where I live and who I live with	87%

n=46

The evaluators found, from the interviews, that many EGL participants had experienced a substantial shift in the degree of independence they had in their lives. Some examples of this are that some appreciated the "chance to grow up and be more independent". Others believed the ability "to be a contributor, not a consumer" was an important outcome. Finally, being in EGL allowed one participant to "get on with my life, knowing that my home and personal care are looked after, so I can look forward".

Families and whānau of EGL participants also spoke of the importance of EGL in their lives "EGL has changed our lives, I don't know where I'd be – divorced?" Some also identified that EGL provided practical, meaningful opportunities that made a difference to them. Some examples of these are:

For her to go swimming and do all that … its enabling her life … she is actually having a good life at the moment

He can go to a concert and stay overnight if he wants

We can't always go to public places so being able to provide activities [at home] has been great

2.1.2.   Experiences of Tāngata Whaikaha and their whānau

Tāngata Whaikaha, Māori disabled people, and their whānau, make up 36% of total active participants, and span all three EGL Waikato action areas,[12] with 79 participants within the Tāngata Whaikaha action area. Of the 30 Tāngata Whaikaha and their whānau selected for the evaluation, most interviews were completed as whānau, reflecting the age of the participants (the average age was 17 years) and the involvement of whānau in the lives of participants and the Demonstration generally.

In general, like the majority of participants, Tāngata Whaikaha also had positive experiences of EGL. Some successes are that whānau identified that they felt safe and supported, particularly in comparison with previous systems they had engaged with. In addition, whānau reported having positive relationships with Tūhono/Connectors and were appreciative there were Tūhono Māori, noting that they "love that they are Māori, it makes a big difference". It was also clear in the interviews that open and ongoing communication is critical and strengthens relationships between Tūhono/Connectors and participants. Finally, respondents noted that they had experienced mātauranga-informed practice when engaging with Tūhono Māori, and appreciated practices that are responsive to them as Tāngata Whaikaha and as whānau.

There were some opportunities for improvements identified by Tāngata Whaikaha:
  • connection with a Tūhono/Connector Māori if they are not in place,
  • planning 'as whānau' could be strengthened,
  • transition between Tūhono/Connector is a critical time, suggesting that bringing in another Tūhono/Connector earlier in the process, providing more crossover between the old and new Tūhono/Connector,

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[12] *The EGL Waikato aims to focus on working with disabled people, families and whānau within three groups or action areas: individual choice (building on the Ministry of Health's Choice in Community Living approach), Tāngata Whaikaha (Māori disabled) and their whānau, and Families (disabled children and young people).*

[13] *Refers to the use of Māori knowledge, language and customs.*

may sustain their positive experience,

• enhance communication, connection and relationships with Tūhono/Connector and EGL whānau across marae communities.

2.1.3.   Experiences of Tagata Pasifika and their families

Tagata Pasifika and their families make up 7% of the total active participants, and span all three EGL Waikato action areas, with families being the main area. Of the 11 Tagata Pasifika participants selected for the evaluation, all interviews were completed as a family, again reflecting the age of the participants (average age was 16 years) and the involvement of families in the lives of the participants and the Demonstration.

Tagata Pasifika also reported positive experiences of EGL. In their view, EGL creates real difference, particularly in relation to opportunities, choice and freedom. The majority of Tagata Pasifika achieved most of what they set out to do. They saw EGL as family focused, not only within the immediate family, but also more widely. Tagata Pasifika said they believe EGL supports re-connection with their wider family and also enables community connection, helping them to find places where they belong and are accepted. Finally, Tagata Pasifika reported positive relationships with Tūhono/Connector.

EGL has helped our family find a place where we are normal

… they care about the needs of our family.

2.2. KEQ2: How and to what extent are disabled people, families and whānau effectively achieving their outcomes? Have there been any unexpected outcomes?

The EGL Waikato Demonstration makes a sustained contribution to disabled people, families and whānau achieving their outcomes and living the lives they want.

Figure 3 shows that 89% (40 of 45 respondents) believe the Demonstration made 'a lot' of difference to them and their whānau. Similarly, just over half (58%, 25 respondents) thought that the Demonstration has helped them 'a lot' to achieve their goals and ideas, with a further 40% (17 respondents) believing that the Demonstration had helped 'somewhat' to achieve their ideas and goals (see Figure 4 below).

Figure 3: How much difference EGL makes to participants and whānau

EGL makes a lot of difference to participants and their whānau

Category	Percentage
A lot of difference	89%
Some difference	7%
A little difference	4%
No difference	0%
Not sure	0%

n=45
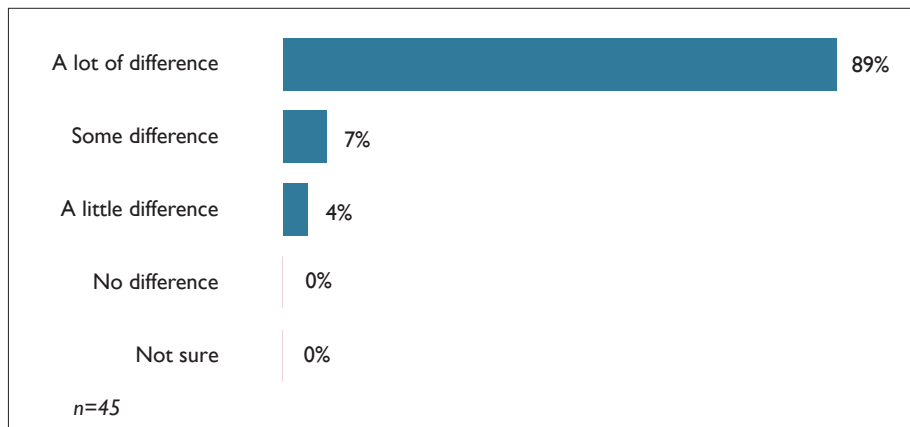
Figure 4: How much participants thought EGL helped them to achieve their goals

More than half of the participants thought EGL had helped 'a lot' to achieve their goals

Category	Percentage
A lot	58%
Somewhat	40%
A little	0%
Not at all	2%
Not sure	0%

n=45
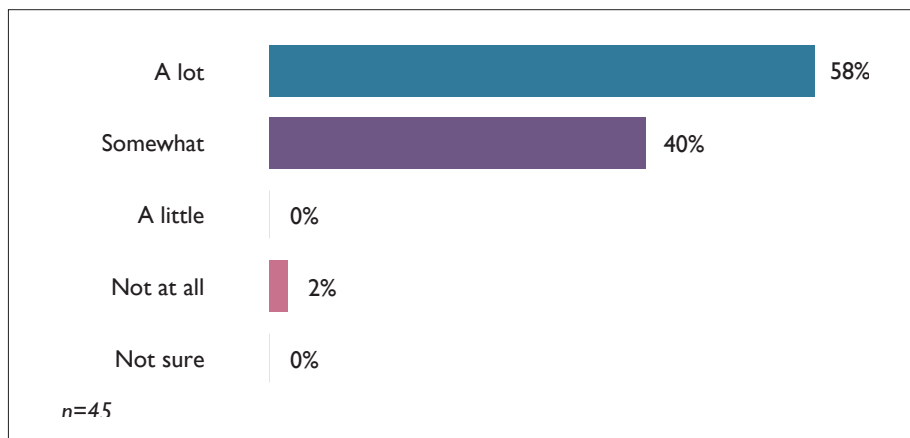
The primary theme arising out of the interviews and files reviewed was that EGL enabled participants and their whānau to assert self-determination, choice and control through several key pathways, as detailed below.

2.2.1. Flexibility and Freedom

The flexibility – it frees me up. We use the supports how we need them, they fit with us versus having to use them only in ways you are allowed. We are in control of our own lives instead of reliant on others.

First, EGL supports flexibility and freedom for participants to direct their own lives. Unpinning this flexibility and freedom is the ease through which people move through the Demonstration processes and how this continues when they receive their budget and operate within the EGL system.

Participants shared experiences of their sense of independence, building confidence, expanding friendships and being able to make choices about who comes into their home and when. They talked about greater access to environments previously not accessible, particularly education and sporting activities, and also re-establishing connections with whānau, marae and other culturally significant spaces.

Some families spoke about how life has changed for them as a family. Opportunities for their children to experience and participate in safe and responsive activities at home and in the community were created through flexible funding and supports. Parents were able to re-establish practices that reduced stress and strengthened relationships such as enjoying spending time together. A few spoke of improved relationships with their children and with their partners.

2.2.2.   Engaging individualised supports

The flexibility and the ability to know that if something needs to change, it can be changed quickly. Knowing you have someone there to call when you need it is a relief.

Second, EGL supports self-determination, choice and control through how supports are engaged. EGL provides participants with a greater degree of choice and control to engage the supports they need, when they need them. This provides participants with access to a range of items, and activities, as well as support people.

This greater degree of choice and control appears to have come with a higher workload for participants. Figure 5 below demonstrates that 80% of respondents in the evaluation spend approximately four hours or less per week managing their supports. Just over one-third of respondents indicated that this was more than with their previous system. However, all those who identified that their workload had increased made it clear that the additional benefits they received outweighed the extra effort.

Figure 5: How much time respondents spend organising their supports

Over three-quarters of respondents spend 4 hours or less per week organising supports

Less than one hour a week	20%
1 - 4 hours a week	60%
5 - 9 hours a week	9%
10 - 14 hours a week	2%
15 hours + a week	7%
Not sure	2%

n=45
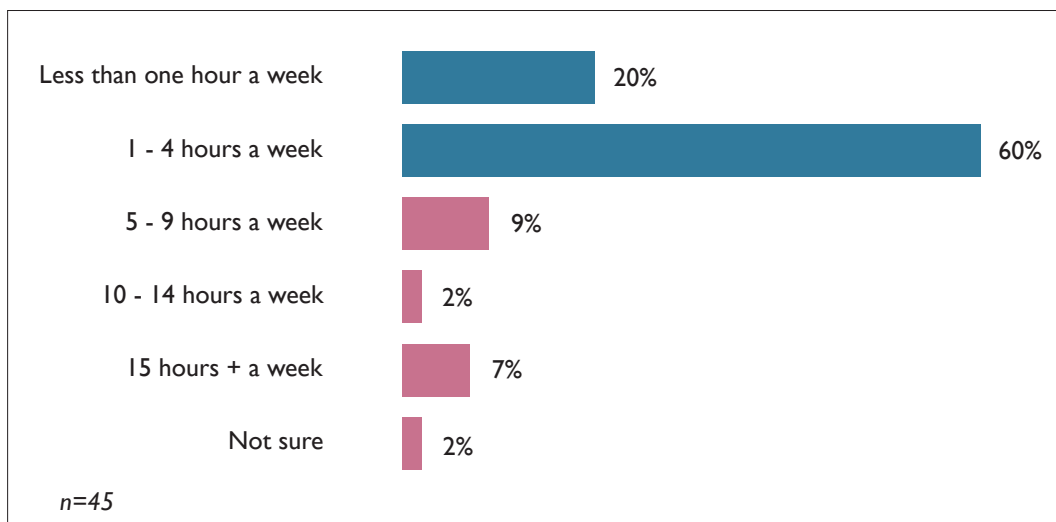
Examples of ways respondents described the benefits of EGL in relation to engaging their individualised supports were:

EGL funding for support workers to help me go on leisure activities of my choice has made life so enjoyable for me.

I now go out and do some volunteer work … I'm on the Board of Trustees for an organisation … I get to travel to Auckland with a support worker that EGL pays for.

I have staff who are on the same page as me and who are not 50 years older [than me] … I have more time to do the things I want … I have a life I enjoy.

The length of time spent managing supports was not the only challenge for respondents when engaging supports. Several identified that being an employer was a big change for them and sometimes was a stressor for them, particularly in the early stages.

It's a learning curve and can suck the energy out of me.

However many noted that the stressors associated with managing their own support does dissipate over time as confidence and systems develop.

2.2.3.   Self-mangaging personal budgets

Knowing we have the flexibility to use our funds appropriately has helped the most.

Third, EGL makes a difference through self-management of budgets. Overall, 80% of those interviewed managed their own personal budgets. Further, 88% of respondents said their current budget management works for them. Interestingly, there were more respondents in the group who had previously been involved in the evaluation, who engaged a host to manage their budget (n=8), compared to only one respondent amongst those who were new to the evaluation. Some participants noted that they have the skills and systems required to self-manage. It is also possible as people are hearing the positive but realistic experiences of existing participants, as expressed above, they feel better equipped to undertake budget management themselves.

For those who are self-managing, a key success is that they can fully use their budget for their needs i.e., they don't need to pay agency fees. Further, they valued being able to determine their budget and saw a "definite advantage" to choosing who and what supports they engaged. Respondents said their Tūhono/Connector provided valuable information and support when working through a budget. One noted that "they make it so you can understand". Most respondents also were aware that they could reconnect with their Tūhono/Connector to discuss their budget and make any changes that were needed.

There were some challenges with self-managing personal budgets. These challenges were mainly around the increased responsibility and work that is inherent in self-managing a budget, particularly initially as they are learning how it works and at times when they feel under pressure. The added responsibility of being an employer was noted by some as reflected by this participant quote, "Onus is on us, as employers, to comply with pay equity legislation". Later in the report, opportunities for improvement to address these challenges will be discussed.

2.2.4.   Tūhono/Connector Relationships

She is very good with guiding me on how to get my supports and manage my funding … she comes and helps whenever I require assistance.

Fourth, EGL makes a difference through the relationships participants and their whānau have with their Tūhono/Connector. Generally, respondents considered the level and intensity of support received from their Tūhono/Connector to reflect their expectations. Respondents saw this relationship as mana-enhancing.

She helps me achieve what I want with no fuss.

Participants also saw the Tūhono/Connectors as trusted and respected facilitators, who helped them navigate critical situations and systems, such as funding committees. This facilitative approach is also reflected where some participants are living with very high and complex social and health needs. They have been actively connected with other services to provide ongoing facilitation, coaching or intensive supports, as noted in phase two. During phase three, the file review highlighted the extensive nature of the intensive collaborative and multidisciplinary approach undertaken when people are living in very complex situations, to enable them to have a good life.

Also valuable was the connections and networks the Tūhono/Connector brought. Tūhono/Connectors were also valued for their ability to introduce new ideas and opening up new ways for participants to think about what they needed to live a good life.

... helped me look forward to tomorrow and the next day.

The word cloud below represents the words that respondents used to describe their engagement and relationship with their Tūhono/Connector.

Figure 6: How some respondents described their engagement and relationship with their Tūhono/Connector

Although, there were many positive reflections from participants about their relationship with their Tūhono/Connector, for some participants there were opportunities for improvement. These areas are discussed on page 22.

2.2.5.   External factors that can assist or hinder people

As expected, participants identified factors outside the Demonstration that made a positive contribution to their outcomes, but in some cases, hindered their progress.

Factors outside EGL that are contributing to participant outcomes include:

• supportive, encouraging whānau,

• empathetic and empowering relationships with trusted people in the community, including other disabled people and whānau,

• participating in sports, learning and other activities that build confidence and skills,

• connections and relationships with other agencies such as schools and service providers.

Factors outside EGL that are hindering participant outcomes include:

• the participant's wellness and energy, including stress and mental wellbeing,

• challenges associated with finding and keeping the right supports, particularly staff,

• lack of community awareness, inclusion and appreciation of diversity,

• limited accessibility and availability of community options, including public spaces and transport,

• other financial resources (not via EGL) being limited,

• challenges associated with finding opportunities for paid employment,

• other agencies not following through.

2.3. KEQ3: How well is the EGL Waikato Demonstration being delivered and how might things be improved?

The evaluators found the Demonstration to be well delivered, with participants able to express what they valued, along with some things that could be changed or improved.

The most valuable aspects participants identified about EGL have been summarised already in this report as the key pathways through which EGL enables self-determination, choice and control (i.e., flexibility and freedom, engaging individualised supports, self-managing personal budgets, Tūhono/Connector relationships). In comparison, the least valuable aspects that participants identified, equating to areas for change or improvement, relate to EGL core systems and support for greater community connectedness. These aspects are similar to what emerged in the Phase Two evaluation even though work is being done by the Demonstration Team to make improvements. However, given the increase in the number of new participants and the essential nature of these aspects, this repetition is not unexpected.

2.3.1. Areas for improvement

As part of the Demonstration team's ongoing commitment to learning and continual improvement, they have committed to improving the experience for each and every participant, even if they are already positively experiencing EGL. Therefore, the areas identified represent areas that will improve experiences more generally, as well as for individual participants.

During the phase one and two evaluations, similar suggestions were raised and in part attempts to address them have been undertaken by the Demonstration team, such as having back up Tūhono/Connectors in place and providing detailed guidance regarding recruitment and financial systems. However, it is not unexpected that with a highly person-centred service, there is a continual need to review and adapt practices, particularly when there are changes in staff and case load size, as has been the case for the Demonstration. That said, cycles of learning and adaption for the Demonstration, which the evaluation phases have aimed to support, continue to be critical as the Demonstration approaches the end of its fourth year of delivery.

Figure 7 on page 24 provides an overview of areas of improvement, rational for change and how the improvements may occur.

Figure 7: Areas for improvement, rationale for change and how might it occur.

Area for improvement:

Facilitate ongoing and supportive engagement between EGL participants and Tūhono/Conectors

Rationale for change:

• A recurring theme from phase two and three
• Times of inconsistency and infrequency of contact and information between some of the Tūhono/Connector and participants
• Possible mismatch between the Tūhono/Connector and the participant and/or whānau.

How might it occur:

• Strengthening expectations and consistency of connection and communication with Tūhono/Connector
• Revisiting the level and intensity of support provided by Tūhono/Connector as part of a regular participant review process
• Support continuity of Tūhono/Connector engagement through connecting/introducing a 'back-up' Tūhono/Connector early to participants
• Further development of the Tūhono/Connector workforce.

Area for improvement:

EGL systems

Rationale for change:

• are not clear what they can do with their funding
• are not receiving the right level of information about employing supports
• are experiencing delays in decision-making by the EGL Waikato Funding Committee[14]
• are not fully aware of Hosting and the range of options available to them, particularly locally-based options [15]
• do not have the necessary resources and guidelines to support decision-making during recruitment and retention.

How might it occur:

• Clearer understanding of how the funding can be used, particularly paying whānau to provide supports and purchasing items, as well as timeliness of funding processes
• Enhanced assistance to find support workers and also more clear information around requirements of employment versus contracting support workers.

Area for improvement:

Community Connectedness [16]

Rationale for change:

Some participants experience:
• a lack of community awareness, inclusion and appreciation of diversity
• limited accessibility and availability of community options, including public spaces and transport.

How might it occur:

• Strengthening connections across the EGL and Disability networks and forums

[14] *The EGL Waikato Funding Committee make decisions regarding approval of personal budgets and business cases put forward to support purchases by participants.*

[15] *Individuals supporting participants close to home*

[16] *A continuing opportunity for the Demonstration is to foster and grow community awareness and connections. However, it is acknowledged that it is not solely the responsibility of the Demonstration to achieve this.*

3

In closing … final reflections from participants

The following quotes are a selection of participant views shared during the interview process, including a final question asking participants if there was anything in closing that they would like to share about their experience of EGL Waikato. They indicate that EGL has the potential to transform the lives of participants and whānau, giving them hope, self-determination, a chance to engage in and with the community and much needed support for whānau.

EGL is transformational … Power needs to be given back to the individuals with disabilities

I thought how could it possibly change. I couldn't see the light at the end of the tunnel, but now there is light all around me

He is out in the community now. Before he was reliant on me, and if I was tired it wouldn't happen…. I kind of have a life too

[EGL has] taken a big weight off my shoulders at this time of my life, and for her as she goes through a transition. I mean that in every way – emotionally, physically and mentally

Figure 8: How some respondents described EGL

ONE

Evaluative Framework for EGL Waikato Demonstration

Success Criteria

The EGL Principles provide the guiding framework for the Waikato Demonstration and initial outcome statements developed during the evaluation co-design process were written to reflect them. You will note that the EGL Principles provide the high-level framework for the success criteria, as this ensures that the principles provide the initial measure of quality. The framework defines what success looks like (outcomes and delivery criteria) as well as determines or makes a judgement about how well or successful something has been developed, implemented or delivered (performance criteria).

Figure 9: EGL Waikato Demonstration Success Criteria

EGL Principles	EGL Waikato Demonstration Outcomes Framework		EGL Waikato Demonstration Delivery Criteria
	Disabled People	Families and Whānau	
Self-Determination	I am in control of my life and what happens to me. I can say what I want and carry out my choices and decisions.	Family and whānau are empowered to express their goals and aspirations and those they care for.	The EGL Waikato Demonstration increases and supports disabled people, and their families and whānau to have control of their lives.
Person-centred	I control and direct my life, including my disability supports. I can choose who can assist me with my on-going supports. Supports work for me when and how I want them. I can do things that are important to me.	Supports work for families and whānau when and how they want these.	Disabled people, and their families and whānau have increased choice and control over supports. These supports take a whole of life approach over time and are tailored to their needs, goals and aspirations.
Beginning Early	I have aspirations and can plan for them. I am in control of my life and what happens to me. I have the supports I need, when I need them.	Families and whānau are aspirational for their child's life and future. We have access to support and funding that contribute to our family and whānau living the life we want.	The EGL Waikato Demonstration ensures that their core systems (Tūhono/Connectors, community connections, supported self-assessment and planning, and personal budgets) are accessible, flexible and easy to navigate.
Mana enhancing	The contribution I can make is recognised and respected. I can contribute to the lives of others and to my community. The EGL Waikato Demonstration is culturally respectful of me.	The abilities and contributions of families and whānau are recognised and respected. The EGL Waikato Demonstration is culturally respectful of our family and whānau.	The EGL Waikato Demonstration created opportunities for the abilities of disabled people; values the abilities, leadership and contribution of disabled people and their families and whānau.

EGL Principles	EGL Waikato Demonstration Outcomes Framework		EGL Waikato Demonstration Delivery Criteria
	Disabled People	Families and Whānau	
Ordinary Life Outcomes	I am supported to live an everyday life in everyday places, like others at similar stages of life. I have citizenship rights, including opportunities for learning and contribution, having a home and family, friends and connections, and employment.	Families and whānau are supported to live an everyday life in everyday places.	The EGL Waikato Demonstration supports equity and citizenship for disabled people, families and whānau.
Easy to use	I find the EGL Waikato Demonstration system easy to use and flexible. I have supports that are simple to use and flexible. I know how to and can access information, support and funding at the time I need it. I have one plan and one amount of funding.	We find the EGL Waikato Demonstration system easy to use and flexible. We know how to and can access all the information our family and whānau needs. We have one plan and one amount of funding.	Disabled people, families and whānau are supported to access community options, connections and services before specialist disability services.
Mainstream First	I am known and connected in my community. I know how to and can access all the information at the time I need it. Community options, connections and services that are for everyone can be used before disability services.	We know how to, and can access all the information our family and whānau needs We are known and connected in our community. Community options, connections and services that are for everyone can be used before disability services.	Disabled people, families and whānau are supported to access community options, connections and services before specialist disability services.
Relationship Building	I can build strong relationships that are important to me. I can contribute to the lives of others and my community.	We are known and connected in our community. We know how to, and can access all the information our family and whānau needs.	The EGL Waikato Demonstration builds and strengthens relationships between EGL Waikato Partners – disabled people, families and whānau community and government.

Performance Criteria

Overall performance criteria were developed to enable judgements to be made about the extent to which disabled people, families and whānau are achieving the outcomes that matter to them, and the extent to which the EGL Waikato Demonstration is contributing to those outcomes (KEQs 1-2). A set of mini-rubrics[17] were designed to support discussions and collective sense making around these criteria (see Figures 10-11).

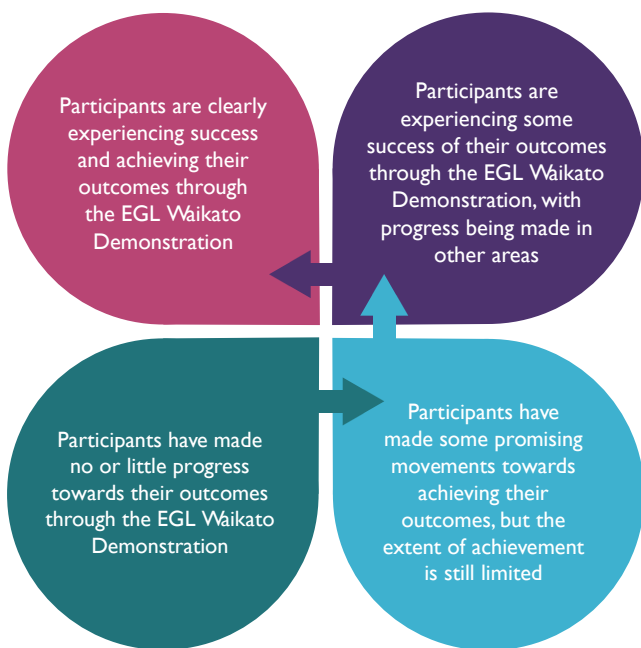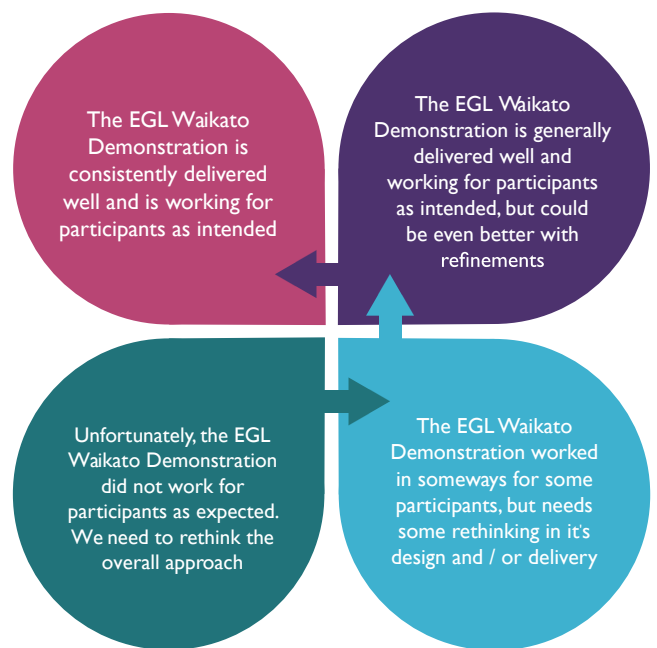*Figure 10: Overall Performance Criteria: EGL Waikato Demonstration Outcomes*

Participants are clearly experiencing success and achieving their outcomes through the EGL Waikato Demonstration

Participants are experiencing some success of their outcomes through the EGL Waikato Demonstration, with progress being made in other areas

Participants have made no or little progress towards their outcomes through the EGL Waikato Demonstration

Participants have made some promising movements towards achieving their outcomes, but the extent of achievement is still limited

Figure 11: Overall Performance Criteria: EGL Waikato Demonstration Delivery

The EGL Waikato Demonstration is consistently delivered well and is working for participants as intended

The EGL Waikato Demonstration is generally delivered well and working for participants as intended, but could be even better with refinements

Unfortunately, the EGL Waikato Demonstration did not work for participants as expected. We need to rethink the overall approach

The EGL Waikato Demonstration worked in someways for some participants, but needs some rethinking in it's design and / or delivery

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[17] *Davidson JE. 2014. Minirubrics. Retrieved 23 September 2017. http://genuineevaluation.com/minirubrics/*

Appendix
TWO

Data collection methods and demographic analysis

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Participant interviews

A sample of 60 participants was selected from the total list of EGL participants (as at 1 February 2018) that reflected the diversity amongst current 'active' [18] EGL participants.

Of the 60 participants selected, the experiences of 55 participants have informed this evaluation report. Forty-six interviews were undertaken, representing 51 participants as some families have multiple participants, with four file reviews also completed. One interviewee withdrew from the Demonstration during the evaluation and four others were unable to be contacted.
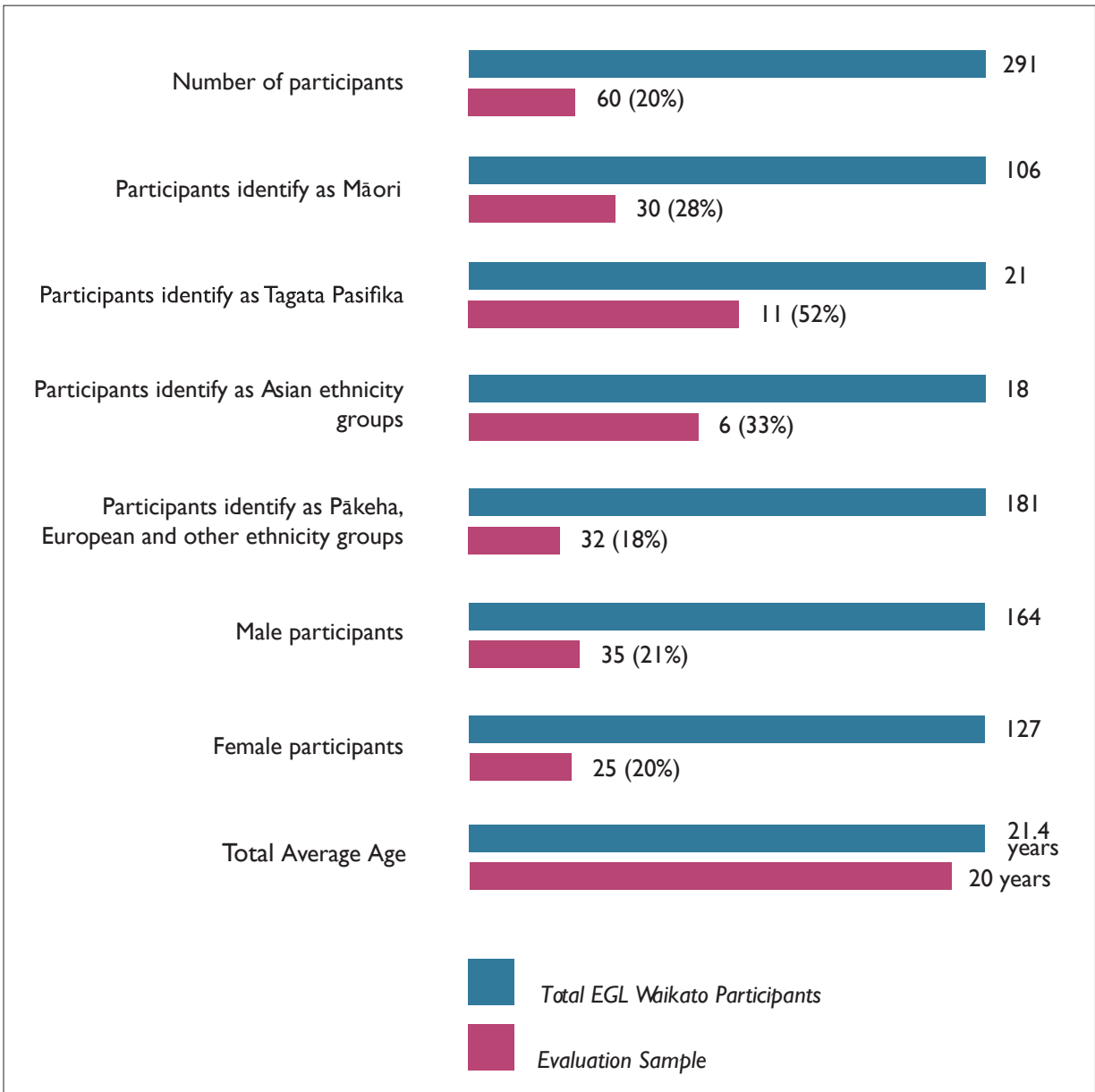
Participants were sampled by a range of objective criteria, such as location, demographics[19] (see Figure 12) and EGL Waikato action area (see Figure 13 below). Those participants who had engaged in the phase one and two evaluations were also selected as part of this sample to provide a longitudinal perspective. Finally, in line with previous phases, the sample was confirmed by the Demonstration Director to ensure that everyone selected was in the best position possible to participate, and the evaluation would not be a burden to them.

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[18] _Being an active participant refers to participants who are actively engaged with Tūhono/Connector/Connectors, are participating in the key steps in the EGL Waikato pathway, including having a personal budget allocated_

[19] _It is important to note that there are some inconsistencies with the ethnicity data, namely the ethnicity categories with which participants can self-identify. Use of the census ethnicity definitions to enable consistent data collection was recommended to the Demonstration team during the phase two evaluation and adjustments were made. Also, as participants can identify with multiple ethnicities, the total number does not equal the total number of participants, with four participants not having their ethnicity recorded at the time the data was accessed._

	Total EGL Waikato Participants	Evaluation Sample
Number of participants	291	60 (20%)
Participants identify as Māori	106	30 (28%)
Participants identify as Tagata Pasifika	21	11 (52%)
Participants identify as Asian ethnicity groups	18	6 (33%)
Participants identify as Pākeha, European and other ethnicity groups	181	32 (18%)
Male participants	164	35 (21%)
Female participants	127	25 (20%)
Total Average Age	21.4 years	20 years

■ *Total EGL Waikato Participants*

■ *Evaluation Sample*

The EGL Waikato Demonstration aims to focus on working with disabled people families and whānau within three groups or action areas: individual choice (building on the Ministry of Health's Choice in Community Living approach), Tāngata Whaikaha - Māori disabled and their whānau, and Families (disabled children and young people). Figure 13 provides an overview of total Demonstration participants in each action area, and the number selected for the evaluation. It is expected that participants belong to more than one action areas. Therefore, when the sample was selected, participants who could reflect multiple action areas and other demographics were prioritised.

Figure 13: Overview of total EGL participants by EGL Waikato Action Areas as at 1 February and sample selected for the evaluation
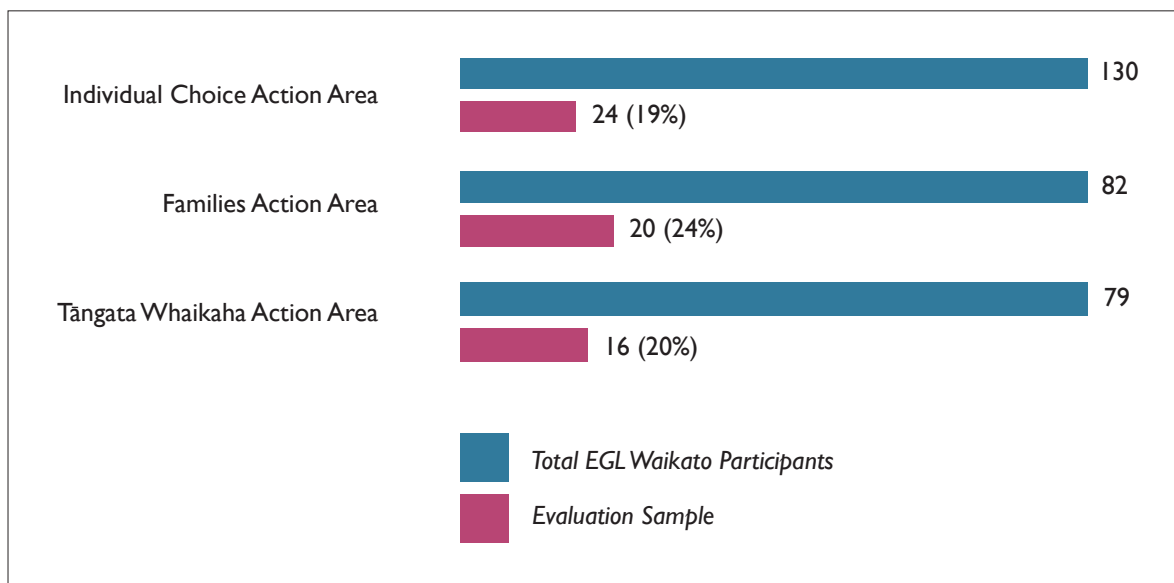
File review

Following guidance from the Demonstration team, file reviews were conducted for four participants, who due to their current circumstances were unable to be interviewed. The file review explored the extent to which Demonstration staff provided support to the participants and the level of working collaboratively with other agencies to provide intensive support.

Workforce survey

An online workforce survey was created to gain the perspective of support workers who are working with those in the Demonstration. This survey was completed by 14 people, 12 of whom identified that they worked directly with an EGL participant. While timely and useful, the survey was distinct from the original phase three evaluation plan. It received only a small sample, therefore limited analysis was possible within this project scope. The top line results from the online workforce survey are outlined in a separate document to this evaluation report.

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[20] All promotion of the survey was undertaken with EGL participants and service providers, as the EGL workforce are independently employed.