Enabling Good Lives Waikato Phase Two Evaluation Summary Report

October 2016



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The Summary Report is structured by the Key Evaluation Themes proposed for the phase two evaluation of EGL Waikato



The EGL Waikato Demonstration is ...



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What makes a 'good' Tūhono/Connector? What support does this role need to be successful?



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Are disabled people and families achieving their goals as planned?



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difference for disabled people and families? What are the success factors?



System Change and Transformation -Learnings from the EGL Waikato Demonstration

The EGL Waikato Demonstration is ...

• Providing an option for disabled people, families and whānau that is **person centred**, offers **more choice and control** and the **flexibility to determine what is possible**

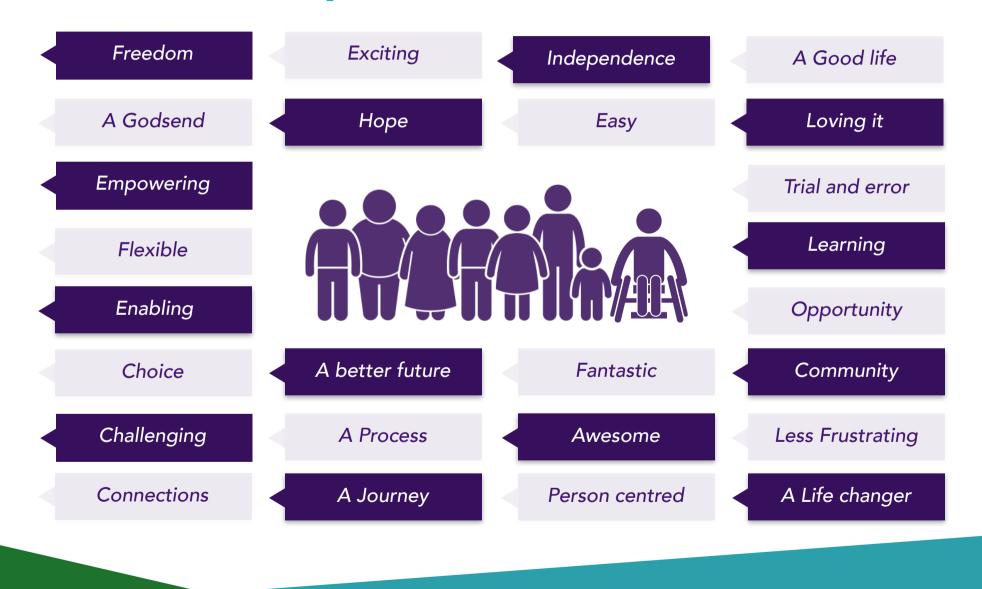
Of the participants interviewed:

- 100% (n=32) felt that **participating in EGL Waikato would be positive**; they would have **more choice and control** and the **flexibility to determine what was possible**, with EGL Waikato
- 97% (n=31) felt what they have achieved would not have been possible without EGL Waikato
- 94% (n=30) have **experienced a positive working relationship** with their Tūhono/Connector
- 81% (n=26) felt the planning process was positive
- 94% (n=30) feel that the Demonstration is making a difference and they are experiencing positive change

The EGL Waikato Demonstration is ...

- **Creating opportunities** that would not be possible in the previous system living an everyday life to achieve aspirations and goals
- Fostering relationships across the sector to ensure there is a continuum of support for participants. There is a need to actively connect with others to provide on-going facilitation, coaching or intensive supports, particularly for participants that are living with high and complex social and health needs
- Enabling and recognising the evolution of relationships for example, parents and grandparents don't have to be solely caregivers; young people can "do ordinary things"
- **Still experiencing issues** regarding delivery. Striking the right balance of achieving Demonstration targets, while meeting and working with people where there are at is challenging. There are some mechanisms in place to address these issues.

For Participants, EGL Waikato is ...



Participant Aspirations for EGL

They should roll it out across the country.

Keep this funding going – first positive experience.

Don't stop it. It's making a difference.

It would be nice if all agencies worked under the same philosophy.

This has given us the opportunity to be independent.

Glad they've got this out there ... Don't stop it, keep it going



Without services like this, families like ours would fall down.

It would be crazy to stop it. Has made everyone's lives better, including extended family.

Would highly recommend it and it should be available for everyone.

One cool programme. Wish it would never end. If it was increased, it would change the nation. Please consider opening for longer to give other people the opportunities.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Self determination: EGL increases and supports disabled people, and their families and whānau to have control of their lives



- Building knowledge and skills of disabled people, and their families and whānau so they may understand and take up opportunities to have more choice and control
- Disabled Leadership present, prominent and visible at all levels of the Demonstration
- Fostering and securing people staff and leadership group members – who are highly skilled, and model and mirror the EGL principles in all places
- Finding a balance between working from where disabled people, families and whānau are at, and being aspirational; understanding that being aspirational may be a gradual process
- Addressing the ability for people, especially those who are rurally isolated or dealing with high and complex needs, to choose who they employ, including family who come to live with them.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Person-centred: Disabled people, and their families and whānau have increased choice and control over supports. Supports take a whole of life approach and are tailored



- Investment in families and whānau to best support their disabled family member to have a good life and help them develop a vision and aspiration for what can be achieved
- Readying families for role or relationship changes particularly at significant transition points is critical, such as leaving school.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Beginning early: EGL ensures its core systems are accessible, flexible, easy to navigate and easy to use



- Tūhono/Connector must reflect the unique qualities identified through the Demonstration and the literature
- Constant use of reflective practice to enhance practice and performance
- Continued separation of Tūhono/Connectors from funding allocation processes, while ensuring they actively support participants to effectively manage and control their budget and supports
- Ensure systems draw on what works and are integrated.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Mana enhancing: EGL creates opportunities for the abilities of disabled people; values the abilities and contributions of disabled people, and their families and whanau



- Committed to being disable-person led, meaning everything is accessible
- Acknowledge that the level and intensity of support participant's need is a continuum. Tūhono/Connectors are encouraged to walk alongside people to ensure they are well resourced to lead their own solutions
- It is vital that a practice of family or whānau centeredness is encouraged, including families and whānau accessing brief support and connections to ensure that as a whole, everyone is flourishing.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation

Ordinary Life Outcomes: EGL supports equity and citizenship for disabled people, and their families and whānau



- Opportunities to connect participants is vital to create networks and share ideas about what's possible and what works
- Ensure processes are as easy to use as possible. Additional guidance to support participants to build confidence and ease into the responsibilities of budget holding and becoming an employer is required and ongoing.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Mainstream first: Disabled people, and their families and whānau are supported to access community options, connections and services before specialist disability services



Continuing to embed the EGL principles to foster and grow community awareness so that communities are more welcoming and accessible, recognise the contribution that disabled people make, and become peoples first choice.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation

Relationship building: EGL builds and strengthens relationships between EGL partners – disabled people, families and whānau, community, and government.



- On-going embedding of the EGL principles by all EGL partners; continue to foster a community of practice approach at all levels – from government to people who provide supports
- Encourage and support changes to service provision by aligning all facets of provider service commissioning, delivery, development and accountability with the vision and principles of EGL
- Transparency, trust and communication between all EGL partners
- Ongoing relationships with Hosts are required to ensure participants are receiving the services and supports that they need and pay for
- Clarity of roles and responsibilities when other agencies or organisations are working with EGL staff and participants.



Key Evaluation Theme 1 Who is participating in the Demonstration? What are the pathways into the Demonstration?



Participants and Pathways

As at 30 June 2016:

- 193 disabled people, families and whānau had contacted or connected with the EGL Waikato Demonstration, with 11 not meeting the Demonstration's eligibility criteria. 29 additional people were also on a waiting list
- 103 were actively engaging with Tūhono/Connectors and participating in key steps in the EGL Waikato pathway. This pathway is working with Tūhono/Connectors, being connected into their community, planning their life and proceeding towards receiving and managing a personal budget via the Demonstration. 99 participants consented to participate in the evaluation
- 79 disabled people, families and whānau were considered not active, that is, no longer undertaking or completing any of the key steps identified above
- For the purposes of this evaluation, participant data for the 'Active' and 'Non-Active' groups will be presented separately
- 30 interviews representing 32 Active participants and 3 interviews presenting 5 Non-Active participants were undertaken.



The **Individual Choice** remains the action area with the highest degree of uptake.



Nearly **87%** of participants have progressed through to budget (86), with nearly **68%** (67) of participants through to contract.



Demonstration participants are located across the greater **Waikato region**. 45% of Demonstration participants (45) are living in Hamilton, followed by the Waipa (18) and Waikato (16) Districts.



There are slightly more **female participants** than male, the opposite to what was occurring during the phase one evaluation.



The Demonstration is reaching people between **3 to 64 years**. Those aged between **20-29 years representing 43%;** continuing the trend from phase one.



The **European** ethnic group **represents 54%** (65)¹ of participants, at least twice the number of participants recorded in phase one. While the number of **Māori**², has risen by 11 (n=37), overall the percentage of Māori has plateaued, but is still double the Waikato Māori population.

2 It is important to note that there are some inconsistencies with the ethnicity data, namely the ethnicity categories that participants can self-identify. Utilisation of the Census ethnicity definitions to enable consistent data collection will be recommended to the Demonstration Team.

¹ As participants can identify with multiple ethnicities the total number does not equal to the total number of participants

Referral Pathways

While the Workshops and Forums were the initial source of referrals, as identified in phase one, it is clear participants have been connected with EGL Waikato through a range of pathways.

33 disabled people, families and whānau have made a self-referral to EGL Waikato, with 21 referrals received through workshops, the Family and Employment Forums facilitated by EGL Waikato and others.





Key Evaluation Theme 2 Who is not participating, why? What are they using instead?





As at 30 June 2016:

- 79 disabled people, families and whānau were considered not active, that is, no longer undertaking or completing any of the key steps towards receiving a personal budget via the Demonstration
- There are however recognised limitations to this analysis due to incomplete data for this group. Earlier in the Demonstration consent was not sought, but this has now been remedied
- A review of the 27 participants who consented to participate in the evaluation has been undertaken to determine if participants were able to derive any benefit from their brief engagement with EGL Waikato through Tūhono/Connector facilitation and/or access to other systems or supports
- Phone interviews were attempted with 10 people who had engaged with EGL Waikato but did not continue. Feedback was received from 3 people representing 5 individuals.

Participants who connected with EGL Waikato but did not continue:

- were aged from 2 to 64 years old, with the majority (74%) over 20 years old (n=20)
- were predominantly male (63%, n=17)
- nearly half (45%) identified as European or Pakeha (n=15)
- Half (52%) were located in Hamilton City) n=14)





A range of reasons were provided for not continuing, of note:



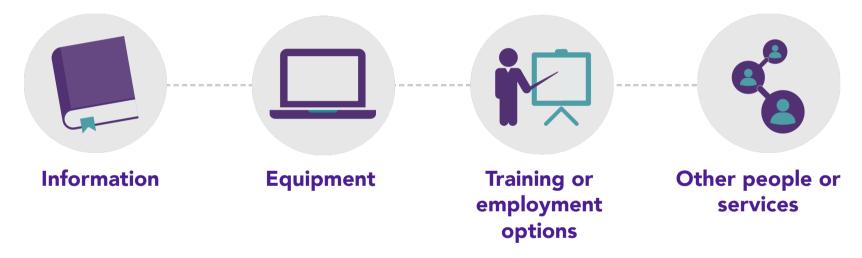
People have not continued because either they had a subsequent increase in their package from the NASC or decided to stay with their current provider or package. One participant also commented that they did not have the energy to change and transition out of Manawanui at the time



People were connected with information or supports or had organised other arrangements outside of DSS services, such as returning to live with family. 9

People were no longer in contact with EGL Waikato, had asked to put their engagement on hold, or as one person described, "[waiting to] see where EGL adds value".

Despite not continuing with EGL Waikato through to a personal budget, at least ten people received tangible benefits from their brief engagement with EGL Waikato.



People were connected to:

Following this brief engagement, a third of all people (n=9) decided that they would remain with DSS services such as Individualised Funding and Residential care, with one person making the choice not to use any services.



Feedback received from 3 people representing 5 individuals highlighted the very different experiences people may go through when connecting with EGL Waikato. Taking into consideration the person's or families' 'starting point' or current situation, a number of key points arose:

- People see the potential in EGL and how it could work for them
- Some people have benefited from receiving information and having the Tuhono as a 'check in' point. They may even consider themselves to still be part of the Demonstration despite not going through to budget
- However, people are choosing to not continue with EGL despite thinking "wow, this sounds really good ... there are options ... EGL sounded like that's what we were looking for". The deciding factor was that EGL was making things more stressful or more complicated, and what was being proposed didn't make sense to the families.
- It is important to understand the immediate needs or current position the person or family is in, "Must recognise what families are about and what they need". It is also vital to identify who else is working with people so a collaborative approach can be fostered.



Key Evaluation Theme 3 What makes a good Tūhono / Connector? What support does this role need to be successful?



Intent of the Tūhono/Connector Role



Offering meaningful support, information and connections according to the Enabling Good Lives Principles, that help people plan for their good life.

- Relationship building: authentic, genuine connection with participants and wider community networks
- Person centred: meeting people where they are at, working alongside people to ensure they are well resourced to lead their own solutions
- Self-Determination: Increases and supports participants to pursue their aspirations and to have control over their lives.

Key Functions of Tūhono/Connector

The functions of the Tūhono/Connector role, are similar to those identified in Lord & Hutchison's 2003 review of ten 'promising' individualised funding initiatives across the globe.

Lord & Hutchison | Functions of Facilitators³

- Build relationships with disabled people, families, networks and local communities
- Provide information about networks, support options, community resources and direct funding
- Help people and families build social support networks
- Assist people and families to plan what they want, using a strengths-based approach, often facilitating planning meetings
- Help people and families to develop detailed support plans and budgets for submission to the funder
- Facilitate community connections
- Assist people to find, purchase or create supports

EGL Waikato | Key Roles⁴

- Get to know you I establish respectful, ongoing relationships
- Turning ideas to action I creating and linking people and opportunities together
- Planning the life you want I assist people with the assessment and planning processes
- Assist people to understand their budget, develop appropriate systems to self-manage or connect them with others who can host their individual budget

3 Lord, J. & Hutchison, P. (2003). Individualised Support and Funding: building blocks for capacity building and inclusion. *Disability and Society, Vol. 18, no.1 (71-86)* 4 Developed as part of the Demonstration co-design process

Unique qualities of Tūhono/Connector

Across the range of evaluation participants, the following unique qualities of Tuhono/Connectors were identified

Values

Reflects, models and mirrors the EGL Principles

- Self-Determination
- Person-centred
- Beginning early
- Mana enhancing
- Ordinary life outcomes
- Easy to use
- Mainstream first
- Relationships building

Attributes

- Spark, energy
- Fresh ideas
- Listen, empathetic
- Encouraging
- Responsive, present
- Flexible
- Optimistic
- Future focussed
- Innovative, creative
- Walks alongside, delivers – do what they say they will do
- Willingness
- Consistent
- Trusted

Skills & Knowledge

- Build effective relationships
- Sound facilitation skills
- Ability to network and connect into new spaces
- Looks for possibilities
- Creates opportunities
- Adaptive
- Culturally responsive
- Excellent communicator
- Sound knowledge base
 sector, community,
 EGL systems (planning,
 budget management)

Participant experiences of working with their Tūhono/Connector are mostly positive

- 94% of active participants interviewed (n=30) have experienced a positive working relationship with their Tuhono/Connector
- However 17% of this group (n=5) also highlighted issues that impacted on their engagement with their Tūhono/Connector
- 6% of active participants (n=2) while still progressing with EGL
 Waikato, described their experience as having resulted in less than positive outcomes.



What enables Tūhono/Connector success?

Tūhono/Connectors are demonstrating the qualities expected

Brought to the table a perspective that we didn't have.

Really good at finding community opportunities that connect to goals. Well connected.

So [the Tūhono] asked what would be helpful.

Tūhono/Connectors have the ability to determine the intensity of support to ensure work with participants where they are at – balancing expectations with knowing what is required

Concerns me that the Tūhono/Connector steps in then steps out, this person [participants] needs someone throughout her life.

What enables Tūhono/Connector success?

- Disabled Leadership present, prominent and visible at all levels of the Demonstration
- Clear job description, deliverables and role boundaries that reflect the EGL principles and align to the other unique qualities of Tūhono/Connectors (lack of role clarity noted as a barrier in the Christchurch Demonstration)
- Deliberate Tūhono/Connector capacity and leadership development with input from the Senior Tūhono, Programme Advisor, Management and the Local Leadership Group
- Use of individual and team reflection and supervision to inform practice and collectively support each other with ideas and strategies.



What are barriers to Tūhono/Connector success?

- Not working from the place where people and families are at
- Not being well networked, having noticeable gaps in knowledge or lack of understanding of the sector or community Tūhono / Connectors are working in
- Do not have a detailed working knowledge of EGL systems and processes, or provide clear information

The connector was keen to have him use the bus. It was difficult to deal with [the Tūhono/Connector] ... [they] would come up with ideas that weren't available in their area. She didn't provide enough guidance.

She arrived and had not completed all her training ... she also wasn't well connected and was new to the area.

It was a little murky, I can't explain it but it seemed like her knowledge was lacking.

What are barriers to Tūhono/Connector success?

- EGL systems can be unresponsive because of timing and detail of information required, for example, participant information is not held in an integrated database, the length of time between preparation of budget to formal acceptance and contact in place
- Limited availability and knowledge of local, community options
- Some agencies are not as flexible or unable to work in an individualised way.





Potential Solutions

- Finding a balance between working from where disabled people, families and whānau are at, and being aspirational; understanding that being aspirational may be a gradual process
- Ongoing training to ensure Tūhono/Connectors have the right mix of local and systems knowledge
- Ongoing review and refinement of processes and documentation to ensure they are easy to use
- Clearer, more regular communication and contact between the EGL Team and participants, so participants are clear about what is possible
- Clarity of roles and responsibilities when other agencies or organisations are working with EGL staff and participants



Key Evaluation Theme 4 How are personal budgets being managed and utilised to support outcomes for disabled people and families?



How are personal budgets set?

A Whole of Life, holistic approach to setting personal budgets has been developed. Information is gathered from multiple sources and is presented by the Senior Tūhono/Connector to the Funding Committee.



How are personal budgets set?

The Funding Committee then reflect on what is presented through a set of five criteria.



Is there a match between the SSA and previous allocation – are there any discrepencies?

How are personal budgets set?

The development and application of the Funding allocation process is:



- Designed and structured to invest
- Draws on collective decision making based on transparent criteria
- Takes into consideration the family's story and where they currently are at
- Initial budget allocation is discussed with the participant
- Provide advice and guidance to ensure the participants have the right financial supports in place
- Three monthly funding reviews built into the EGL pathway.

Participant experiences

Overall, 81% of participants' (n=26) felt the planning process was positive.

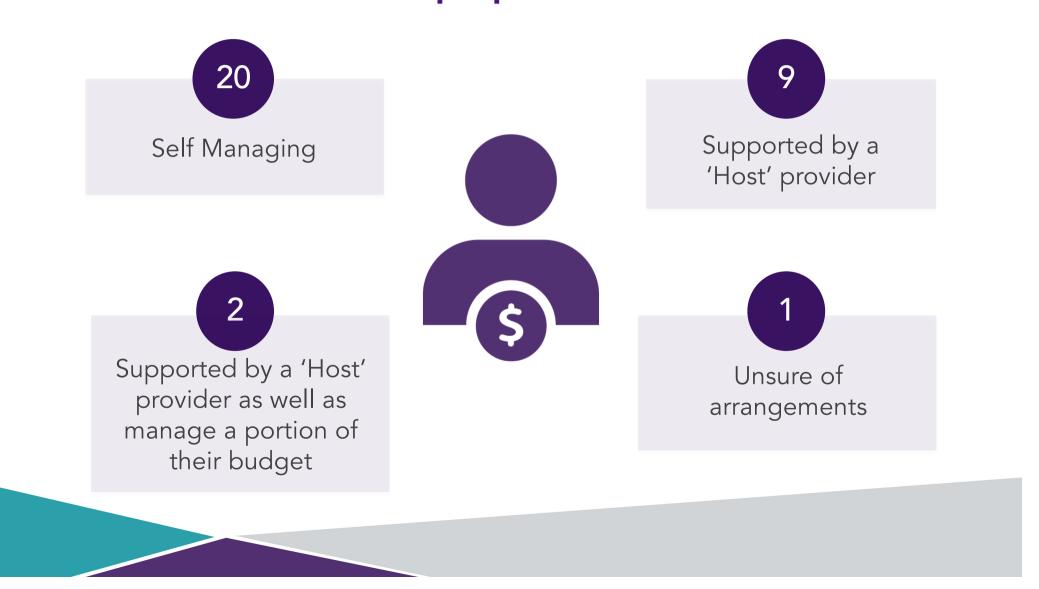
However 19% (n=6) of participant's experiences of the supported self assessment and/or wider planning processes were unhelpful.

Some people said:

- Its about my life
- Could express what I wanted
- Focused on opportunities
- Holistic; Inclusive
- Perfect amount of support from Tūhono/Connector
- Easy; Good process.

- It was rocky
- Left feeling like they didn't get all the information or guidance needed
- Not reflective of what was required to manage complex health needs
- Left feeling 'unsure' or 'unclear' about the outcome.

Managing Personal Budgets Of the 32 people interviewed:



Managing Personal Budgets

For those self managing, it is:

- Enhancing confidence
- Creating greater self-governance and transparency of spend
- Making the funding go further
- Creating greater flexibility
- Developing important skills | financial management, Human Resource skills

We see where every cent of support budget goes. We can discuss that as a family – important having transparency – we had no idea where we were with the [previous organisation].



Managing Personal Budgets



For those working with a 'Host":

- It was a deciding factor for their involvement in EGL Waikato
- Some are receiving a range of supports from their Host not just financial
- Variable success for some, things are working well, for others they are experiencing issues, such as no statements provided, pooling funds for people living together, and for one family the issues they are experiencing is having a significant impact.

It would work better if I could do it myself [self-manage].

Engaging Supports

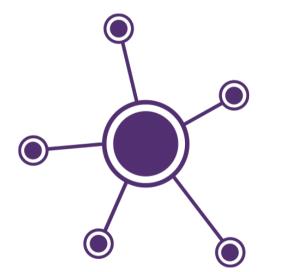
There are four clear areas of supports being purchased:



While some participants are maintaining connections with support and services from the previous model alongside new supports and services, others had no services previously.

Potential Supports

Participants have reflected that there is still scope to expand the potential supports accessible via their personal budget:



- Technology to support learning and communication
- Other equipment to support access to their community
- Specialised, one on one training.



Natural Supports

Overall, natural supports are the same, however for some, they are now able to be used differently due to EGL.

- Participants can now access other supports and lessen the burden and pressure on those who provide natural support
- Recognising the evolution of relationships parents and grandparents don't have to be caregivers, young people can "do ordinary things"
- Some participants are beginning to grow and develop confidence and are connecting with people in new and different ways, such as neighbours
- Relationships are improving between husbands and wives, parents and children, other siblings, and some families are now happier.

Natural Supports



Without this integral part [EGL] we would be very stuck in a rut. 18 months ago, we were neither getting a break or time out. Our son wasn't able to go to the pools or parks, because [my daughter] couldn't go, so [my son] doesn't get some everyday life things. Just 10 minutes with him [now able to collect him from school] means everything. The [EGL] is helping us get along better as a family ... even my son who is six says, EGL helps him.

We get along better.



Natural Supports



My family have always done lots and continue to do lots, but it's nice to be able to kind of reimburse people for things as well. When someone's got really high needs you can't expect family and friends to do things, because they need equipment, they need a van, they need to be able to lift them, and it becomes too much. So it's nice for me to not to have to rely on and exhaust my family.

Natural Supports How is the Demonstration making the difference?



- Accessing supports they need to grow and develop to become selfdetermining
- Enthusiastic Tūhono/Connector encouraging people to do different things
- Enabled to self manage and know that things are possible.

Community Connection & Participation



There is increasing confidence to connect with and participate in communities. Participants are now:

- Volunteering and sharing skills
- Attending social and family events
- Reconnecting with their spirituality
- Participating in community-based activities and courses
- Building their own business
- Attending university
- Training and competing in sporting events
- Connecting with neighbours.

Community Connection & Participation How is the Demonstration making the difference?

EGL Waikato is enabling community connection and participation through participants having:



- the flexibility and autonomy to plan for and access communities in ways that work for them
- the supports that enable access such as transport
- a support worker that is adaptable and flexible and can facilitate access
- Tūhono/Connector ideas, relationships and connections.



Key Evaluation Theme 5 Are disabled people and families achieving their goals as planned?



Experiences prior to EGL

78% (n=25) of participant's experiences of previous services and support was not always positive.

Some people said:

It was a disaster.

[EGL is] a lot more flexible than [NASC] ever was, and I wasn't really utilising the hours.

I wasn't going out much...I was basically a prisoner before.

22% (n=7) of participants had good experiences of their previous system, however were looking for connections and support that would enable them to do or experience other things. Of note, 2 participants were only supported by their school – no disability supports were in place.

Deciding Factors to join EGL Waikato



Overwhelmingly, 100% of participants (n=32) felt that **participating in EGL would be positive**; they would have **more choice and control** and the **flexibility to determine what was possible,** with EGL.

Some people said:

The freedom to do things for ourselves. The power is with us.

Before deficit based, but EGL is aspirational.

Flexibility is an absolute imperative to get the aid and help we need.

Possible without EGL Waikato?



Overwhelmingly, 97% of participants (n=31) felt what they have achieved would not have been possible without EGL.

Some people said:

- No guarantee
- Too much red tape
- Didn't work
- Harder
- Impossible
- No not at all. It wouldn't even come close.

One participant felt that what they are doing now would be possible without EGL, and not experiencing any real difference.

Outcomes aimed for



A diverse range of goals and outcomes are being aimed for. Ultimately, disabled people, and their families and whānau are aiming **to live an everyday life to achieve their aspirations by being:**

- In control of their lives and what happens to them
- Able to say what they want and carry out their choices and decisions
- Able to access information, support and funding at the right time
- Able to choose and access supports that are simple to use, flexible and work for them, when and how they want them
- Supported to live an everyday life in everyday places, like others at similar stages of life
- Able to contribute to the lives of others and their community.



• Autonomous, Self-governing and selfmanaging

Can take control of my life, and Mum doesn't feel like I'm missing out.

The best is that every day can look different.

In residential you don't make your own goals, they make them for you.



- Opened up possibilities
- Giving people hope

My outlook is a bit better now. Makes me keep healthy, looking forward to the day. I look a bit higher, further out at what's around.

It [the equipment] has made a huge difference because he is now safe at night ... so its gives us piece of mind, and we can relax about it now.

I can have a life, we weren't having a life at all.





• Starting early

It's made it a lot easier knowing we've got funding to use for what [she] needs. Especially things she wants to do ... [she] is getting older, there will be more opportunities opening up to her. We see EGL funds will support this.



• Learning to connect and reconnecting with others and making friends

I have a lot to contend with so just having the freedom to to see my friends; I really look forward to that. Without EGL playing that important role, I wouldn't have that time. I've felt like I've been entombed in my house for three years. People take seeing their friends for granted. It means the world to me.

If I didn't have this funding I would be in my room 20 hours a day.

- Potential to create own options / activities
- Future focused
- Knowing that things are possible



I kind of liked creating the plan. I think having another person's perspective was good as well. I also think it kind of gave me the opportunity to think quite big ... and to be aspirational with the things that you wanted in the plan.

It was a broad plan, included getting set up, getting staff involved, training and up-skilling to be more independent and get drivers licence back.

- Freedom to do their best
- Removing red tape
- Helping to change negative behaviours



Being able to control what you do. Like having a shower when I want.

Freedom gained has been life-giving. Its been liberating.





- Reducing the pressure, lessening the stress
- Reconnecting families
- Reconnecting with their culture

Has made everyone's lives better including extended family members. Others outside our family looking in see that there's a difference.



Barriers to Participant Success

Some participants are still experiencing a range of barriers to achieving their outcomes.





Key Evaluation Theme 6 How are Providers working with disabled people and families as part of the Demonstration?

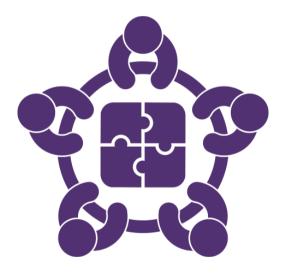
How are Providers adapting to support this?



How are Providers working with the Demonstration and Participants?

There are a range of provider partners who are working with the Demonstration and participants. Six providers were interviewed during this evaluation.

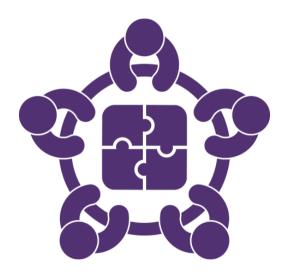
Some Providers are working alongside participants and Tuhono/Connectors, to ensure they have the right supports in place



Some Providers are 'Hosts' or organisations that are contracted to provide financial managment and/or human resource support to participants

Some Providers are contracted to work with participants to walk alongside them in EGL pathway. That means working in way that reflects the Tūhono/Connector role and/or a Host

Provider's Reflection on the EGL Approach

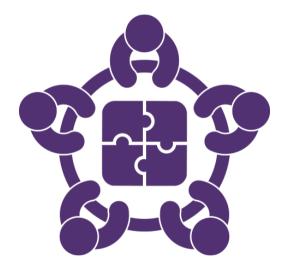


EGL is seen as a fresh new approach and is putting power in people's hands.

Four Providers reflected that they are dedicated to the EGL principles, and believe their organisations align. They are also passionate about disabled people and their families and whānau leading the way.

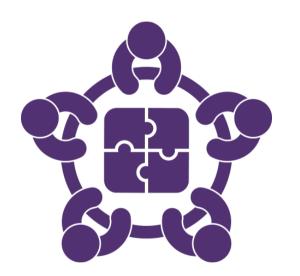
For two of these Providers they have been working in an individualised way and practicing the principles for many years.

Provider Reflections on the Demonstration



There are very limited choices in [rural towns], EGL has had a huge impact and there is potential for EGL to make a significant difference. Delivering EGL collaboratively in rural communities supports connections with community and between participants. Participants are beginning to experience the benefit of these connections.

Provider's Reflections on the Demonstration

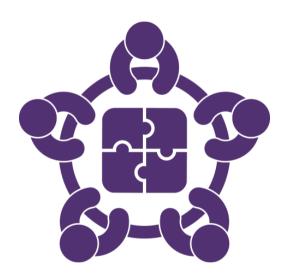


Providers are finding ways to reflect the EGL principles:

- Building relationships to ensure participants have choice
- Building trusted relationships to ensure open dialogue and collaboration with the Demonstration
- Contributing as a member of the Waikato Leadership Group

Asking "What can we do to help the EGL Demonstration" or "What could our place be to help EGL participants and Tūhono/Connectors.

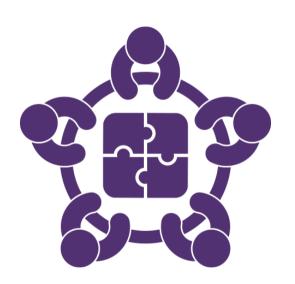
Provider's Reflections on the Demonstration



There have also been some challenges:

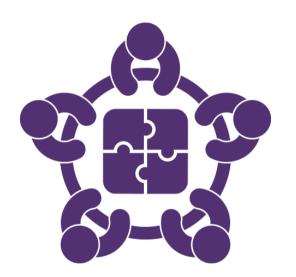
- Where Providers are contracted to work with participants, there has been a lack of clarity of roles. However work is underway to minimise the impact on participants
- For those providing payroll support, being able to be more involved in the personal budget process would enable better support to be provided
- For three providers, connecting with the Demonstration was slow to start. This has improved and things are working well
- Improving communication and sharing of information between agencies would help participants transition more smoothly from one system to another.

How are Providers adapting their practice?



- Four Providers recognise that they have to do things differently to reflect the EGL principles.
 For one provider this is just for EGL participants, for three others, it is being applied service wide
- Two providers are developing and delivering a range of in-service trainings on the EGL principles. One provider is also reflecting the principles in the scope of their roles and in their reporting systems
- Two Providers are also connecting with and sharing their ways of working with others
- The Community of Practice is recognised.

What is hindering Providers from adapting their practice?



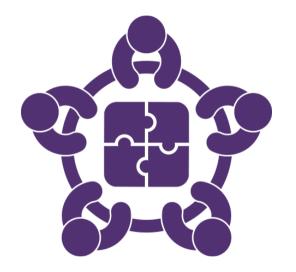
- Providers acknowledge that to work in an EGL way takes time, and is having an impact on some provider's ability to be responsive. In turn, this is having a negative impact on a few participants
- It is however recognised that while the EGL principles have been in place for some time, it does not mean that they are actioned by all
- There is limited sector wide approach to embedding the EGL principles, or some tools are not being well used.

How are Providers working in an EGL way?



- Providers recognise the need to work collaboratively to support and facilitate moving participants plans into action
- Recognition that some participants are living in very complex situations and need a multidisciplinary approach to ensure effective supports are in place to enable a good life to be had
- For one provider it just took one person "to jump on board with EGL and give it a go". This showed others what was possible.

How are Providers creating value for EGL participants?



• Two Providers are supporting people to shift their thinking and expectations

People have always known number of days or hours, or staying in the current thinking of what is delivered

• For participants there is a lot of shifting of expectations and language. It is not just staying in the current thinking of what can be delivered.

The power of giving someone the opportunity to know there are options is great.

• One provider is facilitating a number of workshops.

How are Providers creating value for EGL participants?

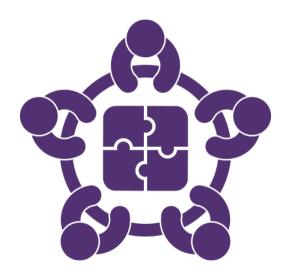


- Two Providers are supporting people to shift their thinking and expectations – people have always known number of days or hours, or staying in the current thinking of what is delivered
- Prompting participants to think about wider community options.
- Participants identifying natural supports.

For participants there is a lot of shifting of expectations and language. It is not just staying in the current thinking of what can be delivered.

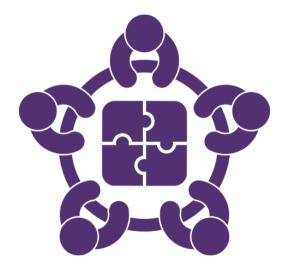
The power of giving someone the opportunity to know there are options is great.

Provider's Reflections on supporting adaption



- EGL principles enhances services for the benefit of disabled people, their families and whānau. Organisations need to reflect on how their values align with the principles
- EGL principles reflected in contracts could help set expectations from government as well as help determine what quality looks like
- Working in an individualised, fee for service way, requires systems and cost structures that some may not have or need to develop
- Foster Community of Practice approach so providers and practitioners can share learnings and insights
- Design and deliver in service training to support workforce to model the EGL principles.

Provider reflections on the value of EGL



People are now making decisions for themselves, now can be creative and decide how to spend their budget, as there is no or limited respite or carer support options, they are employing whānau members to provide vital supports that is working really well.



Key Evaluation Theme 7 What makes the difference? What are the success factors?





- Being person centered, strengths-based
- Skilled Tūhono/Connectors who model the EGL principles
- A whole-of-life, holistic approach to funding allocation
- Options to self-manage or work with a Host provider

Because of EGL we are able to thrive, before we were struggling. I share when I go out that EGL has enabled me to do this.

It was a good process. The team are good partners in doing something differently. It was a good feeling experience.



 Autonomy, flexibility and freedom to determine what, when and how to do things

Happy, I'm living in a flat.

We are individualized now, not part of an agency ... [best thing has been] getting him out of the system, he's an individual.





- Ability to access more flexible and reliable supports in particular support workers
- Ability to access equipment to ensure the health, safety and wellbeing of disabled people, families and whānau

We believe in a living wage and the carers we received from health care organisations were great but were on minimum wage. As a result of paying a living wage we have amazing carers. They are part of the family.



• Developing confidence to think ahead and know that things are possible

EGL helped me with my outlook for the future, others say I'm not so down all the time.

Its about my life.



Does the Demonstration make a positive difference?



Overwhelmingly, 94% of participants (n=30) feel that the Demonstration is making a difference and they are experiencing positive change.

We wouldn't be able to do this without EGL. It benefits our child getting out in the community.

Two participants felt that they were not experiencing any real difference, but felt it could help them in the future or help them experience things they haven't before. EGL provides a lot of opportunities for parents. Parents are really vulnerable.



You have to do your best. When it's just you, my situation is harder simply because I don't have any other family. If I had somebody, just one person, I believe it would make a lot of difference, but I don't, and I just happen to have two children with special needs. So it's incredibly hard, sometimes when you work hard, long hours, you're stressed and tired, not sleeping at night, for years, never sleeping for years. It is silly to expect people to be motivated. Sometimes I see other parents more motivated than me, going to meetings, parent groups, and I feel like I can't do it.

I need someone to look after me, so I can look after my children.



Key Evaluation Theme 8

System Change and Transformation : Learnings from the EGL Waikato Demonstration



Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Self determination: EGL increases and supports disabled people, and their families and whānau to have control of their lives



- Building knowledge and skills of disabled people, and their families and whānau so they may understand and take up opportunities to have more choice and control
- Disabled Leadership present, prominent and visible at all levels of the Demonstration
- Fostering and securing people staff and leadership group members who are highly skilled, and model and mirror the EGL principles in all places
- Finding a balance between working from where disabled people, families and whānau are at, and being aspirational; understanding that being aspirational may be a gradual process
- Addressing the ability for people, especially those who are rurally isolated or dealing with high and complex needs, to choose who they employ, including family who come to live with them.

Person-centred: Disabled people, and their families and whānau have increased choice and control over supports. Supports take a whole of life approach and are tailored

- Investment in families and whānau to best support their disabled family member to have a good life and help them develop a vision and aspiration for what can be achieved
- Readying families for role or relationship changes particularly at significant transition points is critical, such as leaving school.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Beginning early: EGL ensures its core systems are accessible, flexible and easy to navigate

& Easy to use



- Tūhono/Connector must reflect the unique qualities identified through the Demonstration and the literature
- Constant use of reflective practice to enhance practice and performance
- Continued separation of Tuhono/Connectors from funding allocation processes, while ensuring they actively support participants to effectively manage and control their budget and supports
- Ensure systems draw on what works and are integrated.

Mana enhancing: EGL created opportunities for the abilities of disabled people; values the abilities and contributions of disabled people, and their families and whanau



- Committed to being disable-person led, meaning everything is accessible
- Acknowledge that the level and intensity of support participant's need is a continuum. Tūhono/Connectors are encouraged to walk alongside people to ensure they are well resourced to lead their own solutions
- It is vital that a practice of family or whānau centeredness is encouraged, including families and whānau accessing brief support and connections to ensure that as a whole, everyone is flourishing.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Ordinary Life Outcomes: EGL supports equity and citizenship for disabled people, and their families and whānau



- Opportunities to connect participants is vital to create networks and share ideas about what's possible and what works
- Ensure processes are as easy to use as possible. Additional guidance to support participants to build confidence and ease into the responsibilities of budget holding and becoming an employer is required and ongoing.

Mainstream first: Disabled people, and their families and whānau are supported to access community options, connections and services before specialist disability services



Continuing to embed the EGL principles to foster and grow community awareness so that communities are more welcoming and accessible, recognise the contribution that disabled people make, and become peoples first choice.

Using the EGL Principles as our high level framework for success, a number of key learnings for systems change have been highlighted across both phases of the evaluation*

Relationship building: EGL builds and strengthens relationships between EGL partners – disabled people, families and whānau, community, and government.



- On-going embedding of the EGL principles by all EGL partners; continue to foster a community of practice approach at all levels from government to people who provide supports
- Encourage and support changes to service provision by aligning all facets of provider service commissioning, delivery, development and accountability with the vision and principles of EGL
- Transparency, trust and communication between all EGL partners
- Ongoing relationships with Hosts are required to ensure participants are receiving the services and supports that they need and pay for
- Clarity of roles and responsibilities when other agencies or organisations are working with EGL staff and participants.

It would be nice if all agencies worked under the same philosophy or principles [as EGL] and were flexible instead of keeping in their silos.

Funding people with profound disabilities needs to be looked at, because their needs are so unique and its 24-hour care.

Just get more people in [residential services] out in the community.





Going forward a number of key factors that are present in the Demonstration have been highlighted to ensure the future and ongoing success of Tūhono/Connectors:

- Intentional recruitment to ensure diversity, commitment to Māori and seek creative thinkers from outside the disability sector, as well as those from the sector
- Purposeful, active management and support to acknowledge strengths and skills of Tūhono/Connectors and what development is required
- Locally-based leadership, no matter where Tuhono/Connectors are located they are always supported
- Reflective, collective time together to translate learnings into practice and support adaptive, responsive practice
- Ability to determine the level and intensity of support provided understand the vision for people, knowing that some people need other people in their lives, but always clear that Tūhono/Connectors are not there forever.

Going forward a number of key factors that are present in the Demonstration have been highlighted to ensure the ongoing success of Tūhono/Connectors:

- Continued separation of Tūhono/Connectors from funding allocation processes, while ensuring they actively support participants to effectively manage and control their budget and supports
- Ability to respond to and build community awareness and capacity to enhance community participation and connectedness
- Utilise existing infrastructure and systems available that are easily accessible and cost effective, if appropriate.





If it [EGL] was increased it would change the nation. Please consider opening for longer ... to give other people the opportunities.

Too many incredible people just needing a bit of support. People fighting disability in other parts of the country.



