



# **Building on What Works**

**Enabling Good Lives (EGL) Regional  
Leadership Networks**

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**Insight into the successful development of EGL-  
based leadership networks gathered from  
leadership development initiatives from 2013-2023**

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## Context

EGL – based Regional Leadership Networks (RLN) have now existed since 2013. We now have over a decade of insights to draw from. This resource gathers together some of the key things to consider when building, reviewing or sustaining a RLN.

This resource explores what has been learned. Firstly, it examines the purpose and function of a RLN according to the EGL National Leadership Group (NEGL).

### Why an EGL Regional Leadership Group exists

The Leadership Group's purpose can be to:

- Provide a place for local disabled people, families and innovative service providers to lead regional change
- Promote and protect Enabling Good Lives' (EGL) principles and values that the evolving system change is informed by
- Contribute guidance to local initiatives and the implementation of change
- Give direction to any "EGL Entity"
- Provide feedback to the Minister
- Provide feedback to various ministries and public services regarding alignment of service delivery with EGL approach
- Provide connection between local/regional change and National EGL Leadership Group
- To ensure a clear understanding of the priorities and perspectives of disabled people, families and service providers
- To ensure the system will be accountable locally
- To create an 'honourable space' that promotes accessible and inclusive communities
- To bring key stakeholders together to discuss key issues of the community
- To facilitate community development

### What an EGL Regional Leadership Group does

The Regional Leadership Group can:

- use a partnership approach to develop, implement and monitor regional changes

- actively promote regional collaboration between central and regional government agencies so that their activities and projects are aligned with the Enabling Good Lives approach
- be involved in the co-development and oversight of change
- promote good communication with disabled people, families and providers regarding transformation in the region
- increase awareness and understanding of Enabling Good Lives approach
- link with the Enabling Good Lives National Leadership Group.
- Initiate desired changes at a local level with local networks and agencies.

## How Regional Leadership Groups can be set up

There will be many ways to set up a Regional Leadership Group. Each area is best to map assets (people, previous EGL aligned work) and develop in ways best suited to their community. It is critical that disabled people and families lead this development from the beginning.

The successful process demonstrated in the three initial EGL sites has been to:

- a. Hold a series of parallel open community forums about the EGL approach e.g. workshops for disabled people, families, Māori, Pacifica and providers
- b. Encourage interested people in forming a Core Group for each constituency e.g. disabled people, families, Māori, Pacifica and providers
- c. Core Groups then continue an in-depth look at what the EGL approach can mean
- d. Core Groups select a sub-group from their membership to create the Regional Leadership Group i.e. Regional Leadership Group members are mandated by and accountable to their Core Group

External facilitators, knowledgeable in the EGL approach and community development, can assist this process. It is important to note that in the early stages, the first couple of years, a successful external facilitator needs to have both an in-depth understanding of the EGL approach **and** EGL-based facilitation skills.

## Who is on the Regional Leadership Group

The Regional Leadership Network needs to ensure that there is equitable representation from disabled people, family, whānau, Mana Whenua, Pasifika and providers in the region. Group composition varies.

Typically, it is something like:

- five disabled people (including a person with a learning disability ),
- three family members,
- three Mana Whenua (tangata whaikaha or whānau whaikaha),
- two Pacific people (disabled people or families) and
- two providers.

The aim is equity and not equality.

Officials can routinely attend all or part of each meeting. However, they are non-voting members.

Each Core Group determines a process for selecting Regional Leadership Group members and the processes they will use to gather information/opinions prior to meetings and circulate information after meetings.

Regional Leadership members must agree to become familiar with and be committed to the following:

- a. The EGL vision and principles
- b. Te Tiriti o Waitangi
- c. The UN Convention on the Rights of Persons with Disabilities
- d. Working co-operatively within the group
- e. Be a local person willing to be involved in community system transformation

The group may choose to occasionally review its composition.

## What Regional Leadership Groups have needed to think about

<b>Natural justice</b>	-	Transparency and fairness of procedure and freedom from bias on the part of the person making the decision/judgment <sup>1</sup> .
<b>Equity of voice</b>	-	“speaking time should usually be shared more or less equally by the number of the people in the group, and most of our time should be spent listening.” <sup>2</sup>
<b>Safety</b>	-	without fear of negative consequences, feeling accepted and respected.

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<sup>1</sup> [Glossary | New Zealand Ministry of Justice](#)

<sup>2</sup> [Equity of Voice and why it matters | Kate Frykberg](#)

**Honourable space** - “... respect and maintain the sacred space, harmony and balance within relationships”<sup>3</sup>

**Consensus** - “a [generally accepted opinion](#) or [decision](#) among a [group](#) of [people](#)”<sup>4</sup>

Consensus, in the group, is reached when all Leadership Group members present have the chance to give their opinions and nearly all (e.g. 80%) of the voting members agree. If people disagree, this will be recorded and their reasons briefly described.

**Mandate** - the authority that is given to do something

## Role of Support

**Workers** - support workers are here to ‘support’ and not participate – unless, specifically requested by the person being supported

## Having effective links between Core Groups and a Regional Leadership Network/Group

### Core Groups

Core groups are typically parallel forums. This is where disabled people met with disabled people, families with families, Tangata Whaikaha Māori with Tangata Whaikaha Māori and providers with providers.

Core groups exist in order to provide a “safe” space for different groups to explore things important to them and in a way that works for them.

Core groups tend to meet prior to each Regional Leadership Group meeting and their purpose often includes:

- Providing a space for specific stakeholders
- Supporting the people they selected to be on the Regional Leadership Group (RLG)
- Providing guidance to their members on the RLG

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<sup>3</sup> <https://www.leva.co.nz/about>

<sup>4</sup> [CONSENSUS | meaning in the Cambridge English Dictionary](#)

- Offering a space where a wider group of interested local people can discuss ideas, potential impacts and perspectives on suggested changes
- Ensuring there are informed people who can step in, when required, if a member of the RLG is unable to attend a meeting i.e. “back-ups” and succession planning
- Assisting with hosting community forums
- Providing a place where people with specific experiences and expertise can offer their views to the local leaders before RLG meetings

Core Group membership is typically organic and flexible. People self-select, with the understanding that consistent participation is desirable. The core groups are focused ‘working groups’ and will meet monthly for approximately 1 ½ hours each month.

- Participation in core group meetings is voluntary
- Local leaders on the RLG regularly attend the core groups that mandated them to be regional leaders.

## **Making decisions**

The decision-makers are the disabled people, families, Mana Whenua, provider representatives and Pasifika representatives. Officials present, are encouraged to contribute to discussions.

The aim will be for decisions to be made by consensus. Consensus is described as an agreed position reached by the group or where the group agrees to support a decision in the interests of the whole. Consensus can be linked to the idea of mana kotahitanga (the strength and integrity of unity).

Different approaches to building consensus may be used at different times. This may depend on the importance of the decision, its possible impact, the time available and whether people need more information.

Regardless of the approach used, all perspectives will be valued and all people will have the space to put their view forward. Any meeting notes will be clear about whether a statement reflects the consensus of the group or whether it is an opinion expressed (individual views).

Typically, disabled people will speak first on an issue, then families and then others.

After initial discussion, a position will be put to the group. It is likely that discussion goes around the decision makers in the group person by person and ask them to indicate what they think. People indicate whether they agree, disagree or if they want something clarified or changed. These ideas are then considered by the whole group.

After this has happened, it is likely that members go around the decision makers in the group again, person by person, and ask them to indicate what they think now.

The aim is for everyone to have the space to have their views understood and to agree on the “next step” or position the group will express to others. It may be that an outcome of the discussion is just clearly and simply described i.e. how many people agree, disagree or are not sure.

The group may revisit any issue when it considers there is new information available.

## **Meeting Notes**

Notes of the meetings, or any conversations about them, typically do not record who said what. Instead, they reflect the main themes of contributions, the outcome of the discussion and associated actions.

People attending the meeting usually have five working days to approve the notes and then they will be made publicly available to any interested party.

## **External facilitation**

Meetings of Regional Leadership Groups have been externally facilitated until the group is self-sufficient. This is to ensure that the views of people with a lived experience leads discussion, to develop consensus-based processes and to equip group members with techniques related to community development.

External facilitators have generally been people who have: a good understanding of the EGL approach, community development, active facilitation techniques, constructively managing conflict and equity. Sometimes there are co-facilitators – where at least one of the facilitators are disabled people or family members.

## **Requests from officials**

Officials (and others) are requested to send papers two weeks in advance (four weeks to maximise input from networks) and to be clear about what actions they want from the group

## **Link with the EGL National Leadership Group (NEGL)**

As part of creating a cohesive national network, the Regional Leadership Group (RLG) can explore how they can feed into NEGL and how NEGL can support the RLG.

## **How does this get funded/ resourced?**

Ideally, NEGL would like a transparent funding source for all Regional Leadership Groups that does not compromise your autonomy, local ownership or identity.

We have not reached this point yet.

It may be that various funding sources can be considered locally or funding can be obtained through the Whaikaha, Ministry of Health or Ministry of Social Development

NEGL imagines that you will use funding to pay for things like:

- Venue



- Refreshments
- External facilitation
- Guest presenters
- Peoples time
- Running events or projects

NEGL also imagines that, at some point, you may be in a position to hold funding to commission local initiatives that enable more disabled people, families, tangata whaikaha and whānau to understand EGL, explore what a good life looks like, develop skills and build a community where all citizens are valued.

If a Regional Leadership Group chooses to do things like this, you will need to consider how you will build a legal entity, to hold/distribute funding or how you can use another organisation to do this on your behalf.

It is important to consider where funds are coming from because, even though other sources may agree to fund your work, you need to ensure that the funding is given to your group to control and does not remain in the ownership of another entity.

## 2. Insights – what works

**Building an effective and self-sustaining EGL-based Regional Leadership Network is a multi-year project. Success requires vision, optimism and perseverance.**

**The investment in developing a leadership network has significant, enduring benefits to disabled people, families, innovative providers, officials, national networks and the local community.**

This section gathers insights from the work done between 2013 – 2023 and focusses on what has worked well and how this assists communities to build EGL-based regional leadership networks.

### 1. Ensuring leadership development is community-led

**Take time for people to explore what the EGL approach can mean and for existing and emerging local leaders to work collaboratively to develop new networks.**

#### Key Points

- **Take the time to build a strong foundation**
- **Equip leaders with accurate information and required skills**
- **Be clear about existing frameworks and materials**

The success of a regional leadership network appears closely linked to the foundations built by disabled people, families and innovative providers. Ensuring time is taken so people can begin to appreciate the importance and impact of an approach based on the EGL principles is critical. Moving too quickly to 'form a group', without investing time to explore the possibilities and practicalities of a principles-based' approach, can lead to multiple avoidable challenges.

The EGL approach is different from the approaches many are familiar with. It takes time for people to grasp what this difference looks like in practice. It can take several months for groups of disabled people, families and providers to explore the potential of the EGL approach and what the principles look like in practice. It takes time to grasp what local/regional leadership can look like.

There appears to be a direct relationship between the time invested in informing and equipping the community and the focus and strength of local leadership networks. Ensuring that key local disabled people and families are both guiding and co-delivering this initial stage is important. Relax -building relationships and understanding takes time.

An important learning is that it can be counter-productive to simply ask people and communities “what do you want?”. Many disabled people and families have been both deprived of the opportunity to think about what is possible and often people are just too worn down and hurt by existing “systems”. Typically, a number of disabled people and families need to have safe places to let go of their hurt and frustration before they grasp the potential of EGL. Creating safe places, deep listening and “positive reframing” is often constantly required of those facilitating this stage of the process.

Another foundational activity can be providing the community with opportunities to think differently and gather some personal skills that aid both leadership and people’s personal journey. The types of learning opportunities that have repeatedly been highlighted as being regarded as helpful include:

- Aspiration-based planning / imagining better / strengths-based planning etc
- Interpersonal communication skills
- Managing conflict creatively
- Influencing skills
- EGL-based group facilitation skills

## 2. Having an iterative process (a try-learn-adjust approach)

**The Enabling Good Lives approach is an evolving approach. This principles-based approach requires disabled people, families, providers and officials to collectively imagine what can be different, try it, monitor what happens and then either build on success or try another way.**

### Key Points

- **Make sure the community leads** (as long as things are aligned with the principles)
- **Constantly monitor what is happening** (against the vision, principles and Key Messages)
- **Celebrate what works well and build on it and adapt what isn't**
- **Remember there isn't a right way!**

Once there are groups of informed and equipped disabled people, families and providers – then, the journey of “try-learn-adjust” starts. Forming regional leadership networks will take a different journey in different locations. A key learning from existing EGL leadership sites is that it is important to collectively agree on a next step, try it and then look for what is working well and quickly change what is not. There is no “right way”, apart from all ideas and decisions being aligned to the EGL principles!

Some emerging groups have found it really helpful to constantly and systematically map their discussions and decisions against the EGL principles. Consistently asking “is this aligned with the EGL principles?” is often all that is needed in order to provide a framework to continuously adjust what is happening.

It has been observed that it can be a challenge for disabled people and families to take responsibility for their own development journey. Many people have become used to “the Government”, “the Ministry” or influential local service providers being expected to “have the answer”. Or, just provide what is needed. EGL relies on local leaders realising that they have the expertise, they have many of the insights and they know what is needed for their community. Being constructive, being collaborative, being bold and being prepared to “try-learn-adjust” is what has defined successful EGL-based regional leadership networks.

Connecting with other established RLGs and the NEGL can be helpful to guide and support when there are local challenges.

### 3. Starting “wide” by providing multiple forums to identify existing and emerging local leaders

Being inclusive is central to the EGL approach. Providing new spaces, developing new relationships and being mana enhancing can enable powerful alliances that can bring about positive change.

#### Key Points

- **Take the time to build new networks and spaces**
- **Honour the work that has happened (is happening) in the community that is aligned with EGL** (it doesn't matter if it has been called other things)
- **Be staunch about sticking to approaches and behaviours that are aligned with EGL** (immediately describe practices not consistent with EGL in a transparent and mana enhancing way)
- **If you have a “gap” in skills or information then don't hesitate to bring in people who can credibly assist**

The EGL approach that has been successful has:

- Provided **new inclusive** forums that are not directly 'owned' or associated with existing DPO, family or provider networks
- Ensured existing and emerging leaders are identified, their mana is recognised and they are encouraged to actively contribute to change.

Typically, the start of regional leadership networks has involved a series of open advertised public forums that invited disabled people, families and service providers from the community. In the first three locations this was piloted, it was quickly established by the local participants that to provide safe and effective environments, the forums would need to be targeted. In all situations this resulted in parallel open forums i.e. a forum for disabled people, a forum for families and a forum for providers.

In addition to this, parallel forums were also created for Tangata Whaikaha Māori and Pacific Peoples. Two of the three locations then went on to develop specific forums for people with a learning disability and the Deaf Community. The critical point was that the communities decided!

The perspectives of disabled people were given priority.

Identifying existing and emerging leaders was an important initial step. In some communities there were leaders promoting an 'EGL approach' well before the existence of EGL. Often prior to facilitating open community sessions, there was a scan for existing local leaders. Typically, this took the form of having discussions with local disabled peoples networks, family networks and innovative providers. A key element of this scan was to identify disabled people and family members who:

- a) held a vision for positive change
- b) were connected with local networks
- c) were interested in collaborative ways of working
- d) were interested in building a new fit-for-purpose leadership network

In several situations, the existing community leaders were supported to co-develop the local strategy for development. It is important to note that simply reaching out to local disabled peoples and family networks asking "what do you want/need?" was not an effective strategy. Many individuals and networks had been expressing what they wanted and needed for many years through a variety of forums and processes. An effective approach was to provide a safe, inclusive and co-operative space where the key focus question was "**How will we work together to lead positive change?**". Optimism and energy were harnessed when local ideas quickly resulted in action e.g. planning and facilitating community forums or information sharing events.

Considerable time<sup>5</sup> was taken with existing and emerging leaders to begin to explore what the EGL principles looked like when they were translated into:

- a. How groups/forums would function
- b. Individual/group experience of supports and services
- c. Approaches to influencing change
- d. How to prioritise and implement local action

It is important to note the initial four EGL regional leadership networks, established between 2013 and 2023, had involvement of external people who had the following background and skills:

- An in-depth understanding of EGL in action
- Principles-based group facilitation skills
- Community development experience

The 'external' supporters worked with local leaders to cultivate and support the development of a network of EGL informed people who are then able to progress the EGL approach locally.

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<sup>5</sup> This initial period could be from six-twelve months depending on how often groups met.

## 4. Creating parallel development opportunities (Core Groups)

**Different people need different forums and different approaches. EGL requires diversity and flexibility to thrive.**

### Key Points

- **Build multiple forums so that people experience the spaces they need** (The place where everything is woven together is the 'Leadership Group'. It may take many months before people are ready to come together.)
- **Disabled people must lead the process** (other stakeholder perspectives are important – just not the primary one)
- **Be clear in developing the EGL-aligned culture and practices within groups** (some people will need to learn new skills in order to be constructive and collaborative)

Although one site only developed 'Core Groups' after several years, all initial sites developed parallel development groups. It was most successful when the development of these groups immediately followed open community forums. These groups evolved to provide safe and customised spaces for bigger groups to explore the EGL principles and how local change could be influenced. Typically, these parallel groups started for disabled people, families, Tangata Whaikaha Māori and providers. In two sites additional groups were added. These included: people with a learning disability, Pacific Peoples and the Deaf Community.

It was typical for Core Groups to meet prior to each Leadership Group (RLG) meeting.

Their purpose was to:

- a. Provide a place for people to understand EGL approach and gain a shared understand of EGL
- b. Provide a place for people to examine the potential impact of EGL-based change
- c. Select members of the group to be on the Leadership Group (RLG)
- d. Support the people they selected to be on the RLG
- e. Provide guidance to their members on the RLG
- f. Offer a space where a wider group of interested local people can discuss ideas, potential impacts and perspectives on suggested changes

- g. Ensure there are informed people who can step in, when required, if a member of the RLG is unable to attend a meeting
- h. Assist with hosting community forums
- i. Provide a place where people with specific experiences and expertise can offer their views to the local leaders before RLG meetings

It was agreed in all sites that Core Group membership would be organic and flexible. People will self-select, with the understanding that consistent participation is desirable. The core groups will be focused 'working groups' and will meet monthly for approximately 1 ½ hours each month.

- -Participation in core group meetings was voluntary
- -Local leaders on the RLG needed to attend Core Group meetings regularly.

In many respects, the "culture" developed in these groups significantly influenced the "culture" of the Leadership Group. The Leadership Group became the space where locally selected leaders met together in a single forum.

Core group members who are part of the RLGs must be willing to learn and develop their leadership skills and have the capacity to commit to regular meetings as they are responsible for carrying Core Group voices to the RLG and provide feedback from the RLGs back to the Core Groups.

The types of things emphasised in Core Groups were:

- Treat each other with respect
- Listen to each other's views carefully
- Give each other time to speak
- Use every day plain language
- Ask if something needs to be explained
- Make sure the EGL principles guide how we operate and the decisions we make
- Be open with each other
- agree to support the decisions made in the group
- not take it personally if someone has a different opinion
- See conflict (i.e. different views) as a chance to learn and grow



- Proactively identify any missing voices/perspectives from your representative community and consider them when making decisions and forming core group opinions.

Core Groups provided local leaders with not just support and a broad range of perspectives to draw on – but, the local mandate to lead

## 5. Being clear about what is national and already set (including whakapapa) and what is for regional innovation and development

**Provide the macro before the micro.**

**Clarity at the beginning about what is national and what is regional can assist focussed progress.**

<b>National -</b>	<b>EGL principles, EGL elements and key messages etc</b>
<b>Regional -</b>	<b>Assets, priorities and how things can happen locally</b>

### Key Points

- **Disabled people and families have been leading EGL since 2011. Take the time to understand the foundations that have been laid.**
- **Focus on what you have direct control over** (a powerful and credible way to influence nationally is to demonstrate great things locally regionally)

Successful community discussions have typically been associated with a clear understanding related to what is already agreed (in place) and what is over to communities to develop. Taking time to establish solid foundations has assisted communities to be innovative.

Foundations associated with the EGL approach fall into the following categories. These include:

- The EGL Vision
- The EGL principles
- Key elements and characteristics of an EGL approach
- Key messages of the EGL approach

These foundations are located on the EGL website and in numerous publications.

Between 2011-2013 disabled people, families and innovative providers developed the foundations of the EGL approach. This work is recorded in: the initial Enabling Good Lives Report, the EGL Canterbury Report, the EGL Waikato Report and the materials developed by the EGL National Leadership Group in 2013 that describes EGL characteristics, elements and key messages. The building of local leadership

has been easier when local disabled people and families have a good understanding of these foundational ideas and aspirations. Essentially, the “what” of the EGL approach has been clearly described and community leaders are now tasked with “how” will this be brought to life in their communities.

As a principles-based approach, there is considerable scope for local leaders to explore “how” the EGL approach can be brought to life locally. EGL is a social movement. It is intended to be interpreted and implemented according to local strengths, assets and aspirations.

When existing and emerging community leaders have clarity regarding the foundations of the EGL approach they are equipped to explore ‘what do we want this to mean for us?’. At this point, local disabled people, families and providers can embark on the ‘try-learn-adjust’ approach. It appears critical for there to be time invested to establish the EGL foundations first so that time is not wasted by relitigating what is already established.

## 6. Negotiating things from the beginning

**Demonstrate the EGL approach through constant co-creation.  
Negotiate everything!**

### Key Points

- **Take the time make decisions through consensus from the beginning** (it doesn’t matter if things are changed by ‘try-learn-adjust’ down the track)
- **Facilitators may need to focus on breaking dependency/reactive patterns** (positive reframing is a constant process i.e. shifting from “what is wrong” to “what we want to build”)

The most effective approach to developing local leadership networks has been to ensure that the initial groups of local disabled people, families and providers begin to make decisions about how they want things to develop early in the process. Demonstrating “self-determination” and being “mana enhancing” is considerably more important and powerful than talking about it.

At an early stage, local key people and networks are provided with places, spaces and encouragement to determine what EGL looks like for them. It is important to note there can be significant challenges with being a catalyst for self-determination.

Common challenges include:

- Ensuring that self-determination is guided by the EGL principles. It has been common for facilitators and local leaders to be consistently asking

individuals and groups “how does this align with the EGL principles?” for the first two years of EGL-based community development. Individuals and groups need to be vigilant in ensuring that decisions made and actions taken are scrutinised under the lens of the EGL principles. It can be common for strong “personalities” to need to be challenged to stay aligned with the principles.

- Disabled people, families, providers and their associated networks have often been passive to the authority and influence of the Crown, local power organisations and/or influential individuals. Making EGL aligned decisions challenges many people and networks to think differently and behave differently. Honouring the diversity of the community is sometimes different and difficult. It can take some time for individuals and groups to learn the skills of developing and respecting a consensus process. Again, the “try-learn-adjust” process is always informed by “how does this align with the EGL principles?”.
- Assisting local leaders to break free from “dependency”, “submissive” and “reactive” thinking is a core task for those facilitating local leadership development. Shifting focus from “what isn’t working?” to “what do we want to build?” is central to bringing about the shifts required with an EGL-based approach.
- Disabled people and families shifting from reaction or consultation to a collaborative approach where they are active partners when working with local agencies and services. This involves them being proactive in setting their own agendas and identifying their areas of priorities rather than being led by other’ agendas.

Starting this process early by demonstrating “self-determination” enables existing and emerging community leaders to take ownership of local development. When groups will meet, where groups will meet, what is on the agenda, how groups ensure all people are heard and how groups will consider different opinions are all early ways for individuals to exercise choice and control as local leadership development unfolds.

## 7. Co-developing a Terms of Reference

**EGL is about providing a framework for a new way of building relationships and creating tangible ways for people to co-develop things locally.**

### Key Points

- **Describe and explore the attitudes, expectations and practices associated with EGL through co-developing a Terms of Reference**
- **The process of developing the Terms of Reference is as important as the final document**

A successful way to establish an EGL-based leadership group / network “culture” is for local leaders to co-develop an agreed framework and set of expectations when meeting. This “Terms of Reference” enables leaders to explore the behaviours and processes and practices that are EGL and Te Tiriti aligned.

See below for a set of headings that have successfully guided the development of a leadership groups Terms of Reference: -

### **Purpose – why we exist**

The Leadership Group’s purpose is to:

To bring key stakeholders together to discuss key issues of the community

Promote and protect Enabling Good Lives’ (EGL) principles and values that system transformation is based on .....

...

...

### **Role – what we are going to do**

The Leadership Group will:

use a partnership approach to develop, implement and monitor EGL-based transformation

link with the Enabling Good Lives National Leadership Group.

actively promote collaboration between Whaikaha, Ministries of Health, Social Development and Education (and other relevant government agencies) so that their activities and projects are aligned with the Enabling Good Lives transformation ...

...

...

Leadership Group members will:

Attend leadership group meetings (this is likely to be monthly meetings of approximately four hours)

Review the minutes of meetings to make sure they are an accurate record of what we have talked about

Do the things they may have agreed to do at the meeting

Attend “core group” or “pre-meetings” (likely to be 1-2 hours monthly for the first 12 months)

Host (or co-hosting) open community forums. This is where a much wider group of people can learn what is happening and contribute their thoughts.

### **Membership – who we are**

The Leadership Group will ensure that there is equitable representation from persons with disability, family/whānau, Mana Whenua and providers in the region

Each group will determine a process for selecting these members and the processes they will use to gather information/opinions prior to meetings and circulate information after meetings.

Leadership members agree to become familiar with and be committed to the following:

The EGL vision and principles

Working co-operatively within the group

Other ‘criteria’ for membership consideration:

Local person willing to be involved in community system transformation

Willingness to embrace notion of change

### **Link with the Core Group**

The core group will meet prior to each Leadership Group (LG) meeting and its purpose is to:

- Support the people they selected to be on the LG
- Provide guidance to their members on the LG
- Offer a space where a wider group of interested local people can discuss ideas, potential impacts and perspectives on suggested changes
- Ensure there are informed people who can step in, when required, if a member of the RLG is unable to attend a meeting
- Assist with hosting community forums
- Provide a place where people with specific experiences and expertise can offer their views to the local leaders before RLG meetings

People will self-select, with the understanding that consistent participation is desirable. The core groups will be focused ‘working groups’ and will meet monthly for approximately 1 ½ hours each month.

- Participation in core group meetings is voluntary
- Local leaders on the LG will attend core group meetings.

## Foundations

Relevant conventions e.g. the Convention on the Rights of Persons with Disabilities  
 The Enabling Good Lives Vision and Principles  
 Te Tiriti o Waitangi

## Considerations

- Natural justice** - Transparency and fairness of procedure and freedom from bias on the part of the person making the decision/judgment<sup>6</sup>.
- Equity of voice** - “speaking time should usually be shared more or less equally by the number of the people in the group, and most of our time should be spent listening.”<sup>7</sup>
- Safety** - without fear of negative consequences, feeling accepted and respected.
- Honourable space** - “... respect and maintain the sacred space, harmony and balance within relationships”<sup>8</sup>
- Consensus** - “a generally accepted opinion or decision among a group of people”<sup>9</sup>
- Consensus, in the group, is reached when all Leadership Group members present have the chance to give their opinions and at least 75% of the voting members agree. If people disagree, this will be recorded and their reasons briefly described.
- Mandate** - the authority that is given to do something
- Role of Support Workers** - support workers are here to ‘support’ and not participate – unless, specifically requested by the person being supported

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<sup>6</sup> [Glossary | New Zealand Ministry of Justice](#)

<sup>7</sup> [Equity of Voice and why it matters | Kate Frykberg](#)

<sup>8</sup> <https://www.leva.co.nz/about>

<sup>9</sup> [CONSENSUS | meaning in the Cambridge English Dictionary](#)

## **We agree to:**

Base our behaviour on the eight EGL principles

Attempting to present our views in a concise (keeping it brief) and constructive way

Endeavouring to make sure our contribution is relevant and is aligned with the purpose and function of the group. Note; There may be occasions where a contribution is “parked” for discussion at another point

Not interrupt others when they are speaking

.....

## **Way of working – how we will develop a trusting relationship with each other**

The Leadership Group has agreed to work in the following ways:

Treat each other with respect

Listen to each other’s views carefully

Give each other time to speak

Use every day plain language

....

## **Creating a safe environment**

Each meeting will open and close with a karakia and food will be blessed.

There will be an opportunity for people to “check in” at the beginning of each meeting.

A brief “feedback” round will finish each meeting.

There will be opportunities to work in smaller groups of peoples choosing. This enables people to get to know each other more and creates more time for people to express what they believe is important. Typically, ideas agreed in small groups will be shared and “tested” with the wider group.

## **Equity and Leadership**

It is recognised that disabled people and families will lead this process. Different people may need different approaches to feel comfortable and to participate fully

## **Requests from officials**

Officials (and others) will be requested to send papers two weeks in advance (four weeks to maximise input from networks) and to be clear about what actions they want from the group

## **Making decisions**

The decision-makers are the disabled people, families, Mana Whenua, provider representatives and Pasifika representatives. Officials present are encouraged to contribute to discussions.

The aim will be for decisions to be made by consensus. Consensus is described as an agreed position reached by the group or where the group agrees to support a decision in the interests of the whole. Consensus can be linked to the idea of mana kotahitanga (the strength and integrity of unity).

Different approaches to building consensus may be used at different times. ....

### **Meeting Notes**

Notes of the meetings, or any conversations about them, should not record who said what but rather reflect the main themes of contributions, the outcome of the discussion and associated actions.

### **External facilitation**

Meetings of the Leadership Group will be externally facilitated to promote the co-governance approach, to ensure that the views of people with a lived experience lead discussion and to develop consensus. Where there are different views expressed (disagreement) this will be recorded.

### **Links and Networks**

The Leadership Group will form and maintain links with:

The “Core Group” associated with the group they represent

....

### **Terms of engagement**

The Leadership Group will meet .... Members will be advised of the dates of each meeting well in advance.

When participation at meetings is not covered through a person’s employment, there is a schedule of payments for direct costs and an acknowledgement of the person’s time

...

### **Confidentiality**

The Leadership Group will be presented with a range of information and papers on aspects of Enabling Good Lives. Some of this information may be commercially sensitive, or contain personal information about individuals. Group members will need to be mindful of their responsibility to keep information confidential when this is appropriate. Information that is confidential will be clearly identified. Respect for personal information will be a key component of the group’s processes.



Other information can be shared and discussed more widely to gather feedback and ideas. The Leadership Group will need to agree whether information is for sharing or to be kept private.

Members shall at all times comply with the Privacy Act 1993 and the Official Information Act 1982.

### **The group supports the facilitators to:**

Interrupt a person if their contribution is 'too long', not relevant to the current task the group has or has the real potential to disrupt the 'honourable space' of the group.

If a person is interrupted by a facilitator, they may be asked to quickly finish their contribution or to completely stop talking and speak with the facilitator, outside of 'group time', to explore how their views can be considered at an appropriate time and forum

### **If a group member/s have an issue with another group member they agree to:**

Follow a process involving natural justice

Follow the least intrusive approach i.e. the most effective and respectful approach that causes the **least** disruption to the individual and others.

### **Removal of group members**

Core Groups have the ability to replace their representatives on the Leadership Group

### **Decision-making Quorum**

Over 50% of the disabled people and family representatives (i.e. 4 disabled people and 2 family members) + an additional three voting group members i.e. Mana Whenua, Pasifika and Providers

If the stated quorum is not present, then a vote will be taken at the meeting and then facilitators will either seek input, over the next five working days, from absent members via:

a phone poll or,  
email to all members.

### **Attendance of "observers"**

A Core Group may select people to attend the meeting as an 'observer'. The Core Group is responsible for ensuring that this person is oriented to the EGL approach and the Leadership Group ways of working (Terms of Reference) prior to them attending

## Conflicts of interest

Members of the Group or the organisations they are employed by may have existing roles in governance groups or hold contracts for government funded services. Conflicts of interest arise when people's own interests get in the way of their work.

Individual members and the Leadership Group as a whole will need to be mindful of any actual or potential conflict of interest, and raise it at the earliest possible time, first within the Leadership Group. Any actual or potential conflicts of interest will be discussed with those concerned and steps taken to manage them on a case by case basis.

## Expenses and Reimbursement

The Leadership Group members, when people are not in paid roles already where their time is covered by their organisation, will be paid ... per day and pro-rata for half days, for each meeting that they attend.

## 8. Having clear meeting processes

**EGL is about creating positive change. Building safe, inclusive, constructive and action focussed groups and networks is central to the success of EGL leadership development.**

### Key Points

- **Be intentional about what meetings focus on and how things are discussed and decided**
- **Take time to consider all views** (don't rush the process)
- **Focus on positive collective action** (stay aware of the medium and long-term objectives)

The following material has been used as successful guidance when operating EGL-based leadership groups. This guidance includes:

### “Consider the general functions of a meeting

Appreciating the multiple functions of a meeting can assist facilitators to have perspective when prioritising what happens during the meeting. Some functions to consider include:

1. Developing a sense of “collective” identity and strength
2. A space to connect with others
3. A place where members explore, refine and up-date collective (group) knowledge
4. The “creative heart and mind” of the movement

5. A place where ideas are tested, amplified and shaped by discussion and debate
6. A place where individual members can understand how their personal contributions fit with the goals of the wider group
7. An environment where stars are surfaced and rouges are restrained (a place of endorsement and accountability to the whole)

### **Before a meeting**

**a) Determine/clarify the purpose of the meeting**

How will the success of the meeting be determined?

**b) Determine/clarify whether there are specific objectives that need to be prioritised**

**c) Develop an agenda**

This enables people to prepare for what might be discussed.

Note: in an EGL context, the meeting agenda may need to be adapted to the pressing issues for disabled people and families “on the day”

**d) Ensure any preliminary information/papers have been circulated well in advance of the meeting.**

Note 1: in an EGL context, some group members may need to consult with wider networks prior to presenting a perspective at a meeting, so circulating material prior to the meeting is important

Note 2: in some instances, material may be confidential to immediate group members. If this is the situation, these papers need to be clearly marked as confidential to group members

**e) Double check that all of the group members, and those that are part of some people’s reasonable accommodation (meeting assistant, interpreters etc), have the meeting details**

### **During a meeting**

- f) Ensure the meeting follows a clear process
- g) Encourage all to contribute (specific strategies may need to be used to create the space for some people to contribute)
- h) Keep the discussion focused
- i) Encourages different perspectives to be presented

- j) Keep balance between the task (getting something done) and maintenance (how individuals are feeling)
- k) Paraphrase and/or positively reframe contributions
- l) Establish a difference between factual information and people's opinions (both are valuable!)
- m) Encourage the group to come up with options – not single solutions
- n) Monitor whether something is best worked on in 'small groups' or the larger group. If things are discussed in small groups, make sure there is the time for each group to feed back to the wider group
- o) Check that all decisions/actions are understood by all present
- p) Model concise, clear and constructive communication
- q) Conclude the meeting with a summary of progress and acknowledging people's time and expertise

### After a meeting

- r) **Ensure there is a timely and accurate record of key discussions, decisions and actions.**

Note: this might include: when the meeting was, who attended, who is responsible for actions, associated timeframes, how success will be measured and the date and location of the next meeting.

- g) **Check the accuracy of the record of the meeting with participants**<sup>10</sup>

## 9. Having regular checks

### Key Point

- **Embed reflective practice from the beginning** (“how are we going?”, “what is working well?” and “what needs to be changed?” are constant questions)

Part of the successful “try-learn-adjust” process is to constantly be checking to see how things are going. Whether in a Core Group or Leadership Group the EGL approach requires people to be consistently questioning alignment with the EGL principles. This type of reflective practice ‘keeps things on track’ and is the principles-based replacement to rigid rules.

When developing effective EGL-based leadership networks, this process is typically part of every group meeting for the first year or so. When people are EGL fluent, this may reduce to as/when needed or points of significant decision making or monitoring.

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<sup>10</sup> [www.enablinggoodlives.co.nz/resources/facilitator-resources/](http://www.enablinggoodlives.co.nz/resources/facilitator-resources/)

## 9 Ensuring group facilitation is in an EGL context

A clear lesson from the last decade of EGL-based leadership development is that the effectiveness of leadership development relies on the people facilitating EGL leadership groups to have a set of skills that demonstrate EGL!

### Key Point

- **Ensure group facilitators have EGL-aligned facilitation skills** (know what you need in terms of priorities, values and practices in a facilitator)

Simply being an experienced facilitator does not necessarily equip people for this role. The following guidance may be worth considering:

**“Within an EGL context**, there are additional elements for a facilitator to consider.

These include:

- Having a credible understanding of the EGL approach (if it is an EGL aligned process then the facilitator needs to be EGL informed!)
- The deliberate shifting of power so disabled people and families are enabled to lead the process
- Negotiating the inevitable controversy and conflict that occurs when a power balance is changed (i.e. facilitators need a degree of comfort and confidence in managing conflict)
- Ensuring that the information provided is accessible and easy to understand
- Doing more regular “process checks” to make sure the way the group is operating works for all participants (with disabled people being the key informer)
- Breaking things down into achievable steps (from the perspective of the disabled people and families who are participants)
- Shifting authority so that the group takes increasing responsibility for how it operates (this will vary considerably from group to group)
- Demonstrating the EGL principles in action”<sup>11</sup>

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<sup>11</sup> [www.enablinggoodlives.co.nz/resources/facilitator-resources/](http://www.enablinggoodlives.co.nz/resources/facilitator-resources/)

## 3. Perspectives from EGL sites

### Insights

In this section key initial Regional Leadership Network members and evaluators share their experience and views about setting up regional leadership.

#### A. Te Whakamantia te Oranga o Waikato Leadership Group

##### 1. Our Story

##### Tangata Whenua Core Group:

Prior to the emergence of EGL in the Waikato there was a relatively high population of Tangata Whaikaha Māori not engaging with DSS as it took an individualised and medicalised approach to supporting Māori. Whaia Te Ao Marama was housed in MoH and Government Agencies were partnering with Iwi Chairs Forum who doesn't engage with the community. MoH did not have embedded Te Tiriti O Waitangi. There was very little to no voice of Tangata Whaikaha Māori.

With Whaea Tariana Turia blessing both Whānau Ora and EGL initiatives it is recognised that there are parallels between the whānau ora outcomes and the principles of EGL. At the beginning of the formation of the EGLW LG Tangata Whaikaha Māori were present.

It was important the independent facilitator had knowledge and appreciation of whānau ora, Māori perspectives and approaches. It is right for Mana Whenua to be aware of EGL in their area.

##### Disabled Persons Core Group:

- Prior to the emergence of EGL the disabled community was fragmented, siloed into impairment types where disabled people were passive recipients of services.
- Any resource into small pockets of disabled community development was controlled by Providers which meant any community connections was initiated and controlled.

- Conversations were based around what disabled people needed and how they might fit into a service or support.
- We realised it was critically important for disabled people to meet separately from other groups so they could develop their thoughts in a 'safe space' away from people and organisations that usually 'held power' over disabled people.
- EGL principles have underpinned the way we connected and worked together, since a period of rapid growth we've realised this is critically important so that everyone's mana can be upheld and genuine high trust relationships can be developed. Many disabled people are significantly traumatised by interactions with a range of systems that hold power over every detail of their lives. Supporting disabled people through a mindset shift that ultimately enables self-determination, control and choice has taken time, it's really important that we do no harm in the first instance.
- Before The EGL, the Deaf community were struggling and felt their voice have not been heard through the community and Deaf Aotearoa over many years. There were many issues with shortage number of interpreters across NZ, difficult to get equipment through Enable and the Deaf Aotearoa. Many of the Deaf and Deaf with disabilities had their request for equipment declined or did not meet their needs such as studying, the need of help in finding a job. They believed Deaf Aotearoa was controlling them, but not taken their voice or the rights to be heard in the Government, community.
- The number of interpreters has not increased due to one University which is AUT and this made disadvantage for any students wishing to learn the sign language interpreter course because any students have a young family, lives away from Auckland, unable to gain funding/support funding programme etc.
- The lack of advocates around NZ, slowly there has been increasing deaf advocates but they are not on the same level of service e.g. education, health. The Deaf Aotearoa staff failed to take up the action plans in the past.

In Waikato, there were a small number of Deaf people who used EGL funding for their needs and slowly to understand that they have their right to choose whenever they wish to take up studying by paying their own cost to the choice of interpreter, digital equipment for the studying course, around family home. They also choose to stay away from the Deaf Aotearoa as their freedom of making the choices.

I learnt from time to time about EGL Principles and believe these principles with EGL will benefit to the Deaf and Deaf with disabilities in the community away from the Deaf Aotearoa basely their own choice of decision making, not the staff of the Deaf Aotearoa.

Moving to the rural area where my partner and I decided to move away from the city of Hamilton, and I discovered that there were many families of disabled children/ren,

individual disabled living rurally and they had no funding support/struggling to get funding for their needs. I decided to close the gap within urban and rural where there are many disabled individuals around NZ by asking them if they had heard of or know about EGL.

### **Family Core Group:**

The journey began in Waikato, in 2012 or 13, with ODI and MSD talking to families and providers separately about the EGL report, principles and what this can mean for supporting people in the Waikato. The ministries agreed to be flexible around their contracts to allow providers to work with people and their families in a more enabling way. It was noted that the officials had been aware that some creativity was happening under the table, and they now wanted to allow this and identify the barriers. However, despite saying they would be more flexible in how the contracts were delivered, unfortunately they were not. However, some providers and some families became passionate about the principles and continued to support an EGL approach. A small group continued to meet and talk about how to support people better.

Choices was introduced to the Waikato and many families moved their family members from residential to choices. There were presentations about choices and a lot of people became excited and started to understand that a different way of support could mean so much better lives for their sons and daughters and also for the families.

The Christchurch demonstration started and some parents and 'navigators' from this demonstration came and presented the EGL approach, explaining personal budgets and how EGL had made huge impacts on their quality of life. This and the introduction of Choices in Community Living was the beginning of people understanding of what was possible, with system change.

About 2 years after the initial meeting with the ministries about EGL, Mark Benjamin and Gordon Boxall were contracted to work in the Waikato with disabled people, their family and whānau, and providers.

All of this resulted in a number of very passionate families, disabled people and providers in the Waikato wanting to move to the different way. During Mark and Gordon's time in the Waikato the leadership group was established. This was a major step for the families who felt that at last they had a voice and were able to work as an equal with officials and providers to develop an EGL approach. The group of 'core' family members had a real purpose and role. They had the huge task of 'educating' other families about EGL as well as being part of the driving force for change. Connections and partnerships were established between families, disabled people, providers and officials and barriers broke down as we all got to know and understand each other's perspective. The leadership group became a united force that achieved a huge amount before the demonstration and after.

Training was provided through an establishment fund which was integral to building community for families and disabled people. It brought families together and gave



them skills for the 'new' way; topics covered were advocacy, building a vision, knowing what is possible and how to make change.

The leadership group developed the 'plan' – set the priorities. The group involved officials and operated in true partnership. The EGL Principles guided every decision. The group co-developed how and what the demonstration would do. The group and directors operated in partnership and the work was successful. Good and strong facilitation of the leadership group was critical.

It was identified that the personal budgets were the most significant and effective thing which allowed for people to have more control and quality in their lives.

### **Providers Core Group:**

The Waikato region has high levels of community engagement, connection and support. Providers historically developed from these communities and have been really supportive of the pilot. The connection and networks proved invaluable as the journey progressed.

Values driven practice has been a key feature of EGL and one providers truly embrace. The current provider leadership group are made up of organisations that are part of the New Zealand Disability Network with 3 roles that have alternated across providers throughout the pilot, and have covered a range of disabilities, service distinctions and community nuances.

Community of practice initiatives, organisation self-assessments and ensuring the voice of those with disabilities were central to the discussion drove much of our approach. Creating open dialogue about what change can look like, is always a positive pathway.

## **2. Things we did that were really helpful/effective**

### **Tangata Whenua Core Group:**

- We employed a Tuhono Māori who was networked into Māori communities and went into communities to korero about EGL.
- We invested in a local Evaluator who prioritised using equity and Te Tiriti based approaches in carrying out her mahi.
- The LG co designed four action areas including one around targeting Māori.

### **Disabled Persons Core Group:**

- Alongside the emergence of EGL in the Waikato locally coordinated and independently facilitated Forums for disabled people only were organised. The purpose of these Forums was to start building connections, knowledge and confidence with, of and by disabled people.

- The discussions which were led by the independent facilitator in the early stages were themed around disabled people's aspirations, strengths and identity. Guest speakers were invited along e.g. David Corner, a disabled man representing Aotearoa at Inclusion International.
- With the consistency of monthly Forums a sense of common experience, identity, mutuality and comradeship were built and networks developed which were led by, with and as disabled people, leaders naturally emerged.
- Some skills possessed by these leaders include; commitment, perseverance, patience, being bold and brave to initiate and have hard conversations, kindness, empathy, generosity and authenticity.
- The Forums were a catalyst for disabled leadership and the building of disabled identity.
- Glen, People First and his Assistant Nicolina reached out to residential services and day services inviting those with learning disability to the Forums.

### **Family Core Group:**

- Having a common purpose
- Deliberate community building
- Involving the entire area and all of our community
- Having the *right* people in key positions (people who understood the principles and were skilled and determined). LG Facilitator, Directors, Senior connector, and the EGL lead at in Wellington
- Being able to see and experience the huge benefits to people and their families who had personal budgets
- The facilitator's ability to empower the groups and support them and the LG to develop a truly trusting environment, was significant to the development of the Waikato leadership group.

### **Providers Core Group:**

Including providers from the onset was an effective way to begin to talk openly and transparently. We understood the narrative was that providers appeared to be the barrier to the life parties sought, however as discussions progressed and it became clear a range of factors contributed to this.

Providers found it helpful to develop self-assessments, develop training and challenge each other to apply a critical eye to service approaches. Community of practice initiatives sought to create space for reflection and ensure the voice of those

central to the journey were not lost. It was quite clear that providers want to be part of future solutions, look to apply these and continue to apply values driven practice.

### **3. Challenges we faced and what we did**

#### **Disabled Persons Core Group:**

- Disabled people calling out and initiating the inherent power imbalance which was present in the room of 3 Providers, 3 family members and 3 disabled people. At these meetings Providers were interested in how EGL being present would affect their Contracts and disabled people were trying to get a voice and to engage and participate with the resources they had. The conversation on equity vs equality while uncomfortable was necessary and resulted in having more disabled people around the table than the other groups i.e. families and Providers. The independent facilitator enabled this conversation by ensuring the voice of the disabled people around the table were heard and respected.
- A Provider who tried to enter the meeting who was not meant to was ejected by the independent facilitator and this added to the building of a respectful group working relationship.
- It was difficult for disabled people to have the energy to keep momentum going as many of us had day jobs, many had health issues and so there were challenges. It has become easier with the emergence of My Life My Voice so we now have disabled people working in the community development space growing capacity and capability alongside the core group.

#### **Family Core Group:**

- Maintaining a strong core group when families were burnt out.
- After what for many had been traumatic experiences in the old system, once settled on EGL they were busy getting on with it and did not have the time to support the ongoing work of the core group.
- Doing everything as a volunteer was challenging and we would have benefitted from more and better administration support

#### **Providers Core Group:**

- As with any pilot and groups it was hard to know our place in things, creating space to talk and to truly hear are the corner stone of any effective approach one which took some time to get to.
- It was quite clear we had different perspectives on similar issues, developing our collective understanding that looked at collective solutions was a really

valuable pathway. We also acknowledge we do not all have to agree to have shared understanding.

#### **4. Insights we gathered on the journey**

##### **Tangata Whenua Core Group:**

- Prioritise and strategise on engaging Māori early on.
- Use Te Tiriti approaches to engage with Māori and as an underpinning for the identity of the location.

##### **Disabled Persons Core Group:**

- Having a skilled independent facilitator is important to ensure disabled peoples voices are heard and respected.
- Resource is an important component to building disabled communities, capacity and capability. E.g. investment in local coordination and facilitation lead by disabled people.
- The conversation around equity vs equality is a good illustration of how the power shift and shift in authority can be achieved.
- Purposefulness, intentionality and proactivity are essential components in building good group dynamic, trusting respectful relationships and for influencing others.

##### **Family Core Group:**

- Always refer to and operate according to the EGL principles
- People and relationships matter
- Need to bring people along with you
- Trust and respect is key
- Consensus decision making – we have never had a ‘vote’ on anything – always discussed until agreement reached with all groups represented on the LG

##### **Providers Core Group:**

- All parties want to contribute to a better future
- Systemic change requires a mental shift

- We are part of human experience not one person has the answer
- The Waikato Regional approach has strong values approach.

## **5. Suggestions regarding how EGL-based leadership groups can be set up (what we believe are the most important things to do)**

### **Tangata Whenua Core Group:**

- Prioritise having at least one Tangatawhaikaha Māori on the group who is supported.

### **Disabled Persons Core Group:**

- Having an independent facilitator who is grounded in the EGL approach, vision and principles and who has an equity knowledge can ensure all voices and perspectives around the table are heard and respected, especially the disabled perspective as in Aotearoa it is not always a usual and normalised thing for disabled people to have a voice and make decisions for ourselves.
- Disabled community development to have an independent facilitation in the early days while emergent leads are identified and coordination happens by disabled people and is local.
- It is best to keep the communication open, confident and to support each EGL region before roll out.
- For the national roll out – there is the main concern of not enough interpreters across NZ to cover one area for example Waikato - 400 Deaf people to 5-6 interpreters (living in Waikato), often use outside Waikato to travel up to Waikato from BOP. We need to increase from one University - AUT where there is a course for sign language interpreters to across NZ e.g. University of Waikato, Massey, Victoria and Canterbury University etc. other area like New Plymouth, Nelson, West Coast of the South Island - no interpreters living there.

### **Family Core Group:**

- Build community
- Identify leaders – disabled persons and families
- Get providers on board
- Need to allow time for the group to develop
- Start small and grow

- Encourage the development of small businesses to support people managing their budgets and services

#### **Providers Core Group:**

- Take time to identify those there already don't presume the loudest voice is the only voice.
- Ensure support and resources are in place, including support networks and access to technology.
- Take time to develop a collective approach unpack what that may mean and how that may impact those communities.

### **6. Suggestions regarding how to keep a leadership group working well**

#### **Tangata Whenua Core Group:**

- Ensure Tangata Whenua/ Mana Whenua are always at the table being part of the decision making process.
- Endeavour to have more than one Tangata Whenua around the table so they can support one another.
- We have an education/knowledge/Tikanga Māori piece our meetings which are led by the Tangata Whenua around the table for 15 minute presentation on anything which is of significance to the Māori world. This is really important as it helps to add to the identity of the group and engages others and develops confidence.

#### **Disabled Persons Core Group:**

- Disabled leadership group members meet before the LG meetings to identify key messaging and to ensure disabled group members agree to the key messaging and having a clear purpose.
- Independent facilitation remains effective in prioritising the voices and perspectives of disabled people around the table because this helps to ensure the necessary power shifts for the EGL approach to be an effective mechanism for change.
- The collective local identity continues to be at the forefront for the group.

#### **Family Core Group:**

- Strong facilitation

- Principles lead
- Orientation for new people and continuing to build trust and respect
- Continuing to 'lead' as a group
- Having a shared, clear purpose
- Collaborative decision making
- Being able to see peoples' lives change for the better

**Providers Core Group:**

- Important there is a real commitment to the journey not the end destinations, this means ongoing face to face meetings with a focus on tangible outcomes.
- Leadership groups can call on some of the previous learnings, reach out and talk with those who have been involve in the projects.
- Share resources and talents across groups.
- Take time to Whānaungatanga and connect, we cannot presume we know where each person is in their journey, that connection could be what drives things forward.

## B. MidCentral

A perspective from a facilitator

### 1. Our Story

We had many enthusiastic people in our community who wanted to participate and have say over their own lives. It was crucial to establish relationships and trust with the community.

Some people in the early Leadership Team lacked a clear understanding of leadership. It would have been helpful to have some capacity building before leaders were selected by the community (Core Groups).

It took approximately two years to reach a common understanding of community leadership among the majority of the leadership group. We also required a space where people could share their stories and trauma.

Mana of people to be respected in their roles. Sometimes there were conflicts when people made negative remarks about other stakeholders. That was challenging. We had to constantly evolve and adjust to the community's needs. Some people or groups were reluctant to work collaboratively, and sometimes they exhibited destructive behaviour and personal attacks. This was challenging as a facilitator. In retrospect, we needed to ensure the community members/groups felt safe, were equipped with the skills of how to work co-operatively and reference everything back to the EGL principles (behaviours and practices).

We, as facilitators, aimed to transfer the authority to the community and not lead. We also aimed to ensure equal voice was heard and shared in a safe space.

### 2. Things we did that were really helpful/effective

**What we did:** Core groups that ran their own processes and legitimately spoke for their stakeholder group. Groups had the ability to swap people if others could not attend.

Leaders fed into draft policy and documents that helped to shape decision making.

**How this happened:** Core groups formed themselves (with facilitation at the start). Core Groups developed and owned their processes.

Created opportunities at the Leadership Group meetings for co-development with willing partners at Whaikaha



**Why we did this:** For the community to experience having authority to do what they wanted

Community leaders saw their influence by seeing Whaikaha make changes and there was transparency of feedback

### **3. Challenges we faced and what we did**

The challenge: Losing contact with Whaikaha – no clear messaging

What we did: Sent emails with no response back

The outcome: Deflated RLG – what was the point – if they cannot get change.

Next step: Keep on going until we were successful

### **4. Insights we gathered on the journey**

- Ensure Community has the say so
- Build communities to lead – resource them
- Officials have limited ability to make change – the community has opportunities to gain traction, unity and revolutionize the future for themselves and generations to come.

### **5. Suggestions regarding how EGL-based leadership groups can be set up (what we believe are the most important things to do)**

- Understand concepts and ideas and make shared decisions
- Learn from others who have been through this
- Your community , your way
- Engage with Mana Whenua first

### **6. Suggestions regarding how to keep a leadership group working well**

- Find resource and support momentum
- Engagement with the system to experience real change

- Develop mechanisms for the community and allow people to drive what they want
- Focused meetings with outcomes. (don't talk for talks sake)

## C. Extracts from an independent evaluation in the Waikato

### The early days of the EGL Waikato Leadership Group via extracts from the Summary Evaluation Report | Phase One Enabling Good Lives Waikato Demonstration

Prepared by Louise Were, Local Evaluator February 2016

[www.enablinggoodlives.co.nz/assets/Uploads/Evaluation-Phase-One.pdf](http://www.enablinggoodlives.co.nz/assets/Uploads/Evaluation-Phase-One.pdf)

“July 2013 saw the establishment of the Waikato Leadership Group. Representatives from three forums, one each for disabled people, families and providers, provided the local capacity and leadership, supported by an investment from the Government’s 2013 budget.

The aim of the Waikato Leadership Group was to build the skills and confidence of disabled people and families in the Waikato and strengthen local networks and leadership, through creating resources and sharing information via face-to-face meetings.

The purpose of the Waikato Leadership Group is to:

- a. Ensure disabled people, families and whānau, and providers of disability supports are engaged in an Enabling Good Lives approach in the Waikato
- b. Be ‘champions for change’ and to ensure momentum with the introduction of an Enabling Good Lives approach in the Waikato
- c. Promote and protect the Enabling Good Lives principles and approaches in the Waikato. (Waikato Leadership Group meetings, September 2014)

Process and operational decisions stay within the Leadership Group, with every effort taken to develop trusting relationships through their agreed way of working:

- a. Treat each other with respect
- b. Listen to each others’ views carefully
- c. Give each other time to speak
- d. Use plain language
- e. Ask if something needs to be explained.

The Leadership Group has also had the support of an independent and experienced facilitator. This role has supported the creation of an environment that is trusting, voices are heard, and in particular has strengthened the voice of disabled people.

The Waikato Leadership Group is grounded by the vision and principles of the Approach. This is evident in the representation on the Leadership Group, their desire to constantly be driven by the aspirations of disabled people, families and whānau,

and to ensure the potential for system change is realised at individual, community, local, regional and national levels.

The strength of leadership from all representatives and their commitment and constant critical review of their operation against their agreed way of working and the EGL principles has in turn grounded the Demonstration.

The relationship between the Leadership Group and the Ministries is transparent and built on respect and commitment to the EGL principles. This is not to say that misunderstanding or apprehension has not arisen. However through positive, open dialogue, building on a trusting relationship, it is felt that the Leadership Group and Ministries are reaching shared ground.

It has been observed how the Ministries have honoured the co-design process and together, it is felt that the right people, right processes, right power sharing situation is occurring.

The Waikato Leadership Group has maintained strong connections with the forums for disabled people, families and the provider community of practice. These forums have been a source of leadership capacity and a recognised mechanism for mutual, reciprocal communication.

People who attend the Family Forums are able to access information regularly, connect directly to the Demonstration to enable participation. For the Leadership Group, this provides a direct link to disabled people, families, whānau and providers.

As discussed earlier, the Māori Co-Design group has been established to ensure Māori are engaged and lead the development of pathways that are responsive for Māori as Māori, despite happening later in the Demonstration.

The Leadership Group have also demonstrated leadership and oversight of the evaluation and reinforced the importance of being principles-based and locally developed, as a reflection of their self-determination.

The independent facilitation of the Leadership Group and support provided by assistants ensures the abilities and voice of disabled peoples are heard and drawn on

The commitment to being disabled-person led meant everything was accessible. For example:

- i. all documents are accessible (easy to view, read, and understand)
- ii. unique assistance is provided to disabled Leadership group members to ensure their voices are heard.”

## D. Lessons extracted from a section in the EGL Christchurch Demonstration Phase Two Evaluation, 2015

Authors: Diane Anderson (Ministry of Social Development), Rowanne Janes (Ministry of Health) and Paula Pope (Ministry of Education)

[www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives/#Phase2evaluations](http://www.odi.govt.nz/nz-disability-strategy/other-initiatives/enabling-good-lives/#Phase2evaluations)

Note: LAG = Local Advisory Group (this is the term later imposed on the EGL Regional Leadership Group)

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

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

The LAG reported that in the initial stages the paperwork<sup>12</sup> described them as a governance group but that the documentation changed and they were referred to as an advisory group to provide advice to the Demonstration Director. The Terms of Reference for the LAG explicitly said that the LAG was not a decision-making group. Nevertheless the LAG expected to be involved as equal partners in decision-making about the shape of EGL and as result, they were frustrated by:

- *their lack of power to make decisions.* The LAG reported that being only an advisory group limited the effectiveness of their input as officials could choose whether or not to listen to their advice
- *what they perceived as selective engagement by the Ministries:* There was a perception that the Ministries consulted with the LAG when it was beneficial to do so but avoided consultation when it was not
- *decisions affecting the Demonstration being made by agencies without consultation with the LAG:* The LAG reported that decision-making was not shared. They reported that as the conversations became perhaps more difficult, they started to be left out of decision-making and were just being told what to do
- *officials not understanding how to interact meaningfully with the LAG:* For example, officials set up 12 work streams to progress the Demonstration. For the LAG there was an overwhelming amount of paperwork associated with the work streams that they were expected to read and comment on within days of

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<sup>12</sup> See Ministerial Committee agreement to vision and principles for long-term change – September 2012  
<http://www.enablinggoodlives.co.nz/about-egl/enabling-good-lives-context/long-term-change-september-2012/>

decisions being made. As one LAG member reported, *“really, with all the will in the world, with our day jobs, we haven’t got time to go over that paperwork”*. They would have preferred officials to develop options – having worked out what they can give and take on – and given them sufficient time to provide feedback.

***National EGL Leadership Group had limited ability to exercise leadership***

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

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

## **E. Some selected text extracted from the unpublished draft “Preliminary Leadership Insights report – Leadership, governance, and management structure for System Transformation”, commissioned in 2020/21**

Author: Gail Munro

### **“Leadership Development and voice mechanisms**

Community development and adequate timeframes for identifying and meeting with communities were essential. Core groups, their membership and processes were an integral part of the EGL model. Regional Leadership Groups are formed through Core Group mandates, and their focus and style of participation and decision-making is anchored through Terms of References. Independent facilitators are integral to Regional Leadership Group meeting processes as are the relationships with the EGL directors. Membership continuity and renewal is an area for development alongside succession planning. Providers occupy a space at meetings which can be challenging although many report of the positive benefits that have accrued through their membership.

### **Core Groups**

- i. The EGL model established in the three sites is deliberately anchored by the Core Groups in the regional communities they were founded in. The strategy is to have networks of disabled people, whānau and providers connected to and communicating with Core Groups and through them to Regional Leadership Groups. Each site has in common three Core Groups: Disabled Persons Core Group, Whānau and Families Core Group, and Providers Core Group. Additionally, MidCentral Region has a Young Adult and Youth Group (YAAY), a Deaf Group, and a Pasefika group whilst Waikato has a Māori Caucus. The voices of all disabled people are honoured and encouraged.
- ii. The Disabled Persons Core Groups’ membership are based on disability representation and not impairment representation.
- iii. Membership of a Disabled Persons Core Group and Whānau/Family/Aiga Core Group is not conditional on individual or family involvement with EGL. This approach to an open membership aims to develop a wide network of local and regional communities to increase awareness of an EGL approach and service and to provide avenues for communication. Some people argued that the nets weren’t cast wide enough when holding the meetings that preceded the establishment of Core Groups and Regional Leadership Groups. This will need to be considered in the roll out of EGL.
- iv. An important aspect of creating space for voices to be heard are the regular Core Group meetings when people check in with each other, discuss their

Core Group activities and plans, and prepare for the Regional Leadership Group meeting. Whakawhānaungatanga and mihi reflect the kawa of EGL and the importance of welcoming new members to a supportive space.

- v. The Core Groups provide a meeting space for cultivating leadership through the development of an emergent set of people who are promoting a common vision, aligning EGL principles with actions, and are continually building and sharing power. The MidCentral Region provides a good example of this with the creation of, and support for, the Young Adult and Youth Group.

## Regional Leadership Groups

- i. Regional Leadership Groups are formed through Core Group mandates which legitimise voice and representation and facilitate the potential of local networks to represent diverse views and perspectives. They each have a Terms of Reference outlining their membership composition and providing details of the Core Group mandates for representation.
- ii. The role of the independent facilitator
  - Each site has an independent facilitator who facilitates the Regional Leadership Group meetings. The role is said to have an important function to ensure disabled people have equitable voice / priority voice in discussion and decision-making.
  - Independent facilitator or community development facilitator or both?

*According to one facilitator 'Facilitation is about a shift in power and that's uncomfortable. So having someone who can be a guardian of the process helps keep it safer. There's some skill in enabling and holding open the space for that shift in power while keeping the providers and government agencies for example involved, recognising, and acknowledging their roles, whilst making sure it's the Core Groups of disabled people, families and tangata whenua who have the power'. Bev Gatenby, Waikato independent facilitator interview, 2021*

- The facilitators themselves suggest their role is to contribute to the development of capacity within the Groups and is not solely running a meeting. The independent facilitator needs to understand and address the opportunities and the resourcing that disabled people need to be able to engage effectively. Part of this is to make sure the right supports are around the table e.g., People First Assistants, Sign Language Interpreters, and documents in an accessible format.

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- iii. The TORs for each of the three Regional Leadership Groups outline a decision-making process that prioritises the voice of disabled people, then whānau and families, followed by providers. This is consistent with EGL



principles that recognise organisational power and voice must be authorised by those impacted by the organisations work.

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### Similarities

- The three sites follow the same model of Core Groups and a Regional Leadership Group and are careful to prioritise the voices of disabled people at their meetings.
  - They all use an independent facilitator for the Regional Leadership Group meetings.
- .....

### Community Development

The model has the following order, and the recommended time frame is two years before an EGL service is opened for disabled people and whānau.

- i. Initially there is preliminary work needed in communities. People report that it takes a lot to move from a focus on trauma and having no control over services received. It has been likened to Maslow's Hierarchy of Needs in that once basic needs have been met, there is then room to move onto conversations about systems transformation, disability identity and resourcing people so they can get what they need.
- ii. Community development strategies follow the preliminary work as people learn about EGL, disability identity and how they can participate and be heard through Core Groups and Regional Leadership Groups.
- iii. Capacity and capability building. This has a focus on creating the Core Groups and the Regional Leadership Groups and developing an understanding of how they will operate and the skills to do so.
- iv. Design and co-design of sites and agreeing priorities for EGL operations to roll out.

### 12.4 Networking

Opportunities for nationwide networking need to be explored. People from all three sites talked of the potential value that could accrue from meeting together for sharing and collaborating. The significant changes proposed for the Disability Sector make it imperative that local and regional voices are amplified, and leadership of disabled people and whānau are centred and prominent as progress occurs. It will be crucial for disabled people and whānau across the three sites to meet as a group to discuss developments with the opportunity to contribute insights.

### 12.5 Independent Facilitators.

There is generally support for the independent facilitator positions and recognition that the role they have in facilitating meetings in ways that

prioritise disabled people is an essential part of the model. The model could be developed so that there was shared facilitation with a Regional Leadership Group member. Whilst this has the value of building leadership and facilitation skills it is not easy to manage shared facilitation, and the facilitator would in effect become a trainer as well. It would have the benefit of ensuring the independent facilitator lives in the region.

- 12.6 The EGL model has been able to successfully embed and amplify the voices of disabled people and whānau / families supported by the skilled facilitation of independent facilitators. There is room however to develop equitable and inclusive practices so Māori, and Pasefika and other ethnic groups don't have to adapt to a dominant Pakeha cultural framework. The dominant cultural framework may have been adopted because Pakeha have been numerically in the majority. Terms of Reference need to be developed in ways that are inclusive to Māori, and Pasefika and other ethnic groups values and processes.
- 12.7 Relationship between Director and Regional Leadership Group is valuable and needs to be recognised as a key component of the EGL model.”