THE ENABLING GOOD LIVES (EGL) SELF-REVIEW GUIDEBOOK

Four options for conducting a self-review process



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What is the Enabling Good Lives Self-Review Guidebook

The Self-Review Guidebook is designed to assist networks and organisations to review how well they deliver on Enabling Good Lives (EGL) Principles. The EGL Principles are a set of principles devised by disabled people, their families and whānau. The "principles" are statements that form the foundation of how disabled people, their families and whānau want to experience their interactions with others – including supports and services.

The material, contained in this resource, will be of value to networks and organisations wanting to go through a change process to be more fully aligned with an Enabling Good Lives (EGL) approach.

Characteristics that are key to successful transformation include:

- Bravery
- · Clarity of destination
- Dedication
- Reflection
- Flexibility
- Honesty.

A self-review process helps everyone reflect on their experiences and assists everyone to get a clear direction for the future (clarity of destination).

Many disabled people, families and whānau are looking for supports that explore how they can:

- be principles based, ie, EGL Principles
- individualise their supports and services
- shift authority to enable individuals and families to have the "say so" in their lives
- move to a "facilitation based" approach, ie, how to make it easier for people to create good lives for themselves – not attempting to provide people with what they consider to be a "good life"
- use generic or universal (mainstream) community resources
- focus on assisting people to experience ordinary lives in ordinary places (rather than segregated services).

Before support networks/service organisations can allocate resources, equip staff with the relevant skills or develop a strategic plan for change, it is desirable that they gain a deeper genuine understanding of the people they serve.

A prerequisite for an EGL based change is that time is invested in knowing:

- what are people's current experiences
- what connections people have
- how people like (need) to communicate

- people's preferences and strengths
- · what aspirations (dreams) individuals and families have.

Understanding the present to inform positive change

A first step in the change process is knowing what is happening now.

On a journey of change, it can be useful to gain an increased understanding of people's experiences at a point in time. Self-review is one way for this to happen.

There are multiple approaches to undertaking a review process.

Ideally, as a first step towards positive change, a self-review will enable everyone to:

- understand what is working well for different groups who connect with the supports or services
- explore challenges different individuals (or groups) may be facing
- gather together perspectives on what people consider to be "ideal" (great, amazing)
- reflect on perceived strengths and areas for development
- collate ideas and strategies for positive change
- establish a "baseline"
- contribute to the development of a "vision".

Recognising the impact the past has had on some people is critical

Some disabled people, families and whānau have not had good experiences in the past. This can mean people:

- are fearful of expressing what they really think and feel, ie, they are concerned that talking about something that is not working well may result in them being punished
- do not trust, ie, some people may not feel safe and they will say what they think you want them to say
- may have reduced what they think is acceptable, ie, typical life expectations may have been minimised to the point where people are happy about things that the general population may find unacceptable
- are carrying trauma from previous experiences that they need/want to be acknowledged or healed before they believe they can get on with their lives today, ie, people may want to "off-load" things that belong to another time in their life before they express what they think about their experiences today
- o do not have the language to express/communicate what they are thinking
- o require a range of ways to communicate in a way that others can understand.

Some of the ways you can increase the chance that people will feel OK about fully contributing to the self-review might include:

• having peer interviewers/ facilitators

- having group sessions where peer "activists", "outliers", "outspoken people" demonstrate how to talk openly about what is working well for them and what they would like changed
- structure sessions (interviews, group discussion, hui) in a way that tangible examples of what "bad" looks like and what "OK" looks like and what "great" looks like before asking people what they are thinking/feeling/experiencing
- making space for people to "heal" or express previous experiences before wanting to know what they are experiencing now
- clearly expressing that now is the time to be brave (and that you will make sure people are OK and safe to say what they really think)
- assisting people to positively "reframe" what they are expressing, eg, some people can say what they don't want or don't like – but need support to explore what "good" might look like.

Effective self-review

An effective self-review process will:

- a) be proactive, ie, it will constructively address emerging issues before they mature into significant challenges
- b) provide leadership opportunities, ie, people with a lived experience of disability will gather the insights, skills, experiences and evidence to enhance their involvement in peer support and other leadership roles
- c) enable the gathering of information to form a solid evidence base for further innovation
- d) identify particular approaches/strategies that appear to 'work well' for individuals and families, ie, collating real time success stories to inform others
- e) explore the degree to which core values, principles and aspirations are being met.

The EGL Organisational Self-Review will provide an environment where individuals, families, support people and others can express their experiences. It examines the effectiveness of approaches, and it values flexible and creative responses to individual preference and aspiration.

Two things that often determine the depth and breadth of responses to these questions involve: 'who is asking' and 'how the questions are asked'. A successful self-review approach must have certain ways of doing things that maximise:

- Trust, eg, that information will be treated in a respectful manner or that differences will not be judged or exploited.
- Safety, eg, that contributors will not have negative consequences by talking about what is not working well for them at the moment.
- Confidence, eg, the process is designed to ensure an equitable and accurate representation of participants' perspectives.

Key principles and practices

There are a number of key principles and practices that help create an environment more likely to result in a successful self-review.

These are summarised as follows:

- ensuring the self-review approach is built on the foundation of clear principles, eg, full participation of disabled people and families in key roles
- clarity of intent, ie, assisting development, not compliance
- awareness that an important aspect of self-review is to prepare an environment that is likely to result in some people discovering new (and hopefully better) ways of doing things
- an appropriate outcome-based framework
- breaking the process into smaller achievable steps/ideas
- flexible, fair, constructive and inclusive approaches
- approaches that are culturally appropriate.

How a Self-Review works

A successful way of doing a self-review is to ensure a relaxed, personal and informal environment.

Discussions and conversations replace interviews, and participants are invited (not expected) to engage. As discussions progress, the art of a good self-review is to be clear about people's current experiences and opinions, and to bring to the surface new ideas.

An effective self-review enables individuals and supports to:

- pay attention
- take responsibility to seek new knowledge
- commit to change
- discover allies
- share power and authority
- o build trusting relationships.

Overview of Enabling Good Lives (EGL) and "self-review" process

'Enabling Good Lives' (EGL) is a shift to ensure disabled people experience greater choice and control over their lives and supports.

Central to EGL is the shifting of authority so disabled people and their families and whānau have the 'say so'.

EGL is based on a set of principles that guide development. A basis of the EGL approach is that services and supports are tailored to reflect individual strength, preference and aspiration. In this way, EGL will take different forms – person by person, family by family and community by community.

Ideally, disabled people, their families and supports are partners in the process of designing, implementing and monitoring the EGL approach. An objective of the EGL approach is to have clear, principles-based reference points that ensure providers are able to map their current strengths and ways to move towards a full EGL approach. This will take time.

The "EGL Self-Review Tools" will:

- assist disabled people and whānau/family to become clearer about how well supports and services are working for them and improvements that can be made
- help all people by providing a shared frame of reference
- assist supports and services to identify their strengths and areas they can develop further
- enable others to get a sense of how well supports and services are working

- be a basis for how best to invest in staff development and in measuring change
- be one way supports and services are accountable to disabled people and families
- be a contribution to monitoring and external evaluation.

The Enabling Good Lives (EGL) based self-review process will enable everyone (disabled people, family, whānau and supports) to identify areas of current strength and areas for development.

A 'self-review' is intended to create insight and enable everyone to map a pathway forward. It can link people to guidelines that will assist development.

The EGL based self review is intended as one way to:

- enable disabled persons, families and support staff to contribute to service development
- determine areas of current strength
- gather the experiences and perspectives of individuals related to how they believe the service is contributing to them creating a good life for themselves
- identify 'next steps' for development
- be a framework for organisations to prioritise actions that are intended to assist them to become more fully aligned with an EGL based approach
- assist organisations to identify what "guidelines"/resources will be of most value
- enable the measurement of "change over time", according to an outcomes approach, directly related to the EGL approach.

There can be a partnership between self-review and other external points of reference. These coupled with good self-review help inform practice and lead to the development of positive action plans (see the flow diagram below).



The importance of a development focus

There two basic approaches to review or evaluation:

- 1. Compliance
- 2. Development.

The EGL based self-review is part of a "development" approach.

Comparison of approaches

	Compliance Approach	Developmental Approach
Purpose	Promote safe provision	Promote excellence and innovation
	Enable the establishment of consistent and reasonable standards	Enable individuals and whānau to improve their quality of life (QoL)
	Encourage providers to take responsibility for providing those services to the public safely	Encourages everyone to work together to create positive change and assists providers to establish model coherency, ie, ensure principles, processes, procedures and practices align

	Encourage providers to continuously improve	Encourage the continual development of relevant and effective supports based on a partnership approach
Key Concepts	Safety, responsibility and improvement – according to consistent and reasonable standards	Excellence, innovation, quality of life, individual outcomes, effectiveness and partnership
Main relationship	The funder and the service provider	Disabled people, whānau and support systems
How is information mostly gathered	Examining procedures and interviewing key staff	Gathering the perspectives of disabled people, whānau and direct support workers
Main objective	Safety and consistency	Working together to make positive change over time
Main frame of reference	Legislation and contracts	People's experiences – what is working well and what needs to be improved
How does it usually happen	Funders require services to participate	Disabled people, whānau and supports want to work together to build a better experience for everyone
What happens as a result	Providers may be required to make changes	There is a shared frame of reference for short, medium and long-term change

How the Self-Review was initially developed

There were three initial frames of reference for this document:

- 1. The Enabling Good Lives Principles, components, elements and vision (outcomes) statements
- 2. The SAMS "Framework for Evaluation of Services An Outcomes Focus (2011)" Note: this framework was developed in partnership with disabled persons, families and service providers.
- 3. "Progress for Providers: Checking your progress in delivering personalised support for people living at home (December 2012)", published by HSA Press and sponsored by Mears Care Limited and UKHCA (United Kingdom Homecare Association).

The primary contributors to the initial document were:

- The EGL Waikato Leadership Group, ie, disabled people, families, Mana Whenua and service provider representatives
- A Disabled Persons Forum in the Waikato facilitated by People First New Zealand
- A Family Members Forum in the Waikato associated with EGL
- Community Connections (Wellington/Kapiti), Community Care (Dunedin), Enrich+ (Te Awamutu) and Interactionz (Hamilton) undertook a trial of the documents and process in November 2013. Feedback received from these providers assisted in compiling a final draft.
- Various experienced SAMS evaluators.

How the revised EGL Self-Review (2021) was developed

The EGL Waikato Leadership Group contracted SAMS to work collaboratively to review and refine the initial Organisational Self-Review. A 'working group' of disabled people, families, Mana Whenua and providers, drawn from the EGL Waikato Leadership Group, worked with key SAMS people to undertake this work. A range of service providers, from around New Zealand, were invited to contribute their thoughts about how the self-review process could be more effective.

Enabling Good Lives based Self-Review (2021)

The Enabling Good Lives (EGL) approach is based on eight principles. Key to these principles is the idea of increasing people's choice and control.

Self-determination, building relationships and enhancing people's mana are all foundations to the approach. This resource provides options for how the self-review can happen. Some of the options have indicators or questions that are already developed and can just be implemented. Some of the options involve people in the network or organisation building their own set of indicators using the EGL Principles as a foundation.

All insights are good – but constructive action is the goal

The value of any review or evaluation is that it paints a picture. A self-review can make sense of what is happening now and can provide insights that assist our:

- understanding about what is happening now. It can enable us to see the different views on the same thing
- appreciation of what is working well (a basis for celebration and a foundation for possible development)
- consideration of what needs to be worked on more (ie, ideas and practices that need to be changed or developed)
- building connections and channels of communication
- focussing on what different people/groups think is most important
- ability to measure where things are up to. When we repeat the process, we can see what has really changed
- being better informed so we can be more strategic about where we put our energy
- being creative and innovative.

Different approaches to review and evaluation have different benefits.

In this situation, it is most important that both the framework for the review, and the way that the review or evaluation is done, is based on the EGL Principles.

While insight and increased information is useful, a self-review is only as good as the affirmation or informed positive action (development) it brings about.

Difference between self-review and external evaluation

Both approaches are useful. However, they are not the same thing and offer different advantages. A self-review is conducted by people directly associated with the network, support system or organisation. An external evaluation, by definition, is typically conducted by people not directly involved.

Some organisations have contracted in external people to conduct a self-review. This may confuse the process – unless the external contractor is simply assisting the network/organisation to understand how to best do their own self-review.

Some potential advantages with self-review:

- build new channels of communication within the network organisation
- establish a shared reference point within a network/organisation
- everyone can develop some new skills
- people are sensitised to the key issues that are going on for people
- there may be more "ownership" of the results which means more action is possible
- it may encourage people to be more open with each other on a day to day basis
- everyone is 'stretched' in their thinking (personal and professional development).

Some potential advantages with external evaluation:

- the evaluators may have more expertise in how to set the process up and make sense of the information that is gathered
- the evaluators may have more expertise with in-depth interviewing. This
 may provide richer or deeper information
- some people feel 'safer' talking with an 'outsider'
- the evaluators may have more experience with how to use the information to best understand what is happening and how these insights can be used to develop the network/organisation.

How accurate do you want to be with the "self-review"

The following things may determine how accurate the information you get is:

- How many people you listen to (interview) or complete a questionnaire?
- How you choose who takes part?
- How you ask the questions?
- Who asks the questions?

The more people who can provide information, in a way that is safe and accessible, the more likely you are to get an accurate picture of how things are going.

If your network/organisation is small enough, everyone might be able to contribute to the self-review. This could be done with individual discussions, people self-completing questionnaires or in small groups. In a larger network/organisation, it may be too costly or time consuming for everyone to contribute. In this situation, it may be good to use a "sample" group.

This Guidebook for Self-Review offers four ways you can paint a picture of what is happening for all of the people involved in a network or organisation. This helps everyone think about their own experience and also consider how other people see

and experience things. This approach helps all of the people involved by increasing their understanding and making it easier to celebrate what is working well and decide what can be developed further. If you go through a process like this, you can also repeat it in one or two years and see what has changed over time.

These four different approaches provide networks and organisations with choices and frameworks to undertake a self-review. Each situation will be different. Some approaches might be more relevant in some situations.

The four options

Option 1: A continuums approach

This involves the network or organisation implementing the provided material (page)

This may be best suited to smaller to medium sized networks or organisation.

Option 2: Self-complete questionnaires

This involves the network or organisation implementing the provided material (page)

This may be best suited to medium to large organisations and situations where people prefer clear guidance and you want specific information.

Option 3: Developing continuums

This involves the network or organisation taking the suggested framework and building their own "indicators". Indicators are simply 'clues' to whether something is happening.

This may be best suited to networks or organisations that want to use this process to be a catalyst for focussed discussion and exploration.

A value of this approach is that it helps people think about what is important to them and what each principle could look like in practice. Thinking about how to develop the "indicators" for the framework can help build 'evaluative thinking' into the network or organisation.

It can be really useful for each part of the whole network to work on their part of the framework separately, ie, disabled people, families and support people all look at it from their own perspective.

Option 4: Developing graduated indicators

This is similar to developing continuums. It involves the network or organisation taking the suggested framework and building a series of 'indicators' that describe how different people would see these principles come to life in their direct experience. In following the process described (page...), networks and

organisations would also have a clear framework to measure progress from different points of view.

This may be best suited to networks and organisations who choose to use this process as a way not just gather information – but as a framework for on-going monitoring of change.

How to use this resource

This document provides more than just a set of surveys and continuums. These are tools to help you understand how things are going, but the real message is what people have to say.

All views need to be treated as valid whether they come from disabled people, families, whānau, support workers or managers. Some views may seem to be outliers that do not seem to fit the trend, but these may have content others had not considered. Sometimes the problem with collating statistics is real experiences get turned into numbers that may be misinterpreted, or worse reinterpreted. It is important to listen to the narrative (what people say) as well.

There are a number of avenues to guide your self-review. These may include self-completed surveys, assisted surveys, interviews and meetings/hui, and more likely, a combination of these methods.

For collating the results, we suggest using continuums for each EGL Principle (provided in this document) but including in each written explanation to explain how conclusions were reached.

This document includes:

- the EGL continuums for self-review (resource for option 1)
- a survey for disabled people (resource for option 2)
- a survey for family, whānau and advocates (resource for option 2)
- a survey for support workers and managers (resource for option 2)
- an organisational survey (resource for option 2)
- a guide for developing your own continuums (resource for option 3)
- a guide for developing your own graduated indicators (resource for option 4).

Choosing a method that best fits your network or organisation

This self-review resource is designed for both large and small organisations or groups. Small organisations, eg, less than 30 people supported by a service, or smaller support groups, may wish to simply use the continuums (option1 or 3) or graduated indicators (option 4) rather than the survey documents (option 2). The continuums work in much the same way but information gathering can occur in large or small meetings/hui, focus groups and/or interviews.

For larger organisations use of the surveys may be the best course of action, at least initially. However, care should be taken when using surveys especially with disabled people who may have difficulty understanding what is being asked. We will offer some guidance for these situations. For larger organisations, taking a sample of various stakeholders (disabled people, families, whānau and staff) is recommended. Providing a randomised sample will help to ensure everyone is represented.

As a rule of thumb you survey at least ten percent of each stakeholder group (disabled people, families, whānau, support workers and managers) and preferably more (20-30 percent). Statistically representative samples may even ask for more.

If there are multiple divisions within the organisation (ie, supported living, residential services, supported employment, community participation services etc), then collate these separately. Have a minimum number of people within each of these groups (ideally 20 or more if using the surveys for statistical purposes).

Finally, collating the results will require mixed methods that take into account verbal or written comments. The continuums may be used as a summary tool for each EGL principle and each group being reviewed (see 'How to analyse the information').

Completing the self-review with groups or using focus groups

- Discussion of the continuums (option1), or surveys (option 2), can be completed in a group setting (approx. 6 8 people) but it is important that one or two people do not dominate or influence the choices others make. In group situations provide morning or afternoon tea, encourage people to move around if they needed to, and be able to take regular breaks. Allow time at the start of the meeting for introductions, eg, where we are from, what we do for work/fun. This information is very useful for facilitating discussion throughout the session.
- In group situations allow time for each person to have their say and to provide a description of where they place themselves within each question or continuum. There may be variation within the group based on personal circumstances. If providing one scale for the group for each question or continuum (particularly if using the continuums with a focus group), then a single point on each scale should be agreed between everyone involved (consensus). When reporting on findings, clarify where people did not agree (ie, the reasons for the differences). These differences may be important.

How to analyse the information

Each question allows people to provide a response on a sliding scale. There should also be room for comments as people may wish to explain their answers. Ideally, responses would be collated for each question and then a summary provided for each section of the survey (as each relates to a EGL principle).

The ratings people provide may vary considerably and any variation must be carefully reviewed. It is typical, however, for a single group of people (for example, disabled people who use particular supports/services) to provide similar answers. These can be collated as averages or described as a percentage (eg, people who believe X works very well). If using statistics to help collate the results include as much of verbal or written explanation by participants as possible to give depth the responses. Also, if using statistics collate with at least 20 people per group (and preferably more) as smaller groups can provide misleading statistical results.

There may be differences between the perspectives of different groups. Support workers may vary from managers, or both may vary from whānau or disabled people. The person(s) collating the results should simply just collate and point out points of difference and any other trends.

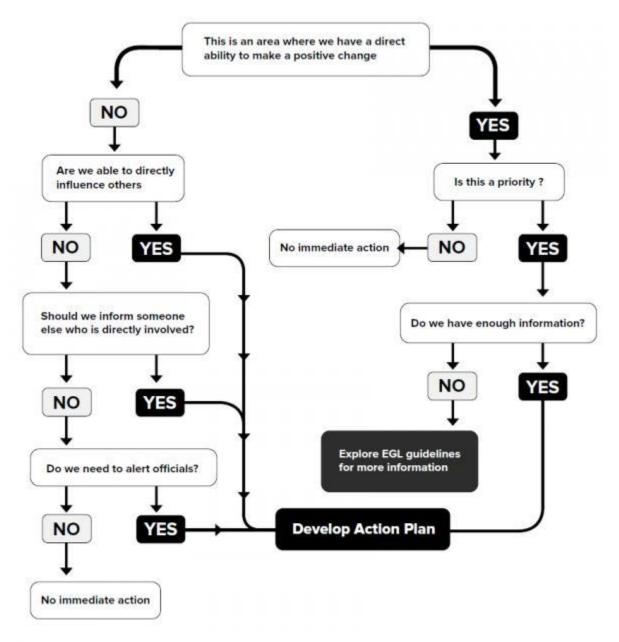
The next step would be to take the collated results to a reference group that includes representatives of all stakeholders and discuss the results. The conclusions of that group could then be recorded, and the review be written up formally in a format decided by the group. Using the continuums to help summarise each principle may be helpful as this gives a visual overview that is easy to understand. If this is done for each stakeholder group, then any variation in viewpoints can lead to further discussion and review.

How to use the results of the review

Provide the written review to members of the reference group and ideally disseminate the material to all participants in various accessible formats.

Based on the conclusions of each section of the report (reflective of each EGL principle) decide how an action plan will be formulated. This may be done in a hui with all interested parties or between members of the reference group and may coincide with strategic planning.

Consider the following flow diagram when formulating an action plan:



Definitions for Action Plans

Aim

The direction you are heading in, anticipated destination or what you want to achieve.

Objective

How you imagine you will achieve the aim (often medium term – can be parallel or sequential).

Inputs

The resources used to achieve the objectives, eg, time, specific service types, defined activities, finances.

Outputs

What is actually delivered by the service/programme and can be quantified, eg, number of people supported into employment, the number of counseling sessions held, the number of courses held.

Outcomes

The **results** of supports/services/outputs, ie, what has happened because of what you have done (the difference made). Often subjective and qualitative, eg, increased confidence, stronger identity.

Indicators (Outcome Indicators)

Things that show progress towards outcomes, clues that desired outcomes are occurring or something that may signify an outcome is being met.

Impact

The bigger/wider effect or change.

Option One: A continuums approach

The continuums are used:

- for small groups or organisations (ie, rather than also using the survey questions), or
- as a tool to summarise all the survey and interview findings.

Each EGL principle is presented as a continuum (one to ten) and is provided with some guiding questions/considerations, especially for smaller groups or organisations. Please note: the "suggested questions" are an example or guide only. You will need to modify these questions depending on who is participating.

Self-determination: disabled people are in control of their lives

ie, disabled people have the "say so" over what they do in services.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators

- Others control
- Minimal or no personal autonomy
- Compliance to predetermined options
- Limited involvement in decisions.

High end indicators

- Individuals make informed decisions
- Supports are tailored to preferences
- Resources are allocated and designed based on individual preference
- Individuals and whānau have a leadership role in service and sector developments.

Suggested questions/areas when reviewing Principle 1

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

- Am I making key decisions?
- Are others assisting me to make decisions?
- Do others understand how I communicate and what I am expressing?
- Are the views of my whānau are valued and supported?
- Do I have all the information I need to make informed decisions?

Begin early: Invest early in disabled people and whānau to maximise life outcomes and support options

le do not wait until there is a crisis, support people to become as independent as possible, support whānau resilience, build natural support networks and community.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

- Minimal information available & limited knowledge base
- Too many barriers, delays, inconsistencies and complexities
- Dependence on service sector
- Few natural and/or community supports
- Poor communication.

High end indicators RESPONSIVE

- Right information at the right time
- Support structure already in place to facilitate future planning
- Access to natural supports and universally available supports
- Planned approaches to services and support that are maintained and consistent
- Transition planning is in place
- Decisions start with the person/whānau and are driven by them.

Suggested questions/areas when reviewing Principle 2

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

- Were options immediately made available?
- Did people talk with me to find out what I needed?
- Was I provided with sufficient information to make choices?

Person-Centred: disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

- Supports are not customised to the individual
- Most activities are group-based and there is minimal opportunity for individual activities or support
- The organisation's internal structure and/or use of resource makes individual support difficult
- Personal aspirations may not be the basis of planned activities
- Activities may be based on a predetermined 'programme' rather than personal aspirations
- Internal policies (ie, staff ratios) impact the type of planned activities that take place.

Suggested question when reviewing Principle 3

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• Are my supports based around what I really want?

- Supports and services are tailored to the individuals needs and goals
- People's lives are not compartmentalised into day, night, home, community, etc
- The individual's personal preferences and aspirations drive services and supports
- Supports are co-ordinated and assist the individual with achieving their aspirations
- Supports are customised to the individual.

Ordinary Life Outcomes: disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation – like others at similar stages of life.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators **REACTIVE**

- People are excluded from participating in the community
- People have limited social participation and connection with others
- Primary involvement is with "specialised" or "segregated" services
- Individuals have limited choice in the activities provided
- Individuals have limited opportunities to being exposed to a range of experiences/activities.

RESPONSIVE

High end indicators

- Individuals contribute to the community through a range of activities (ie, educational, social, recreational, employment and/or personal activities)
- Individuals have a range of roles that are socially valued
- As citizens, disabled persons have the same rights and responsibility as other members of the community
- Supports assist people to be 'part of' their community through social participation and relationship building.

Suggested question when reviewing Principle 4

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• Am I supported to be involved in my community?

Mainstream First: disabled people are supported to access mainstream services before specialist disability services.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

 Disabled people primarily access segregated services or specialist disability services.

High end indicators RESPONSIVE

- Disabled persons have access to mainstream services
- Disabled persons have information to make informed decisions about supports.

Suggested question when reviewing Principle 5

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• What sort of networks/community services/groups have I been supported to make contact with?

Mana Enhancing: the abilities and contribution of disabled people and their families are recognised and respected.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

- Minimal or no contributions from disabled persons and their families are sought
- Contribution is tokenistic
- Contribution is sought but has limited authority
- Disabled persons and their families' abilities are not recognised or valued
- Hierarchical approach to service provision.

Suggested question when reviewing Principle 6

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• Am I recognised for what I have to offer and respected for my contribution?

- Individuals' abilities and contributions are valued
- Disabled persons and their families are given opportunities to contribute
- Individuals and families have a range of opportunities to influence policies and practice
- A partnership approach is central to how services are provided
- Individuals' experience of supports is valuing.

Easy to Use: disabled people have supports that are simple to use and flexible.

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

- Disabled persons and their families do not understand what supports are available to them or how to use them
- Supports are complex and lack transparency
- Supports are inflexible and cannot meet the changing needs of the disabled person and their families
- Disabled persons and families are "locked into" services.

Suggested question when reviewing Principle 7

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• Is it easy for you to get what you want, and do things change if your needs/wants change?

- Disabled persons and their families have a clear understanding of what supports are available and how to use them
- Accessing multiple supports is easy to co-ordinate and the process is transparent
- Supports can meet the changing needs of the disabled person and their families.

Relationship Building: supports build and strengthen relationships between disabled people, their whānau and community

Continuum (choose a point (or points) on the continuum that provides the best representation)



Low end Indicators REACTIVE

- Disabled persons are isolated and have few relationships outside of paid staff
- Individuals have limited opportunities to build new or strengthen existing relationships
- The importance of family/whānau is not recognised
- The individual has minimal opportunity to explore their culture and identity
- Family/whānau have minimal involvement or input into supports.

Suggested question when reviewing Principle 8

Modify depending on the person(s)/groups being involved (ie, the person, whānau, agency staff, managers etc):

• Am I supported to keep in contact with family/friends or extend my networks?

- Services are involved in developing relationships and actioning practices that result in increased opportunities for people with a disability in the community
- Services operate in a manner that develops, strengthens and maintains relationships
- The individual is encouraged to explore their culture and identity.

Option Two: Self-complete questionnaires

Using the self-complete surveys

These can be used in several different ways. This includes:

- developing a network or organisation specific set of 'explanation' materials and then circulating them for people to complete themselves
- holding small group meetings where people complete their responses in a group. Note: this may require you to hold a couple of meetings so you can go through the material at a pace that works for participants. It might be that you have peer facilitators to assist people through the process
- having some skilled people use these "surveys" as an interview guide.

Using interviewers to administer surveys

There will be some situations where the use of interviewers will provide the clearest and most valid responses to survey questions. This is particularly the case for disabled people who may have difficulty navigating or understanding the survey tool.

EGL Self-Review Processes and Considerations

The survey questions provided with this document are derived from a survey developed to review the implementation of EGL in MidCentral Region in 2018. They were designed for an interviewer to go through each question with a disabled person or family member rather than leave the forms simply for people to complete. This is particularly important if the disabled person has a learning disability or other disability that may impact on their comprehension. There can also be issues relating to fatigue. Ultimately it is up to the person to decide whether they complete the survey alone or with the assistance of an interviewer.

Prerequisites for the interviewer:

- Good familiarity with the questions, and what kind of information each one is trying to elicit so that the interviewer can re-word / explain the question in multiple ways, and so that they can interpret people's answers correctly.
- Having good communication skills is essential, and an ability to explain information in plain English. Also, it is preferable for the interviewer to not be too familiar with or close to the people being interviewed; in order to limit any pressure people might feel to respond in a particular way.
- Experience in asking open (but not leading) questions to elicit as much information from people as possible and provide clarity to their responses.

Considerations / Validity Challenges:

- Ideally it would be good to have people self-report what they believe their situation to be (to avoid any bias from interviewers or second parties). However, this may be a challenge if participants have limited ability to understand the intent of the question, or if they have particular grievances that are not directly related to the self-review (sometimes a personal grievance can cloud a perspective or judgement).
- The questions in the self-review provide a sliding scale for responses (typically one to five). Wherever possible, the respondent would choose where they placed themselves on the scale. For individuals who find this approach difficult, flash cards can be used that explain points on the scale in writing, pictorially (eg, use the pictures on the survey document) and in audio. In most cases, people are able to respond using this system, with practice, by pointing at the card that sits best with them. It would be good to have some practice questions ready. In some cases, the number of points on the scale can be reduced to three options.
- If there is situation where a person cannot respond to the sliding scale, there is
 also a high likelihood they may have difficulty understanding or comprehending
 the question. In these cases, a proxy (usually a family member or someone
 close to the person who is not a paid support worker) can be enlisted. If a proxy
 is used, try to have them answer as if it is the disabled person making the
 response, rather than their own opinion. Note: this is a necessary, but not
 preferred, option.
- It is important to be clear when reporting, situations that are or are not the disabled person making the responses.
- When interviewing some people, there is a possibility they will provide the
 response they think you want to hear. Or, if there are comprehension issues,
 they may simply reply in the affirmative regardless of what is being asked. Both
 of these issues need to be considered carefully as both will invalidate the
 responses.
- It is important to use a random selection process to ensure that a diverse sample is interviewed, and not just the people who wished to volunteer (who tend to give more positive answers). Potential randomly selected participants need to have all of the information they need to make an informed choice to participate.
- People need to agree to participate. For this to happen, they need to understand what the interview is for and what will happen as a result. They need to be reassured of anonymity, confidentiality and safety.

Interview set up:

- It may be important to have people's networks and teams involved, to assist with getting people to the location where the interview happens (although ideally interviewers should go to the person) and to help explain the reason for the interview beforehand.
- Creating an informal interview environment is important to encourage people to feel free to speak openly.
- Give people the option to have a support person attend an interview with them, but it is important the support person does not influence how the person responds. They can, however, help rephrase questions as they often know how best to communicate with the person.
- Maybe spread the survey across multiple sessions. Also, some people may only
 want to answer a few questions if this is the case pick the questions that are
 most relevant and use these with all survey respondents.
- It is best not to launch into a discussion of the Enabling Good Lives approach as it may not be familiar to many people. Instead focus the discussion on how happy people are with their lives and their support.

SELF-REVIEW - SURVEY FOR DISABLED PEOPLE

The survey for disabled people can be used for larger groups or organisations. Ideally participants are randomly selected and are representative of all of the disabled people within a group or organisation. In some cases, everyone can be surveyed, but bear-in-mind, if interviewers are enlisted to help administer the survey, then there will be time constraints.

In an interview format a single survey may take half an hour.

If the survey is used as a baseline, then remember it is best to go back to the same people next time the survey is used as this is the best way to show changes over time. However, it is important in all cases to totally protect the identity of participants. Therefore, if using the survey as a baseline then assign a number to each person and keep their names (with numbers) secure in a separate location.

Consider earlier discussion about how to set up and run interviews, and also discussions about processes and other considerations.

PRINCIPLE 1: SELF-DETERMINATION

				F 50	(Marketon.co. 11-35)21445	
	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
I am understood and responded to when I communicate.						
I choose what happens in my life.						
I have help to make choices if I need/ want it.						

PRINCIPLE 2: BEGIN EARLY

I can easily find out about the things I need for my support.			
I get to try new things.			
I am learning new things.			

PRINCIPLE 3: PERSON-CENTRED

I can take part in my interests.			
I can make plans based on what I want and what I'm good at.			
I am achieving the things I want in my life.			
I am encouraged to think about what I want in my life.			
My plan and goals reflect my culture, beliefs and values. ¹			

PRINCIPLE 4: ORDINARY LIFE OUTCOMES

				05 50	(Marchaeles-272444)	
	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	Never
I have a network of people in my life (family, whānau, friends, community and, if needed, paid support workers).						
I feel I belong in my community.						
I am supported to be an active member of my community. ²						

PRINCIPLE 5: MAINSTREAM FIRST

I use typical/universal			
community services			
(eg,hair dressers,			
dentists, cafes, bars,			
doctors, shops etc).			

¹ Whāia Te Ao Mārama: Priority action 1.1 Māori disabled are culturally appropriate and specifically identify and address the individual's cultural needs.

² Whāia Te Ao Mārama: Priority action 3.2 Improve the quality of the community engagement process with Māori, particularly with hapū, iwi, and community leaders and groups / Faiva Ora 2016–202, Priority 2, Pasifika communities are able to better engage with and support individuals with disabilities and their families to participate in their communities

PRINCIPLE 6: MANA ENHANCING

				05 ES	WATER GROCK TO 1 200 54855.	\$
	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	Never
My culture (ie, ideas, beliefs and ways of doing things) is respected.						
My spirituality/beliefs are respected (eg, go to marae, church, talk to elders, meet with others who share my beliefs).						
I am involved in developing support services ³ if I wish to be.						
I feel safe.						
The people in my life value what I can do.						
My support staff have access to training that focuses on my support needs, culture and safety. ⁴						

³ Faiva Ora 2016–2021, Priority 4, Stakeholders working in partnership to address challenges experienced by Pasifika disabled people and their families

 $^{^4}$ Whāia Te Ao Mārama: Priority action 2.1 Culturally appropriate training and 4.2 Strengthen the cultural competencies of workers

PRINCIPLE 7: EASY TO USE

				05 55 D	CHARGO (15-35)3441	0.5
	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
I have choices about the kind of support I receive. ⁵						
My support matches my priorities and schedule.						
My support fits my life.						

⁵ Whāia Te Ao Mārama: Priority action 1.2 ...offer Māori disabled and their whānau more personalised support arrangements and greater choice and control over the supports they use / Faiva Ora 2016–2021, Priority 3, Disability services and supports meet the needs of Pasifika disabled people and their families

PRINCIPLE 8: RELATIONSHIP BUILDING

I can choose who my support staff will be if I have any.			
My whānau is recognised as part of my life and the supports I/we require. ⁶			
My whānau is as involved in my life as I want them to be.			
I have friends outside of where I live (not paid staff/flatmates etc).			
My supports assist me to strengthen my relationship with my community (incl. culture/community of choice). ⁷			
My supports help me connect to people and places that are important to me (incl. culture, whānau and culture). ⁷			
I know where to get help to manage my own supports.			

⁶ Whāia Te Ao Mārama: Priority action 2.2 Develop the New Model for Supporting Disabled People to respond to whānau needs and priorities / Faiva Ora 2016–202, Priority 1, Improved outcomes for Pasifika disabled children, youth and their families.

⁷ Whāia Te Ao Mārama: Priority action 3.2 Improve the quality of the community engagement process with Māori, particularly with hapū, iwi, and community leaders and groups / Faiva Ora 2016–202, Priority 2, Pasifika communities are able to better engage with and support individuals with disabilities and their families to participate in their communities

SELF-REVIEW - FAMILY/WHĀNAU

The whānau survey is derived from a survey used to evaluate the implementation EGL in MidCentral Region in 2018. It has been modified for the purposes of this document and to align it with the priorities of Whāia Te Ao Mārama and Faiva Ora 2016–2020.

This survey was originally designed as either a self-administered tool for whānau and advocates, but with an interviewer present to either read out and paraphrase the questions as needed. For some whānau and advocates, telephone interviews were conducted using the questions.

The blue sections in each question provide a guide for paraphrasing questions. The reason for involving interviewers was to provide assistance as needed and to ensure the surveys were completed when permissions were provided. Quite simply it helped improve the response rate.

If this and other surveys in this document are being used as a baseline, then it would be valuable to go back to as many of the same people as possible if the process were to be repeated at a later date. This helps provide a clearer picture of change over time. For this to occur it would be best to provide each participant with a number and to then keep a record of who was assigned each number in a separate and secure location. Protecting the identity of participants is of the upmost importance.

PRINCIPLE 1: SELF-DETERMINATION: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
I know what the funding is used for.						
Example: I know how much money there is/ where it goes / how it is used.						
I support my whānau/family member / friend / partner / spouse to make their own decisions in life.						

PRINCIPLE 2: BEGIN EARLY: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
Supports anticipate what I/we need.						
Example: we experience supports/services that are proactive / looking ahead.						
I think information, from support services is easy to understand.						
Example: Information, from the service being reviewed, using language and a format which means it is easy for me to understand it.						
I have been informed about funding options, including self-directed funding.8						

⁸ Whāia Te Ao Mārama: Priority action 2.1. Have control over their disability support / Faiva Ora 2016–2021, Priority 1.3 Promote and encourage Pasifika disabled to use person-directed purchasing approaches... Increased numbers of Pasifika disabled people use Individualised Funding, Enhanced Individualised Funding, Enabling Good Lives, Choices in Community Living

PRINCIPLE 3: PERSON-CENTRED: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
Contact with the disability support system helps us achieve our goals.						
Example: you are able to make progress with what you are wanting because of the involvement of supports/services.						
I have the skills and confidence to support [disabled person(s)] to live the life they want.						
I/we know where we are heading and have the supports in place to build the life we want.9						

⁹ Whāia Te Ao Mārama: Priority action 1.2 ...offer Māori disabled and their whānau more personalised support arrangements and greater choice and control over the supports they use / Faiva Ora 2016–2021, Priority 3, Disability services and supports meet the needs of Pasifika disabled people and their families

PRINCIPLE 4: ORDINARY LIFE OUTCOMES: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
We are supported to be connected in the community. ¹⁰						
Example: we are given information that enables us to make contact with other community-based networks/ services if we choose to do this, supported to be connected with Te Ao Māori, connected with other disabled people in my community and supported to do this in a way that helps me to develop my own relationships.						

PRINCIPLE 5: MAINSTREAM FIRST: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
We can use community options, connections and services that are for everyone before we have to use specialised disability services.						
Example: we are not always directed straight into disability services.						

¹⁰ Whāia Te Ao Mārama: Priority action 3.2 Improve the quality of the community engagement process with Māori, particularly with hapū, iwi, and community leaders and groups / Faiva Ora 2016–202, Priority 2, Pasifika communities are able to better engage with and support individuals with disabilities and their families to participate in their communities

PRINCIPLE 6: MANA ENHANCING: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
I feel welcomed by the supports we use. Example: they know who we are, they are friendly and they are interested in what we have to say.						
I believe my views are valued by supports/services. 11 Example: they listen well, accurately record information and act on what we say/agree.						
Supports respect our culture. ¹² Example: our way of doing things (including beliefs) is respected, services are responsive to Te Ao Māori.						
Supports value our preferences. Example: what they do is linked to what you have said and what you think is important.						

¹¹ Whāia Te Ao Mārama: Priority action 5.1...[whanau will] be involved in designing and delivering cultural responsiveness training to providers / Faiva Ora 2016–202, Priority 3.2 Support the provision of advice by the Faiva Ora Leadership Group by holding twice-yearly meetings and 3.5 Pasifika people have a 'voice' and contribute to service improvement and 1.8 Pasifika disabled people and their families participate in community conversations on how best to support them in their communities.

¹² Whāia Te Ao Mārama: Priority action 3 Tāngata whaikaha are active participants in their whānau, hapū and iwi and 3.1 ensure that the disability support system supports tāngata whaikaha to maintain their connection to Te Ao Māori

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
I am valued for the support I provide. Example: both at home and generally, I am recognised for the contribution I make this includes with other disabled people in my community.	Sure					
Paid support workers are reliable and consistent.						
In general, I believe my family member / friend / partner/ spouse is safe. ¹³ Example: I am not concerned my family member / friend / partner/ spouse is at risk.						
Our wellbeing benefits from contact with the disability support system. Example: as a family we believe we are better off because of contact with the supports and services.						
My/our rights are respected. Example: as a whānau/family, as a legal decision maker on behalf of the person.						

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 $^{^{13}}$ Whāia Te Ao Mārama: Priority action 2.1 Culturally appropriate training and 4.2 Strengthen the cultural competencies of workers

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
We can be involved in developing support services. ¹⁴						
Example: co-design, making things happen and seeing how well things are going.						
I can work with others so they understand more about disability.						
Example: share our story, lead training.						

¹⁴ Whāia Te Ao Mārama: Priority action 1.1 actively involve tāngata whaikaha and whānau in co-designing, implementing, monitoring and evaluating the disability support system / Faiva Ora 2016–2021, Priority 4, Stakeholders working in partnership to address challenges experienced by Pasifika disabled people and their families

PRINCIPLE 7: EASY TO USE: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
Supports are easy to access and use. ¹⁵						
Example: there is clear information about what is happening and you don't need to repeat yourself or follow-up on what is decided.						
I think the funding allocation process is clear.						
Example: we understand how to obtain funding and get decisions reviewed.						
I believe the funding allocation process is positive. Example: we think getting funding values who we are						
I know how much money is allocated for support.						
Example: I know how much money is provided and what this is for.						
The funding is sufficient to meet our needs.						
Supports work when we want them. Example: when things happen to suit us (time of the day/week).						

¹⁵ Whāia Te Ao Mārama: Priority action 2.2 remove barriers that prevent tāngata whaikaha from independently accessing information / Faiva Ora 2016–2021, Priority 1.5 Pasifika people are more aware of and understand accessible information on available disability support services

Supports work how we want them. Example: what happens is consistent with what suits us and what we have agreed with.			
Overall our supports work flexibly (how we want them to).			
Supports enable us to do the things that are important to us.			
We can make changes to our supports as we need to.			
We choose who provides assistance for ongoing support.			
Overall supports for my family member work well.			
Example: things are happening the way we though they would (doing the right things at the right time and place).			

PRINCIPLE 8: RELATIONSHIP BUILDING: WHĀNAU SURVEY

	N/A Not sure	No /Never	Occasionally	Sometimes	Most of the time	Yes/ Always
Our supports help us connect to people and places that are important to us.						

SELF-REVIEW - SELF-COMPLETE SURVEY SUPPORT WORKERS AND MANAGERS

When reviewing the opinion of support workers and managers make sure you have a representative sample or survey all or most of the workforce.

As with the other surveys, if this is being used as a baseline, then as many of the same people as possible should be included in subsequent surveys. This allow you to accurately describe change over time. Again, it is important to protect personal identities when conducting surveys. Therefore, if you wish to review the same group of people again then assign a number to each person and keep the master list of names with numbers secure and separate.

To provide a clear baseline, try to avoid conducting the survey directly following EGL training or better still provide the survey before training has occurred. However, if your group or organisation is already heavily invested in EGL then the initial survey will provide a snap shot of the present time and, if repeated at a later date, allow you to analyse whether things have changed (either positively or negatively).

This survey, as with the other surveys used in this document, are initially derived from a survey used to review the implementation of EGL in MidCentral Region in 2018. There have been additions to align the surveys with Whāia Te Ao Mārama and Faiva Ora 2016–2020.

PRINCIPLE 1: SELF-DETERMINATION: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/ SO SO	NOT REALLY	NO/ NEVER				
Enables us to be proactive in our assistance of disabled people										
Enables us to make it easier for disabled people to experience an everyday life.										
In our organisation we actively	In our organisation we actively									
Respond to disabled people's preferences										
Value the involvement of disabled people and their families/whānau in decision-making										
Provide services that give disabled people and their whānau choice and control over their supports and recognise their cultural, religious, gender and other differences (with appropriate emphasis for Māori, Pasifika). ¹⁶										

PRINCIPLE 2: BEGIN EARLY: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to respond to disabled people in creative and flexible ways						
Enables us to work collaboratively with mainstream (ie, universal) services.						
In our organisation we actively						
Anticipate disabled people's support requirements						
Are responsive to disabled people's changes in support requirements						
Provide training designed to anticipate the needs and aspirations of the people we support. ¹⁷						

 $^{^{16}}$ Whāia Te Ao Mārama: Priority 2, Action 2.1 / Faiva Ora 2016—2020, priority 1.3

¹⁷ Whāia Te Ao Mārama: Priority 5 & 6 Actions 5.2, 5.3, 6.1, / Faiva Ora 2016–2020, priority 1.6, 3.1

PRINCIPLE 3: PERSON-CENTRED: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to tailor our support according to people's aspirations and goals.						
In our organisation we actively						
Work with disabled people to plan ahead and set goals and outcomes.						

PRINCIPLE 4: ORDINARY LIFE OUTCOMES: SUPPORT WORKER/MANAGER SURVEY

	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER				
In our organisation we actively										
Assist disabled people to have multiple valued roles										
Connect disabled people with community (non-disability specific) resources and services										
Support Māori, Pasifika and people of other cultures to participate in and contribute to their own cultural communities ¹⁸										
Facilitate opportunities for tāngata whaikaha to participate and/or lead in Te Ao Māori. ¹⁹										

¹⁸ Whāia Te Ao Mārama: Priority 4, Action 4.2

¹⁹ Whāia Te Ao Mārama: Priority 3, Action 3.1

PRINCIPLE 5: MAINSTREAM FIRST: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to work collaboratively with mainstream (ie, universal) services.						
In our organisation we actively	•					
Create opportunities for disabled people to experience everyday lives in everyday places.						

PRINCIPLE 6: MANA ENHANCING: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Encourages and values our input						
Enables us to provide services that are responsive to Māori						
Enables us to provide services that are responsive to Pacific peoples and other cultures.						
In our organisation we actively						
Provide services that are responsive to Māori						
Provide services that are responsive to Pacific peoples and other cultures						
Ensure staff undertake cultural competency training including disability responsiveness ²⁰						
Equips us to respect diversity.						

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 $^{^{20}}$ Whāia Te Ao Mārama: Priority 5, Action 5.1 / Faiva Ora 2016—2020, priority 1.5

PRINCIPLE 7: EASY TO USE: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER			
Enables us to easily understand its requirements									
Enables us to raise issues and improve systems.									
In our organisation we actively									
Ensure people understand what services we do and do not provide, and we make this information available, eg, on a website									
Ensure materials are in a format suited to people who use our service, eg, easy read, braille, large font, words with visual descriptions, pictorial, etc									
Encourage staff to promote information to Māori, Pasifika and other cultural communities and disability groups in accessible formats. ²¹									

PRINCIPLE 8: RELATIONSHIP BUILDING: SUPPORT WORKER/MANAGER SURVEY

The support system/network/organisation	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to build trusting relationships with disabled people and their families/whānau						
Allows workforce undertakes cultural competency training. ²²						
In our organisation we actively						
Work well together with disabled people and their families/whānau						
Build partnerships with Māori to support service delivery to tāngata whaikaha. ²³						

²¹ Whāia Te Ao Mārama: Priority 6, Action 5.2 / Faiva Ora 2016–2020

²² Whāia Te Ao Mārama: Priority 5, Action 5.2 Disability Support Services can... / Faiva Ora 2016–2020

²³ Whāia Te Ao Mārama: Priority 5, Action 5.2 Disability Support Services can... / Faiva Ora 2016–2020

SELF-REVIEW – SURVEY FOR ORGANISATIONS

PRINCIPLE 1: SELF-DETERMINATION: ORGANISATION

Our network/groups/agencies processes and policies	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enable us to respond to disabled people in a creative and flexible way						
Enable us to make it easier for disabled people to experience an everyday life.						
In our network/organisation	n we a	actively				
Respond to disabled people's preferences						
Value the involvement of disabled people and their families/whānau in decision-making						
Involve disabled people and families/whānau in staff interviews						
Have disabled people and families/whānau on our Board of Governance						
Provide services that give disabled people and their whānau choice and control over their supports (with appropriate emphasis for Māori, Pasifika and people of other cultures). ²⁴						

 $^{^{24}}$ Whāia Te Ao Mārama: Priority 2, Action 2.1 / Faiva Ora 2016—2020, priority 1.3

PRINCIPLE 2: BEGIN EARLY: ORGANISATION

Our network/group/agency	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to be proactive in our assistance of disabled people.						
In our network/organisa	ation w	ve actively				
Anticipate disabled people's support requirements						
Are responsive to disabled people's changes in support requirements						
Provide staff training designed to anticipate the needs and aspirations of the people we support. ²⁵						

PRINCIPLE 3: PERSON-CENTRED

Our network/group/agency 	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to tailor our support according to people's aspirations and goals.						
In our network/organisa	ation w	ve actively				
Work with disabled people to plan ahead and set goals and outcomes.						

 $^{^{25}}$ Whāia Te Ao Mārama: Priority 5 & 6 Actions 5.2, 5.3, 6.1, / Faiva Ora 2016—2020, priority 1.6, 3.1

PRINCIPLE 4: ORDINARY LIFE OUTCOMES: ORGANISATION

	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER				
In our network/organisation we actively										
Assist disabled people to have multiple valued roles										
Support Māori, Pasifika and people of other cultures to participate in and contribute to their own cultural communities ²⁶										
Facilitate opportunities for tāngata whaikaha to participate and/or lead in Te Ao Māori. ²⁷										

PRINCIPLE 5: MAINSTREAM FIRST: ORGANISATION

Our network/group/agency	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to work						
collaboratively with mainstream (ie, universal) services.						
In our network/organisati	on we	actively				
Create opportunities for disabled people to experience everyday lives in everyday places						
Connect with community (non-disability specific) resources and services.						

²⁶ Whāia Te Ao Mārama: Priority 4, Action 4.2

²⁷ Whāia Te Ao Mārama: Priority 3, Action 3.1

PRINCIPLE 6: MANA ENHANCING: ORGANISATION

Our network/group/agency 	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Encourages and values our input						
Enables us to provide services that are responsive to Māori						
Enables us to provide services that are responsive to Pacific peoples and other cultures.						
In our network/organisa	ation v	ve actively				
Provide services that are responsive to Māori						
Provide services that are responsive to Pacific peoples and other cultures						
Ensure staff undertake cultural competency training including disability responsiveness. ²⁸						

 $^{^{28}}$ Whāia Te Ao Mārama: Priority 5, Action 5.1 / Faiva Ora 2016—2020, priority 1.5 $\,$

PRINCIPLE 7: EASY TO USE: ORGANISATION

Our network/group/agency	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
Enables us to easily understand its requirements						
Enables us to raise issues and improve systems.						
In our network/organisa	ation w	ve actively				
Ensure people understand what services we do and do not provide, and we make this information available, eg, on a website						
Ensure materials are in a format suited to people who use our service, eg, easy read, braille, large font, words with visual descriptions, pictorial, etc						
Encourage staff to promote information to Māori, Pasifika and other cultural communities and disability groups in accessible formats. ²⁹						

 29 Whāia Te Ao Mārama: Priority 6, Action 5.2 / Faiva Ora 2016—2020

PRINCIPLE 8: RELATIONSHIP BUILDING: ORGANISATION

Our network/group/agency	N/A	YES/ TOTALLY	MOSTLY	OKAY/SO SO	NOT REALLY	NO/NEVER
•••						
Enables us to build trusting relationships with disabled people and their families/ whānau						
Allows workforce undertakes cultural competency training. ³⁰						
In our network/organisa	ation w	ve actively				
Work well together with disabled people and their families/whānau						
Build partnerships with Māori to support service delivery to tāngata whaikaha. ³¹						

³⁰ Whāia Te Ao Mārama: Priority 5, Action 5.2 Disability Support Services can... / Faiva Ora 2016–2020

³¹ Whāia Te Ao Mārama: Priority 5, Action 5.2 Disability Support Services can... / Faiva Ora 2016–2020

Option 3: Developing Continuums

Using self-review to assist people to think through what is important and what the principles look (and feel) like in practice may be the most valuable element of a review.

A self-review is only as good as the insights, and subsequent positive actions, that come from the review.

Enabling Good Lives is about self-determination and about enhancing mana. While two options/approaches have been provided in this document, it is important to note that 'the journey is as important as the destination' and that involving disabled people, family, whānau and support workers in the development of a self-review frame of reference is one way to:

- practically acknowledge the mana of the people involved
- ensure that the "indicators" you develop are relevant to the people involved in your network or organisation
- provide an opportunity for creating insights and links long before the "results" are in.

Developing "indicators" for the continuums is probably the easier of the two last options in this resource.

There are some steps to follow:

Steps

Step 1. With an individual, or in a group, go through each continuum provided and identify examples of what it might be like at either end of the continuum, ie, when things are really not working well/the principle is not being understood or actioned at one end. At the other end describe what it looks like when they are working really well. In the example provided, earlier in this resource, they are described as "low end indicators" and "high end indicators".

It is important that you develop these indicators from your own perspective, ie, what I think as a disabled person about the experience of disabled people or what I think as a family member about your direct experience as a family member.

It is often useful to have separate groups when developing this material. If there are "mixed groups" then people can try and express what is not their own direct experience, ie, a support person saying 'I think disabled people really value ...'. At best, this is confusing the right of people to have the space to express themselves. There may need to be four or five separate groups that develop the indicators (depending on the complexity of the network or organisation).

Write the "high end" and "low end" indicators for each principle (see below).

- Step 2. Rate your current experience. This can be achieved by the groups³² of people doing this collectively or individual discussions. Note: this particular option does note easily lend itself to developing a self-complete "survey", as much of the ability for a person to "rate" their experience often comes through the discussion that happens.
- Step 3. Compare the results from different people and different roles/perspectives. What is it describing? What are the strengths/great experiences? Where are the experiences not so advanced/great?

If it is small group of people (eg, a personal network of support or a smaller service), there is probably no need to compile results and go through a statistical analysis process. It can be clear enough just to present the different responses.

- Step 4. Identify what needs to happen for this principle to be more embedded (central) to how things happen. Agree on a plan describing what you will do to develop this further.
- Step 5. Repeat this process (in 6 months or 1 year) and see what has changed. Have the strategies you last developed and implemented worked? What do we need to celebrate? What do we need to do more work on?

Self-determination

Disabled people are in control of their lives.



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³² The separate groups are generally disabled people, family and support workers

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.



•	•
•	•
•	•

Person-centred

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



• •	•	Not being actioned	Working really well
•	•	•	•
	_	•	•
•	•	•	•

Ordinary life outcomes

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



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Mainstream first

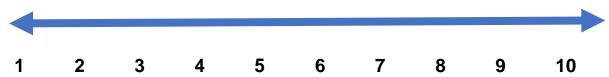
Disabled people are supported to access mainstream services before specialist disability services.



Not being actioned	Working really well
•	•
•	•
•	•
•	•

Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected.



•	•
•	•
•	•

Easy to use

Disabled people have supports that are simple to use and flexible.



Not being actioned	Working really well
•	•
•	•
•	•

Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community.



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Option 4: Developing graduated indicators³³

Graduated progress indicators are a great way for people to think about their experience of the EGL approach, review what is happening now and map out the next steps for development.

Bringing people together to develop the indicators for each principle may be as useful for the network or organisation as conducting the self-review.

Graduated progress indicators can show the complexity of the change process and represent the information that can be gathered in order to monitor achievements towards the desired outcome.

A set of progress indicators represents a change model that illuminates the depth and complexity of the change being sought.

The progress indicators should advance in degree from the minimum one would **expect to see** as an early response to implementing the EGL Principles, to what people would **like to see** happening, to what people would **love to see** occurring if implementing the principles were having a profound influence.

Progress indicators are generally framed as follows: "Who? Is doing what? How?"

Cumulatively, they illustrate the complexity and logic of the change process.

Progress Indicators must be able to be monitored and <u>observed</u>. They describe what we:

- Expect to see
- Like to see
- Love to see.

There are some steps to follow:

Steps

Step 1.

With an individual, or in a group, explore what this principle would look and feel like when it is applied. Look at it from the specific perspective of how you connect with the network or organisation, eg disabled people, family, support worker etc. There may need to be four or five separate groups that develop the indicators (depending on the complexity of the network or organisation). Write the graduated indicators for each principle (see below).

³³ Adapted from ideas and material from Sarah Earl, Fred Carden, and Terry Smutylo

- Step 2. Rate your current experience. This can be achieved by the groups³⁴ of people doing this together, individual discussions or developing a "survey" that can be sent out.
- Step 3. Compare the results from different people and different roles/perspectives. What is it describing? What are the strengths/great experiences? Where are the experiences not so advanced/great?
- Step 4. Identify what needs to happen for this principle to be more embedded (central) to how things happen. Agree on a plan describing what you will do to develop this further.
- Step 5. Repeat this process (in 6 months or 1 year) and see what has changed. Have the strategies you last developed and implemented worked? What do we need to celebrate? What do we need to do more work on?

Self-determination

Disabled people are in control of their lives.

1	2	3	4	5	6	7	8	9
Expect	t		Like			Love		
develope would ex experier basic) if applied	nce (the m this princ	at you nost	develop would ex experier was app	e description ed, ie, who ed, ie, who expect to nce if this folied to yo ion/work i	at you principle ur	develope would ex principle your cor	e descrip ed, ie, wh xperience was app nnection/v t amazing nate!	at you if this lied to vork in
evidence to happe	e the clue e this is b en? What seeing and ncing?	eginning t would	evidence now rea how thin What we	e the clue e this prin Ily influen ngs happe ould you b and experi	ciple is cing n? pe	evidence well is e working	e the clue e this prin mbedded really we ou be see ncing?	ciple and II? What

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³⁴ The separate groups are generally disabled people, family and support workers

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available.

1	2	3	4	5	6	7	8	9
Expect	t		Like			Love		
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Person-centred

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

1	2	3	4	5	6	7	8	9	
Expect	t		Like			Love			
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Ordinary life outcomes

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

1	2	3	4	5	6	7	8	9	
Expect	:		Like			Love			
develope would ex experier basic) if applied	Insert the description you developed, ie, what you would expect to experience (the most basic) if this principle was applied to your connection/work.			Insert the description you developed, ie, what you would expect to experience if this principle was applied to your connection/work in a good way.			Insert the description you developed, ie, what you would experience if this principle was applied to your connection/work in the most amazing way. The ultimate!		
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Mainstream first

Disabled people are supported to access mainstream services before specialist disability services.

1	2	3	4	5	6	7	8	9
Expect	Expect					Love		
develope would ex experier basic) if applied	nce (the m this princ	at you nost	develope would ex experier was app	Insert the description you developed, ie, what you would expect to experience if this principle was applied to your connection/work in a good way. Insert the description you developed, ie, what you would experience if the principle was applied to your connection/work the most amazing way. Insert the description you developed, ie, what you would experience if the principle was applied to your connection/work the most amazing way.				at you if this lied to vork in
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Mana enhancing

The abilities and contributions of disabled people and their families are recognised and respected.

1	2	3	4	5	6	7	8	9	
Expect	Expect					Love			
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Easy to use

Disabled people have supports that are simple to use and flexible.

1	2	3	4	5	6	7	8	9	
Expect	:		Like			Love			
develope would ex experier basic) if applied	ed, ie, wh xpect to nce (the m this princ	developed, ie, what you developed to would expect to would experience if this principle principle was applied to your connection/work in a good the most connection.				develope would ex principle your cor the mos	Insert the description you developed, ie, what you would experience if this principle was applied to your connection/work in the most amazing way. The ultimate!		
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Relationship building

Supports build and strengthen relationships between disabled people, their whānau and community.

1	2	3	4	5	6	7	8	9	
Expect	t		Like			Love			
develope would ex experier basic) if applied	developed, ie, what you vould expect to would expect to would experience (the most asic) if this principle was pplied to your connection/work in a good developed, ie, what you would expect to experience if this principle was applied to your connection/work in a good developed, ie, what you would expect to your connection/work in a good developed, ie, what you would expect to would expect to your connection/work in a good developed, ie, what you would expect to would expect to your connection/work in a good developed, ie, what you would expect to would expect to your would expect to a specific principle was a policy of the princi				t the description you loped, ie, what you described experience if this iple was applied to connection/work in lost amazing way.				
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