

Summary of the Enabling Good Lives (EGL) approach

1. Context

In 2008 New Zealand ratified the Convention on the Rights of Persons with Disabilities (CRPD) and there was a review into how things were going in New Zealand.¹ The convention talked about what things should be like and the review made it very clear that lots of change needed to happen in New Zealand.

There were many disabled people, families and allies that realised the most important thing was for disabled people and families to have more control. This means control in their lives and supports as well as the ability to lead change.

2. How EGL was created

The EGL approach came from the community. Between 2008 and 2013, hundreds of disabled people and their families contributed to the development of the EGL approach directly and indirectly (through networks).

There were many ways disabled people and families built the EGL approach.

- Between 2009 and 2012, there was a group of community organisations², governed and staffed by disabled people and/or families, that worked with the Minister for Disability Issues. They were connected with many hundreds of disabled people and families and spent lots of time explaining how new approaches could work.
- In 2011, the Minister for Disability Issues invited a group of leaders in the disability sector to develop a “clean sheet” approach to positive change. This group of disabled people, families and allies wrote the first Enabling Good Lives report (EGL).
- In 2012, groups of disabled people, families and providers in Christchurch and the Waikato each had a series of in-depth meetings to explore what a new way of doing things might look like. This became the EGL Canterbury Report and EGL Waikato Report. These reports were independent and community driven. They both strongly supported the first EGL report.

¹ The Social Services Select Committee's 2008 - inquiry into the quality of care and service provision for disabled people.

² People First NZ, Disabled Persons Assembly (DPA), Parent to Parent, SAMS (Standards and Monitoring Services) and Imagine Better.

- In 2012/13 the EGL National Leadership Group was set up by the Minister for Disability Issues. This group was made up of disabled people, tangata

whaikaha Māori, Pacific people, family members and a service provider. This group published a series of “key messages” about the EGL approach. This group is the guardian (kaitiaki) of the EGL approach.

3. EGL and Māori

The group of leaders that wrote the initial EGL Report included Māori. Also, some of the people who developed the EGL approach also knew about the Whanau Ora approach. The approaches overlap. The EGL approach supports that both all services and supports become appropriate for disabled Māori and also that some things are developed by Māori for Māori.

4. EGL is an approach and not a model

An approach means it is a general guide to how we think and do things rather than a specific ‘system’. EGL is a principles-based approach (Appendix One). This means individuals, families, cultures and communities work out how they want EGL to look for them. A key thing in the EGL approach is flexibility. It is universal so that it can apply to anyone in any situation.

5. The EGL approach and system change

There are two different but connected things with EGL-based change. There is the EGL approach which is the foundation and guide for change since 2012. All disabled people and families can use the principles of EGL in their lives and when working things out with services and supports. Secondly, there is the changes that are slowly being made to “the system”. This system change is based on the EGL approach and has been successfully demonstrated in three sites. EGL-based system change will take time to happen across New Zealand.

6. The EGL approach

The EGL approach is about disabled people and their families having the “say so” in their lives, having supports that make things easier and having the ability to influence “the system”. Some people use the term ‘disabled community social movement’ to describe EGL.

The EGL principles are the basis of the approach. They help everyone think about what is important help people act in a way consist with positive change. The

principles guide how the EGL approach works. The EGL vision helps us think about some of what we are wanting to achieve.

EGL suggests one principles-based system across all government agencies.

The EGL approach recognises disabled people belong to networks and cultures e.g. family, friends and community. These networks need to be respected as being fundamental to identity, belonging and citizenship.

Investing in disabled people and their families is central to EGL. This means resources go to networks and organisations led by disabled people and families so they are able to build knowledge, skills and connections.

The EGL approach requires changes are made to communities, government systems and service provision. These changes need to be built on the EGL vision and principles. The aim of these changes is to build person directed supports, accessible communities and a society that values the contribution of disabled people.

The changes to the system EGL promote include the following shifts:

- Moving from assessments based on what people cannot do to having plans based on people's strengths, preferences and aspirations (see page ...)
- Moving from people being "lost" in the system or unaware of options to people being able to have contact with an independent ally (see page ...)
- Moving from the bulk funding of services to personal budgets that people have control of (see page)
- Moving from disabled people having to only use specialist and segregated services to having all community services be available and accessible to disabled people
- Moving from waiting until there is a diagnosis or crisis to beginning early and breaking cycles
- Moving from officials, clinicians and service providers making decisions about what the system should be like, to regional and national leadership by groups of disabled people and their families

EGL is about disabled people and families having control of resources so they can build what they need. This might look different person by person, family by family, culture by culture and community by community. The main thing is disabled people decide.

Leadership by disabled people and their families

An important part of the EGL approach is that disabled people are not just able to build a good life for themselves but that they have ways to influence the disability support system and all government agencies. This includes building the new way of doing things and checking that it is working well for individuals, families and communities.

EGL is about both regional and national leadership by disabled people and families. In March 2024, EGL-based regional leadership groups exist in the Waikato,

Christchurch, MidCentral and Taranaki areas. EGL-based regional leadership groups are beginning to be built in Northland, West Auckland, Gisborne and the Hawkes

Bay. These groups sometimes do things differently because they are all unique. All of these groups are there to promote and protect EGL as an approach and influence the way EGL-based changes are made.

In EGL some things are national. These are things like the principles, vision and the main features of the EGL approach (see page ...). However, different communities have different strengths and challenges. So, while what needs to be done is the same nationally, how it is done might vary from place to place.

EGL-based system changes

The role of the independent ally

The Enabling Good Lives report states that there is an independent person who can “assist disabled persons and family/Whānau to consider existing options and create new possibilities.” The degree of involvement an individual or family has with this independent ally is negotiated between the parties.

Where EGL-based system change has been piloted this role has been called Kaitūhono or Connector.

Note: More content for this section is currently being developed.

The creation and purpose of a Good Life Plan

The Enabling Good Lives report states that “all supports and services are led by the preferences, strengths, aspirations and needs of disabled people and their families. An aspiration-based personal plan is the central document to design and measure paid supports. While the core components of plans may be similar, plans may take different forms.”

The EGL approach suggests people:

- can make a plan based on their strengths and interests.
- are in control of planning their support, and they have help to make informed choices if I need and want it.
- have one plan that can be used by multiple services and supports

Note: More content for this section is currently being developed.

The importance, and general use of, flexible budgets

EGL states “disabled people and family/Whānau have control of funding i.e. bulk funding, according to service type, will be replaced with personal budgets where people can choose how they create a good life for themselves. All government funders will contribute to one funding pool that is determined through a simple process of self-assessment (or supported self-assessment) and confirmation.

Disabled people and family/whānau will be able to move their funding as their preferences and needs change.”

Note: More content for this section is currently being developed.

Appendix One

Enabling Good Lives Vision

In the future, disabled children and adults and their families will have greater choice and control over their supports and lives, and make more use of natural and universally available supports.

Disabled people and their families, as appropriate, will be able to say:

- I have access to a range of support that helps me live the life I want and to be a contributing member of my community.
- I have real choices about the kind of support I receive, and where and how I receive it.
- I can make a plan based on my strengths and interests.
- I am in control of planning my support, and I have help to make informed choices if I need and want it.
- I know the amount of money available to me for my support needs, and I can decide how it is used – whether I manage it, or an agency manages it under my instructions, or a provider is paid to deliver a service to me.
- The level of support available to me is portable, following me wherever I move in the country.
- My support is co-ordinated and works well together. I do not have to undergo multiple assessments and funding applications to patch support together.
- My family, whānau, and friends are recognised and valued for their support.
- I have a network of people who support me – family, whānau, friends, community and, if needed, paid support staff.
- I feel welcomed and included in my local community most of the time, and I can get help to develop good relationships in the community if needed.

The Government will get better value for the funding it provides because:

- the new approach will generally provide better quality of life outcomes for disabled people and their families (based on international evidence)
- less money will be spent on providers premises and more on support
- government agencies will work more closely together, for example using shared way to determine support needs, integrated funding and contracts.

Appendix Two

Enabling Good Lives Principles

Self-determination

Disabled people are in control of their lives.

Beginning early

Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural support; 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.

Ordinary life outcomes

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

Mainstream first

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

Mana enhancing

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

Easy to use

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

Relationship building

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