



Enabling Good Lives

National EGL Leadership Group (NEGL) position statement on the Social Model and its relationship with Enabling Good Lives

Social Model

The social model¹ of disability argues that environments and attitudes disable people living with impairments. It was developed by disabled activists following the lead of the civil rights movement and second wave feminism in the early 1970s. It is best understood when contrasted with the dominant *individual model*.

The individual model (often called the 'medical' model) makes no distinction between impairment and disability, uses the terms interchangeably and argues that if an individual has an impairment the individual has a disability. Disability is thus located in the individual and is seen as a problem to which the individual must adjust their life to and get on as best they can. To aid in this, the individual is encouraged to seek medical intervention to fix or ameliorate their disability. Medicalisation, exclusion and welfare dependency are highly likely outcomes of this way of thinking about disability.

Disabled people critiqued this model showing that it did not reflect how they experienced disability and went about developing their own model². They began by separating *impairment* from *disability*.

- *Impairment* is the lack or malfunction of sensory, cognitive or physiological structures of the body or mind.
- *Disability* is the disadvantage caused by the social, economic, political and environmental factors which restrict or exclude those with impairments from participating in their communities.

Looked at this way, disability is created by and located in society and social organisations designed by and for able-bodied people and underpinned by ableist³ ideology. Disability is thus imposed on people living with impairments in a disabling and disableist society; disability, in other words, is a form of social oppression: it is something that is imposed upon people living with impairments. Disabled people require social and structural change to society, its organisations and values if they

¹ Unlike a theory, a model does not claim to explain every aspect of the phenomenon under investigation

² See The Union of Physically Impaired Against Segregation and The Disability Alliance (1975) *Fundamental Principles of Disability* <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-fundamental-principles.pdf>

³ Ableism prioritises able-bodiedness and able-mindedness as the ideals to which all must strive; it punishes those with impairments with degradation and exclusion

are to have good lives. Disability is thus a socio-political problem, not an individual problem. This understanding of disability is known as the social model of disability⁴.

Two important consequences of the social model were:

- 1) consciousness raising – disabled people learnt that they weren't the problem, society was e.g. "I'm not at fault; society is!"
- 2) it set the political agenda for the disability rights movement (human rights, barrier removal, voice, greater choice and control etc).

With a social model analysis and a clear political agenda, disabled people, their organisations and allies achieved some remarkable things in the following decades. In Aotearoa New Zealand, for example, schools had routinely refused to accept disabled children up until the 1989 Education Act which stipulates they now had to accept all students from their local area; disability was included in the Human Rights Act 1993; New Zealand Sign Language was made an official language (2006); the last institution, Kimberley, was closed (2006) as were sheltered workshops a year later; New Zealand played a major role in the ad hoc committees of the UN Convention on the Rights of Persons with Disabilities (CRPD) and ratified it in 2008. In addition, official disability strategies and action plans were co-developed with disabled people regularly from 2001.

Three themes underpin all these advances:

- 1) "nothing about us without us"
- 2) the articulation of the rights and freedoms disabled people have alongside all citizens
- 3) barrier removal to participation.

Once won, however, the point is to make these rights and freedoms in law real for real people on real occasions. This is where Enabling Good Lives enters the fray.

Enabling Good Lives

The [Enabling Good Lives report \(2011\)](#) was written in the context of New Zealand's ratification of [CRPD](#) in 2008 and The Social Services Select Committee Inquiry into the care and service provision for people with disabilities report (2008). The Whanau Ora approach was also influential in the early stages of the development of the EGL approach⁵.

⁴ In the USA, disability activists have largely followed a minority group model – by virtue of belonging to a minority, one is subject to discrimination and exclusion – rather than the structural, social oppression model of their UK counterparts. For British writers, merely joining the game as it was, was not enough. Their agenda was to create a new, nondisabling society in which not only impaired people would be emancipated, but others such as workers, women, blacks, LGBTQ+ could also freely participate. In Aotearoa New Zealand, the disability rights movement has largely followed the British approach. But this does not mean the social model is widely dispersed and understood in Aotearoa; indeed, the individual model dominates as taken-for-granted obviousness by the general population.

⁵ *Overview of Enabling Good Lives and System Transformation*
<https://carematters.org.nz/whakapapa-of-enabling-good-lives/>

The EGL **Vision** looks forward to a future when “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.”⁶ This vision captures personal and structural aspects of disability. For example, having greater control over their supports is a personal matter while the vision of ‘universally available supports’, be they housing, education or employment, is about structural change, of building a society in which all can participate. A set of 8 **Principles** are presented as the means to this future:

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

The principles⁷ have become the pivot around which EGL turns.

The social model claims that the solution to disability is not medical intervention for individual cure or segregated pathways for specialist supports, but barrier removal for universal access. From this perspective, each of the EGL principles aims to remove barriers impeding disabled people in their pursuit of lives determined by themselves. Recast in terms of barrier removal, the EGL Principles become a set of levers to pull to operationalise the social model, to increase the authority and control disabled people have in creating good lives and as steps towards a nondisabling society.

For example:

- *self-determination*: is about removing disbelief in disabled peoples’ ability to conceive and forge their own direction in life;
- *beginning early*: is about removing diagnostic barriers, ableist expectations and creating a better chance for a good life;
- *person-centred*: is about removing bulk-funded, ‘one size fit all’ approach to supports;
- *ordinary life outcomes*: removes barriers to age appropriate participation in one’s community and active citizenship;
- *mainstream first*: is about creating nondisabling mainstream services;
- *mana enhancing*: is about not imposing limitations on the expertise disabled people have about their own lives and focusing on their strengths and abilities;
- *easy to use*: is about removing bureaucratic processes for support(s);

⁶ Care Matters Resource on Enabling Good Lives www.carematters.org.nz p.11

⁷ See <https://www.enablinggoodlives.co.nz/about-egl/egl-approach/principles/> for a fuller explanation.

- *relationship building*: involves the removal of impediments to connection between disabled people, their whānau and community.

Nothing About Us Without Us

Following the articulation of the social model “nothing about us without us” became the battle cry of the disability rights movement. It demands **voice** in the decisions made which affect one’s life either as an individual or as part of a collective (disabled people). Moreover, “nothing about us without us” is the social (re)construction of disabled people as capable, choice-making, decision taking beings.

In EGL, ‘nothing about us without us’ is manifest in:

- Tripartite arrangements between disabled people, Māori and officials:
 - for this to work there must be respect, trust, transparency and full disclosure between partners;
 - this can be problematic as while authentic relationships might exist between partners, the context is political and answerable to higher authorities;
 - for NEGL’s position statement on Tripartite Partnership see here (**insert link**)
- Mana, Self-determination and Voice
 - Mana is valuing disabled people in and of themselves and respecting their natural authority, agency and capability.
 - Self-determination recognises that disabled people are experts in their own lives.
 - Voice is not just about having a say but exercising decision-making authority over one’s life.
 - For NEGL’s position statement on *Mana, Self-determination and Voice* see [here](#)
- Capability and Capacity Building (CCB)
 - is primarily about educating disabled people and their [whānau/families](#) about the EGL approach, building leadership/taking control of their lives;
 - it is about decolonising disabled people, tāngata whaikaha Māori, whānau and families who have internalised individualised ways of thinking and acting about disability and themselves;
 - it’s about shifting mind-sets from dependence on diagnostic-based services to thinking about what a good life looks like and the supports needed to achieve this;
 - CCB is building relationships between disabled people, their whānau and community to develop natural supports;
 - CCB aims to ameliorate the lack of investment in disabled people and whānau throughout their lives;
 - CCB providing funding in support of the above;

- for the NEGL position statement on CCB see here **(Insert link)**
- Regional Leadership Groups (RLG) and Core Groups (CG):
 - CG and RLGs are the foundational building blocks of EGL;
 - they promote and protect EGL principles and values that system transformation is based upon;
 - they give direction to system transformation 'management' team;
 - RLGs provide feedback to the Minister;
 - for disabled people, tāngata whaikaha Māori, whānau/families and providers, the Core Group is a place to learn about EGL, make connections, develop a sense of the collective, build solidarity and develop leadership. It also serves as a voice mechanism for the direction of EGL, expression of problems and proposing solutions;
 - for NEGL's position statement on RLGs and CGs see [here](#)
- Monitoring, Evaluation, Analysis and Learning (MEAL):
 - M&E led, designed and conducted by disabled people;
 - gives disabled people a chance to say if and how the disability system is working for them and to influence the system to improve;
 - the voices of disabled people and whānau are heard and their insights drive system change;
 - for the NEGL statement on MEAL see here **(Insert link)**

Social Model: relationship to Enabling Good Lives

Enabling Good Lives can be understood as a set of beliefs, approaches and practices closely aligned to operationalising the social model in Aotearoa New Zealand. EGL does not replace the social model. Rather, it stands on its shoulders to advance the choice and control disabled people, tāngata whaikaha Māori, whānau and families have over their lives. Further, it is a 21st century reading of the social model which draws upon the knowledge, wisdom and worldviews of tāngata whenua locating it firmly in Aotearoa New Zealand.

Foremost in this is the role of Te Tiriti o Waitangi and the influence of Whānau Ora. Te Tiriti is the korowai ensuring equity of access, equity of participation and equity of outcome for all EGL participants, especially tāngata whaikaha Māori and whānau. Whānau Ora moves away from individual models of wellbeing by asserting it occurs within the collective context of whānau. This means that sometimes resources must be directed towards strengthening whānau and families to assist in how to increase choice and control and better support disabled members.

At its simplest, Enabling Good Lives is about removing barriers to increase choice and control in the lives of disabled people, tāngata whaikaha Māori, whānau and families; it is about clearing the way for disabled people to determine what a good life looks like for them and supporting them in the making of and living that good life.

But a good life cannot be achieved by people with impairments living in a disabling society. So, EGL is not just about disability support system transformation. More importantly, it is also about structural change; of re-building society, social organisations and values so that they can accommodate a diversity of populations which can freely participate. In this EGL bears no contradictions with the aim of the social model: a nondisabling society in which impaired people flourish.

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