Enabling Good Lives (EGL) is Universal and Enduring

A resource for community leaders and officials

Central Obligations

A. To recognise disable people and their families as citizens and taxpayers

B. To promote inclusion and well-being for people with disabilities. This involves providing resources and services that enable disabled people to participate fully in society, access necessary care, achieve their personal goals and contribute to family wellbeing.

C. To ensure each taxpayer dollar counts, we have a responsibility to ensure immediate needs are met (short term objectives) while, at the same time, incrementally building a new approach (medium and long-term objectives).

A significant asset is that much of the work has been done and has recently been endorsed by the Abuse in Care report: '*Whanaketia – Through pain and trauma, from darkness to light*[1]'.

Four key points

1. **We have defined many of the "problems"**

2. **We have co-designed a better way (the Enabling Good Lives approach)**

3. **We have tested the new approach and it works better for disabled people and their families**

4. **To create equal opportunity[2] and fairness, we need to expand EGL-based system change**

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[1] www.abuseincare.org.nz/reports/whanaketia/
[2] Creating equal opportunity eliminates the postcode lottery scenario

We have defined many of the "problems"

There have been numerous in-depth reviews and working groups that have detailed challenges associated with the current system and the importance of increased choice and control for disabled people. These have included:

- The Office for Disability Issues Review of Equity and Coherence (renamed the Review of Long-Term Disability Supports)

- The Social Services Select Committee's 2006 to 2008 **Inquiry into the Quality of Care and Service Provision for People with Disabilities** (the Select Committee Inquiry)[3.]

- Putting People First: A Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services[4]

- In 2012 the Ministerial Committee on Disability Issues agreed fundamental change to the disability support system was needed. This change to be based on the Enabling Good Lives vision and principles

- The Machinery of Government working group, comprised of officials and disability community representatives, developed advice in partnership on proposed new organisational arrangements. The Machinery of Government Working Group also produced 'Mana, Self-determination and Voice' [5] which is a paper emphasising the critical importance of independent voice and key features.

- "*Whanaketia – Through pain and trauma, from darkness to light*"[6]. This comprehensive report details systemic problems and endorses the EGL approach as a way of the future. "The government should prioritise and invest in work to support contemporary approaches to the delivery of care and support, including devolution, social investment and whānau-centered and community-led approaches, such as Enabling Good Lives and Whānau Ora, and avoid the State-led models that contributed to historical abuse and neglect in care".[7]

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[3] Select Committee Disability Inquiry Report
[4] Review of Disability Support Services, Putting People First: A Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services » The Hub (sia.govt.nz)
[5] www.enablinggoodlives.co.nz/assets/ResourceSnippets/Mana-Self-determination-and-Voice.pdf
[6] www.abuseincare.org.nz/reports/whanaketia/
[7] Tūtohi 115 | Recommendation 115

We have co-designed a better way (the Enabling Good Lives approach)

Between 2012-2017 there have been numerous opportunities for disabled people and their families to describe a better approach. Co-development harnessed insights from national networks and specific opportunities included:

- The influence of the "Coalition" (2009 -2013)[8]
- the initial EGL Report [9]
- the Christchurch and Waikato Plans[10]
- the Disability Action Plan 4(a) Working Group: Advice on the components for a transformed system[11]
- Disability Support Services Framework Redesign Group (2013)
- the "High-Level Design Working Group" (2017-18)[12]
- Over 4400 disabled people have been involved in the EGL sites[13]. These sites operate within a "try-learn-adjust" approach and are consistently learning and adapting according to feedback from disabled people, their families and regional leadership network input

We have tested the new approach and it works better for disabled people and their families

Between 2013-2023 there have been numerous reviews regarding the effectiveness of an EGL-based approach. Examples of findings include:

"Qualitative data gathered from each Enabling Good Lives site demonstrates positive impacts of the approach on the lives of disabled people, including:

- improved independence, self-confidence and personal development, expanded social networks, and opportunities to do things not possible under the previous system
- tāngata whaikaha Māori, Pacific disabled people and disabled children and young people reported increased uptake of and satisfaction with supports." [14]

"….More positively, participants who accessed EGL principles-based funding had increased choice and control over the support they received, leading to greater enjoyment of their human rights. Participants also expressed cautious optimism

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[8] Five national community networks governed by disabled people and families. The organisations were: the Disabled Persons Assembly (DPA). People First NZ, Parent to Parent, Standards and Monitoring Services (SAMS) and Imagine Better
[9] Developed by disability community leaders
[10] Developed through multiple, independently facilitated community forums
[11] A paper describing key components drawn from national and international evidence
[12] This included multiple parallel working groups that included disabled people, families and subject experts
[13] www.whaikaha.govt.nz/about-us/corporate-publications/reports-to-the-minister
[14] www.whaikaha.govt.nz/about-us/corporate-publications/reports-to-the-minister

about the potential of Whaikaha - Ministry of Disabled People, and hoped for equitable access to EGL principles-based funding and services for all disabled people as quickly as possible."[15]

Enabling Good Lives (EGL) and Value for Money (VfM)

" EGL Waikato performs highly across all VfM criteria…. EGL is a highly effective programme. It is delivering positive outcomes for disabled people, families and whaanau…. Improved access, choice and control are unequivocal outcomes of EGL Waikato."[16]

To create equal opportunity and fairness, we need to expand EGL-based system change

This is an intentional, phased multi-year process[17].

The type of process that can be useful in bringing about the essential positive change required can involve:

Setting a destination

- Describing how we want things to be (what would we experience?)
- Developing key critical shifts[18] (looking at what needs to change to get from where we are now to where we want to be)

Developing a pathway

- Defining and prioritising the key steps/actions that will get us to where we want to be (the phased approach[19])
- Who needs to do what in order for change to happen (strategy, responsibility and accountability)

Monitoring change and adjusting

- Being clear about what evidence will indicate positive change
- Gathering information and adapting as we go (Try-Learn-Adjust)

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[15] Key findings of the Disabled People Led Monitoring Research, presented to the DPO Coalition by Donald Beasley Institute - www.infoexchange.nz/dpo-coalition-statement-changes-to-whaikaha/
[16] Were, L., King, J., Crocket. A, and Schiff, A. (2021). Enabling Good Lives Waikato: Value for Money Evaluative Insight Report. Huurae 2021.
[17] See co-design supporting papers for many key components of the phased process @ www.enablinggoodlives.co.nz/system-transformation/
[18] See Appendix One
[19] See Appendix Two

Setting a Destination

Examples of some critical shifts are:

1. Attitude and altitude shifts

Crown shifts might include things like:

From	To
Disabled people and their families require others[20] to make decisions in their best interests	Disabled people and their families have the natural authority to make decisions about their lives, supports and the systems they interact with
Decisions can be made with no or minimal input by disabled people and their families	Disabled people and their families must have the ability, authority and mechanisms to influence decisions at all levels
The Crown should define and lead consultation forums	The Crown should negotiate with community partners to co-develop collaborative forums
The disability community is divided to the degree that consensus approaches are not feasible	Given resources and opportunity the community can work together to represent its interests in a constructive and collaborative way

Community shifts might include things like:

From	To
We need the Crown to provide supports and systems that work for us	We will work with the Crown to co-develop, monitor and refine approaches that work well for us
We need to fight to keep what we have	We will work collaboratively to build better ways of doing things

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[20] For example: professionals, officials and providers

2. Infrastructure investment

Crown shifts might include things like:

From	**To**
The Crown invests in building its capacity and capability to understand the diverse and detailed needs of the community	The Crown invests in building community voice and forums for the community to share insights

Community shifts might include things like:

From	**To**
Community leadership competes for inadequate funding in order to survive	A plan is co-developed that invests in growing independent voice and collective independent voice

3. Equipping everyone with new skills

Crown shifts might include things like:

From	**To**
We need people with the skills to sustain the current system	We will attract, train and retain people with the technical skills to effectively implement a new way of doing things

Community shifts might include things like:

From	**To**
We need leaders with the skills to fight a system that does not work for us	We identify and support leaders who can describe and support the development of a better way of doing things

4. Refining

Crown shifts might include things like:

From	**To**
We focus on what is not working in the current system and describing problems	We identify current strengths, successes and how to expand sustainable good practice

Community shifts might include things like:

From	**To**
We encourage people to use complaints processes	We equip people to be clear about what they need, how constructive change can happen and connect them with personal networks

Developing a pathway related to community voice

Examples of a phased approach

Growing Individual Autonomy and Voice

Phase One	**Phase Two**	**Phase Three**
Years 1 and 2	**Years 3-5**	**Years 6-10**
Increased awareness	**Increased skills**	**Increased choice**
National strategy	**National strategy**	**Regional strategy**
• EGL 101 forums across New Zealand • Mapping and stocktake of existing community located resources (by disabled people and families for disabled people and families)	• Develop additional generic resources (by disabled people and families for disabled people and families) • Provision of a range of skill-based learning in core areas: personal planning, communication, negotiation, employer skills and conflict management	• Regional leadership networks commission local skill development

Growing Collective Independent Voice

Phase One	**Phase Two**	**Phase Three**
Years 1 and 2	**Years 3-5**	**Years 6-10**
Increased understanding	**Increased access to independent voice forums**	**Increased control**
National strategy	**National strategy**	**Regional strategy**
• Leadership networks and providers identified i.e. disabled peoples and family networks and organisations • Community forums begin across the country	• Core Groups formed in regions (parallel development) • Regional leadership networks formed.	• Regional Leadership Networks (RLNs) become self-managing • A national network of RLNs