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Disabled Person-Led Monitoring of the UNCRPD

My Experiences, My Rights: Disability Supports and Services

Report 4 - Enabling Good Lives (EGL)

**Whakarakatira te tākata,
ahakoa ko wai, ahakoa nō hea.**

Respect and treat all with dignity,
irrespective of who they are and where they come from.

Author: Donald Beasley Institute (DBI). The DBI is an independent charitable trust that conducts disability research and education. The DBI is committed to ethical, inclusive, and transformative research and projects that promote the rights of disabled people.

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Disclaimer: The Disabled People's Organisations Coalition (DPO Coalition) has made every effort to ensure the information in this report is reliable but does not guarantee its accuracy and does not accept liability for any errors.

Kōrero Whakamārama: We apply the Kāi Tahu dialect when writing in te reo Māori, which includes Kāi Tahu specific words and replaces the 'ng' with a 'k'.

Tohu description: The DBI's tohu depicts the round shape of a wharerau, a temporary shelter once built at mahika kai sites (food gathering areas). The top of the wharerau sits above the earth with a rau (lined pit) below. As a place of shelter and story sharing, the wharerau reflects the DBI's commitment to working respectfully alongside whānau whaikaha to share and grow knowledge and understanding.

Project Artwork: Eve McCoy.

Ihiraki / Table of Contents

1 Whakarāpopototaka Mātua / Executive Summary	5
1.1 Project brief.....	5
1.2 Key research findings.....	5
1.2.1 A way of life	5
1.2.2 Disabled-led and community-driven	5
1.2.3 Building relationships and community	6
1.3 Recommendations	7
2 Whakatakika / Introduction	8
2.1 Enabling Good Lives (EGL)	8
3 Te Aramahi / Methodology.....	11
4 Kiteka / Findings.....	14
4.1 A way of life.....	14
4.2 Disabled-led and community-driven.....	15
4.3 Building relationships and community	16
4.4 Investment	18
4.5 Information about EGL	19
4.6 EGL experiences	20
4.6.1 Strengths-based assessment	20
4.6.2 Choice, control and flexibility of funding	21
4.7 Concerns about EGL.....	22
5 Tūtohi / Recommendations.....	26
6 Kupu Whakamutaka / Concluding Remarks.....	28
7 Tohutoro / References.....	29
8 Kupu Rāpoto / Acronyms.....	30

1 Whakarāpopototaka Mātua / Executive Summary

1.1 Project brief

In 2021, the Disabled People's Organisations (DPO) Coalition asked the DBI to do disabled person-led monitoring on how well the New Zealand government is making the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) a reality in Aotearoa New Zealand. Disability supports and services (DSS) was the chosen monitoring topic. During this cycle of monitoring, disabled people and their families, whānau, aiga and close supporters who took part in the research discussed Enabling Good Lives (EGL) and the impact of its eight principles on DSS.

The disabled person-led monitoring team collected data through interviews, focus groups and a nationwide questionnaire. The findings presented in this report focus on disabled people's perspectives and experiences of EGL, which were shared through interviews with disability sector leaders and EGL focus groups with disabled people and their whānau.

1.2 Key research findings

1.2.1 A way of life

Disability sector leaders who had been involved in the development of EGL discussed how the aspiration had been for its principles to be adopted as a way of life for disabled people, and their families, whānau, aiga and service providers; and as a guiding framework for organisations.

1.2.2 Disabled-led and community-driven

Participants highlighted the importance of EGL being disabled-led and co-designed with the disability community and the public sector. Being disabled-led meant that the principles could challenge negative ideas about disability and help build

community. The way EGL has been developed is an example of the disability rights mantra 'nothing about us without us'.

1.2.3 Building relationships and community

Disability sector leaders highlighted that strong relationships were necessary for the success of EGL. Community meetings in some regions were considered to be a useful and safe process for disabled people and whānau to share their challenges, connect, and work together as a community. Participants said intersectionality was an important factor when building relationships and ensuring representation, which can be a challenge. Another aspect of relationship building involved engaging with local boards and inviting public servants to EGL meetings. However, when meetings are led by government officials, participants felt they were prevented from authentically engaging with, and leading, community building.

1.2.4 Investment

Participants reflected on the positive impact of government investment into EGL. This was felt through community building efforts during the development of EGL pilot sites and disabled-led processes. Participants expressed a strong desire for the investment to continue.

1.2.5 Information about EGL

Participants expressed concern that disabled people were uninformed about EGL. Even though EGL had been implemented in some regions, some disabled people still did not know about it. In areas without EGL, many disabled people had no, or limited knowledge. Participants who did not yet have access to EGL, but knew about it, were looking forward to accessing it in the future. However, the future of EGL is currently unknown due to the Government's pause on its national rollout.

1.2.6 EGL experiences

Participants reported an improvement to the needs assessment process, describing the former model as deficit-based. The improved EGL assessment process instead focuses on aspirations and enables disabled people and their whānau to express what they need for their wellbeing. Participants who had access to EGL funding described feeling like their lives had improved. This was attributed to the flexibility of

funding and having choices. However, there was still some unease around having to ask for permission to use funding for specific things, and the power that some connectors held over disabled people's access to support and resources.

1.2.7 Concerns about EGL

Some participants reported concerns such as a lack of continuity in the EGL funding model, a lack of security in their day-to-day support, and a lack of understanding of the EGL principles by disability supports and services providers. Some participants felt the EGL principles were not reflected in their everyday lives or did not reflect the nuanced needs of their disability community.

1.3 Recommendations

Participants suggested the following recommendations:

- Take a whole-of-government approach to adopting and implementing EGL principles and approaches.
- Increase government budget and resources for EGL and community building.
- Develop robust disabled-led monitoring and evaluation processes to understand if, and how well EGL is being utilised in the community.
- Develop a peer-to-peer mentoring support system to equip disabled people to utilise the EGL approach.

2 Whakatakika / Introduction

In 2018, the Donald Beasley Institute (DBI) was commissioned by the Disabled People's Organisations Coalition (DPO) to conduct Disabled Person-Led Monitoring of the UNCRPD. Drawing on the findings of previous monitoring cycles (Housing and Health and Wellbeing),¹ in 2021, the third monitoring topic was selected as Disability Supports and Services (DSS). During this monitoring cycle, participants reflected on the establishment of Enabling Good Lives (EGL) and the impact of its eight principles on DSS. This short report is the fourth of five reports, which aims to capture the original intent, experiences, and aspirations of disabled people for EGL, as well as their reactions to the Government's recent decisions regarding EGL.

2.1 Enabling Good Lives (EGL)

Disabled person-led monitoring of disability rights in Aotearoa New Zealand has consistently shown that disabled people, and their family, whānau, aiga and close supporters experience significant challenges when it comes to disability supports and services (Donald Beasley Institute, 2025). These challenges have been widely reported on, including in the 2008 Social Services Select Committee inquiry into the quality of care and service provision for people with disabilities (Social Services Committee, 2008). In response to this inquiry, in 2011 the Minister for Disability Issues, Honorable Tariana Turia, established an Independent Working Group comprised of people from the disability sector, and government officials from the Office for Disability Issues, Ministry of Health and Ministry of Social Development to explore “the types of supports government should provide so disabled people can have the life they aspire to like other New Zealanders (The Independent Working Group on ‘Day Options’, 2011, p. 2). The Working Group had an explicit commitment to the New Zealand Disability Strategy (2001) and the UNCRPD, and, while the original brief was to improve day services and community participation for disabled people, it quickly became apparent that the whole disability support system needed

¹ Donald Beasley Institute. (2020). My Experiences, My Rights: A Monitoring Report on Disabled Person's Experience of Housing in Aotearoa New Zealand. [Monitoring Report]. New Zealand Disabled People's Organisations Coalition; Donald Beasley Institute. (2022). My Experiences, My Rights: A Monitoring Report on Disabled People's Experiences of Health and Wellbeing in Aotearoa New Zealand. [Monitoring Long Report]. New Zealand Disabled People's Organisations Coalition.

to be investigated (The Independent Working Group on 'Day Options', 2011). As a result of this work, the report '*Enabling Good Lives*' was published, which introduced a series of guiding principles and a funding model. This new approach aimed "for disabled people, families and whānau to have greater choice and control over their lives and supports. This includes having the 'say so' in how resources are used" (Mikkelson & Cosgriff, 2016, cited in Were, 2016, p.11). The final eight EGL principles included: self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use, and relationship building. The principles are intended to guide how government agencies and disability services organisations operate.

The new funding model was designed to effectively realise these eight principles. During the development of EGL, one of the challenges identified by the Working Group was the siloed funding systems within DSS (The Independent Working Group on 'Day Options', 2011). Disabled people often receive funding from multiple government agencies such as the MoH, MSD, Ministry of Education (MoE) and Accident Compensation Corporation (ACC). A lack of collaboration and communication between agencies often limits how funding can be used, which impacts disabled people's access to disability supports and services. Based on these principles, the EGL model suggests combining disability funding so that disabled people, their families, whānau and aiga can control how they use their funding from a single source. The pilot funding model has been trialled in Christchurch since 2012/2013, and in the Waikato since 2015. A prototype from these pilot projects, Mana Whaikaha, was then established in MidCentral in October 2018 (Anderson et al., 2014; Lovelock, 2020; Were, 2016). The key elements of the EGL pilot were:

- a. Self-directed planning and facilitation;
- b. Cross-government individualised and portable funding;
- c. Considering the person in their wider context, not in the context of 'funded support services';
- d. Strengthening families and whānau; and
- e. Community building to develop natural supports (The Independent Working Group on 'Day Options', 2011; Were, 2016).

Along with these key elements, the pilot projects also introduced the position of Kaitūhono / Connector (Jones & Kelly-Costello, 2021). There are multiple responsibilities involved in this position, including but not limited to: providing information about support; supporting disabled people and their family and whānau to explore what a 'good life' means for them; facilitating relationships between the disabled person, their family, whānau and aiga, service providers and the community; and navigating crisis with disabled people and their family and whānau (Jones & Kelly-Costello, 2021).

Each pilot site had different eligibility criteria. Christchurch was selected as the initial pilot site as changes to support had already begun to occur in the aftermath of the 2011 earthquake (The Independent Working Group on 'Day Options', 2011). This initial pilot was only open to young people who were transitioning from school to adult life (Anderson et al., 2014). The Waikato pilot project was available to a wider cohort of disabled people and their families, whānau and aiga. However, it was limited to 245 individuals, families and whānau across three years (Were, 2016). The Mana Whaikaha prototype in MidCentral did not have any eligibility criteria; however, when it became available, the uptake exceeded the capacity of the staff employed to establish the prototype (Lovelock, 2020). Then, in October 2021, Cabinet agreed to a national rollout of the EGL approach to disability supports and services (Ministry of Social Development, 2021).

The EGL principles and funding models align with the UNCRPD, specifically the progressive realisation of Article 19—Living Independently and Being Included in the Community. In 2022, the UN Committee on the Rights of Persons with Disabilities (2022) welcomed and commended the New Zealand Government's intention to roll out EGL nationally. However, since the restructuring of Whaikaha - Ministry of Disabled People in August 2024 (Minister for Disability Issues, 2024), the expansion of EGL has been halted. As highlighted in an earlier monitoring report, this decision was made without proper consultation with the disability community (Donald Beasley Institute, 2025).

3 Te Aramahi / Methodology

This monitoring research utilised the Disability Rights Promotion International (DRPI) methodology, whereby data were collected from 219 participants across three key phases:

- Phase one: Interviews with disability sector leaders
- Phase two: Focus groups
- Phase three: Nation-wide questionnaire

Phase One: Individual interviews with disability sector leaders

The first phase of this research involved qualitative DRPI interviews with disability sector leaders who were or had been actively involved in the establishment of Whaikaha - Ministry of Disabled People and/or the development of the Enabling Good Lives approach (EGL). In total, 16 disability sector leaders were interviewed twice between August 2022 and October 2023. Leaders identified as having a wide range of genders, ethnicities, ages and disability backgrounds. Some of the leaders were family members of people with multiple and complex disabilities.²

Phase Two: Focus groups

The second phase of this research involved DRPI monitoring focus groups and individual interviews with specific cohorts of disabled people and their families, whānau, aiga and close supporters. The focus groups and interviews were primarily determined by the system(s) of support (or funding) a participant had access to, either under the Ministry of Health's outgoing Disability Support System (DSS) or another government agency. The monitoring team also conducted a series of targeted focus groups and interviews with harder-to-reach and intersectional populations to ensure the research included people known to experience challenges in accessing supports and services. Each focus group included between two and six participants and was organised according to the support they received, disability type, or intersecting identity, including:

² To maintain confidentiality, leader demographics have not been included in this report.

- ACC (Māori 3, Pākehā 2; disabled people 4, whānau 1)
- Individualised Funding (IF) (Pākehā 14; disabled people 4)
- Personal budgets based on Enabling Good Lives principles (EGL pilots) (Pākehā 5; disabled people 5)
- Home and Community Support Services (Pākehā 6, Māori 2; disabled people 8)
- Te Whatu Ora (formerly DHBs) (Pākehā 4, Asian 1; disabled people 4)
- Māori (Tākata whaikaha and whānau hauā Māori 1)
- Pasefika (Pasefika disabled people and Tagata Sa'ilimalo 6)
- Migrants and refugees (Asian 1; disabled people 1)
- LGBTQIA+ (Pākehā 3; disabled people 3)
- Women (Pākehā 1, Pasefika 1; disabled people 2)
- People living in group homes and/or people with learning disabilities (Pākehā 15, Asian 3; disabled people 14, whānau and close supporters 2)
- People with psychosocial disabilities (mental health) (Pākehā 3; disabled people 3)
- Ministry of Education supports and parents of disabled children (Pākehā 3, Māori 1; Parents of a disabled child 2, disabled people 2)
- Family, whānau, aiga and close supporters of people with multiple and complex disabilities (Māori 2, Pasefika 1, Asian 1, Pākehā 1; family, whānau and aiga 5)
- D/deaf people (Pākehā 4, Māori 1, Pasefika 1; Deaf 6)
- People with no access to supports or services (Pākehā 6, Māori 2, other 1; disabled people 7, whānau and close supporters 2)

In total, 29 interviews/focus groups³ involving 82 participants took place between April 2023 and March 2024. Sixty-three participants identified as female, 17 as male, and two as non-binary. The participants were between the ages of mid-20s and early 90s. Fifty-seven participants identified as Pākehā, 13 as Māori, nine as Pasefika, including Cook Island Māori, six as Asian and one person identified as 'other'.⁴

³ If a person indicated they preferred individual interviews for accessibility reasons, this was arranged.

⁴ The total equates to more than 82 as some participants registered multiple ethnicities.

Seventy participants identified as being disabled, including whaikaha Māori, whānau hauā, Pasefika disabled people and tagata sa'ilimalo, and twelve participants were family, whānau, aiga and close supporters of people with multiple and complex disabilities.⁵ The purpose of this phase of data collection was to explore disabled people's access to disability supports and services under Articles 9, 19, and 21⁶ of the UNCRPD, and their experiences of the establishment of Whaikaha - Ministry of Disabled People, and EGL.

Phase Three: Nation-wide questionnaire

The third phase of this monitoring research was a DRPI monitoring questionnaire. The questionnaire enabled a greater range and number of disabled people and their families, whānau, aiga and close supporters to share their experiences. The questionnaire was translated into accessible formats and languages and made available online. A total of 121 participants completed the questionnaire. Seventy-one participants identified as male, 38 as female, seven as non-binary, three as gender diverse, and two chose not to disclose their gender. Nineteen participants were aged between 18 and 30, 77 participants were between 31 and 64, 22 participants were older than 65 years, and three people chose not to disclose their age. One hundred and three participants identified as Pākehā, 20 participants as Māori, four as Chinese, two as Cook Island Māori, one as Fijian, one as Indian, and five 'other' ethnicities, and one chose not to disclose their ethnicity. Eighty-seven participants identified as disabled (including tākata whaikaha Māori and whānau hauā), 13 as tākata turi/Deaf, and 28 as family members, whānau, aiga or close supporters of people with multiple and complex disability.⁷

This report draws on insights, experiences and perspectives across the three phases. In particular, it draws on Phase One interviews with disability sector leaders who were actively involved in establishing EGL, as well as participants from EGL focus groups during Phase Two data collection.

⁵ For the purpose of anonymity, participant details are not specified in the findings of this report.

⁶ Articles relevant to this monitoring cycle are not limited to these three articles. A full list of UNCRPD Articles related to disability supports and services will be discussed in subsequent reports.

⁷ The total equates to more than 121 as participants often registered multiple identities.

4 Kiteka / Findings

When the interview and focus group transcripts alongside questionnaires were analysed for responses related explicitly to Enabling Good Lives, five key themes emerged: EGL as a way of life; the importance of disabled-led and community-driven; EGL's role in building community; information about EGL; EGL experiences; and concerns about EGL.

4.1 A way of life

The first key finding highlighted the role and purpose of EGL, including how its eight principles can be practically applied in everyday life. Disability sector leaders who had been involved in the development of EGL emphasised how the aspiration had been for disabled people, and their families, whānau, aiga and service providers to adopt the principles as a way of life, even before EGL budgets were in place.

[Y]ou don't need money [...] the personal budgets to actually start thinking in the mindset of Enabling Good Lives, you know having goals and having work towards it because the opportunities are there if they use the principles. (Disability Sector Leader 13-01)

Sector leaders emphasised that EGL principles should be used as a guiding framework, particularly for organisations as they transition to a mana-enhancing approach to delivering disability supports and services.

I've been fascinated by the bit, we're not even talking about 'what can we do now to get EGL into our community', which doesn't include the allocation of resources. A simple example is what should organisations do to make their services mana-enhancing for disabled people, that kind of stuff. Because if we wait for the rollout, there is going to be some people who might not know what this is for another 20 years. (Disability Sector Leader 03-01)

As summarised by one participant, while informing policy decisions was a goal, the disability community must also recognise the potential of EGL.

[W]e'd prefer communities to be getting really fired up and talk about EGL before there are any policy decisions so they are contributing to them. So on the EGL website, [there's an] established section for the national leadership where [they've] started posting position papers about advice the national leadership group has for communities and how they might think about EGL. (Disability Sector Leader 09-01)

4.2 Disabled-led and community-driven

The second aspect of EGL that was important to participants was that it was disabled-led and community-driven. Sector leaders emphasised that EGL's principles were co-designed by the disability community and the public sector. The strong focus on being 'disabled-led' ensured the principles were crafted in a way that both challenged societal perceptions of disability and helped build community. The development of EGL is an example of the disability rights mantra 'nothing about us without us,' whereby disabled people were involved in the decision-making processes of matters that impacted them and their communities.

Enabling Good Lives is about consensus building, and collective thought, from the flax roots up. (Disability Sector Leader 11-01)

When discussing the importance of the 'disabled-led' principle within the EGL approach, one leader reflected on the importance of EGL in promoting disability expertise:

[T]hey are experts in their own lives and that by honouring that, by supporting them to be, to develop that expertise like beginning early, supporting families to think to not think in highly medicalised and ableist ways about their child or son, daughter or sibling or whatever, and that this person has, can have a really good life if we get in and provide the supports really early. (Disability Sector Leader 07-01)

4.3 Building relationships and community

A third aspect of establishing EGL's disabled-led and community-driven approach was building relationships and community. While there were some regional differences, disability sector leaders articulated that the success of EGL is based on strong relationships, particularly within regional communities.

For example, a large number of community members had attended local EGL meetings in both the Waikato and MidCentral regions. Through these meetings, there was an open selection process where people could self-nominate to be part of the local leadership group, followed by a voting process. Disability sector leaders noted that these community meetings created a safe space for disabled people and their whānau to share their frustrations and challenges, which was an important part of the community-building process. Once these feelings were shared, there were opportunities to work together and more constructively as a community.

[I]t began from our place of disabled people kind of being fragmented and siloed into impairment types and so just beginning to create a safe and a place for disabled people just to be ourselves and connect and that was it. [...] overtime developed into a community where disabled people across the board, like pan-disability, were connecting through strengths and abilities and also through having things in common including disability and really building their disability identity. (Disability Sector Leader 04-01)

Evaluations of EGL pilots also emphasised the importance of relationships between disabled people and EGL connectors (Lovelock, 2020; Were, 2016). These findings confirm that one of the EGL principles - building relationships - is a critical component of establishing disability supports and services that work well for disabled people and their family, whānau, aiga and close supporters.

Slowly start building up all the networks and then the whole thing can't go backwards anymore because the whole community is sort of linked, pushing forward to the next stage and that's my hope of what will happen because I think the worst thing that could happen is if there's entrenchment and not a generosity between us as community to

scaffold and lift others up because if we don't do that we are not going to get that change we need to see. (Disability Sector Leader 11-01)

Acknowledging and responding to intersectionality was also a key component of building relationships and community, with challenges also being noted. For example, one disability sector leader shared the challenges of ensuring representation from mana whenua in the EGL community:

One of the fundamental things that I feel was wrong was the Ministry contracted an external person who was supposed to [appoint a mana whenua liaison person] but what ended up happening was the person actually decided who was in and who was out basically, and that has taken out years to sort out and I don't know if we are there yet. (Disability Sector Leader 16-01)

Another leader stressed the importance of acknowledging regional differences when delivering the EGL approach:

[E]very region will be different when EGL rolls out because every region has a different make up of people but we were quite clear in [location] that we wanted to prioritise Māori disabled people as a cohort and children and young families so that those young families might never need to deal with the harsh system that we currently have. So we've prioritised those two groups and preventing people going into residential group homes, so there's been a smaller group of people there, but we feel quite proud in [location removed] that we've managed to, 35 percent of our participants are Māori so they obviously think it's culturally responsive to what they need, so we feel quite proud of that. (Disability Sector Leader 11-01)

The importance of EGL in building relationships also extended to the wider community. For example, one participant shared how public servants had been invited to their meetings, while EGL members also sat on local boards to ensure the wider community (including public servants) could learn about EGL, disability and diversity in their local community.

[W]e've met every month since 2013 and that group of disabled people are starting to work with councils and DHBs. We have all sorts going on to make our community more inclusive of the needs of disabled people some of us are on [location removed] at the DHB, someone else is on an urban design panel, and we've got another person working on regional infrastructure technical specifications work, you know so that they are starting to get layers and layers in [location removed]. (Disability Sector Leader 11-01)

However, in contrast, examples were provided where EGL processes driven by government officials were perceived as having prevented disabled people from authentically engaging and leading the process of community building.

We woke up one morning and here is Enabling Good Lives. It didn't have that acceptance in the community. And it took a long time for core groups to get established. [...] Everyone was appointed by the Minister, which made things incredibly strained. (Disability Sector leader 02-01)

As summarised by one leader:

I think [the] national roll out of EGL under Whaikaha needs to be community driven, and run, and the very start needs to have independent facilitation. Not a provider that actually will bring work into their own mahi, it needs to be independent. I think that's the starting point. (Disability Sector Leader 16-01)

4.4 Investment

The fourth collection of key findings related to the necessity of funding and resources when building community. Participants acknowledged the positive impact that government investment in EGL had had on community building efforts, particularly during the development of EGL pilot sites. Government investment in EGL had provided a platform for community members to come together and participate in genuinely disabled-led processes. There was a strong desire to see investment in EGL continue:

The EGL approach requires targeted investment in Disabled Persons and Family networks to establish trusted relationships and leadership structures so that they can make decisions that positively influence the way that disability and impairment are addressed in their region.

(Disability Sector Leader 09-01)

[A]ll of the sudden you get regional leadership groups that grow and develop together, find some common themes and rally together and come in with [a] united front and I don't think it's ever been seen before and that's huge. (Disability Sector Leader 16-01)

4.5 Information about EGL

There were concerns, however, that disabled people who live in areas where EGL has not been rolled out are still unsure about what EGL is:

I think that a lot of people don't understand what Enabling Good Lives is, that's another thing that I think is really crucial is that we're saying, "Oh we're going to do this, it's going to be amazing blah blah blah," and I have met some people in Northland through other work, I've met Māori and Pacific people they've got no idea what that means what it is or what it will mean for their lives and if it will mean anything for them, so I think I think that we should really be considering how we are communicating about EGL as well.

(Disability Sector Leader 01 - 01)

Reflecting these concerns, many focus group participants and questionnaire respondents who lived in areas without EGL pilots or prototypes reported having limited knowledge of EGL. In particular, participants highlighted the lack of information about EGL in alternative formats, as is required under Article 9 of the UNCRPD.

Not much information from EGL (Questionnaire participant)

[T]he information is just not good enough, we've got no clarity about what this looks like in the future and you know, that situation we're in at the moment. (Deaf Focus Group)

Even though many participants did not have access to EGL, some were looking forward to engaging with it in the future:

[Disability supports and services] could be so much more and better with an EGL approach and personalised budgets. (Questionnaire participant)

For example, one participant who lives in a residential group home expressed their desire to have access to EGL's ways of support:

We want to have a change from here, come off [service provider] and go into something that's more empowering and another company, either the My House My Choice or EGL (People with Learning Disabilities Focus Group)

However, due to the Government's decision to pause the national rollout of EGL, it is currently unknown when EGL budgets will be consistently and widely available. This is despite the UN CRPD Committee's recommendation for a commitment to the national rollout of EGL (UN Committee on the Rights of Persons with Disabilities, 2022).

4.6 EGL experiences

The fifth key finding related to the experiences of disabled people and their whānau who had been involved in the EGL pilots and prototypes, including reflections on the assessment process, funding choice, control, and flexibility.

4.6.1 Strengths-based assessment

One of the significant changes implemented through EGL is the needs assessment process. Participants reported that historically, the assessment process was deficit-based and focused on what a disabled person cannot do. However, the EGL assessment process focuses on aspirations and enables disabled people and their whānau to express what they need for their wellbeing.

EGL assessment was positive and [I] really enjoyed it and find it a positive experience [...] EGL funding is suitable and appropriate and managed in an affirming way. (Questionnaire participant)

[T]he language the NASC is using is changing. And it's becoming more ability focused and it's about making a good life plan. (Ministry of Education supports and parents of disabled children focus group)

4.6.2 Choice, control and flexibility of funding

Affirming these positive shifts in the assessment process, participants who had access to the EGL funding model shared how their lives have improved through their participation in the pilot programme.

Being on the Enabling Good Lives demonstration since 2016, which has been really, something that increased my quality of life to no end. (EGL focus group)

I feel looked after, I suppose, by EGL. A lot better in terms of my health. (EGL interview)

A contributing factor to these improvements was the flexibility of funding, which enables participants to choose how they are supported and by whom. Having choices meant having more control in their lives.

I'm just really pleased with what [EGL's] been able to do. The independence it's given me, and the way I can just actually do things. Now I can choose how my day looks, and I'm pretty routine anyway, but, just to be able to go to the shopping mall is great, and go for coffee and just have a good relationship with the person who supports me. (EGL focus group)

Before I was on Enabling Good Lives, I was under the disability lead system, where they sent someone into your home, at a time that worked for them. And, basically, to get you out of bed, get you in a shower, and get you on the couch; and I felt like a prisoner still in my home [...] having a team that knows me and knows my situation can help me live my life. (EGL focus group)

Participants also noted that the ability to provide koha for whānau through the flexibility of EGL allowed them to recognise their support in culturally appropriate ways:

We use our EGL funds to provide koha to whānau who assist with care in various ways. A koha based approach is far more culturally appropriate and less demeaning for whānau. (Questionnaire participant)

In other cases, participants highlighted limitations in the choice and control they had over the funding they received and how they could use it, noting that funding use is still scrutinised and can be rejected by a funding provider.

[A]gain you're having to go through your host who holds your money going 'this is how we think' not how the parents think. That's where the whole mix up is because we still have to ask them and if they decide that 'no you don't need that'. (Family, Whānau and Close Supporter Focus Group)

Another participant cautioned about influence and power connectors can hold over people's access to support and resources:

I have noticed the amount of support that you get, or the access to the resource that you get, or what you can and can't do is really dependent on your connector, their experiences, their understandings, and [...] their biases (EGL Focus Group).

4.7 Concerns about EGL

While participants who have access to the EGL funding model primarily reported positive experiences, there were also concerns shared by both participants who have EGL and those who do not have access to the EGL funding model. The main concerns reported by EGL participants were the lack of continuity in the EGL funding model, a lack of security in their day-to-day support, and a lack of understanding of EGL principles by disability supports and services providers. For example, one participant whose son was part of the EGL pilot had a positive experience until the

support was discontinued due to their son aging out of the pilot programme's eligibility criteria. This raised concerns about continuity of care.

I found it really brilliant, the principles associated to what we did. Once it was not a pilot it really got chopped to pieces. [...] we have a navigator with Enabling Good Lives, but because he's now in residential they basically, like when you hit adulthood, see you later. Nobody knows what to do. (Family, Whānau and Close Supporter Focus Group)

While EGL enabled participants to have choice and control over their supports, the challenges associated with the skilled labour shortage in the disability support work workforce remained unchanged.⁸ Challenges with coordinating support were also highlighted.

[I]t's just, it's hard. I think the other thing with having EGL and support staff, it is fantastic to have support, and to be able to choose my staff. But I think there are still major challenges and barriers that we're not looking at and considering, also. What do I do when my staff have mental health problems? What do I do when they don't turn up? What do I do when I need to be up for work in the morning, and someone calls in sick? You know, because at the moment, it goes to my partner and my flatmate; and I'm really lucky that I have them there. (EGL Focus Group)

Another participant who is not part of the EGL funding pilot or prototype shared that while their support provider claims to be equipped with EGL principles, they have not experienced any difference in the way their support is delivered.

[M]y provider says they're getting training in Enabling Good Lives and they talk about, you know, how they're trying to turn their service around. And I don't see any evidence of it. But also they don't really understand the whole try to give the disabled person more choice. It's

⁸ See Report 3 for a full discussion about support workforce challenges (Donald Beasley Institute, 2025).

not about them being nicer to us. It's about actually having services that are focused around our needs and our rights. (Home and Community Support Focus Group)

Other participants who did not have access to EGL pointed out that without the actual funding and resources attached to the EGL principles, these principles did not improve their everyday realities.

And so the Enabling Good Lives model the principles are promoted robustly but [...] you can tell people they've got choice and control until you're blue in the face. It means absolutely nothing if there's nothing out there to choose from. And there is nothing out there to choose from (No Support Focus Group)

Another criticism shared by family, whānau and close supporters of people with multiple and complex disabilities was that EGL principles are not reflected in their everyday lived experience.

Interpretations inconsistent from whoever. Enabling Good Lives to be honest for me [...] in my head they are words. They are lovely, really flowery words but actually practical, like yeah. There's no practicality in any of it because it gets diluted. (Family, Whānau and Close Supporter Focus Group).

Other participants noted that some of the EGL principles did not reflect or capture the nuanced needs of their disability community. It was recommended that further discussion about the principles take place, involving the wider disability community, including the Deaf community, whānau, and close supporters of people with multiple and complex disabilities.

There's not been enough discussion about it. There's no consultation, there's not been communication [of] the principles [...] those principles say you know, mainstream first for example, and for the Deaf community maybe that's not actually the best concept that's not necessarily matching our needs. So maybe there needs to be more conversation about what that means and what that means for the Deaf

community. Because for the disabled community maybe that makes sense for them, they don't want to have that segregation or separation, they don't want to be set aside, and separated from the rest of society you know, they want to be integrated into society. (Deaf Focus Group)

5 Tūtohi / Recommendations

Outlined below are recommendations identified by participants about how to better utilise the EGL principles and approach.

Take a whole-of-government approach to adopting and implementing EGL principles and approaches:

EGL is meant to be a cross-government response to the way that we address impairment and disability in this country but just as people are telling me, people are worried that it's all going to be pinned on Whaikaha to deal with (Disability Sector Leader 09-01)

My hope for the new ministry is that for every disabled New Zealander to experience the Enabling Good Lives approach and that's about 1.1 million of us, but that to be just the beginning. So, it would be great for all New Zealanders to experience the Enabling Good Lives approach, especially for those populations that experience disempowerment. (Disability Sector Leader 04-01)

Increase government budget and resources for EGL and community building:

The intent is that ahead of system transformation rollout, there will be resource given from Whaikaha, we haven't got that funding agreed yet but that in a staged way regional leadership groups will be, you know communities will start moving and gathering together to establish groups in their regions before roll out so people understand [EGL]. Because it's about the dynamic of shifting power and the way authority and mana from service providers or decision makers within government to disabled people and their whānau (Disability Sector Leader 11-01)

Develop robust disabled-led monitoring and evaluation processes to understand if, and how well EGL is being utilised in the community:

[M]onitoring is a massive part of this mahi, I mean how do we keep on track to make sure that what we are doing is right and it needs to evolve in ways that still keeps the foundational EGL approach and principle while upholding Te Tiriti and the human rights United Nations all of that stuff, so they are our foundational building blocks so we need to monitor against that. (Disability Sector Leader 16 - 01)

To monitoring evaluation analysis and learning, so there's been quite a conversation around what does voice look like so we are going to have a partnership and we've got the structures but we also need to collect voices of every disabled person in New Zealand and have all that information coming through to Whaikaha and in a partnership way as well because up until now information has been collected about us but not shared with us. And as a community we haven't been part of making this sense. (Disability Sector Leader 11-01)

Develop a peer-to-peer mentoring support system to equip disabled people to utilise the EGL approach:

[...] using those that have been on EGL for a lot longer to help guide and show that process or, sharing the experiences and learnings ourselves, within ourselves. (EGL focus group)

6 Kupu Whakamutaka / Concluding Remarks

As expressed by the Independent Working Group on 'Day Options' (2011), Enabling Good Lives was initially created as a tangible expression of the NZDS and the UNCRPD within DSS. The data for this report was collected between 2022 and 2024, before it was announced that the national rollout of the EGL funding model was paused for the foreseeable future. However, this report offers valuable insights into how disabled-led support services can be designed and implemented. For example, interviews with disability sector leaders highlighted the importance of community building, using EGL as a platform. These leaders also shared their hope for improved disability support services that enable more flexibility, choice and control for disabled people, their family, whānau and aiga. Furthermore, they recognised EGL principles as tools for advocacy and community building, which they believed would ultimately lead to disabled people reclaiming their sense of power. These hopes, however, reflect the stark reality that many disabled people in Aotearoa do not have 'good lives' as envisioned by the EGL principles, such as self-determination, mana enhancing, relationship building, and beginning early. Moreover, as highlighted in earlier monitoring reports, there have been criticisms of EGL, including a lack of information about EGL, DSS's failure to implement the principles, continued challenges in securing appropriate EGL-based disability supports and services, and its limited utilisation for people with multiple and complex disabilities. For EGL to give expression to the NZDS and UNCRPD, the national rollout of EGL must occur, with targeted utilisation for Deaf communities, people with multiple and complex disabilities and others who are yet to benefit from its principles.

7 Tohutoro / References

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8 Kupu Rāpoto / Acronyms

DSS - Disability Supports and Services

EGL - Enabling Good Lives

MoE - Ministry of Education

MoH - Ministry of Health

MSD - Ministry of Social Development

NZDS - New Zealand Disability Strategy

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities



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