

NEGL guidance to leaders working for positive change at this challenging time

1. Don't get enmeshed in myths and distractions

- There is a myth the EGL is a postcode lottery and therefore unfair.

This misrepresents the rationale for why there are three “EGL sites”. The concept of having three sites was not to exclude anyone. The purpose of having the governments response to EGL contained in three sites was so that these sites became the place where disabled people and their families could co-develop ideas, monitor what happens and learn. Limiting system change to three sites was to provide the chance for real partnership and understanding to happen before system change was expanded throughout the country. It was always intended for the “pilots”, “demonstration sites” and prototype site to inform national change.

When it became clear how to successfully bring about positive change, and when there was evidence these changes had positive outcomes for disabled people and their families, then the changes could be “rolled out”. These “sites” have fulfilled their function. We know what to do and we know how to do it. People report better lives due to co-developed, tried and tested EGL-based changes. What didn't happen was for the system changes to be incrementally expanded throughout New Zealand so everyone could benefit from the new and better way of doing things.

- There is a myth that EGL does not work for everyone

The beauty of EGL is that it is intended to be interpreted by individuals, families, cultures and communities. EGL is not a programme or project with set rules. EGL is a way of seeing things and doing things that will vary and evolve. There are now hundreds of examples of how the EGL approach has been successful for a wide variety of individuals, families and communities.

- There is a myth that we must now enter a period of disabled people and families being asked what they need and want (consultation)

Disabled people and families have been clear about what they need and want for over a decade. There have been multiple reviews and papers. There are substantive documents that clearly describe what disabled people and families need, want and don't want. The UN Convention on the Rights of Disabled People, the Abuse in Care Report and Enabling Good Lives all describe in detail what people need and want. Not only is what people want well described – but, how this can happen in practice has also been co-developed in the three EGL sites and in the high-level design process. Disabled people and their families don't need to describe what they want. They need to experience the change they have already described.

- There is a myth that EGL is controlled by a small group of disabled people and families

EGL is still evolving. The EGL National Leadership Group (NEGL) promotes and supports the honouring of existing disabled people's organisations and family networks as well as the development of regional leadership networks to inform, influence, monitor and adapt regional initiatives. These regional leadership networks are an initial stage of EGL-based change that provide a local and accessible mechanism for the diverse community to come together and collaborate for positive change.

2. Don't "give up" or "give in"

EGL is not "paused". EGL is a social movement that gains its mandate and momentum from the community.

All a government can do is "pause" EGL-based system change. It has done this by diverting our focus and stealing financial resources (i.e. EGL contingency drawdown) to attempt to strengthen the broken system and fund the latest imposed change. EGL is a community movement. It can't be paused by government. The worst government can do is starve the EGL movement and EGL-based system change of needed resources (which is bad enough!).

The process of deinstitutionalisation took approximately thirty years in New Zealand. EGL-based change will also take a considerable period of time as well. It is tragic that a "rollout" of EGL-based change has been put on hold. However, it is important to note that the current government also stated their commitment to "the EGL vision and principles" in the August 2024 Cabinet Paper. Our challenge, over the next three or four months, is to ensure that Ministers, the Taskforce, Whaikaha, and the Ministry of Social Development commit to a whole of government system change based on Te Tiriti, the UNCRPD and EGL.

3. Do keep a focus on EGL and EGL-based positive change

- a. Know what you want to achieve. Focus on describing what you do want and don't get tricked into reacting to what you don't want.
- b. Say it again. Don't assume decisionmakers know or understand the messages that are already contained in the UNCRPD or EGL materials.

There are now hundreds of stories that describe how increased choice and control have made a positive difference in people's lives and communities. These stories need to be told again and can illustrate what the UNCRPD and EGL look like in practice.

- c. Find allies. There are many disabled people, families and networks that want positive change. Collaborate with them to make both individual and joint submissions.
- d. Target and invest in influencing decisionmakers. Try not to let too much time be absorbed in fighting misinformation in multiple social media forums. Rather, discover who will be making key decisions and build a direct relationship with them.
- e. Keep messages to decisionmakers clear, concise and constructive.
- f. Direct representation. Because you are aware some people or networks have already stated something you believe in, don't hesitate to say it again from your perspective. Decisionmakers need to know the same thing from multiple perspectives.
- g. Use multiple channels to influence decisionmakers. Talk to your local MP, the involved Ministers, key officials and allies. Send written materials and reference previous documents. Use social media and media releases.
- h. Insist on multiple conversations with decisionmakers. Keep contributions to the point and in the context of constructive change.
- i. Initiate public forums where you inform others and encourage them to use their voices.
- j. Lobby, use and support existing leadership networks and organisations governed and staffed by disabled people and/or families. There will be different views. However, it is powerful to work with others when you agree on things in common.
- k. Hold on to the optimistic expectation that positive change is possible. Keep your expectations high and work for them. Resist any pressure to lower your aspirations. Remember you have hundreds of disabled people and families that have already invested in describing how positive change happens. Hundreds of disabled people and families have already experienced better ways of doing things. All disabled people and their families should be able to experience the same.