



Enabling Good Lives

EGL National Leadership Group Guidance on the Kaitūhono/Connector Role

1. Role of the Kaitūhono/Connector¹

The Kaitūhono/Connector role is a relationship-based role that respects the autonomy and authority of disabled people. Kaitūhono/Connectors (Independent facilitators) walk alongside a disabled person and/or their family, aiga and whānau and support them to realise their goals and aspirations so they can live a good life. Fundamental to the role is a strong belief that connection to, and participation in, community is the basis for living a good life.

2. Describing and defining the independence of Kaitūhono/Connector Role

This role was included as a core element of the Enabling Good Lives approach because disabled people and families emphasised they wanted access to an independent “ally” who was able to help them understand and navigate the disability support system and plan for a good life. Disabled people and their families described what an ‘ally’ was and said it was someone who was “there just for me.”

Disabled people should be able to have full and rich lives, like other citizens. Independent facilitation helps to ensure they are seen in the context of their whole life, and not as a collection of components that systems may choose to respond to, or not.

Feedback from participants in the ‘EGL demonstrations’ reinforced the value placed on the perceived **independence** of the role.

Definition of “Independence”

Someone who:

- Is there as an ally to support the self-determination of disabled people, and whose other loyalties do not impede on this
- Is not in a position, organisation or situation that can benefit from the decisions made by disabled people and whānau
- is not controlled, influenced or directed by any other entity or person, in any way, that may impact decisions made by disabled people and whānau

¹ The Kaitūhono/Connector role was initially referred to as an Independent Facilitator. Other names that have been associated with this role have been Local Area Co-ordinator and Navigator.

Why “independence” is important

It is important that a Kaitūhono/Connector remains independent because it means they are more likely to connect with the person/family with “no strings attached”. Coming to the relationship from a position of independence makes it easier to explore all options because they don’t feel obliged to only put a few solutions on the table. Being ‘independent’ makes it less likely that a Kaitūhono/ Connector will be able to influence a person’s choice.

Examples of where ‘Independence’ can be compromised:

- A family member who relies on the disabled persons income
- A support provider that could benefit from a person “choosing” their service
- A family member who has control over where the disabled person lives
- An organisation, or group of organisations, whose other work may promote specific options
- An organisation, or group of organisations, based on a belief system, that limits some choices as being “inappropriate”

3. How Kaitūhono/ Connectors support people to live a good life:

- working, and being seen to be working, in the person’s interests;
- building intentional and trusting relationships with a disabled person, their family, aiga and whanau;
- exploring life opportunities with the disabled person and assisting people to create plans for building the life they want;
- providing disabled people, their family, aiga and whanāu with timely, personalised information to allow them to make informed decisions;
- working with local communities, organisations, and disabled people, their family, aiga and whanāu to build welcoming and inclusive communities so that all people belong and can contribute;
- engaging with, developing and supporting disabled people’s and their aiga and families’ natural networks and community connections;
- assisting disabled people, their family, aiga and whanāu to seek a range of support and services, including government-funded disability support, as required, to meet their goals; and,
- promoting and supporting self-advocacy by disabled people (which may be with the assistance of their family, aiga, whanāu or other natural supports), and facilitate access to independent advocates.

Disabled people and families should be able to describe the Kaitūhono/Connector as someone who:

- Is my ally (just focussing on my interests, preferences, needs and wants)
- Can make it easier for me to explore all options
- Is a “safe” person to talk things through with (I am not concerned about what I say)
- Can explain options in a way that make sense to me
- Is well connected in the community
- Is able to assist me to “stretch my thinking” above and beyond how things in my life are at the moment

4. What Kaituhono/ Connectors do

Examples of how an independent facilitator can work include:

- take the time to work with people and understand their situations;
- support the person to deal with their immediate situation;
- assist with planning in order to figure out what a good life looks like and what steps need to be taken to get there;
- be a catalyst to the person developing relationships and building a strong network of family and friends;
- ensure the person, in the context of their family and friends, is the decision maker;
- assist people to be good at planning and decision making;
- know the people and places in which the person lives so they can assist them to build a life in their neighbourhood and community;
- assist people to explore natural networks and connect them with the community;
- help move ideas into action;
- assist the community to include and value all people and their contributions;
- assist people to explore ways to most effectively develop their skills to build a rich, rewarding life that meets their hopes and goals;
- assist in safeguarding so that a person can continue to have a good life;
- Enable the person to replace the Kaituhono role through their own networks, community connections or mainstream service. They can also use their own funds or allocated disability support funds to buy it;
- have access to small amounts of discretionary funding to support people in mutually agreed ways.

5. What Kaituhono/ Connectors do not do

Limits to the role:

- they should not be responsible for determining the level of government disability support funding/personal budget that a disabled person is allocated;
- they do not assist disabled people and their family by directly managing the government disability support funding/ personal budget they are allocated, or purchase, or deliver the support paid for with that funding;
- they do not advocate, on their own volition, for the disabled person;
- they do not have roles or responsibilities that conflict with the disabled person's choices; and
- they are not "support workers" who carry out activities with, or on behalf of, the disabled person.

6. Requirements for success

- Kaituhono/ Connectors should respond to the particular situations and wishes of disabled people and their family, aiga and whanāu. This means that the particular things that are done are agreed from time to time, and based on principles rather than being specified in a prescriptive task based 'role description' or limited by funding or administrative rules.
- Strong leadership by disabled people and families, aiga and whanāu to drive communities to be genuinely inclusive of disabled people.
- Informed and supportive management, who understand and own the underpinning principles, are clear about the role and its limits
- A consistent national approach that also enables local and regional variation.
- People in Independent Facilitator (Kaituhono/ Connectors) roles walk alongside disabled people, their families, aiga and whanau to inform, and be part of, a broader system transformation that is guided by the EGL principles.

7. What 'qualifies' people to be a Kaituhono/Connector

The Kaitūhono/Connector role is a values, and skills based, role. The effectiveness of the role relies heavily on a person's ability to quickly build a trusting relationship with, and be led by, the disabled people, family, aiga and whānau they are working with.

The EGL National Leadership Group believe the experiences many disabled people and whānau have can be an invaluable foundation from which success in the role can be built. Disabled people and whānau are equipped with skills and

knowledge about the experience of disability and the experience of navigating disabling systems that are required for success in this role.

NEGL believes this is an 'attributes' and 'skills based' role and **not** a 'qualifications based' role. It is critical that the lived experience of being disabled, or the experience of being a family, aiga or whānau member of a disabled person, underpins the practice of this role now and in the future.

8. Who might employ Kaitūhono/Connectors

The EGL approach emphasises leadership by disabled people, their families, aiga and whānau. The EGL National Leadership strongly supports Kaitūhono/Connectors being employed by organisations governed, managed, and staffed by disabled people and/or their families².

National EGL Leadership Group encourages any organisation, who will employ Kaitūhono/Connectors, to have a comprehensive approach to equipping and supporting disabled people and/or family, aiga or whānau to be successful in the role.

² It is possible the Ministry may need to grandparent or host organisations until the needed infrastructure and skilled staff are in place.