

National EGL Leadership Group (NEGL) Position Statement on the Role of Families

NEGL supports the critical role that family, whānau and including, but not limited to, aiga, play in the lives of disabled people, and acknowledges the interdependence and reciprocity within families. Disabled people – as parents, partners, siblings, children etc – give and receive care within their family. The Enabling Good Lives (EGL) approach is about whanau ora (**improving family wellbeing**, focusing on the family as a whole, and addressing individual needs within the context of the family).

Families play an important role in supporting disabled people's right to choice, control and self-determination. Families can help amplify the voices of disabled people so that their preferences, priorities, and concerns are at the forefront. The voices and perspectives of families should never overshadow the voices and perspectives of disabled people.

In some instances, families are "the voice" of their disabled family member. This is often when their family member is a child, if their family member relies on others to interpret their communication, or is temporally unable to advocate for themselves e.g. medical condition, illness or injury. In these situations, families need to be respected as attempting to best represent the interests of their family member.

So, to support families to champion and amplify the voice and independence of disabled people, they should have access to family-led:

- education,
- networking,
- mentoring,
- resources, and
- relationships.

Connected, resourced, and informed families are powerful disability allies in the creation of a non-disabling society.

Families make important contributions to the lives of disabled people at individual and community levels. Individual families are often strong advocates for the rights of their disabled family members, fighting for equity, access, and full participation. Collectively, families can challenge the barriers that marginalise disabled people economically, politically, socially, and educationally. Families can be powerful forces for prompting positive social change and challenging ableism.

NEGL supports families to participate at all levels of governance and leadership.