

FAMILY GOVERNANCE

About Family Governance

What is it?

Individual, family and whanau governance are where the disabled person, and/or families take an active role as an equal partner in the design and oversight of services provided, including determining how the available funding will best be used, adapting the model of support as needed to meet the goals and aspirations of the people being served, including the development of the policies, principles and values within which the support will be provided.

What it is not:

It does not involve disabled people living together

- Where individuals, families, whanau come together to create a collective model it is critically important to note that this does not mean that individuals in the collective live together.
- Family governance does not involve families who choose a service to provide supports to a group of people living in the same house who need support by staff shared amongst all people living there. That is a Service.
- Traditional service providers and some corporate service agencies say they offer family governance approaches. While such approaches may indeed increase the sense that individuals and families have a degree of authority over what the service provides, it still doesn't give you full autonomy and is not family governance.

Pros and cons of family governance

Pros	Cons
<p>People remain connected to family and others close to them.</p>	<p>Not all families/whānau, have a strong vision of what is possible in the life of the person with a disability.</p>
<p>Supports are guided by a deep and enduring care for the individual.</p>	<p>People and families/whānau who know a lot about existing disability support systems may benefit disproportionately, while those who are less knowledgeable will benefit less.</p>
<p>Supports are guided by personal values and ethics.</p>	<p>Life can be unpredictable and there are lots of different factors which may limit the success of family governance. For example, another family member becoming critically ill and needing care, etc.</p>
<p>It is up to the person and their family, whānau to decide what service they get, where, when and by whom.</p>	<p>People and families/whānau who know a lot about existing disability support systems may benefit disproportionately, while those who are less knowledgeable will benefit less.</p>
<p>Increased flexibility and responsiveness to the goals and needs of the person.</p>	<p>Achieving increased personalisation of support may come at a cost for families/whānau because of the complexity of issues that need to be managed.</p>

Pros	Cons
Supports provided are relevant to the needs of the person.	The level of funding available may not be adequate to address the needs of the person.
Minimal bureaucratic intrusion into the support arrangements.	The person with the learning disability and/or their family/ whānau, may not be capable of creating a high-quality support arrangement.
Family culture is respected, influential and safeguarded.	There may be extra risks present for the person that are not properly recognised by family/whānau and therefore are not offset by sufficient safeguards.
People are active members of their community.	Families are not perfect and it is possible that they may be attempting to meet the needs of family/whānau at the expense of the person with the intellectual disability
People retain their unique identities.	Families/whānau may have limiting ideas of what people with learning disabilities may be capable of or need. They may never have been exposed to what's possible.
<p>Where governance occurs through a collective of like-minded people, there are additional benefits of:</p> <ul style="list-style-type: none"> ▪ The capacity to pool funding to achieve better results ▪ People and families are less likely to become isolated ▪ Greater capacity to develop a network of families and family leaders with similar values and goals. 	<p>Inadequate attention may be given to the renewal of the supports so that the person settles into a dull and mundane existence. Everyone needs something to want to bounce out of bed for.</p> <p>Planned change and the unexpected can often bring new opportunities for personal growth.</p>

FAMILY SUPPORT

Family Governance Models.

Individual support arrangements

The individual or family/whānau essentially:

- Designs, delivers and manages the supports
- Obtains a personal budget, or self-directed funding for themselves or their family member
- Employs their own staff directly or employs someone or an agency for various administrative tasks.

Incorporated Agency, Hosted Arrangement

- There is an Agreement between the agency, the person and/or their family.
- The hosting agreement defines what the person and/or family is in charge of, and what the agency is responsible for.
- Families maintain decision making authority.
- The design of the service arrangement is co-designed with the person and the agency.
- The agency takes care of most of the administrative tasks.
- The service to the person operates independently from how the agency runs its other services.
- The hosting arrangement can be dissolved by either party, should they no longer want it to continue.

Agency Hosted, Collectively Governed Support Arrangements

- This option involves multiple families.
- The Family Collective creates a governance board.
- It is hosted by an agency.
- The Family Collective has a hosting agreement with the host agency.
- As a result, it comes under its legal structure.
- The Family Collective negotiates and settles their host agreement details with the host agency.

- Service arrangements can be organised by the agency. Families don't need to worry about admin and other bureaucratic tasks, unless they choose to.
 - Can be quite complicated to set up, though the day-to-day operations once established are usually relatively easy to oversee.
 - The governing board of the collective negotiates and settles their host agreement details with the host agency. This negotiation can often take several years to finalize.
- However, once finalised, they can often be in place for years without any adjustment. (A Place to Belong, Brisbane, developed from this type of arrangement with Anglicare in Queensland).
- Families need to be very proactive and provide considerable leadership to bring them into existence. They also need to be on their guard that the host agency doesn't impose its own policies and constraints on the collective.

Collective Governance Models.

The Member Directed Mini Agency

- Individuals, families and whanau come together to establish a mini agency.
- Each member has a unique service planned and designed to meet their needs and aspirations.
- Each member might have different levels of funding, because they need different levels of support.
- The members have the governing authority.
- Each member and their family are in charge of their own service arrangement.
- Members contribute a management fee to employ a manager or a coordinator. This is an additional cost.
- Size is limited so the members have more influence.
- The mini agency is responsible for the usual reporting requirements. For example, audits, periodic reporting, adherence to agreements and so on.
- Mini agencies tend to last the lifespan of the individuals involved.

Micro Boards

- Supports one person at a time.
- The service is legally incorporated to hold and administer personal budget (funds).
- Acts as a trustee of the funding.
- The Micro Board manages the funding and pays for the individualised supports.
- Usually made up of 5-7 family members, friends, and volunteers
- Operates under the belief that the person with impairment has the capacity to make their own decisions.
- Demonstrates regard for the person's safety, comfort, and dignity.
- Support the person to have choice and control.
- May support in succession planning.