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Tōku Whānau, Tōku Kāinga My Family, My Home Visual Report

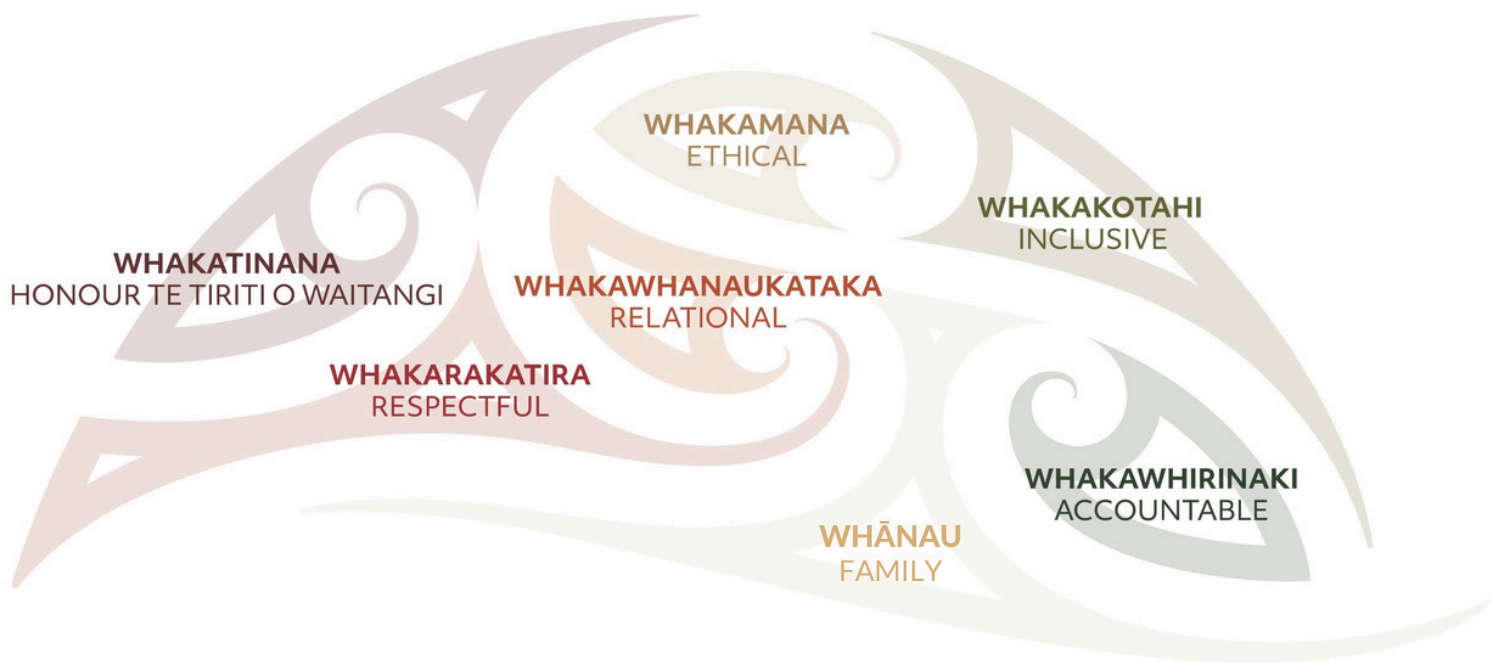
A research project funded by the Jubilee Trust

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Kā Mātāpono

Our Values



Whakatinana – Honouring Te Tiriti o Waitangi

Whakarakatira – Being respectful

Whakawhanaukataka – Being relational

Whakamana – Being ethical

Whakawhirinaki – Being accountable

Whakakotahi – Being inclusive

Whānau – Through uplifting whānau our journey
will be one of prosperity

Project Aims

Our Project

The aim of this research was to have a **disability-led conversation** about family/whānau and home.

We wanted to understand disabled people's perspectives on Article 23 of the UNCRPD - the **right to respect for home and the family**, within the multicultural context of Aotearoa New Zealand.

To do this, 81 disabled people, family, whānau, aiga, and close supporters participated in a questionnaire, and 14 took part in an interview.

Participants had a wide range of disabilities, ethnicities, and identities.

This research is based on the **social and human rights models of disability**.

UNCRPD

United Nations Convention on the Rights of Persons with Disabilities.

In 2008, the New Zealand Government signed the UNCRPD and agreed to respect and uphold disabled people's human rights in Aotearoa.

Article 23

Article 23 of the UNCRPD is about Respect for Home and the Family.

It requires the New Zealand Government to prevent discrimination against disabled people in all matters relating to marriage, family, parenthood, and relationships.

I believe that we should be treated with respect and dignity.



Frameworks

Te Tiriti o Waitangi

Te Tiriti o Waitangi is the founding document of Aotearoa. It sets out an agreement between Māori and the Crown on how to exist in partnership.

Te Tiriti upholds the rights of Māori, including tāk_ātata whaikaha and whānau hauā Māori - Māori disabled people and their whānau.

Te Ao Māori & Disability

In te ao Māori, disability is understood differently from Western worldviews. There are two main understandings of disability in te ao Māori: whaikaha and whānau hauā.

Whaikaha acknowledges the strength of disabled people. It is a more recent term created by tāk_ātata whaikaha Māori (Māori disabled people) to reflect a strength-based approach to understanding disability and impairment.

Whānau hauā refers to the idea that the impact of disability is balanced through whānau working together.



Frameworks

Social Model of Disability

Disability can sometimes be considered a curse or defect within an individual that prevents them from fully participating in society.

However, this perspective doesn't reflect how disabled people feel or think about themselves. This led disabled people to develop the social model of disability.

The social model identifies the root cause of disability as barriers created by society through attitudes, behaviours, and structures. These socially constructed barriers can limit disabled people's participation in society on an equal basis with others.

Human Rights Model of Disability

The human rights model of disability says that disabled people have the same human rights as non-disabled people.

Both the social and human rights models of disability challenge the barriers that disabled people experience when establishing a home and forming a family.



Frameworks

Whanaketia:

Through pain and trauma, from darkness to light

In 2024, the final report from the Royal Commission of Inquiry into Abuse in Care was released. It detailed the experiences of children and adults who experienced abuse in state care between 1950 and 1999.

A significant finding of the inquiry was that families of D/deaf and disabled children were encouraged to place their children into state care. This led to the segregation of D/deaf and disabled children from their families and whānau.

NZDS

The New Zealand Disability Strategy (2016-2026) guides the work of government agencies on issues affecting disabled people.

The NZDS helps advance the rights of disabled people by supporting the implementation of the UNCRPD in Aotearoa.

Pacific Frameworks of Disability

Pacific Peoples come from diverse cultures and islands throughout the Pacific.

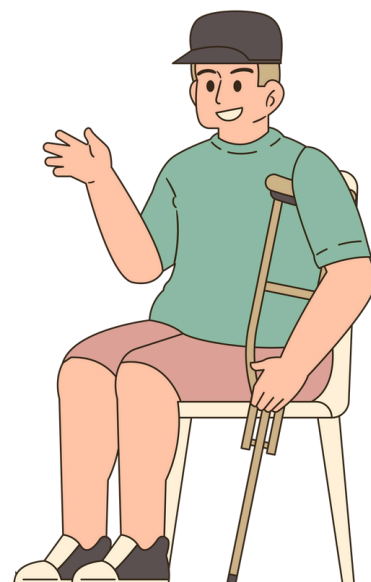
Tagata Sa'ilimalo is a framework created by Pacific disabled people in Aotearoa.

Tagata Sa'ilimalo reflects the determination, aspiration, and the collective vitality of Pacific Peoples and is inclusive of all disability types.



Research Questions

1. What does 'family/whānau' mean to you?
2. What does 'respect for home and family' mean for disabled New Zealanders?
3. How is Article 23 of the UNCRPD realised within multicultural communities?



My Family, My Whānau

Participant Responses



My family is my husband and children, my parents, in-laws, siblings, nephew, aunts and all ancestors.

Knowing family has no specific look, families can be chosen.



When we talk about biological siblings, it's been the two of us, but we've been blessed to have a lot of first cousins, a lot of aunts and uncles who are part of that ecosystem of support.

Family are one of the building blocks of community and culture. In Aotearoa, ideas about family vary depending on culture and life experience.

Participants shared their definitions of family, whānau and aiga, and what it means to them. For some participants, family includes their immediate relations through blood or by marriage. For other participants, family includes extended family, people unrelated by blood or marriage, people with shared identities, ancestors, and sometimes pets.

My Culture

Participant Responses

Culture influences values, goals, beliefs, and behaviours.

Participants shared how culture shapes their family dynamics, relationships, roles, and responsibilities.

Culture also influences how people understand disability and how a family or community supports its disabled members.

Deaf Culture

My family is generally pretty good, however I'd love it if they were more proactive about learning NZSL and being more Deaf aware.



Pacific Culture

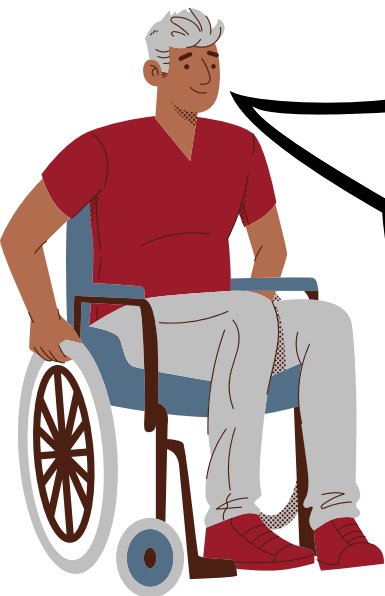
[It] means respecting the cultural values of our home e.g. alofa (love), fa'aaloalo (respect), loto maualalo (humility).

Māori Culture

As a Māori family we respect each other by loving and showing that we care, helping those one[s] who really need help by respect, each showing that you are there for them, respect our Māori culture and doing what we can do to help each other in the community.

Queer Culture

Both like a rainbow identity and disability have been a huge marker in shaping what I think family is.



My Supports

Participant Responses

Some of my son's support workers are almost like family.



Supports can be an important part of disabled people's lives. Informal support (also known as natural support) is often provided by family, whānau and aiga and can include emotional, practical, and financial support. Formal support is usually paid and might include care workers, respite, or specialist services. Formal supports often assist disabled people in their home and family life, with things like personal care, home management, and community participation.

I have a lot of family support, they are always there for me when I am sick they help out, when I have a bad day they are always there for me any time, they are loving and caring and supportive.



So, like, Mum comes in and helps me with my cooking and doing my washing. And this helps me keep myself, my house tidy-ish, because that's one of my weaknesses.

My Aspirations

Participant Responses

I'm looking forward to the next part of my family life, which is becoming a grandparent [...] that'll add another layer of you know, I guess perception of things to offer the next generation within my family.

Participants shared their home and family aspirations. For example, marriage, having kids and grandkids, and passing on their knowledge to the next generation.

Participants wanted to see change - more acceptance of disability, and greater respect for different cultural understandings of disability, home and family.

[A]lways show humility always be grateful for what you have, and always be, you know, thankful for the things that they're able to pass on and share to others [...] and none of that's attached to my disability, is it?

I don't think there should be any barriers to marriage or relationships. Doesn't matter about disability or Deafness. For me, that's my view on that. I think that's a person's choice. I think that's, you know, an individual's right to choose.



My Home

Participant Responses



Treating everyone as worthwhile and equal. Respect for values, issues, decisions made.

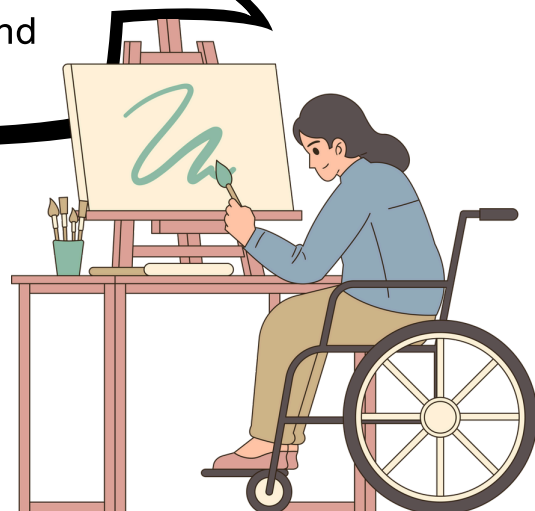
According to participants, home can be physical or symbolic - a space where people feel physically, emotionally, and culturally safe.

Participants shared the importance of having a home that is accessible, safe, and a place where they are respected.

I think also in terms of security and having a safe home, lack of stress in the home is very, very valuable.

I think when you don't have a place where you feel safe for those things to happen, you're just living in a perpetual state of, like, hypervigilance, which has its impacts on your physical health, your mental health, and then your relational health with others.

Well, [home] is a place where I'm strong.



Barriers

To Home and Family

Throughout participant responses, it was evident that many disabled people experience barriers to realising their right to respect for home and the family.

Barriers to Roles and Responsibilities

I am not well supported by the system to be a mother.



Barriers to Aspirations

[P]eople view you as another creature, not really as a human creature, as another type of creature, you know, you are suddenly disabled and you're not able to be a husband or a father. I find that very difficult.

Barriers to Cultural Expressions of Disability, Home, and Family

The system itself was hard because families' voices had never been brought up. United Nations Article 23 states it - yes, but how it's practiced and interpreted by providers in our experience has been far from equitable.

Barriers to Support

I find that I am often stuck to do it alone and that I should just be grateful we get our groceries delivered or they buy a meal for us during a visit.



Key Themes

**Aspirations:
Same but Different**

**Intersections of Culture,
Disability, Home and Family**

Natural Support and Reciprocity

**Formal Supports:
Family-like But Not Family**



Be[ing] here for them and be[ing] involved. I take [my children] to their sport. I take them to their events and their activities, and I show them things. We watch movies together; we go camping together.

Aspirations

Same But Different

Disabled people have the same aspirations as non-disabled people, such as **relationships**, **respect**, and **safety**.

However, these aspirations are often impacted by **attitudes**, **systems**, and **environments** that are inherently ableist or disablist.

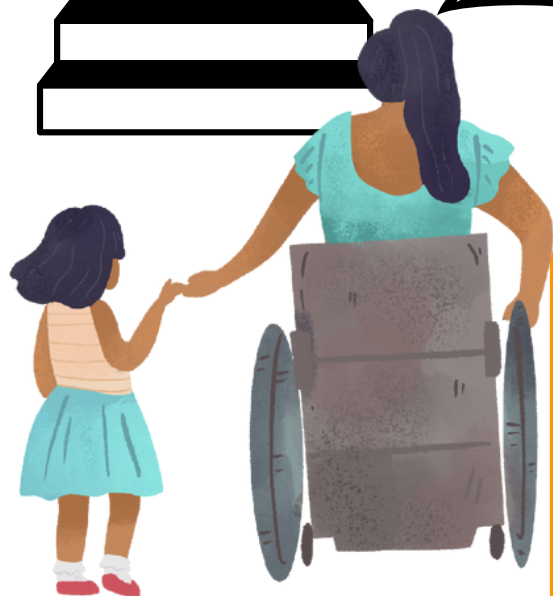
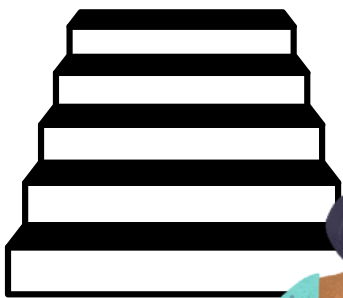
There are underlying prejudices in Aotearoa that inhibit disabled people's experiences of home and family.



[...] there's no different level or entitlement for disabled people. When, like, making babies and raising babies is different for us and has more barriers.

Ableism: Indirect discrimination through the preferential treatment of those who fit within society's idea of 'normal'.

Disablism: Direct discrimination and prejudice against disabled people.



Intersections of Culture

Disability, Home, and Family

Culture informs what people think about disability, home and family. Whether a culture is **individualistic** or **collective**, it influences how people understand and respond to disability, home and family.

For example, Western and individualistic cultures often value **self-reliance** and **independence**.

In te ao Māori, **whānau** is central to everyday life and includes extended family and ancestors. Participants spoke about the significance of whānau and their **collective responsibility to show manaakitaka** to all whānau members, including tākata whaikaha and whānau hauā.



There is an ecosystem of our own that we operate in, even though I'm born in New Zealand, but the ecosystem actually is built on a basis of culture.

For Pacific Peoples, **aiga** is a central part of everyday life. According to participants, aiga embodies the values of **collectivism, community, spirituality, reciprocity, and respect**.

This includes **tautua (service)** and a **shared responsibility** to care for elders, children, sick people, and tagata sa'ilimalo (disabled people).

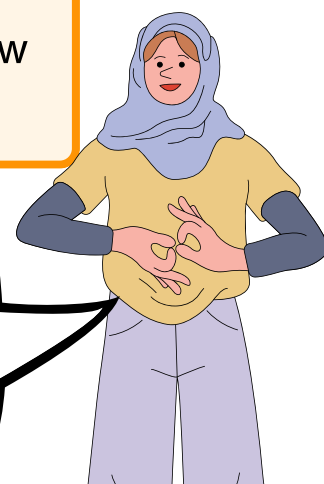
Intersections of Culture

Disability, Home and Family

The Deaf community shares a unique set of **values**, **attitudes**, and **norms**. Deaf culture influences Deaf participants' experiences of home and family.

For example, one participant spoke about using sign language as a first language with their children and how this strengthened family relationships.

We've brought [our children] up with them having sign language. We have a better relationship with our children than I think that I had with my parents.



Queer culture also has its own **values**, **traditions**, and **interpretations of family**.

Some queer participants experienced prejudice that **intersected with other identities**, such as disability.

Because of prejudice, some participants were not accepted by their biological family, so they created new definitions to include their close friends with shared life experiences and identities.

This is sometimes called **chosen family**.



As I explored my rainbow identity, and then was able to find that loving and mentoring from older rainbow people, having a sense of rainbow family.

Natural Supports & Reciprocity

Participants shared that informal supports, or **natural supports** were **important in their home and family**.

Participants' natural support was usually **family**. Participants wanted **support to be mutual and not one sided**.



However, participants' **ability to reciprocate support** was impacted by their ability to **access formal supports**.

If participants were unable to access appropriate formal supports, they were unable to enjoy their right to respect for home and the family.



I would love more support for my family as they are always willing to help me, and I would love to feel like I could reciprocate more.

Barriers to formal support are often underpinned by **negative attitudes** about disability and disabled people.

This can lead to assumptions, processes, and practices that **undervalue disabled people's contribution to home and family roles**.

It can also perpetuate the idea that disabled people are **dependent** and one-sided **recipients of support**.

Formal Supports

Family-like but Not Family



I love my support worker. My support worker provides brilliant assistance to me and enables me to live a fulfilling life, which I can then pay it forward to my community.

Formal and paid supports are a critical part of daily life for some disabled people. Support workers can help with disabled people's **independence, social connections, and community participation.**

However, participants said that formal supports, such as support workers, were family-like, but not family.

I have a home help but they don't play any role in my family.

As far as support goes, it's okay because I can call people and they'll help ... It's not that fantastic. It's not 100% fantastic. I have to book in advance if I need anything specific. And many times my support [person] is not available on a specific date or time.

There is boundaries, definite boundaries, but I would be lost without them.



Enabling Good Lives

Enabling Good Lives (EGL) is an approach to supporting disabled people that offers **greater choice and control over the supports they receive.**

Developed by disabled people, EGL is based on eight core principles that can be applied in any given situation - six of which relate directly to participant responses.

Self-Determination

Participants want choice and control over how they define disability, home, and family, particularly in relation to cultural values, roles, and responsibilities.



Beginning Early

Beginning early means investing in families, whānau and aiga and supporting them to build community and natural supports. Participants said natural supports are crucial to realising their right to respect for home and the family, and fulfilment of family roles and responsibilities.



Person-Centred

Participants emphasised that support should be person-centred and reflect their culture, values, and identity.

Enabling Good Lives



Ordinary Life Outcomes

Participants said that like all people, disabled people want to have a home and family, but they often don't receive enough support.

Mana Enhancing

Participants spoke about the importance of reciprocity, mutual support, and feeling respected and valued in their families. The importance of recognising, respecting and valuing the contributions of natural supports (family, whānau and aiga) was also highlighted.

Relationship Building

Participants want appropriate, affordable, and accessible formal supports that help them to build and strengthen relationships between themselves and their family, whānau and aiga, natural supports, and the wider community.

I want to be respected as a mother and this means supporting me in this role. I have a right to a full life which includes having a family of my own.



Recommendations

Realising disabled people's right to respect for home and the family requires duty bearers (for example, the Government, DSS, and support workers) to be confident in their human rights responsibilities.

This includes training and awareness in:

Te Tiriti o Waitangi
Disability Rights
Cultural Responsiveness
Supported Decision-Making
Enabling Good Lives



Duty bearers should ensure disabled people have access to accessible resources, funding, training, and education to improve their human rights knowledge, and in particular, their rights under Article 23 of the UNCRPD.

Disabled people must also be empowered with education, awareness, and understanding of their right to respect for home and the family.



Research Impact



This research has started an important disability-led conversation about home and family.

Participants talked about their home, whānau, aiga, close supporters, and formal supports. They also identified barriers to home and family, and their aspirations.

The findings provide unique insight, guidance, and direction for duty-bearers on the right to respect for home and family.

This research can be used to inform policy and practice.

Family and home is safety and security, it is essential to my well-being. Home is where I can be my most authentic self.



Key References

For a complete list of references please see the full report

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Project Artwork by Jeffery Oliver

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